

NAACCR Annual Conference

ABSTRACT BOOK

*Discovering Gems Using Cancer
Surveillance Data*

June 25 - 27, 2024



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KEYNOTE PRESENTATION

Opening Ceremonies and Welcome

Tuesday, June 25th

8:45am – 9:30am

Opening Keynote - Research Gems, Clinical Pearls and IRASicible Genes

Dan Zuckerman

MD, FASCO, Director of Research, St. Luke's Cancer Institute

Overview

We'll review how data derived from the NAACCR have helped inform clinical trial development at the national level and how those trials are implemented through the NCORP. We'll discuss challenges to delivering standard of care and conducting research across a rural population. We will cover how SEER insights have been critical to bringing awareness to the young onset colorectal cancer story. Finally, we'll go over the implications of molecular tumor profiling for the future of defining and cataloging cancer and that means for NAACCR.

Objectives

- Understand the role of the NCORP in advancing cancer research in the United States
- Appreciate the challenges and opportunities of delivering cancer care in rural America
- Recognize the contributions of NAACR and SEER to the evolving story of young onset colorectal cancer
- Develop strategies to incorporate molecular tumor profiling into the data collected by cancer registries



PLENARY PRESENTATIONS

Plenary Session 1 – (Panel Discussion) Advancing Cancer Research: Collaborative Insights from the Cancer Center Informatics Society

Tuesday, June 25th
9:30am – 10:30am

The Cancer Center Informatics Society & NAACCR: Collaborative Opportunities for Advancing Cancer Surveillance and Research

Sorena Nadaf-Rahrov

MS, MMI; CEO and Chief Digital Officer, Cancer Center Informatics Society

Overview & Objectives

The Cancer Center Informatics Society (Ci4CC) and the North American Association of Central Cancer Registries (NAACCR) offer promising collaborative avenues to advance cancer surveillance and research. Through synergizing the expertise and resources of both organizations, we can discuss opportunities that could further elevate the caliber and breadth of cancer data collection, analysis, mining, and dissemination. Such a collaboration could facilitate discussions leading to initiatives on refining innovative methodologies spanning biomedical and clinical informatics, AI in Oncology, and data science. By pinpointing emerging trends and tackling pivotal research inquiries, we aim to enhance cancer data science, precision oncology, advanced diagnosis, and treatment strategies. Together, we stand poised to make significant strides in unraveling the complexities of cancer, ultimately translating into improved outcomes for patients and populations on a global scale.

The Role of Cancer Informatics in Cancer Surveillance

Eric Durbin

DrPH, MS; Director, Kentucky Cancer Registry, Lexington, USA

Overview

The presentation will describe current and future applications of cancer informatics to improve and enhance cancer surveillance.

Objectives

To describe current and future practical examples of how cancer informatics methods and applications can be leveraged to improve and enhance cancer surveillance.



Empowering the Cancer Registry Workforce with AI and Data Science

Madhusmita Behera

PhD; Chief Informatics and Data Officer, Winship Cancer Institute, Emory University

Overview

The presentation will explore how AI technologies can support the cancer registry workforce, streamline processes, and improve overall registry operations.

Objectives

To discuss real-world examples of AI applications in cancer registries, including data mining and quality control. It will highlight successful implementations of AI and their impact on registry operations and will emphasize the need for training cancer registry professionals in AI and data science.



Plenary # 2 – Winds of Change

Tuesday, June 25th

2:00pm – 3:30pm

Implementing Change: A Registry Software Perspective

Jim Hofferkamp

ODS-C, Program Manager of Education and Training, NAACCR

Overview

During this presentation we will meet 3 individuals that work for hospital registry software vendors. We will hear from an individual involved with updating software, another responsible for developing plans of implementation, and from someone that provides client support.

Objectives

Understand the technical issues related to changes in reporting requirements. Understand hospital software vendors plan for implementation issues. Understand how hospital software vendors support their clients through times of change.

The Association of Medicaid Expansion with Overall Survival among Cancer Patients

Ahmedin Jemal

DVM, PhD, Senior Vice President, American Cancer Society

Overview

In 2010, President Obama signed the Affordable Care Act (ACA) into law in order to expand access to healthcare. The act provides states financial incentives to expand Medicaid eligibility to adults aged 18-64 years with household income up to 138% federal poverty line regardless of parental status. 24 states and the District of Columbia expanded Medicaid eligibility on January 1, 2014, with more states opting in during later years. To date, 11 states have yet to expand Medicaid. Previous studies have reported associated Medicaid expansion with reduced insurance rate, a shift to early-stage diagnosis, improved receipt of treatment, and improved short-term survival. It is unknown, however, whether the expansion is associated with long-term survival (4-5 years) among individuals with cancer.

Objectives

Provide an overview of the positive effects of Medicaid expansion as part of the ACA on improving access to care (reduces uninsured rate), receipt of preventive and curative care for cancer, and short-term (2-year) survival among adults aged 18-64 years diagnosed with cancer.

Present and discuss findings on whether improvements in 4 (or 5) years survival among individuals aged 18-64 years diagnosed with cancer before vs after 2014 is greater in the 24 states and DC that expanded Medicaid in January 2014 than in those 10 states that have yet expanded Medicaid as of January 2024.



Partnerships and Advocacy Lead to Success

[Lori Swain](#)

Executive Director, National Cancer Registrars Association

Overview

As a small association, NCRA recognizes that strong partnerships and coalition building can lead to policy outcomes that best support NCRA's membership, and those of the cancer surveillance community. This presentation will review NCRA's advocacy approach, noting the role of partnerships and grass-roots advocacy to reach success.

Objectives

To gain knowledge of NCRA's advocacy approach. To learn about NCRA's advocacy outcomes.



Plenary # 3 – Childhood Cancer

Wednesday, June 26th

2:00pm – 3:30pm

National Childhood Cancer Registry Update

Johanna Goderre

MPH, Health Data Scientist, Surveillance Research Program, National Cancer Institute

Overview

An update on progress in the National Childhood Cancer Registry and the Data Platform.

Objectives

- Understand the availability of cancer surveillance and linked real-world data for use in new research and analytic projects investigating the causes, effective treatments, recurrences, comorbidities, subsequent malignant neoplasms (SMN), and late effects of cancer among children, adolescents, and young adults in the US
- Learn about the National Cancer Institute's processes enabling researchers to explore and analyze de-identified, controlled-access childhood cancer data
- Learn how the National Cancer Institute supports the principles of findability, accessibility, interoperability, and reusability (FAIR) in childhood cancer research in a new, cloud-native computing infrastructure

International Childhood Cancer: Updates from the Pediatric Conference in Paris

Lynne Penberthy

MD, Associate Director, Surveillance Research Program, National Cancer Institute

Overview

This presentation will cover updates on the Paris Conference regarding the International Childhood Cancer Data Partnership highlighting the importance of international data sharing for understanding pediatric cancer and providing an update on subsequent work towards the goal of data sharing.

Objectives

- Participants will understand the rationale for creating an international childhood cancer data partnership
- Participants will understand the major advantages to pooling childhood cancer data internationally as well as the major barriers and tools to overcome the barriers
- Participants will be able to name 3 post-conference pilot projects and /or initiatives that are currently underway that advance the goals of the conference



Reporting Childhood Cancer Incidence in Kentucky Leads to Recurring Investments in Childhood Cancer Research

Eric Durbin¹, Chaney Blu¹, Bin Huang¹, Stephanie Barber¹, Ivelina Todorova¹, Isaac Hands¹

¹Kentucky Cancer Registry, Lexington, USA

Background

Childhood cancer is relatively rare, representing less than 1% of all cancers diagnosed in Kentucky. However, a diagnosis is severely burdensome to children and their families, including side effects from treatment and lifelong economic and social costs.

Purpose

To develop an annual report to document the burden and notable disparities in childhood cancer incidence.

Methods

Incidence data reported to the KCR for children ages 0-19 were grouped into International Classification of Childhood Cancer (ICCC) sites for analysis. Data for the most recent ten-year period (2011-2020) were used to generate a variety of informative data tables and graphics by sex, age, and ICCC site group. Age-adjusted rates were generated by site group, sex, diagnosis year, and geographic regions. Comparisons were made between Kentucky, the United States (U.S.), and other U.S. states.

Results

Data reveal higher incidence among males (54%), the greatest number of cases among very young children (ages 0-4), and greater numbers of cases among males for 9 out of the 11 major ICCC sites. Comparisons with rates in the U.S. show significantly high rates of brain and central nervous system tumors, lymphoma, epithelial tumors, retinoblastoma, and other sites. Joinpoint regression analysis for all sites combined shows a significant 1.78% annual percent change rate increase from 2011-2019.

The publications have been well received by public health professionals, childhood cancer advocates, and government authorities. Advocates used the report data to convince Kentucky legislators to invest \$27.5 million in childhood cancer research, including an investigation into the high rates of brain and CNS tumors.

Conclusion

The quantification of the childhood cancer burden for a geographic region is an important first step towards identifying potential disparities and prioritizing evidence-based research objectives. Due to the rarity of the disease, the calculation of stable rates by cancer type, sex, race, and sub-regions must include multiple years of incidence data. Generating a widely distributed, annualized report of childhood cancer incidence has been an effective approach towards informing the public and policy makers in Kentucky. Our approach for increasing childhood cancer awareness could be leveraged to inform and advocate for additional childhood cancer research investments in other populations.

Plenary # 4 – Occupational and Environmental Studies

Thursday, June 27th

2:00pm – 3:15pm

Evaluation of Cancer Incidence among Marines and Navy Personnel and Civilian Workers Exposed to Contaminated Drinking Water at USMC Base Camp Lejeune: A Cohort Study

Frank Bove

ScD, MS, Senior Epidemiologist, Agency for Toxic Substances and Disease Registry

Background

Drinking water at USMC Base Camp Lejeune, NC was contaminated with trichloroethylene and other industrial solvents from 1953 to 1985.

Methods

A cohort cancer incidence study was conducted of Marines/Navy personnel who, between 1975 and 1985, began service and were stationed at Camp Lejeune (N=154,821) or Camp Pendleton, CA (N=163,484), and civilian workers employed at Camp Lejeune (N=6,494) or Camp Pendleton (N=5,797) between October 1972 and December 1985. Camp Pendleton's drinking water was not known to be contaminated between 1972 and 1985. Individual-level information on all primary invasive cancers and in-situ bladder cancer diagnosed from 1996 to 2017 was obtained from data linkages with 54 cancer registries in the U.S. Survival methods were used to calculate hazard ratios (HRs) comparing cancer incidence between the Camp Lejeune and Camp Pendleton cohorts. Precision of effect estimates was evaluated using the 95% confidence interval (CI) ratio.

Results

Cancers among Camp Lejeune Marines/Navy personnel and civilian workers totaled 12,083 and 1,563, respectively. Cancers among Camp Pendleton Marines/Navy personnel and civilian workers totaled 12,144 and 1,416, respectively.

Compared to Camp Pendleton, Camp Lejeune Marines/Navy personnel had adjusted HRs ≥ 1.20 with 95% CI ratios (CIRs) ≤ 3 for acute myeloid leukemia (HR=1.38, 95% CI: 1.03, 1.85), all myeloid cancers including polycythemia vera (HR=1.24, 95% CI: 1.03, 1.49), myelodysplastic and myeloproliferative syndromes (HR=1.68, 95% CI: 1.07, 2.62), polycythemia vera alone (HR=1.41, 95% CI: 0.94, 2.11), cancers of the esophagus (HR=1.27, 95% CI: 1.03, 1.56), larynx (HR=1.21, 95% CI: 0.98, 1.50), soft tissue (HR=1.21, 95% CI: 0.92, 1.59) and thyroid (HR=1.22, 95% CI: 1.03, 1.45). Compared to Camp Pendleton, Camp Lejeune civilian workers had adjusted HRs ≥ 1.20 with 95% CIRs ≤ 3 for all myeloid cancers including polycythemia vera (HR=1.40, 95% CI: 0.83, 2.36), squamous cell lung cancer (HR=1.63, 95% CI: 1.10, 2.41) and female ductal breast cancer (HR=1.32, 95% CI: 1.02, 1.71). Sensitivity analyses indicated that confounding bias due to unmeasured risk factors (e.g., smoking and alcohol consumption) is unlikely to significantly impact the findings.

Conclusion

Increased risks of several cancers were observed among Marines/Navy personnel and civilian workers likely exposed to contaminated drinking water at Camp Lejeune compared to personnel at Camp Pendleton.



Firefighter Study Status and Plans

[Miriam Siegel](#)

PhD, MPH, Research Epidemiologist, National Institute for Occupational Safety and Health, Centers for Disease Control and Prevention

Overview

Firefighters are exposed to chemicals on the fireground that could increase their risk of developing cancer. But there are still unanswered questions about how cancer risk may vary across our nation's diverse fire service. The National Institute for Occupational Safety and Health (NIOSH) is recruiting firefighters to join the National Firefighter Registry for Cancer (NFR) so that we can better understand the link between firefighting and cancer. The NFR is an exposure registry that is designed to be linked with population-based cancer registries periodically over time for prospective follow-up of participants' cancer status. Presenters from NIOSH will discuss firefighter cancer, the design of the NFR, progress of participant enrollment, and plans for cancer registry linkages.

Objectives

- Understand cancer-related hazards faced by firefighters and remaining knowledge gaps
- Learn about ways that cancer registry data has improved our understanding of firefighter cancer
- Become familiar with the design and status of the National Firefighter Registry for Cancer

The Military Aviator Cancer Study (MACS)

[Shauna Stahlman](#)

PhD, MPH, Senior Managing Epidemiologist, Department of Defense

Overview

This presentation will provide an overview of the Congressionally mandated military aviator cancer study, including background, methods, and approach. The aviator cancer study was conducted in response to section 750 of the William M. (Mac) Thornberry National Defense Authorization Act (NDAA) for Fiscal Year 2021(FY 2021) (Public Law 116-283), "Study on the Incidence of Cancer Diagnosis and Mortality among Military Aviators and Aviation Support Personnel." The Act mandated a Phase 1 study on the incidence of cancer diagnosis and mortality among military fixed wing aviators and aviation support personnel (ground crew) compared to the U.S. population. A Phase 2 study is required if findings indicate a higher risk of cancer diagnosis or mortality among aviators or ground crew. The findings from the Phase 1a study were released in February 2023. The Phase 1b study findings are pending release. Phase 1b will include data from the Veterans Administration (VA) and 41 state cancer registries that were not included in the Phase 1a study. The findings and implications for the Phase 2 study will also be discussed.

Objectives

- Define the NDAA FY 2021 Sec. 750 Congressionally mandated aviator cancer study
- Summarize background on cancer epidemiology and occupational exposures for aircrew and ground crew
- Describe methods and results of Phase 1A study, the need for the Phase 1B study, and next steps



ORAL PRESENTATIONS

Concurrent 1.A – Evaluations of Data Quality

Tuesday, June 25th

11:00am – 12:30pm

Assessing the Completeness of Key Data Items Across NCCR Registries for Pediatric and Adult Cancer Cases

Fernanda Silva Michels¹, Dr. Gonçalo Forjaz², Stephanie Hill¹, Betsy Kohler¹

¹NAACCR, Springfield, USA, ²Westat, Rockville, USA

Background

The National Childhood Cancer Registry (NCCR) was developed under the National Cancer Institute's Childhood Cancer Data Initiative (CCDI) to identify and follow childhood cancer cases in the U.S. Its primary goal is to provide a platform to better understand the causes, outcomes, effective treatments, and later effects of cancer among children, adolescents, and young adults in the U.S. Each year, participating registries submit data for all patients diagnosed from 1995 onward at age 0-39 for inclusion in the NCCR. NAACCR serves as the NCCR coordinating center, working with NCCR registries, and NCI to facilitate this project. The NCCR Data Quality Working Group (DQ WG), led by NAACCR, develops appropriate methods to monitor the quality and consistency of pediatric cancer data in the NCCR and identify areas where additional quality assurance activities may be needed.

Purpose

Assess completeness of key pediatric data items in the NCCR, including histology, primary site, International Classification of Childhood Cancer (ICCC) site recode, and summary stage. These data items are necessary for basic analysis of pediatric data.

Methods

To assess the completeness of these four data items in NCCR participating registries, we used the Median/Multiple Outlier Testing (MMOT) Method, a quality control tool developed by the NCI's Surveillance Research Program, to identify outliers in the proportion of cases with unknown histology, unknown primary site, unknown summary stage, and unknown ICCC in each year of the period 1995-2020. Besides presenting MMOT results for all four data items, we compared results for the three first data items between pediatric (0–19 years old) and adult (20+ years old) cancer cases.

Results

We will present the results of our analyses on these four initial data items. Results will allow the NCCR team and registry managers to investigate pediatric data quality compared to adults (for unknown histology, unknown primary site, unknown summary stage data items). The results may provide insight into the collection, coding, and other processes that may impact the quality of data submitted to NCCR and guide the development of standard quality assurance activities for pediatric cases.



Comparing the Accuracy of Race and Ethnicity in Cancer Registry Data Source Records to Patient Self-Reported Data

Ms. Kimberly Herget¹, Rachel Codden¹, Ms. Valerie Yoder¹, Ms. Marjorie E. Carter¹, Mr. Seth Otto¹, Ms. Kacey Wigren¹, Dr. Jennifer A. Doherty^{1,2,3}, Morgan M. Millar^{1,3,4}

¹Utah Cancer Registry, Salt Lake City, USA, ²University of Utah, Salt Lake City, USA,

³Huntsman Cancer Institute, Salt Lake City, USA, ⁴University of Utah, Department of Internal Medicine, Salt Lake City, USA

Background

Reporting cancer incidence by race and ethnicity is an important aspect of cancer surveillance. Central cancer registries collect race and ethnicity from a variety of sources, including NAACCR Abstracts, electronic pathology reports, and vital records. These records may not always have complete or accurate race and ethnicity information.

Purpose

To identify patient characteristics associated with accurate race and ethnicity information and evaluate the accuracy of record sources.

Methods

Utah Cancer Registry collected self-reported race and ethnicity on 3,162 Utah cancer survivors through four surveys from 2015-2022. We compared accuracy of registry-reported race and ethnicity to self-reported race and ethnicity, and conducted logistic regression to identify factors associated with an incorrect assignment. We reviewed source records available to our registry to determine the accuracy of race and ethnicity data by record type.

Results

Patients who were coded by the registry as Hispanic were more likely to have race coded incorrectly compared to those coded as non-Hispanic (OR 6.49, 95%CI 4.48-9.42). Patients under 45 were more likely to have an incorrect race compared to those aged 55 to 64 (OR 1.66, 95%CI 1.02-2.70). Patients with more than one cancer were less likely to be coded incorrectly compared to patients with only one (OR 0.48, 95%CI 0.28-0.85). Women were more likely to have an incorrect ethnicity than men (OR 2.75, 95%CI 1.86-4.05). When race and ethnicity were included on a source record, the information was most accurate for birth certificates (98.5% race, 96.6% ethnicity), death certificates (95.2% race, 97.9% ethnicity), and NAACCR abstracts (94.4% race; 94.5% ethnicity). Only 11.1% of electronic pathology records had race coded, and were accurate 94.4% of the time when race was available. For ethnicity, electronic pathology records were only accurate 50.0% of the time.

Conclusion

Registries have limited time to individually review race and ethnicity of all reportable cancers. Registries should focus quality control efforts on female, young, and Hispanic patients, and those diagnosed with only one cancer. Birth certificate records were the most accurate source of race information, whereas death certificates were the most accurate for ethnicity. These results suggest registries should prioritize vital records for race and ethnicity information when available.



The Unknown Race Challenge: Greater California's Relentless Efforts to Mitigate the Ongoing Issue

Kyle Ziegler¹, Mr Scott Riddle, Mrs. Judy Vang, Mrs Winny Roshala

¹Cancer Registry Of Greater California, Sacramento, United States

Background

Ascertaining a <3.0% of unknown race on patients is becoming increasingly difficult to maintain. It is becoming more common for physician offices to not collect the patient's race; pathology reports obviously do not have a race, which is an important factor when many cases are abstracted directly from the pathology report (Path Only Cases); and hospitals may inadvertently submit cases with unknown race coded but documentation within the text indicates a known race.

Purpose

Each year the CRGC works diligently to maintain an unknown race rate below the NAACCR standard of 3.0%. Over the past several years, meeting this benchmark has become challenging. The CRGC has developed a four-pronged approach to achieve this metric. The approaches utilized are: an MD office directed followback, data mining of modified records, and a text-to-code verification. In 2023 the CRGC piloted a fourth approach following back to hospitals who have submitted cases with an unknown race and asked them to re-review the medical record for race information.

Methods

Two of the approaches are manual and consist of creating a packet of information, including patient lists for each physician office or hospital and either faxing or posting the packet for review. One of the approaches is a SQL query ran on the submitted Modified Records to identify a change in the Race data field. The remaining approach is another type of query in the Eureka Data base comparing submitted text from the hospital to the reported race code.

Results

Across all four efforts, there were 757 MD offices and 72 hospitals contacted, inquiring on 4,717 patients. Of those inquires 1,338 (28.3%) patients were able to be updated from an unknown race to a known race and 108 updates made via text mining.

Conclusion

Even though the results of these efforts were successful, they were barely enough to reach the <3.0% NAACCR goal. The number of resources and time required is becoming burdensome and is not sustainable for long term mitigation. We need to look for a better long-term solution that can be beneficial to all registries and to the research community.



Evaluation of Completeness, Quality, and Source Bias in Birthplace Data in the Texas Cancer Registry

Paige Miller¹, Erin Gardner¹, Keisha Musonda¹, Miriam Robles¹, Alison Little¹, Dr. Natalie Archer¹

¹Texas Cancer Registry, Austin, USA

Background

Understanding differences in cancer incidence, survival, and mortality between US-born and foreign-born Texans is of great interest to the cancer research community. Given that Texas is the second most populous state in the US, with a diverse and growing population, the Texas Cancer Registry (TCR) receives numerous inquiries to use its data for nativity-related research questions. However, using population-based cancer registry data to study the impact of nativity on the burden of cancer is limited without complete birthplace data, especially if the data are not missing at random.

Purpose

Evaluate TCR data to (1) determine the completeness, quality, and source of birthplace information and (2) identify strategies aimed at improving completeness and quality and lessening potential source bias, which would enhance the fitness of these data.

Methods

We evaluated all NAACCR/NPCR-reportable Texas resident cases (1995-2021) to calculate completeness of country of birth information, stratified by race/ethnicity, vital status, age at diagnosis, and diagnosis year. We identified sources of birthplace information overall and within each broad nativity category (US-born, foreign-born, and unknown). In addition, we evaluated data linkages conducted by TCR in the past 5 years for operational or research purposes to identify potential sources of birthplace information and conducted an environmental scan of external sources of birthplace data to augment TCR data through future linkages.

Results

An evaluation of birthplace completeness, quality, and source by race/ethnicity, vital status, age at diagnosis, and diagnosis year is underway. Preliminary data show that country of birth was unknown for 40.1% of patients, whereas 54.6% were US-born and 5.3% were foreign-born. Of patients with known nativity, 84.3% linked with death certificate records. The remaining birthplace information was reported to TCR from cancer reporting facilities.

Conclusion

TCR primarily obtains birthplace information from death certificate records, which introduces bias into any nativity-related cancer research question. We are presently investigating strategies to improve data collection and identify data sources that could be used to augment nativity information, including data linkages with birth certificate records and the Social Security Administration Numerical Identification System.

Concurrent 1.B – Pathology Reporting and Processing Solutions

Tuesday, June 25th
11:00am – 12:30pm

Dedicated Staff, Off the Shelf Technologies, and Artificial Intelligence Restores Standardized Electronic Pathology Reporting in Kentucky

***Eric Durbin**^{1,2}, Isaac Hands^{1,2}, Michele Hoskins¹, Strehphanie Carmack¹, Dr. Scott Grimes^{1,2}, Branson Repass^{1,2}, Aaron Sword^{1,2}, Dr Alena Smith², Ivelina Todorova¹*
¹Kentucky Cancer Registry, Lexington, USA, ²Markey Cancer Center, Lexington, USA

Background

After years of reliance on a commercial electronic pathology (E-Path) reporting mechanism, widespread E-Path reporting to the Kentucky Cancer Registry was abruptly terminated due to a licensing issue. An alternative, low-cost solution for secure transport and filtering was needed to restore mandated E-Path reporting from Kentucky's reporting facilities.

Purpose

To quickly evaluate and implement a low-cost and sustainable solution for standardized E-Path reporting in Kentucky.

Methods

KCR explored a variety of applications that could support electronic reporting, preferably in the NAACCR Volume V Health Level Seven (HL7) standard. KCR operations and informatics staff established a prioritized list of disrupted reporting facilities and initiated contact to explore alternative solutions. Technical discussions established protocols for messages, secure transport, testing, and timelines that were acceptable to the reporting facilities and to the central registry. A preliminary natural language processing API from the Modeling Outcomes using Surveillance data and Scalable Artificial Intelligence for Cancer (MOSSAIC), a collaborative partnership between US Department of Energy's Oak Ridge National Laboratory and the National Cancer Institute's SEER Program was implemented for filtering non-cancer E-Path reports.

Results

KCR succeeded in restoring E-Path feeds in multiple reporting facilities within three months. Mirth-Connect was implemented within KCR's infrastructure to receive and process messages. Most facilities were capable of formatting and securely transmitting NAACCR standard Volume V HL7 messages. Significant testing and repeated technical discussions were needed to finalize standardized report content and transport mechanisms. The preliminary MOSSAIC filter was configured to favor recall to reduce the probability of missing reportable cases. As a result, a significant number of reports for non-reportable conditions require manual screening at the central registry. Efforts are ongoing to fully restore population-based E-Path reporting in Kentucky.

Conclusion

Reliance on a single vendor creates unnecessary vulnerabilities for central registries that should be carefully considered. However, KCR was able to identify alternative and affordable technologies that aided in a rapid restoration of E-Path reporting in Kentucky. Concerted efforts by KCR's operations and informatics staff, and technical staff at hospital and pathology laboratories were required for each restored data feed. Improving the filtering mechanism emerged as a high priority to reduce non-reportable E-Path records.



Automating the eMaRC Plus Data Preprocessing Using Python to Enhance Cancer Surveillance

[Mohammad Beheshti](#)^{1,2}, [Lucinda Ham](#)¹, [Nishant Jain](#)¹, [Sue Stulgo](#)¹, [Chester Schmaltz](#)¹, [Iris Zachary](#)^{1,2}

¹Missouri Cancer Registry, Columbia, United States, ²University of Missouri, Columbia, United States

Background

The Missouri Cancer Registry and Research Center (MCR) investigated innovative approaches to integrate pathology laboratory cases from eMaRC Plus into the CRS Plus database. The eMaRC Plus data requires preprocessing to incorporate requisite default values specific to each cancer primary site prior to integration into the CRS Plus database. MCR has transitioned from SAS to Python for automating the processing of default values for each cancer site, aligning with reporting requirements.

Purpose

This project aimed to automate and streamline the processing of default values for cancer cases obtained from eMaRC Plus, facilitating smooth integration for import into CRS Plus. The ultimate objective was to increase the number of surveillance cases, aligning with NAACCR and NPCR goals of achieving 95% for 24-month data and 90% for 12-month data.

Methods

An Excel template for default values with each row representing a specific cancer site was created. A Python script was developed to take input from two files, a CSV file containing eMaRC Plus records and a default value template file. A cancer site was assigned to each eMaRC Plus record based on rule-based criteria. Fields were populated for each record using values from the template. The final dataset was converted to NAACCR XML format using a SAS script via SASPy library in Python. Finally, for accuracy validation, GenEdits was employed to address minor edits.

Results

MCR was able to automate cleaning the eMaRC Plus data and successfully imported over 700 cancer incidence cases into CRS Plus by using Python automation as outlined above. This process is now regularly implemented for preprocessing the eMaRC Plus data at MCR.

Conclusion

This project highlights Python as a valuable tool for efficiently populating default values for pathology laboratory cases in eMaRC Plus offering an alternative to traditional methods.

Expansion of Standardized Cancer Pathology Reporting to a Cloud Platform

***Sandy Jones**¹, Ms Barbara Weatherby², Ms Charlotte Marshall³, Mrs. Neha Jayaswal², Dr. Temitope Alimi², Ms Vanessa Holley⁴, Ms Brooke Beaulieu⁴, Mr Tim Longo⁵, Mr. Joseph Rogers¹, Ms. Vicki Benard¹*

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Background

Achieving real-time reporting requires solutions to address ongoing challenges with data processing and case reporting, including interoperability and timeliness. Despite the implementation of data exchange standards, central cancer registries (CCRs) face barriers to establishing connectivity with pathology laboratories. These challenges and barriers often require time-consuming, manual interventions and one-off solutions to ensure data linkage and accurate abstraction of case data, including review of clinical notes to collect missing information. These interventions can reduce the timeliness of downstream public health interventions for reducing the cancer burden within communities.

Purpose

To summarize the outcomes of the work conducted by the National Program of Cancer Registries and the Association of Public Health Laboratories (APHL) to expand electronic surveillance reporting to include cancer pathology data.

Methods

As part of the CDC's Data Modernization Initiative (DMI), pathology laboratories have been onboarded so that the cancer data they receive from healthcare systems can be reported directly to CCRs via the APHL Informatics Messaging Services (AIMS) platform. Laboratories received technical assistance from project leadership so that their test messages met mandated requirements prior to moving to production. Reporting agreements between pathology laboratories and CCRs were established.

Results

As of December 2023, seven laboratories (Quest Diagnostics, QDx Path Services, PathGroup, ICM Diagnostics, Inform Diagnostics, NeoGenomics, and VitalAxis) are actively reporting electronic cancer pathology data via the APHL AIMS platform to all CCRs. Six additional laboratories are in the process of validating test messages. There were 15,000 cancer pathology reports transmitted to CCRs over the past four weeks. Data were reported daily compared to once a month previously.

Conclusion

The onboarding and continued engagement of laboratories highlights how a cloud-based platform can improve standardized reporting for public health surveillance. This increase in reporting frequency and shift to fully electronic transmission demonstrates how this approach can streamline data exchange between healthcare systems and CCRs. This has the potential to prevent delays in case processing, which is essential to achieve real-time reporting.



Concurrent 1.C – Integration of Individual Residential Histories in Cancer Research

Tuesday, June 25th

11:00am – 12:30pm

Introduction to Integration of Individual Residential History in Cancer Research

Zaria Tatalovich¹, Lynne Penberthy¹, Li Zhu¹

¹National Cancer Institute, Rockville, USA

We are proposing a collaborative breakout session called Integration of Individual Residential Histories in Cancer Research.

