PRIVACY AND CONFIDENTIALITY CONSIDERATIONS IN CANCER REGISTRATION: A NEXUS OF LAW, ETHICS, AND POLICY

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NCRA

(National Cancer Registrars Association) editors for the forthcoming, 4th edition of Cancer Registry Management Principles & Practices For Hospital and Central Registries, invited a new chapter to reconcile the public functional purpose of cancer registration, with the private nature of the individual-level data, patient experiences, and human interest that support cancer surveillance.

"As is widely recognized in the cancer registry community, cancer data exist because of public demands that individual cases be counted and understood not only in terms of the experiences of individual patients, but also with respect to patterns and trends, with the systematic compilation of data enabling the population-based study of who gets cancer, why, when, under what circumstances, and with what range of outcomes. The activity of cancer registration depends, however, on an extension of the underlying trust and the legal privilege of confidentiality that exist between a patient and his or her doctors. That privilege exists to support the free and clear communication necessary to the provision of the optimal treatment and care. The confidentiality of the relationship relates to the completeness, accuracy, and timeliness of the information a patient provides. These same qualities are essential to the cancer data on which research, surveillance and cancer control depend." [DRAFT]

Purpose

We aim to confront the complexity and professional anxiety associated with privacy and confidentiality in cancer registration with an articulation of durable principles and practices in support of CTRs (certified tumor registrars) and their work.

Implications

The ethics of cancer registration involve an integration of law, policy, and practice; they pertain to understanding how the endeavor of cancer registration and possibility of disease surveillance is supported by public health derive from and constitute a legal and ethical extension of the confidential relationship between patient and physician.

Results

The final text is anticipated for publication by the NCRA in Cancer Registry Management Principles & Practices for Hospital and Central Registries, 4th edition.

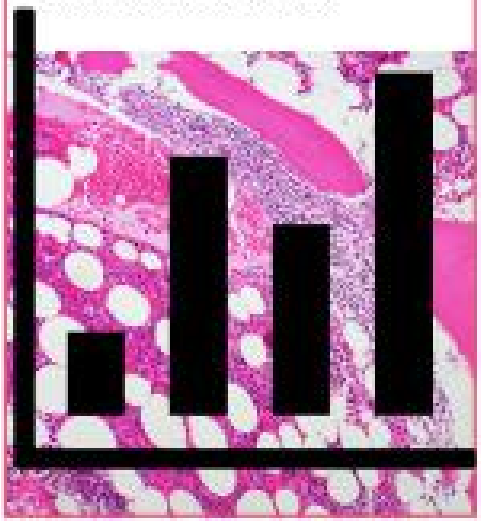
Approach

An integrated chapter:

I. LEGAL ASPECTS OF CANCER REGISTRY DATA
- Establishing Cancer as a Priority
- Privacy of Personal Health Information–Then and Now
- Confidentiality of Medical Records

II. HEALTH INFORMATION PRIVACY AND SECURITY
- Cancer Registry Data as Confidential Health Information
- Incidents that Compromise Confidentiality
- Privacy, Confidentiality, and Security
- Duty of Care
- Patient Interests
- Identifying Confidential Information

III. REGISTRAR ETHICS AND PROFESSIONALISM
- Professional Ethics in the Field of Cancer Registries
- Professional Resources
- Professional Development



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The Influence of the Affordable Care Act-Dependent Care Expansion on Insurance Coverage among Young Cancer Survivors in California

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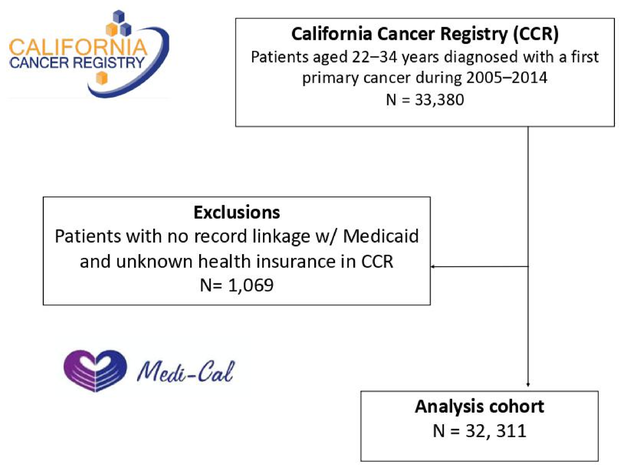
Introduction

- Adolescents and young adults (15–39 years) have been historically underinsured in the United States (US), and only allowed to stay on their parents' insurance until age 18 or while in school through age 21 years.
- The implementation of the Affordable Care Act-Dependent Coverage Expansion (ACA-DCE), which started in October 2010, allowed young adults aged < 26 years to remain on their parents' insurance.
- Previous studies in the US did not distinguish between young adults who had public insurance before cancer diagnosis and those who were uninsured and became publicly insured through Medicaid at cancer diagnosis.
- We assessed changes in health insurance coverage for young cancer survivors pre/post the ACA-DCE provision and examined differences in coverage by socioeconomic status and race/ethnicity in California.

Methods

- Data were obtained from the California Cancer Registry (which captures 99% of all cancer diagnoses in the state) and California Medicaid enrollment files.
- We included young adults aged 22–34 years diagnosed with a first primary invasive cancer during March 2005 to December 2014 **(Figure 1)**.
- Difference-in-difference analyses were conducted to examine changes in insurance coverage pre/post ACA-DCE among patients aged 22–25 years ("intervention group") and 26–34 years ("control group").
- We also examined the combined effect of race/ethnicity and neighborhood socioeconomic status (nSES) on insurance coverage.
- Medicaid enrollment was classified into 3 mutually exclusive categories, focusing on insurance enrollment 6 months prior to and 6 months after diagnosis: (1) continuous enrollees, (2) Medicaid at diagnosis, and (3) discontinuous Medicaid coverage.

Figure 1: Study cohort , California, 2005–2014.



The authors declare no conflict of interest.

Patient's Characteristics

Table 1. Characteristics of young adults diagnosed with cancer pre- and post-ACA-DCE implementation in California, 2005–2014.

Characteristics	ACA-DCE group 22–25 years % (N)	Control group 26–34 years % (N)	p-value
Insurance status			
Private/military	61.0 (4446)	65.2 (17,017)	<0.001
Continuous Medicaid	10.5 (767)	12.4 (3235)	
Discontinuous Medicaid	5.3 (387)	4.3 (1128)	
Medicaid at cancer diagnosis	12.3 (893)	9.8 (2553)	
Other public	2.7 (197)	1.8 (469)	
Uninsurance	4.8 (352)	3.3 (867)	
Unknown	3.3 (244)	3.2 (825)	
Time period			
Pre ACA-DCE (March 2005–September 2010)	55.8 (4064)	53.9 (14,071)	0.005
Post ACA-DCE (October 2010–2014)	44.2 (3222)	46.1 (12,023)	
Sex			
Female	49.7 (3622)	60.7 (15,845)	<0.001
Male	50.3 (3664)	39.3 (10,249)	
Race/ethnicity			
Non-Hispanic white	45.5 (3314)	46.0 (11,996)	<0.001
Non-Hispanic black	4.5 (327)	4.8 (1262)	
Hispanic	37.3 (2718)	34.3 (8959)	
Asian/Pacific Islander	9.7 (707)	11.6 (3023)	
Native American	0.6 (44)	0.7 (170)	
Other/unknown	2.4 (176)	2.6 (684)	
Marital status			
Married	17.2 (1250)	44.7 (11,655)	<0.001
Not married	76.8 (5598)	48.5 (12,656)	
Unknown	6.0 (438)	6.8 (1783)	
Cancer site			
Breast	3.5 (252)	14.6 (3814)	<0.001
Central Nervous System	5.7 (416)	4.4 (1145)	
Cervix	2.8 (201)	6.6 (1715)	
Colorectal	2.8 (207)	5.6 (1451)	
Hodgkin Lymphoma	12.1 (879)	5.8 (1511)	
Leukemia	7.9 (575)	5.3 (1371)	
Melanoma	10.3 (747)	11.4 (2983)	
Non-Hodgkin Lymphoma	7.7 (558)	6.4 (1673)	
Ovary	2.9 (212)	2.5 (656)	
Sarcomas	7.6 (555)	6.3 (1634)	
Testis	19.6 (1425)	12.7 (3320)	
Thyroid	17.3 (1259)	18.5 (4821)	
Stage at diagnosis			
Stage I	45.0 (3279)	47.7 (12,455)	<0.001
Stage II	13.1 (953)	14.3 (3726)	
Stage III	10.5 (767)	11.0 (2871)	
Stage IV	6.0 (438)	6.6 (1713)	
Unstaged*	21.2 (1546)	15.9 (4150)	
Unknown	4.2 (303)	4.5 (1179)	
Neighborhood Socioeconomic Status			
Low	34.2 (2491)	30.0 (7841)	<0.001
Medium	34.3 (2501)	35.7 (9323)	
High	31.5 (2294)	34.2 (8930)	
Total	21.8 (7286)	78.2 (26,094)	

Abbreviations: ACA, Affordable Care Act; DCE, Dependent Care Act
*Unstaged includes central nervous system tumors, leukemias, and sarcomas.

Results

- Of 32,311 patients included in the analysis, 7,402 were aged 22–25 years and 25,269 were aged 26–34 years.
- Most patients were non-Hispanic whites, had private insurance, and were diagnosed with stage I disease. Compared to the control group, a slightly higher proportion of patients in the intervention group resided in low nSES **(Table 1)**.
- The most substantial differences between the pre- and post-ACA-DCE were a 52.7% reduction in the proportion of uninsured patients and a 35.7% increase in the proportion of privately insured patients **(Table 2)**.
- There was a significant reduction in the proportion of patients enrolled in Medicaid at cancer diagnosis (-17.3%,) and with discontinuous Medicaid (-27.5%). The proportion of patients with continuous Medicaid or with other public insurance remained unchanged **(Table 2)**.
- There was an increase of private enrollment among non-Hispanic whites living in medium and high SES neighborhoods (54.1% and 50.4%, respectively), as well as among Hispanic and Asian patients living in high SES neighborhoods (54.0% and 78.8%, respectively).
- The proportion of uninsured patients decreased significantly among non-Hispanic whites living in medium and high SES neighborhoods (-97.9% and -94.6%, respectively).
- We did not observe differences in health insurance enrollment among young adults who lived in low SES neighborhoods or, whenever numbers allowed comparisons, among those of non-Hispanic black race/ethnicity.

Conclusions

- The ACA-DCE broadened insurance coverage for young adults with cancer, supporting evidence that the implementation of this policy has been important for these high-risk patients.
- Unfortunately, only certain subgroups of young adults benefited from this policy: those of non-Hispanic white race/ethnicity who resided in medium and high SES neighborhoods, and Hispanic and Asian/Pacific Islander patients who resided in high SES neighborhoods.
- Efforts should be made to ensure that enrollment benefits extend to all populations of young adults in California.

Table 2. Changes in health insurance coverage related to the ACA-DCE in young adults diagnosed with cancer during 2005–2014 in California.

	ACA-DCE Group (22–25 years)		Control Group (26–34 years)		Unadjusted % changes		Adjusted[c] % net change	
	2005–2010[a]	2010–2014[b]	2005–2010[a]	2010–2014[b]	Difference-In-Difference[d]	p-value	Difference-In-Difference[d]	p-value
	(n=3906)	(n=3136)	(n=13,578)	(n=11,691)	% (95% CI)		% (95% CI)	
Type of insurance[e]	%	%	%	%				
Private/military	62.9	63.3	69.9	64.3	27.0 (15.9, 38.1)	<0.001	35.7 (23.4, 47.9)	<0.001
Continuous Medicaid	9.4	12.8	11.0	14.9	-0.4 (-17.1, 16.4)	0.96	-1.6 (-19.1, 15.9)	0.86
Discontinuous Medicaid	5.7	5.2	4.2	4.8	-25.3 (-49.2, -1.4)	0.04	-27.5 (-51.8, -3.2)	0.03
Medicaid at cancer diagnosis	12.0	13.5	8.9	11.4	-14.1 (-30.4, 2.2)	0.09	-17.3 (-34.4, -0.3)	0.04
Other public	3.2	2.3	1.9	1.8	-22.3 (-56.9, 12.4)	0.21	-23.3 (-58.2, 11.5)	0.19
No insurance	6.7	2.9	4.0	2.8	-49.9 (-78.1, -21.8)	<0.001	-52.7 (-81.1, -24.3)	<0.001

Abbreviations: ACA, Affordable Care Act; DCE, Dependent Care Act; CI, confidence interval

[a]March 2005 to September 2010 and [b]October 2010 to December 2014. [c]Adjusted for sex, stage at diagnosis, race/ethnicity, socioeconomic status, and cancer type.
[d]Estimates are from generalized models using the logit link function. [e]Excludes 1069 patients with unknown insurance status.

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

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BACKGROUND

The New Jersey State Cancer Registry (NJSCR) is a population-based registry that collects data on all persons, regardless of residence, who are diagnosed and/or treated for cancer or another reportable condition in the state of New Jersey.

Ensuring complete case capture is necessary in order for the NJSCR to fulfill its state-mandated mission to monitor trends in cancer incidence and mortality in New Jersey. In 2015, the NJSCR established a case-finding audit program with the purpose of ensuring that all reportable cases are identified and reported to the NJSCR as required by state law. The NJSCR aims to audit each of the state's 63 acute care hospitals at least once every five years.

To comply with this mandate, NJSCR conducts yearly audits of selected healthcare facilities. Beginning with the reporting year of 2014, NJSCR transitioned from manual onsite facility auditing to electronic remote auditing. This effort was undertaken to reduce cost, improve efficiency and timeliness of the auditing process, and utilize advancing technology.

METHODS

The NJSCR estimates the annual expected number of cases for each reporting facility based on a weighted average of the last five years of submissions. Estimated completeness for the auditing year is determined by the number of cases submitted for that reporting year, divided by the expected number of cases (weighted average).

Each year, NJSCR selects facilities for audit. A facility is scheduled for audit if it meets at least one of three criteria:

- Below 90% estimated completeness
- A total of 10 or more electronic pathology reports (HL7) without a corresponding hospital abstract
- Healthcare facility has not been audited in the past five years

One of three types of audits is performed for each selected facility:

- Disease Index (DI) –The facility is required to submit its annual disease index – a listing of all inpatient and outpatient admissions – filtered for reportability based on the SEER ICD-10-CM Casefinding Lists. NJSCR staff conduct probabilistic linkages with files in the SEER*DMS registry database using MatchPro to identify unreported cases. The resulting list is provided back to the facility for review and reconciliation.

- Electronic pathology report (HL7) – Several reports 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, a list of potential missed cases is created and forwarded to the facility for review and reconciliation. Currently, 33 NJ hospitals submit electronic pathology reports.

- Combined (DI/HL7) – A combined audit is conducted for facilities with completeness below 90% and more than 10 unreported HL7 cases. The combo audit merges the two processes defined above to create a collective list of unreported cases for the facility.

During the audit process, all correspondence and data exchanged between the healthcare facility and NJSCR must be transmitted securely and encrypted following NJSCR current policy.

Figure 1. Audit Timeline Process

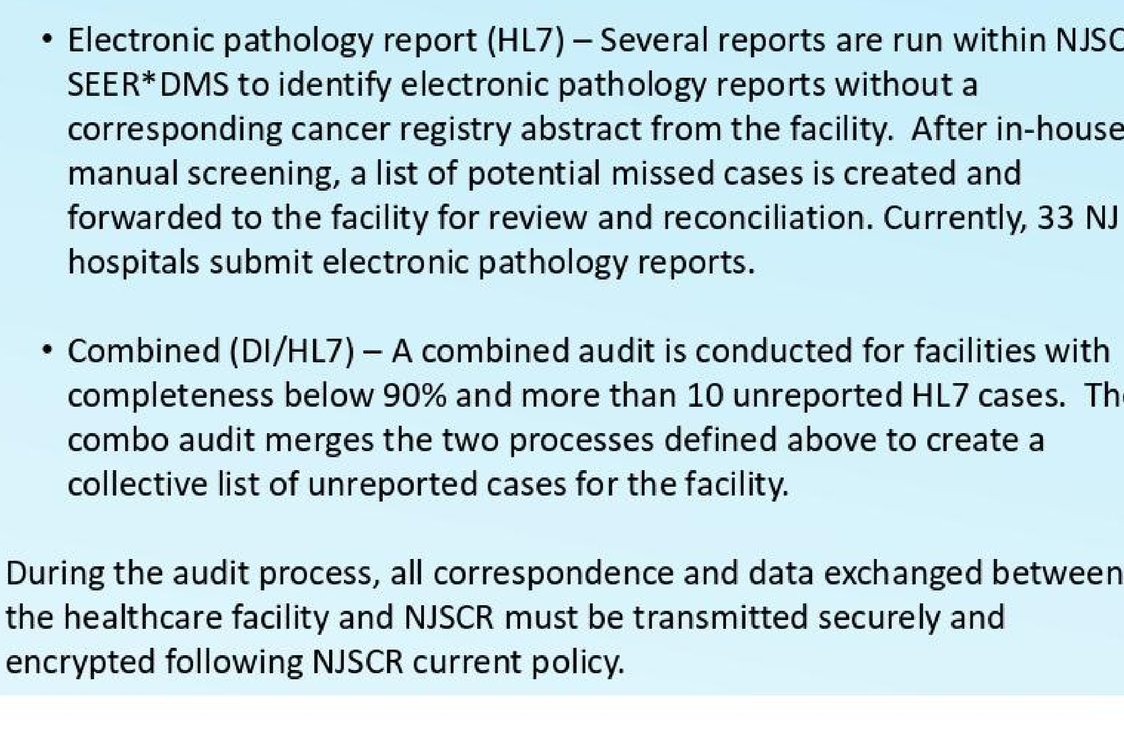

Figure 1. The steps by audit type and the required timeframes.

RESULTS

The results of NJSCR remote auditing are illustrated in Figure 2, Figure 3, and Table 1.

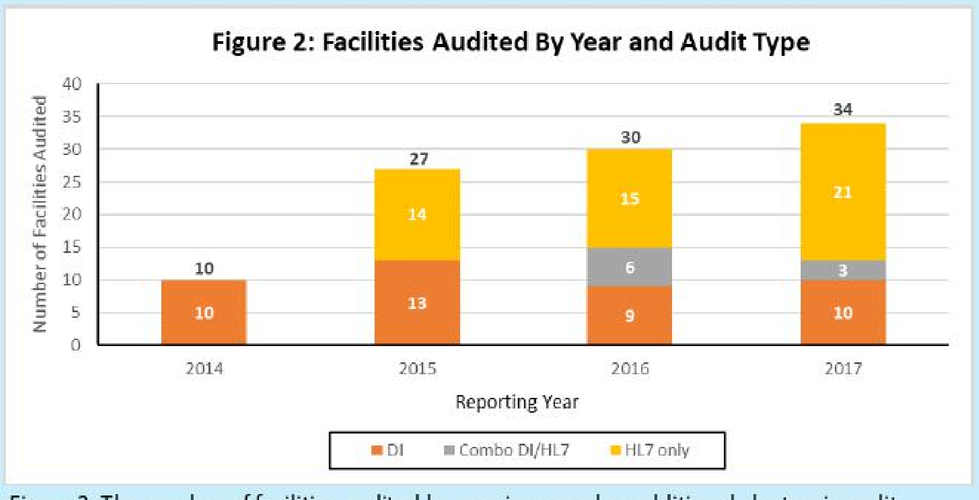

Figure 2. The number of facilities audited by year increased as additional electronic audit sources identified (HL7 and Combo DI/HL7).

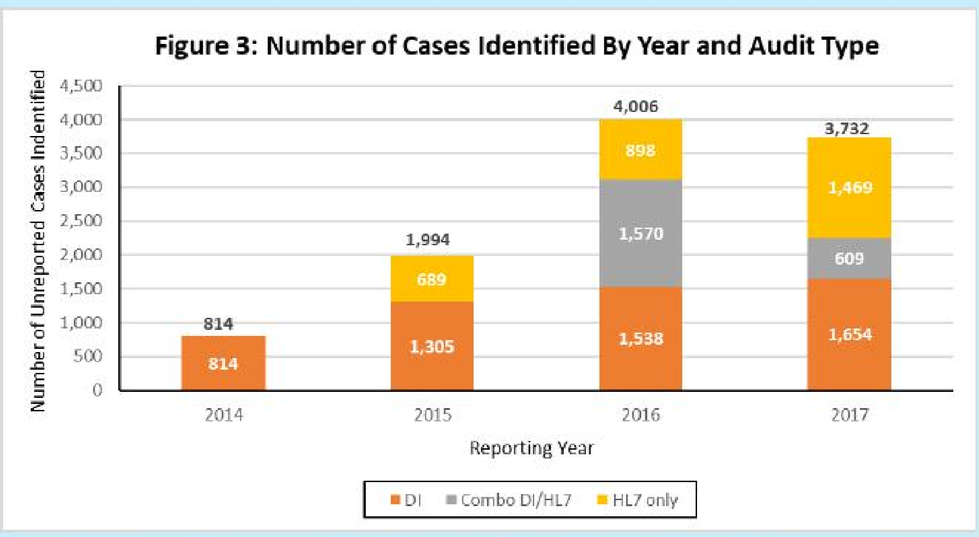

Figure 3. The significant increase in the number of cases identified by year is associated with expansion of the audit process.

Table 1: Percentage of cases retrieved from audited facilities per year from 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%**

Table 1. The number of cases submitted by facilities after the audit increased over time by an average of 7%.

DISCUSSION

The progress in remote auditing from 2014 to 2017 in the number of facilities audited and the number of cases retrieved is largely attributed to expanding data sources from which audits can be performed.

Challenges

- Visual review labor and time intensive due to increasing volume of electronic pathology reports
- Maintaining confidential communications despite variations in facility-specific encryption capabilities and policies
- Changing/merging healthcare facility affiliations
- Outsourced facility cancer registry and IT personnel
- Adherence to specific audit time frames by facilities and audit team
- Implementing the use of new software technology
- Healthcare facility IT issues

Rewards

- Greater data completeness for both healthcare facilities and NJSCR
- Improving facility casefinding, reporting, and communications with NJSCR
- Process improvements for NJSCR auditing

CONCLUSION

The use of remote auditing has reduced the time consumed by the audit process and costs associated with audits. Efficiency was increased, human error was decreased, and staff travel to facilities was eliminated.

Healthcare facility auditing enhances the awareness, support, involvement and understanding necessary to capture and identify all reportable cases leading to improved routine casefinding procedures. Adopting remote auditing by NJSCR has exceeded our expectations compared to onsite facility auditing.

ACKNOWLEDGMENTS

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Residential mobility among adults with a history of cancer:
an analysis of the 2013-2018 National Health Interview Survey

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BACKGROUND

- Residential mobility plays an important role in shaping people's health and health-related behaviors.
- We aim to identify sociodemographic factors associated with neighborhood relocation after the first cancer diagnosis among U.S. adult with a history of cancer.

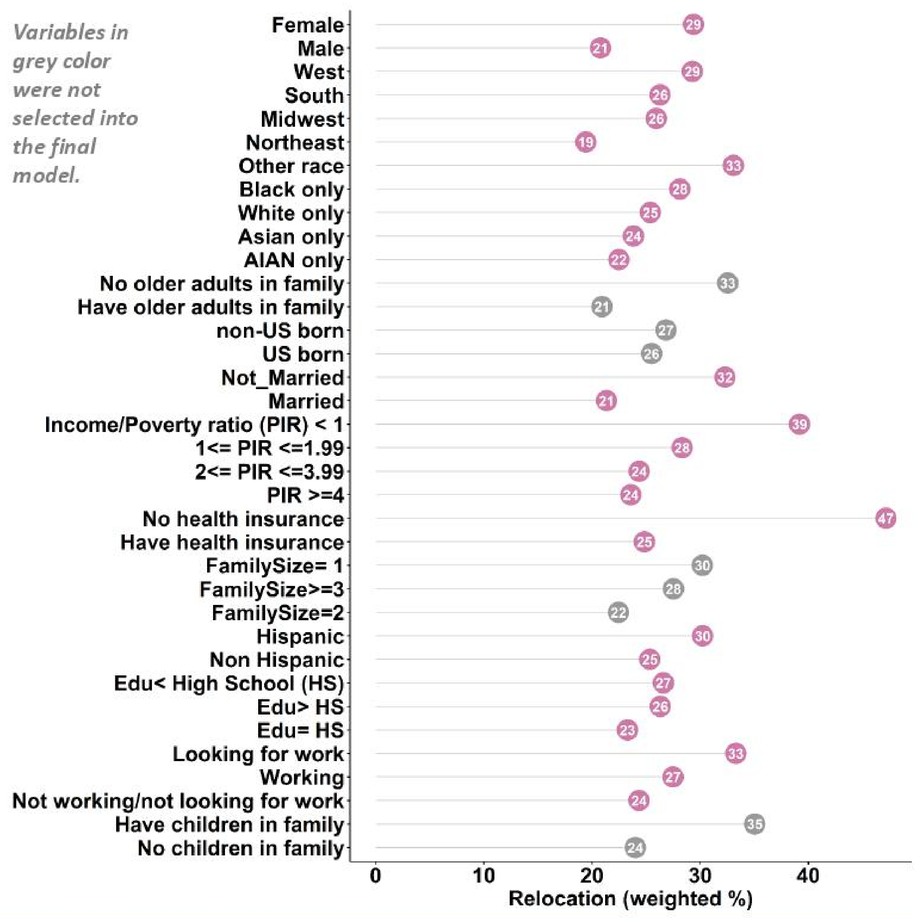
METHODS

- **Design:** Cross-sectional study
- **Data sources:** The 2013-2018 National Health Interview Survey
- **Study population:** A nationally representative samples of non-institutionalized civilian adults (≥18 years), who self-reported to have a history of cancer.
- **Outcome:** Neighborhood relocation after the first cancer diagnosis
  - T1 = Time since 1st cancer diagnosis: 1, 1-3, 4-10, 11-20, > 20 years.
  - T2 = Neighborhood tenure: 1, 1-3, 4-10, 11-20, > 20 years.