The presentations will cover efforts to link, consolidate, and reconstruct residential history of patients, mechanics of linking residential address data with environmental data for exposure assessment, and examples of use of residential addresses in epidemiological studies. The session will include:

- An introduction by Lynne Penberthy, MD, MPH providing a brief overview of NCI's Surveillance Research Program efforts to link historical residential address information with SEER patients and augment cancer surveillance data with longitudinal environmental data.
- Individual presentations from the following researchers and collaborators:
 - Zaria Tatalovich, PhD. Health Geographer. Surveillance Research Program, National Cancer Institute. Heidi Hanson, PhD. Group Leader, Biostatistics and Biomedical Informatics. Oak Ridge National Laboratory: "NCI-SEER-ORNL Residential History Data Linkage with Environmental Data"
 - Mr. Patrick Ringwald, MPH. Research Associate. (Westat), Ms. Diane Ng. MPH. Research Associate. (Westat): "Deriving Residential Histories for Population Health Research: An Example from the Sister Study"
 - Johnie Rose, MD, PhD. Associate Professor. Director, Case Comprehensive Cancer Center Population Cancer Analytics Shared Resources (Case Western Reserve University School of Medicine): "Developing Environmental Exposure Histories for Population Cancer Research"
 - Iona Cheng, PhD, Professor. (University of California, San Francisco, School of Medicine): "Investigating the use of LexisNexis residential addresses in studies of cancer epidemiology: The Multiethnic Cohort Study"
 - Antoinette Stroup, PhD, Professor. (Rutgers Cancer Institute of New Jersey): "Leveraging population-based residential history data through central cancer registries: Studies in New Jersey"



NCI-SEER-ORNL Residential History Data Linkage with Environmental Data

Zaria Tatalovich¹, Heidi Hanson²

¹National Cancer Institute, Rockville, USA, ²Oak Ridge National Laboratory, Oak Ridge, USA

Cancer control community has long recognized the importance of having historical residential address information pre- and post-diagnosis. It provides an opportunity to investigate the role of neighborhood adverse social and environmental conditions on cancer risk and outcomes over the life course, as well as the impact of a cancer diagnosis on cancer survivorship issues. From the perspective of cancer surveillance data linkages, having residential histories of cancer patients can facilitate linkages with multiple sources of longitudinal data and enhance the quality of data linkages.

National Cancer Institute's (NCI) Surveillance Research Program (SRP) in collaboration with the Department of Energy's (DOE) Oak Ridge National Laboratory (ORNL) initiated effort to link historical residential address information of SEER (Surveillance Epidemiology and End Results Program) cancer patients with a set of longitudinal environmental exposure datasets.

In 2017, SRP obtained and linked historical residential address information to over 3 million cancer patients. This presentation covers the mechanics of historical residential address linkage with individual patients' records; quality of data linkage; effort to derive continuous patients' residential history; landscape analysis of publicly available sources of environmental data; and a protocol for linkage of longitudinal environmental exposure measures to historical address information. The results demonstrate the feasibility of creating a specialized longitudinal patient-centered database to facilitate exposomic research.



Deriving Residential Histories for Population Health Research: An Example from the Sister Study

Patrick Ringwald¹, **Diane Ng**¹, David Stinchcomb¹, Deborah Bookwalter¹, Aimee D'Aloisio², Jennifer Ish³, Dale Sandler³, Alexandra White³

¹Westat, Rockville, United States, ²DLH, Atlanta, United States, ³National Institute of Environmental Health Sciences (NIEHS), Durham, United States

Background

Epidemiologic studies of cancer etiology are increasingly focused on the impact of environmental exposures over the life course. Obtaining complete and accurate residential histories for study participants, however, is often costly or impractical.

Purpose

To apply a method for deriving residential histories in the Sister Study cohort to assess residential mobility from 1980 through enrollment (2003-2009).

Methods

We submitted a file with participant names and identifiers (e.g., DOB, enrollment address) for the full cohort of 50,884 women (ages 35-74 years) to a commercial data vendor (LexisNexis) for address linkage. The returned addresses were combined with existing self-reported addresses and geocoded to build a comprehensive residential history. Addresses outside of the 1980-2009 period were excluded; further, we linked the USPS Residential Delivery Indicator to identify and exclude businesses. The cleaned dataset was then processed with free, open-source SAS programs developed by Westat which use an algorithm to match and combine common addresses and to resolve overlaps/gaps between dates. Modifications were made to prioritize participant's self-reported addresses.

Results

LexisNexis returned at least one address for 93.5% of the cohort. Those older than 64 at enrollment were less likely to be matched compared to the younger women. On average, we received 8 addresses per person for the years of interest. We excluded 15,414 businesses (4% of addresses returned). Based on the available data, we derived complete residential histories covering 1980 through enrollment for 40% of participants with improved results over time (74% starting in 1985; 96% starting in 1990).

Conclusion

We have demonstrated a practical approach to assessing residential mobility in a large, national prospective study by sourcing commercial address data, using an open-source algorithm, and integrating with self-reported residence data to generate plausible residential histories.

Developing Environmental Exposure Histories for Population Cancer Research

Johnie Rose¹, Ms. Fatima Hussain², Dr. Jayakrishnan Ajayakumar², Dr. Randy Vince³, Dr. Qian Wang³, Dr. Maeve MacMurdo⁴, Dr. Jennifer Cullen¹

¹Case Comprehensive Cancer Center, Cleveland, United States, ²Case Western Reserve University Department of Population and Quantitative Health Science, Cleveland, United States, ³University Hospitals Cleveland Medical Center, Cleveland, United States, ⁴Cleveland Clinic Foundation, Cleveland, United States

Background

Epidemiologic studies of environmental cancer risk are challenging due to the difficulty of capturing exposure histories for multiple substances over the decades prior to cancer diagnosis, when exposure-induced genetic insults accumulate. To comprehensively assess an individual's cumulative environmental exposures, it is crucial to understand their residential history.

Purpose

We describe ongoing work to develop a database containing historical residential addresses of patients within a large health system linked with neighborhood-level environmental data.

Methods

For each of 650,000 Accountable Care Organization patients within a large Northeast Ohio health system, we obtained a maximum of 20 historical addresses (each associated with start/stop dates) gathered from public and proprietary data sources by a commercial vendor. We mapped each address to a single hexagonal area measuring approximately 0.74 km². We used the U.S. Environmental Protection Agency (EPA) Risk Screening Environmental Indicators (RSEI) Geographic Microdata to attach estimates of toxicity-weighted concentrations in air and water of up to 787 chemicals to each hexagon covering a five-state area. RSEI provides modeled small area concentrations of each substance reported through EPA's Toxic Release Inventory, along with cancer and non-cancer relative toxicity levels.

Results

For each of 719,350 hexagons (each with area of 0.74 km²) covering the entirety of Ohio, Michigan, Pennsylvania, West Virginia, and Indiana, the database contains annual estimates of concentrations and toxicity-weighted concentrations for each chemical within the RSEI data for 1988 through 2021. This represents 7,031,996,440 chemical observations. Each available historical address of each of the 650,000 health system patients is linked to one of these hexagons, enabling estimation of cumulative exposure to, and toxicity from, each RSEI substance for each patient. Summing relative toxicity-weighted concentrations allows for estimation of cancer and non-cancer toxicity from multiple substances simultaneously.

Conclusion

The exposure history database described here will permit numerous future studies to identify possible associations of health outcomes with exposure to one or more substances using case control or retrospective cohort methods. This approach is readily expandable to encompass additional environmental data sources; and it can be applied to cancer registry data.

Investigating the Use of LexisNexis Residential Addresses in Studies of Cancer Epidemiology: The Multiethnic Cohort Study

Iona Cheng¹, Dr. Juan Yang¹, David Stinchcomb², Dr. Sandi Pruitt³, Dr. Jun Wu⁴, Dr. Christopher Haiman⁵, Dr. Loic Le Marchand⁶, Dr. Anna Wu⁵, Scarlett Gomez¹, Dr. Lynne Wilkens⁶, Dr. Salma Shariff-Marco¹

¹University of California, San Francisco, San Francisco, USA, ²Westat, Rockville, USA, ³University of Texas Southwestern Medical Center, Dallas, USA, ⁴University of California, Irvine, Irvine, USA, ⁵University of Southern California, Los Angeles, USA, ⁶University of Hawaii, Honolulu, USA

Background

Residential histories offer an opportunity to capture geospatial exposures over time. To investigate the reliability of residential histories from commercial databases among racially and ethnically diverse populations, we examined the agreement of area units and geospatial exposures using residential histories from LexisNexis with those collected prospectively for the Multiethnic Cohort (MEC).

Methods

Over 215,000 MEC participants were linked to LexisNexis, and residential histories were constructed using an algorithm developed by NIH/Westat. 826,687 complete addresses from LexisNexis were geocoded to parcel or street segment centroid. We computed the concordance of census tract, census block group, and geospatial buffers within 1600m, 500m, and 50m based on residential histories (1993-2016) from LexisNexis and the MEC. We also assessed the correlation of geospatial exposures—census block group percent poverty and kriging interpolated air pollutants (PM10 and NOX) from both sources. Subgroup analyses were conducted by age, race and ethnicity, sex, and residential mobility.

Results

The average concordance in census tract, census block group, and geospatial buffers within 1600m, 500m, 50m between LexisNexis and the MEC were 66.0%, 63.2%, 69.8%, 67.8%, and 54.0%, respectively. The concordance of census tract was highest for Japanese American participants (77.6%) followed by Native Hawaiian (70.8%), White (61.8%), Latino (60.5%), and African American (60.2%) participants; similar racial and ethnic patterns were seen for other area units. The correlation for census block group percent poverty was 0.85, and decreased with the number of residential moves (r for non-movers=0.92, 1-2 moves=0.78, and 3+ moves=0.67). Based on monthly average NOX and PM10 exposures, the correlation was 0.71 and 0.80, respectively, and lower for ages 45-64 vs. 65+ (NOX r =0.63 vs. 0.79; PM10 r =0.72 vs. 0.87). Correlation for NOX and PM10 was lowest among Latino (r =0.63 and r =0.71, respectively) and highest among African American (r =0.78 and r =0.87, respectively) participants. No subgroup differences were seen by sex.

Conclusion

Overall, the assignment of area units and estimation of geospatial exposures based on LexisNexis addresses were variable across subgroups, with implications for disparity studies. The lower concordance for Latino and African American populations suggests that these data should be used with caution; methods in improving residential history assessment should be examined.



Leveraging Population-Based Residential History Data through Central Cancer Registries: Studies in New Jersey

[Antoinette Stroup](#)¹

¹*Rutgers Cancer Institute of New Jersey, New Brunswick, United States*

Background

Spatial-temporal studies contribute to our understanding of the socio-spatial mobility patterns of individuals diagnosed with cancer and may help to improve our understanding of geographic patterns. However, a long-standing shortcoming of cancer registry data has been our inability to provide longitudinal residential data for cancer patients for both etiological and survival studies.

Purpose

Describe how researchers who are interested in exploring cancer risk and outcomes beyond the diagnostic time window are using residential history data made available through a linkage between the New Jersey State Cancer Registry and LexisNexis.

Methods

Describe studies using themes that were identified by Namin and colleagues (2021) in their seminal review of the role of residential history in cancer research: Social environment factors, Built environment and/or Neighborhood factors, and Individual factors.

Results

Social and economic determinants such as census tract poverty and residence in ethnic enclaves were significant in studies using long-term residential histories and assessing their impact on colon cancer survival and risk of late-stage colon cancer, respectively. Residential histories have also been used to elucidate the role of built environment/neighborhood factors in spatial-temporal studies of cutaneous T-cell lymphoma (CTCL), landscape characteristics and regional-stage colon cancer survival, and walkability and physical disorder in colorectal cancer outcomes. Finally, individual mobility has been examined in New Jersey residents through the residential history data. Notably, in a small cohort of colon cancer patients, 35% moved at least once, 10% moved to another state, and a larger proportion (42%) of individuals living in census tracts with >20% poverty moved compared to those in tracts with <5% poverty (32%), and 32.6% of Hispanic colon cancer cases lived in a Hispanic enclave over the ten years preceding diagnosis.

Conclusion

These studies would not be possible without our ability to link population-level cancer surveillance data to residential histories. However, more research is needed to validate and augment LexisNexis residential data with other datasets (e.g., U.S. Postal Service, vital records) and examine potential sources of information bias along demographic factors such as birth cohort and race/ethnicity. Additionally, robust spatial-temporal statistical methods that can be used with large scale longitudinal spatial data must be developed.



Concurrent 1.D – Patterns in Cervical, Endometrial and Prostate Cancers

Tuesday, June 25th

11:00am – 12:30pm

Trends in Endometrial Cancer Incidence in Texas, 2012-2021

Erin Gardner¹, Paige Miller¹, Keisha Musonda¹, Ms. Adrienne Moreno¹, Dr. Natalie Archer¹

¹Texas Department of State Health Services, Austin, USA

Background

In the US, endometrial cancer incidence rates have increased by about 1% per year in White women and 2%-3% in non-White women over the last decade. Differences in endometrial cancer mortality that disproportionately affect Black women are well documented. Reports of rises in endometrial cancer incidence among Hispanic women are present but warrant further investigation and attention. Texas is the second most populous state and one of the fastest growing states in the US, with a Hispanic female population of almost 6 million. Therefore, investigating endometrial cancer incidence rates and trends in Texas can provide valuable insight into this increasingly common and understudied cancer that disproportionately affects certain groups, and can help to enhance our understanding of the impact of this cancer among Hispanic women.

Purpose

To characterize trends in invasive endometrial cancer incidence by race/ethnicity and age at diagnosis in the past decade in Texas.

Methods

This analysis used 2012-2021 Texas Cancer Registry data, SEER*Stat, and Joinpoint to examine patterns and time trends in endometrial cancer incidence rates by race/ethnicity and age group. Annual percent change (APC) from 2012 to 2021 and 5-year age-adjusted incidence rates (2017-2021) were calculated. Diagnosis year 2020 was excluded from the estimation of trends but was included in rate calculations.

Results

Preliminary results found that endometrial cancer rates rose significantly among Texas women from 2012-2021. Among Hispanic women, a statistically significant increase in rates was observed for every increasing 10-year age group from 40-79. The steepest rise over time occurred among Hispanic women ages 40-49 (APC=4.9%). There was also a significant increase in rates over time among non-Hispanic (NH) White women ages 40-49, but of a lower magnitude (APC=2.3%). Hispanic women ages 40-49 also experienced a significantly higher 5-year incidence rate (29.9 cases per 100,000 population) compared to other race/ethnicity groups in this age group (NH White women: 20.7/100,000; NH Black women: 16.2/100,000).

Conclusion

In Texas, endometrial cancer incidence rates have risen in the past decade, with the most significant increase over time observed among Hispanic women ages 40-49. The reasons underlying these increasing rates remain unclear and warrant further investigation using population-based cancer surveillance data.



A More Accurate Measure of Endometrial Cancer Incidence Rates in New Mexico: A Hysterectomy-Corrected Analysis

Dr. Ashlee Candelaria², [Angela Meisner](#)¹, Dr. Charles Wiggins², Dr. Colleen McCormick²
¹New Mexico Tumor Registry, Albuquerque, USA, ²University of New Mexico Comprehensive Cancer Center, Albuquerque, USA

Background

Endometrial cancer (EC) is the sixth most common female cancer, with incidence increasing worldwide. Significant racial inequities within EC have been documented.

Purpose

To characterize the incidence of EC among the three largest race/ethnicity groups in NM by calculating rates that have been corrected for hysterectomy.

Methods

We used existing records from the NM Tumor Registry to identify all incident cases of EC diagnosed among NM residents from 2016-2020. Estimates of hysterectomy prevalence in NM's resident population during the study period were obtained from the Behavioral Risk Factor Surveillance System; these data were used to derive estimates of the population that was truly at risk for developing endometrial cancer. Average annual age-adjusted incidence rates (US 2000 standard) and age-specific incidence rates were calculated using hysterectomy-adjusted population estimates derived from US Census Bureau.

Results

1,556 incident EC cases were diagnosed among NM residents during the study period. Hysterectomy-adjusted incidence rates (per 100,000) were higher than unadjusted rates in NM's three largest race/ethnic groups: 34.2 vs. 21.8 for non-Hispanic White (NHW); 33.3 vs. 21.4 for Hispanic White (HW); and 30.7 vs. 23.5 for American Indian/Alaska Native (AIAN). Hysterectomy-adjusted incidence rates for EC were similar among NHW, HW and AIAN. Age-specific incidence rates for women 35-44 years of age were higher among AIAN (26.8) than for NHW (8.9), which was statistically significant. NHW patients had the highest age-specific rates in every age-category above 55 years of age. For each racial/ethnic group, the percentage of endometrioid to non-endometrioid cancer cases was similar. For histology groups endometrioid/clear cell or papillary/carcinosarcoma/other histology respectively, the percentage of EC cases were 77/2.4/3.8/16 among NHW vs 78.7/1.9/4.5/15 among HW and 79.3/3.6/5/12 among AIAN. EC cases by stage were also similar among racial/ethnicity groups. The percentage of EC cases were 66/21.1/7.8/4.8 among NHW vs 69.8/17.8/8.7/3.4 among HW and 62.9/22.9/10/4.3 for AIAN.

Conclusion

Hysterectomy-adjusted incidence rates of EC were similar among racial/ethnicity groups in NM. The EC incidence among reproductive age AIAN patients were higher than those for HW and NHW patients. These results may have reproductive consequences, as well as implications on the differential diagnosis for abnormal bleeding for younger women in these populations.

Recent Trends in Prostate Cancer Incidence by Stage, Age, Race/Ethnicity, and State

[Tyler Kratzer](#)¹, [Breanna McKinnon](#)¹, [Ms. Jessica Star](#)¹, [Ms. Rebecca Siegel](#)¹

¹*American Cancer Society, Atlanta, United States*

Background

Prostate cancer incidence has been increasing since 2014, although statistically significant increases are limited to advanced stage disease. Contemporary trends have not been comprehensively examined.

Purpose

Analyze prostate cancer incidence trends by stage, age, race/ethnicity, and state and their correlation with screening, for the Cancer Facts & Figures 2025 Special Section.

Methods

Age- and delay-adjusted NAACCR incidence rates from 1998-2019 for 49 states (excluding Nevada) and the District of Columbia were stratified by stage (local, advanced [regional and distant], unstaged), age (20-54, 55-69, 70+), race/ethnicity (non-Hispanic racial groups: White, Black, American Indian and Alaska Native [AIAN], Asian American and Pacific Islander [AAPI], and Hispanic), and state. Trends were quantified using Joinpoint regression average annual percent changes during 2015-2019. Statistical significance was determined using the empirical quantile method ($\alpha=0.05$). BRFSS data were the source for prostate-specific antigen (PSA) screening data. Pearson correlation coefficients were used to quantify the correlation between trends in prostate cancer incidence and changes in screening prevalence.

Results

Prostate cancer incidence increased from 2015-2019 overall (3.2% per year), in every racial/ethnic group, and in 28/50 states. Localized stage incidence was stable nationally and in all racial and ethnic groups ages 20-54 years but increased by 1.9%-4.1% per year in Black, AIAN, and AAPI men ages 55-69 years, by 4.3%-4.5% per year in White, AIAN, and AAPI men ages 70+, and in 19 states, mostly in the East. Advanced stage disease increased by 4.8% per year overall, in men of every racial/ethnic group ages 55-69 and 70+ years, in Black and Hispanic men 20-54 years, and in 37 states. The prevalence of PSA testing declined from 2014 to 2018 by 10%-38% in every state, 19%-38% by age, and 8%-30% by race/ethnicity and was not correlated with overall or stage-specific prostate cancer incidence ($r=-0.11$, $P=0.45$ for overall).

Conclusion

In addition to established increases in advanced-stage disease, localized-stage prostate cancer incidence is increasing in 19 states and in many men 55 years and older, and does not appear to be explained by changes in PSA testing. These findings warrant further investigation.



Cervical Cancer in Manitoba: Are We Moving Towards Elimination?

Donna Turner^{1,2,3}, Mr. Oliver Bucher¹, Mrs. Jen Bravo¹, Cathy Webber¹, Muhammad Aldhshan¹, Austin Hill¹, Carla Krueger¹, Kelly Bunzeluk¹

¹CancerCare Manitoba, Winnipeg, Canada, ²University of Manitoba, Winnipeg, Canada,

³Paul Albrechtsen Research Institute CancerCare Manitoba, Winnipeg, Canada

Background

The World Health Organization aims to eliminate cervical cancer by 2030, targeting human papillomavirus (HPV) vaccination rates of 90%, screening rates of 70%, and treatment rates of 90%. Led by the Canadian Partnership Against Cancer, Canada has its sights on eliminating cervical cancer by 2040, focusing on improved HPV vaccination rates and the introduction of HPV primary testing for cervical screening.

Purpose

To assess the province of Manitoba's progress towards the elimination of cervical cancer.

Methods

Data were collated from the Manitoba Cancer Registry, the provincial government (Manitoba Health), and CancerCare Manitoba's CervixCheck screening program. Joinpoint analysis of the Manitoba Cancer Registry's data assessed cervical cancer incidence (counts and rates) over the past 30 years, while HPV vaccination rates were retrieved from Manitoba Health. Cervical screening data were acquired from CervixCheck, including results from a novel population-based randomized trial of 25,000 un- and under-screened women (those with no screen in the past 5 years), comparing response to mailed HPV self-sampling kits, letters offering these kits, and usual practice.

Results

Between 1992 and 2021, Joinpoint analysis showed a -1.43 average percent change (APC) ($p < 0.05$) in the age-standardized incidence rate and -0.52 APC ($p < 0.05$) in number of women diagnosed with invasive cervical cancer. However, recent years show an increase that will be monitored as more data become available, since national Canadian data indicate a significant APC=+3.7 for cervical cancer since 2015. Prevention efforts in Manitoba are promising, with data for 2021 showing that by age 17, most girls (72.6%) have received HPV vaccination compared to none before 2007. Screening uptake remains challenging: in 2015-17 the cervical screening rate had declined to 65% in the eligible population, from 69% a decade previously. However interim analysis of a randomized trial suggests that self-sampling could contribute significantly, with increased screening rates of up to 22% in un- and under-screened women.

Conclusion

Data from many perspectives is key to informing progress towards the elimination of cervical cancer. While there are promising recent efforts in terms of prevention and screening for cervical cancer, ongoing monitoring is required in the face of concerns of a recent rise in cervical cancer incidence.

Concurrent 1.E – Global Perspectives

Tuesday, June 25th

11:00am – 12:30pm

Worldwide Adherence to Clinical Guidelines for Cervical Cancer (VENUSCANCER)

***Pamela Minicozzi**¹, **Veronica Di Carlo**¹, **Claudia Allemani**¹, on behalf of the VENUSCANCER Working Group*

¹Cancer Survival Group, London School of Hygiene and Tropical Medicine, London, United Kingdom

Background

In CONCORD-3, we analyzed individual records for 660,774 adult (15-99 years) women diagnosed with cervical cancer during 2000-2014 in 62 countries. During 2010-2014, age-standardised 5-year net survival ranged from 52% in Ecuador to 77% in Korea. Survival was below 55% in Argentina, Bulgaria and Poland, 67% in Canada and 63% in the United States (US), but reached 73% in Cuba and Norway.

The VENUSCANCER project on women's cancers aims to explain whether these international differences in survival are attributable to differences in disease biology, or patterns of care, or socio-economic status.

Purpose

To examine indicators of adherence to clinical guidelines for adult women diagnosed with cervical cancer in North America, and world-wide.

Methods

Cancer registries were invited to submit data for a single year of complete incidence during 2015-2018, for which availability and completeness of high-resolution variables (e.g., stage, staging procedures, biomarkers, treatment) were highest. We analyzed data from cancer registries with at least 70% of known stage and known information on treatment (surgery, radiotherapy or chemotherapy).

We examined the proportion of women surgically treated for an early-stage tumor (T1N0M0) and of those who received radiotherapy or chemotherapy for an advanced-stage tumor (T4, anyN, M0 or M1).

The odds of receiving guideline-compliant treatment will be explored by age, race and socio-economic status.

Results

We received data for 8,967 women from 69 registries in 30 countries. Stage at diagnosis was available in 52 registries, 11 of which in North America.

Of 2,028 women with cervical cancer in Canada and the US, 44% were diagnosed at an early stage (63% Canada; 42% US) and 13% at an advanced stage (7% Canada; 14% US).

Around 50% of women diagnosed at an early stage were surgically treated in both countries; 78% of women diagnosed at an advanced stage were treated with radiotherapy or chemotherapy (93% Canada; 77% US).

Conclusion

These results will offer the first global picture of adherence to treatment guidelines for cervical cancer. More detailed analyses will help explain the differences found in North America, and in other continents.



Trends in Avoidable Premature Deaths for Breast Cancer, by Race (VENUSCANCER)

Veronica Di Carlo¹, Pamela Minicozzi¹, Prof Michel P Coleman¹, Claudia Allemani¹, on behalf of the CONCORD-VENUSCANCER Working Group

¹Cancer Survival Group, London School Of Hygiene And Tropical Medicine, London, United Kingdom

Background

The CONCORD programme highlighted increasing trends in age-standardised 5-year net survival for breast cancer, during 1995-2014, in the US, Israel, New Zealand and Singapore, where ethnic/racial disparities in prognosis and access to treatment are well-documented.

Purpose

To investigate trends in 5-year net survival for breast cancer by race/ethnicity, and to estimate the proportion of avoidable premature deaths among ethnic/racial minorities.

Methods

We analyzed trends in 5-year net survival by race/ethnicity (Whites and Blacks in the US; Jewish and Arabs in Israel; Chinese and Malay in Singapore; non-Māori and Māori in New Zealand), age group (15–44, 45–54, 55–64, 65–74 and 75–99 years), stage (node-negative, node-positive, metastatic and locally advanced) and calendar period of diagnosis (1995-1999, 2000-2004, 2005-2009 and 2010-2014) using the non-parametric Pohar Perme estimator, correcting for background mortality by single year of age, race/ethnicity, county-level SES (US) and calendar year in each country.

We estimated the number (and %) of avoidable premature deaths in the minority racial/ethnic group in each country as the number of deaths that could be avoided if 5-year net survival for breast cancer among the minority racial/ethnic group were as high as net survival in the majority group.

Results

In each country, and throughout 1995-2014, the minority racial/ethnic group had a less favorable stage distribution and consistently lower 5-year net survival than the majority group.

The proportion of avoidable premature deaths fell slightly among Māori women in New Zealand and among Arab women in Israel. By contrast, the proportion of avoidable premature deaths was high, and showed no improvement over the 20-year period, among Black women in the US (range 43-48%) and Malay women in Singapore (46-52%).

In the US and Singapore, the racial/ethnic gap in 5-year net survival was seen for each stage of disease. By contrast, there was no racial/ethnic gap in survival when stratifying analyses by stage in Israel and New Zealand.

Conclusion

Trends in avoidable premature deaths provide actionable evidence on the number of lives that could be 'saved' if ethnic/racial inequalities were reduced and can help planning cancer control strategies that promote equal opportunity for the best possible outcomes after a breast cancer diagnosis.

Conditional Survival of Young Patients (0-24 Years) Diagnosed with Leukaemia during 2000-2014 Worldwide: CONCORD-3

Naomi Ssenyonga¹, Prof Michel P Coleman^{1,2}, Claudia Allemani¹, on behalf of the CONCORD Working Group

¹Cancer Survival Group, Department of Non-Communicable Disease Epidemiology, London School of Hygiene and Tropical Medicine, United Kingdom, ²Cancer Division, University College London Hospitals NHS Foundation Trust, United Kingdom

Background

Conditional survival is the probability of a patient living an additional number of years given that the person has already survived a specified number of years since diagnosis. Advances in treatment have led to dramatic improvements in the prognosis of children with leukaemia, especially in high-income countries. In CONCORD-3, we highlighted global variations in five-year survival trends from leukaemia and its morphological sub-types for children, adolescents and young adults (0-24 years) diagnosed during 2000-2014.

Purpose

Here, we examine world-wide trends in five-year survival conditional on surviving to one year after diagnosis for young patients with leukaemia, by age and country.

Methods

We included data for 164,563 young people diagnosed during 2000-2014, among whom 135,980 survived for one year. Data were provided by 258 population-based cancer registries in 61 countries. Age was grouped as 0-14 (children), 15-19 (adolescents) and 20-24 years (young adults). We estimated net survival up to five years, and at five years conditional to surviving one year (conditional survival), using the non-parametric Pohar-Perme estimator. To control for background mortality, we used life tables of all-cause mortality by single year of age, sex, region or country, and calendar year. All-ages survival estimates were standardised to the marginal age distribution of all persons included in the analysis.

Results

Age-standardised conditional 5-year net survival in children, adolescents and young adults increased over time and by 2010-2014, it ranged from 62% in Mexico to over 90% in most high-income countries, including the United States (91%) and Canada (93%). On average, 5-year conditional net survival was at least 5 to 10% higher than 5-year unconditional net survival. Conditional net survival was systematically higher in children (> 90%) than in adolescents and young adults in most high-income countries. Differences in conditional five-year net survival between the youngest and oldest age groups were 20% or more.

Conclusion

Our analysis highlights marked inequalities in survival by age at diagnosis, even after taking into account the effect of treatment in the first year. Adolescents and young adults are more likely to be diagnosed with more advanced disease, and more likely to have limited access to optimal treatment than children.

Future Perspectives for the Global Surveillance of Cancer Survival Trends – CONCORD-4

On behalf of the CONCORD Working Group, [Claudia Allemani](#)¹, [Veronica Di Carlo](#)¹, [Ms Fatima Khan](#)¹, [Melissa Matz](#)¹, [Pamela Minicozzi](#)¹, [Dr Naomi Ssenyonga](#)¹, [Prof Michel P Coleman](#)¹

¹Cancer Survival Group, London School of Hygiene and Tropical Medicine, London, United Kingdom

Background

CONCORD is an ambitious global public health programme for the long-term surveillance of cancer survival. In 2015, the second cycle (CONCORD-2) established world-wide surveillance of trends in cancer survival over 1995-2009. In 2018, CONCORD-3 updated the global surveillance of survival trends to include 37.5 million patients diagnosed up to 2014. The programme was extended in calendar time (2000-2014), geography (322 registries in 71 countries and territories; 47 with national coverage) and the number of cancers (18 cancers in adults and 3 in children). The CONCORD programme now involves 600 investigators.

Purpose

To showcase CONCORD-4, now in progress, and some broader activities designed to improve world-wide strategies for cancer control.

Methods

We are collecting data for adults diagnosed with one of 18 cancers during 2000-2019, or later years. Older registries are invited to submit data from 1990. We will examine trends in age-standardised net survival for patients diagnosed during the 32 years 1990-2021. In collaboration with St. Jude Children's Research Hospital (Memphis, TN), we will also examine survival trends for all cancers in children, to monitor progress towards the target in WHO's Global Initiative for Childhood Cancer, to increase five-year survival for all children with cancer to 60% by 2030.

Results

By November 2023, we had received over 46 million records for adults and 336,880 for children, from 207 cancer registries in 45 countries. We may receive data from up to 400 registries in 80 countries. We will present the state of the art for CONCORD-4 in June 2024: data collection, quality control, life tables and preliminary results.

Conclusion

Survival estimates from the CONCORD programme have become the de facto standard for international survival comparisons, and as a metric of health systems performance, cancer policy and improvement in outcomes. The Organisation for Economic Co-operation and Development, in partnership with the CONCORD programme, has included survival estimates for 48 countries in its regular Health at a Glance publications since 2017.

The NAACCR meeting will offer a great opportunity to announce a wider initiative in cancer control triggered by the CONCORD programme.

48-Year Trends in the Cancer Survival Index for All Cancers Combined in England and Wales: Patients Diagnosed during 1971-2018

Melissa Matz¹, Pamela Minicozzi, Veronica Di Carlo, Claudia Allemani, Prof Michel P Coleman

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Background

The survival of all patients following a cancer diagnosis is a key measure of the overall effectiveness of the health system in managing cancer. An index of survival for all cancers combined offers a single summary measure that can be monitored over time to show overall progress in the effectiveness of the healthcare system.

Purpose

We set out to produce trends in the cancer survival index for England and Wales for patients diagnosed during the 48 years 1971-2018.

Methods

We obtained anonymised individual records for all adults (15-99 years) diagnosed with cancer in England and Wales during 1971-2018 (10,769,854 adults) and followed up for their vital status to 31 December 2019.

The all-cancers survival index for England and Wales was constructed as a weighted average of the net survival estimates for every combination of five age groups (15–44, 45–54, 55–64, 65–74 and 75–99 years), for 18 cancers in women and 17 cancers in men, plus all other cancers combined, again for each sex. The weights used were the proportions of patients with cancer diagnosed in England and Wales during 1996–99 in each of the 185 combinations of cancer, sex and age group.

Results

The index of net survival in England and Wales for all cancers and both sexes combined increased substantially between 1971 and 2018. For example, for patients diagnosed in 1971-72, the all-cancers survival index was only 46.5% at one year after diagnosis, but for patients diagnosed in 2018, the ten-year survival index had reached 49.8%.

For men, the 1-, 5-, 7- and 10-year survival indexes have improved steadily since 1971-72 (1-year survival index 40.9% in 1971-72 vs. 10-year survival index 45.1% in 2018).

For women, we also observed a continuous increase in the 1-, 5-, 7- and 10-year survival indexes (1-year survival index 52.0% in 1971-72 vs. 10-year survival index 54.4% in 2018).

Conclusions

A major goal for Cancer Research UK's strategy is that 10-year net survival for all cancers combined should reach 75% by 2034. The analyses reported here suggest that progress towards this goal has slowed down considerably over the last 10-15 years.

Concurrent 2.A – Use of AI in Determining Reportability

Tuesday, June 25th

4:00pm – 5:30pm

Enhancing Cancer Registry Data with MOSSAIC: Deep Learning Solutions for Reportability Screening

Heidi Hanson¹, Dr. Adam Spannaus¹, Dakota Murdock¹, Patrycja Krawczuk¹, Dr. John Gounley¹, Eric Durbin², Isaac Hands², Dr. Elizabeth Hsu³, Lynne Penberthy³

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Background

Incident cancer diagnoses are mandatory, reportable diseases for public health surveillance in the United States. Medical records, pathology reports, radiology reports, and other unstructured clinical reports are collected by state central cancer registries and used for national level cancer reporting.

Purpose

The Modeling Outcomes using Surveillance data and Scalable Artificial Intelligence for Cancer (MOSSAIC) project develops deep learning algorithms to automatically translate unstructured text into North American Association of Central Cancer Registries (NAACCR) common data standards. Our team has developed a Reportability API that is being tested across the National Cancer Institute's (NCI) Surveillance, Epidemiology, and End-Results (SEER) registries.

Methods

We utilized a set of 3,108,418 pathology reports from the Seattle Cancer Registry from 2018 – 2023 that had been manually annotated as “reportable disease” or “non-reportable disease” by a trained registrar. Data were randomly split into train (70%), validation (15%), and test (15%) sets, with the training and validation corpus consisting of 2,642,155 pathology reports (NReportable = 619,856; NNon-reportable = 2,022,299). We use a deep learning architecture, the Hierarchical Self-Attention Network (HiSAN), to train a reportability classification model using this corpus of data. Given the large class imbalance, we trained four models for testing: (1) an unweighted model; (2) an equally weighted model, where reportable disease records are upweighted and non-reportable disease records are down weighted to give equal weight to the classes during training; (3) a 10:1 weighted reportable disease to non-reportable disease model, where reportable disease records are upweighted in an attempt to lower the false-negative rate; and (4) a 50:1 weighted reportable disease to non-reportable disease model.

Results

The model accuracy is 0.999 for the in-distribution test data. In addition to analyzing model performance using the in-distribution Seattle test set, we evaluated the model using two out of distribution datasets from the Los Angeles, Kentucky, Louisiana, New Mexico, and Utah cancer registries.

Conclusion

There are numerous natural language processing solutions for the identification of reportable cancer cases. Our Reportability API differs from other solutions commonly used by registries because the deep learning framework gives it maximum flexibility and adaptability for use across multiple registries.



Revolutionizing Cancer Pathology Reporting: eMaRC Plus Lite Unveiled

***Sandy Jones**¹, Mr Sanjeev Baral², Dr. Temitope Alimi³, Ms Barbara Weatherby², Mr. Tim Demint², Ms Charlotte Marshall³, Mrs. Neha Jayaswal², Mr. Joseph Rogers¹*

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Background

Central Cancer Registries (CCRs) rely on laboratories to identify and report only the pathology and biomarker reports that have a reportable cancer diagnosis. While ICD-10-CM diagnosis codes are becoming available in laboratory information systems to trigger specific cases for reporting, many laboratories are unable to adequately filter the reportable cases without utilizing significant resources.

Purpose

CDC developed the eMaRC Plus Lite tool to assist laboratories and CCRs with identifying reportable cancer diagnoses in pathology reports. This reduces the number of non-reportable cases received in the CCRs, thereby minimizing the time spent on extraneous tasks and streamlining their activities.

Methods

eMaRC Plus Lite utilizes the eMaRC Plus rule-based natural language processing (NLP) functionality to provide a simplified user interface, the base CDC NPCR model, that can be used as is or further modified to meet specific CCR, hospital, and laboratory reporting requirements. This is done by: (1) using the additional functionality of auto-coded values for histology, primary site, behavior, and laterality; (2) sharing models across users; and (3) comparing and incorporating modifications between multiple models. The CCRs train a model unique to them for identifying reportable cases, and then shares this with hospitals or laboratories for use as an API that runs on a local, secure server. This API can be called to import HL7 messages from a folder, and then output HL7 messages into designated folders for reportable vs nonreportable cases.

Results

We present results from statistical analysis of feedback compiled from pilot sites (CCRs, hospitals, laboratories) on their experience with implementation, usability, performance, and ability to produce the expected output for reportability.

Conclusion

eMaRC Plus Lite eliminates the need for manual review of all pathology reports to determine reportability for both CCRs and laboratories and enables CCRs to easily provide updated models to laboratories annually with new reportability rules. It also provides laboratories the ability to automate reporting of cancer pathology data in real-time without human intervention. The eMaRC Plus Lite tool is freely available.

A Mixed Language Model Approach to Tumor Reportability Status Classification

Lovedeep Gondara¹, Jonathan Simkin¹, Gregory Arbour², Dr. Raymond Ng², Ognjenka Djurdjev¹, Tarandeep Dhaliwal¹

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Background

Cancer is a leading cause of death in the world. A population-based cancer registry's (PBCR) function is to collect data on all new cancer cases in a defined population, which is then used for cancer surveillance, health policy, clinical research, etc. Registry records are primarily sourced from pathology. Most PBCRs rely on manual record abstraction, which is time-consuming and leads to significant delays in information capture.

Purpose

Increased availability of electronic information systems presents new opportunities for PBCRs. Most PBCRs in the US and a few in Canada use the Electronic Mapping, Reporting, and Coding Plus (eMaRC) software, developed by the Centers for Disease Control and Prevention, for processing electronic pathology reports. eMaRC uses a rule-based text analytics engine to identify reportable tumor pathology reports. Rule-based approaches are known to suffer from reduced accuracy as the complexity of the underlying text increases. Models from deep learning in natural language processing that do not rely on hand-crafted rules present new opportunities for PBCRs to automate data extraction from pathology reports.

Methods

At the British Columbia Cancer Registry (BCCR), we receive all provincial pathology reports as HL7 messages and use eMaRC to identify reportable tumors. However, eMaRC's rule-based approach is not robust, resulting in a large volume of false positive labels, requiring extensive manual review. As a solution, we have developed and deployed an NLP pipeline for detecting post-eMaRC reportable tumor pathology reports.

Our NLP pipeline consists of two large language models, BlueBERT and Gatortron, both finetuned on BCCR's electronic pathology reports. The different model properties and different data pre-processing methods ensure output variability, required for collaborative decision-making, where we consider a pathology report to be reportable if either of the models consider it as a reportable tumor.

Results

The models were finetuned on 40,000 reports from the diagnosis year of 2021 and the evaluation shows that our mixed-model approach provides 99% and 92% accuracy on true reportable and non-reportable tumors respectively.

Conclusion

Our study shows that deep learning methods provide significant advantages over rule-based NLP for distinguishing between reportable and non-reportable cancers.



Auditing Language Models in a Healthcare Setting

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Background

Rapid advancements in artificial intelligence have led to the development of language models (LMs) such as BERT, ChatGPT, etc. Success of which has inspired the use of LMs in healthcare, where models have been developed to facilitate clinical documentation, and classifying medical records, among other applications.

Purpose

LMs, similar to other machine learning models, are prone to errors which are often produced with high confidence. Errors can occur due to various underlying reasons such as a biased dataset, and they pose a significant risk of providing unreliable information, which can have serious consequences in the healthcare domain.

Model auditing provides a principled mechanism for risk management and mitigation associated with the deployment of LMs. Model auditing for LMs is at its infancy, where most approaches rely on evaluating conversational models for toxicity and bias. There is a paucity of literature for evaluating LMs in healthcare, especially when used for information extraction and classification.

Methods

The British Columbia Cancer Registry (BCCR) receives a population-based feed of electronic pathology reports in near real time and is transitioning from the use of rule-based systems to LMs for identifying reportable cancer pathology reports.

At BCCR, we have developed a novel auditing process consisting of manual review of the pathology reports by an Oncology Coding Specialist (OCS), who are unaware if the report has been previously classified as reportable cancer or non-reportable cancer by either the LMs or the rule-based system. OCS, instead, follow the standard reportability guidelines. This process mimics a single blind clinical trial where the OCS are unaware of the previously assigned reportability status, minimizing bias while allowing us to use the statistical theory for design and analysis.

Results

The audit process provides us with real-world performance metrics of the LMs compared to the manual gold standard and showcases the importance of human-in-the-loop machine learning.

Conclusion

We have proposed a LM audit scheme based on a single blind clinical trial design which showcases the importance of subject matter experts. This reinforces our belief that irrespective of how advanced the machine learning models get, subject matter experts are an important asset.

Concurrent 2.B – Electronic Reporting and Automation to Increase Timeliness of Cancer Data

Tuesday, June 25th

4:00pm – 5:30pm

Consensus-Based Framework for Evaluating Data Modernization Initiatives: The Case of Cancer Registration and Electronic Reporting

*Sujha Subramanian¹, Florence KL Tankga², Dr. Paran Pordell², Dr. Jenny Beizer³, Reda Wilson², Sandy Jones², Joseph D Rogers², Ms. Vicki Benard², Dr. Lisa C Richardson²
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Background

As part of its data modernization initiative (DMI), the Centers for Disease Control and Prevention's (CDC), Division of Cancer Prevention and Control is testing and implementing innovative solutions to improve cancer surveillance data quality and timeliness. Alongside this effort, a systematic approach can guide evaluations to identify best practices and lessons for optimizing DMI implementation.

Purpose

To describe a consensus-based effort for creating a framework to guide the evaluation of cancer surveillance modernization efforts by addressing specific context, processes, and costs related to cancer registration.

Methods: We drew on prior theories, consulted with experts, and sought feedback from cancer registry staff to develop a framework with broad applicability. As a first step, we developed a potential set of constructs for broad categories related to context, process, and content. Second, we engaged experts in cancer registry operations to review and provide feedback on the initial framework constructs. Third, we interviewed nine cancer registry directors and nine data managers using detailed interview guides. Finally, we conducted two focus groups with these directors and data managers to seek additional feedback on the findings from the interviews.

Results

Using the four-step process described above, we developed the cancer surveillance systems, context, outcomes, and process evaluation (CS-SCOPE) framework to explain the ways that cancer registry data quality, timeliness, and efficiency are impacted by external and internal contextual factors and interrelated process and content factors. The framework includes implementation measures to understand acceptability of process changes. Outcome and cost measures to assess DMI initiation and ongoing sustainability were included.

Conclusion

The framework provides a theory-driven systematic approach to ongoing evaluations that assess innovative, already-adopted processes and those being tested in pilot studies. A toolkit with a data dictionary, standardized measures, and definitions are currently under development so that the framework can be applied in practice. In the future, the CS-SCOPE framework can be used by central cancer registries to evaluate their individual DMI activities so that informed data-driven decisions can be made and implementation efforts can be optimized.

Comparing the Resources Required for Acquiring and Preparing Paper versus Electronic Pathology Reports

Randi Rycroft¹, Florence KL Tankga², Dr. Jenny Beizer³, Sujha Subramanian⁴

¹Cancer Data Registry of Idaho, Boise, USA, ²CDC, Atlanta, USA, ³RTI International, Research Triangle Park, USA, ⁴Implenomics, Dover, USA

Background

Receipt of timely pathology reports in a readily usable format can speed up reporting of cancer cases. The National Program of Cancer Registries has been actively working to enhance automated electronic capture and reporting of pathology data to central cancer registries.

Purpose

To evaluate the processes, time, and labor cost of pathology data acquisition via paper reports compared to electronic reports at the Cancer Data Registry of Idaho (CDRI).

Methods

We initiated prospective data collection to assess resources used for pathology data acquisition and preparation for further processing. First, we mapped out the detailed steps based on whether pathology data were received electronically or via paper. Second, we conducted a modified time-and-motion assessment to identify the time spent by individual registry staff during each step of the process. Third, we collected salary and fringe benefits of each registry staff involved in the process steps to estimate the direct labor cost. The data collection for the prospective tracking of pathology reports was initiated on January 4th, 2021 and completed on March 5th, 2021.

Results

During the two-month study period, the registry received 1,698 paper pathology reports and 3,801 electronic pathology reports (formatted data that can be readily processed). The average time for acquiring and preparing an individual record from a paper report was 8.13 minutes versus 1.50 minutes from an electronic report. The direct labor cost for preparing an individual record from a paper report was \$7.01 versus \$1.41 from an electronic report.

Conclusion

The acquisition and processing of paper pathology reports was about five times more expensive than electronic pathology reports. This study supports that enhancements of electronic pathology reporting led to lower direct labor costs in CDRI. Future studies could evaluate how to optimize use of electronic pathology reporting through software and hardware investment needs and the mix of registry staff expertise requirements.



Assessing Resources Devoted to Electronic Reporting and Automation among Central Cancer Registries Meeting National Program of Cancer Registries (NPCR) Quality Standards

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Background

The goal of the Centers for Disease Control and Prevention's (CDC) data modernization initiatives (DMIs) is to get better, faster, actionable data at all levels of public health, including cancer surveillance data. More timely cancer registry data can inform cancer control strategies that decrease the incidence of and death from cancer and address health disparities.

Purpose

To understand the resources required to generate high-quality cancer registry data.

Methods

We collaborated with 21 central cancer registries (CCRs) to collect data for the program year July 2020 to June 2021. We explored the potential relationship between resources devoted to electronic reporting and automation and the quality of CCR data. We compared activity-based costs of registries that always (n=8), sometimes (n=6), or seldom/never (n=7) met data quality standards for data completeness, timeliness, duplicate rate, and missing values. We used cost data collected retrospectively for our analysis. We collected prospective labor hours devoted to cancer registration activities to validate the retrospective cost estimation.

Results

On average, registries that always met the quality standards spent \$1,735,846 during the program year compared to registries that sometimes (\$981,573) or seldom/never met the quality standards (\$1,221,486). There was wide variation in total resources expended across all three registry groups. Compared to registries that seldom/never met quality standards, we found that registries that always met data quality standards used more resources on data acquisition, staff training, and data processing. Compared to registries that always met the quality standards, registries that seldom/never met the quality standards spent the most on case finding/data abstraction of non-hospital records.

Conclusion

This study provides baseline data and key findings for resource use, which can guide advancements in the implementation of electronic reporting and automation to improve CCR operations.

Quantifying the Change from Initial Report to Completed Case: Implications for Early Case Capture

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Background

Central cancer registries strive to identify cancer cases in a complete, accurate, and timely manner. To improve timeliness and early incidence reporting, a registry could create cases shortly after diagnosis from sources with minimal data, such as pathology reports. Relying on those early records may affect case completeness and accuracy, and changing the initial case values takes registry effort and time. Registries also conduct rapid case ascertainment projects (RCA) by identifying eligible cancer cases using early sources. RCA projects provide an opportunity to determine the extent of changes in critical incidence data items from initial ascertainment based on minimal data compared to final data based on more complete data sources.

Purpose

To evaluate the quality of critical incidence data items in records identified for RCA projects compared to finalized cases.

Methods

We evaluated 5,470 pathology reports identified as melanoma (event dates 2020-2021) or hematopoietic cancer (event dates 2019-2021) which were deemed eligible for RCA projects. For a set of data items that are commonly used for incidence reporting (SEER site recode, behavior, date of diagnosis, state of residence at diagnosis, SEER reportable disease), we compared values recorded in UCR's research database when the record was selected for the study to the final consolidated case value in SEER*DMS.

Results

Behavior had a higher proportion of change on records selected as melanoma (8.6%) than records selected as hematopoietic (0.7%), whereas SEER site recode had a higher proportion of change on hematopoietic records (14.5%) than melanoma records (0.9%). Year of diagnosis changed on 6.4% of hematopoietic records and 3.0% of melanoma records. State at diagnosis changed on 2.2% of selected records, and 2.1% of selected records were determined to be a non-reportable disease.

Conclusion

Handling changes to data items is a routine part of consolidation and editing processes, but dealing with non-reportable disease requires more effort and time. Reporting cancer incidence based on early sources should be approached with caution, as we observed different degrees of change by cancer type and data item.

Concurrent 2.C – Geospatial Epidemiology

Tuesday, June 25th

4:00pm – 5:30pm

Associations Between Economic Segregation and Stage of Cancer at Diagnosis in Urban and Rural Areas of Idaho

Daniel Wiese^{1,2}, Breanna McKinnon¹, Dr. Kevin Henry^{2,3}, Dr. Recinda Sherman⁴, Christopher Johnson⁵, Dr. Farhad Islami¹

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Background

Previous studies in urbanized areas reported an association between greater economic segregation (defined by the Index of Concentration at the Extremes [ICE]) and advanced-stage cancer diagnosis. However, it is unclear if a similar association exists in rural settings.

Purpose

To address this gap, we examined the association between income-based ICE and stage of cancer diagnosis in urban and rural areas of Idaho.

Methods

Data on adults aged ≥ 20 years diagnosed with a first primary invasive cancer in 2008-2018 were derived from the Cancer Data Registry of Idaho. All cases were categorized into localized ($n=31,960$) or advanced stage (regional, distant; $n=31,531$) and assigned an ICE quintile based on the residential tract at the time of diagnosis. For each ICE quintile (Q1-Q5), we calculated stage-specific age-adjusted incidence rates (IR) and incidence rate ratios (IRR) stratified by urban/rural status for all cancers combined and four screenable cancers: female breast (breast), colorectal, lung and bronchus (lung), and prostate.

Results

For all cancers combined in urban areas, patients residing in census tracts of concentrated deprivation (Q1/most-deprived) had lower localized-stage IRs (IRR=0.83, 95%CI=0.8-0.87) and higher advanced-stage IRs (IRR=1.14, 95%CI=1.1-1.19) than those residing in tracts of concentrated affluence (Q5/most-affluent). The ratio of advanced-to-localized stage IRs was highest in most-deprived tracts (IRR=1.14, 95%CI=1.09-1.2) and lowest in most-affluent tracts (IRR=0.83, 95%CI=0.8-0.86).

In rural areas, patients residing in most-deprived tracts also had a lower localized-stage IRs for all cancers combined (IRR=0.88, 95%CI=0.8-0.96), but advanced-stage IRs were comparable between most-deprived and most-affluent tracts. Similarly, in rural areas the ratio of advanced-to-localized stage IRs was highest in tracts with elevated levels of deprivation (Q2-IRR=1.14, 95%CI=1.06-1.22; Q1-IRR=1.12, 95%CI=1.02-1.24), whereas there was no difference in most-affluent tracts.

By cancer type, in urban areas localized-stage IRs for breast and prostate cancer were statistically significantly lower in most-deprived than most-affluent tracts, and advanced-stage colorectal and lung cancer IRs were higher in most-deprived than most-affluent tracts. In rural areas, however, the only statistically significant association was for advanced-stage lung cancer, with higher IRs in most-deprived than most-affluent tracts.

Conclusion

In this study, the association between economic segregation and advanced-stage cancer diagnosis was stronger in urban areas than rural areas.



The Impact of Rural Area of Residence and Persistent Poverty on Cancer Quality of Care

Dr. Arti Parikh-Patel¹, Brenda M. Hofer¹, Dr. Shehnaz Hussain^{1,2}, Dr Theresa H.M. Keegan³

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Background

Rurality has been associated with suboptimal cancer treatment and barriers to accessing quality care can result in poorer outcomes for rural patients. Previous studies reported rural patients are less likely to receive guideline-concordant radiation, chemotherapy, and surgery. As rurality is strongly associated with poverty, disentangling the impacts of the two factors is challenging. Residents of persistent poverty areas (PPAs) (areas with >20% of population living below poverty level for 30+ years) are an especially vulnerable population. While California has a large rural land mass, the population is largely urban, with fewer people in rural designated areas and large pockets of urban poverty.

Purpose

To evaluate the independent impact of rurality on quality of cancer care among individuals living in California PPAs.

Methods

Individuals living in PPAs diagnosed with breast, ovarian, endometrial, cervical, colon, lung, or gastric cancer during 2008-2020 were identified in the California Cancer Registry. Rurality was assessed using the Medical Study Service Area classification scheme. Quality of care was evaluated using established Commission on Cancer quality measures. Multivariate logistic regression and Cox proportional hazards models were generated to assess the effect of residential area on care quality, adjusting for age, sex, insurance, race/ethnicity, comorbidity, and treatment at a comprehensive cancer center.

Results

Of 948,391 individuals with the cancers of interest, 62,011 (6.5%) were identified as living in PPAs. Individuals with breast cancer living in rural (vs. urban) PPAs were less likely to receive radiation after breast conserving surgery. (Odds Ratio (OR)= 0.74, 95% Confidence Interval (CI) 0.60, 0.91). Individuals with colon cancer living in rural PPAs were less likely to have the recommended number of lymph nodes surgically removed and examined (OR=0.62 95% CI: 0.41, 0.94). No other significant treatment differences were found between individuals living in urban vs. rural PPAs.

Conclusion

Rurality is independently associated with receipt of guideline-concordant surgery and radiation for select cancer types. Our findings may relate to rural PPAs having limited access to radiation treatment facilities, a dearth of surgical oncologists, and logistical constraints associated with traveling long distances for treatment. More granular investigation into the individual and structural factors underlying these associations is warranted.

Social Disadvantage and Colorectal Cancer Outcomes in Minnesota

*[Kenneth Adams](#)¹, [Paula Lindgren](#)¹, [Dr. Jay Desai](#)¹, [Christina Nelson](#)¹, [Dr. Judy Punyko](#)¹
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Background

Area-level social disadvantage has been associated with elevated cancer burden. We evaluated differences in colorectal cancer (CRC) outcomes in Minnesota residents according to census tract measures of social disadvantage.

Purpose

Explore the utility of area-based social measures (ABSM) in identifying geographic areas to guide cancer control efforts.

Methods

We analyzed Minnesota cancer registry data using SEER*Stat to estimate 2016-2020 incidence and survival. Survival was based on cases diagnosed from 2013-2019. We compared incidence rate ratios (IRR) across three census tract ABSM: Yost Index quartiles, Median Household Income quartiles, Percent Poverty (percent below federal poverty level), as quartiles and 4-level categorical (<5%, 5-<10%, 10-<20%, ≥20%). We report IRRs for each measure comparing the most disadvantaged with most advantaged group (baseline). All reported results were statistically significant at $p < 0.05$.

Results

Overall, 45% of Minnesota residents lived outside the seven-county Twin Cities metropolitan area (non-TCM), and 19% of Minnesotans were non-White or Hispanic. Demographic characteristics differed by quartile within each ABSM and the distributions of characteristics also differed between the measures. To illustrate, the majority of people in the most disadvantaged Yost (71%) and Household Income quartiles (62%) were non-TCM residents. Whereas the proportion of people in the most disadvantaged poverty quartile were equally distributed between TCM (49%) and non-TCM areas (51%). There were disproportionately higher non-White or Hispanic residents (28%, 30%, 34% respectively) in the most disadvantaged Yost, Income, and Poverty quartiles.

CRC incidence rates were higher among male residents with the most disadvantaged Yost quartile (IRR=1.23), lowest Median Household Income quartile (IRR=1.19), highest Percent Poverty quartile (IRR=1.10), and the highest Percent Poverty category (IRR=1.19, ≥20% vs. <5% poverty). We found no significant associations between CRC incidence and ABSM among females. Five-year relative survival was lower among residents of census tracts with ≥20% vs. <5% poverty (60 vs 52 percentage points, males and females combined).

Conclusion

CRC incidence was higher (males) and survival was lower (males and females) in more socially disadvantaged census tracts. These tracts tended to be either outside the TCM or have higher proportions of nonwhite or Hispanic residents. These census tracts may benefit from enhanced CRC prevention and control intervention. Examples with Minnesota maps will be presented.

Geocoded Data Quality and Fit for Use for Geospatial Analysis

Recinda Sherman¹, Payton Baldrige, Daniel Goldberg, Mandi Yu

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Background

One strategic initiative identified by the NAACCR Board for 2024-2027 is to improve cancer registry data to support health equity research. Because geospatial epidemiology is one tool that can support this research, a new CiNA Research Dataset, CiNA Geographic, is being developed to expand the cancer surveillance geospatial analysis infrastructure. However, a key element hindering applicability and interpretation of such analysis is the underlying data quality of the geocoded data. Following CiNA Survival Dataset model, RDU is developing a Fit for Use for Geospatial Analysis Recognition to establish registry inclusion criteria for the dataset.

Purpose

The purpose of this presentation is to inform cancer registries of the development of CiNA Geographic, detail concerns with the quality of geocoded data, and provide guidance and resources to help registries improve their geocoded data quality.

Methods/Results

Data collected during CFD identified that geocoding operations at most registries do not include manual review. This results in a high percentage of poorly geocoded data. Because geocoding quality is closely tied to case demographics, the potential for biased results is high—often resulting in Type II error and, in some cases, reversed associations. Examples using CiNA will be shown.

During the assessment of geocoding quality of CiNA, it was identified that NAACCR Item #86, Geocoding Quality Code, was not as useful as intended in helping registries prioritize which cases to manually review to ensure high quality geocoded data. Therefore, this variable was evaluated, and additional categories were developed. These categories will be described along with best practices for use of this. Draft Fit for Use for Geospatial Analysis Recognition, which includes both operations and data-driven components, will be presented along with the progress of CiNA Geographic Dataset development.

Conclusion

Health disparities are well documented using cancer registry data. And cancer registry data are essential to the evidence-based solutions approach of health equity research. Because health equity research evaluates the social, economic, and environmental factors resulting in health differences, geospatial analysis of cancer registry data are fundamental to these investigations. It is critical that high quality data are available so that results are as accurate and interpretable as possible.



Concurrent 2.D – Recurrence and Metastatic Disease

Tuesday, June 25th

4:00pm – 5:30pm

Ascertaining Population-Based Breast Cancer Recurrence through Patient-Reported Outcomes

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Background

Cancer recurrence is not routinely captured in population-based cancer registries. Complex algorithms have been developed to identify cancer recurrence using linked health administrative claims and electronic health records. Ascertaining recurrence directly from patients has never been examined at a large population-based registry even though previously published studies have shown excellent sensitivity and specificity.

Purpose

To assess the feasibility and accuracy of identifying cancer recurrence through patient-reported outcomes (PRO) in a large population-based cancer registry.

Methods

In 2021-2023, we recruited adult female breast cancer survivors diagnosed between 2015-2017 with stage I-III cancer identified by the Kentucky Cancer Registry (KCR). Patients were invited to complete a short survey regarding their breast cancer diagnosis and recurrence using an online or paper form, then followed up with a similar short survey six months later.

Results

Out of 6037 eligible patients identified by KCR, 3,541 (58.7%) patients were successfully contacted by KCR, 2,388 (39.6%) patients agreed to release their information to the study, and 829 (13.7%) completed the first survey with 87.2% (723/829) of them submitting the online version. Respondents of the first survey were more likely to be white, younger, and reside in an urban area, compared to non-respondents. 529 out of 621 (85.1%) patients completed the second survey. 34 (4.1%) recurrences were reported from both surveys. Only 11 of the reported recurrences were captured by the KCR data. Accuracy of reported recurrences are to be determined.

Conclusion

The relatively low study participation rate is comparable to other population-based survey studies without incentives. The high percentage of follow-up survey completion suggests that patients who have participated in the study are likely to continue to engage. More research on how to initially engage patients is needed as improved study participation rates will be key for PRO as a viable approach for ascertainment of cancer recurrence.



Metastatic Recurrences among California AYA Patients Diagnosed with Seven Common Cancers, 2006-2018

Ann Brunson¹, Dr. Ted Wun¹, Dr. Renata Abrahão¹, Dr. Charles Quesenberry², Dr. Jessica Chubak³, Dr Lawrence Kushi², Dr Kathryn Ruddy⁴, Dr Chun Chao^{5,6}, Dr Erin Hahn^{5,6}, Dr Candice Sauder¹, Dr Hazel Nichols⁷, Dr Theresa H.M. Keegan¹

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Background

While cancer treatment continues to improve for adolescents and young adults (AYAs), metastatic recurrence remains one of the leading causes of death. Historically, cancer registries have not collected recurrence data after initial cancer diagnosis, making it difficult to understand predictors and outcomes of metastatic recurrences.