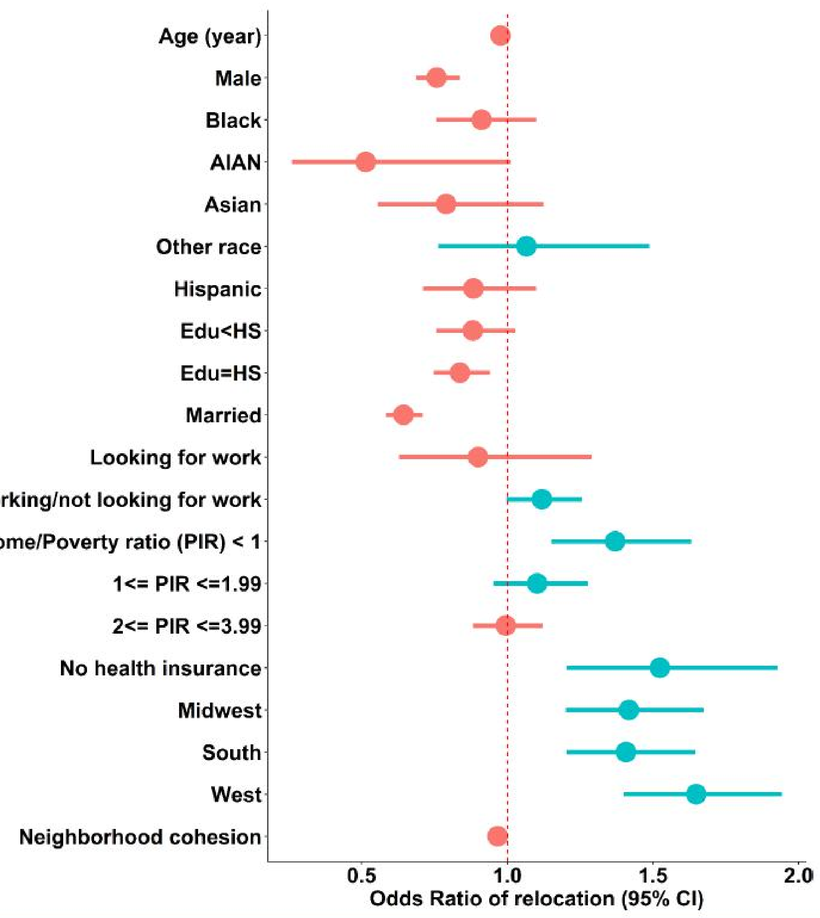
  If T2 < T1 ➔ Relocation= Yes
- **Exposure variables:** Demographic and socioeconomic factors
- **Statistical analysis:** Logistic regression model incorporating the complex NHIS design. Only a subset of the 15 demographic and socioeconomic factors were used as predictors, which were selected from a forward selection steps (entry significance level= 0.05).

RESULTS

- Approximately 40% of the adults with a cancer had resided in their neighborhood ≤ 10 years.



- 25.6% (~ 5.4 Million) relocated.
- Residential mobility was associated with multiple socioeconomic factors:
  - **OR>1:** below poverty income, no health insurance, not working/not looking for work, living outside of Northeast US.
  - **OR<1:** age, perceived neighborhood social cohesion, male, high school education, being married.



IMPLICATIONS

- Incorporating and addressing modifiable risk factors associated with residential mobility among cancer patients and survivors may offer new intervention opportunities to improve care delivery and reduce cancer disparities.

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Disclosure of Potential Conflicts of Interest: None to report.

Ethical approval and Data sharing statement: This article does not contain any studies with human participants performed by any of the authors. This study used the publicly available data from the National Health Interview Survey (NHIS), which is regularly conducted by the U.S. Census Bureau on behalf of the National Center for Health Statistics (NCHS). Survey participants were informed about the purpose and process of the NHIS in an advance letter prior to in-person interview, and verbal consent were obtained at the time of interview. The publicly released data contain no information that could identify any individual participants, and data were available from the NIHS website, https://www.cdc.gov/nchs/nhis/data-questionnaires-documentation.htm.

Cancer incidence rate variations among the Chinese, South Asian, and Vietnamese in Massachusetts, 2011-2015

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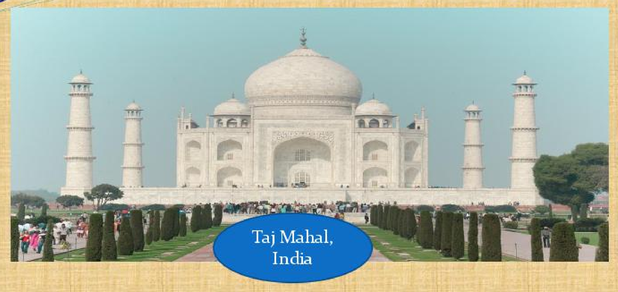
OBJECTIVE: To examine variations in cancer incidence among the three specific Asian, non-Hispanic ethnicities with the highest frequency of cases (South Asian, Chinese, and Vietnamese).



BACKGROUND:

- The US Census defines Asians as people having origins in any of the original peoples of the Far East, Southeast Asia, of the Indian subcontinent.
- For 2011-2015 US Census estimates, Asians constituted 5.9% of the general population in Massachusetts and 5.1% in the US.

Massachusetts 2011-2015 Asian Population*		
Ethnicity:	**Population**	**Percent**
Chinese	149,236	37%
South Asian (India/Pakistan)	86,775	22%
Vietnamese	47,240	12%
Cambodian	32,544	8%
Korean	26,421	7%
Filipino	12,219	3%
Japanese	10,119	2%
Other	36,121	9%
TOTAL ASIAN	400,675	100%
*-US Census American Community Survey estimates.		

- While Asians represent 5.9% of the Massachusetts population, they represent only 2.5% of cancer cases.
- Analyses were limited to the Asian ethnic groups with the largest number of cases (Chinese, South Asian, Vietnamese).

Massachusetts 2011-2015 Asian Cancer Cases *		
Ethnicity:	**Population**	**Percent**
Chinese	2,159	43%
South Asian	857	17%
Vietnamese	672	13%
Cambodian	240	8%
Korean	176	7%
Filipino	190	3%
Japanese	142	2%
Other	97	2%
Not Specified	470	9%
TOTAL ASIAN	5,003	100%
*-Massachusetts Cancer Registry		

ANALYSES:

Adjustment for Asian, Not Otherwise Specified Cases (NOS):

- From 2011-2105, 9% of Asian cases were reported to the MCR without a specific ethnicity (NOS), a percentage that would lead to an underestimate of incidence rates for ethnic groups.
- NOS cases were recoded based on the distribution of selected cancer types among cases with a specified ethnicity.
  1) Distribution of Asian cases with a known ethnicity for a cancer was determined. (For example, 48% of prostate cases were reported as Chinese, 16% were South Asian and 9% were Vietnamese.)
  2) Prostate cases among Asian, NOS males were then recoded based on these distributions.

Calculation of Rates:

- Limited to cancers with highest frequencies (all invasive, female breast, colorectal, liver, lung, thyroid, and prostate).
- Age-adjusted incidence rates with 95% confidence intervals were calculated for the cancers to assess statistical significance. Rates were not calculated for cancers with fewer than 20 cases.
- Rates were compared between South Asians, Chinese, and Vietnamese. These groups were then compared to all Asians and to all invasive cancer cases, regardless of race/ethnicity.

Age-Adjusted Cancer Incidence Rates Among Specific Asian Ethnicities Compared to All Asians and All Massachusetts (MA)* Cases, 2011-2015					
FEMALES					
Cancer:	**South Asian (n=484)**	**Chinese (n=1159)**	**Vietnamese (n=324)**	**All Asian (n=2226)**	**All MA Cases (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)
MALES					
Cancer:	**South Asian (n=373)**	**Chinese (n=1000)**	**Vietnamese (n=348)**	**All Asian (n=2777)**	**All MA Cases (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 MA 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.					

RESULTS:

- South Asian and Vietnamese females had significantly elevated rates of all invasive cancers compared to Chinese females, though significantly lower than all MA females.
- South Asian females had a significantly elevated breast cancer rate compared to all Asians but comparable to all MA females..
- Vietnamese males had a significantly elevated rate of all invasive cancers compared to Chinese and South Asian males, though significantly lower than all MA males.
- Vietnamese males had a significantly elevated liver cancer rate compared to Chinese males, all Asians, and all MA males.
- South Asian males had a significantly lower rate of colorectal cancer compared to all Asians and all MA males.
- Vietnamese males had significantly elevated rates of lung cancer compared to South Asian, Chinese, all Asian males **AND** all MA males.
- The percentage of known past/current tobacco use among all invasive cancers for males was significantly elevated ($p<.05$) for Vietnamese males (64%) compared to all males (53%).

CONCLUSIONS:

- These analyses showed a significant difference of rates for several cancers by specific Asian ethnicity, underscoring the heterogeneity of the broader Asian category.
- Ethnic-specific data can aid in the development of prevention programs that are culturally specific within this group, such as:
  - Breast cancer screening for South Asian women.
  - Smoking cessation for Vietnamese men.
  - Hepatitis B screening and treatment for Vietnamese men.
- The MA Department of Public Health Women's Health Network works with various Asian community groups for outreach and education on health screening.

We acknowledge both the Centers for Disease Control and Prevention under cooperative agreement 5 NU58DP006271-03-00 and the National Cancer Institute under contract HHSN261201800008I for their support of the staff and the printing and distribution of this report awarded to the Massachusetts Cancer Registry at the Massachusetts Department of Public Health. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the Centers for Disease Control and Prevention.

Epidemiology of Gliomas near Brainstem in Children and Adolescent in the United States, 2000-2016: High-grade gliomas, Ependymomas, and Pilocytic Astrocytomas

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BACKGROUND

- Limited population-based data exists for brainstem gliomas of children, which include:
  - high grade, aggressively-growing tumors such as diffuse intrinsic pontine glioma (DIPG or diffuse midline glioma H3-K27M positive) and
  - low grade tectal glioma.
- We examined the overall incidence and survival patterns in children with brainstem gliomas by age, sex, and race and histology

METHODS

- We used data from Central Brain Tumor Registry of the United States (CBTRUS)[1], obtained through data use agreements with Centers for Disease Control (CDC) and the National Cancer Institute's (NCI), from 2000 - 2016 for malignant gliomas in the brainstem for ages ≤19 years (per WHO ICD-O-3 codes).
- The final incidence dataset included the incidence data representing 100% of the US population.
- Information on patient outcomes (survival) was derived from SEER specialized Radiation/Chemotherapy Databases (1975-2016), representing a subset of the population included in the CBTRUS dataset and approximately 28% of the US population[2].
- Age-adjusted incidence rates (AAIR) and survival data were used to assess differences overall and by age, sex race, and treatment type.
- Survival was assessed with Kaplan-Meier survival curves (generating median survival times and log rank tests) and multivariable Cox proportional hazards models (generating hazard ratios with 95% confidence intervals (95% CI)).

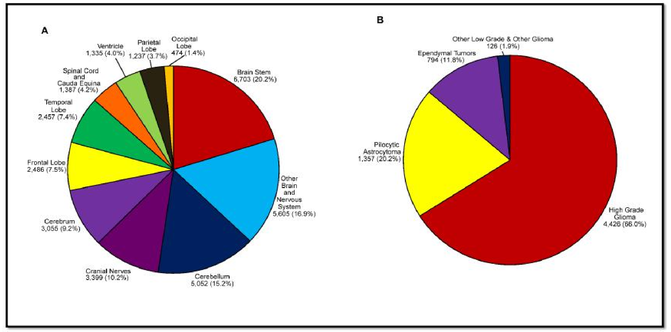

Figure 1) Distribution of Primary Childhood and Adolescent (age ≤19 years) Brain and Other CNS Gliomas[b] by A) Site and B) Histology Subtypes within Brainstem (ICD-O-3 site code C71.7).

RESULTS

- Overall, from 2000 to 2016, there were 33,190 patients with primary malignant glioma originating from brain and other CNS locations among children ages 0-19 years.
  - 6,703 (20.5%) patients were identified with gliomas in the brainstem (Figure 1)
- The incidence (AAIR= 0.32, 95% CI: 0.31–0.33) of high-grade glioma were highest compared to pilocytic astrocytoma (AAIR=0.097, 95% CI: 0.09-0.10) and ependymal tumors (AAIR=0.06, 95% CI: 0.05-0.06) (Figure 2).

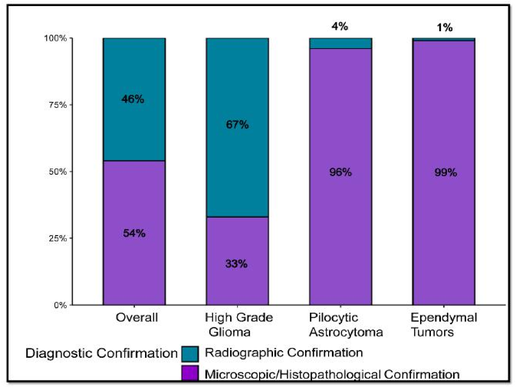

Figure 3) Diagnostic Confirmation of the Primary Childhood Brainstem Glioma by Histology, 2000-2016.

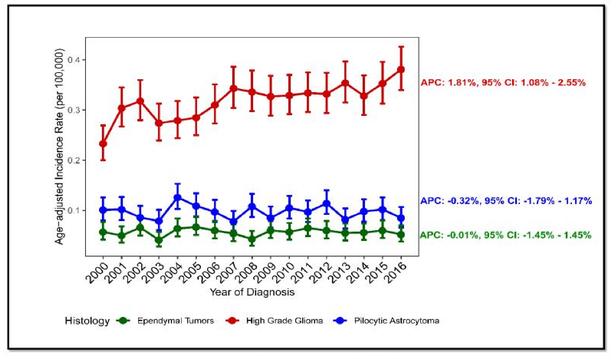

Figure 4) Age-Adjusted Incidence Trends With 95% Confidence Intervals of Primary Childhood and Adolescent Brainstem Glioma by Histology, 2000-2016.

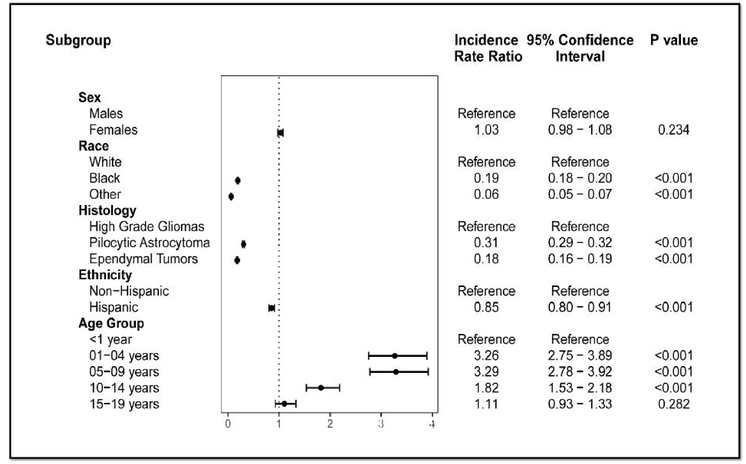

Figure 2) Age-Adjusted Incidence Rates Ratios with 95% Confidence Intervals by Patient Characteristics for Gliomas near Brainstem in Children and Adolescent in the United States: 2000-2016.

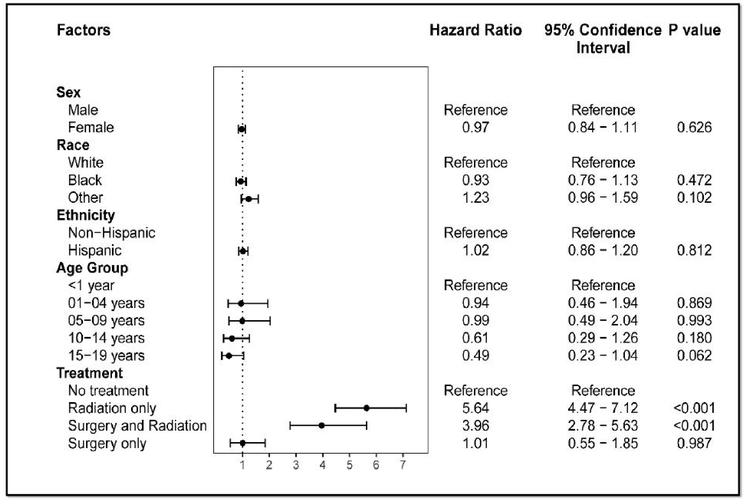

Figure 5) Multivariable Cox Proportional Hazards Model Results (With Hazard Ratio, 95% CI and P-Values) For Primary High-Grade Childhood Brainstem Glioma using SEER 2000-2016 (N = 1,237)

CONCLUSION AND FUTURE DIRECTIONS

- During the study period (2000-2016), the incidence of primary malignant brainstem glioma in children age 0-19 was increasing, especially that of High-grade glioma.
- High grade glioma was most common and fatal histology compared to pilocytic astrocytoma and ependymal tumors.
- Survival among patients with high grade glioma did not differ by sex, race, ethnicity, age groups and diagnostic confirmation.
- Further research is warranted to determine the advantage or disadvantages of treatment options that provide maximal benefit with minimal risk to these patients.

ACKNOWLEDGEMENTS

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Cervical Cancer in Bermuda: An in-depth analysis on invasive cervical cancer for the time period of 2007-2016.

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Bermuda Hospitals Board

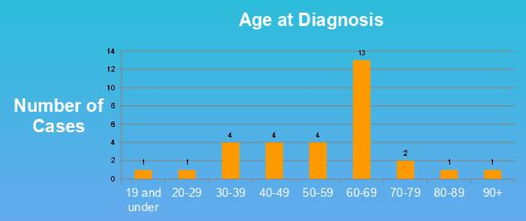
Introduction

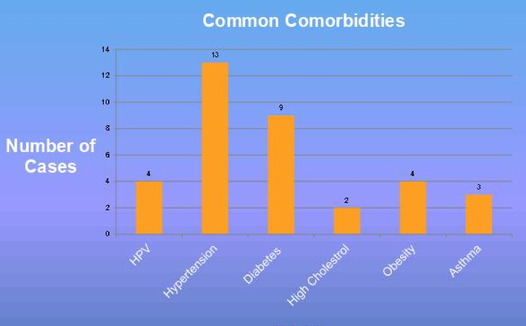
Invasive cervical cancer is the second most common cancer amongst women worldwide however, in Bermuda, it does not even rank in the top 10 of most-commonly diagnosed sites. The objective of this study was to examine invasive cervical cancer cases during the ten-year period of 2007-2016 and detailed smoking status, HPV status, family history of disease, common comorbidities and age at diagnosis.

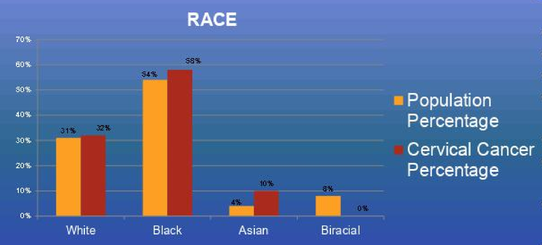
age	cases(d,)	BDA 2014 census	age-spec. rate (r,)	st. pop (US)	std.r.
0-4	0	3684	0.00	18988520	0.00
5-9	0	3577	0.00	19919940	0.00
10-14	0	3619	0.00	20086779	0.00
15-19	1	3578	27.96	19819518	2.02
20-24	0	3625	0.00	18257225	0.00
25-29	1	4383	22.82	17722067	1.47
30-34	1	4485	22.30	19311370	1.86
35-39	3	4244	70.69	22179936	5.71
40-44	1	4767	20.98	22479229	1.72
45-49	4	5127	78.02	19805793	5.63
50-54	2	5741	34.84	17224359	2.16
55-59	2	4942	40.47	13307234	1.96
60-64	9	3980	226.13	10684272	8.77
65-69	4	3221	124.19	9,409,940	4.26
70-74	2	2284	87.57	8,725,574	2.76
75-79	1	1685	59.35	7,414,559	1.6
80-84	0	1230	0.00	4,900,234	0
85+	2	958	208.77	4,239,173	3.24
Total	33	69128	30.67	274633642	42.92
Crude Rate	30.67	Crude rate			
ASR (W) =	42.92	Age-standardized rate (using 2000 U.S standard population)			

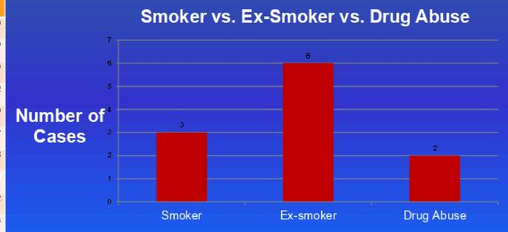
Table 1: Age-standardized rate

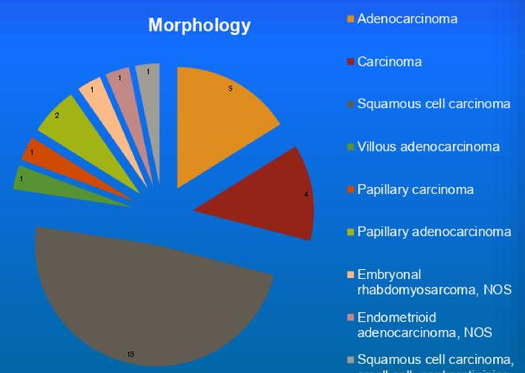
Graphs











Methodology

- Age at diagnosis ranged from 19yrs to 94yrs
- Study population of N=31, Black (N=18), White (N=10), Asian (N=3).
- Data were stratified by age-group, morphology, comorbidities, race, habits (smokers, ex-smoker etc.) and family history.
- The Bermuda National Tumour registry was used to identify patients between the time-period of 2006-2017 who had invasive cervical cancer.
- King Edward Memorial Hospital IV (KEMH) Health Information Management Services (HIMS) department collected 31 patient charts and the missing fields were then registered and input into CanReg (Tumour Registry Software).
- Histology and morphology codes were defined according to the ICD-O-3.
- Age-standardized rate was calculated using the U.S Standard Population 2000
- Bermuda population percentage distribution by race (2010): 54% Black, 31% White, 4% Asian, 8% Biracial

Results

- Age-group with the highest number of new cases is 60-69.
- Hypertension was the most common comorbidity.
- Asian women had a higher incidence rate than any other race.
- With respect to morphology, 48 percent of invasive neoplasms were squamous cell carcinoma.
- Race: 58% Black , 32% White , 10% Asian, 0% Biracial
- None of the cases had a positive family history, 17 had a negative family history and 14 had an unknown family history.
- Out of 31 cases, 10 are deceased of those 6 died from invasive cervical cancer. The case fatality rate is 60 percent.
- Out of 31 cases, 4 were HPV positive, other cases were either, not tested, negative or unknown.
- 3 Smokers, 6 Ex-smokers and 2 Drug abusers

Limitations

- The small sample size increases the likelihood of the outcome that could have occurred by chance therefore, the degree of probability is small
- There is a possibility of missed cases due to persons being diagnosed or treated abroad
- Although the abstracted cases are mainly complete, several unknown fields (comorbidities/HPV status, habits, family history etc.) were marked as unknown.

Conclusion

Findings from the analysis of this data should provide Bermuda and researchers some insight into the particulars of invasive cervical cancer cases during a specific time period . Smoking is a known independent risk factor for invasive cervical cancer and 29 percent of the women were smokers. The largest disparity is evident in the Asian race which had the overall highest incidence rate. Although, incidence is relatively low, case fatality is high. More research must be done to decrease the morbidity and mortality on this population.

Acknowledgements

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Ependymoma, NOS and anaplastic ependymoma incidence and survival in the United States varies widely by patient and clinical characteristics, 2000- 2016

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BACKGROUND

Ependymoma is a rare central nervous system tumor arising from the ependymal lining of the ventricular system. General differences in incidence and survival have been noted, but not examined on a comprehensive scale for all ages and by histology. Despite the rarity of ependymomas, morbidity/mortality associated with an ependymoma diagnosis justifies closer examination.

METHODS

Incidence data were obtained from the Central Brain Tumor Registry of the United States in collaboration with the CDC and NCI, and survival data from SEER, from 2000 - 2016 for anaplastic ependymoma and ependymoma, NOS. Age-adjusted incidence rates (IR) per 100,000 person-years were analyzed by age, sex, race, location. Survival analysis was performed with Kaplan-Meier curves and multivariable Cox proportional hazards models.

RESULTS

Incidence of anaplastic ependymoma was highest in ages 0-4 years. Black populations had lower incidence but had a 78% increased risk of death compared to White populations[HR:1.78,(95%CI:1.30,2.44)]. Incidence was highest for anaplastic ependymoma in the supratentorial region. Adults (40+ years) had almost twice the risk of death compared to children (0-14 years) [HR: 1.97, (95% CI: 1.45, 2.66)]. For ependymoma, NOS, subtotal resection had a risk of mortality 1.61 times greater than gross total resection [HR: 1.414, (95% CI: 1.32, 2.83)].

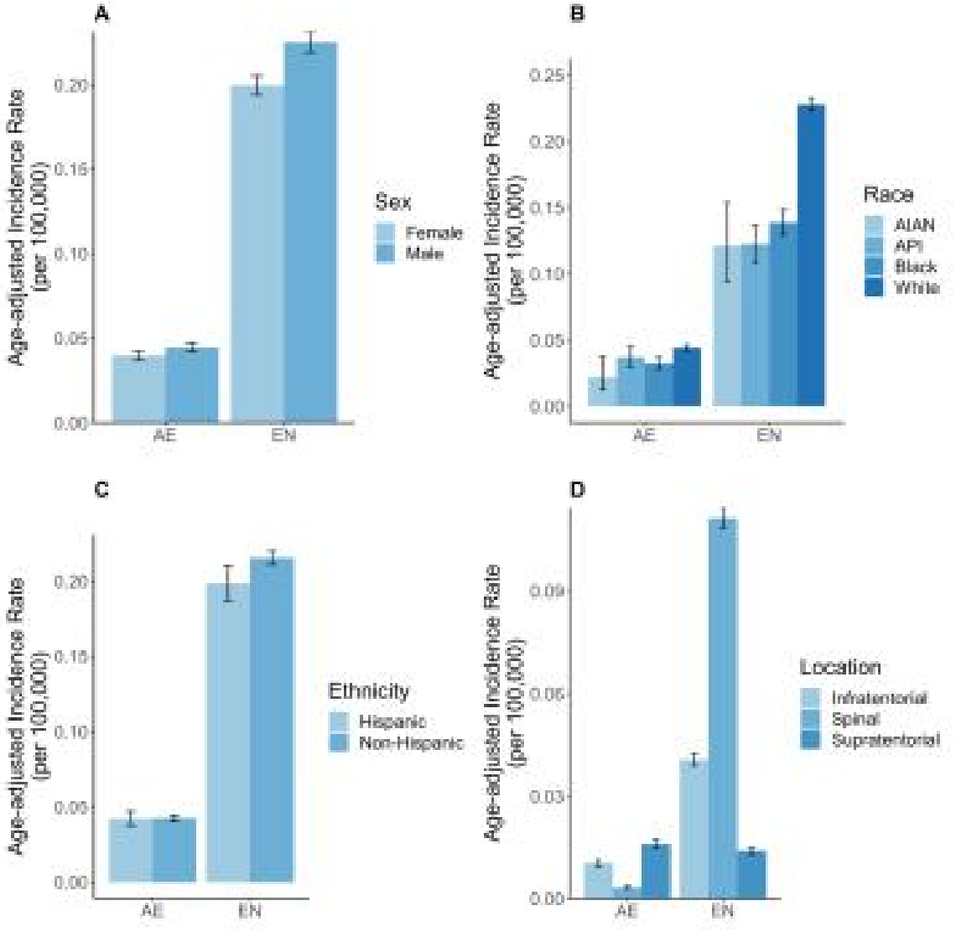

Figure 1) Age-adjusted incidence rates for A) Sex, B) Race (API – Asian or Pacific Islander, AIAN- American Indian / Alaskan Native) C) Ethnicity D) and Location, by histology (AE – Anaplastic Ependymoma, EN – Ependymoma, NOS). (CBTRUS 2000-2016)

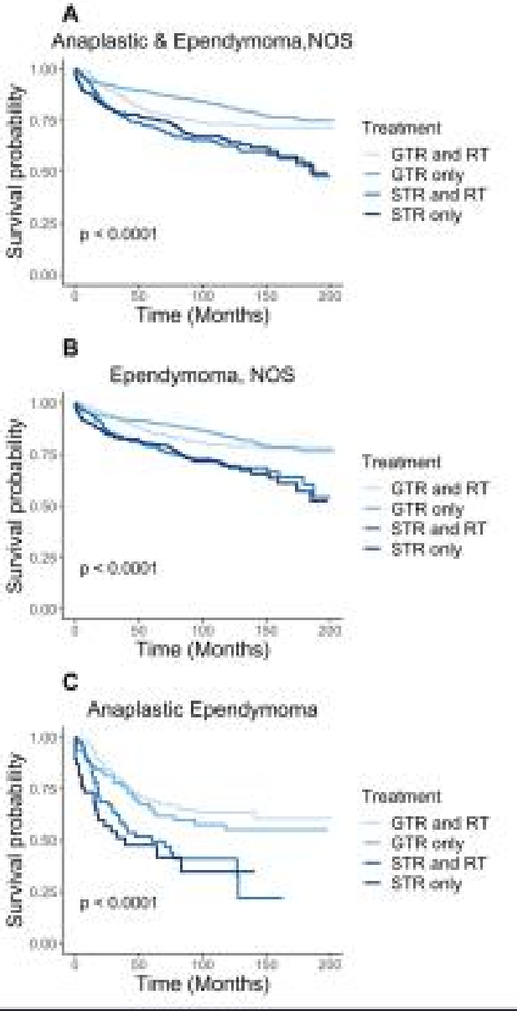

Figure 2) Kaplan-Meier survival curves stratified by gross-total resection (GTR), subtotal resection (STR), GTR + radiation (RT), or STR + RT, for A) for anaplastic ependymoma and ependymoma, NOS. B) ependymoma, NOS. C) anaplastic ependymoma (CBTRUS 2000-2016)

CONCLUSION AND FUTURE DIRECTIONS

Black populations experienced higher mortality rates despite lower incidence compared to White populations. Extent of resection is an important prognostic factor for survival. This highlights need for further evaluation of treatment patterns and racial disparities in the care of patients with ependymoma subtypes.

ACKNOWLEDGEMENTS

Funding for CBTRUS was provided by the Centers for Disease Control and Prevention (CDC) under Contract No. 75D30119C08058, the American Brain Tumor Association, The Sontag Foundation, Novocure, the Musella Foundation, National Brain Tumor Society, the Children's Brain Tumor Foundation, the Uncle Kory Foundation, the Zelda Dorin Tetenbaum Memorial Fund, as well as private and in-kind donations. OTO is supported by a Research Training Grant from the Cancer Prevention and Research Institute of Texas (CPRIT; RP180097T). Contents are solely the responsibility of the authors and do not necessarily represent the official views of the CDC.

Evaluating Types of Diagnostic Confirmation and Unknown Rate between Benign/Borderline and Malignant Brain Tumors among Central Cancer Registries in the United States

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[1]Louisiana Tumor Registry; [2]Central Brain Tumor Registry of the United States; [3]New York State Cancer Registry; [4]Baylor College of Medicine; [5]American Cancer Society; [6]Centers for Disease Control and Prevention; [7]Kentucky Cancer Registry; [8]NAACCR

Background

Diagnostic confirmation is commonly used in selecting eligible cases in population-based cancer studies. Most of studies will include only microscopically confirmed cases. However, for brain/CNS tumors the first confirmation is often a diagnosis by radiography such as computerized tomography (CT) or magnetic resonance imaging (MRI) scan. Particularly in benign/borderline (BB) brain/CNS tumors diagnosed, these tumors are frequently diagnosed via radiography without microscopic confirmation. Furthermore, the variation of age-adjusted incidence rate of BB brain tumors among central cancer registries (CCRs) is greater than that of malignant brain tumors. It is unclear if this variation is related to the differences in the degree of thorough casefinding processing across CCRs.

Objective

- To evaluate the unknown rate of brain tumor diagnostic method by patient demographics, subsite, and diagnosis year as well as to identify CCR(s) with higher unknown diagnostic method.
- To compare the diagnostic confirmation method of brain tumors by behavior, age, subsite, and CCR.

Table 1. Percent of brain/CNS tumors with unknown diagnostic method by behavior and covariate: 2012-2016

Variables	Benign/Borderline		Malignant	
	N	% Unknown	N	% Unknown
Sex	p = 0.8654		p < 0.0001	
Male	71,766	0.97	61,653	1.18
Female	145,181	0.96	48,536	1.59
Race	p = 0.0024		p = 0.0042	
White	178,202	0.94	96,609	1.32
Black	24,487	0.97	8,330	1.63
AI/AN	1382	1.30	599	1.50
Asian or Pacific Islander	9,181	1.07	3,415	1.49
Unknown	3,695	1.54	1,236	2.35
Age	p < 0.0001		p < 0.0001	
00-19 years	7,812	1.01	14,114	0.79
20-39 years	20,286	0.78	13,562	0.68
40-59 years	67,292	0.85	29,193	0.78
60-79 years	88,760	0.93	42,615	1.30
80+ years	32,797	1.39	10,705	4.78
Brain/Other CNS subsite	p < 0.0001		p = 0.1687	
Meninges	152,442	0.74	1,876	1.71
Brain	22,049	2.18	102,159	1.36
CNS	37,984	0.86	4,901	1.10
Endocrine glands	4,472	3.42	1,253	1.68
Metro/Non-Metro 2013	p = 0.0022		p < 0.0001	
Metro	182,358	0.96	90,323	1.33
Non-Metro	29,586	1.07	16,716	1.71
Unknown	5,003	0.56	3,150	0.29
Diagnosis Year	p < 0.0001		p < 0.0001	
2012	42,027	1.13	21,802	1.70
2013	42,832	1.02	22,202	1.61
2014	43,834	1.02	22,006	1.25
2015	44,776	0.83	22,198	1.20
2016	43,478	0.83	21,981	1.05

Materials and Methods

Reportable BB and malignant brain tumors diagnosed in years 2012-2016 were obtained from CiNA analytic file and CCRs of 50 states and the District of Columbia in the United States were included. Eligible cases were those with ICD-O-3 primary site codes C70.0-C72.9, C75.1-C75.3 and histology codes 8000, 8680-9136, 9141-9582. Cases identified solely from death certificate or autopsy were excluded. The method of diagnostic confirmation is categorized into microscopically confirmed; radiographic diagnosis only; clinical diagnosis only; and unknown. Clinical diagnosis only includes positive laboratory test/marker study and direct visualization without microscopic confirmation. Other covariates included sex, race, age, subsite, metropolitan status, and diagnosis year. The metropolitan area is defined using 2013 Rural/Urban Continuum Code.
Frequency distributions of diagnostic method by CCR were computed. CCRs with unusually higher unknown rate were assessed using box-and-whisker plot. Chi-square test was used to identify factors associated with unknown diagnosis. Logit model was carried out to evaluate tumor behavior and other factors that were associated with diagnostic method. We also calculated age-adjusted incidence rates by tumor behavior and CCR.

Figure 1. Diagnostic method by tumor behavior and age group: 2012-2016

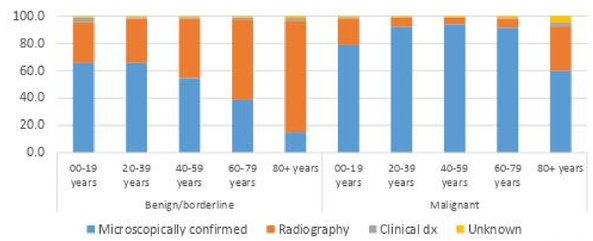
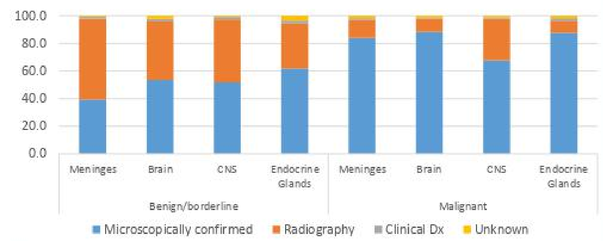


Figure 2. Diagnostic method by tumor behavior and subsite: 2012-2016



Results

Two-third of the 327,136 eligible cases were BB brain tumor cases (66.3%) and of them 66.9% were females. Patients having BB tumor in endocrine glands or having malignant tumor at age 80+ years had the highest unknown diagnosis, 3.4% and 4.8%, respectively (Table 1). From 2012-2016, unknown rate decreased from 1.1% to 0.8% for BB cases and from 1.7% to 1.2% for malignant cases. Among 51 CCRs, the average of unknown diagnosis was 1.0% (Range 0.0%-5.5%) for BB cases with 5 CCRs having unknown rate above upper whisker and 1.4% (Range 0.0%-6.8%) for malignant cases (Table 2). Patients with malignant tumor at age 40-59 years had the highest percent of microscopic diagnosis (94%) and only about 15% of BB tumor patients aged 80+ were diagnosed thru this method (Figure 1). Whereas, percent of radiographic diagnosis increased as age increased for BB tumors. Among subsites, malignant brain tumors had the highest percent of microscopic diagnosis (88%) and meninges BB tumors had the highest percent diagnosed thru radiography (61%) (Figure 2). Overall 54.2% of BB tumors were diagnosed by radiography (Figure 3a); while 87.4% of malignant cases were microscopic diagnosis (Figure 3b). Seventeen CCRs had lower percent of radiographic diagnosis as compared to microscopic confirmation for BB tumors and 16 of them had significantly lower BB brain incidence rates than the national rate ($p < 0.05$).

Figure 3a. Types of Diagnostic Confirmation and Incidence Rate for Benign/Borderline Brain/CNS Tumor by registry: 2012-2016

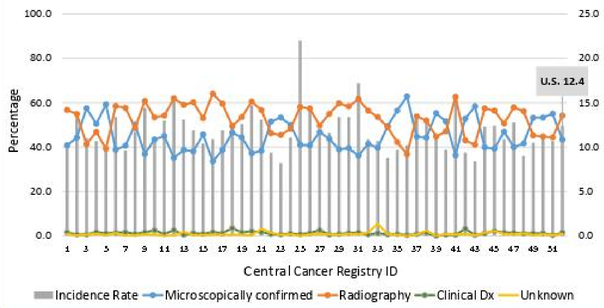


Figure 3b. Types of Diagnostic Confirmation and Incidence Rate for Malignant Brain/CNS Tumor by registry: 2012-2016

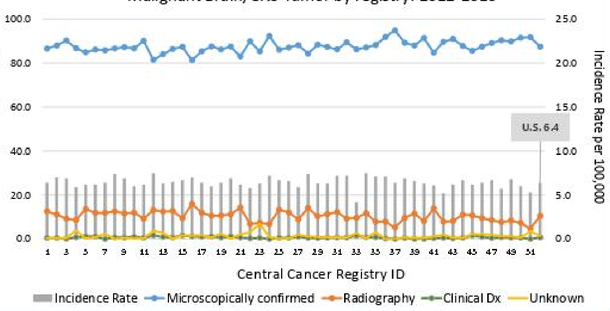


Table 2. Unknown diagnostic method by behavior based on 51 CCRs

Registry Level	BB	Malignant
25-75% Percentile (IQR)	0.4%-0.9%	0.4%-2.1%
Minimum	0.0%	0.0%
Mean	1.0%	1.4%
Median	0.6%	1.7%
Maximum	5.5%	6.8%
Upper Whisker*	1.7%	4.7%
# outside of upper whisker	5	1

Upper Whisker: extends to largest data point within the boundary of Q3 + 1.5x (Q3-Q1); where Q1 is the first quartile of unknown rate and Q3 is the third quartile of unknown rate.

Table 3. Adjusted odds ratio (OR) and 95% confidence interval (CI) using logit model for factors associated with brain/CNS tumor diagnostic methods

Variables	Diagnosis Method		
	Radiography	Clinical	Unknown
	OR (95% CI)	OR (95% CI)	OR (95% CI)
BB vs Malignant	7.37 (7.13-7.60)	4.63 (4.13-5.18)	2.83 (2.55-3.14)
Female vs Male	1.28 (1.26-1.30)	1.20 (1.12-1.28)	1.31 (1.22-1.40)
Black vs White	1.11 (1.08-1.14)	1.33 (1.20-1.47)	1.28 (1.15-1.43)
AI/AN vs White	1.08 (0.97-1.20)	1.70 (1.22-2.36)	1.49 (1.02-2.20)
API vs White	0.87 (0.83-0.90)	1.10 (0.94-1.28)	1.20 (1.02-1.42)
Unknown vs White	1.10 (1.03-1.17)	1.36 (1.08-1.72)	2.15 (1.72-2.68)
20-39 vs 00-19 years	0.43 (0.41-0.45)	0.30 (0.26-0.36)	0.79 (0.66-0.96)
40-59 vs 00-19 years	0.57 (0.55-0.60)	0.37 (0.32-0.42)	1.15 (0.98-1.35)
60-79 vs 00-19 years	1.02 (0.99-1.06)	0.63 (0.55-0.71)	1.94 (1.66-2.27)
80+ vs 00-19 years	4.23 (4.05-4.42)	3.03 (2.65-3.46)	9.34 (7.95-10.98)
Brain vs Meninges	0.59 (0.58-0.61)	1.03 (0.92-1.15)	2.60 (2.33-2.90)
CNS vs Meninges	0.93 (0.91-0.95)	1.43 (1.31-1.57)	1.48 (1.31-1.66)
Endocrine glands vs Meninges	0.49 (0.46-0.53)	1.35 (1.11-1.65)	4.55 (3.85-5.39)
Non-metro vs Metro	1.04 (1.01-1.06)	1.21 (1.11-1.32)	1.21 (1.10-1.32)
Unknown vs Metro	0.71 (0.67-0.75)	0.40 (0.30-0.54)	0.37 (0.27-0.51)
2013 vs 2012	1.01 (0.98-1.03)	1.06 (0.95-1.17)	0.93 (0.84-1.03)
2014 vs 2012	1.03 (1.01-1.06)	1.08 (0.97-1.19)	0.85 (0.77-0.94)
2015 vs 2012	1.03 (1.00-1.06)	1.11 (1.00-1.23)	0.74 (0.66-0.82)
2016 vs 2012	1.02 (0.99-1.05)	1.10 (0.99-1.21)	0.70 (0.63-0.78)

Table 3 delineates factors associated with diagnostic method. Comparing to malignant tumor, BB tumor had 7 folds (95% CI 7.13, 7.60) of diagnosed by radiography than thru microscopic confirmation. Also patents 80+ years old were most likely to be diagnosed thru other methods than microscopic diagnosis as compared with younger patients.

Conclusions

Overall the unknown diagnosis decreased overtime. The percent of brain tumors with unknown diagnosis and type of diagnostic methods varied by age, subsite, and CCR for both BB and malignant tumors. For CCRs with an extremely lower percent radiographic diagnosis of BB tumors, the efforts to ensure the complete case ascertainment from outpatient and/or radiology log sources may be necessary to further elucidate underreporting. CCR with unknown diagnosis percentage above the upper whisker is considered having data quality issue.

Acknowledgments

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Neighborhood-based Survival Disparities in Pediatric and AYA Acute Leukemia

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Background

Sociodemographic disparities in survival among patients with acute lymphoblastic (ALL) and myeloid leukemias (AML) aged less than 39 years have been reported in the United States with some conflicting results

Objective

To evaluate the impact of multiple neighborhood factors, using a novel archetype approach, on survival among young patients with ALL and AML in California

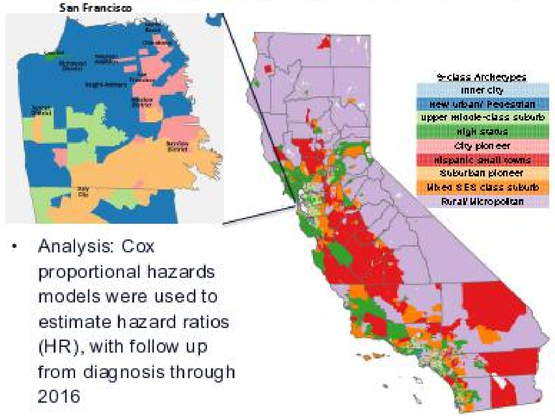
Hypothesis

Living in low SES neighborhoods with predominantly non-White populations is associated with lower survival among young patients with acute leukemia

Methods

- Cohort: 8,761 patients aged 0-39 years reported to the California Cancer Registry with a diagnosis of ALL or AML in 2006-2016
- Outcome: overall survival (OS)
- Neighborhood Exposures (at diagnosis):
  - nSES quintiles: composite index derived from principal components analyses of 7 indicators (education, income, poverty, employment, occupation, house value, rent)
  - 9-class neighborhood archetype: single classification system derived from latent class analysis of 39 social and built environment attributes

Neighborhood Archetype Distribution in California



- Analysis: Cox proportional hazards models were used to estimate hazard ratios (HR), with follow up from diagnosis through 2016

Table 1: Patient Characteristics

	ALL (N=6338)	AML (N=2423)
Race/Ethnicity		
non-Hispanic White	26.0%	32.3%
non-Hispanic Black	3.5%	5.6%
Hispanic	59.9%	46.6%
Asian/Pacific Islander	9.4%	14.3%
Unknown	1.2%	1.2%
Sex		
Male	58.4%	51.8%
Female	41.6%	48.2%
Age at Diagnosis		
0-9	53.4%	19.9%
10-19	25.1%	19.9%
20-29	12.5%	26.5%
30-39	9.0%	33.8%
Leukemia Type		
ALL		
B cell	81.9%	
T cell	13.3%	
Other	4.8%	
AML		
Other		78.6%
Acute ProMyelocytic Leukemia		21.4%
Health Insurance Status		
None	1.9%	2.8%
Private	44.6%	47.7%
Medicare	0.5%	0.9%
Public/Medicaid	50.9%	46.0%
Unknown	2.1%	2.5%
Chemotherapy		
No	3.2%	8.0%
Yes	96.8%	92.0%
Treatment at a pediatric cancer center		
No	30.8%	53.9%
Yes	69.2%	46.1%
Neighborhood SES		
Quintile 1 - lowest SES	28.5%	25.9%
Quintile 2	22.9%	22.9%
Quintile 3	18.8%	19.5%
Quintile 4	15.4%	17.4%
Quintile 5 - highest SES	14.4%	14.3%
Archetype		
1.Class 4-Suburban pioneer	10.5%	10.2%
2.Class 2-Mixed SES class suburb	7.8%	8.4%
3.Class 8-High Status	9.8%	9.5%
4.Class 5-Inner city	26.4%	21.9%
5.Class 7-Rural Micropolitan	5.4%	6.1%
6.Class 9-New urban/ pedestrian	7.5%	9.7%
7.Class 3-Hispanic small towns	13.8%	13.0%
8.Class 6-Upper middle-class suburb	11.8%	12.9%
9.Class 1-City pioneer	5.7%	7.3%
Missing	1.2%	1.2%

Neighborhood Archetype Characteristics

	Urban-icity	SES	Demo-graphics	Households	Land Use	Commuting and Climate	Food
Upper middle-class suburb		High	White/API	Midlife, fewer female HH	Greenspace, recreation	Low connectivity	
High status		High	White	Older	Greenspace, recreation		Healthy
New urban/Pedestrian	Downtown		Diverse (non-Hispanic)	Young singles	Mixed use	High traffic	
Mixed SES class suburb				Families	Some mixed use, recreation	Commuting, low connectivity	Healthy
Suburban pioneer	City	Middle	Diverse	Families, owning	Mixed use		
Rural/Micropolitan	Rural	Low	White	Older, single headed households		Low traffic	
City pioneer	City	Lower-middle	Diverse	Older, single female HH, renters	Mixed use	High traffic	
Hispanic small towns		Lower-middle	Hispanic		Some mixed use, less greenspace	Less commuting, low traffic	Unhealthy
Inner city	Urban city	Low	Black, Hispanic	Renters, Vacancy			Unhealthy