Purpose

To estimate the cumulative incidence (CMI) of metastatic recurrences and compare survival between AYAs with metastatic disease at diagnosis and those with metastatic recurrence.

Methods

Incident first primary cancers diagnosed from 2006-2018 were identified from the California Cancer Registry. Metastatic recurrence was identified from statewide hospitalization, emergency department and ambulatory surgery encounters from the California Department of Health Care Access and Information (HCAI). Patients included were those diagnosed at ages 15-39 years with sarcoma, melanoma, testicular, thyroid, colorectal, breast or cervical cancer. Metastatic disease at diagnosis was defined as stage IV for all cancers except testis (stage III). Among patients with stage I-III and unknown, metastatic recurrence was identified from HCAI ICD-9/ICD-10 metastatic disease codes ≥ 6 months after cancer diagnosis or a cancer-related cause of death. We calculated the CMI of metastatic recurrence, overall and by stage at diagnosis, accounting for death from other causes as a competing risk. We estimated overall survival using the Kaplan-Meier method.

Results

Of a total of 50,541 patients, 8.6% had metastatic disease at diagnosis and 10.5% had metastatic recurrence. The 5-year cumulative incidence of metastatic recurrences was higher for sarcoma (26%) and colorectal (22.0%), intermediate for cervical (17%) and breast (16%), and lowest for melanoma (6%), testicular (6%) and thyroid (2%) cancers. The CMI for metastatic recurrence increased with later stage at diagnosis, with the highest CMI for stage III sarcoma (49%) and cervical (43%) cancer. Overall survival was better among patients with metastatic disease at diagnosis (vs metastatic recurrence) for all sites except testicular, melanoma, and thyroid cancers (for which there was no survival difference).

Conclusion

Our findings suggest metastatic recurrences occur among a substantial proportion of AYAs and are associated with worse survival than metastatic disease at diagnosis for many cancers. Future work is needed to understand differences and mitigate risk factors for poor outcomes in AYA cancer survivors.



Trends in Age and PSA at Diagnosis in US Prostate Cancer Patients Suggest an Explanation for Increases in Metastatic Disease Incidence

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Background

De novo metastatic prostate cancer diagnoses increased in the United States between 2010 and 2019. It is unclear whether these increases are attributable to decreased prostate-specific antigen (PSA) screening following USPSTF recommendations in 2008 and 2012 or to other factors, such as the dissemination of advanced imaging technologies with improved sensitivity for detecting distant metastases.

Purpose

Increased age and PSA level at diagnosis would reflect delayed detection rather than stage inflation due to imaging. Therefore, this study examined trends in these quantities over the period in which metastatic prostate cancer incidence increased.

Methods

Case listings of patients diagnosed with prostate cancer between 2010 and 2019, ages 50 to 79, were extracted from the SEER-17 database. For each calendar year, we calculated 25th, 50th, 75th, and 85th percentiles of PSA at diagnosis. We analyzed calendar trends in these percentiles using quantile regression controlling for age at diagnosis. We also computed the calendar year trend in age at diagnosis, weighted to adjust for the aging of US male population in general. Both analyses also examined whether Black men showed different trends over time.

Results

We analyzed data from 526,237 prostate cancer cases, 78,700 of which were Black men. All four PSA quantiles of interest showed a positive trend over the period, with annual increases ranging 0.06 ng/mL (95% CI 0.05–0.06) for the 25th percentile to 0.41 ng/mL (95% CI 0.33–0.49) for the 85th percentile. Black men had a significantly greater trend in the 75th and 85th percentiles, but not in the lower ones. The mean age at diagnosis increased by 0.16 years annually (95% CI 0.16–0.17), with little difference in trend between Black and non-Black men.

Conclusion

The rise in the upper quantiles of PSA at diagnosis and trend toward older ages at diagnosis are consistent with delayed detection of prostate cancers and suggests that reduced screening has contributed to the increase in de novo metastatic disease.

Predictors of Distant Stage Colorectal Cancer Overall and Among Medicaid Enrollees in New York State

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Background

Colorectal cancer incidence and mortality have decreased substantially over the past several decades; however, this trend has been driven by local and regional stage cancers and diagnoses in individuals ages 50 and older, with little change in incidence of distant stage disease and increasing incidence in younger individuals.

Purpose

We examined predictors of distant stage colorectal cancer overall and among Medicaid enrollees in New York State, to better understand factors influencing risk of metastatic colorectal cancer.

Methods

We retrieved data from the New York State Cancer Registry SEER*DMS database for individuals ages 45-75 diagnosed with a first primary colorectal cancer between 2008 and 2020. We used multivariable-adjusted logistic regression to estimate odds ratios and 95% confidence intervals for distant stage vs. all other invasive cancers combined.

Results

We observed a statistically significant increased odds of distant stage cancer among younger individuals (OR=1.36, 95% CI=1.27-1.45 for ages 45-49 vs. 70-75), individuals with non-Hispanic Black vs. non-Hispanic White race (OR=1.14, 95% CI=1.09-1.20), single (including divorced or widowed) vs. married individuals (OR=1.22, 95% CI=1.18-1.26), and individuals with current or past Medicaid enrollment based on linkage with New York State Medicaid data (OR=1.07, 95% CI=1.03-1.11), which was strengthened when restricted to individuals ages 45-64 at diagnosis (OR=1.16, 95% CI=1.11-1.22). In contrast, the odds of distant stage cancer were lower among all other racial/ethnic groups examined. The results were similar when restricted to individuals ages 45-64 with current or past Medicaid enrollment.

Conclusion

These results indicate that certain populations have an increased risk of being diagnosed with distant stage colorectal cancer, including individuals who are younger, non-Hispanic Black, single, and Medicaid enrollees. These differences are likely related to disparities in screening use, as well as possible contributions of differences in lifestyle risk factors and health care access. These results, as well as planned analyses of screening history in relation to stage at diagnosis in Medicaid enrollees, will help to inform activities to improve screening use and early detection in populations at higher risk of metastatic colorectal cancer.

Concurrent 2.E – Survivorship Issues

Tuesday, June 25th

4:00pm – 5:30pm

Cancer Diagnosis as an Emergency in U.S. Populations – A Marker of Disparities and Important Risk Factors for Short-Term Mortality

Caroline Thompson¹, Ms Yuelin He, Ms Sharon Peacock Hinton, Ms Rebecca Rohde, Dr. Eman Metwally, Ms Sarah Soppe, Ms Jamie Halula, Dr. Megan Mullins, Dr. Matthew Barclay, Dr. Allison Kurian, Dr. Ellis Dillon, Dr. Nicholas Pettit, Dr. Matthew Thompson, Dr Sandi Pruitt, Dr. Georgios Lyratzopoulos
¹UNC Chapel Hill, Chapel Hill, USA

Background

About 1 in 5 cancers worldwide are diagnosed as emergencies. Such “emergency presentations” (EPs) are more common among patients with later stage disease and members of marginalized and underserved populations. EPs are associated with undertreatment, and reduced survival compared to patients diagnosed via elective pathways. With the exception of a recent international study including Canadian registries, EP burden has not been a focus of North American surveillance efforts despite its potential to explain variation in outcomes and disparities among newly diagnosed cancer patients.

Purpose

To improve evidence about emergency cancer diagnosis in U.S. populations we estimated the prevalence of EP and 1-year all-cause mortality by EP status for the top 8 cancers.

Methods: We analyzed SEER-Medicare data for 641,856 Medicare beneficiaries diagnosed with first cancers of the lung, breast, colon, rectum, pancreas, liver, or ovary (2009-2018), classifying EPs as patients whose diagnosis occurred during an emergency/acute inpatient hospitalization. We estimated EP prevalence by tumor type and patient demographics, and estimated risk differences comparing EPs to non-EPs for 1-year all-cause mortality directly standardized to the sex-, age- and stage- distribution of the total (cancer-specific) population.

Results

Across 8 tumor sites, 15% of patients were diagnosed as emergencies, with variation by site (ranging from ~30% of colon and pancreas to ≤5% for breast, and prostate) and stage (32% distant, 16% regional, 5% localized). Compared to the average EP rate of 15%, EP was higher for people who were older (26% for 85+ year-olds), Southeast Asian-American (20%), Black (19%), Hispanic (17%), East Asian-American (17%), Native Hawaiian/Other Pacific Islander (16%), unmarried (20%), dually Medicaid-eligible (24%), and living in lowest SES neighborhoods (18%). Standardized absolute risks of 1-year mortality were 15% to 30% higher for EP patients, with risk differences >25% for breast, liver, and ovarian cancer patients.

Conclusion

In the U.S. emergency diagnosis of cancer affects 1 in 6 patients, and the burden is disproportionately higher for members of marginalized and underserved groups. Emergency diagnosis appears to be a strong risk factor for short-term mortality, potentially compounding outcome disparities in these groups. Collecting data on EPs through surveillance efforts could improve understanding of this burden and facilitate interventions.



Characterizing Potentially Avoidable Emergency Department Presentation among Cancer Patients in California

[Julianne Cooley](#)¹, Dr. Bryn Mumma², Brenda M. Hofer¹, Dr. Arti Parikh-Patel¹, Dr Theresa H.M. Keegan^{1,3}

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Background

Although Emergency Department (ED) visits are necessary for cancer patients with acute concerns, studies show that as many as 56% could be prevented or treated outpatient. ED visits are costly, stressful, can lead to fragmented care, and expose patients to nosocomial infections. Identifying subgroups of patients who are most vulnerable to potentially avoidable ED visits can inform policy and the development of targeted interventions to better coordinate outpatient cancer care.

Purpose

To quantify associations of sociodemographic and clinical characteristics with potentially avoidable ED visits among cancer patients in California.

Methods

Using California Cancer Registry data linked to Department of Health Care Access and Information (HCAI) statewide ED records, we identified 700,730 patients diagnosed with a first primary cancer from 2017-2021 and 598,854 ED visits within one year of diagnosis. The New York University algorithm was used to classify ED visits as potentially avoidable or unavoidable. Among the five most common types of cancer to present to the ED, multivariable logistic regression will be used to assess characteristics associated with potentially avoidable ED visits.

Results

32.4% of patients presented at least once and 17.2% more than once to the ED within one year following diagnosis. Among all ED visits within one year of diagnosis, patients with lung and bronchus (11.9%), breast (10.0%), prostate (7.6%), pancreas (5.5%), and liver (4.1%) cancers comprised the most visits. The most common principal diagnosis codes included sepsis, urinary tract infection, pneumonia, pain, and kidney failure. Patients with the highest proportion of potentially avoidable ED visits included patients aged 15-39 years, females, non-Hispanic Black/African Americans, those residing in the highest socioeconomic status (SES) neighborhoods, unmarried, rural residents, those with comorbidities, those diagnosed with in-situ/localized/regional disease, and publicly insured patients (all p-values <0.001). The percent of potentially avoidable ED visits (30.2% overall) varied by cancer type from 24.6% (liver cancer) to 34.9% (breast cancer) (p<0.001).

Conclusions

Nearly one-third of ED visits in the year following cancer diagnosis were potentially avoidable, with disparities by age, sex, SES, race/ethnicity, and health insurance type. Strategies to decrease ED utilization through better-coordinated outpatient cancer care is warranted.

Factors Associated with Cancer-Related Pain among Utah Cancer Survivors

Rachel Codden¹, Blessing Ofori-Atta, Ms. Marjorie E. Carter, Ms. Kimberly Herget, Dr. Jennifer A. Doherty, Anne Kirchhoff, Morgan M. Millar
¹University Of Utah, Salt Lake City, USA

Background

Cancer survivors are commonly burdened by the effects of cancer for years after completing treatment. For some survivors, cancer and treatment come with long-term or chronic pain. The prevalence of long-term pain is two times higher in cancer survivors compared to the general population. There is a gap in the knowledge of which factors are associated with the occurrence of cancer-related pain in cancer survivors.

Purpose

To identify the cancer and sociodemographic factors associated with cancer-related pain among Utah cancer survivors 3-5 years after diagnosis.

Methods

Participants to date include 1,982 Utah cancer survivors who responded to the Cancer Survivor Experiences Project, a probability-based sample survey administered by the Utah Cancer Registry between 2018-2022. Participants self-reported current presence of cancer-related physical pain, pain control, and methods of pain control. Registry data items were combined with survey responses to comprise a set of cancer-related and sociodemographic covariates. We calculated counts and weighted percentages of these covariates and quantified the responses of pain control and respective pain control treatments. After integrating 2023 survey data, we will conduct logistic regressions to determine predictors of cancer-related pain, and ordinal regressions to evaluate significant predictors of pain severity.

Results

The majority of survivors were diagnosed with local stage cancer (64.7%) and received one modality of cancer treatment (62.0%). Just over 20% of participants reported currently experiencing physical pain caused by their cancer or cancer treatment (20.9%). Of those reporting pain, 25.7% reported their pain was not under control; 37.0% indicated their pain was under control with medication and 37.2% reported it was under control without medication. The most frequently used pain control methods included opioids (67.5% of survivors reporting pain) and nonopioid analgesics (47.8%). Additional results will be presented.

Conclusion

Twenty percent of Utah cancer survivors report experiencing pain related to their cancer or cancer treatment. For some this pain is well managed, but over a quarter continue to deal with uncontrolled pain. Of particular concern is that opioids are the most common approach survivors use to help control their pain and are used in a proportion substantially higher than the noncancer pain population.

Chemotherapy-Induced Peripheral Neuropathy in Children, Adolescents and Young Adults with Cancer and Medicaid Insurance in California

Theresa Keegan¹, Julianne Cooley^{1,2}, Ann Brunson¹, Dr Kathryn Ruddy³, Dr Elysia Alvarez¹, Dr Anjlee Mahajan¹, Dr Ted Wun¹, Dr Rashmi Verma¹, Dr Theresa H.M. Keegan¹

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Background

Chemotherapy-induced peripheral neuropathy (CIPN) can lead to delays or discontinuation of cancer treatment, negatively impacting survival and quality of life. There is a lack of population-based data on CIPN incidence among young cancer survivors.

Purpose

To examine the association of chemotherapy with development of CIPN in children (<15 years), adolescents and young adults (AYAs, 15–39) with cancer.

Methods

Using California Cancer Registry, Medicaid, and hospitalization data, we identified 418 children diagnosed with Hodgkin lymphoma (HL) or non-Hodgkin lymphoma (NHL) and 6,028 AYAs with HL, NHL, female breast, colorectal (CRC) or testicular cancer during 2005–2017. Patients were classified as receiving specific neurotoxic drugs (e.g., taxanes, vinca alkaloids, platinum) vs. non-neurotoxic agents identified in Medicaid claims through National Drug Codes and the Healthcare Common Procedure Coding System. We estimated the cumulative incidence (CMI) of CIPN and the association between chemotherapy and CPIN by cancer site.

Results

Of 6,446 patients, 16% developed CIPN (median follow-up of 4.8 years from cancer diagnosis). The median time in months from cancer diagnosis to CIPN was 8 for NHL, 13 for CRC and testicular cancer, and 21 for HL and breast cancer. Across all cancer sites, CIPN incidence was substantially higher among patients who received neurotoxic agents. For example, 1-year CMI was 13% among CRC patients treated with oxaliplatin and 10% among breast cancer patients treated with paclitaxel vs. 2.5% and 1.7% in patients who received non-neurotoxic agents, respectively. In multivariable Cox models adjusted for sociodemographic factors and diabetes, the hazard of CIPN was about 2–9.5-fold higher among patients who received neurotoxic chemotherapy. The agents with the strongest association with CPIN were brentuximab (alone or with other neurotoxic drugs) for HL (Hazard Ratio (HR)=9.5), brentuximab for NHL (alone or with vinca alkaloids) (HR=7.0), paclitaxel for breast cancer (HR=4.0); oxaliplatin for CRC (HR=3.5), and cisplatin and etoposide for testicular cancer (HR=2.1).

Conclusion

Our study revealed a high burden of CIPN within a socioeconomically disadvantaged population of young cancer survivors. It underscores the need for delivering the least toxic therapy possible without compromising survival outcomes and developing novel less toxic agents to reduce the risk and potentially debilitating impact of CIPN.

Concurrent 3.A – Future Directions in Standards and Operations

Wednesday, June 26th

8:00am – 9:30am

Cancer PathCHART: Mining for Data Quality Gems Among Site-Histology Combinations

Ms. Margaret Adamo¹, Alison Van Dyke¹, Ms. Lois Dickie¹, Dr. Gonçalo Forjaz², Jim Hofferkamp³, Serban Negoita¹

¹NCI SEER, Bethesda, United States, ²Westat, Rockville, United States, ³NAACCR, Springfield, United States

Background

Cancer Pathology Coding Histology and Registration Terminology (Cancer PathCHART) is a first-of-its-kind initiative for North America and worldwide to update and harmonize cancer surveillance standards for tumor site, histology, and behavior code combinations and associated terminology. The principal aim is to improve cancer surveillance data quality.

Purpose

Cancer PathCHART standards are the single source of truth for cancer surveillance site, histology, and behavior codes and terms and improves the quality of data made available for research. We will demonstrate the relevance of these improvements for population cancer statistics.

Methods

Subject matter expert pathologists and experienced cancer registrars reviewed site and morphology combinations to determine if they are biologically impossible, unlikely, or valid. Site and morphology combinations that are "biologically impossible" cannot be entered into registry data. Site and morphology combinations that are "unlikely" trigger a site/type edit which prompts the registrar to manually review the case and either revise the site and/or morphology or set an override flag if the combination is determined to be correct as is. An analysis was conducted of the potential impact of these changes on cancer incidence rates.

Results

Among the site and morphology combinations reviewed for 2024 implementation, the majority of valid site and morphology combinations by 2023 standards remained valid after expert review. Many of the site and morphology combinations that were designated as newly "biologically impossible" had zero counts in 20 years of data in US Cancer Statistics (USCS). We will discuss examples of newly impossible site and morphology combinations that may have an impact on age-adjusted cancer incidence rates and trends over time.

Conclusion

As the first major review of site and morphology combinations in over 15 years, Cancer PathCHART identified tumor site-morphology combinations that were historically valid or unlikely that are biologically impossible according to expert reviewers. While no cases were reported for most of these entities in 20 years of USCS data, monitoring the impact of these changes will be critical to accurate interpretation of trends in cancer incidence rates over time.



Future Direction of the AJCC Staging System: Version 9 and Beyond in the Age of AI

[Martin Madera](#)¹

¹*American College of Surgeons, Chicago, USA*

Background

The American Joint Committee on Cancer (AJCC) has developed and published cancer staging manuals for over forty years. Recently, the AJCC evolved to provide critical information in digital formats and, with Version 9, more frequent updates. The AJCC's move towards structured content has coincided with the emergence of Natural Language Processing (NLP), Large Language Models (LLMs) and Artificial Intelligence (AI).

Purpose

The presentation has two sections. Firstly, it provides insights to the AJCC's latest content offerings, emerging themes, and integration of biomarker and genomic elements. Secondly, it explores how AJCC's content management process aligns with the exciting capabilities of LLMs and AI.

Methods

An overview of how biomarker and genomic elements are considered and incorporated into the AJCC Cancer Staging System will be provided, offering the audience a clear understanding of the evolving landscape of cancer staging.

In the second section, the alignment of technological advancements in the AJCC content development and management process with the capabilities of LLM and AI will be discussed. The presentation will showcase concrete examples of how structured content has positioned the AJCC Cancer Staging System to leverage the potential of AI effectively.

Results

Drawing on the insights from the AJCC's journey towards a structured content approach, the presentation will conclude by emphasizing the critical role of machine-readable content in the age of AI. The AJCC's foresight in adopting structured content has not only facilitated the development of Version 9 but has also positioned the Cancer Staging System to adapt and thrive in an era where AI capabilities are contingent on the quality of underlying content.

Conclusion

The implications of this structured content approach for the future of cancer staging, AI applications in oncology, and the broader healthcare landscape will be discussed. The conclusions will underscore the symbiotic relationship between structured content and AI, highlighting the importance of ongoing collaboration between medical experts and technology developers to ensure the continued refinement and efficacy of cancer staging systems in the age of AI.

Implementing Modified Record Reporting: Lessons Learned After Year 1

[Kaitlin Kruger](#)¹, Mrs. Emily Bunt¹

¹Ohio Department of Health, Columbus, USA

Background

For many years, Ohio's hospitals experienced challenges for state reporting as they were unable to provide updated information after an abstract was initially submitted. For this reason, hospitals would hold their data to ensure they submitted the most complete and accurate data, especially for treatment. Ohio needed to find an automated method to receive updates for abstracts.

Purpose

This presentation will discuss the challenges, benefits, roadblocks, and facilitators to implementing modified (M) record reporting in Ohio (NAACCR Record Type M abstracts). We will cover our information gathering phase, our experience piloting M record reporting, lessons learned after requiring M records for a full year, existing challenges, and the impact of M records on our completeness and timeliness.

Methods

In 2020, OCISS investigated the option of collecting M records; we met with hospitals, hospital software vendors, and other state registries. In 2021, we completed an M record pilot with a small subset of hospitals. In 2022, OCISS started requiring M records from all reporting hospitals. In 2023, OCISS had a full year experience of processing M record submissions.

Results

In 2020, this seemed like a daunting task, but years later, M record processing has become one of the standard tasks we complete. Our hospitals shared with us how they appreciate being able to provide updated information, and no longer need to hold on to their abstract until treatment is completed. Because of this, during Data Submission 2023, we found that our 12-month data was more complete compared to past years. Additionally, since implementing M record reporting, we have seen improvements in our average timeliness.

Conclusion

Modified record reporting has improved our registry operations. Our data is reported more quickly and completed sooner. While implementing M record reporting was challenging and several years in the making, we have now found that as data timeliness becomes increasingly important, we are well positioned to improve our timeliness by leveraging M record reporting.

How Cancer Surveillance Can Use Crowdsourcing to Achieve Higher Quality Reports

Joseph Rogers¹, Sandy Jones¹, Ms. Caitlin Kennedy¹, Sean Porter¹, Ms. Vicki Benard¹, Mr Sanjeev Baral², Michelle Esterly², Ms. Jennifer Wike², Mr. Ian McClendon²

¹CDC/NPCR, Atlanta, United States, ²Katmai Government Services, Anchorage, United States

Background

The Centers for Disease Control and Prevention (CDC) has embarked on a multi-year, billion-plus dollar effort to modernize core data and surveillance infrastructure across the federal, state, tribal, local, and territorial public health landscape. This effort is known as the Data Modernization Initiative (DMI). CDC/National Program of Cancer Registries (CDC/NPCR) has made considerable progress in implementing key priority objectives aligned with the overall DMI strategic implementation plan. Crowdsourcing for quality control is a crucial CDC/NPCR DMI objective.

Purpose

To provide the CDC/NPCR vision on how cancer surveillance can use crowdsourcing on a common platform for subject matter experts (SMEs) to share their collective experience and education.

Methods

Over the past seven years, CDC/NPCR has developed new and innovative use cases to improve data exchange methods, timeliness, quality, and completeness. These methods are implemented using the CDC/NPCR Cancer Surveillance Cloud-Based Computing Platform (CDC/NPCR CS-CBCP). This platform will allow SMEs to adjust quality control rules to improve data reports and case ascertainment. By bringing SMEs together from multiple jurisdictions, quality control efforts can be maximized through their shared understanding of edits, case ascertainment, audits, and other activities that focus on data quality.

Results

This presentation will detail the CDC/NPCR crowdsourcing efforts with data reporters and central cancer registries (CCRs). This use case will demonstrate how the data quality of reports sent to CCRs can increase dramatically.

Conclusion

Modernizing cancer surveillance can achieve a fully integrated approach to upstream data collection and processing. This approach can potentially break down barriers that inherently exist within traditional systems used for data collection, processing, and analysis. These barriers exist because systems are siloed and fragmented, require manual intervention, and need more standards to exchange data between systems seamlessly. The CDC/NPCR CS-CBCP, coupled with crowdsourcing, has the potential to overcome these barriers by modernizing and improving electronic data exchange, as well as improving the quality of data reporting.

Concurrent 3.B – Progress in Testing US Interoperability Standards

Wednesday, June 26th
8:00am – 9:30am

Landscape for EHR Cancer Reporting

Sean Porter¹, Mr. Joseph Rogers¹, Sandy Jones¹, Ms. Vicki Benard¹, Ms. Jennifer Young², Michelle Esterly², Ms. Jennifer Wike²

¹CDC/NPCR, Atlanta, United States, ²Katmai Government Services, Anchorage, United States

Background

Meaningful Use (MU) began in 2011 to encourage Electronic Health Record (EHR) systems use. Since then, these systems have been rapidly developed, deployed, and used across the United States. Certain general requirements focused on clinical care have become mandatory for receipt of payment from Centers for Medicare and Medicaid Services (CMS). Data received from an EHR is often not complete for public health use. Central cancer registries use additional data from pathology or laboratory reports. Even though these are sent to the requesting physician, it is often not sent in a way that can be incorporated into the EHR system. Due to this incompatibility, the pathology or laboratory results are often unable to be further shared with other systems.

Purpose

To develop an understanding of how data from EHRs can be interoperable in the future.

Methods

United States Core Data for Interoperability (USCDI) and USCDI+ set standardized health data classes and data elements. Cancer Reporting Implementation Guides (IGs) direct EHR and Laboratory systems on how to report cancer cases to central cancer registries. These guides set specific data and data formats for reporting this information. The HHS Data Strategy contains 5 priorities for improving data infrastructure and capabilities: (1) cultivate data talent, (2) foster data sharing, (3) integrate administrative data into program operations, (4) enable whole-person care delivery by connecting human services data, and (5) responsibly leverage artificial intelligence. The strategy includes an expansion of the role of the Office of the National Coordinator for Health Information Technology (ONC) to include the coordination of human services interoperability in addition to its current role in enabling interoperability in the U.S. healthcare system.

Results

More data sharing is possible if there are changes to the data flow throughout the healthcare system.

These strategies have important implications for the cancer registry community, especially and those using EHRs. Leveraging recent technologic advancements in EHR systems and HHS Data Strategy is key to getting faster, better, and more complete data reporting for clinical and public health use cases.

Conclusion

Standardization, integration, high-quality, and easily usable data will be the way forward in utilizing EHR reporting for interoperability.



Exploring Cancer Registry Data Modernization Readiness: NPCR DMI Analysis to Evaluate Recipient Adoption Level Categorization

Dr. Paran Pordell¹, Ms. Sofia Huster¹, Ms. Emily Nethercott¹, Ms. Corinne Fukayama¹, Ms. Melissa Alvarado¹, Mr. Joe Rogers¹

¹CDC, Atlanta, United States

Background

In 2023, CDC Cancer Surveillance Branch evaluators conducted a mixed methods analysis of National Program of Cancer Registries (NPCR) monitoring and evaluation data from central cancer registries (CCRs) to assess CDC Data Modernization Initiative (DMI) adoption levels.

Purpose

This project sought to identify definitive and contributing criteria that affect cancer registry DMI readiness so that CCRs can be categorized as low, medium, or high DMI adopters.

Methods

Evaluators identified data sources that either clearly reflect a CCR's performance on DMI activities (definitive criteria) or reinforce a registry's ability to perform DMI-related activities (contributing criteria). Definitive criteria included: (a) NPCR Program Evaluation Instrument (PEI) responses on electronic reporting and early case capture (ECC) and (b) participation in DMI or advanced surveillance activities. Contributing criteria included: (a) NPCR childhood cancer project participation, (b) information technology percent staff time, and (c) NPCR Component 2 project participation. Evaluators analyzed PEI data using SAS software and organized the results in MS Excel. They created a rubric to categorize CCRs into three DMI adoption levels, weighing six definitive and four contributing criteria as low (0), medium (1), and high (2). Binary contributing criteria was assigned half the weight (low = 0, high = 1). Evaluators calculated the average across definitive and contributing criteria to generate a final "score" for each CCR.

Results

Based on final scores, evaluators categorized 16 CCRs as high, 14 CCRs as medium, and 17 CCRs as low DMI adopters. Of the high adopters, 56% had two or more IT staff, 94% received electronic reporting from all hospitals without a cancer registry, 75% received electronic reporting from all out-of-state labs, and 50% received electronic reporting from all in-state labs. Of the low adopters, 100% had no IT staff, 47% electronic reporting from all hospitals without a cancer registry, 23% from out-of-state labs, and 6% from in-state labs.

Conclusion

Increasing hospital and lab electronic reporting, having adequate IT staff, and implementing early case capture processes influenced DMI readiness more than case volume in most CCRs. Our results may inform DMI evaluation study methodology, cancer registry program priorities, and technical assistance to CCRs.



Enhancing Cancer Surveillance Data Collection via a Combined NAACCR Vol V and SMART on FHIR Approach

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Background

Central Cancer Registries (CCRs) depend on physicians, hospitals, and laboratories to send cancer data on all patients diagnosed and/or treated for cancer. Periodically, data reported from EHRs will be missing critical information. CCRs request missing data from physicians by letter or email, which impacts the timely release of cancer statistics.

Purpose

To describe a methodology using industry standards that enables CCRs to query the appropriate EHR system for missing diagnosis and/or treatment information for a single or multiple cancer patients.

Methods

The College of American Pathologists (CAP) and the CDC created a pull-based method for retrieving required data from the EHR based on triggers. This approach leveraged industry standards including NAACCR, Fast Healthcare Interoperability Resources (FHIR), minimum Clinical Oncology Data Elements (mCODE), and CAP electronic Cancer Protocols (eCPs). This case study simulated interaction between an EHR and CCR using a test patient. The Cancer Registry SMART on FHIR Application (CR-SoFA) was developed to demonstrate this data collection method. The process includes:

1. A NAACCR Volume V Electronic Pathology Laboratory report ("Vol V") sent from EHR to CCR
2. Patient information extracted from Vol V reports in CCR
3. CCR uses CR-SoFA to initiate a FHIR request based on information in the received Vol V. Request is sent to EHRs at the corresponding patients' institutions.
4. EHR sends a FHIR response back with requested patient information

Results

This presentation will describe the Query-and-Response workflow via CR-SoFA on 6 test patients in the EHR sandbox, demonstrating automated function without human intervention. The CR-SoFA was able to pull the correct patient data including problems, medications, procedures, radiology reports, additional pathology reports, radiotherapy data, occupational data, and US Core Profiles (race, ethnicity, birth sex, gender), using standard FHIR-formatted resources.

Conclusion

The CR-SoFA facilitates timely, efficient data exchange between EHRs and CCRs using NAACCR vol V as the trigger and FHIR to query and return additional information. The use of a CR-SoFA in a "triggered pull" approach has potential to scale beyond this use case to benefit cancer surveillance and real-world health care scenarios.



Concurrent 3.C – Data Visualization: Approaches to Process, Maintenance, and Impact

Wednesday, June 26th

8:00am – 9:30am

Visualizing Cancer Registry Data: A Framework for Developing and Testing New Tools

Cathy Bledsoe¹

¹One Health Insights, Lake Tapawingo, USA

Background

Central cancer registries have an enormous amount of data which is typically shared in the form of data dashboards and annual reports. Most external users do not have the specific skills and experience needed to properly interpret and use the information in those products. Registry professionals, however, are experts in the analysis and interpretation of cancer data. An understanding of the design process (e.g., defining the problem, prototyping) and design best practices (e.g., spacing, size) can help to bridge the gap between the experts and data users so that registries can develop tools that clearly convey the data to our target audiences.

Purpose

To propose a framework for approaching a cancer data visualization project, including real-world examples.

Methods

For nearly a decade, One Health Insights (OHI) has been refining a process for communicating cancer registry data using interactive data query tools and dashboards. During this time, OHI has worked with five states to develop data visualization tools using the following process: (1) define the problem and the target audience, (2) identify the necessary data and analyze it as needed, (3) brainstorm and prototype, (4) develop the tool, and (5) conduct user testing and iterate.

Results

Qualitative user experience testing has revealed many important ideas to consider when building cancer data dashboards. First, the use of text to explain charts and graphs is helpful for both experts and lay audience members, though the content of that text varies by audience. For lay audiences, the concepts of rates and stage at diagnosis may require extra explanation. For expert audiences, explanations of methodology and limitations are more valuable. Also, presenting the same data in multiple ways can help ensure data are disseminated widely by appealing to multiple audiences. Finally, getting user feedback during the prototyping stage can help to refine the tool early and save time on development.

Conclusion

Central cancer registries can present cancer data in ways that make it possible for users to understand the important stories in the data. Good design processes are essential to ensure these data are communicated in a way that the audience finds trustworthy, useable, and easy to understand.



Visualizing Florida Cancer Data: Digging into the Design Process to Explore Connections

Peyton Lurk², [Monique Hernandez](#)¹

¹Florida Cancer Data System, Sylvester Comprehensive Cancer Center, University of Miami, Miami, United States, ²Florida Department of Health

Background

Central Cancer Registry (CCR) data are a powerful source of information for understanding cancer burden and risk factors. However, before people can develop data-driven research, policies, and programs, they must be able to find and understand the data. Data visualization products represent an opportunity for communicating these data in innovative and informative ways.

Purpose

To communicate complex cancer registry data and to engage audience members in the development of data visualizations to ensure effective communication, use, and comprehension.

Methods

The Florida Cancer Data System (FCDS) combined cancer registry data with a census tract poverty indicator to investigate their potential association. Communicating the results involved identifying the various audiences, clarifying the questions, prototyping, developing multiple products (a data dashboard, infographic, and brief report), and two rounds of user testing.

Results

Initial testing of the data dashboard revealed that users - even those with cancer expertise - benefited from a written explanation of the methods and interpretation of the data. An infographic was developed to walk readers through the data, but this still lacked enough detail to satisfy some users. Finally, a brief write-up was developed to supplement the dashboard and infographic. The second round of user testing engaged a total of ten test users. The feedback from the interviews yielded three main themes. 1) Readers rely on both good design and written explanations to better understand the message. 2) Providing a brief write-up of the project can help to provide more detail that supports the data dashboard. 3) Understanding the audience is key in developing data visualizations, and multiple products may be needed to communicate with multiple audiences to ensure accurate interpretation of the data.

Conclusion

CCRs can communicate cancer data to a wide variety of audiences through data visualization platforms. Various approaches can help to reach wider audiences. Ideally, the process involves identifying the intended audience(s) and engaging them early to adequately address their needs. Additionally, user testing can identify the specific changes necessary to fine-tune tools and ensure their proper interpretation. Finally, regular updates to the products make them dynamic and consistently relevant and must be considered in the design process.

Visualizing California Cancer Registry Data: Assessing Impact of 5 Years of Interactive Maps and Dashboards

Debora Oh^{1,2}, *Meg McKinley*^{1,2}, *Katherine Lin*^{1,2}, *Dan Meltzer*^{1,2}, *Dr. Salma Shariff-Marco*^{1,2,3}, *Scarlett Gomez*^{1,2,3}

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Background

Interactive data visualization has become an increasingly popular way for cancer registries to share cancer rates, demographics, and risk factors.

Purpose

To describe the impact of data visualization tools developed by the Greater Bay Area Cancer Registry on users and on cancer registry staff.

Method

California Health Maps (californiahealthmaps.org), an interactive mapping tool of health data for geographies beyond the county level in California, was released to the public in October 2019. Users of the tool can map cancer incidence rates for 12 of the most common invasive cancer sites and filter by sex and race/ethnicity for seven different geographic levels. Data analytics for the website were passively collected via Google Analytics starting from 2019.

The Greater Bay Area Cancer Registry dashboard (cancerregistry.ucsf.edu) was built in using Tableau and released in 2020. The dashboard features county-level cancer incidence and mortality rates for the 9-county region. The UCSF Helen Diller Comprehensive Cancer Center dashboard (cancer.ucsf.edu/catchment-area-dashboard) was also built in Tableau and released in 2021. It features county-level cancer incidence and mortality rates for the 25-county catchment area. Information on data requests from 2017 to 2023 was extracted from a data requests tracking system to assess if the tools reduced burden on cancer registry staff.

Results

From October 2019 to January 2024, there have been >16,000 users and >24,000 sessions documented in Google Analytics for California Health Maps. In 2020, there were 1462 users and 2503 sessions documented. In both 2022 and 2023, there were over 5000 users and 7500 sessions documented per year.

In 2017 and 2018, there were 89 and 88 data requests (respectively) for various cancer rates and case counts submitted to the Greater Bay Area Cancer Registry. In 2022 and 2023, the number of requests were reduced to 42 and 45 (respectively).

Conclusion

We showed that data visualization dashboards can reduce the burden of data requests to the registry. While these tools have been valuable, there are issues to consider when building dashboards including staff time for cancer rate generation, access to detailed denominator data, geocoding quality, and costs for development.

Applications for Visualizing Cancer Risk Factors and Mortality Across the University of Kansas Cancer Center Catchment Area

Mohammad Mahmudur Rahman¹, Md Robiul Islam Talukdar¹, Murshalina Akter¹, Sam Pepper^{1,2}, Dr Isuru Ratnayake¹, [Dinesh Pal Mudaranthakam](#)^{1,2}

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Background

An increasingly diversified demographic landscape in rural and urban America warrants the attention of The University of Kansas Cancer Center (KU Cancer Center) researchers, clinicians, outreach staff, and administrators as the institution assesses ways to reach its expansive, bi-state catchment area. Within the counties of the KU Cancer Center catchment area, patient level and public health data are available and categorized by varying geographic regional boundaries. Multiple data sources and different data collection processes complicate summarizing catchment area data.

Purpose

A curated data warehouse that retrieves and structures the data with a common denominator can support meaningful use of the data in a standard and consistent format.

Methods

The KU Cancer Center built a data warehouse to Organize and Prioritize Trends to Inform the KU Cancer Center (OPTIK), which functions to streamline the process of synthesizing data regarding Kansas and Missouri demographics, cancer risk factors, and incidence and mortality rates.

Results

OPTIK standardizes these diverse data sources to enable analyses of the cancer burden at local, regional, and national levels while upholding a strict standard of patient privacy. The OPTIK database enables researchers to use available data and create heat maps and other visualizations to aid in funding proposals, presentations, and research activities.

Conclusion

Furthermore, using the knowledge provided by OPTIK, the KU Cancer Center can prioritize action items for research and outreach and more effectively communicate the impact of those efforts.

Concurrent 3.D – Special Populations: American Indian and Alaska Native Peoples

Wednesday, June 26th

8:00am – 9:30am

Earlier Detection of Colorectal Cancer among Alaska Native People

Elena Roik¹, Garrett Zimpelman¹, Renee Corvalan¹, Keri Miller¹

¹ANTHC, Alaska Native Epidemiology Center, ANTR, Anchorage, United States

Background

Alaska Native (AN) people have the highest rates of colorectal cancer (CRC) incidence and mortality rates globally. The burden of CRC has led to an increased focus on CRC screening and prevention by Tribal and clinical leadership within the Alaska Tribal Health System. The Alaska Tribal Health System has implemented several strategies to increase screening. In 2013, the Alaska Native Medical Center updated their CRC screening policy and began screening AN people at 40 years of age, rather than 50 years as is nationally recommended.

Purpose

This study aims to examine long-term CRC trends among people to determine changes in the descriptive epidemiology of CRC.

Methods

Cancer data were collected by the Alaska Native Tumor Registry, a population-based central cancer registry. The primary focus of the given analysis is on CRC diagnosed from 1969 through 2020. For the purpose of analysis, diagnosis years are divided into 10-year intervals (1969-1979; 1980-1989; 1990-1999; 2000-2009; 2010-2020). Differences in patient and clinical characteristics are assessed using the Chi-squared test, and Pearson Chi-squared test for trends.

Results

We have not found statistically significant differences in the prevalence of CRC among women and men over the last 50 years of surveillance ($p=0.425$). However, for the last 15 years the minimum age at diagnosis for men has remained relatively stable, while the minimum age for women has continued to decline. During the years 2000-2009, and 2010-2020 the odds of being diagnosed with CRC at advanced stages (III, IV) has decreased, resulting in increased odds of being diagnosed with CRC at earlier stages (OR 5.34; 5.03 $p < 0.001$). We found no significant difference in the age at diagnosis between women and men diagnosed with cancer at early or advanced stages ($p=0.652$; $p=0.642$)

Conclusion

Colorectal cancer prevention efforts across the Alaska Tribal Health System have resulted in CRC being diagnosed at earlier stages. Furthermore, we believe that continued monitoring of early onset CRC in AN women is warranted.

Racial Disparities in Early-Onset Colorectal Cancer

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¹American Cancer Society, Atlanta, USA

Background

Colorectal cancer (CRC) incidence and mortality in the US is highest among American Indian and Alaska Native individuals, followed by Black individuals. It is unknown whether these patterns differ for early-onset disease given the increase in incidence since the mid-1990s that varies by race/ethnicity.

Purpose

Analyze early-onset CRC incidence in the US by race and ethnicity.

Methods

Annual age-standardized CRC incidence (1998-2019) and mortality (1990-2020) rates for people ages 20-54 years were obtained from the NAACCR for 43 states with high-quality data and the National Center for Health Statistics, respectively. Ages 50-54 years were included because incidence and mortality trends match ages <50. Cases were stratified into five non-Hispanic race groups (White, Black, Asian/Pacific Islander, Alaska Native, American Indian) and Hispanic. The annual percent change was evaluated using Joinpoint regression and described as increasing/decreasing when the two-sided p-value was statistically significant (<0.05) and otherwise stable. Incidence rates were delay-adjusted except for disaggregated Native Americans because a state variable is unavailable in the database. Due to sparse data, mortality trends could not be estimated for Alaska Native individuals disaggregated from American Indian individuals.

Results

From 1998-2019, CRC incidence rates in adults <55 years increased by 2.5%-3% per year in Alaska Native and American Indian individuals; 1.3%-1.5% per year in Hispanic and White individuals; 1% per year in Asian/Pacific Islander individuals; and were stable in Black individuals. Average annual incidence rates during 2016-2020 were highest among Alaska Native individuals (34 per 100,000), approximately 2-times higher than second-ranking American Indian individuals (17.3), followed by Black (13.4); White (12.6), Hispanic (10.1), and Asian/Pacific Islander (9.7) individuals. CRC mortality in adults <55 years has increased in American Indian and Alaska Native individuals since at least 1990 by 2.5% per year, versus upticks since the mid-to-late 2000s of approximately 2% per year in Hispanics, 1.5% per year in Whites, and 1% per year in Asian/Pacific Islanders.

Conclusion

Native American individuals have an increasingly disproportionate burden of early-onset CRC, particularly Alaska Native individuals, who have 2-3 times higher incidence than any other racial/ethnic group. Greater resources, screening interventions, and etiologic research are urgently needed to understand and address this alarming inequality.

Evaluating Cancer Survival among American Indian and Alaska Native People Living in Purchased/Referred Care Delivery Areas (PRCDA) and Non-PRCDA Counties

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Background

There is continued differential misclassification of American Indian and Alaska Native (AIAN) race among cancer survivors (and the general population) living in Purchased/Referred Care Delivery Areas (PRCDA) versus non-PRCDA counties. Thus, AIAN cancer statistics are commonly restricted to PRCDA counties to reduce misclassification bias in risk estimates. This practice results in the exclusion of the ~46% of AIANs living in non-PRCDA counties from cancer statistics, potentially impacting generalizability and accuracy of these statistics. NAACCR is evaluating this practice.

Purpose

To evaluate differences in socio-demographics, tumor characteristics and survival between AIANs living in PRCDA and non-PRCDA counties.

Methods

We calculated age-standardized 5-year relative survival ratios (RSRs) among people aged 15+ years with malignant cancers diagnosed during 2013–2019 and included in CiNA Survival data (November 2022 submission). Patients were followed through December 31, 2019, using blended survival time. Life tables used to calculate expected survival were adjusted for socioeconomic status, county geography, and race/ethnicity. Patients were classified as AIAN if so identified by a reporting facility or linked to Indian Health Service records. RSRs were calculated for all AIAN by PRCDA residency at time of diagnosis.

Results

Of 61,951 tumors diagnosed among AIANs, 43,006 (69%) were among people living in PRCDA counties. For all sites combined, RSRs for AIANs were 0.556 (95% CI: 0.548, 0.563) in PRCDA and 0.623 (95% CI: 0.611, 0.635) in non-PRCDA counties. In contrast, all sites combined RSRs for NHWs were similar between PRCDA versus non-PRCDA counties. Differences in AIAN survival between PRCDA and non-PRCDA counties were driven by prostate cancer (PRCDA = 0.892, non-PRCDA = 0.944), non-Hodgkin lymphoma (PRCDA = 0.578, non-PRCDA = 0.722), and leukemia (PRCDA = 0.472, non-PRCDA = 0.608). Large quantitative but statistically equivalent differences in survival were noted for other primary sites.

Conclusion

There were substantial differences in 5-year survival between individuals living in PRCDA versus non-PRCDA counties. Elucidating the reasons for these differences warrants further research, but highlight the need to present and monitor cancer statistics for residents of non-PRCDA counties.



What Can We Learn from Examining the Cancer Burden among the American Indian and Alaska Native People in California?

Lihua Liu¹, Kai-Ya Tsai¹, Ziwei Song², Jonathan Wang³, Dr. Kori Novak⁴, Dr. Sue E. Kim⁵, Dr. Claradina Soto⁵

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Background

Cancer control among the American Indian and Alaska Native (AIAN) people falls behind the other major racial/ethnic populations in the US, largely due to lack of reliable cancer statistics specific to this population. Population-based cancer surveillance among AIANs faces many unique challenges, from small but diverse population groups to racial misclassification, strict federal definitions for tribal recognition and affiliation, underfunded healthcare, and undercounted census enumeration. The geographic distribution of AIANs also warrants state-specific understanding.

Purpose

Given 24% of the nation's AIANs live in California, we aimed to evaluate the AIAN cancer statistics as compared with those for other racial/ethnic populations in California.

Methods

Using the California Cancer Registry (CCR) January 2023 Statewide Research File, we examined the patient and tumor characteristics and age-adjusted (2000 US Standard) incidence rate (AAIR) and mortality rate (AAMR) for all cancer sites and the top five common cancers among AIANs by sex against those of the non-Hispanic (NH) white, NH black, Hispanic, and Asian and Pacific Islander (API) counterparts during 2000-2020. Kaplan-Meier survival curves and multivariable Cox hazard model were used to evaluate survival and control for confounding.

Results

AIANs had a higher share of younger cancer patients aged 40-64 years (48.5% female, 45.4% male) than all races combined (41.3%, 36.3%), but a lower share of those aged 75+ years (19.6% female, 18.4% male vs. 28.3%, 29.1%). AIAN cancer patients also had more comorbidity conditions. For all cancers combined, AIANs ranked 3rd in AAIR trailing behind NH whites and NH blacks, but 1st in cancer mortality. AIANs displayed highest AAIR for uterus, liver (in males), and kidney cancers; and highest AAMR for lung, colorectal, kidney, and liver (in males) cancers. In general, AIAN females survived better than AIAN males. Controlling for age, cancer stage, socioeconomic status, and comorbidity, Female AIANs showed significant reduction in mortality risk from their NH black counterparts for uterus (-43%), breast (-25%), colorectal (-13%), and all cancers combined (-10%); and from their NH white counterparts for colorectal (-11%) and all cancers combined (-5%), respectively.

Conclusion

The validity of these AIAN cancer statistics in California is subject to the completeness of reporting and identification of AIANs.



Concurrent 3.E – Strategies for Using Registry Data for Research

Wednesday, June 26th

8:00am – 9:30am

VPR-CLS: Facilitating Primary and Secondary Sharing of Cancer Registry Data

Castine Clerkin¹, Dr. Dennis Deapen², Lynne Penberthy³, Betsy Kohler¹, Dr. Eric Jacobs⁴, Dr. Kathy Helzlsouer³

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Background

The Virtual Pooled Registry Cancer Linkage System (VPR-CLS) is an NCI-sponsored online service managed by NAACCR that efficiently connects existing research studies with U.S. cancer registries to facilitate minimal risk linkages and sharing of cancer incidence data on matched cases.¹ Under the NIH Data Management and Sharing Policy (effective January 25, 2023), the primary recipient of the cancer data may be required to further share data thereby “enabling validation of research results, providing accessibility to high-value datasets, and promoting data reuse for future research studies.”² This secondary sharing of cancer registry data is practice that is highly encouraged.

Purpose

In this presentation, we will describe how the VPR-CLS initiative is addressing both primary and secondary sharing of cancer registry data in an efficient, thoughtful, and protected manner.

Methods

The VPR-CLS uses a Templated IRB/Registry Application (TIRA), a Templated Data Use Agreement (VPR DUA), and a Central IRB (CIRB) to simplify the data request and release process for registries and researchers. The NAACCR DUA Task Force developed a Flow Through Agreement to cover secondary sharing of a study data set that includes cancer registry data between the primary researcher and an external party. Education and promotion of these efficiencies is an ongoing endeavor.

Results

To date, 25 studies have utilized the VPR-CLS to efficiently link with 45 participating U.S. registries. Thirty-nine registries have adopted the TIRA, 25 registries use the VPR DUA, and 16 registry IRBs have ceded review to the CIRB. The Flow Through Agreement passes the terms and conditions of the VPR DUA on to the secondary researcher and prohibits any further sharing except with a controlled access repository. Adoption and use of the Flow Through Agreement is in the initial stages.

Conclusion

The VPR-CLS provides registries and researchers a streamlined and standardized way to perform minimal risk linkage and share data in a manner that enhances research and protects the registry data.

¹This project has been funded in whole or in part with Federal funds from the National Cancer Institute, National Institutes of Health, Department of Health and Human Services, under Contract No. 75N91021D00018

²<https://sharing.nih.gov/data-management-and-sharing-policy/about-data-management-and-sharing-policies/data-management-and-sharing-policy-overview#after>



Update on a Secure Cloud-Based Environment for Remote Data Analysis and Lessons Learned

Eric Miller¹, Pamela Sanchez¹, Anne-Michelle Noone¹, Annelie Landgren¹, Serban Negoita¹, Paul Pinsky¹, Jerome Mabie², Tom Riley², Rusty Shields², Matthew Butcher², Tim Evans², Doug Flynn², Spiro Razis², Scott Depuy²

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Background

While there is currently increased pressure for more data sharing in cancer research, this is counterbalanced by the need to ensure data security and protect patient or study participant identities. To address data sharing needs and issues related to secondary sharing of linked cancer registry data, the National Cancer Institute (NCI) developed the Virtual Cancer Data Access System (VCDAS), a cloud-based environment for secure remote analysis of data. Approved researchers can access data in VCDAS individually or within collaborative workspaces while NCI maintains control of the data. The current proposed use cases are for more sensitive Surveillance, Epidemiology and End Results (SEER) data and data from NCI-funded studies linked with cancer registry data. In January 2024, NCI began pilot testing VCDAS and will be gathering feedback from testers on the benefits and limitations of this platform.

Purpose

To provide an overview and demonstration of VCDAS, including security protections, along with a summary of feedback from testers. In addition, we will provide lessons learned on the complications associated with the development and administration of VCDAS.

Methods

Twenty-six testers were selected that include 21 users and 5 system administrators. Selected testers were given approximately 6 weeks for testing. Feedback will be collected through one survey and two focus group meetings.

Results

Testing is ongoing. Feedback will be gathered on ease of use and administration of the platform, security controls, and ability to meet the needs of varying levels of statistical programming abilities.

Conclusion

VCDAS is intended to meet the needs of current data sharing requirements and security concerns. While the cloud environment provides a viable solution, it has limitations as well. This pilot test will help determine if VCDAS is a feasible solution for secure sharing of registry and registry-linked data.



Challenges and Facilitators of Recruitment and Data Collection Efforts: Lessons Learned from Two Research Projects

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Background

Studies involving primary data collection often face challenges in achieving participation goals. In two recently conducted studies at The Cancer Registry of Greater California, the National Cancer Institute's SEER Patterns of Care (POC) study and the RESPOND Study, a national study of African American men diagnosed with prostate cancer, we initially experienced difficulty achieving consistent weekly recruitment goals, ensuring timely follow-up, and preemptively identifying potential risks to project timelines.

Purpose

To describe the challenges we experienced and share processes we implemented to effectively address them.

Methods

For both studies, we adopted an Access database with features to visualize project tasks and report weekly progress on key elements, such as the number of requests sent/received alongside the date and method of sending/receiving. We added automation to generate lists of participants or facilities who needed to be contacted. The database also collected details such as outcomes from previous contact attempts and overall status for each participant or facility. These databases were set up to 1) mirror the steps of the data collection process, 2) incorporate automation to move cases from one step to another, and 3) generate real-time progress reports.

Results

In both projects, the new tracking systems provided transparency on project needs, workflows, and weekly progress, allowing us to reallocate resources or adjust procedures early to maintain project timelines and troubleshoot low response rates. In the RESPOND study, our survey response rate steadily increased from around 12% to 25% percent within 6 months. We consistently maintained this rate throughout the remaining recruitment period and met our target goal of recruiting 665 participants. In POC, we were able to identify potential resource constraints and actively work with the team to reallocate resources and maintain a steady workflow pace without additional burden to staff.

Conclusion

A tracking system that can easily provide a real time snapshot of various project elements is critical for meeting weekly goals, resource management, and proactively mitigating issues. While developing a well-thought-out tracking system required a large effort, it was invaluable to achieving timely project goals. Moreover, it can be easily replicated for future projects.



Assessing the Validity of Rapid Case Ascertainment Methods to Support Research Eligibility Determinations

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Background

Some research studies supported by central cancer registries require rapid case ascertainment (RCA) to determine study eligibility before a consolidated case is finalized. RCA may rely on manual review or auto-coding of pathology reports for unconsolidated cases, consolidated but unedited cases, or a combination. RCA is limited by the records available at the time eligibility determinations are made. Understanding the validity of different RCA approaches for determining eligibility will help registries best support these studies.

Purpose

To assess accuracy of study eligibility determinations made using different RCA methods compared to eligibility of the cancer diagnosis in the finalized cancer case.

Methods

Utah Cancer Registry (UCR) evaluated 7,465 potential cases diagnosed 2019-2022 for eligibility for three RCA research projects. Studies of hematopoietic and oropharyngeal cancers used Oncology Data Specialist (ODS) review of unconsolidated cases and unedited cases, and a study of melanoma utilized non-ODS coding of unconsolidated cases and computerized selection of unedited cases. We compared 6,741 cases initially determined eligible for inclusion through RCA to the eligibility determination that would have resulted from the finalized case to identify the proportion of RCA-eligible cases that should have been deemed ineligible.

Results

For unconsolidated cases, 1,646 were reviewed by an ODS, and of those, 229 (13.9%) were ineligible when compared to the finalized case. Another 2,974 unconsolidated cases were initially identified as eligible using non-ODS or computerized identification, of which 216 (7.3%) were ineligible when compared to the finalized case. For unedited cases, 529 had ODS review, and 20 (3.8%) would have been ineligible based on the finalized case. In another 1,592 unedited cases initially identified as eligible using non-ODS review or computerized methods, 63 (4.5%) were found to be ineligible based on the finalized case. We will present additional details on variation by cancer and by time between diagnosis and eligibility assessment.

Conclusion

RCA using unconsolidated cases was associated with inclusion of a larger proportion of ineligibles, compared to using unedited, consolidated cases. Determining whether these patterns are similar across cancer types is important to understand whether RCA studies should wait to determine study eligibility until consolidated cases are available.

Concurrent 4.A – Leveraging Partnerships to Improve Operations and Data Use

Thursday, June 27th

9:00am – 10:30am

Using Innovative Solutions to Advance Cancer Data in Canada

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¹Canadian Partnership Against Cancer, Toronto, Canada

Background

The Canadian Partnership Against Cancer and the Canadian Cancer Society released the pan-Canadian Cancer Data Strategy (cancer data strategy) in collaboration with partners. The cancer data strategy aligns with the foundational priorities within the pan-Canadian Health Data Strategy (PCHDS) focusing on modernizing how cancer information is collected, shared and used, while building upon the foundational pillars of interoperability, clarifying accountabilities, protecting individual privacy, and respecting data sovereignty of First Nations, Inuit and Métis peoples.

Purpose

Engagements with pan-Canadian partners identified timelier cancer case ascertainment and staging as immediate areas of focus for collective action. Currently, this data can lag up to two years before entering into provincial cancer registries. Timely access to high quality cancer data would facilitate faster responses to cancer system challenges, enable advancements in patient-focused value-based care, and improvements in cancer surveillance. By convening federal, provincial/territorial and cancer system partners, solutions can be identified to advance shared priorities in a federated system.

Methods

An environmental scan was conducted to identify tech-enabled solutions (e.g., artificial intelligence, natural language processing) to achieve timelier case ascertainment and staging. Inputs included surveys to identify challenges, process workflow analyses, interviews with key stakeholders, and market analysis of known products. Additional analyses are underway to ensure that the recommended tools align with the desired future state of modernized healthcare data systems across Canada.

Results

Process flow recommendations focused on the use of software solutions to realize efficiencies, including transitioning from paper to digital reporting, leveraging natural language processing to create structured data, and adopting standardized data formats. Cross-cutting recommendations encompass broader systemic considerations, automated linkages, flexible data processing approaches, leveraging emerging tools, and fostering collaborative partnerships to advance automation efforts. A key takeaway is the necessary shift towards a digital service delivery approach, achieved by maximizing the cooperation of provincial and territorial registries to co-build a unified technology stack or tool set to meet this challenge.

Conclusion

Engagements will be held with partners to prioritize environmental scan recommendations. This includes continued collaborations and knowledge exchange opportunities with key stakeholders to achieve timelier case ascertainment and staging and supporting implementation that aligns with federal, provincial and Indigenous priorities.

Wisconsin Cancer Reporting System Partnerships in Three Vignettes

[Lena Swander](#)¹, [Dr. Jessica Link Reeve](#)¹, [Dr. Jeffrey Bond](#)¹

¹Wisconsin Department of Health Services, Office of Health Informatics, Wisconsin Cancer Reporting System, Madison, United States

Background

Population-based cancer registry staff are tasked with two competing time- and resource-intensive processes: first, to collect, classify, consolidate, and link information to generate high quality surveillance data; second, to support programming decisions with our data made by a variety of cancer prevention and control partners. It remains a challenge for limited staff to balance both priorities with limited resources.

Purpose

To highlight three mutually beneficial partnerships the Wisconsin Cancer Reporting System (WCRS) strategically prioritized in 2023 to address and balance these competing priorities.

Methods

In 2023, WCRS prioritized three collaborative partnerships. With the Wisconsin Well Woman Program, we held dedicated training sessions on an annually required linkage and are actively building small area estimation services to guide programmatic decisions. With the Wisconsin Cancer Collaborative, we collaborated to publish surveillance data in response to incoming community requests. Finally, we implemented monthly standing meetings with epidemiologists from the Bureau of Environmental and Occupational Health to facilitate data sharing in response to community cancer cluster concerns.

Results

By strategically prioritizing three cancer prevention and control partnerships, we improved their understanding of our registry's data model and our knowledge of their programming, published co-branded materials using registry data, eliminated internal agency silos, and reduced response time for data requests.

Conclusion

Results and lessons from these three improved, strategic partnerships will guide our registry's and cancer prevention and control partners' programmatic decisions in the future.



Revolutionizing Death Certificate Only (DCO) Case Follow-Back with Health Information Exchange (HIE)

Vijay Medithi¹

¹*Myriddian - Maryland Cancer Registry, Baltimore, United States*

Background

The Maryland Cancer Registry faced a persistent challenge with DCO cases. Despite efforts, the DCO rate remained around 3%, highlighting the need for more effective strategies to reduce this rate and enhance data completeness. The Death Follow Back process, which involved seeking information on unregistered cases from healthcare facilities, was resource-intensive and yielded poor ROI. Facilities were burdened with additional reviews of older cases that did not meet reporting requirements, adding to the workload. Thus, there was a pressing need to streamline the process and improve efficiency.

Purpose

The purpose of this initiative was to revolutionize the DCO follow-back process by leveraging technology and collaboration. Myriddian, in partnership with CRISP (Chesapeake Regional Information System for our Patients), aimed to streamline the process and reduce the DCO rate while saving time and resources for both the registry and facilities.

Methods: Myriddian forged a collaborative partnership with CRISP to facilitate the sharing of unregistered patient demographic information and leverage CRISP's data for efficient case matching. CRISP provided critical information such as Facility Seen, Date First Seen for a cancer diagnosis, Cancer Diagnosis, Diagnosis Description, Race, and Ethnicity. This enriched dataset was used to follow up with healthcare facilities to submit Cancer Case Reports or update patient records, thereby excluding cases from the DCO category.

Results

The intervention led to significant results, with numerous cases being identified with comprehensive tumor information, effectively reducing the DCO rate from 3% to below 1%. The streamlined process not only enhanced the case completeness but also saved considerable time and resources for both central registry and facilities personnel. Overall, the intervention was phenomenally successful in achieving its goals and improving data completeness.

Conclusion

The collaboration between Myriddian and CRISP successfully revolutionized the DCO follow-back process, leading to a remarkable reduction in the rate and more efficient use of resources. The sustained utilization of CRISP in the death follow-back process, along with proactive strategies, will ensure the continued success of this approach and further enhance overall case completeness over time. This initiative exemplifies how technology, coupled with the right partnerships, can bring about transformative solutions in Cancer Registry Management.