Table 2: Multivariable Models of Overall Survival

	ALL			AML		
	Mortality (%)	Adjusted HR	Adjusted HR	Mortality (%)	Adjusted HR	Adjusted HR
All Cases	17.9%			35.9%		
Race/Ethnicity						
non-Hispanic White	12.9%	1.00 (reference)	1.00 (reference)	35.0%	1.00 (reference)	1.00 (reference)
non-Hispanic Black	18.0%	**1.45 (1.03 - 2.05)**	**1.47 (1.04 - 2.08)**	47.8%	**1.59 (1.20 - 2.09)**	**1.54 (1.16 - 2.04)**
Hispanic	20.3%	**1.57 (1.33 - 1.87)**	**1.59 (1.34 - 1.90)**	35.7%	1.12 (0.94 - 1.33)	1.09 (0.91 - 1.30)
Asian/Pacific Islander	16.8%	**1.44 (1.13 - 1.83)**	**1.47 (1.16 - 1.88)**	35.5%	1.03 (0.83 - 1.27)	1.00 (0.80 - 1.25)
Unknown	14.1%	1.49 (0.81 - 2.74)	1.47 (0.80 - 2.71)	20.7%	0.65 (0.29 - 1.46)	0.64 (0.28 - 1.44)
Health Insurance Status						
None	33.9%	**1.58 (1.14 - 2.20)**	**1.67 (1.20 - 2.32)**	44.9%	0.93 (0.63 - 1.36)	0.93 (0.63 - 1.37)
Private	15.5%	1.00 (reference)	1.00 (reference)	35.1%	1.00 (reference)	1.00 (reference)
Medicare	43.3%	1.48 (0.84 - 2.59)	1.44 (0.82 - 2.53)	52.2%	1.44 (0.81 - 2.58)	1.47 (0.83 - 2.63)
Public	19.1%	**1.20 (1.05 - 1.38)**	**1.20 (1.05 - 1.37)**	35.9%	1.04 (0.89 - 1.21)	1.04 (0.89 - 1.21)
Unknown	18.8%	1.03 (0.67 - 1.57)	1.01 (0.66 - 1.54)	36.7%	0.69 (0.44 - 1.07)	0.65 (0.41 - 1.04)
Treatment at a pediatric cancer center						
No	29.9%	**1.19 (1.03 - 1.37)**	**1.21 (1.05 - 1.39)**	38.9%	1.13 (0.97 - 1.32)	1.12 (0.96 - 1.31)
Yes	12.5%	1.00 (reference)	1.00 (reference)	32.5%	1.00 (reference)	1.00 (reference)
Neighborhood SES						
Quintile 1 - lowest SES	20.7%	**1.43 (1.11 - 1.84)**		38.6%	**1.34 (1.04 - 1.72)**	
Quintile 2	19.8%	**1.39 (1.09 - 1.79)**		38.8%	1.26 (0.99 - 1.61)	
Quintile 3	17.8%	**1.42 (1.11 - 1.83)**		34.7%	**1.29 (1.00 - 1.67)**	
Quintile 4	16.6%	**1.29 (1.00 - 1.66)**		34.2%	1.11 (0.86 - 1.43)	
Quintile 5 - highest SES	10.7%	1.00 (reference)		30.3%	1.00 (reference)	
Neighborhood Archetype						
1.Class 4-Suburban pioneer	19.2%		**1.46 (1.06 - 2.01)**	35.8%		1.33 (0.96 - 1.84)
2.Class 2-Mixed SES class suburb	20.9%		**1.87 (1.35 - 2.60)**	40.9%		**1.43 (1.03 - 1.98)**
3.Class 8-High Status	9.6%		1.00 (reference)	31.7%		1.00 (reference)
4.Class 5-Inner city	20.6%		**1.50 (1.12 - 2.02)**	37.5%		**1.36 (1.01 - 1.83)**
5.Class 7-Rural Micropolitan	15.2%		**1.55 (1.07 - 2.26)**	29.7%		1.01 (0.69 - 1.48)
6.Class 9-New urban/pedestrian	16.2%		**1.44 (1.02 - 2.02)**	31.2%		0.99 (0.71 - 1.37)
7.Class 3-Hispanic small towns	21.2%		**1.82 (1.34 - 2.47)**	38.5%		1.30 (0.96 - 1.76)
8.Class 6-Upper middle-class suburb	13.8%		1.32 (0.96 - 1.82)	35.6%		1.19 (0.88 - 1.62)
9.Class 1-City pioneer	18.5%		1.37 (0.96 - 1.96)	37.3%		1.17 (0.82 - 1.65)
Missing	15.2%		1.27 (0.68 - 2.37)	44.8%		1.80 (0.97 - 3.33)

1 Both models adjusted for sex, race/ethnicity, age, year, leukemia type, treatment site, receipt of chemotherapy/radiation, and insurance status

2 Because nSES is a component of the neighborhood archetype two separate models were creased, one for each exposure of interest

Results

- The cohort is made up of mostly Hispanic patients with similar proportions of publicly and privately insured patients and with more patients were found in low SES neighborhoods and inner city areas
- Black and Hispanic race/ethnicity, older age (>19 years), lack of insurance, and treatment at an adult center were associated with inferior survival in multivariable models
- Patients in the lowest quintile of nSES had inferior survival for both ALL and AML relative to the highest quintile of nSES
- Relative to high status neighborhood archetype, other neighborhood archetypes demonstrated inferior survival with the most pronounced effects in inner city and mixed SES class suburban neighborhoods

Conclusions

- The substantial effect of neighborhood factors on overall survival highlights an important and persistent disparity
- When other aspects of the social/built environment in addition to nSES are incorporated into the neighborhood archetypes, stronger associations with survival are observed
- The greater effects of neighborhood and health insurance among patients with ALL (relative to AML) may be linked to the prolonged, outpatient nature of ALL therapy and non-adherence to oral medication

Trends in Incidence and Clinical-Pathological Patterns of Thyroid Cancer in New York State

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INTRODUCTION

- New York State (NYS) has one of the highest thyroid cancer (TC) incidence rates in the nation and, similar to other states, has had a substantial increase in incidence over the past several decades.
- A recent study using SEER 13 data suggested that the rate of TC had slowed and possibly started to decrease.[1]
- There are large differences in health outcomes by county in NYS.
- The study's aim was to examine trends in incidence and clinical-pathological patterns of TC in NYS and to assess whether county-level differences in health outcomes are correlated with TC incidence.

METHODS

- Using 1988-2017 NYS Cancer Registry data, we examined TC incidence rates by demographic and tumor characteristics.
- We used Joinpoint Regression Program (JP, version 4.6.0) to evaluate annual trends.
- Using the 2018 County Health Rankings from the Robert Wood Johnson Foundation, we examined the overall "Health Factors" measure and the specific domains "Clinical Care" and "Health Behaviors" in relation to county-level TC incidence.

RESULTS

Fig. 1 Trends in Thyroid Cancer Incidence by Sex, New York State, 1988-2017

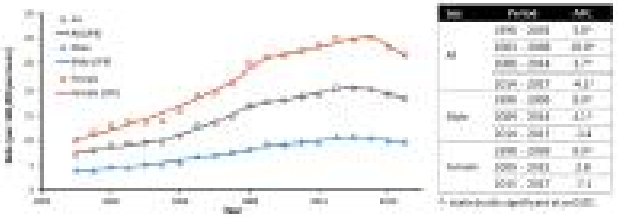

Fig. 2 Trends in Thyroid Cancer Incidence by Sex and Stage at Diagnosis, New York State, 1988-2017

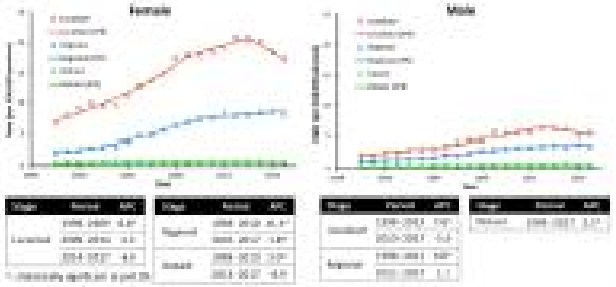

Fig. 3 Trends in Thyroid Cancer Incidence by Sex and Histologic Subtype, New York State, 1988-2017

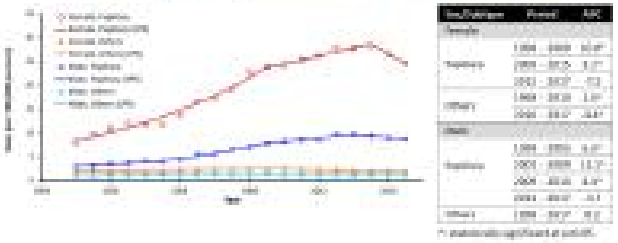

Fig. 4 Trends in Thyroid Cancer Incidence by Sex and Tumor Size, New York State, 1988-2017

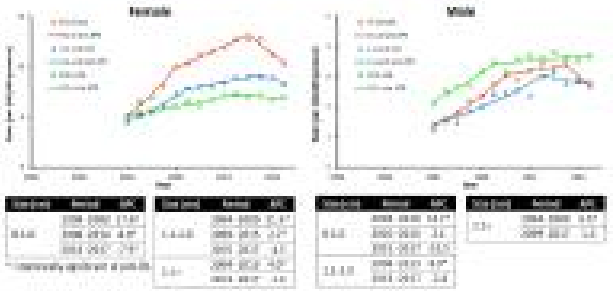

Fig. 5 Thyroid Cancer Incidence by Sex and County, New York State, 2013-2017

Fig. 6 Correlation between 2013-2017 Thyroid Cancer Incidence and Specific Domains of the 2018 County Health Rankings

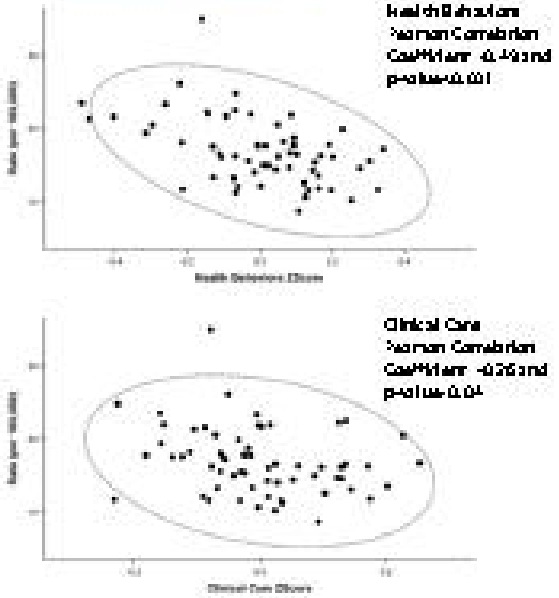

Fig. 7 Five-year Average Annual Percentage Changes for Thyroid Cancer Incidence by County, New York State, 2013-2017

CONCLUSIONS

- Thyroid cancer incidence in New York State may have reached a plateau, which appears to be driven by a decrease in the diagnosis of local-stage papillary microcarcinomas. This change may reflect a positive response from the healthcare system to overdiagnosis warnings.
- It appears that, in New York State, higher thyroid cancer incidence is associated with better health behaviors and better clinical care at the county level.

ACKNOWLEDGMENTS

This work was supported in part by:

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REFERENCE

1. Al-Refaie WB, et al. Changes in Trends in Thyroid Cancer Incidence in the United States, 1992 to 2016. JAMA. 2019;322(24):2440-1.

NATIONAL CENTER FOR CHRONIC DISEASE PREVENTION AND HEALTH PROMOTION

Modernizing an on-line data monitoring system for the CDC's National Program of Cancer Registries

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INTRODUCTION

- **Rapid and effective data monitoring is critical for cancer surveillance systems.**
- **CDC's National Program of Cancer Registries (NPCR) modernizing an on-line 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 Program 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

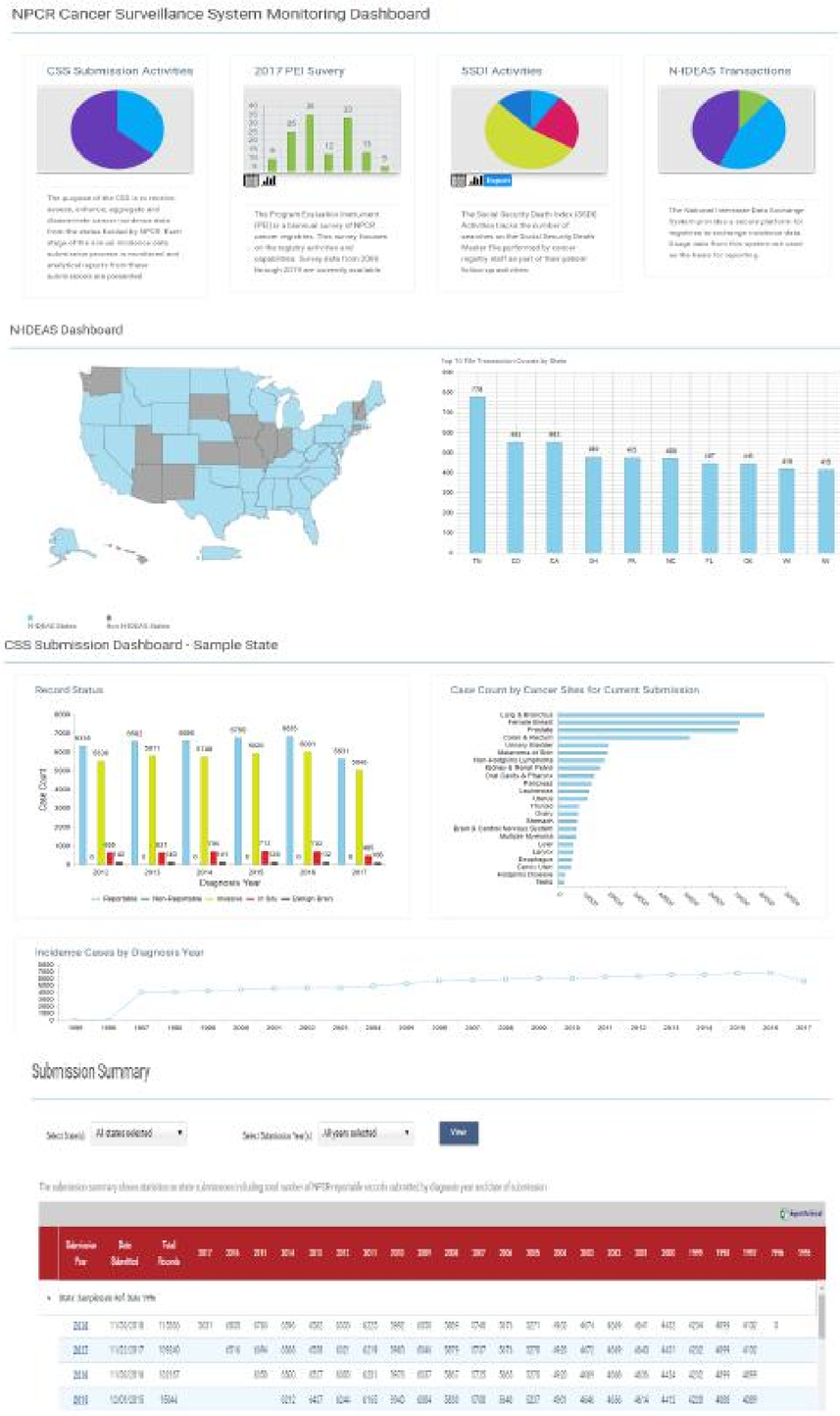
This presentation illustrates the design of a secure and modernized on-line tracking system that facilitates NPCR program monitoring and management. This modernization effort aims to enhance the existing CSS by providing a secure web portal for CDC and state users to monitor and track data submission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

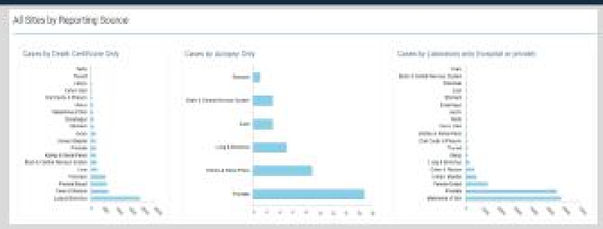
METHODS

Data visualization and secure data-driven query building are the key components of the MDB's modernization. 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**
- **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 MS Excel or 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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Trends and patterns of incidence of myelodysplastic syndrome (MDS) in SEER 21 regions: 2001 – 2016

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Background

- Myelodysplastic syndromes (MDS), a reportable malignant neoplasm in the Surveillance, Epidemiology, and End Results (SEER) Program since 2001, is a poorly understood malignancy consisting of a group of bone marrow disorders where stem cells either fail to mature or are defective.[1]
- MDS affects both children and adults. However, it is most prevalent in the older population, with about 90% of the patients being diagnosed at ≥ 60 year of age and with a median age at diagnosis of 76 years.[2,3]
- New information and diagnostic tools available since 2001 have improved both our understanding and identification of this disease.4 This has resulted in multiple revisions of the World Health Organization's classification of MDS, with the most recent significant changes adopted by the SEER Program in 2010.

Purpose

- To assess trends in incidence of MDS from 2001 to 2016, overall and by sex, age, race/ethnicity, and histologic subtype, applying the coding changes implemented in 2010.

Methods

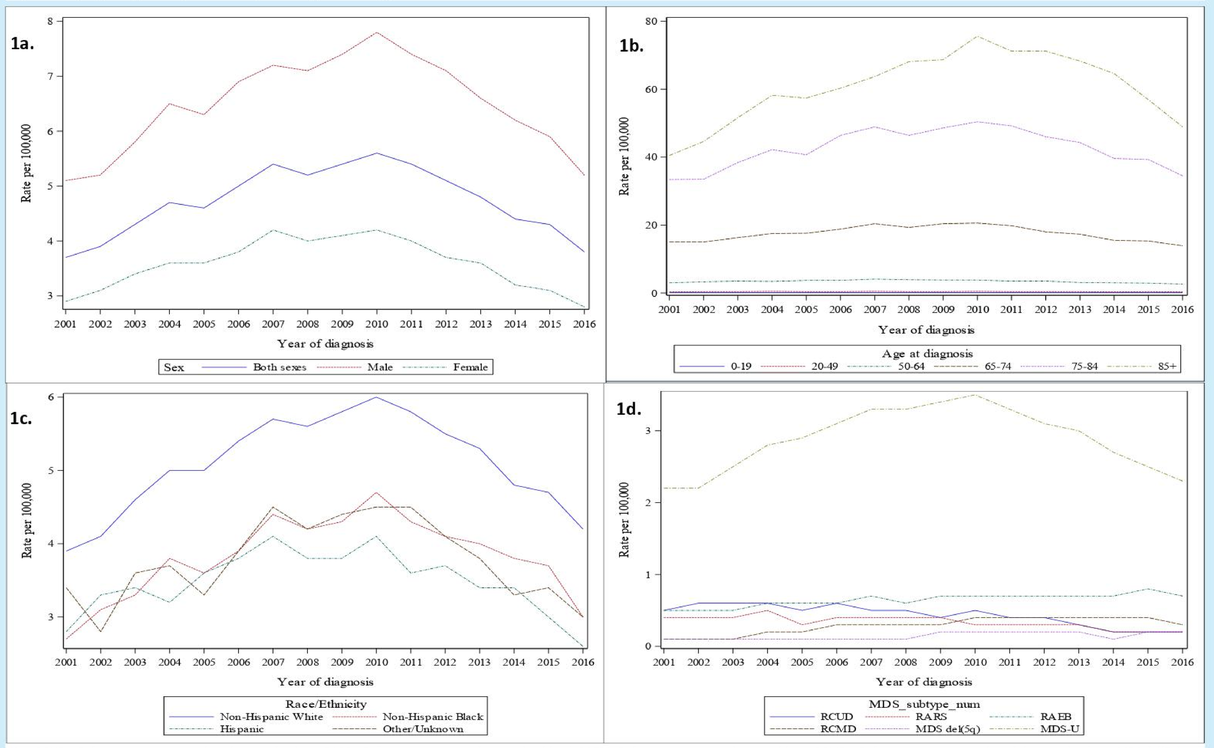
- Incidence data from SEER 21 regions for 2001-2016 period (November 2018 submission) were used to estimate age-adjusted incidence rates using SEER*Stat, version 8.3.6 (SEER, 2018).
- SEER 21 includes data from 21 registries covering approximately 36.7% of the population in the United States (US) and include the following geographic areas:
  - California, Connecticut, Detroit, Georgia, Hawaii, Idaho, Iowa, Kentucky, Louisiana, Massachusetts, New Jersey, New Mexico, New York, Seattle, Utah, and Alaska natives
- All MDS cases diagnosed between January 1, 2001 and December 31, 2016 with the following ICD-O-3 histology codes were included: 9980, 9982-9986, 9989, 9991-9992.
- All incidence rates were age-adjusted using the 2000 US standard population.
- Rates were estimated for the total population as well as by histology, sex, age, and race/ethnicity, applying histologic coding changes implemented in 2010 as described below:
  - New ICD-O-3 codes, 9991 and 9992, were added to categorize refractory neutropenia and refractory thrombocytopenia separately. These, along with refractory anemia (ICD-O-3: 9980) are combined to form refractory cytopenia with unilineage dysplasia for trend analysis by histology in this analysis.
  - Refractory anemia with excess blasts in transformation (RAEB-t, 9984) was combined with RAEB (ICD-O-3: 9983).
  - Therapy-related MDS (9987) was excluded from the analysis since it was recategorized with other therapy-related myeloid neoplasm.

Table 1. Age-adjusted incidence rates and counts of myelodysplastic syndrome for SEER 21 geographic regions by sex, age, race/ethnicity, and histology: 2001 – 2016.

	Both Sexes		Male		Female	
	Rate[1]	Count	Rate[1]	Count	Rate[1]	Count
Total[2]	4.7	86146	6.5	48293	3.6	37853
Age at diagnosis						
0 - 19	0.1	529	0.1	273	0.1	256
20 - 49	0.4	3051	0.4	1507	0.4	1544
50 - 64	3.4	11284	4	6310	2.9	4974
65 - 74	17.4	20576	22.5	12120	13.2	8456
75 - 84	42.6	31880	60.3	18503	30.3	13377
85+	61.2	18826	96.1	9580	44.5	9246
Race/ethnicity						
Non-Hispanic White	5.1	68734	7	39364	3.7	29370
Non-Hispanic Black	3.8	6151	4.9	2974	3.2	3177
Hispanic of all races	3.5	5993	4.3	3066	2.9	2927
Non-Hispanic Asians/Pacific Islanders	3.5	4513	4.5	2484	2.7	2029
Non-Hispanic American Indian/Alaska Native	3.0	271	3.7	149	2.4	122
Unknown	~	484	~	256	~	228
Histology Subtype (ICD-O-3)						
Refractory anemia (9980)	0.4	7678	0.5	4037	0.3	3641
Refractory anemia with ring sideroblasts (9982)	0.3	6130	0.5	3443	0.3	2687
Refractory anemia with excess blasts (9983)	0.6	11508	0.9	6972	0.4	4536
Refractory anemia w excess blasts in transformation (9984)	0.0	326	0.0	189	0.0	137
Refractory cytopenia with multilineage dysplasia (9985)	0.3	5179	0.4	3379	0.2	1800
Myelodysplastic syndrome associated with isolated del5q (9986)	0.1	2422	0.1	934	0.1	1488
Myelodysplastic syndrome unclassifiable (9989)	2.9	52636	4.0	29193	2.2	23443
Refractory neutropenia (9991)	^	^	^	^	^	^
Refractory thrombocytopenia (9992)	0.0	259	0.0	144	0.0	115

[1]Rates are per 100,000 and age-adjusted to the 2000 US standard population.
[2]Reflects 2010 histology code changes adopted by SEER Program, which groups therapy-related myelodysplastic syndrome (ICD-O-3: 9987) with other therapy-related myeloid neoplasms and adds refractory neutropenia and thrombocytopenia as new categories.
~Statistics could not be calculated.
^Statistics not displayed due to fewer than 16 cases.

Figures 1a – d. Trends in annual age-adjusted incidence rates of myelodysplastic syndrome in SEER 21 geographic regions during 2001-2016 period by: a) Sex, b) Age, c) Race/ethnicity, and d) Histology.



Key: RCUD = Refractory cytopenia with unilineage dysplasia, RARS = Refractory anemia with ring sideroblasts, RAEB = Refractory anemia with excess blasts, RCMD = Refractory cytopenia with multilineage dysplasia, MDS del(5q) = Myelodysplastic syndrome associated with isolated del(5q), MDS-U = MDS unclassifiable.

Results

- A total of 86,146 MDS cases were diagnosed during the study period, with the majority diagnosed at age ≥ 65 (83%), non-Hispanic white (80%), and classified as MDS unclassifiable (MDS-U, ICD-O-3: 9989, 61%).
- The overall age-adjusted incidence rate was 4.7 cases per 100,000 population with the rates higher among males than females (6.5 vs 3.6 per 100,000), among non-Hispanic whites (5.1) than other race/ethnicity (3.0-3.8), and among patients aged 65 and older (17.4 – 61.2) as compared to those under age 65 (0.1 – 3.4, Table 1).
- Annual rates increased from 3.7/100,000 in 2001 to 5.6/100,000 in 2010, then slowly declined to 3.8/100,000, making a slightly wide inverted v-shaped pattern.
  - This pattern was observed for both sexes, all racial/ethnic groups, and among ≥ 65 age groups (Figures 1a-c).
  - When assessed by histology, this pattern was observed for MDS-U, but not for other MDS subtypes (Figure 1d).

Conclusions

- The patterns of incidence rates observed during the study period are dominated by the incidence rates for MDS-U, a provisional diagnosis given before all diagnostic information becomes available to indicate a specific diagnosis.
- The decline in rates since 2010, observed mainly for the MDS-U, is most likely a reflection of the following types of diagnostic and coding changes, most of which occurred in 2010 to incorporate WHO's 2008 guidelines:
  - 1) definitive diagnostic methods were applied to identify specific subtypes and/or to rule out MDS,
  - 2) therapy-related MDS (9987) is no longer captured under MDS, and
  - 3) diagnosis criteria for AML were expanded to include cases with 20%-30% bone marrow blasts, which means that most cases previously defined as refractory anemia with excess blast in transformation (9984) are now classified as AML.
- Further analysis is warranted to conclusively determine all factors leading to the changes observed.

Acknowledgments

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

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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) 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 two months after this initial breast cancer diagnosis.

Identification of Subsequent Breast Cancer:

Women with an index breast cancer diagnosis were followed for ten 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 one of three 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 sub-distribution hazard regression analyses were performed. Only factors with an overall $p < 0.15$ 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 ten 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 one year after the first cancer diagnosis, 28.7% between one and five years, and 66.3% between five and ten years.