Student Engagement through Internships and Volunteer Opportunities at the Missouri Cancer Registry and Research Center

Iris Zachary¹, Lucinda Ham¹, Mrs. Stacy Barr¹

¹Missouri Cancer Registry and Research Center, Columbia, United States, ²University of Missouri, Columbia, United States

Background

The Missouri Cancer Registry and Research Center (MCR) located on the campus of the University of Missouri, in the College of Health Sciences, Department of Public Health has extended its commitment to fostering academic engagement by initiating a student engagement program. This initiative, providing intern and volunteer opportunities each semester, is a deliberate effort to streamline and enhance the educational experiences available to students within the College of Health Sciences programs and across the broader University of Missouri (MU) campus.

Purpose

The primary goal of the MCR student engagement initiative is to offer students valuable experiences and extended knowledge while assisting the MCR team with projects that might be constrained by limited staff time and resources. This collaboration fosters a mutual relationship, wherein students acquire practical skills and cancer surveillance insights, while MCR benefits from their varied backgrounds.

Methods

Students apply for internships or volunteer opportunities through their current programs via Handshake, undergraduate, Master, and PhD students undergo an interview process. MCR typically accepts 2-3 students in different areas per semester, matching them with team members based on expertise and interests, spanning clinical abstracting, health administration, coding, programming, program development, workflow improvement, automation, and epidemiological studies.

Results

Successful students volunteering or meeting their internship requirements can apply and get hired as part-time employees. Cancer registry internships involve projects, such as teaching students to abstract specific cancer sites for students with clinical interests, contributing significantly to meeting NPCR and NAACCR goals. Master and PhD students engage in processing of path lab cases, conducting facility audits using Match*Pro and Python, gaining direct experience in cancer data management and registry operations.

Conclusion

Student engagement and participation at MCR has proven to be a success and mutually beneficial. Students bring new ideas and introduce new technologies to our program contributing to its success.



Concurrent 4.B – Advances in Machine Learning for Cancer Registries

Thursday, June 27th

9:00am – 10:30am

Real Time Reporting: Path Processing in SEER Systems

Fabian Depry¹

¹*Information Management Services, Inc., Calverton, USA*

It is a priority of the SEER program to modify registry operations to report data as soon as two months after the end of a diagnosis year (i.e., “real time” reporting). SEER registries submit preliminary incidence data at the end of February each year. The goal is to take advantage of advances in electronic reporting and data processing so that the February submission includes data from the previous calendar year.

Real time reporting would involve only the minimal # of fields to produce basic incidence trends. This presentation will provide an overview of recent and upcoming changes to pathology report processing in SEER computer systems related to the real time reporting initiative.

The following processes will be discussed:

- Parsing free text from non-standard HL7 files into specific data items.
- Identifying reports with reportable diseases.
- Using NLP to extract core data items.
- Changes to registry workflows to create preliminary case in real time.

Considerations For Assessing Ai-NLP Solutions For Cancer Registries

Jon Patrick¹, Mr. Steve Tan¹, Dr. Ying OU¹

¹Health Language Analytics Global LLC, South Eveleigh, Australia

Background

The emergence of Ai-NLP technologies for analyzing and generating texts has staff wondering how one might assess this technology as to its usefulness, accuracy and dangers. The manner in which Ai-NLP is implemented is important to answering these questions.

Purpose

The essence of Ai-NLP is to identify semantic entities of interest in target reports. The technology used for this task is more broadly known as “machine learning” (ML). The ML process requires selecting an algorithm suited to the type of data to be analyzed, and the relevant content for each report that needs to be identified for a given task.

Methods

The algorithm is trained with a corpus of reports and their respective target values - training the machine learner produces a language model of pathology reports. The trained algorithm performs by being input an unclassified report. It then finds the best matching report in its training set and adopts its values for the input report. As simple as the process sounds there are many issues that affect the quality of the results and therefore the acceptability of a particular ML implementation.

Results

The major issues to consider are:

1. The definition of the modelling task
2. The pre-processing algorithms applied to the training corpus for ingestion into the algorithm
3. The variables investigated in selecting the training and test corpora
4. The source of the training corpus used to create the model
5. The variables selected to assess the accuracy of the model
6. The test corpora selected to represent the variables
7. The characteristics of the variables used in the assessment of accuracy
8. The methods for improving the model for particular clients
9. The methods for updating the model for changes in standards

Conclusion

It is an open question as to how well a model trained for one jurisdiction might be applicable in another jurisdiction. The resolution of these issues have a material effect of the scope, accuracy and relevance of a particular classifier for a given jurisdiction.

The approach used for building a case identification classifier for the California Cancer Registry will be described in terms of these issues.

DeepPhe-CR: Natural Language Processing Software Services to Assist Oncology Data Specialist Case Abstraction

Dr. Jong Cheol Jeong, [Sean Finan](#), Dr. Harry Hochheiser, Dr. Ramakanth Kavuluru, David Rust, Dr. Guergana Savova, Dr. Jeremy L. Warner, Zhou Yuan, Eric Durbin, Isaac Hands, Dr. Xiaocheng Wu

Background

Manual extraction of cancer abstracts from patient records for cancer surveillance is a source-intensive task. Natural Language Processing (NLP) techniques have been proposed for automating the identification of key elements from clinical notes. Our goal was to develop NLP application programming interfaces (APIs) for integration into cancer registry data abstraction software in a computer-assisted abstraction setting.

Methods

Cancer registry manual abstraction processes were used to guide the design of DeepPhe-CR, a web-based NLP service API. The coding of key variables was performed through NLP methods validated using established workflows. A container-based implementation of the NLP methods and the supporting infrastructure was developed. Existing registry data abstraction software was modified to include results from DeepPhe-CR. An initial usability study with oncology data specialists provided early validation of the feasibility of the DeepPhe-CR API.

Results

The DeepPhe-CR API supports submission of single documents for a single case and summarization of cases across one or more documents. The container-based implementation uses a REST router to handle requests and support a graph database for storing results. NLP modules extract topography, histology, behavior, laterality, and grade at 0.79-1.00 F1 across multiple cancer types (breast, prostate, lung, colorectal, ovary, and pediatric brain) from data of two population-based cancer registries. Usability study participants were able to use the tool effectively and expressed interest in the tool.

Conclusion

The DeepPhe-CR system provides an architecture for building cancer-specific NLP tools directly into registrar workflows in a computer-assisted abstraction setting. Improved user interactions in client tools may be needed to realize the potential of these approaches.



Enhancing Precision in Information Extraction: Strategies for Optimizing Abstention Rates

Jamaludin Mohd-Yusof¹, Sayera Dhaubhadel¹

¹Los Alamos National Laboratory, Los Alamos, US

Background

Deep learning methods for natural language processing (NLP) are becoming widely used to automate information extraction from pathology reports. The MOSSAIC Information Extraction API is a real-world NLP application of the Deep Abstaining Classifier (DAC), a novel deep learning architecture which allows the model to 'abstain' on those samples which are low confidence, often because of missing or ambiguous information. In previous work, we have shown that the DAC learns patterns within the data that can make prediction unreliable, allowing it to be trained to a specified level of accuracy at the expense of reduced coverage (abstaining on some fraction of the samples, which must then be manually classified).

Purpose

Develop methods to improve abstention rates while retaining accuracy, through the modification of training protocols.

Methods

We present the results of a series of experiments where we inject noise into the training set labels, with varying levels of noise and with different patterns which mimic those seen in real-world data. For example, we include site/subsite classifications which are more or less specific than the label, or commonly confused histologies. We also investigate the effect of relaxing the target accuracy threshold, especially compared to the noise level. We use explainability methods to investigate the differentiating factors between abstained and non-abstained samples.

Results

We show that, because of the unique patterns that the DAC learns, noise injection can lead to abstention rates which are significantly higher than the noise level. The discriminators for abstention also become less meaningful as the abstention increases. Furthermore, reducing the target accuracy for a nominally noise-free set can dramatically reduce abstention, possibly implying that there is poor quality of the ground truth. We observe that lack of consistency in labeling in small subsets of the data can lead to abstention of entire classes, and that training on smaller, but higher-quality, data sets has particular advantages for the DAC compared to other deep learning models.

Conclusion

With better training protocols, we demonstrate that abstention rates can be reduced, allowing the Information Extraction API to improve coverage without loss of accuracy, and further reduce the manual annotation workload for registrars.

Concurrent 4.C – Clusters and Small Area Analysis

Thursday, June 27th

9:00am – 10:30am

Lessons from a Decade of Addressing Community Cancer Concerns in the Greater Bay Area, 2014-2023

Meg McKinley¹, Mr. Terence Kelley², Dr. Anshu Shrestha³, Dr. Salma Shariff-Marco¹, Scarlett Gomez¹

¹UCSF Greater Bay Area Cancer Registry, San Francisco, United States, ²Chronic Disease Surveillance Research Branch, California Department of Public Health, Sacramento, United States, ³Cancer Registry of Greater California, Sacramento, United States

Background

The 2022 CDC Guidelines for Examining Unusual Patterns of Cancer and Environmental Concerns defines a cancer cluster as “a greater than expected number of the same or etiologically related cancer cases that occurs within a group of people in a geographic area over a defined period of time.” Population-based cancer registries frequently address concerns about cancer occurrence in neighborhoods, schools, and occupational sites. Strategies include educating the public about cancer, advising on publicly available data resources, and conducting analyses to investigate whether an excess number of cases exists.

Purpose

We describe the Greater Bay Area Cancer Registry’s experience handling 105 cancer concerns over ten years (2014-2023).

Methods

We classified cancer concerns based on cancer site, geographic location, type of concern, requestor classification, and type of response. We summarized our approach to addressing the various types of concerns, with specific attention to the suitability of registry data to manage and identify other tools that could be provided in light of the new CDC guidance released in December 2022.

Results

Of a total of 105 requests, 70% were in neighborhoods/residential areas, 12% were school sites, and 18% were occupational sites. Nearly half (48%) of the requests came from the public (concerned citizens contacting the registry). Most requests included all cancer sites combined or multiple sites (56%). The majority (87%) were addressed by providing education, with 13% involving reviewing registry data or calculating a standardized incidence ratio.

Conclusion

The annual number of cancer concerns has been consistent, but those related to occupational sites have increased slightly. Methods and tools exist to address cancer concerns from an educational and statistical approach. However, for many cancer concerns, current available data resources and statistical approaches have many limitations when used to address cancer concerns. These limitations will be discussed. Tools to examine data in smaller-than-county-level geographies are becoming more available. They can be used broadly to educate the public about cancer occurrence and clustering effects. In this sense, cancer concerns intersect with health communications, and registries must continue to monitor and address this important aspect of our responsibilities.



Developing a New Tool for Cancer Registries to Detect Cancer Hot Spots for Small Geographic Areas

***Sarah Nash**¹, Dr. Grant Brown¹, Dr. Emily Roberts¹, Mr Jacob Clark¹, Ms. Carly Mahoney¹, Ms. Erin Wissler Gerdes¹, Dr. Caglar Koylu¹, Dr. Mary Charlton¹, Dr. Brittany McKelvey², Dr. Charles Wiggins³, Angela Meisner³, Bin Huang⁴, Dr. Jay Christian⁴, Dr Jacob Oleson¹
¹University of Iowa, Iowa City, United States, ²Friends of Cancer Research, Washington, United States, ³University of New Mexico, Albuquerque, United States, ⁴University of Kentucky, Lexington, United States*

Background

Central cancer registries are often asked to analyze, interpret, and present cancer data (rates, counts) for sub-state geographic areas, and to identify hot spots for cancer risk in their states. Yet, it is challenging to calculate reliable cancer rates for geographic areas with small case counts and populations (e.g., townships, rural counties) because computing rate and risk estimates in this context often results in unstable measures and large standard errors.

Methods

We developed a software tool that provides estimates of age-adjusted cancer rates and cancer risk in geographic regions with small case counts and populations (e.g., Zip Code Tabulation Areas). The tool implements a Bayesian hierarchical model that borrows strength from neighboring areas and over time to produce reliable estimates for such small areas. The estimated rates include both incidence and mortality for eight common cancers. Our methodology also identifies areas with significant clusters of high and low cancer prevalence. We began by examining data for Iowa, and have extended this work through collaboration with the New Mexico Tumor Registry and the Kentucky Cancer Registry.

Results

Age-adjusted cancer rates generated by the model, as well as probability of elevated risk, are displayed in interactive maps accessible for free on the web. Our interactive visualization tools allow users to switch between these various maps depending on the type of data they wish to view. In this presentation, we will demonstrate the mapping tool and highlight its potential use for central cancer registries and beyond.

Conclusion

Ultimately, these maps allow users to compare risk for cancer where they live to other cities in the state and identify areas with high risk that may require interventions. We are planning to make this tool more broadly accessible to central cancer registries, especially those with challenges visualizing data with small case counts, such as rural or frontier areas.

Mesothelioma Incidence by State and Sub-State Geography, United States 2001-2020

Jane Henley¹, Dr. Angela Werner, Dr. David Blackley, Mary Elizabeth O'Neil, Mr. Aaron Vinson, Mr. Theodore Larson, Reda Wilson, Mr. Constantine Katsoudas, Dr. Manxia Wu
¹CDC, Atlanta, USA

Background

Mesothelioma is rare with fewer than 3,000 cases reported each year in the United States. Exposure to asbestos causes most cases of mesothelioma. A state-level analysis that aggregates areas with higher and lower asbestos exposures may mask disparities within the state. A county-level analysis may suppress areas with high asbestos exposure but population too sparse to calculate reliable rates. Analysis with spatio-temporal aggregation would allow a comprehensive, nationwide snapshot of mesothelioma incidence.

Purpose

We examined differences in malignant mesothelioma incidence at state and sub-state levels in the United States.

Methods

We used high-quality U.S. Cancer Statistics county-level incidence data from 44 states and the District of Columbia. We defined mesothelioma by ICD-O-3 histology codes 9050–9055. We calculated age-adjusted mesothelioma rates using counts and populations aggregated over time and across space. Data from 2001–2020 were aggregated into one time period. State-level rates were calculated, then geographic areas were aggregated to counties, or if counties had less than 50,000 annual population, counties were grouped to a combined minimum 50,000 population, using standardized 50K geographies recently developed by CDC's National Environmental Public Health Tracking Program. Rates were suppressed if counts <6.

Results

The overall age-adjusted mesothelioma incidence during 2001–2020 was 0.94 per 100,000 standard population, ranging 3-fold by state from 0.47 to 1.48, and varying even more by sub-state area from 0.20 to 4.07. Before spatial aggregation, data from about half of counties in the analysis would have been suppressed.

Conclusion

Using newly developed sub-state areas, we were able to assess incidence of a rare cancer, mesothelioma, within states, and observed substantial variation, potentially reflecting differential asbestos exposure. Asbestos is still imported and used in some consumer products and in certain industries, may be in imported goods, is present in some older homes and buildings, and there is ambient pollution from industrial sources. Ensuring that people are protected from exposure to asbestos in their workplaces, homes, schools, and communities may reduce future risk of mesothelioma. Improving industry and occupation data collected as part of cancer reporting may be able to identify high-risk jobs where prevention efforts can be focused.

Proactive Cancer Cluster Monitoring: Now What?

***Christopher Johnson**¹, **Bozena Morawski**¹, **Ms. Srijana Mainali**², **Randi Rycroft**¹*

¹Cancer Data Registry Of Idaho, Boise, USA, ²Boise State University, Boise, USA

Background

Pursuant to the Frank R. Lautenberg Chemical Safety For The 21st Century Act, effective December 2016, the Centers for Disease Control and Prevention (CDC) and the Agency for Toxic Substances and Disease Registry (ATSDR) released updated “Guidelines for Examining Unusual Patterns of Cancer and Environmental Concerns” in 2022. These guidelines “encourage proactive evaluation of cancer registry data to monitor cancer trends and identify unusual patterns.” If a cluster is proactively detected, the guidelines point to next steps, including “examining other potential risk factors,” but do not provide detailed guidance on how to do this.

Purpose

To demonstrate Idaho’s semi-automated proactive cancer cluster detection methods and next steps using multivariable adjustment for risk factors.

Methods

We analyzed 10 years of cancer incidence data in SaTScan to detect statistically significant spatial clustering at the census tract level in Idaho. Separate analyses were conducted for each of 24 primary site categories. We further analyzed high and low clusters with multilevel models to understand cancer incidence patterns while adjusting for biologically plausible risk factors. Risk factors considered varied by primary site, but may have included county-level screening behaviors, smoking prevalence, county- and tract-level social measures, and environmental risk factors.

Results

The proactive assessment of 2012-2021 cancer incidence revealed high and low clustering by census tract for several cancer sites. For example, SaTScan detected statistically significant clustering of colorectal cancer incidence: one high ($p < 0.001$) and one low ($p < .001$) cluster. Spatial clustering of colorectal cancer incidence was attenuated by adjustment for area-based screening, physical activity and obesity risk factors, and social measures in multilevel models ($p > 0.07$). The presentation will cover additional cancer sites.

Conclusion

If a jurisdiction decides to conduct proactive cancer cluster surveillance, it is important to adjust for risk factors. Using statistical analyses that include area-based covariates will help jurisdictions explain the patterns that they are seeing and communicate findings to public health partners and other interested parties.

Concurrent 4.D – Impact of Natural Disasters

Thursday, June 27th

9:00am – 10:30am

Changes in Cancer Diagnosis in Alaska Native People During the First Year of the Covid-19 Pandemic

Elena Roik¹, Keri Miller¹, Garrett Zimpelman¹, Renee Corvalan¹, Dr. Julia Morris¹

¹ANTHC, Alaska Native Epidemiology Center, Anchorage, United States

Background

COVID-19 pandemic reduced the number of cancer diagnostic procedures and delayed cancer diagnoses worldwide, resulting in decreased numbers of newly diagnosed cancer cases in 2020. Nationwide changes in access to care at the beginning of the pandemic were intended to slow the spread of SARS-CoV-2. Some changes were self-imposed while others were the result of policy decisions made at national, state, local, and facility levels. The impact of the COVID-19 pandemic on the number and distribution of cancer diagnosis captured in the Alaska Native Cancer Registry (ANTR) has not been determined.

Purpose

We aimed to examine and report changes in the number of cancer diagnoses, age, and stage distribution in Alaska Native people during the first year of the COVID-19 pandemic.

Methods

In this cross-sectional study, we examined all cancer cases added to the ANTR in the years 2015-2019 leading up to the pandemic and compared it to the year 2020, which represents the first full year of US involvement. Monthly counts, sex, and stage distribution were calculated for all cancers combined using T-test, and Chi-Square.

Results

The most common cancer sites captured by the ANTR from 2015 to 2020 were breast, colorectal cancer, lung, prostate, and kidney cancer. Though we observed fluctuations in the number of average monthly diagnosis during 2020. There were no statistically significant structural change/decrease in the number of average cases monthly diagnosed during the first year of COVID-19 pandemic compared with previous years' trend (46.8 vs 44.1 $p=0.942$). There was no statistically significant differences in average monthly cancer diagnoses between the two study periods for males (21.0 and 20.8; $p= 0.870$) and females (26.2 and 25.1; $p= 0.943$). Changes in the stage distribution for all cancer during the two study periods were not significant ($p=0.361$)

Conclusion

Though we did not find any significant changes in the short-term, we believe it is crucial to commit to long-term monitoring of the pandemic effect on survival, and mortality.

Lung Cancer Incidence, 2019–2020, United States: The Impact of the COVID-19 Pandemic

Christine M. Kava, David A. Siegel, Susan A. Sabatino, Jin Qin, Thomas B. Richards, Jane Henley

¹Centers for Disease Control and Prevention, Atlanta, USA

Background

Recent reports have shown a decrease in lung cancer incidence rates from 2019 to 2020. Delays in screening and diagnosis due to the COVID-19 pandemic might have contributed to these decreases. Most studies to date have focused on changes in lung cancer incidence among a limited number of subgroups.

Purpose

Describe and compare lung cancer incidence in 2019 and 2020 to better understand the impact of the COVID-19 pandemic on changes in incidence.

Methods

We used 2019–2020 United States Cancer Statistics data from 49 cancer registries covering 97% of the US population. Our analysis included patients diagnosed with lung and bronchus cancer. We calculated the number of new lung cancer diagnoses in 2019 and 2020, age-adjusted lung cancer incidence rates per 100,000 persons, and 2019-to-2020 percentage changes in incidence rates. We calculated number and percentage of new lung cancer diagnoses by month and stage at diagnosis.

Results

Of 370,051 reported lung cancer diagnoses, age-adjusted lung cancer incidence rates decreased from 2019 (47.9) to 2020 (41.4)—a 13.6% decrease. Differences in the 2019-to-2020 percentage decrease in rates were observed by age, race and ethnicity, US census region, histology, stage at diagnosis, and receipt of surgery. Patients with the largest incidence rate decreases were ages ≥ 85 years (-17.8%); non-Hispanic Asian or Pacific Islander (-17.6%); in the West US census region (-15.0%); had non-small cell carcinoma (-14.0%); diagnosed at unknown stage (-26.2%); or had an unknown surgery status (-18.2%). For all months except February, the number of new diagnoses was larger in 2019 vs. 2020. Differences were largest in March, April, and May. A higher percentage of patients were diagnosed at distant stage in 2020.

Conclusion

Observed lung cancer incidence rates decreased from 2019 to 2020, overall and across all subgroups examined. The overall percentage decrease (13.6%) was larger than decreases observed between 2016-2019 (<5%). Health care challenges during the first year of the COVID-19 pandemic may have contributed to decreases in diagnosis of incident cases. Continued efforts to monitor trends in health care delivery and lung cancer incidence could increase our understanding of how the COVID-19 pandemic impacted lung cancer screening, diagnosis, and treatment outcomes.

Assessing NPCR 36-month and 24-month Case Counts before and after the COVID-19 Pandemic

Suzanne Bock¹, Jane Henley¹, Mary Elizabeth O'Neil¹, Dr. Manxia Wu¹

¹CDC, Atlanta, United States

Background

Beginning in March 2020, the COVID-19 pandemic disrupted cancer screening, diagnosis, and patient access to medical care. Some cancer registries' operations were also impacted, which may have increased reporting delays. Prior publications indicate the number of reported cancer cases to CDC's National Program of Cancer Registries in diagnostic year 2020 were lower than expected.

Purpose

To assess differences in cancer cases for diagnostic year 2020 reported to NPCR within 24 months and 36 months of diagnosis.

Methods

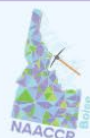
Percentage change was used to compare the number of cases diagnosed in 2020 from the 2022 (24 month) and 2023 (36 month) NPCR data submissions for common cancer sites and by selected variables such as sex, race, age, stage, reporting source, diagnostic confirmation, and jurisdiction. Additionally, percentage change for cases diagnosed in 2019 from 2021 and 2022 NPCR data submissions was used for comparisons.

Results

Based on preliminary 2023-submission data, cases diagnosed in 2020 (36-month) increased 2.9% compared to the 24-month data. By jurisdiction, the percent change ranged from -0.2% to 12.2%. The analysis will be updated when final 2023-submission data are available. For 2019-diagnoses, cancer cases increased 3.2% in the 2022-submission (1,993,323) compared to the 2021-submission (1,931,450). This percentage change varied by cancer site and other characteristics. The percentage change by most common cancer sites ranged from 1.5% in breast cancer to 5.1% in leukemias. By jurisdiction, the percent change ranged from -0.7% to 5.3%. Examining cases by reporting source, the percentage change ranged from 5.5% for laboratory reporting to 60% for nursing/convalescence/hospice reporting.

Conclusion

Cancer registries regularly experience delays in reporting, as evidenced in our analysis by the 3.2% increase in 2019 cancer cases after 12 additional months of reporting. Our analysis found a smaller increase (2.9%) in 2020 cancer cases after 12 additional months of reporting, suggesting that the previously observed decreases in cancer diagnoses in 2020 may be due to fewer cancer cases being diagnosed, rather than to longer delays in reporting. By using NPCR and U.S. Cancer Statistics data, evaluation of the COVID-19 pandemic's impact on cancer registry operations and longer-term cancer outcomes can be evaluated.



Where are Cancer Survivors Contending with High Levels of Climate Change-Related Hazards?

Bian Liu¹, Dr. Perry Sheffield¹, Dr. Nihal Mohamed¹, Dr. Furrina Lee², Dr. Hannah Thompson¹

¹Icahn School of Medicine at Mount Sinai, New York, United States, ²New York State Department of Health, Menands, United States

Background

Early detection and improved clinical management contribute to higher survival rates across most cancer types. However, survivors can be at increased risk for physical and physiological deficits after their diagnoses. Climate change, through increased frequency and intensity of natural disasters and extreme weather as well as prolonged periods of poor air quality, may impact cancer survivors by disrupting healthcare access, treatment, and daily activities, as well as increasing mental stresses and harmful environmental exposures.

Purpose

To identify areas with co-occurring heightened cancer prevalence and risks to climate-related hazards.

Methods

Age-adjusted cancer prevalence – as a proxy for survivorship - for four major cancers (lung, breast, colorectal, and prostate) among Medicare fee-for-service beneficiaries in 2022 was obtained using the public-use data from the CMS. Risk index score for natural hazard was from the FEMA. We examined county-level spatial correlations between cancer prevalence and risk scores using Lee's L statistics, which integrates the correlation between two variables and their bivariate spatial dependence. Statistical significance was determined by using 999 permutations across 3,108 contiguous US counties and adjusting for multiple testing.

Results

The average cancer prevalence was 10% (SD 1.2%). Based on percentile rankings, 47.8% of the counties (n=1,486) had a hazard risk rating of very low, 35% (n=1,087) as relatively low, 12.6% (n=392) as relatively moderate, 4.1% (n=128) as relatively high, and the remaining 0.5% (n=15) as very high. The mean of Lee's L was 0.24 (SD 0.70, ranging from -2.6 to 4.9), and 27.8% (n=537) of the counties had significant spatial correlations between cancer prevalence and hazard risks. We identified 215 counties with significantly high correlations between cancer and hazard risks. Most of them were located along coastlines, specifically the Atlantic and Gulf of Mexico, and some pockets around the Great Lakes region.

Conclusion

Overall, we found moderate spatial correlations between cancer prevalence and risk to natural hazards, with substantial variations across US counties based on Lee's L statistic distributions. The spatial co-patterning between high cancer prevalence and high climate-hazard risks can help identify communities needing preparation and recovery strategies to support areas with higher health vulnerabilities related to cancer survivorship.

Concurrent 4.E – Studies of Cancer Subgroups and Risk Factors

Thursday, June 27th
9:00am – 10:30am

Hepatocellular Carcinoma Etiology Drives Survival Outcomes: A Population-Based Analysis

Hannah Cranford¹, Dr. Patricia D. Jones^{2,4}, Qinran Liu¹, Dr. Tulay Koru-sengul^{3,4}, Dr. Isildinha Reis^{3,4}, Paulo Pinheiro^{1,4}

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Background

Previous studies on survival differences according to etiology of hepatocellular carcinoma (HCC) (5-year observed survival of 23%) are limited to hospital-based series and restricted cohorts.

Purpose

We performed a population-based survival analysis by major HCC etiologies, inclusive of hepatitis-C virus (HCV), hepatitis-B virus (HBV), alcohol-related liver disease (ALD), and non-alcoholic fatty liver disease (NAFLD) as singular causes, in addition to unexplored dual etiological groups, (HCV&HBV, HCV&ALD, and HBV&ALD), and accounting for age at diagnosis, tumor characteristics, and socio-demographics.

Methods

All 19,956 cases of HCC diagnosed in Florida during 2005–2018 from the Florida Cancer Data System (FCDS) were linked for HCC etiology using Agency for Healthcare Administration and Florida Department of Health viral hepatitis data. Survival analysis was performed for the 15,759 linked HCC cases, comparing HCC etiologic groups (4 single and 3 dual). Results included age-adjusted 5-year survival, Kaplan-Meier curves, and adjusted hazard ratios from Cox regression models.

Results

The leading single etiology was 'HCV only' (n=4,983; 31.6%); the leading dual etiology was 'HCV&ALD' (n=2,694; 17.1%). The age-adjusted 5-year survival was low (<22%) across all HCC etiologies; however, non-ALD causes showed higher survival ['HCV only' (21.5%; 95%CI:20.2%–22.8%), 'HBV only' (20.2%; 95%CI:16.6%–23.9%), 'NAFLD only' (19.9%; 95%CI:18.7%–21.2%)] than ALD-related etiologies ['ALD only' (14.4%; 95%CI:12.7%–16.0%), 'HCV&ALD' (10.4%; 95%CI:9.0%–11.9%), 'HBV&ALD' (8.1%; 95%CI:2.2%–14.1%)]. Compared to the reference category 'HCV only,' age-adjusted hazard ratios were 1.69 (95%CI: 1.41–2.03; p-value<0.0001) for 'HBV&ALD,' 1.33 (95%CI:1.26–1.40; p-value<0.0001) for 'HCV&ALD,' and 1.35 (95%CI:1.28–1.43; p-value<0.0001) for 'ALD only.' Multivariable analysis including additional factors showed minimal variation from these results.

Conclusion

Significant differences in survival based on HCC etiology are important for prevention, surveillance, and targeted treatments based on etiologic-specific biomarkers. Specific pathophysiological mechanisms for ALD in addition to viral hepatitis could be responsible for poorer outcomes for dual etiologies involving alcohol use, compared to viral etiology alone. To increase overall survival, improved screening is needed for patients with multiple HCC risk factors.

Breast Cancer Subtype by Race/Ethnicity, Age, and Stage among Texas Women

Keisha Musonda¹, Paige Miller¹, Erin Gardner¹, Cindy Dorsey, ODS-C¹, Dr. Natalie Archer¹
¹Texas Cancer Registry, Austin, USA

Background

Breast cancer is the most common cancer among women in Texas, with an estimated 20,300 cases diagnosed annually. Molecular subtyping research has significantly advanced understanding of breast cancer carcinogenesis. Since 2010, results from molecular testing have been collected by population-based cancer registries such as the Texas Cancer Registry (TCR), allowing for examination of differences in disease progression, prognosis, and survival. Because of its diverse and growing population, Texas data allow for a comprehensive investigation into the role of race/ethnicity and age on incidence of breast cancer by molecular subtype.

Purpose

We aimed to (1) assess the availability of breast cancer molecular subtype data within TCR and (2) if sufficiently available, characterize the distribution of molecular subtypes among Texas women by race/ethnicity, age, and stage at diagnosis.

Methods

Invasive female breast cancer cases diagnosed between 2018 and 2021 (n=75,180) were examined using TCR data, excluding cases reported only from autopsy or death certificates. Cancers were categorized into molecular subtypes using HR/HER2 status: luminal A (HR+/HER2-), luminal B (HR+/HER2+), HER2-enriched (HR-/HER2+), and triple-negative (HR-/HER2-). Using SEER*Stat, we calculated incidence rates per 100,000 women and age-adjusted to the 2000 US standard population for each subtype. Rates were stratified by race/ethnicity, tumor stage, and age at diagnosis.

Results

Preliminary analyses showed that only 9% of cases could not be classified due to incomplete ER, PR, or HER2 status information. Luminal A was the most common subtype, accounting for 67.2% of cases (79.4 cases per 100,000 population), followed by triple-negative (13.9/100,000), luminal B (10.6/100,000), and HER2-enriched (4.4/100,000). Non-Hispanic (NH) White women had the highest rates of luminal A and luminal B subtypes, whereas NH Black women had the highest rate of triple-negative breast cancer. Women less than 34 years had a higher percentage of triple-negative subtype (21.5%) compared to other age groups. All four subtypes were most common at the local stage.

Conclusion

Preliminary results show breast cancer subtype distributions among Texas women differ by race/ethnicity and age group. Future investigations into breast cancer survival by subtype are warranted and would support the development of targeted screening and prevention strategies in Texas.

Long-Term Impact of a Restrictive Tobacco Use Hiring Policy in Florida Firefighters

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Background

Tobacco restriction policies can have an important impact on smoking rates and, subsequently, on cancer risk. This analysis documents firefighter smoking rates following a 1989 policy in Florida prohibiting the hiring of firefighters who used tobacco products. It also examines trends in tobacco-associated cancer incidence rates in firefighters compared with trends for all Floridians.

Methods

Florida firefighter employment and certification records were linked with State cancer registry data (1982-2014), including tobacco use at the time of cancer diagnosis. Non-tobacco-associated cancers were extracted for the state of Florida cancer cases and for Florida firefighters; smoking point prevalence in five-year periods was calculated and compared with statewide trends. Trends in the rates of tobacco-associated cancers were calculated for these groups using Joinpoint. Current smoking rates in Florida firefighters were estimated and compared to other workers using Behavioral Risk Factor Surveillance System data pooled over the years 2013, 2015, 2016, and 2017. We hypothesized that smoking rates would decrease more rapidly among firefighters than the general population and that recent smoking rates in Florida would be lower in Florida firefighters than in other broad categories of workers. We also hypothesized that the incidence of tobacco-associated cancers in firefighters would show evidence of decline after a lag of 5-15 years after policy implementation.

Results

Smoking rates for Florida firefighters with cancer were initially ten percentage points higher than statewide cases (1981-1985); more recent rates (2011-2014) were slightly lower in firefighters, indicating steeper declines in smoking rates (group*time interaction=0.92; 95% Confidence Interval=0.86-0.98; p-value=0.0152). The estimated smoking rate in Florida firefighters based on BRFSS data is markedly lower than non-firefighters versus other workers (1.8% [0.0-3.5] versus 16.7% [15.8-17.5]). There was a non-significant annual increase in tobacco-associated cancers among Florida firefighters in the years 1982-1994, followed by a significant annual decrease of 1.95% from 1995-2014. In contrast, rates for Floridians were stable in the years 1982-1990 followed by significant declines in subsequent time periods: (-0.80 [1991-1999]; -2.65 [1990-2007]; and -1.08 [2007-2014]).

Conclusion

Implementation of a restrictive tobacco use policy targeting Florida firefighters may have contributed to lowered smoking rates, ultimately reducing the incidence of tobacco-associated cancer in these workers.



Body Mass Index, Stage at Diagnosis and Survival among Colorectal Cancer Patients

Qian Lj^{1,2}, Theresa Keegan¹, Frances Maguire¹, Ann Brunson¹, Dr Theresa H.M. Keegan^{1,2}, Brenda M. Hofer¹

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Background

Overweight and obesity, measured by body mass index (BMI), are associated with a higher risk of colorectal cancer (CRC). However, at the population-level, little is known about the association between BMI and stage at diagnosis, and studies considering the association between BMI and survival have been inconsistent.

Purpose

To examine the association between BMI, stage at diagnosis and CRC-specific survival.

Methods

Patients diagnosed with first primary CRC from 2014-2019 were identified in the California Cancer Registry and classified as underweight (<18.5 kg/m²), normal (18.5-24.9), overweight (25-29.9), obese (30-39.9), severely obese (>40) or unknown. Due to the high proportion of missing BMI (38.8%), a multivariate imputation by fully conditional specification methods was performed. Multivariate logistic regression assessed associations of BMI and late (III, IV) vs. early (0, I, II) AJCC stage at diagnosis. Multivariable Cox proportional hazards regression examined the associations of BMI with CRC-specific survival. Both methods adjusted for sociodemographic and clinical factors. Deaths from other causes were considered as competing risks.

Results

Of 68,848 patients (median age 65 years), 2.5% were underweight, 21.9% normal weight, 20.0% overweight, 14.1% obese, and 2.6% severely obese. Patients with missing BMI were more likely to be non-Hispanic Black (45.1%), reside in the lowest socioeconomic status neighborhoods (40.9%), and have early-stage disease (45.6%). In multivariable models, underweight (vs. normal) patients had lower odds of being diagnosed with late stage (odds ratio (OR)=0.69, 95% confidence interval (CI) 0.62-0.76) and obese (OR=1.12, CI 1.07-1.17) or severely obese (OR=1.19, CI: 1.08-1.31) patients had higher odds of late stage. Compared to normal weight, underweight patients had worse CRC-specific survival (hazard ratio (HR)=1.17, CI 1.09-1.27), whereas overweight (HR=0.89, CI 0.86-0.93), obese (HR=0.87, CI 0.83-0.91), and severely obese (HR=0.88, CI 0.81-0.97) patients experienced better CRC-specific survival.

Conclusion

Our findings are consistent with recent studies that observed the obesity paradox, with overweight, obese, and severely obese (vs. normal weight) patients having better survival. Despite being more likely to have advanced stage disease. Worse CRC-specific survival we observed among underweight patients may relate to pre-diagnosis weight loss. Future studies are warranted to better understand these findings.

Concurrent 5.A – Improvements in Data Quality Processes

Thursday, June 27th

11:00am – 12:30am

Evaluating, Monitoring, and Improving Hospital Reporting Timeliness in Ohio

*Kaitlin Kruger*¹, *Mrs. Emily Bunt*¹

¹*Ohio Department Of Health, Columbus, USA*

Background

In Summer 2023, NPCR announced it would re-institute the 12-month Advanced National Data Quality Program Standards in 2024. As a result of this change, we needed to evaluate our current practices and procedures to determine how to encourage more timely reporting in Ohio.

State law requires data to be reported within six months of diagnosis or first contact; however, our hospitals experience many challenges to reporting within that timeframe. As the central registry, we need to learn what these barriers are, hold our hospitals accountable, and serve as a resource to improve hospital reporting timeliness.

Purpose

Leveraging a NAACCR Tip sheet (<https://www.naacccr.org/wp-content/uploads/2022/02/Facility-completeness.pdf>), we developed a “canned” report to share quarterly with hospitals. This presentation will cover how the report was generated, its intended uses, and steps to understand and improve hospital timeliness.

Methods

OCISS developed the report template using SQL queries and MS Excel. For all hospitals, the report shows the completeness and timeliness of hospital data submitted by quarter. An indicator shows whether hospitals are on track to submit their 12-month data within the expected timeframe.

Results

We gathered input from our advisory committee and incorporated their feedback into the template. We shared the report with our 145 hospitals each quarter. In our communication, we stress the importance of reporting their data faster and asked for feedback on challenges and facilitators to timely reporting. Hospital feedback indicates the report is a resource to their registry and administration in addressing the barriers to timely reporting.

Conclusion

This report allows us to monitor the completeness and timeliness for our 12-month data without having to run individual reports for each hospital. Other steps we have taken to monitor, evaluate, and improve our reporting timeliness include implementation of modified record reporting, one-on-one meetings with high volume hospitals to discuss timeliness challenges and barriers, and facilitating a discussion with our advisory committee to better understand these barriers to reporting within 6-month of diagnosis or contact.

Overview of 2023-2028 CDC's National Program of Cancer Registries Data Quality Evaluation

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³National Cancer Registrars Association, Alexandria, United States, ⁴Westat, Rockville, United States

Background

CDC's National Program of Cancer Registries (NPCR) serves as one of the cornerstones for monitoring cancer burden and measuring progress toward cancer prevention and control activities in the United States. High quality data are critical to the success of these efforts. NPCR conducts Data Quality Evaluations (DQE) annually to its funded Central Cancer Registries (CCRs) as part of its data quality control activities. CDC has a five-year contract with Westat, Inc to assess and improve data quality.

Purpose

To inform NPCR-funded cancer registries in preparation for the new DQE cycle.

Methods

The new DQE cycle has five components: 1) Data Quality Assurance and Evaluation Plan Guidance for CCRs; 2) Online Validation Reconsolidation Tool; 3) validation of record consolidation at the tumor level and treatment data items of selected cancer sites; 4) validation of treatment agents coded as chemotherapy, hormone therapy, and biological response modifier (BRM); and 5) evaluation of the accuracy of applying Solid Tumor Rules for malignant brain and central nervous system (CNS) sites.

Results

We will provide an overview of the newly five planned DQE activities. A status update of the Data Quality Assurance and Evaluation Plan Guidance will be provided, including the data quality life cycle, components of cancer data quality, and data quality activities. We will discuss enhancements made to the Online Validation Reconsolidation Tool, which will be available for interested NPCR-funded CCRs. We will share validation results of selected data items across leukemias, lymphomas, multiple myeloid, and non-malignant brain tumors from 12 participating CCRs.

Conclusion

Participants will increase their knowledge about the Data Quality Assurance and Evaluation Plan Guidance as they prepare for its distribution. Discussions on the Online Validation Reconsolidation Tool could be used to decide if CCRs would like to implement it for internal evaluations. Validation results could be used to facilitate additional training activities for data quality.

NPCR-CSS Pre-Edits Evaluation and Process Improvements

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Background

To improve the robustness of CDC's NPCR data submission files' quality checks, we implemented a process improvement project to enhance the Pre-Edits Verification Program, to determine if a data file can be accepted as submitted or if a resubmission is needed. The current program required visual review of a minimum of nine reports for each submission file. Several reports did not provide sufficient detailed information to correctly identify data quality issues. The goals of the process improvements were to streamline data quality evaluations, expand automation and data quality checks, and enhance output reporting. This would improve efficiencies and increase the ability to identify and address issues earlier in the submission review process.

Purpose

Describe processes to streamline data quality evaluations.

Methods

All output reports and summaries generated by the 2022 NPCR-CSS submission Pre-Edits Verification Program were reviewed to identify evaluation parameters, additional data evaluation needs, and improvements to output reports and summaries. Data evaluation specifications for specific cancer sites and time periods were created. Specific data items were also identified as critical for evaluation across diagnosis years and code values for the current and previous year's NPCR-CSS submission. Data visualization tools were reviewed to identify the best method to display and easily review output.

Results

The data evaluation specifications document provides streamlined parameters like evaluations identifying missing or significant changes in values for the hormone receptor data items that are limited to the breast schema and appropriate diagnosis years. A minimum of nine reports were consolidated into two reports for each CCR. NPCR staff can view all critical data items for each CCR on the NPCR-CSS Monitoring Database and can select individual items to review in more detail. Additional stratification is available by threshold levels and diagnosis year.

Conclusion

The process improvement evaluation identified ways the Pre-edits Verification Program could be more efficient and effective by (1) reducing staff time to perform reviews and (2) correctly identifying issues requiring additional information from the CCR. The enhancements were successfully deployed with the 2023 submission. NPCR-CSS will continue to identify and implement processes to streamline and improve the Program.

Leveraging Social Media and Network Analysis for Complementing Information from Central Cancer Registries

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Background

Central Cancer Registries (CCRs) are pivotal in the fight against cancer, providing accurate and comprehensive data essential for cancer control and epidemiological research. Despite the transformative impact of web and social media platforms on healthcare outreach, a centralized effort integrating these tools into CCRs is lacking.

Purpose

This study primarily explored the untapped potential of leveraging social media and web presence for Central Cancer Registries, focusing on the impact of these platforms on cancer. We identify how data from Cancer Registries can be complemented by information from social media channels.

Methods

Our approach involved the development of a dashboard and search mechanism to analyze real-time state-name-wise cancer trends. Qualitative analysis of posts from users in California, Missouri, Minnesota, Alabama, and Maryland, categorized by cancer-related topics, is complemented by quantitative analysis of comorbidities conversations during COVID-19 pandemic.

Results

We showcase the outcomes of our qualitative and quantitative analyses emphasizing the importance of state-wise categorization and the prevalence of comorbidity discussions on social media. Social Network Analysis reveals key insights from 12,030 users and 19,497 tweets in August, with cancer, diabetes, and obesity emerging as prominent themes. Our dynamic dashboard includes websites, social media channels (Threads, Reddit, Facebook, X, YouTube), and live links associated with cancer and COVID-19 conversations across 50 US states in real time. Using cancer terms, our study used social network analysis to create state-wise sociograms, providing nuanced insights into population health via exploration of cancer-related interactions.

Conclusion

This approach allows for a holistic view of ongoing discussions and facilitates immediate state wise trend analysis on various platforms. This research underscores the potential of social media and web presence in reinforcing the impact of Central Cancer Registries. By harnessing these platforms, we aim to contribute to the Cancer Care Continuum, providing valuable insights that complement traditional health records and influence health behaviors as intervention tools.

Concurrent 5.B – IT Solutions in Registry Operations

Thursday, June 27th

11:00am – 12:30am

Successful Conversion of Cancer Registry Data

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Background

Accurate conversion of cancer data is a crucial task required to update information previously collected to meet current cancer surveillance reporting standards. Through conversion, researchers can analyze cancer surveillance data over time in a meaningful manner. Data conversion has a widespread impact across the cancer registry community as cancer reporting software and cancer databases need to be modified for cancer data to be converted and transmitted in a standardized manner. Communication is one of the most important components for assessing conversion requirements and disseminating precise conversion specifications.

Purpose

To describe the data conversion process, to explain the reasons for conversion of cancer data, to illustrate how conversion specifications are evaluated and analyzed, and to review challenges and lessons learned.

Methods

An overview of data conversion will be provided including steps for gathering conversion requirements, evaluating conversion specifications for accuracy and validity, updating and testing the Registry Plus NorthCon utility program in coordination with the NAACCR Edit Metafile, and implementing conversion instructions.

Results

Representatives involved in the planning process evaluate specifications from all standard setting organizations to identify potential complications or conflicts with reporting standards and to prevent compromising the high-quality data that has been collected. All aspects of the cancer surveillance continuum are considered including impacts for vendor implementation, data collection, editing, central registry reporting, data submission, and analysis.

Conclusion

Effective implementation requires coordination among all partners to confirm all organizations are synchronized. Data conversion is very complex and necessitates a comprehensive understanding of cancer surveillance reporting standards, organization requirements, and data item dependencies. Understanding the details involved in the cancer surveillance data conversion process begins with knowing how standard setting organizations collaborate to identify data conversion needs, and how successful implementation is possible by addressing the important lessons learned.

Streamlining the Creation and Distribution of Registry Specific Customizations of Applications

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Background

The central registry community and software developers have struggled with creating customized abstracting software for end users and distributing it to them. Customizations can be extensive, and spread among local XML Dictionaries, edit metafiles, abstracting displays, local fields, and lookups. In addition, any changes or updates to these elements during mid-version release require redistribution or multi-step instructions to incorporate the updated files. The goal of the Registry Plus team was to develop utilities to easily create, export, and incorporate these customizations into a generic version of the abstracting software, thus rendering it a fully customized edition for end users, central registries, and software development teams.

Purpose

To present the various customization utilities in terms of importing established resources, incorporating new resources, and modifying the various customization elements. To demonstrate exporting the customization package, distributing the package, and incorporating the customizations into generic versions of the software. The benefits and use cases of this process will summarize the effectiveness of the utilities.

Methods

An overview of the customization management features within Abstract Plus will be provided. Explanations on how the burden of creating multiple customized versions of software is reduced, while increasing timeliness and availability to facilities that use the software, will be provided.

Results

Customization creation and testing within Abstract Plus is possible in terms of Abstracting Displays, Local Fields and Menu Lookups, XML Dictionaries, and Edit Metafiles. There were reduced burden on end users, central registries, and the software development and support team based on the exporting and importing of these customization files and the use cases in using the features.

Conclusion

More timely updates and more effective support are possible with the key features and capabilities of the specific customization process within Abstract Plus. The design of the utilities helped to demonstrate the impact of this approach.

CDA Processing: Overcoming Challenges and Implementing Solutions the Myriddian Approach

[Carol Carlson](#)¹, [Vijay Medithi](#)¹

¹*Myriddian - Maryland Cancer Registry, Baltimore, United States*

Background

The Maryland Cancer Registry grappled with significant challenges in managing a large volume of unprocessed Clinical Document Architecture (CDA) files, exceeding 100,000, characterized by high quantity but low quality. Compounded by problematic software, the process of cleaning up and abstracting these files proved to be time-consuming. Furthermore, delinquent facilities posed additional hurdles, prompting a reevaluation of reporting methods to facilitate compliance.

Purpose

The primary objective was to devise a streamlined process to sort and prioritize large volume submissions, expedite case abstraction, and efficiently rectify errors introduced by the software. If successful, the aim was to engage with delinquent facilities and offer the optimized reporting option to new reporters during onboarding.

Methods

Engagement with facilities involved identifying key contacts and involving in-house IT support where available. Collaboration with facility software vendors and NPCR Resources aimed to leverage their expertise in resolving technical issues, optimizing data quality, and encouraging low-tech support tools like copy-paste options to reduce errors and gather quality data. Prioritization of ambulatory facilities' diagnosed Dermatology, Urology, and Hematology cases as they are traditionally missed or underreported. Training initiatives focused on retrieving information from Electronic Medical Records (EMRs) and minimizing abstract efforts.

Results

The implementation of robotic processes for file management, utilizing internally developed Myriddian Quality Assessment Tool (MQAT) for Matching and sorting, alongside interim processing solutions, facilitated efficient handling and prioritization of submissions. Training and assistance from software vendors streamlined the import and processing of CDA files, although challenges persisted with certain software functionalities. The updated Exchange Plus and technological solutions enabled an independent CTR process with minimal tech support reliance, compensating for software weaknesses to ensure data integrity. This reflects years of Continuous Process Improvement, saving time and resources.

Conclusion

Despite ongoing challenges, the registry achieved notable successes in managing large volumes of data and engaging with reporting facilities. The adoption of IT solutions and collaboration with software vendors optimized data processing efficiency. However, challenges remain in maintaining quality and resolving issues with established reporters. Moving forward, continued collaboration and innovation are essential to address persisting challenges and enhance the effectiveness of electronic reporting methods within the registry.

Leveraging Data Automation to Improve Completeness, Timeliness and Accuracy of Cancer Registry Data

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¹MD Anderson Cancer Center, Missouri City, United States

Background

Oncology Data Specialists (ODS) are challenged to report accurate data in support of cancer program development and compliance with reporting standards. Consequently, data automation becomes a crucial piece of this process. Automated importation of cancer data into a database takes full advantage of electronic resources available and reduces the time and labor needed in cancer data collection.

Purpose

The purpose of this work was to reduce manual data entry by extracting and importing structured data elements automatically into a registry system. Additionally, we aimed to improve case identification and increase completeness of case reporting by improving the usage of electronic resources.

Methods

- The data was extracted from our institution's data warehouse on patients presenting between 01/01/2022 and 12/31/2022. Reportable cases were identified based on appointment data (date of first and last completed appointments), ICD- 10 billing codes, pathology data, and treatment charge data.
- Structured data elements were identified and automatically populated from information contained in an EHR and Pathology sources into the Registry system.
- Data was validated and curated manually by the ODS team before reporting.

Results

- Observed 43% of all required fields can be currently automated.
- Wide variability in discrete elements (87% demographic data; 22 % disease fields; 20% of follow-up data)
- Could accurately identify second opinions versus those who received treatment by using a treatment algorithm.
- Identification of meaningful associations between treated/non-treated patients and analytical status and variables such as treatment charges, pathology and appointment data.

Conclusion

Our analysis accurately identified second opinions as well as meaningful associations between Treatment/Analytical Status and variables such as treatment charges and appointment data.

Additionally, we concluded that almost half of the fields can be automated. This is promising, since the availability of electronic resources containing different types of patient-level variables, such as demographics, diagnoses and problem lists that can be used for data automation. We need to help bridge the gap and make use of all means for providing higher quality, more timely data, so it is critical to expand the usage of data mining in the Cancer Registry world.

Concurrent 5.C – Racial and Ethnic Disparities

Thursday, June 27th

11:00am – 12:30am

Racial/Ethnic Disparities in Non-Small Cell Lung Cancer Stage at Diagnosis: A Population-Based Study

Qinran Liu¹, Dr. Tulay Koru-sengul^{1,2}, Paulo Pinheiro^{1,2}

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Background

The prognosis of lung cancer significantly relies on accurate and timely staging. However, notable disparities in staging and outcomes among different racial/ethnic groups exist. This population-based study aims to identify factors contributing to these disparities in the stage of non-small cell lung cancer (NSCLC) diagnoses, focusing on Hispanic ethnic subgroups.

Methods

Incident cases diagnosed from 2005–2018 were extracted from the Florida State Cancer Registry. Stage was categorized as resectable (Stage I-IIIa) or nonresectable (Stage IIIB/IIIC/IV). Multivariable logistic regression models were used to assess the association between race/ethnicity and stage at diagnosis, adjusted for socioeconomic, smoking status and clinical factors. Regional stratification was further conducted (South Florida vs. Rest of Florida).

Results

Among 157,034 NSCLC patients, 81.0% were White, 8.3% Black, and 9.2% Hispanic; 43.2% were diagnosed at a resectable stage. Compared to White patients, Black patients had a 12% higher likelihood of non-resectable stage diagnosis (OR_{adj}=1.12; 95% CI: 1.11-1.14). In age-adjusted models, all Hispanic patients and their subgroups demonstrated higher odds of non-resectable stage at diagnosis compared to White patients; however, in fully adjusted models, this association was significant only for Central Americans (OR_{adj}=1.41; 95% CI: 1.35-1.47). Notably, regional differences were remarkable; Hispanic patients in South Florida showed better staging outcomes compared to those in the rest of Florida (South Florida: OR_{adj}=0.95; 95% CI: 0.94-0.97 vs. Rest of Florida: OR_{adj}=1.09; 95% CI: 1.07-1.10).

Conclusion

The study highlights significant disparities in NSCLC staging among Black and certain Hispanic groups. The marked regional differences between South Florida and the rest of the state underscore the importance of considering intra-state geographic and cultural factors in lung cancer prevention and control strategies, as well as in enhancing health access.

Insights into Race/Ethnicity and Female Breast Cancer in Canada Using Linkage-Based Population Cohorts

[Carmina Ng](#)¹

¹*Statistics Canada, Toronto, Canada*

Background

Race/ethnicity identifiers are not available in the Canadian Cancer Registry or deaths database in Canada. Breast cancer incidence and mortality patterns vary by race/ethnicity groups.

Purpose

This study describes rates of breast cancer mortality and incidence, as well as patterns of age at diagnosis, distributions of stage at diagnosis and subtypes of female breast cancer by race/ethnicity groups in Canada.

Methods

The Canadian Census Health and Environment Cohorts (CanCHECs) are linkages between the long-form Censuses or National Household Survey 2011, Canadian Cancer Registry (CCR), deaths database, and hospitalization data. Analyses included follow-up of 3.6 million women aged 20+ on census day, up to 9.6 years for cancer incidence and up to 13.6 years for mortality. Age distributions of breast cancer diagnosis, and proportions of stage at diagnosis and subtypes were explored. Age-specific incidence and mortality rates were calculated by various race/ethnicity groups.

Results

Breast cancer incidence and mortality patterns vary by race/ethnicity. Breast cancer incidence rates among Filipina women aged 40-49 and 50-59 may be higher compared to White women. Breast cancer mortality rates among Black women aged 40-49, as well as among First Nations and Métis women aged 60-69 may be higher compared to White women.

Conclusion

Linkage-based population datasets with the CCR are useful for allowing analyses of specific groups for whom differences in cancer risk patterns may exist. Small sample sizes for specific groups of interest remain a significant limitation. Updating these databases with more cohort members and years of follow-up data will further enhance the statistical power of this valuable resource.

Epidemiological Analysis of Cancer Patterns among Populations of African Descent in the United States – the Numident-Social Security Administration Project on Nativity

Paulo Pinheiro^{1,2}, *Steve Scoppa*³, *Jennifer Stevens*³, *Kathy Cronin*⁴, *Mandi Yu*⁴

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Background

Population-based cancer registry data on disaggregated non-Hispanic Black (NHB) populations as well as other detailed racial-ethnic groups often suffer from inaccuracy, incompleteness, and lack of standardization, which hampered global population comparisons and limited our understanding of cancer epidemiology. Utilizing nativity data from the SSA Numident Project, SEER has achieved over 95% of complete birthplace information. This comprehensive dataset enables detailed analysis of cancer incidence and survival within such populations. This presentation addresses key questions pertaining to the epidemiology of prostate, breast, and endometrial cancers that disproportionately affect US NHB populations, particularly those born in the US, the Caribbean and West/East Africa.

Purpose

We estimated incidence rates by detailed racial-ethnic grouping spanning the years 2010 to 2018, encompassing contributions from 15 SEER states.

Methods

Our preliminary analyses relied on denominator data derived from American Community Survey samples for assessing rates. Robust bias-corrected rate estimators as implemented in NCI's SPARC tool were used to account for sampling errors. Prostate cancer rates were stratified by stage, distinguishing between Localized and Regional/Distant stages to account for potential inflationary effects related to PSA testing intensity in different populations. We also explored prognostic factors, including PSA and Gleason scores. For female breast cancer, the analysis extended to hormonal (HR) and HER2 receptors, enabling the study of triple-negative breast cancers (TNBC) and HR+ and HER2+ types. Additionally, stratification by histology allowed for the examination of endometrial cancer type 2 (ECt2).

Results

Our study encompassed a total of 791,211 prostate cancer cases, 939,165 breast cancer cases, and 209,919 endometrial cancer cases. The disclosure of aggregate data from this study is contingent upon pending legal authorization from the Social Security Administration.

Conclusion

Our research confirms elevated incidence rates of prostate cancer, TNBC, and ECt2 among NHB populations compared to other demographic groups. These findings are contextualized in light of etiological hypotheses, considering the role of environmental factors in cancer risk, noting instances where US-born NHB rates surpass those of other groups, and genetic factors such as African genetic ancestry, which decreases from Africa to the Caribbean and is lowest among US-born NHB individuals.



Reporting Cancer Incidence Rates for Asian American, Native Hawaiian, and Pacific Islander Ethnic Populations: Overcoming Denominator Limitations

Scarlett Gomez¹, Mandi Yu², Joe Zou³, Dr. Joseph Gibbons⁴, Meg McKinley¹, Katherine Lin¹, Alison Canchola¹, Dr. Brenda Hernandez⁵, Miyagi Kohei⁵, Steve Scoppa³, Dr. Salma Shariff-Marco¹

¹University Of California, San Francisco, San Francisco, USA, ²National Cancer Institute, , , ³IMS, ⁴San Diego State University, ⁵University of Hawaii

Background

For Asian American, Native Hawaiian, and Pacific Islander (AANHPI) ethnic groups, population estimates for calculating age-standardized cancer incidence rates are provided only for decennial census years. This limits the timely reporting of rates for disaggregated groups, creating a data equity issue.

Purpose

We evaluated the feasibility of using American Community Survey data for disaggregated AANHPI ethnic groups to calculate age-standardized cancer incidence rates using SPARC, a tool that accounts for sampling errors in the denominator to produce bias-corrected rate estimators and corresponding variance estimators.

Methods

Cancer case count data for six Asian American ethnic groups – Chinese, Filipino, Japanese, Korean, South Asian, and Vietnamese - were derived for California and Hawai'i from SEER 22 for years 2016-2020. Population estimate data were derived from American Community Survey 2016-2020. The algorithm used in the SPARC tool was used to estimate age-standardized rates for the six Asian American groups. Additional AANHPI ethnic groups, including NHPI, and additional SEER22 registries will be presented at the conference.

Results

Cancer incidence rates varied substantially across the six Asian American groups, with variations between California and Hawai'i. For example, while breast is the most common cancer in all groups, incidence rates ranged from 70.3 (95% CI: 66.8-74.0) per 100,000 among Vietnamese to 114.7 (111.6-117.8) among Filipinas. Breast cancer rates were considerably higher in Hawai'i, ranging from 119.8 (78.7-182.6) among Vietnamese to 181.4 (170.5-192.9) among Japanese. Prostate cancer ranged from 30.7 (28.3-33.2) among Vietnamese to 54.3 (51.9-56.8) among Filipinos in California, and a nearly four-fold difference in Hawai'i was observed, from 43.0 (22.9-80.9) in Vietnamese to 111.2 (98.7-125.2) among Chinese. Disaggregated data revealed unique disparities, including for stomach and colorectal cancers in Korean males, thyroid and uterine cancers in Filipinas, lung and liver cancers in Vietnamese males, kidney cancer in Korean and Filipino males, and bladder cancer in Korean males.

Conclusion

Using American Cancer Survey data for cancer rate denominators, with bias-corrected rate estimators from SPARC, can be a feasible approach to overcoming denominator data unavailability for disaggregated AANHPI ethnic groups.

Concurrent 5.D – Infectious Disease

Thursday, June 27th

11:00am – 12:30am

HIV Elevates Cancer Mortality Risk More in AIDS-Defining Malignancies than Non-ADM Cases

*Xiao-Cheng Wu*¹, *Dr. Yong Yi*¹, *Mrs. Lauren Maniscalco*¹, *Dr. Qingzhao Yu*², *Dr. Mei-Chin Hsieh*¹

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Background

The concurrent presence of cancer and HIV poses distinctive challenges to oncology and HIV care providers, including management of comorbid conditions, drug interactions and side effects, and care services. While research has suggested less favorable outcomes for HIV-associated cancers, there is an absence of recent information addressing this concern within Louisiana, which has higher incidence rates of HIV and cancer in the United States.

Purpose

This study aimed to assess disparities in the risk of overall death (OD) for cancer patients with and without HIV by AIDS-Defining Malignancy (ADM) and non-ADM.

Methods

Invasive cancer cases diagnosed between 1995 and 2021 among Louisiana residents from the Louisiana Tumor Registry were linked with the state STD/HIV registry. The sociodemographic and clinical differences were compared between cancer patients with HIV-infection (HIV-Ca) and those without HIV infection (Ca). The association of HIV with the risk of OD was, stratified by ADM and non-ADM, examined using Cox proportional hazards regression models.