RESULTS (CONTINUED)

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 sub-distribution 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 Sub-distribution Hazard Regression Analysis		Multivariate Sub-distribution Hazard Regression Analysis[2]	
			Count	%	2 Months – 1 Year		1 – 5 Years		5 – 10 Years		Crude	P Value	Adjusted	P Value
					Count	%	Count	%	Count	%	sHR		sHR	
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	0.0001	0.57	0.0004
	50-59	4,724	186	3.9	10	5.4	45	24.2	131	70.4	0.50	<0.0001	0.53	<0.0001
	60-69	4,790	219	4.6	13	5.9	67	30.6	139	63.5	0.58	0.0003	0.63	0.0022
	70-79	3,788	151	4.0	8	5.3	46	30.5	97	64.2	0.51	<0.0001	0.54	0.0001
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	0.01	1.18	0.14
	Non-Hispanic API	637	22	3.5	0	0.0	3	13.6	19	86.4	0.81	0.31	0.73	0.15
	Hispanics	1,361	59	4.3	0	0.0	24	40.7	35	59.3	1.02	0.90	0.95	0.69
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	0.80	-	-
	10% - <20%	4,154	177	4.3	9	5.1	43	24.3	125	70.6	1.01	0.93	-	-
	20% - 100%	2,698	131	4.9	4	3.1	40	30.5	87	66.4	1.16	0.18	-	-
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	0.45	-	-
	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	0.64	-	-
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	0.73	-	-
	Infiltrating Duct/Lobular/or Other Types Mixed	2,481	109	4.4	8	7.3	29	26.6	72	66.1	1.03	0.77	-	-
	All Other Types Combined	1,771	90	5.1	6	6.7	36	40.0	48	53.3	1.20	0.12	-	-
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	<0.0001	0.73	0.02
	Borderline/Unknown	1,968	86	4.4	6	7.0	26	30.2	54	62.8	0.75	0.03	1.07	0.84
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	0.02	1.10	0.44
	Borderline/Unknown	2,271	93	4.1	6	6.5	31	33.3	56	60.2	0.82	0.11	0.74	0.30
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	0.77	-	-
	2006	4,545	209	4.6	7	3.4	67	32.1	135	64.6	1.07	0.51	-	-
	2007	4,331	187	4.3	14	7.5	43	23.0	130	69.5	1.00	0.98	-	-
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	0.14	0.96	0.64
	Unknown	1,124	59	5.3	0	0.0	19	32.2	40	67.8	1.11	0.49	1.08	0.61
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	0.61	-	-
	Unknown	925	40	4.3	1	2.5	14	35.0	25	62.5	0.98	0.91	-	-
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	0.0002	0.83	0.04
	Unknown	812	44	5.4	0	0.0	18	40.9	26	59.1	1.14	0.40	1.22	0.22

Notes: [1] **Fifty-three patients with unknown race/ethnicity were excluded from the regression analyses;** [2] **Only variables with an overall P-value < 0.15 in the univariate analysis were included in the multivariate analysis; - indicates that the variable was not in the model.**

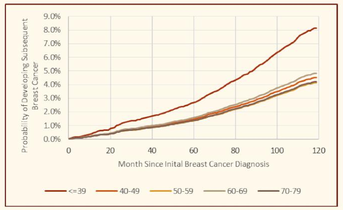

Fig. 1A

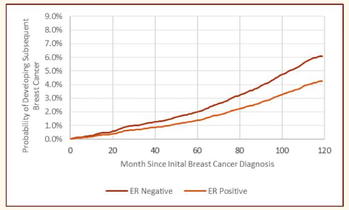

Fig. 1B

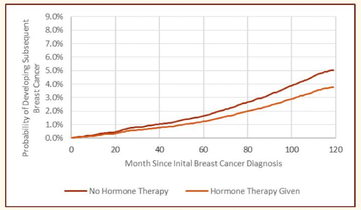

Fig. 1C

Figure 1. Cumulative incidence function (CIF) of developing a subsequent breast cancer among breast cancer survivors by age at the first cancer diagnosis (Fig. 1A), ER status (Fig. 1B) and hormone treatment status

RESULTS (CONTINUED)

- 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% 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 sub-distribution 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.

STRENGHS 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 under-estimated. The under-estimation 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 U.S 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 ten 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.

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NEW YORK STATE Department of Health

NATIONAL CENTER FOR CHRONIC DISEASE PREVENTION AND HEALTH PROMOTION

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

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INTRODUCTION

- CDC's National Program of Cancer Registries (NPCR) represents ~97% of the U.S population.
- Since its inception, NPCR Cancer Surveillance System (CSS) used the 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 35GB, especially burdensome.
- Efficient and convenient XML data processing is critical.

This poster presents two 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 datasets, 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.ElementTree package 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

Table 1

- The maximum 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.

Figure 1

- For all test data sizes, SAS managed to use 21 MB memory constantly.
- For Python with Xml.etree.ElementTree package, 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.

Figure 2

- Both SAS and Python runtime increases linearly with the increase of XML data sizes whereas SAS' 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 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.

DISCUSSION

- 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 30-40% 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 30-40% faster than SAS.
  - SAS and Python parse XML data reasonably efficiently.
- Python requires more memory than SAS.
  - A 30 GB XML dataset requires 413MB 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 Multi-threading	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

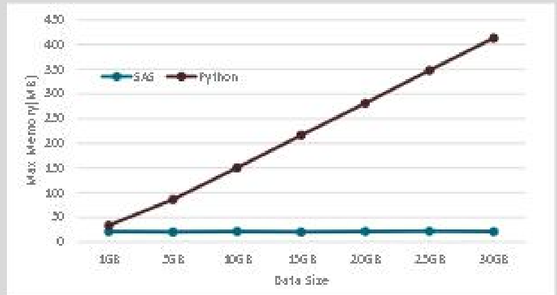
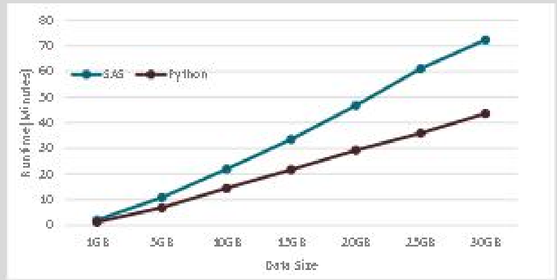


Figure 2: Comparisons of runtime performance of SAS and Python for parsing NAACCR XML data



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Use of Polygenic Risk Scores to Select Screening Intervals After Negative Findings From Colonoscopy

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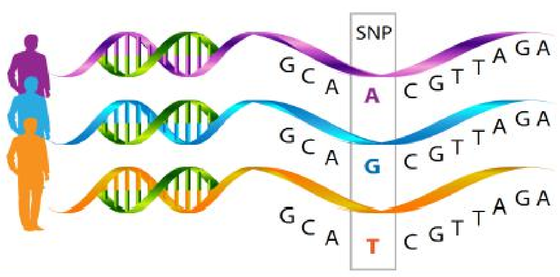
Background

- 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 3827 cases and 2641 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

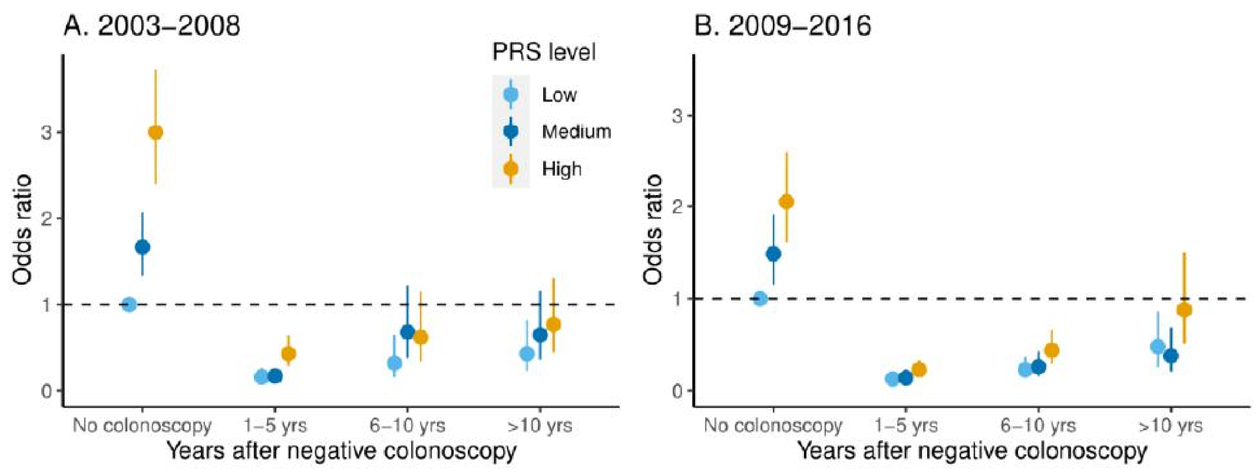
- When using participants without colonoscopy in the respective PRS groups as the reference, a negative colonoscopy was significantly associated with low CRC risk for time windows within and beyond 10 years after negative colonoscopy in all PRS groups (Table below).
- Compared to individuals without 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 below).

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)

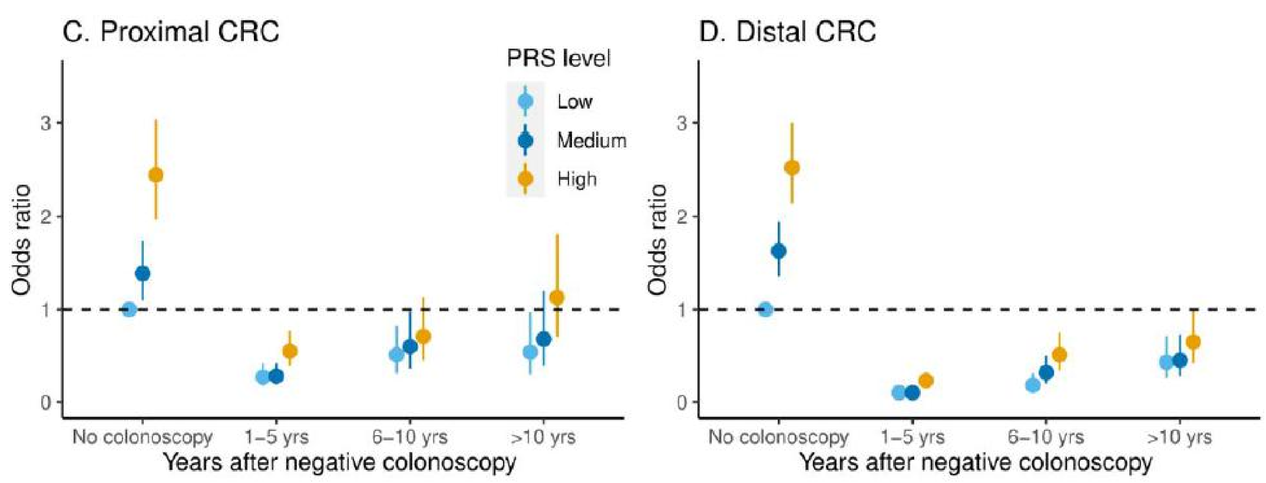
[a] Adjusted for age, sex, education, body mass index, participation in a health check-up, family history of colorectal cancer, smoking, ever regular use of nonsteroidal anti-inflammatory drugs, and ever regular use of hormone replacement therapy

Results

- 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 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 (Figure C and D).



Conclusion & 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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Tobacco-Related Cancer Trends Among Adolescents and Young Adults in California

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Background

- Tobacco-related cancers are an important cause of death, both in California and worldwide.
- Adolescents and young adults 15-39 years (AYAs) comprise nearly half (45.5%) of the over 3.5 million current smokers in California, and smoking prevalence among California's regions vary from 12.3%-21.1%.
- Although previous research has examined trends in tobacco-related cancers in the state, little is known regarding the regional differences in trends of tobacco-related cancers among California AYAs.

Purpose

To identify region-specific trends in tobacco-related cancer incidence rates among AYAs in California.

Methods

- 15,680 AYAs ages 15-39 diagnosed with tobacco related cancers during 2010-2017 were identified by the California Cancer Registry.
- For statistical analysis, the cancer sites were grouped according to anatomic systems, including acute myeloid leukemia (AML), ear nose and throat (ENT), genital and urinary (GU), lung, and gastrointestinal (GI).
- California counties were divided into 9 regions. SEER*Stat and Joinpoint software were used to analyze the average age-adjusted percent change (AAPC) in incidence rates for each group of cancer by anatomic group and region, anatomic group and race/ethnicity, and anatomic group and sex within California.

Results

- The AAPC in incidence for the tobacco related subgroups of AYA cancers differed among the regions of California as well as by race/ethnicity and sex in some cases.
- Consistent with overall state trends, GI cancer incidence increased for Hispanic, Non-Hispanic White, and Non-Hispanic Black AYAs over the study period (Table 1). This increase was shown for both males and females (Table 3), and in the San Diego/ Imperial, Inland, Central Valley, and LA/ Orange County regions (Table2).
- GU cancer incidence increased in the Central Coast region (Table 2) and for Asian/ Pacific Islander AYAs (Table 1).
- ENT cancers decreased in the Central Valley over the study period (Table 2).

Conclusion

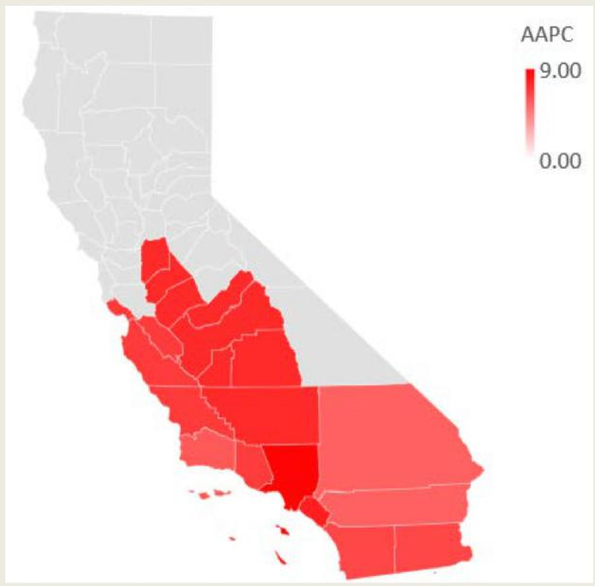
- From 2010-2017, significant trends in the AAPC of tobacco-related cancer incidence among AYAs were identified across the 9 California regions.
- Many trends differed between males and females, and among racial/ethnic groups.
- These results may be helpful in targeting specific regions and demographics of AYAs in the state for screening and interventions for tobacco, other risk factors, and cancer subtypes. Future analyses will incorporate tobacco status data and cancer sites.

Table 1. Significant (p <0.05) associations between tobacco related cancers by anatomic system and region, race, and sex in California AYAs (ages 15-39) diagnosed from 2010 to 2017

Variables	Anatomic System	AAPC	P-Value
Region			
Central Valley	ENT	-9.8404	0.0037
San Diego/ Imperial	GI	6.5042	0.0132
Inland	GI	5.5595	0.0267
Central Valley	GI	7.5052	0.03
LA/ Orange	GI	5.8655	<0.001
Central Coast	GU	6.9297	0.0466
Race			
Hispanic	GI	7.321	0.0008
Non-Hispanic Black	GI	4.667	0.0423
Non-Hispanic White	GI	4.836	0.0003
Asian/ Pacific Islander	GU	3.381	0.0024
Hispanic	GU	3.137	0.0231
Sex			
Male and Female	GI	5.2263	0.0001
Male	GI	4.4905	0.0013
Female	GI	5.6383	0.0003

Figure 1. Decreasing AAPC of ENT Cancers in California AYAs by Region

Figure 2. Increasing AAPC of GI and GU Cancers in California AYAs by Region



COMPLETE PREVALENCE OF PROSTATE CANCER IN THE UNITED STATES

A comparison of estimates obtained using SEER and NHANES data

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NAACCR 2020 Virtual Conference, June 23-25, 2020 Correspondence: nparihar@teamdrg.com

BACKGROUND

Complete prevalence of cancer represents the proportion of people alive on a certain day who were diagnosed with the disease, regardless of how long ago the diagnosis was made.

The Surveillance, Epidemiology, and End Results (SEER) program in the United States provides estimates of complete prevalence of cancer.

Self-reported cancer diagnoses from cross-sectional population-based surveys such as the National Health and Nutrition Examination Survey (NHANES) in the US can be used to estimate prevalence of cancer. However, there are concerns over underreporting and misclassification of disease in these surveys (Byrne et al., 1992).

This study aimed to compare estimates of complete prevalence of prostate cancer using data from the NHANES with those from the SEER program.

Byrne J, Rosenberg LE, Devesa SS. The prevalence of cancer among adults in the United States: 1987. Cancer 1992; 69(8):2154-2159.

METHODS

nhanes

NHANES is a nationally representative cross-sectional survey of the civilian noninstitutionalized population of the United States. We used SAS software (version 9.4; SAS Institute Inc., Cary, NC) to run statistical analysis and combined the NHANES 2011-12, 2013-14 and 2015-16 cycles. Cancers had binary answer choices for prevalence (ever diagnosed: yes/no) in the NHANES questionnaire.

Complete prevalence of prostate cancer was estimated by projecting the proportion of respondents who reported a history of prostate cancer diagnosis to the 2016 US national population estimates of males aged 20 years or older (UN, 2015).

CDC. Centers for Disease Control and Prevention, National Center for Health Statistics (NCHS). National Health and Nutrition Examination Survey Data. 2018

UN. United Nations Department of Economic and Social Affairs, Population Division. World Population Prospects. 2015

SEER

SEER Cancer Statistics Review (Howlader et. al. 2019) provided counts for complete prevalence of prostate cancer in 2016, based on data from the SEER 13 Areas (excluding the Alaska Native Registry) and 1/1/2016 U.S. male population estimates from the US Bureau of the Census.

SEER estimates of complete prevalence were based on the completeness index method (Capocaccia et. al. 1997, Merrill et. al. 2000).

Capocaccia R, De Angelis R. Estimating the completeness of prevalence based on cancer registry data. Stat Med 1997; 16(4):425-440.

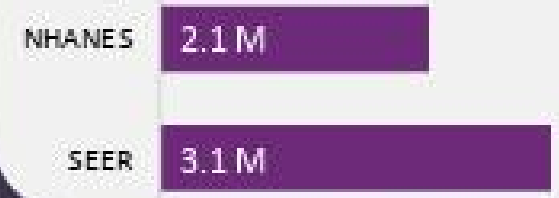
Howlader N et al (eds). SEER Cancer Statistics Review, 1975-2016, National Cancer Institute. Bethesda, MD. April 2019

Merrill RM, Capocaccia R, Feuer EJ, Mariotto A. Cancer prevalence estimates based on tumour registry data in the Surveillance, Epidemiology and End Results (SEER) Program. Int J Epidemiol 2000; 29(2):197-207.

RESULT

SEER estimated 3.1 million prevalent cases of prostate cancer in the U.S. in 2016, while the estimation using NHANES data led to 2.1 million cases, suggesting a difference of 31%.

Complete prevalence (no. of cases) of prostate cancer in the US in 2016



CONCLUSION

Diagnosed prostate cancer patients undergo frequent monitoring by physicians. It is therefore difficult to comprehend why a third of males comprising SEER-estimated complete prevalence would not remember or not report a history of prostate cancer diagnosis in their response to NHANES questionnaires. Therefore, the reason for the discrepancy between estimates of prostate cancer complete prevalence by SEER and NHANES is unclear.

DRG
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Evaluating the impact of social and built environments on health-related quality of life among cancer survivors

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DREA.I.I.LAB

Background

- With over 17 million cancer survivors in the US, understanding factors that impact health-related quality of life (HRQOL) after cancer diagnosis is critical to improving survivorship outcomes.
- Few studies have evaluated the impact of neighborhood factors (nSES, poverty, segregation) on HRQOL.
- Objective: To examine independent and joint associations between a comprehensive set of social and built environment attributes and HRQOL among cancer survivors.

Methods

We pooled data from three SEER-based studies in CA:

- **Assessment of Patients' Experience of Cancer Care** (APECC), PI: Oakley-Girvan: 774 bladder, colorectal, or leukemia survivors; interviewed 2003-2004 (2-5 years after diagnosis)
- **Experiences of Care and Health Outcomes of survivors of Non-Hodgkin's Lymphoma** (ECHOS-NHL), PI: Hamilton: 408 non-Hodgkin's Lymphoma survivors; interviewed 2003-2005 (2-5 years after diagnosis)
- **Follow-up Care Use among Survivors** (FOCUS), Bay Area PI: Oakley-Girvan and Los Angeles PI: Hamilton: 1,666 breast, colorectal, ovarian, prostate or uterine cancer survivors; interviewed 2005-2006 (4-14 years after diagnosis)

Multilevel dataset

- Survey data: sociodemographics, treatment, follow-up care, social support, cognitive health appraisals, health behaviors, HRQOL (physical and mental composite scores, PCS and MCS, from SF36)
- California Cancer Registry data: age at diagnosis, stage
- California Neighborhoods Data System data (2000): nSES, racial/ethnic composition, population density, housing characteristics, street connectivity, commuting patterns, businesses, food environment, recreational facilities, parks, traffic density
- Final analytic study population included 2,477 cancer survivors (excluded 285 missing HRQOL and 86 with addresses that were not geocodable)

Analyses

- Used 3-level models with participants nested within block groups, which are nested within study/region, we calculated least squares means, with and without adjustment for individual-level covariates, for individual neighborhood attributes and a summary neighborhood variable, or archetypes, developed using latent class analyses (LCA). Archetypes accounted for the synergistic effects of 39 social and built environment attributes.

Results

Study population characteristics

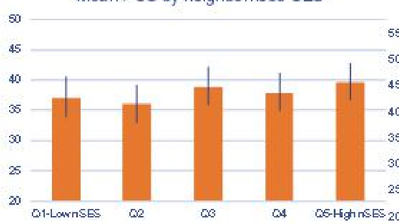
	n (col %)	Mean PCS	Mean MCS
All		44.7	50.6
Sex			
Male	1134 (45.8%)	46.1	51.2
Female	1343 (54.2%)	43.5	49.9
Age at interview			
<40	74 (3.0%	51.0	49.7
40-49	192 (7.8%)	48.9	46.2
50-59	432 (17.4%)	47.3	47.8
60-69	646 (26.1%)	45.7	51.3
70+	1133 (45.7%)	42.0	51.9
Race/Ethnicity			
NH White	1284 (51.8%)	45.3	50.6
Hispanic	324 (13.1%)	45.1	48.6
African American	398 (16.1%)	42.2	50.4
API	424 (17.1%)	45.2	51.4
Education			
<=High school	612 (24.7%)	41.8	49.2
Some college or college grad	1299 (52.4%	44.7	50.7
>College	552 (22.3%)	47.8	51.5
Neighborhood Attributes			
Neighborhood SES			
Low Q1-Q3	896 (36.2%)	42.3	49.5
High Q4-Q5	1581 (63.8%)	46.0	51.1
Racial/ethnic composition			
Predominantly minority	1072 (43.3%)	43.2	49.8
Mixed	1188 (48%)	45.9	50.9
Predominantly white	217 (8.8%)	45.7	51.8
Population density			
Low Q1-Q3	1334 (53.9%)	45.9	51.3
High Q4-Q5	1143 (46.1%)	43.3	49.5
Street connectivity			
Low Q1-Q3	1535 (62.0%)	45.4	51.0
High Q4-Q5	942 (38.0%)	43.5	49.6
Restaurant Environment			
No unhealthy restaurants	518 (20.9%)	45.8	51.5
Any unhealthy restaurants	1722 (69.5%)	44	50.1
No restaurants	237 (9.6%)	46.9	51.1
Recreational facilities			
None	338 (13.6%)		50.3
Any	2139 (86.4%)		50.5
Parks			
0	598 (24.1%)	45.4	51.2
1-2	1191 (48.1%)	44.3	50.6
3+	688 (27.8%)	44.9	49.7

Neighborhood associations with HRQOL

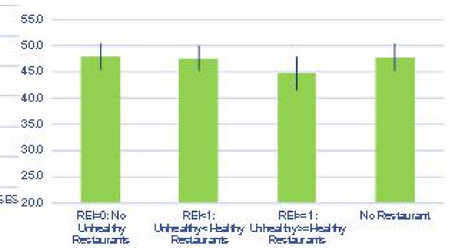
Among a diverse cohort of cancer survivors, the following neighborhood attributes were associated with HRQOL:

- **PCS**: With increasing nSES*, cancer survivors reported better HRQOL
- **MCS**: With increasing nSES, decreasing population density, street connectivity, parks, fast food restaurants*, % rental units* and % non-single family households, cancer survivors reported better HRQOL

Mean PCS by neighborhood SES



Mean MCS by restaurant environment index



Neighborhood archetypes associated with physical and mental composite score (PCS, MCS)

Neighborhood archetypes	Model 1: Minimally adjusted[a] Mean (95% CI)	Model 2: Fully adjusted[b] Mean (95% CI)
PCS		
Class 8-*Upper middle class sub*	45.1 (43.1-47.1)	39.1 (35.8-42.4)
Class 6-*High status/Status fringe*	44.8 (42.9-46.7)	39.0 (35.8-42.2)
Class 9-*New urban/Pedestrian*	43.9 (42.1-45.8)	39.0 (35.7-42.2)
Class 2-*Mixed SES suburb*	43.0 (40.2-45.9)	38.5 (34.7-42.3)
Class 7-*Rural/Micropolitan*	40.2 (35.1-45.3)	35.2 (29.8-40.6)
Class 4-*City pioneer*	42.3 (40.3-44.3)*	38.2 (35.0-41.5)
Class 1-*Suburban pioneer*	40.2 (38.0-42.3)*	36.9 (33.6-40.2)*
Class 3-*Hispanic small town*	39.9 (36.9-42.9)*	36.6 (32.8-40.5)
Class 5-*Inner city*	39.3 (37.2-41.4)*	36.6 (33.3-40.0)*
MCS		
Class 8-*Upper middle class sub*	50.4 (48.9-52.0)	47.2 (44.6-49.8)
Class 6-*High status/Status fringe*	52.1 (50.7-53.4)*	48.7 (46.2-51.2)*
Class 9-*New urban/Pedestrian*	50.1 (48.7-51.5)	47.5 (45.0-50.0)
Class 2-*Mixed SES suburb*	50.0 (47.7-52.3)	47.9 (44.9-50.9)
Class 7-*Rural/Micropolitan*	49.2 (44.9-53.5)	45.9 (41.4-50.4)
Class 4-*City pioneer*	49.4 (47.9-51.0)	47.5 (45.0-50.0)
Class 1-*Suburban pioneer*	48.0 (46.4-49.7)*	46.6 (44.0-49.2)
Class 3-*Hispanic small town*	48.2 (45.7-50.6)	47.3 (44.2-50.4)
Class 5-*Inner city*	48.7 (47.1-50.3)*	48.1 (45.4-50.7)

*p<0.05 compared to the first category (reference level). a. PCS: Minimally adjusted for age at interview (years), stage (localized, regional, distant, unknown, not applicable), and self-reported recurrence (no, yes, unknown), using a 3-level model with a random effect for study-region and a random effect for census tract nested within study-region. MCS: Minimally adjusted for age at interview (years) and self-reported recurrence (no, yes, unknown), using a 3-level model with a random effect for study-region and a random effect for census tract nested within study-region. b. PCS: Same as minimally adjusted PCS model but additionally adjusted for gender, race/ethnicity, employment, income, marital status, moderate and strenuous physical activity, BMI, report of ever having depression/anxiety, and radiation. MCS: Same as minimally adjusted MCS model but additionally adjusted for gender, race/ethnicity, education, employment, income, marital status, insurance, moderate physical activity, BMI, and report of ever having depression/anxiety.

Summary Results

- Among diverse cancer survivors, some neighborhood attributes including nSES were associated with HRQOL.
- Beyond the independent associations of neighborhood attributes and HRQOL, archetypes provide an approach to capture how neighborhood attributes interact and impact HRQOL.

Limitations

- Data are cross-sectional.
- Data are pooled from studies done of Californian participants and may not be reflective of participants who live elsewhere.
- Uses secondary geospatial data to describe neighborhood environments and may not capture how residents perceive and use their environments.

Conclusions

- As the first study to evaluate a comprehensive suite of social and built environment features on HRQOL in a diverse cohort of cancer survivors, this study will help inform HRQOL interventions by leveraging neighborhood features that are health promoting and mitigating those that present barriers in order to improve survivorship outcomes for the growing number of cancer survivors.
- The strength of this study is the robust set of multilevel data captured by capitalizing on cancer registry data from a population-based sample of cancer survivors, self-reported data for participants' HRQOL, and neighborhood data.
- Elucidating the pathways through which nSES and neighborhood attributes impact HRQOL will be important in improving survivorship outcomes.

Acknowledgements

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- *National Research Service Award fellowship training grant: T32HP19025. (Chu)*
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Treatment patterns and survival in older adults with diffuse large B-cell lymphoma, a population-based study

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Background

Diffuse large B-cell lymphoma (DLBCL) is the most common type of non-Hodgkin lymphoma, with a median age of diagnosis of 70 years. Anthracycline containing regimens are the most common treatments, but toxicity concerns can limit their use in adults >80 years, a growing population that is often excluded from clinical trials. Understanding treatment patterns and associated survival in much older adults >80 (vs. older adults 65-80 years) can help determine effective management strategies in this population.

Objective

To describe the impact of age on treatment regimens used and associated survival in older adults with DLBCL.

Methods

Data for 17,859 patients ages ≥65 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 (OS). Models were adjusted for insurance, race/ethnicity, neighborhood socioeconomic status, comorbidity score, symptoms at diagnosis, rural/urban residence, year of diagnosis, initial treatment at National Cancer Institute (NCI)-designated cancer center, stage at diagnosis, radiation treatment, sex, and age.

Results

- Across both age groups, the most common treatment was anthracycline regimens followed by other drug combinations (Table 1).
- For patients >80, fewer received anthracyclines (32.4%) and more received other drug combinations (17.6%) or had no treatment (13.1%) vs ages 65-80 (61.6% anthracyclines, 10.4% other combinations, 5% no treatment) (Table 1).
- Greater comorbidity, treatment at non-NCI designated cancer centers, more recent years of diagnosis, female sex, and increasing age were associated with no treatment (Figure 1).
- For patients > 80, anthracyclines, R-CEOP/R-CEPP/R-CNOP, R-CVP conferred a survival advantage compared to other combinations (Figure 2).

Conclusion

In this large, population-based group of older adults with DLBCL, much older patients were less likely to receive initial treatment and more likely to receive other drug combinations despite an overall survival advantage with more standard anthracycline regimen protocols. Further analyses examining patient cardiovascular comorbidities and treatment-related toxicities are warranted.

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Table 1. Initial treatments for N=17,859 DLBCL patients 65 years and older, California, 2006-2017

Treatment	Age >80, % (N) 33.3%, (5,947)	Age 65-80, % (N) 66.7% (11,912)
Anthracycline Regimens[a]	32.4% (1,924)	61.6% (7,332)
R-CEOP/R-CEPP/R-CNOP	1.1% (68)	0.7% (83)
R-CVP	2.0% (116)	0.7% (83)
R-ICE	1.0% (62)	0.9% (105)
R-Bendamustimine	2.5% (151)	1.0% (119)
Methotrexate combinations[b]	1.1% (65)	3.9% (461)
Other combinations[c]	17.6% (1,044)	10.4% (1,244)
No Treatment	13.1% (777)	5.0% (594)
Unknown	29.3% (1,740)	15.9% (1,891)

[a]R-CHOP, CHOP, R-EPOCH/EPOCH, mini-CHOP with/without R, other doxorubicin combinations

[b]Rituximab and temozolomide most common

[c]Cyclophosphamide, etoposide, cytarabine, rituximab, prednisone, brentuximab, vincristine, temozolomide

Figure 1. Multivariable-adjusted odds ratios (OR) and associated 95% confidence intervals (CI) of associations with no systemic treatment among DLBCL patients >80

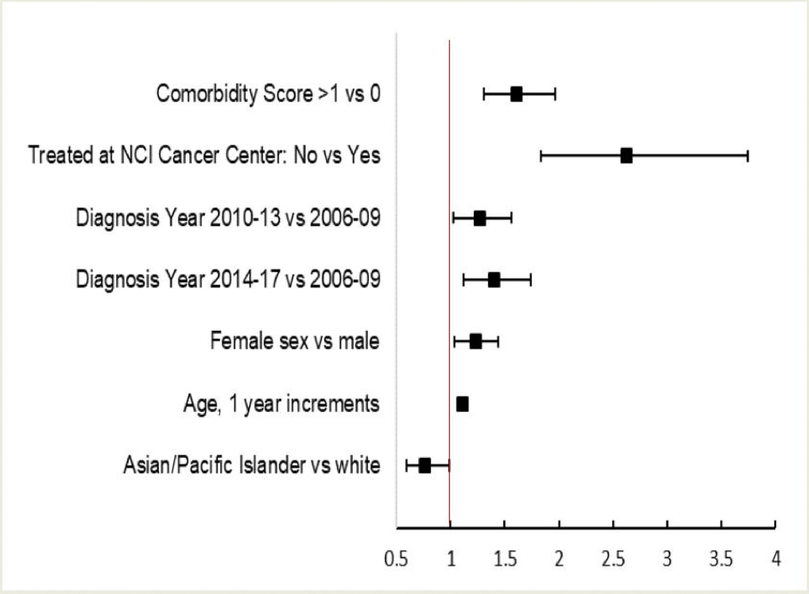
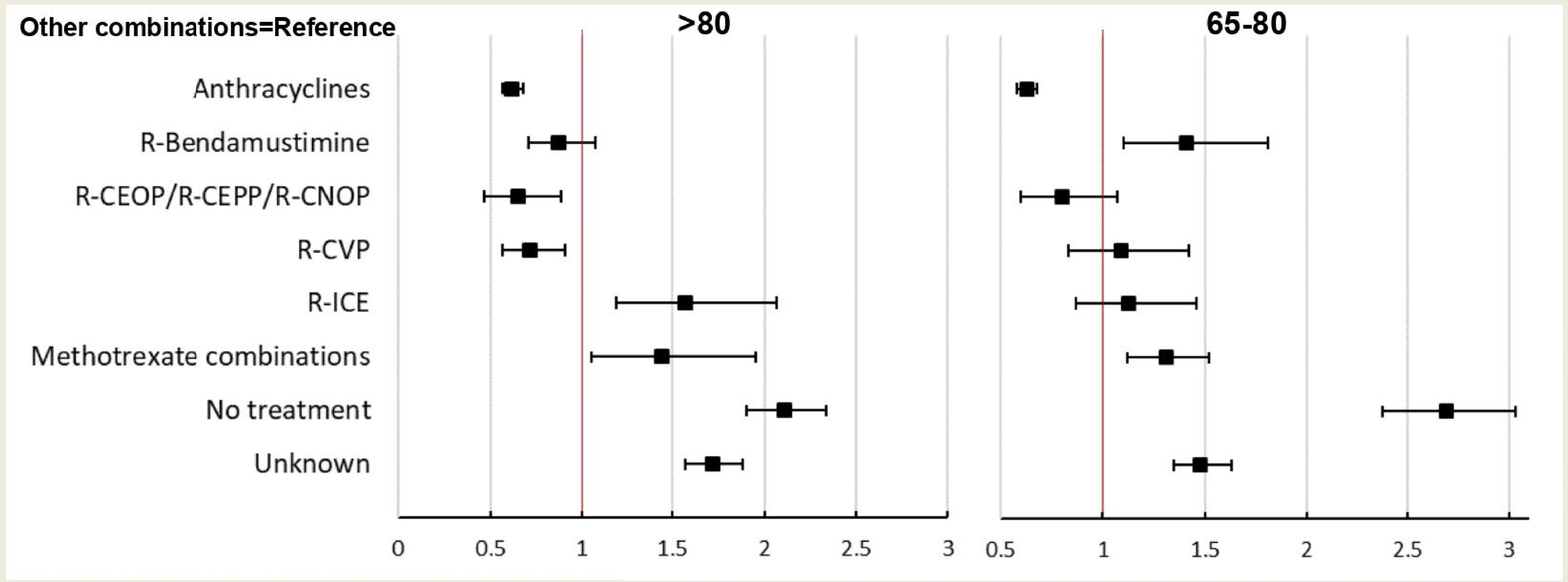


Figure 2. Multivariable-adjusted hazard ratios (HR) and associated 95% confidence intervals (CI) of treatments among DLBCL patients 65 years and older, 2006-2017, California



MDCSS

Will Data Quality Suffer *without* Visual Editing Review of "Resolve Patient Set Tasks" in the SEER*DMS?

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Background and Methods

"Resolve Patient Set Tasks" – auto-created in SEER*DMS:

- When at least 1 path record + 1 abstract auto-linked to patient
- *Demographic, tumor and staging* data are visually reviewed and edited in Detroit for this early work-flow task

SEER*DMS:

- Detroit requested an *enhancement*
- Hospital abstractors' name initials now come in on abstracts
- MDCSS can now track quality of individual hospital staff

Method:

- Random sample, N = 1,320 cases, 9 cancer sites, 25 hospitals
- 9 Editors (CTRs) reviewed 574 variables
- Variables categorized as:
  - Major – Affects staging and treatment
  - Minor – Doesn't affect staging
- Calculated by Cancer Site:
  - N Cases and Errors
  - Overall, Major & Minor error rates (OER) and
  - Average # of errors per case (AEC)
  - Cut-points to Automate: <=3% OER and <=1.2 (AEC)
- Calculated by Hospital (those w/40+ cases shown):
  - N Cases and Errors
  - Overall, Major & Minor Avg. # of errors per case (AEC)
  - Cut-points to Automate: Overall/Major/Minor <=1.2 (AEC)

NCI Comprehensive Cancer Center
A Cancer Center Designated by the National Cancer Institute

Analysis, Results and Conclusions

Table 1. Cancer Site Analysis of Whether Data Quality would Suffer without Visual Editing Review of "Resolve Patient Set Tasks" in SEER*DMS

Site	Cases			Overall				Major				Minor				Outcome
	N	Cases with Errors	Range of errors per case	Total Errors	Var	OER	AEC	Total Errors	Var	OER	AEC	Total Errors	Var	OER	AEC	
Breast	600	405	0-19	1515	43	6%	2.5	1401	34	7%	2.3	114	9	2%	0.2	
Colorectal	272	205	0-15	594	41	5%	2.2	530	29	7%	2.0	64	12	2%	0.2	
Lung	133	103	0-9	285	35	6%	2.1	222	23	7%	1.7	63	12	4%	0.5	
Ovarian	21	20	0-8	59	35	8%	2.8	39	24	8%	1.9	20	11	9%	1.0	
Prostate	134	132	0-9	314	39	6%	2.3	190	26	5%	1.4	124	13	7%	0.9	
Lymphoma	50	43	0-16	171	36	10%	3.4	54	13	8%	1.1	117	23	10%	2.3	
CLL	13	7	0-6	16	40	3%	1.2	9	17	4%	0.7	7	23	2%	0.5	
Melanoma	69	36	0-6	64	40	2%	0.9	61	31	3%	0.9	3	9	0%	0.0	Auto
NETs	26	21	0-9	65	29	6%	2.5	44	29	6%	1.7	21	10	8%	0.8	

Var - number of variables reviewed, OER - Overall Error Rate, AEC - Average number of Errors per Case,
Auto - cancer site was automated due to <= 3% OER and <=1.2 AEC; visual editing suspended for this site

Table 2. Hospital Analysis

Hospital	Cases					Overall		Major		Minor		Outcome
	N	[illegible]	[illegible]	[illegible]	[illegible]	Total Errors	AEC	Total Errors	AEC	Total Errors	AEC	
[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	
[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	Auto
[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	
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[illegible]

Conclusions – Detroit automated (highlighted in tables in grey) RPS tasks for:

- Melanoma cancer site
- 3 hospitals
- Individual CTRs with almost no errors (data not shown)

Patterns of Care and Survival in Adolescents and Young Adults with Hodgkin Lymphoma

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Background

Hodgkin lymphoma (HL) is one of the most treatable cancers affecting adolescent and young adult (AYA) patients (15-39 years), however optimal therapy for de novo disease in this population remains a subject of debate. Population-based studies in HL consistently report a survival disadvantage for AYAs when compared with younger patients, but analyses are often limited by lack of information about therapeutic exposures.

Objective

To examine initial treatment regimen and the impact of sociodemographic and clinical variables on overall survival (OS) and disease-specific survival (DSS) in AYAs compared to children.

Methods

Data for 4,426 patients aged 0-39 years diagnosed with first primary classical HL (2007-2016) were obtained from the California Cancer Registry. Detailed treatment information for each patient was extracted from unstructured free-text fields. Chemotherapy regimens were classified based on standard treatment approaches for adult and pediatric HL. Multivariable cox models were used to examine the influence of sociodemographic and clinical variables on OS and DSS.

Results

- Specific chemotherapy treatment information was found for 92% of patients.
- Front-line therapy for patients with HL differed significantly across age groups, with 42% of patients <21y vs. 69% of 22-39y receiving ABVD (Table 1).
- In survival models, the hazard of death from HL was two to three-fold higher in patients 15-21y, 22-29y, and 30-39y, than patients <14y (Figure 1).
- Non-Hispanic black patients and Hispanic patients experienced worse OS and DSS than non-Hispanic white patients.
- Having public or no insurance also conferred worse OS.
- Among all age groups combined, initial therapy did not significantly impact OS or DSS.
- Modified treatment regimens (vs. ABVD) among those aged 22-39y were associated with worse OS, but did not significantly impact DSS.

Conclusion

In this large, population-based cohort of children and AYAs with HL, we observed that initial therapy varies, but that the majority of AYAs receive ABVD. Variation in therapy was largely insufficient to explain observed survival disparities, as older age, black and Hispanic race/ethnicity, and public or no insurance each conferred increased risk of death, even after adjustment for chemotherapy regimen.

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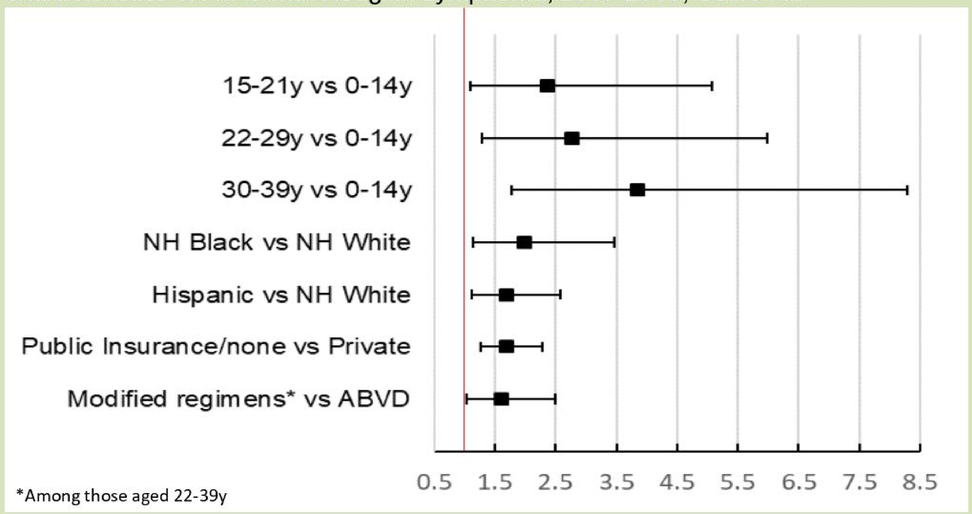
Table 1. Initial treatment regimen and baseline characteristics of N= 4,426 children and AYAs with classical Hodgkin lymphoma reported to the California Cancer Registry between 2007 and 2016.

	ABVD[a], N (row%)	ABVE-PC[a]	BEACOPP[a]	STANFORD V[a]	CHOP[a]	MODIFIED*	NONE
	2640 (60%)	131 (3%)	91 (2%)	225 (5%)	79 (2%)	644 (15%)	51 (1%)
Age							
<1 – 21y	615 (42)	130 (9)	61 (4)	94 (6)	62 (4)	361 (24)	9 (1)
22 – 39y	2025 (69)	1 (<1)	30 (1)	131 (4)	17 (1)	283 (10)	42 (1)
Race/ethnicity							
NH White	1328 (62)	42 (2)	29 (1)	132 (6)	28 (1)	264 (12)	28 (1)
NH Black	190 (61)	8 (3)	10 (3)	7 (2)	4 (1)	60 (19)	3 (1)
Hispanic	810 (55)	70 (5)	41 (3)	43 (3)	38 (3)	266 (18)	17 (1)
Asian/PI	271 (62)	10 (2)	11 (3)	40 (9)	9 (2)	51 (12)	3 (1)
Insurance							
Private	1841 (62)	76 (3)	51 (2)	167 (6)	52 (2)	389 (13)	26 (1)
Public/none	751 (57)	53 (4)	36 (3)	50 (4)	27 (2)	246 (19)	20 (2)
NCI (for AYAs)							
Yes	622 (52)	52 (4)	46 (4)	154 (13)	38 (3)	210 (18)	8 (1)
No	2018 (62)	79 (2)	45 (1)	71 (2)	41 (1)	434 (13)	43 (1)
Stage							
I/II	1590 (62)	72 (3)	15 (1)	156 (6)	44 (2)	358 (14)	32 (1)
III/IV	1004 (61)	58 (4)	75 (5)	67 (4)	33 (2)	269 (16)	9 (1)
Radiation							
Yes	768 (54)	92 (6)	21 (1)	206 (14)	43 (3)	206 (14)	3 (<1)
No	1872 (63)	39 (1)	70 (2)	19 (1)	36 (1)	438 (15)	48 (2)

Unknown/other treatments not shown in table (row percentages do not add to 100%). PI, Pacific Islander; NCI, National Cancer Institute
*Regimens were considered modified if they omitted one drug from a standard protocol. The most common modified regimens were ABV and AVD.

Figure 1. Multivariable-adjusted hazard ratios (HR) and associated 95% confidence intervals (CI) of characteristics of AYAs with Hodgkin Lymphoma, 2007-2016, California



[a]Regimen Acronym Definitions

ABVD: doxorubicin, bleomycin, vinblastine, dacarbazine
ABVE-PC: doxorubicin, bleomycin, vincristine, etoposide, prednisone, cyclophosphamide
BEACOPP: bleomycin, etoposide, doxorubicin, cyclophosphamide, vincristine, procarbazine, prednisone
STANFORD V: doxorubicin, vinblastine, nitrogen mustard, etoposide, vincristine, bleomycin, prednisone
CHOP : cyclophosphamide, doxorubicin, vincristine, prednisone

A comparison study of 2016 county-level female breast cancer prevalence using Missouri Cancer Registry and Missouri County-level Study data

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[1] *Missouri Cancer Registry and Research Center (MCR-ARC);* [2] *University of Missouri-Columbia (MU), College of Arts & Sciences, Department of Statistics;*
[3] *MU School of Medicine, Department of Health Management & Informatics;* [4] *MU Institute for Data Science and Informatics, Columbia, Missouri;* [5] *University of Nebraska-Lincoln, Department of Statistics, Lincoln, Nebraska.*

1. Background

- For many diseases, including the second most common cancer in women, female breast cancer (FBC), county-level data sources for calculating prevalence estimates are limited due to small sample sizes.
- In Missouri, the Missouri Cancer Registry (MCR) and the Missouri county-level study (CLS) are two available sources to conduct such analysis.
- The MCR, a population-based (since 1985) central cancer registry, collects cancer-specific information and annually updates vital status.
- In contrast, the CLS, which is based on the Behavioral Risk Factor Surveillance System (BRFSS), is a survey of a sample of the population and includes additional risk factor information not collected by cancer registries.

2. Objective

- Investigate differences in FBC prevalence and related statistical inferences between cancer registry and survey data.

3(a). Methods

- All the analyses were based on female adults (the target population) in Missouri.
- To reflect the most recent and accurate estimates regarding FBC prevalence in Missouri, we used the latest CLS data (2016) and MCR data through the latest complete (> 95% of expected incidence cases) diagnosis year (2016).
- Our analyses were implemented by two steps.

Step1 Generate county-level FBC prevalence estimates (along with their standard deviations) using MCR and CLS, respectively. 20 years (1996-2016) limited-duration prevalence (LDP) FBC estimates by stage were obtained from MCR via SEER*Stat software. Complete prevalence (CP) FBC estimates by obesity were obtained from 2016 CLS via SAS software. (See Figures 5-6)

Step2 Perform Bayesian linear regressions for MCR and CLS with the calculated prevalence estimates, respectively. The modeled responses were the logit-transformed 2016 county-level estimates and the corresponding standard deviations were calculated via the delta method. A conditional autoregressive (CAR) prior was used to account for the spatial variability. A flat prior was used for the overall mean and weakly informative priors were used for the rest of regression coefficients.

- Besides an overall mean, covariates (See Figures 1-4) included:
  - **stage effects** (early [local, regional]/late [distant]) for MCR;
  - **obesity effects** (obese/non-obese) for CLS;
  - **spatial effects** (114 counties in Missouri and St. Louis City);
  - **county attributes** (percentages of women age 65+, income [at or above poverty level], race [white and black] and ethnicity [Hispanic/non-Hispanic]), which were aggregated from the latest American Community Survey (ACS) 2014-2018 5-year file.
- The Gibbs sampling was used to generate samples of posterior distributions. For each model, we used 20,000 samples after discarding the first 10,000. For each paramter, we collected posterior means, standard deviations (SD) and 95% credible intervals (CI).

3(b). Methods

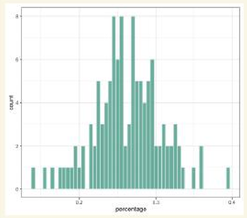


Figure 1: County-level percentages of women in age group 65+.

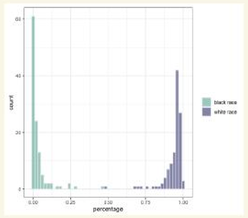


Figure 2: County-level percentages of black race and white race.

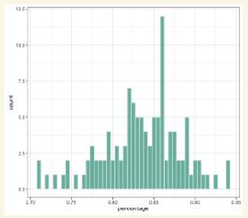


Figure 3: County-level percentages of women living at or above poverty level.

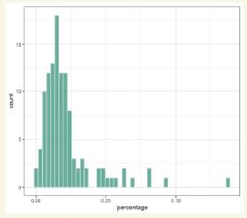


Figure 4: County-level percentages of women who are hispanic.

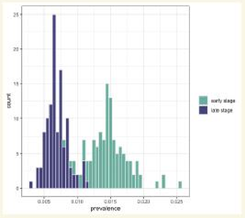


Figure 5: County-level FBC prevalence estimates by stage based on MCR.

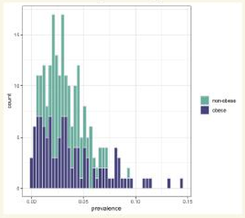


Figure 6: County-level FBC prevalence estimates by obesity based on CLS.

4(a). Results

- Compared with the CLS, the MCR showed smaller variability and produced more precise estimates, which were demonstrated by both shorter CIs and more dense scatterplots. (Figures 7-11)
- Among county attributes, women aged 65 and over and living at or above poverty level were associated with higher FBC prevalence while others were not associated. (Figure 7)
- Early stage was associated with higher FBC prevalence while obesity was not associated. This agreed with Figures 10 and 11, where FBC prevalence was well explained by the inclusion of stage instead of obesity. There was less variation across counties for MCR compared with CLS. (Figure 8)
- The overall mean for MCR was significantly smaller than CLS, which indicated MCR had less prevalent cases than CLS. This reflected the possible different underlying true effects due to differing measures. (Figure 9)

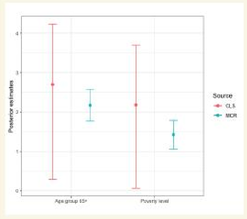


Figure 7: Posterior means and CIs for the county attributes.

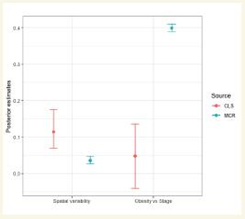


Figure 8: Posterior means and CIs for obesity/stage and spatial variability.

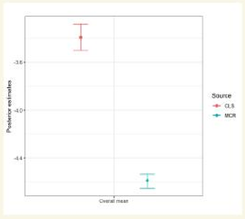


Figure 9: Posterior means and CIs for the overall mean.

4(b). Results

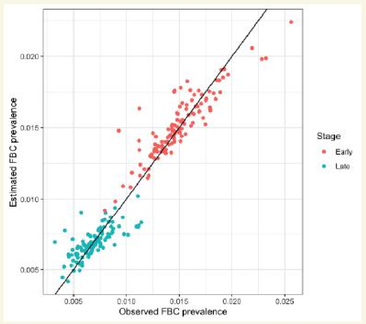


Figure 10: County-level FBC prevalence estimates by stage.

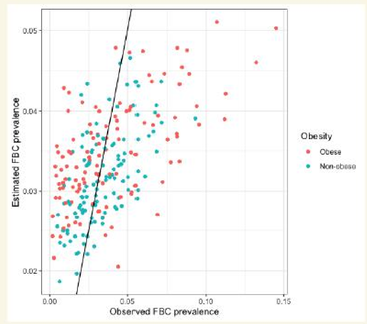
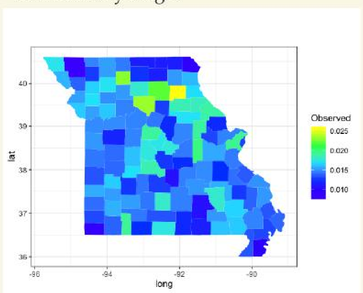


Figure 11: County-level FBC prevalence estimates by obesity.



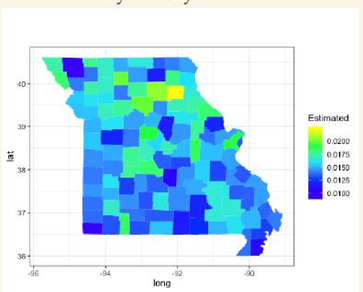
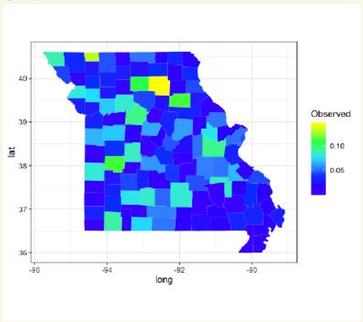


Figure 12: For county-level FBC prevalence regarding early stage, our estimated values (right) were close to the observed values (left). Similar results applied to late stage.



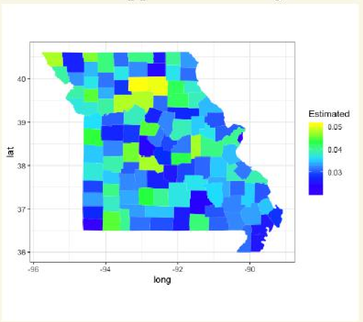


Figure 13: For county-level FBC prevalence regarding obese level, our estimated values (right) were underestimated compared with the observed values (left).

5. Discussion

- This study showed FBC was prevalent for women aged 65 and over, living at or above poverty level and diagnosed at early stage. Health care resources should be allocated to these groups.
- Our ongoing project indicates that there exists other health-related information in the CLS (e.g., cholesterol level information) highly associated with the FBC prevalence. Additionally, as county attributes are shown to be important for both data sources, data combining is promising to broaden the analyses.

Acknowledgement: MCR-ARC core activities are supported in part by a cooperative agreement between the Centers for Disease Control and Prevention (CDC) and the Missouri Department of Health and Senior Services (DHSS) (NU58DP006299-02/03) and a Surveillance Contract between DHSS and the University of Missouri.
We would like to thank the MCR-ARC Quality Assurance staff, and the staff of facilities throughout Missouri and other states' central cancer registries, for their dedication and desire for continuous quality improvement and submitting their reportable cases to MCR-ARC.

Late effects following non-Hodgkin lymphoma in HIV-uninfected and HIV-infected adolescents and young adults: a population-based study

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UCDAVIS Center for Healthcare Policy and Research

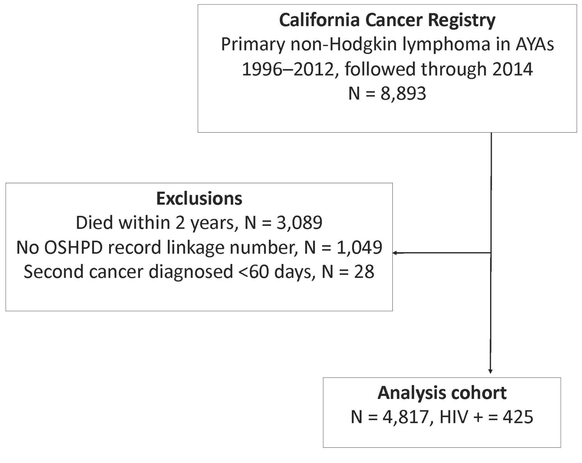
Introduction

- 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 in adolescents and young adults (AYA , 15–39 years) of NHL.

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.

Figure 1. Study cohort, NHL, California, 1996–2012.



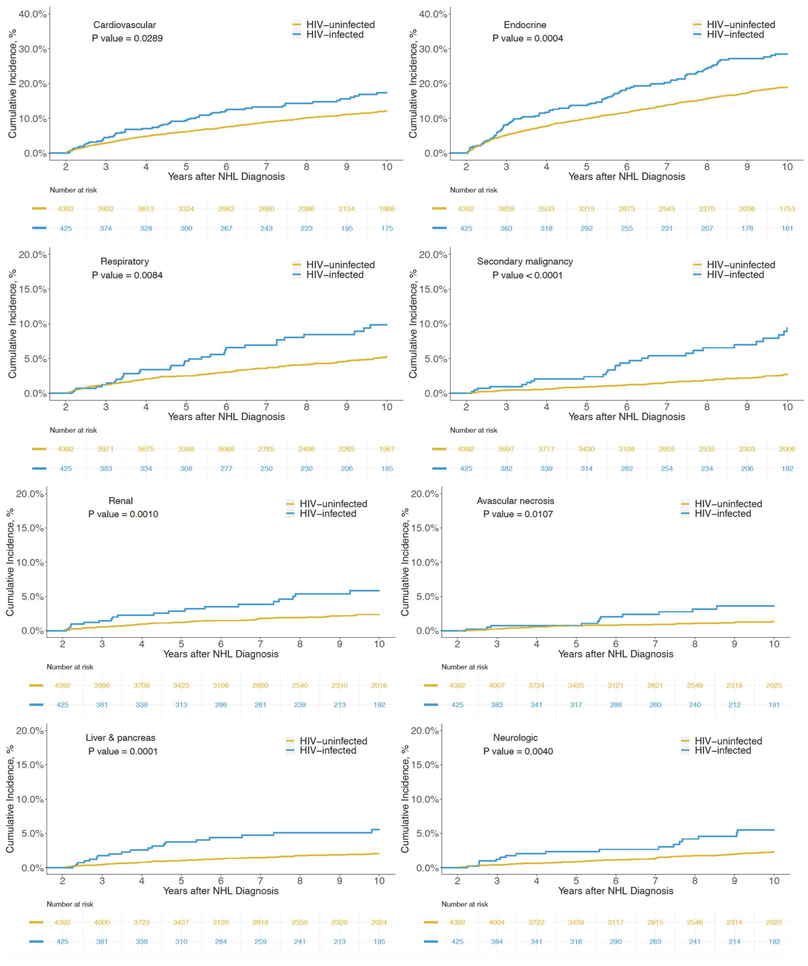
The authors declare no conflicts of interest.

Patient's Characteristics

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	2285	52.0	201	47.3
Hispanics	1156	26.3	132	31.1
Stage at diagnosis				
Localized/regional	2417	55.0	208	48.9
Advanced	1638	37.3	203	47.8
Health insurance				
Private	3186	72.5	197	46.4
Hematopoietic stem cell transplant				
Yes	584	13.3	23	5.5
Radiation				
Yes	1274	29.0	75	17.6
Neighborhood socioeconomic status				
Lower (quintiles 1–3)	2270	51.7	286	67.3

Figure 2: Cumulative incidence of late effects after NHL, by HIV status, California, 1996–2012.



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 (Figures 3A-C).
- 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)** .

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.

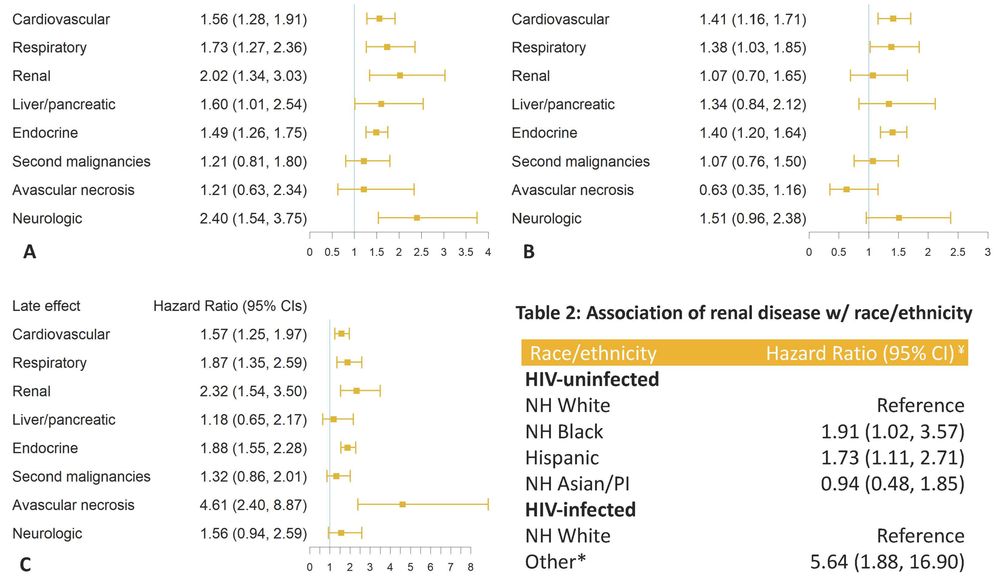


Table 2: Association of renal disease w/ race/ethnicity

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.

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.

Ependymoma, NOS and anaplastic ependymoma incidence and survival in the United States varies widely by patient and clinical characteristics, 2000- 2016

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BACKGROUND

Ependymoma is a rare central nervous system tumor arising from the ependymal lining of the ventricular system. General differences in incidence and survival have been noted, but not examined on a comprehensive scale for all ages and by histology. Despite the rarity of ependymomas, morbidity/mortality associated with an ependymoma diagnosis justifies closer examination.

METHODS

Incidence data were obtained from the Central Brain Tumor Registry of the United States in collaboration with the CDC and NCI, and survival data from SEER, from 2000 - 2016 for anaplastic ependymoma and ependymoma, NOS. Age-adjusted incidence rates (IR) per 100,000 person-years were analyzed by age, sex, race, location. Survival analysis was performed with Kaplan-Meier curves and multivariable Cox proportional hazards models.

RESULTS

Incidence of anaplastic ependymoma was highest in ages 0-4 years. Black populations had lower incidence but had a 78% increased risk of death compared to White populations[HR:1.78,(95%CI:1.30,2.44)]. Incidence was highest for anaplastic ependymoma in the supratentorial region. Adults (40+ years) had almost twice the risk of death compared to children (0-14 years) [HR: 1.97, (95% CI: 1.45, 2.66)]. For ependymoma, NOS, subtotal resection had a risk of mortality 1.81 times greater than gross total resection [HR: 1.414, (95% CI: 1.32, 2.63)].

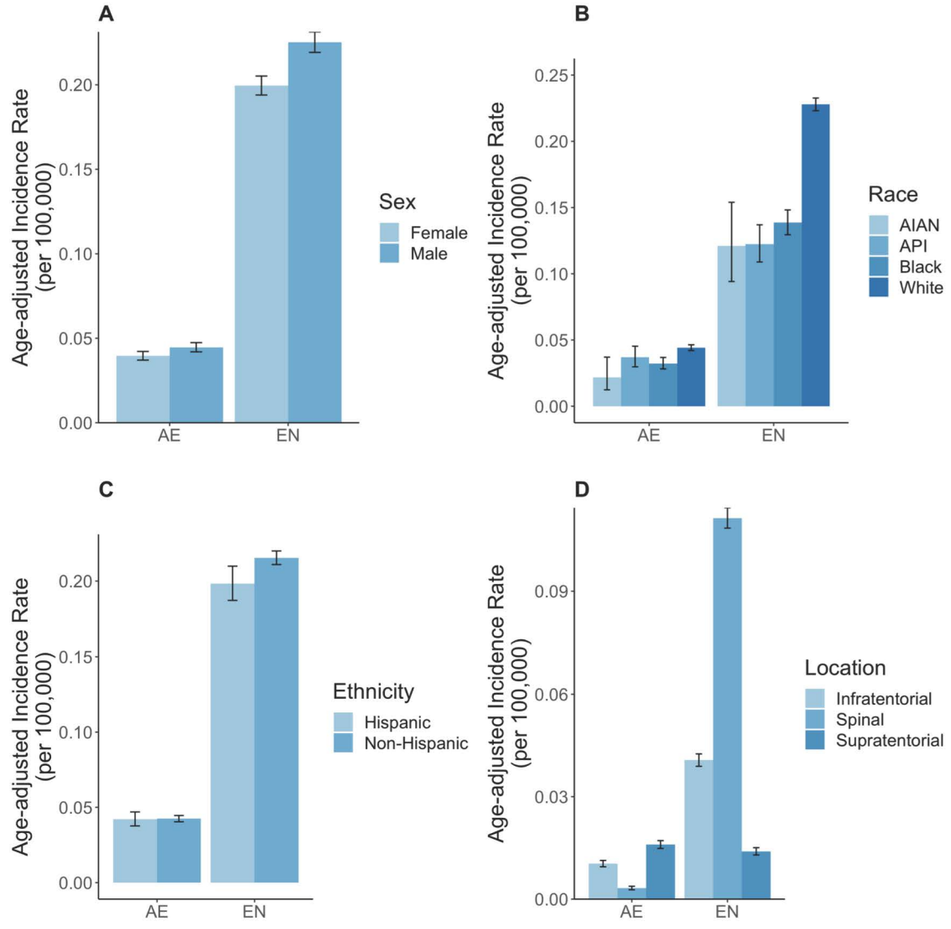

Figure 1) Age-adjusted incidence rates for A) Sex, B) Race (API – Asian or Pacific Islander, AIAN- American Indian / Alaskan Native) C) Ethnicity D) and Location, by histology (AE – Anaplastic Ependymoma, EN – Ependymoma, NOS). (CBTRUS 2000-2016)

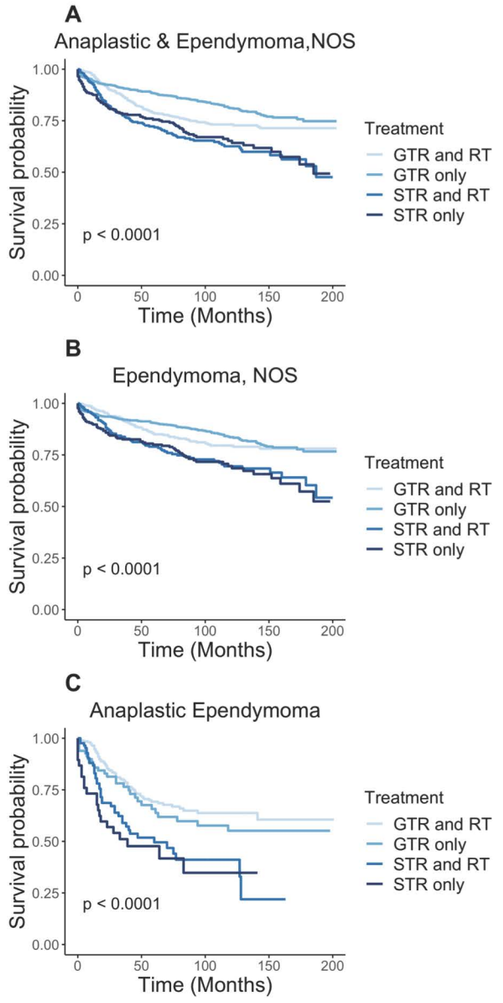

Figure 2) Kaplan-Meier survival curves stratified by gross-total resection (GTR), subtotal resection (STR), GTR + radiation (RT), or STR + RT. for A) for anaplastic ependymoma and ependymoma, NOS, B) ependymoma, NOS, C) anaplastic ependymoma (CBTRUS 2000-2016)

CONCLUSION AND FUTURE DIRECTIONS

Black populations experienced higher mortality rates despite lower incidence compared to White populations. Extent of resection is an important prognostic factor for survival. This highlights need for further evaluation of treatment patterns and racial disparities in the care of patients with ependymoma subtypes.

ACKNOWLEDGEMENTS

Funding for CBTRUS was provided by the Centers for Disease Control and Prevention (CDC) under Contract No. 75D30119C06056, the American Brain Tumor Association, The Sontag Foundation, Novocure, the Musella Foundation, National Brain Tumor Society, the Children's Brain Tumor Foundation, the Uncle Kory Foundation, the Zelda Dorin Tetenbaum Memorial Fund, as well as private and in-kind donations. QTO is supported by a Research Training Grant from the Cancer Prevention and Research Institute of Texas (CPRIT; RP160097T). Contents are solely the responsibility of the authors and do not necessarily represent the official views of the CDC.

Trends in Incidence and Clinical-Pathological Patterns of Thyroid Cancer in New York State

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INTRODUCTION

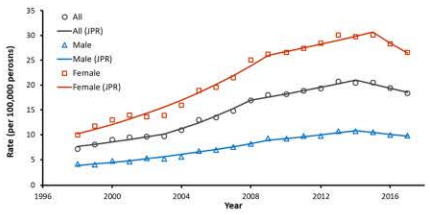
- New York State (NYS) has one of the highest thyroid cancer (TC) incidence rates in the nation and, similar to other states, has had a substantial increase in incidence over the past several decades.
- A recent study using SEER 13 data suggested that the rate of TC had slowed and possibly started to decrease.[1]
- There are large differences in health rankings by county in NYS.
- The study's aim was to examine trends in incidence and clinical-pathological patterns of TC in NYS and to assess whether county-level differences in health rankings are correlated with TC incidence.

METHODS

- Using 1998-2017 NYS Cancer Registry data, we examined TC incidence rates by demographic and tumor characteristics.
- We used the Joinpoint Regression Program (JPR; version 4.6.0) to evaluate secular trends.
- Using the 2018 County Health Rankings from the Robert Wood Johnson Foundation, we assessed the overall "Health Factors" measure and the specific domains "Clinical Care" and "Health Behaviors" in relation to county-level TC incidence.

RESULTS

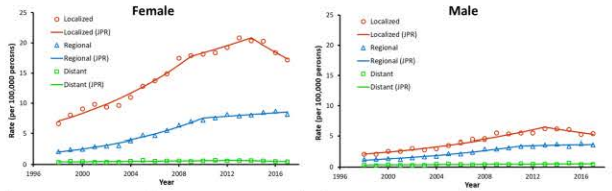
Fig. 1 Trends in Thyroid Cancer Incidence by Sex, New York State, 1998-2017



Sex	Period	APC
All	1998 - 2003	5.8^
	2003 - 2008	10.9^
	2008 - 2014	3.7^
	2014 - 2017	-4.1^
Male	1998 - 2009	8.0^
	2009 - 2014	4.1^
	2014 - 2017	-3.4
Female	1998 - 2009	8.9^
	2009 - 2015	2.8
	2015 - 2017	-7.1

^: statistically significant at p<0.05.

Fig. 2 Trends in Thyroid Cancer Incidence by Sex and Stage at Diagnosis, New York State, 1998-2017



Stage	Period	APC
Localized	1998 - 2009	8.8^
	2009 - 2014	3.3
	2014 - 2017	-6.0

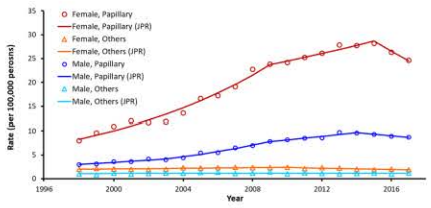
Stage	Period	APC
Regional	1998 - 2010	11.3^
	2010 - 2017	1.8^
Distant	1998 - 2013	3.0^
	2013 - 2017	-8.9

Stage	Period	APC
Localized	1998 - 2013	7.6^
	2013 - 2017	-5.0
Regional	1998 - 2011	9.0^
	2011 - 2017	1.1

Stage	Period	APC
Distant	1998 - 2017	2.5^

^: statistically significant at p<0.05.

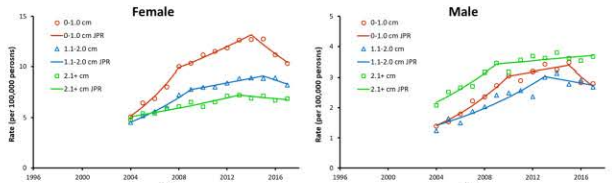
Fig. 3 Trends in Thyroid Cancer Incidence by Sex and Histologic Subtype, New York State, 1998-2017



Sex/Subtype	Period	APC
Female		
Papillary	1998 - 2009	10.0^
	2009 - 2015	3.2^
	2015 - 2017	-7.5
Others	1998 - 2010	1.6^
	2010 - 2017	-3.4^
Male		
Papillary	1998 - 2003	6.6^
	2003 - 2009	11.1^
	2009 - 2014	4.4^
	2014 - 2017	-3.7
Others	1998 - 2017	0.2

^: statistically significant at p<0.05.

Fig. 4 Trends in Thyroid Cancer Incidence by Sex and Tumor Size, New York State, 1998-2017



Size (cm)	Period	APC
0-1.0	1998 - 2008	17.6^
	2008 - 2014	4.9^
	2014 - 2017	-7.5^

Size (cm)	Period	APC
1.1-2.0	2004 - 2009	11.5^
	2009 - 2015	2.7^
	2015 - 2017	-4.5
2.1+	2004 - 2013	4.0^
	2013 - 2017	-1.6

Size (cm)	Period	APC
0-1.0	2004 - 2010	13.7^
	2010 - 2015	2.1
	2015 - 2017	-10.5
1.1-2.0	2004 - 2013	8.9^
	2013 - 2017	-2.4

Size (cm)	Period	APC
2.1+	2004 - 2009	9.5^
	2009 - 2017	1.0

^: statistically significant at p<0.05.

Fig. 5 Thyroid Cancer Incidence by Sex and County, New York State, 2013-2017

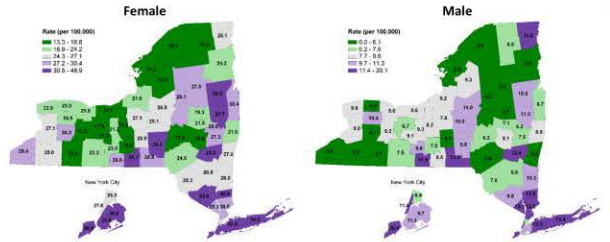
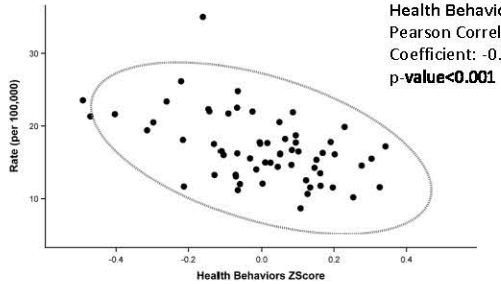
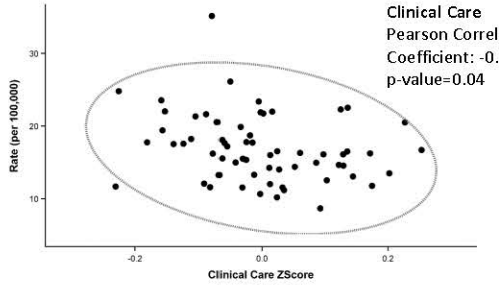


Fig. 6 Correlation between 2013-2017 Thyroid Cancer Incidence and Specific Domains of the 2018 County Health Rankings



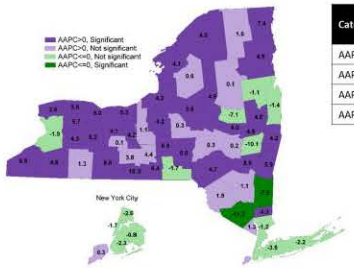
Health Behaviors
Pearson Correlation Coefficient: -0.49 and p-value<0.001



Clinical Care
Pearson Correlation Coefficient: -0.26 and p-value=0.04

Note: a lower z score indicates better health behaviors/clinical care.

Fig. 7 Five-year Average Annual Percentage Changes for Thyroid Cancer Incidence by County, New York State, 2013-2017



Category	# of Counties		
	All	Female	Male
AAPC<0, Significant	2	0	0
AAPC≤0, Not significant	13	21	15
AAPC>0, Not significant	15	14	28
AAPC>0, Significant	32	27	19

CONCLUSIONS

- Thyroid cancer incidence in New York State may have reached a plateau, which appears to be driven by a decrease in the diagnosis of local-stage papillary microcarcinoma. This change may reflect a positive response from the healthcare system to overdiagnosis warnings.
- It appears that, in New York State, higher thyroid cancer incidence is associated with better health behaviors and better clinical care at the county level.

ACKNOWLEDGMENTS

This work was supported in part by:

- Cooperative agreement 6NU58DP006309 awarded to the New York State Department of Health by the Centers for Disease Control and Prevention, and
- Contract 75N91018D00005 (Task Order 75N91018F00001) from the National Cancer Institute, National Institutes of Health, Department of Health and Human Service.

REFERENCE

1 AE Powers et al. Changes in Trends in Thyroid Cancer Incidence in the United States, 1992 to 2016. JAMA 2019;322(24):2440-1.

NAACCR ANNUAL CONFERENCE POSTER APRIL 27, 2020

PRIVACY AND CONFIDENTIALITY CONSIDERATIONS IN CANCER REGISTRATION: A NEXUS OF LAW, ETHICS, AND POLICY

Ann Griffin, PhD, CTR ♦ Robert McLaughlin, JD, PhD ♦ Maureen Romero, RHIA, CTR

NCRA

(National Cancer Registrars Association) editors for the forthcoming, 4th edition of Cancer Registry Management Principles & Practices for Hospitals and Central Registries, Invited a new chapter to reconcile the public function and purpose of cancer registration, with the private nature of the individual-level data, patient experiences, and human lives that support cancer surveillance.

"73 Cents Mural - Nurse turned away from the patient" by Ted Eytan is licensed under CC BY-SA 2.0 (mural by R. Halliday)

"As is widely recognized in the cancer registry community, cancer data exist because of public demands that individual cases be counted and understood not only in terms of the experiences of individual patients, but also with respect to patterns and trends, with the systematic compilation of data enabling the population-based study of who gets cancer, why, when, under what circumstances, and with what range of outcomes. The activity of cancer registration depends, however, on an extension of the underlying trust and the legal privilege of confidentiality that exist between a patient and his or her doctors. That privilege exists to support the free and clear communication necessary to the provision of the optimal treatment and care. The confidentiality of the relationship relates to the completeness, accuracy, and timeliness of the information a patient provides. These same qualities are essential to the cancer data on which research, surveillance and cancer control depend." (*DRAFT*)

Purpose

We aim to confront the complexity and professional anxiety associated with privacy and confidentiality in cancer registration with an articulation of durable principles and practices in support of CTRs (certified tumor registrars) and their work

Implications

The ethics of cancer registration involve an integration of law, policy, and practice; they pertain to understanding how the endeavor of cancer registration and possibility of disease surveillance in support of public health derive from and constitute a logical and ethical extension of the confidential relationship between patient and physician.

Results

The final text is anticipated for publication by the NCRA in *Cancer Registry Management Principles & Practices for Hospitals and Central Registries*, 4th edition.

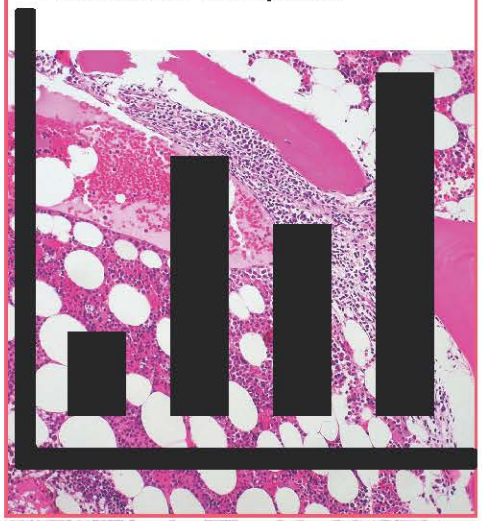
Approach

An integrated chapter:

I. LEGAL ASPECTS OF CANCER REGISTRY DATA
- Establishing Cancer as a Priority
- Privacy of Personal Health Information–Then and Now
- Confidentiality of Medical Records

II. HEALTH INFORMATION PRIVACY AND SECURITY
- Cancer Registry Data as Confidential Health Information
- Incidents that Compromise Confidentiality
- Privacy, Confidentiality, and Security
- Duty of Care
- Patient Interests
- Identifying Confidential Information

III. REGISTRAR ETHICS AND PROFESSIONALISM
- Professional Ethics in the Field of Cancer Registries
- Professional Resources
- Professional Development



"Follicular Lymphoma, Paratrabecular Involvement of Bone Marrow" by euthman is licensed under CC BY 2.0

Epidemiology of Pediatric Cancer in New Mexico's American Indian, Hispanic, and Non-Hispanic White Populations

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[3] New Mexico Tumor Registry, [4] University of New Mexico, School of Medicine, Department of Internal Medicine, Division of Epidemiology, Biostatistics, and Preventive Medicine

Background

Childhood cancer is the second leading cause of death in children ages 1 to 14, and the primary cause of death by disease.[1] Every year approximately 15,300 children will be diagnosed with cancer, and childhood cancer rates have been rising slightly in the past few decades.[2] Based on a report from the Centers for Disease Control and Prevention (CDC), the incidence rate of pediatric cancers was 158.7 per million people during the time period 2003-2014 in New Mexico, estimating about 100 new diagnoses of childhood cancer each year.[3] The epidemiology of childhood cancers in New Mexico was last assessed in 1982[4]. The population-based data highlighted the racial/ethnic variation of our population and the relationship to the variation in the incidence of cancer providing insights into cancer etiology.

New Mexico is the fifth largest state in geographic area, but ranks 46th in population size. As a result, many New Mexicans reside in rural areas that are physically distant from high-quality cancer-related care. New Mexico's resident population is comprised of Hispanics (47%), Non-Hispanic Whites (41%), American Indians (10%), and other racial/ethnic groups (2%).

Purpose

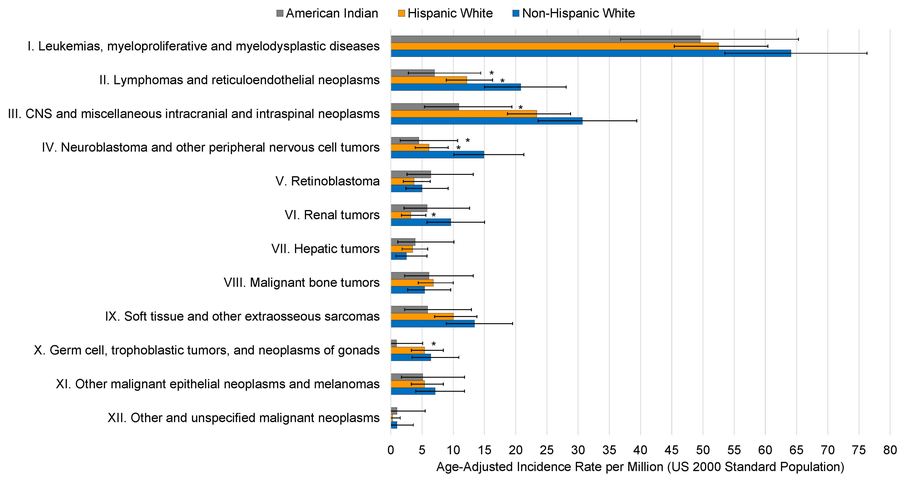
The investigators will use existing, population-based cancer surveillance data to characterize the incidence rates of pediatric cancer in New Mexico's American Indians, Hispanics and Non-Hispanic Whites.

Data Sources and Methods

The population-based New Mexico Tumor Registry (NMTR) was queried to identify all incident cases of pediatric cancer (0-14 years of age) that were diagnosed among New Mexico residents during the time period 2000-2016. Pediatric cancers were identified and classified in accordance with the International Classification of Childhood Cancers (ICCC), and restricted to cases with malignant disease (Behavior Code of 3 as designated in the International Classification of Disease for Oncology – Third Edition (ICDO-3)), but included intracranial neoplasms with an ICDO-3 Behavior Code of 0 (benign), 1 (uncertain), 2 (*in situ*) and 3 (malignant). Results were restricted to New Mexico's three largest race/ethnic groups (American Indian, Hispanic, Non-Hispanic White) as they account for the overwhelming majority of childhood cancers in the state's resident population. Age-adjusted incidence rates (per million person-years) were calculated by the direct method using the United States 2000 standard population. Corresponding 95% confidence intervals (CI) were calculated using the Tiwari adjustment. Statistical significance of comparisons was assessed at an alpha level of 0.05.

Results

Figure 1.
Incidence of pediatric cancer by ICCC group among New Mexico children (0-14 years), 2000-2016



* The rate ratio (not shown) indicates that the rate is statistically different than the rate for Non-Hispanic Whites (p<0.05)

Table 1.
Incidence of selected pediatric cancer ICCC subtypes by race/ethnicity among New Mexico children (0-14 years), 2000-2016

	Rate** (95% Confidence Interval)		
Selected ICCC Subtype	American Indian	Hispanic	Non-Hispanic White
I(a). Lymphoid leukemias	35.5 (24.9,49.2)*	46.1 (39.4,53.5)	53.3 (43.6,64.5)
I(b). Acute myeloid leukemias	11.0 (5.5,19.7)	3.8 (2.1,6.3)	7.4 (4.1,12.2)
II(a). Hodgkin lymphomas	2.1 (0.2,7.3)	4.1 (2.3,6.7)	3.5 (1.4,7.1)
II(b). Non-Hodgkin lymphomas (except Burkitt lymphoma)	4.0 (1.1,10.2)	6.0 (3.7,9.1)*	11.4 (7.2,17.0)
II(c). Burkitt lymphoma	0.0 (0.0,3.6)*	1.6 (0.6,3.5)	4.5 (2.0,8.5)
III(b). Astrocytomas	5.9 (2.2,12.9)	11.8 (8.6,15.9)	14.4 (9.6,20.6)
III(c). Intracranial and intraspinal embryonal tumors	3.9 (1.1,10.1)	3.5 (1.9,6.0)	6.0 (3.1,10.5)
VIII(a). Osteosarcomas	1.0 (0.0,5.5)	4.1 (2.3,6.7)	2.8 (1.0,6.2)
VIII(b). Chondrosarcomas	0.0 (0.0,3.6)	0.0 (0.0,1.0)	0.0 (0.0,1.8)
VIII(c). Ewing tumor and related sarcomas of bone	4.1 (1.1,10.4)	2.2 (0.9,4.3)	2.0 (0.5,5.2)
IX(a). Rhabdomyosarcomas	2.0 (0.2,7.1)	3.0 (1.5,5.3)	6.4 (3.4,11.0)

** Rates are per million and age-adjusted to the 2000 US standard population

* The rate ratio (not shown) indicates that the rate is statistically different than the rate for Non-Hispanic Whites (p<0.05)

Results

- Leukemias, lymphomas and central nervous system tumors were the most common cancer types diagnosed in all three race/ethnic groups (Figure 1).
- Racial/ethnic differences were observed in many, but not all cancer categories (Figure 1 and Table 1). Incidence rates for lymphoid leukemias, for example, were similar among Hispanics (46.1, 95%CI=39.4-53.5) and Non-Hispanic Whites (53.3, 95%CI=43.6-64.5), but were much lower among American Indians (35.5, 95%CI=24.9-49.2). Rates for non-Hodgkin lymphoma among Hispanics (6.0, 95%CI=3.7-9.1) and American Indian (4.0, 95%CI=1.1-10.2) were much lower than those in Non-Hispanic Whites (11.4, 95%CI=7.2-17.0), while rates for Hodgkin lymphoma were similar in all three groups (Table 1).
- Rates for central nervous system tumors in American Indians were consistently lower than those for Non-Hispanic Whites and Hispanics (Figure 1 and Table 1).

Conclusions

- Incidence rates for many types of pediatric cancer vary by race/ethnicity in New Mexico.
- Relatively small case numbers in some categories constrain our ability to readily interpret such differences.
- Our findings underscore the need for additional research that will explain determinants of racial/ethnic differences in disease patterns.

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Characteristics and Outcomes of Never Smokers with Lung Cancer

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Background

In the United States, approximately 10% to 15% of lung cancer occurs in never smokers and this proportion is increasing. Lung cancer in never smokers is more frequently associated with adenocarcinoma histology, female sex, and Asian American Pacific Islander (AAPI) race/ethnicity. It has been suggested that lung cancer in never smokers is a distinct entity with a different pathogenesis than in ever smokers. Population-based studies in the United States are sparse and have not examined differences among AAPI subgroups in patients with lung adenocarcinoma.

Objective

To describe demographic and clinical characteristics and outcomes of never smoker patients with lung adenocarcinoma with a focus on AAPI subgroups.

Methods

We obtained data for 48,702 lung adenocarcinoma patients diagnosed from 2012 to 2017 from the California Cancer Registry (CCR). Smoking status came from CCR variables on tobacco use and from mining CCR text fields. Multivariable Cox proportional hazards regression models examined overall survival in never and ever smokers as well as in never smokers. Models were adjusted for insurance type, stage at diagnosis, receipt of systemic treatment, comorbidity, sex, age, socioeconomic status (SES), and treatment at National Cancer Institute-designated cancer center.

Results

- Nineteen percent of patients were never smokers, 61% were ever smokers, and 20% had an unknown smoking status.
- More never smokers were female, diagnosed with stage IV disease, AAPI, had high SES, lived in urban areas, and had a low comorbidity score (Figure 1).
- AAPI never smokers were mainly Chinese (40%), Filipino (22%), and Vietnamese (15%) (Figure 2).
- In adjusted models, never (vs. ever) smokers had better overall survival (HR: 0.84, 95% CI: 0.81,0.87).
- Among never smokers, females (vs. males), Chinese, Filipino, Korean, and Vietnamese (vs. non-AAPI) had better survival while those with low SES (vs. high SES) had worse survival (Figure 3).
- The proportion of never smokers increased from 14.5% of the cohort in 2012 to 21.4% in 2017 while the percent unknown decreased from 32% to 18%.

Conclusion

Never smokers with lung adenocarcinoma tend to be healthier, AAPI (mostly Chinese, Filipino, Vietnamese), female, urban, and of high SES; they also experience better overall survival. The proportion of never smokers with lung adenocarcinoma has been increasing in California, warranting further research examining exposures, especially among AAPI subgroups, and possible causative agents in this disease.

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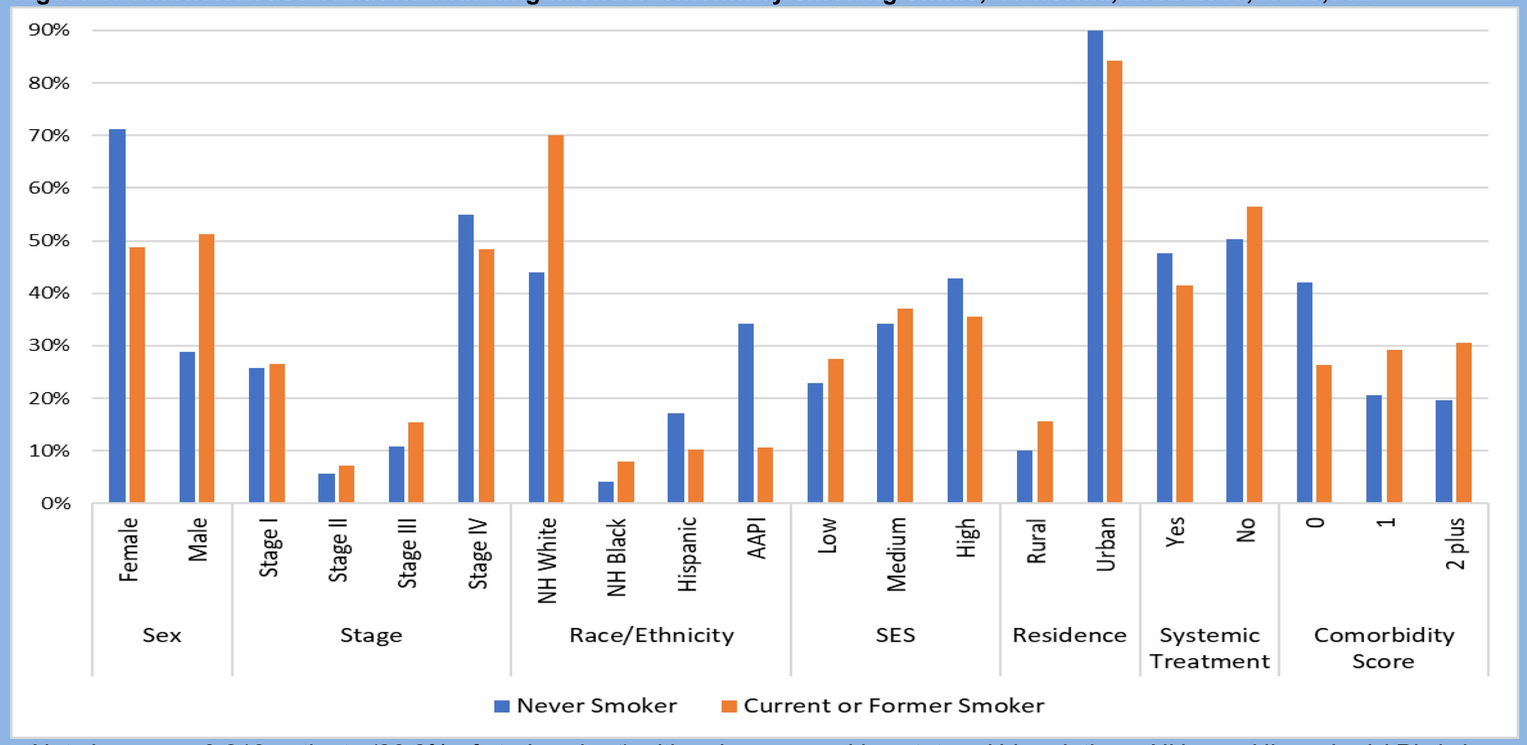
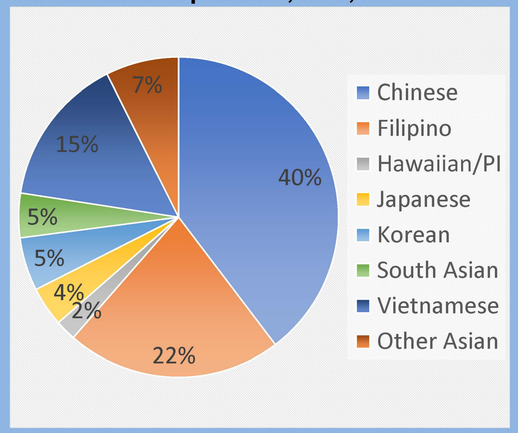
Figure 1. Characteristics of adults with lung adenocarcinoma by smoking status, California, 2012-2017, N=48,702[a]



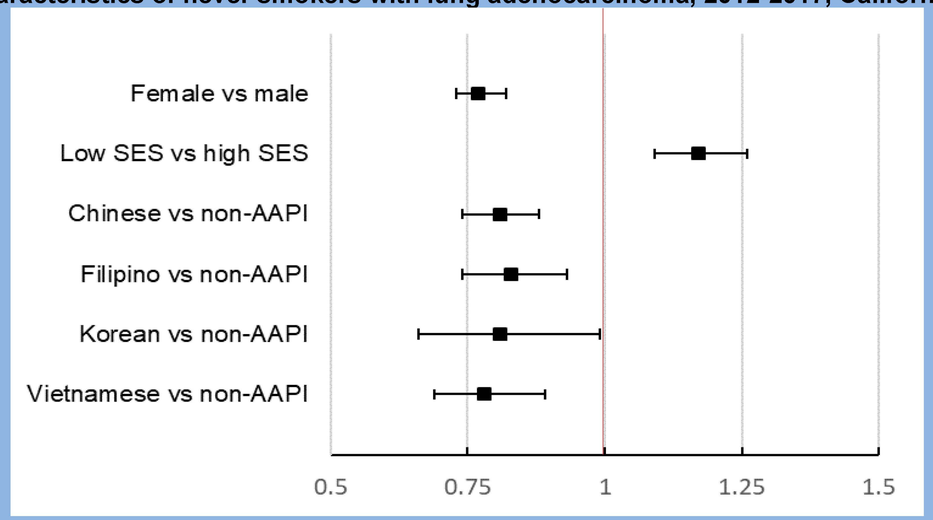
[a]Not shown are 9,813 patients (20.2% of study cohort) with unknown smoking status. Abbreviations: NH, non-Hispanic; AAPI, Asian American Pacific Islander; SES, socioeconomic status

Figure 2. Asian American Pacific Islander subgroup breakdown among never-smoker patients, N=3,180



PI=Pacific Islander

Figure 3. Multivariable-adjusted hazard ratios (HR) and associated 95% confidence intervals (CI) of characteristics of never smokers with lung adenocarcinoma, 2012-2017, California



AAPI=Asian American Pacific Islander

Will Data Quality Suffer *without* Visual Editing Review of "Resolve Patient Set Tasks" in the SEER*DMS?

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Background and Methods

"Resolve Patient Set Tasks" – auto-created in SEER*DMS:

- When at least 1 path record + 1 abstract auto-linked to patient
- *Demographic, tumor and staging* data are visually reviewed and edited in Detroit for this early work-flow task

SEER*DMS:

- Detroit requested an *enhancement*
- Hospital abstractors' name initials now come in on abstracts
- MDCSS can now track quality of individual hospital staff

Method:

- Random sample, N = 1,320 cases, 9 cancer sites, 25 hospitals
- 9 Editors (CTRs) reviewed 574 variables
- Variables categorized as:
  - Major – Affects *staging and treatment*
  - Minor – Doesn't affect staging
- Calculated by Cancer Site:
  - N Cases and Errors
  - Overall, Major & Minor error rates (OER) and
  - Average # of errors per case (AEC)
  - Cut-points to Automate: <=3% OER and <=1.2 (AEC)
- _____ - Calculated by Hospital (those w/40+ cases shown):
  - N Cases and Errors
  - Overall, Major & Minor Avg. # of errors per case (AEC)
  - Cut-points to Automate: Overall| Major| Minor <=1.2 (AEC)

NCI Comprehensive Cancer Center

A Cancer Center Designated by the National Cancer Institute

Analysis, Results and Conclusions

Table 1. Cancer Site Analysis of Whether Data Quality would Suffer without Visual Editing Review of "Resolve Patient Set Tasks" in SEER*DMS

	Cases			Overall				Major				Minor				
Site	N	Cases with Errors	Range of errors per case	Total Errors	Var	OER	AEC	Total Errors	Var	OER	AEC	Total Errors	Var	OER	AEC	Outcome
Breast	603	425	0-19	1515	43	6%	2.5	1401	34	7%	2.3	114	9	2%	0.2	
Colorectal	271	215	0-15	594	41	5%	2.2	530	29	7%	2.0	64	12	2%	0.2	
Lung	133	101	0-9	285	35	6%	2.1	222	23	7%	1.7	63	12	4%	0.5	
Ovarian	21	20	0-8	59	35	8%	2.8	39	24	8%	1.9	20	11	9%	1.0	
Prostate	134	112	0-9	314	39	6%	2.3	190	26	5%	1.4	124	13	7%	0.9	
Lymphoma	50	43	0-16	171	36	10%	3.4	54	13	8%	1.1	117	23	10%	2.3	
CLL	13	7	0-6	16	40	3%	1.2	9	17	4%	0.7	7	23	2%	0.5	
Melanoma	69	36	0-6	64	40	2%	0.9	61	31	3%	0.9	3	9	0%	0.0	Auto
NETs	26	21	0-9	65	39	6%	2.5	44	29	6%	1.7	21	10	8%	0.8	

Var - number of variables reviewed, OER - Overall Error Rate, AEC - Average number of Errors per Case,
Auto - cancer site was automated due to <=3% OER and <=1.2 AEC; visual editing suspended for this site.

Table 2. Facility Analysis

	Cases					Overall		Major		Minor		
Facility	N	% of Cases at Facility	Total Cases w/Errors	Range of errors per Record	% of Cases w/Errors	Total Errors	AEC	Total Errors	AEC	Total Errors	AEC	Outcome
A	312	24%	216	0-13	69.2	919	2.9	832	2.7	87	0.3	
B	194	15%	98	0-8	50.5	235	1.2	167	0.9	68	0.4	Auto
C	166	13%	152	0-11	91.6	511	3.1	412	2.5	99	0.6	
D	111	8%	56	0-8	50.5	125	1.1	113	1.0	12	0.1	Auto
E	85	6%	85	1-10	100.0	311	3.7	276	3.2	35	0.4	
F	55	4%	52	0-14	94.5	180	3.3	144	2.6	36	0.7	
G	51	4%	38	0-9	74.5	102	2.0	64	1.3	38	0.7	
H	45	3%	17	0-5	37.8	38	0.8	31	0.7	7	0.2	Auto
I	41	3%	35	0-9	85.4	128	3.1	95	2.3	33	0.8	
J	40	3%	26	0-9	65.0	96	2.4	77	1.9	19	0.5	

Var - number of variables reviewed, OER - Overall Error Rate, AEC - Average number of Errors per Case,
Auto - hospital was automated due to <=1.2 AEC; visual editing suspended for this hospital's cases.

Conclusions – Detroit automated (highlighted in tables in grey) RPS tasks for:

- Melanoma cancer site
- 3 hospitals
- Individual CTRs with almost no errors (data not shown)