Results

Of 489,708 cancer patients, 3,201 were identified as HIV-Ca (0.65%). Compared to cancer patients without HIV (Ca), those with HIV-Ca were more likely to be black, male, Medicaid-insured, under age 50, in high poverty, ADM, and with advanced stage. Overall, HIV-Ca patients had a higher risk of death than Ca patients. After adjusting for race, sex, cancer stage, insurance, poverty, urban/rural, and cancer treatment, the risk of death was 44% higher among HIV-Ca patients compared to Ca patients among those without ADM (HR: 1.44; 95% CI 1.37-1.52), whereas the risk of death was 102% higher among HIV-Ca patients compared to Ca patients among those with ADM (HR 2.02; 95% CI 1.85-2.20).

Conclusion

The HIV-Ca patients face a higher risk of death than Ca patients. HIV infection has a more pronounced adverse impact on ADM patients than on non-ADM patients. More research is warranted to examine HIV- and cancer-care factors associated with the increased risk of death among HIV-positive ADM patients.



HIV-Associated Diffuse Large B Cell Lymphoma in the Black and White Population in South Africa 2011-2021

Carole Metekoua^{1,2}, *Dr Mazvita Muchengeti*^{1,3,4}, *Mr Yann Ruffieux*², *Ms Patricia Kellett*¹, *Prof Matthias Egger*², *Dr Eliane Rohner*², *Dr Tracey Wiggill*^{4,5}

¹National Health Laboratory Service, Johannesburg, South Africa, ²University of Bern, Bern, Switzerland, ³University of the Witwatersrand, Johannesburg, South Africa, ⁴University of Stellenbosch, Stellenbosch, South Africa, ⁵Tygerberg Hospital, Cape Town, South Africa

Background

Diffuse large B cell lymphoma (DLBCL) is HIV-associated and the most common type of non-Hodgkin lymphoma worldwide. We examined the impact of the HIV epidemic and antiretroviral therapy (ART) roll-out on incident DLBCL in South Africa (SA) by comparing characteristics and temporal trends of incident DLBCL between the Black and the White populations.

Methods

We identified DLBCL diagnosed in South Africa from 2011-2021 in the pathology-based National Cancer Registry using International Classification of Disease Oncology, 3rd Edition morphology codes. Using direct standardisation, we computed age-specific incidence rates and estimated yearly age-standardised incidence rates (ASIR). We used Joinpoint regression to estimate annual percentage changes (APC) in the ASIR of DLBCL.

Results

In South Africa, 13,560 DLBCL were diagnosed from 2011-2021; 55% (n=7410) were among men. The median age at DLBCL diagnosis was 47 years (IQR=37-59). Two-thirds of incident DLBCL occurred in Black (65% [n=8790]) and 22% in White individuals (n=3006). The incidence of DLBCL was highest among middle-aged adults in the Black population and older White people. The overall ASIR of DLBCL per 100,000 persons was 5.8 in the White and 1.8 in the Black population. The ASIR of DLBCL was higher in the White population across all calendar years. In the Black population, we noted an annual increase of 5.9% (95%CI 0.02 to 37.1) from 2011-2017 with a declining trend thereafter (APC -4.2%; 95%CI -22.8 to 3.7). Similarly, in the White population, the ASIR of DLBCL showed a yearly increase of 5.6% (95%CI 4.8 to 7.9) from 2011-2019 with a declining trend thereafter (APC -3.4%; 95%CI -8.1 to 2.4).

Conclusion

Whereas incident DLBCL in the White population mostly occurs among elderly individuals, the high DLBCL incidence rates among middle-aged Black individuals in South Africa indicate that HIV primarily drives incident DLBCL in this population. However, despite the introduction of ART in 2004, the DLBCL rates continued to increase in the Black population for more than a decade and only decreased one year after introducing the universal-test-and-treat policy in 2016. This suggests that wide coverage and timely initiation of ART are needed to reduce the DLBCL incidence in the Black population in South Africa.

Declining Incidence of Burkitt Lymphoma with Improved Antiretroviral Treatment Access in South Africa (1986 – 2021)

[Carole Metekoua](#)^{1,2}, [Dr Eliane Rohner](#)², [Mr Yann Ruffieux](#)², [Dr Mazvita Muchengeti](#)^{1,3,4}, [Dr Tracey Wiggill](#)^{4,5}

¹National Health Laboratory Service, Johannesburg, South Africa, ²University of Bern, Bern, Switzerland, ³University of Witwatersrand, Johannesburg, South Africa, ⁴University of Stellenbosch, Stellenbosch, South Africa, ⁵Tygerberg Hospital, Cape Town, South Africa

Background

Burkitt lymphoma (BL) is an aggressive B-cell non-Hodgkin lymphoma which may be HIV-associated. There is limited published data on trends of this cancer in South Africa, where HIV is highly prevalent.

Purpose

To describe the temporal trends in Burkitt lymphoma (BL) incidence in the context of the evolving HIV epidemic and antiretroviral therapy (ART) rollout in South Africa.

Methods

We analysed data of all histologically diagnosed BL (ICD-O-3 morphology codes 9687-3 and 9826-3) from the National Cancer Registry in South Africa between 1986-2021. We used direct standardisation to compute yearly age-standardised incidence rates (ASIR) stratified by sex and race, and Joinpoint regression to compute the Annual Percentage Change in the ASIR of BL over time.

Results

Over 35 years, 2,907 incident BL cases were recorded, with 55% (n=1,599) diagnosed among males. The ASIR per 100,000 persons was 0.16 overall and higher in males (0.19) than females (0.14). Between 1986-2011, the ASIR of BL in the overall study population increased yearly by 10.3% (95% Confidence Interval [CI] 8.7 to 12.0), whereas from 2011 (seven years post ART roll-out) BL had an annual decrease of 7.3% (95% CI 4.5 to 10.6). The temporal trends in ASIR of BL differed substantially by race. Among the black population, the ASIR of BL showed a yearly increase of 12.6% (95% CI 10.6 to 14.6) between 1986-2011 and a subsequent yearly decrease of 9.6% (95% CI 6.4 to 12.7) from 2011-2021. In contrast, the ASIR of BL among the white population increased yearly by 3.4% (95% CI 2.0 to 4.8) throughout the study period.

Conclusion

The temporal trends in BL incidence in South Africa reflect changes in the HIV epidemic over time, particularly among the black population which has a high HIV prevalence. The ASIR of BL increased with the spread of HIV and limited access to ART; and it decreased in recent years with increasing ART coverage. Further studies are needed to investigate the steady increase in the ASIR of BL among South Africa's white population.

Ascertainment of Hepatitis B and C Infection from Linked Data Sources for Residents of New York City Diagnosed with Liver or Intrahepatic Bile Duct Cancer

Margaret Gates Kuliszewski^{1,2}, Baozhen Qiao¹, Dr. Xiuling Zhang¹, Holly Anger³, Dr. Maria Schymura^{1,2}, Tabassum Insaf^{1,2}

¹New York State Cancer Registry, New York State Department of Health, Albany, United States, ²Department of Epidemiology and Biostatistics, University at Albany School of Public Health, Rensselaer, United States, ³Bureau of Hepatitis, HIV, and STI, New York City Department of Health and Mental Hygiene, New York, United States

Background

Chronic infection with hepatitis B or C substantially increases risk of hepatocellular carcinoma. However, central cancer registries do not routinely collect information on hepatitis diagnoses.

Purpose

We evaluated the extent to which information on hepatitis B or C diagnosis could be ascertained from linked external data sources for cancer cases reported to the New York State Cancer Registry.

Methods

We linked data for 14,747 New York City (NYC) residents diagnosed with liver or intrahepatic bile duct cancer in 2004-2018 to two data sources: 1) the NYC Viral Hepatitis Surveillance Registry, which collects information on probable and confirmed cases of hepatitis B and C from NYC laboratories, and 2) the New York Statewide Planning and Research Cooperative System (SPARCS), which captures hepatitis diagnosis codes from hospital inpatient stays and outpatient encounters. We determined whether documentation of hepatitis B or C was present in one or both data sources and used kappa statistics to measure concordance.

Results

Of the 14,747 cancer cases included in the analysis, 4,165 had documentation in either data source of hepatitis B (28.2%), 7,677 had documentation of hepatitis C (52.1%), and 9,822 had either diagnosis (66.6%). The kappa statistic was 0.64 for hepatitis B (19.0% positivity in Hepatitis Registry, 25.2% in SPARCS) and 0.73 for hepatitis C (41.0% positivity in Hepatitis Registry, 49.5% in SPARCS). The percent of any unrecorded hepatitis infection was 13.3% for the Hepatitis Registry and 6.3% for SPARCS, and discordance in hepatitis positivity was more common among individuals with age ≥ 70 years, non-U.S. birthplace, intrahepatic bile duct cancer, Hispanic ethnicity (Hepatitis Registry only), and Black race (SPARCS only).

Conclusion

These results indicate that hospital discharge data can be used to estimate hepatitis B and C diagnosis in individuals diagnosed with liver cancer. Possible reasons for discrepancies between the data sources include unavailability of diagnoses outside of NYC or incomplete reporting in the Hepatitis Registry, especially for earlier diagnosis years, and differing case inclusion criteria, as diagnoses reported in SPARCS may not have met the Hepatitis Registry's case definition. This information can be used to enrich cancer registry data for epidemiologic analyses of hepatocellular carcinoma and other cancers.

Concurrent 5.E – Special Populations: Children, Adolescents, and Young Adults

Thursday, June 27th

11:00am – 12:30am

STAR Project Develops Scalable Method to Measure NPCR-NOAH's Case Finding Results

***Christina Hiller**¹, **Mr. Richard Batson**¹, Mrs. Elaine Flores^{3,4}, Dr. Qianru Wu⁴, Ms. Kasey Diebold², Mr. David Butterworth², Mrs. Kimiko Sanders², Dr. Erin Stair², Sandy Jones², Ms. Kioka Jenkins⁵, Ms. Paulette Zinkann⁵, Veronica Boudreaux¹*

¹Tanaq Health, Anchorage, United States, ²Centers for Disease Control and Prevention (CDC/NCCDPHP/DCPC/CSB), Atlanta, United States, ³Westat, , United States, ⁴Nebraska Cancer Registry, , United States, ⁵Peers and Partners, Atlanta, United States

Background

The aim of the Childhood Cancer Survivorship, Treatment, Access, and Research (STAR) Project was to establish a robust infrastructure for the rapid reporting of childhood cancers. This project led to development of the National Program of Cancer Registries' National Oncology rapid Ascertainment Hub (NPCR-NOAH) in 2022. A pivotal milestone in this endeavor was the implementation of pilot activities on NPCR-NOAH, which highlighted the need to evaluate NPCR-NOAH's case finding (CF) performance.

Purpose

This evaluation seeks to identify holistic improvements to the CF algorithm for all data processed through NPCR-NOAH. These improvements aim to increase the accuracy of pathology reports classified as reportable or non-reportable.

Methods

A secure web application, the NPCR-NOAH CTR Observation Portal, was developed as part of a pilot study. Subject matter experts (SMEs) from the STAR Project tested and piloted the system in collaboration with the Nebraska Cancer Registry. NPCR-NOAH's case finding results were manually reviewed using the Observation Portal, which allowed SMEs to confirm that the pathology reports were correctly classified as reportable, non-reportable, or review. For reports that were incorrectly classified, SMEs identified areas for future improvement.

Results

The pilot study showed that 75% of reports were correctly classified. Of the cases that were incorrectly classified, 40% were skin cancer cases that have nuanced reportability rules and 45% of the cases were about words that suggest a case should be reported but were used in a non-cancer context. For example, NPCR-NOAH did not accurately distinguish between ALL (an abbreviation for acute lymphocytic leukemia) and "all" (the word).

Conclusion

Future directions include adapting system features to hospital cancer registries and refining reporting features encompassing facility-specific, state-specific, and aggregate data. This study aims to optimize childhood cancer CF processes and facilitate broader utilization of NPCR-NOAH in diverse public health surveillance settings.



Excess Deaths Among Childhood Cancer Survivors in the United States

Theresa Devasia¹, Mr. Ron Dewar², Dr. Nadia Howlader¹, Dr. Angela Mariotto¹

¹National Cancer Institute, Bethesda, USA, ²Nova Scotia Health Authority, Halifax, Canada

Background

Monitoring survivorship and treatment-related adverse effects is vital for childhood cancer survivors. The 5-year survival rate has traditionally served as a gauge for improvements in cancer survival, but the relevance of this measure diminishes significantly for those who have survived several years post-diagnosis. Annual excess deaths may serve as a more comprehensive measure of the long-term burden of childhood cancer.

Purpose

Our aim was to quantify excess deaths stratified by time since diagnosis (<5, 5-<10, 10-<20, and 20-<30 years) in children diagnosed with any childhood cancer (All sites), acute lymphocytic leukemia (ALL), central nervous system (CNS) tumors, or Hodgkin's lymphoma (HL) using Surveillance, Epidemiology, and End Results (SEER) program data.

Methods

Relative survival data on first primary tumors from nine SEER registries for children diagnosed ages 0 to 19 from 1975 to 2018 were used for analysis. Flexible parametric survival models were fit to each cancer site, and the predicted cumulative failure probability was estimated as (1- predicted relative survival). The sum of individual predicted probabilities up to time t represents the cumulative excess deaths, and interval estimates of excess deaths were computed as the difference between the relevant cumulative totals. US excess deaths were calculated by applying age, sex, and race-specific population weights for each year.

Results

The total numbers of excess deaths were 24,303 (ALL); 39,271 (CNS); 10,504 (HL); 162,763 (All sites). Excess deaths within 5 years of diagnosis represented 77%, 69%, and 71% of total excess deaths for ALL, CNS, and All sites. For HL, 50% of all excess deaths occurred 20-30 years post-diagnosis. For ALL and HL, excess deaths have been steadily decreasing over time for all follow-up intervals, whereas for CNS and All sites, excess deaths have been slightly increasing since 2000 due to the increase in excess deaths 20-30 years post-diagnosis.

Conclusion

Most excess deaths occur within the first 5 years following diagnosis, apart from HL. For CNS and All sites, the number of excess deaths occurring more than 20 years post-diagnosis has increased. Excess deaths stratified by time since diagnosis offer a more accurate perspective on long-term childhood cancer survivorship by quantifying the excess mortality burden.



Estimating the Burden Due to Brain and Other CNS Tumors in Adolescents and Young Adults in the United States

Mackenzie Price¹, Corey Neff^{1,2}, Carol Kruchko¹, Kristin Waite^{1,3}, Gino Cioffi^{1,3}, Brittany Cordeiro⁴, Mark Gilbert⁴, Terri Armstrong⁴, Marta Penas-Prado⁴, Jill Barnholtz-Sloan^{1,3,5}, Quinn Ostrom^{1,2}

¹Central Brain Tumor Registry of the United States/Duke University School Of Medicine, Durham, USA, ²Department of Neurosurgery, Duke University School of Medicine, Durham, USA, ³Trans Divisional Research Program (TDRP), Division of Cancer Epidemiology and Genetics (DCEG), National Cancer Institute, Bethesda, USA, ⁴Neuro Oncology Branch, Center for Cancer Research, National Cancer Institute, National Institutes of Health, Bethesda, USA, ⁵Center for Biomedical Informatics & Information Technology (CBIT), National Cancer Institute, Bethesda, USA

Background

Brain and other central nervous system (CNS) tumors in adolescents and young adults (AYA) are a unique group of tumors that are biologically distinct from both younger and older age groups. As a result, this poses challenges to treatment and reporting.

Purpose

To describe the epidemiology of brain and other CNS tumors in AYA (ages 15-39 years) in the United States, including incidence, mortality, survival, and prevalence.

Methods

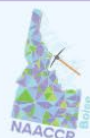
The Central Brain Tumor Registry of the United States (CBTRUS) data, which contains data from the CDC's NPCR and NCI's SEER data were used to calculate average annual age-specific incidence rates (AASIR) per 100,000 population overall and by five-year age group, behavior, sex, and race/ethnicity. Average annual age-specific mortality rates (AASMR) per 100,000 population for deaths resulting from all primary malignant brain and other CNS tumors were calculated using mortality data from NCHS. NPCR survival data were used to calculate relative survival (RS). Estimated prevalence counts as of December 31, 2024 were estimated using incidence from CBTRUS and SEER, and overall survival rates from SEER.

Results

AASIR for all brain and other CNS tumors among AYA was 12.00 per 100,000 population, with the highest histopathology-specific incidence in tumors of the sellar region (AASIR=4.47/100,000). Incidence varied with each five-year age group, sex, and race/ethnicity. Overall, incidence was higher for non-malignant tumors, females, people who were non-Hispanic American Indian/Alaska Native, and ages 35-39 years. Overall AASMR was 0.96 per 100,000 population, with the highest rate occurring in males, non-Hispanic White persons, and those ages 35-39 years. Total five-year RS was 91.1%. Tumors of the sellar region had the highest RS (five-years=99.1%) and glioblastoma had the lowest (five-years=27.3%). Prevalence was highest for tumors of the sellar region (57,850 cases).

Conclusion

Incidence, prevalence, and survival patterns for brain and other CNS tumors vary between AYA, older adults, and children. It is important to provide an accurate statistical assessment of brain and other CNS tumors in AYA to better understand risk and impact of these tumors on this unique population, as well as to serve as a reference for afflicted individuals, for researchers investigating new therapies, and for clinicians treating patients.



Exploring Mental Health Disorder Prevalence Before and After Childhood Cancer Diagnosis among Medicaid Beneficiaries

Feitong Lei¹, Dr. Thomas Tucker^{1,2}, Eric Durbin^{1,2}, Bin Huang^{1,2}

¹Markey Cancer Center, University Of Kentucky, Lexington, USA, ²Kentucky Cancer Registry, Lexington, USA

Background

The mental health of cancer patients has received increasing attention in recent years. However, there's a limited understanding of the prevalence of mental health disorders before and after a childhood cancer diagnosis, particularly among the relatively underserved Medicaid beneficiaries.

Purpose

To explore the mental health disorder prevalence before and after childhood cancer diagnoses among Medicaid beneficiaries in Kentucky.

Methods

The Kentucky Cancer Registry data were utilized to identify patients aged 19 or under with a first primary childhood cancer diagnosis during 2001–2017. Linking KCR data with Medicaid claims, we included patients with continuous Medicaid enrollment 12 months before and after their cancer diagnosis. Mental health disorders were identified using the International Classification of Diseases (ICD)-9 and ICD-10 codes. A descriptive analysis was conducted.

Results

In the 898 patients, the median age was 9 (Quartile(Q)1-Q3: 4-14), 54% were male, and 39% were from Appalachian counties, and the most common cancers were leukemias (n=217), central nervous system (n=193), and lymphomas (n=141). 12 months prior to cancer diagnosis, 32% (n=282) of the patients had a mental health disorder, increasing to 55% (n=489) 12 months post-diagnosis. The most frequent mental disorder diagnoses were mood disorder (before n=108; after n=282) and neuropsychiatric/ developmental disorders (before n=210; after n=250). Mood disorder diagnosis is associated with older age and cancer sites both before and after cancer diagnosis. The mood disorder diagnosis increased from 10% before cancer diagnosis to 40% after for cancers diagnosed during 2014–2017, from 10% to 38% for lymphomas patients, and from 15% to 60% for bone cancer patients. Neuropsychiatric/developmental disorders diagnosis was associated with being male and residing in non-Appalachian regions both before and after cancer diagnosis.

Conclusion

In the study, over half of the Medicaid-enrolled childhood cancer patients in Kentucky had mental health disorder(s) within a year of their cancer diagnosis, with a notable increase from pre-diagnosis levels. This increased prevalence post-diagnosis may result from the identification of pre-existing mental health conditions during cancer treatment, or the emergence of new mental health issues as a consequence of the cancer diagnosis and treatment. Future research is essential to comprehensively understand these dynamics and their broader implications.

POSTER PRESENTATIONS

A Data Infrastructure to Study Cancer Outcomes in Persons Insured by Medicaid

[Dr. Siran Koroukian](#)¹, Dr. Jamie Shoag, Mr. Long Vu, Dr. Weichuan Dong, Dr. Johnie Rose, Dr. Uriel Kim, Dr. Wyatt Bensken, Dr. Kirsten Eom, Dr. Jennifer Tsui, Lihua Liu

¹Case Western Reserve University, Cleveland, United States

Background

Cancer patients insured by Medicaid have heightened vulnerability to poor outcomes. Data infrastructures to support detailed analysis of cancer outcomes among those Medicaid insured are sorely lacking, resulting in a significant knowledge gap. Accordingly, we constructed an integrated data infrastructure by linking cancer registry data with Medicaid administrative data, mirroring the structure of the linked SEER-Medicare database, and adding area-level measures on social determinants of health.

Purpose

To evaluate the potential of linked cancer registry and Medicaid data in studying cancer outcomes in persons insured by Medicaid.

Methods

Our patient population included all cancer patients younger than 65 years old, diagnosed with incident cancer between 1996-2020, and residing in Ohio or Los Angeles County (LA-County). These regions were selected given longstanding relationships with registry leadership and willingness to share individual identifiers for linkage. Linkage with 2016-2020 Medicaid data was accomplished by the Centers for Medicare & Medicaid Services (CMS). To evaluate cancer screening patterns, CMS also identified a random sample of 3-times as many cancer-free individuals insured by Medicaid as the number of cancer patients in the same regions. From cancer registries, we will retrieve demographic and cancer-related data, vital status, and cause of death. We will use Medicaid data to identify enrollment patterns, comorbid conditions, relevant health services, and outcomes.

Results

The Ohio Cancer Incidence Surveillance System and the Los Angeles Cancer Surveillance Program included 733,024 and 443,932 individuals, respectively. Of those, 132,386 and 99,908 individuals matched with 2016-2020 Medicaid files. Our cancer-free cohort included 2.2 million from the State of Ohio, and 1.3 million from LA-County. These data will be highly instrumental in analyzing outcomes along the cancer care continuum—from cancer screening to diagnostic evaluation, treatment, survivorship, and end-of-life care. Our study population will include children, adolescents, and young adults that are diverse geographically, racially, and ethnically; those who are recently diagnosed with cancer or at various stages of survivorship; those with intellectual, developmental, and physical disabilities; and those with multiple chronic somatic and psychiatric conditions.

Conclusion

Our large, diverse, and integrated data infrastructure opens new frontiers in health equity research, allowing us to explore cancer outcomes in previously un/understudied populations.



A Mixed-Methods Assessment of Cancer Registry Technical Assistance Requests

Ms. Sofia Huster¹, [Dr. Paran Pordell](#)¹, Emily Nethercott¹, Ms. Melissa Alvarado¹

¹Centers for Disease Control and Prevention, Chamblee, United States

Background

The Centers for Disease Control and Prevention (CDC) is implementing the National Program of Cancer Registries (NPCR) Evaluation Plan for the 2022-2027 funding cycle. Evaluation goals are to increase completeness, timeliness, and quality of registry data and understand NPCR promising practices, facilitators, and barriers to effective cancer surveillance program implementation.

Purpose

A key component of the NPCR Evaluation Plan is understanding NPCR registry technical assistance (TA) needs, requests, and resolution by CDC staff.

Methods

To understand registry TA needs, CDC evaluators conducted a quantitative analysis of TA requests submitted in the Award Management Platform (AMP) from June 2022 through September 2023. Two CDC evaluators reviewed and coded a total of 114 AMP TA requests by category, subject theme, and time to resolution. CDC evaluators also held 23 informal interviews with registries to gather additional qualitative information on TA needs and satisfaction with CDC resolution of TA requests.

Results

Of the 114 requests, most fell under the category of operations/general (69.3%), followed by data submission (15.8%), evaluation and data management plans (8.8%), education and training (5.3%), and registry software/informatics (0.9%). Requests submitted under “operations/general” were primarily focused on AMP (51.9%) and NPCR reports and reporting requirements (31.6%). Regarding TA request resolution, 22 of the 114 requests remained unresolved (19.3%). Of the 92 resolved requests, over 75% were resolved in a timely manner (within 7 days). CDC evaluators are in the process of qualitatively analyzing additional data from informal interviews to capture TA needs and satisfaction with CDC request resolution.

Conclusion

Many TA requests were related to AMP’s functionality and NPCR reporting requirements. Registry staff are still becoming familiar with AMP’s functionality, as AMP use is not standardized across NPCR-funded registries. Additional training on AMP TA request reporting functions for registries may be useful. AMP is a promising resource to capture recipient TA needs in an efficient way and allows CDC evaluators to regularly analyze TA requests to inform cancer registry training and technical assistance needs.

A Mixed-Methods Evaluation of SOGI Data Collection in an Academic Hospital Setting

Ms. Alice Guan¹, Dr. Salma Shariff-Marco^{1,2}, Ms. Christine Duffy^{1,2}, Ms. Zinnia Loya^{1,2}, Ms. Michelle Wadhwa^{1,2}, Scarlett Gomez^{1,2}

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Background

Collecting Sexual Orientation and Gender Identity (SOGI) data in healthcare settings is vital for understanding the health needs of this population including their cancer burden. It is imperative to implement best practices to accurately capture patients' lived experiences and ensure that implementation is widespread.

Purpose

To understand patients' perspectives on answering SOGI questions in the healthcare setting and assess collection of these data in an academic hospital setting.

Methods

We conducted a mixed-methods study to evaluate the acceptability and feasibility of SOGI data collection practices. We interviewed 12 patients on the importance of SOGI questions, their willingness to provide this data, and how to best collect this data. Additionally, we analyzed electronic health records (EHR) data of adult patients with at least 1 healthcare encounter between 2018-2022 to assess the completeness of SOGI data.

Results

While some participants felt entirely comfortable providing SOGI data, emphasizing its importance for medical care, others hesitated or preferred contextual considerations before disclosure, citing concerns about past experiences or the perceived inclusivity of healthcare settings. Most patients stated a preference for answering SOGI questions through their online patient portal or an intake form, stating concerns about privacy and desire to reserve time spoken with their medical team to discuss healthcare concerns. Most also deemed the inclusion of SOGI questions to be important for their care, though one participant notably highlighted the necessity for follow-through in utilizing collected data (e.g., clinicians checking preferred names and pronouns before patient encounters). In the EHR data, we observed an overall increase in the completeness of data on both sexual orientation (from 4.4% to 55.7%) and gender identity (5.4% to 62.8%). Among cancer patients specifically, data completeness was even higher for sexual orientation (69.1%) and gender identity (77.5%) by the end of the study period.

Conclusion

Our findings confirm that patients recognize the importance of SOGI data collection efforts and are willing to provide this data. However, it will be critical for healthcare systems to implement flexible approaches to data collection, paying careful attention to patient privacy. The positive trends in SOGI data completeness within our healthcare system indicate the feasibility for data collection.

A Tale of Two Iowa's: Differences in Treatment Receipt and Timeliness of Treatment Between African American/Black and White Iowan Men

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Background

NHB Iowans experience higher Prostate Cancer (PCa) mortality than any other racial/ethnic group within the state of Iowa. It is still unclear whether there are factors within the healthcare system linked to unfavorable and unequal outcomes for NHB Iowans.

Purpose

We assessed whether there is a difference in treatment receipt and or timeliness to treatment receipt for Black Iowans and their non-Hispanic White counterparts and how those differences may vary by treating facility.

Methods

Demographic, tumor, treatment, and hospital characteristics of men 40-99 years old Iowa residents were gathered from the Iowa Cancer Registry for patients diagnosed between 2010 and 2020. Rurality was defined using the 2013 Rural-Urban Continuum Codes. Hospital characteristics included rural-urban location and type—Commission on Cancer (CoC)-accredited, NCI-designated, or neither. Logistic regression was used to estimate the likelihood of receiving definitive treatment, time from diagnosis to treatment, the type of treatment to be received.

Results

Of the 18,747 total PCa patients, 18,197 (97.07%) identified as non-Hispanic White (NHW), and 550 (2.93%) were non-Hispanic Black (NHB) and Hispanic (155, or 0.83%). NHB men were younger at the time of their diagnosis, and more likely to have a lower cancer staging (I or II).

The likelihood of receiving definitive treatment is less likely among NHB men (adjusted odds 0.70; 95%CI, 0.54-0.92) & (adjusted odds 0.37; 95%CI, 0.25-0.55). They are also less likely to receive surgery as their form of definitive treatment within the first 180 days after diagnosis. NHB Iowans are however, more likely to receive radiation treatment within the first 90 days of treatment. Additionally, we found that NHB patients at an NCI designated cancer center or a cancer center that is neither NCI/CoC-accredited were less likely to receive definitive care than NHW patients.

Conclusion

Despite having similar access to high quality cancer care services, NHB Iowans had lower odds of receiving definitive treatment, as well as less likely to receive prostate surgery within the first 180 days after diagnosis.

Adapting North American Tools to Allow Cancer Registries Worldwide to Assess Data Quality

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Background

As part of routine data quality assessment procedures, software applications or “Data Edits” programs are used to detect inconsistencies in data generated by population-based cancer registries (PBCRs).

The International Agency for Research on Cancer/International Association for Cancer Registries (IARC/IACR) in the IARC Technical Report No. 42 provides details for data consistency. This includes intra-record accuracy, validity and consistency checks to detect invalid codes and impossible/unlikely combinations of codes within a record; and inter-record edits to detect duplicate records or records considered to be multiple primary records.

Purpose

Software applications based on international standards are limited and need updating. Furthermore, edits to accommodate ICD-O-3.2 changes have not been made available to the international community. To address these needs, we identified available software tools from NAACCR and are adapting and testing for use by PBCRs.

Methods

The NAACCR International Data Edits Tool was developed by adapting software programs used in NAACCR quality assessments to international standards. The software package consists of two processes: intra-record and inter-record checks.

For the intra-record process, three freely available, CDC software programs were identified and adapted by NAACCR. NAACCR data items, comparable to internationally used core data items, were identified and adjustments made to accommodate international coding differences. Invalid codes and impossible/unlikely code combinations within a record were programmed following the IARC/IACR guidelines.

Adaptations for inter-record checks using international rules are being explored.

Results

Intra-record checks performed by the NAACCR International Data Edits software are currently being tested and compared to existing IARC/IACR tools using cancer incidence datasets from Caribbean PBCRs. Preliminary results have shown that checking ICD-O-3.2 rules is essential to promoting high-quality data. Modifications are being made to the software program to ensure all international rules have been accurately incorporated into the NAACCR International Data Edits Tool.

Conclusion

It is important that Data Edits programs incorporate ICD-O-3.2 beginning with 2020 diagnoses and that these updates are available to all PBCRs. This work will improve the availability and routine use of tools to assess and improve data quality in cancer registries globally.

Addressing the “Small Number Problem” at the Max-Census-Tract Level in Cancer Surveillance and Epidemiological Research: An Example of Colorectal Cancer Incidence and Screening

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Background

Federal agencies, cancer registries, and cancer epidemiological research often present data down to the county level, ignoring large within-county variations, especially in areas with high population density. Research adopting a sub-county geographic unit, such as census tract and ZIP Code, often needs to mask areas with statistics derived from small numbers to reduce the risk of de-identifying individual patients – known as the “small number problem”. This dilemma hinders cancer disparities research and limits its capability to design subsequent interventions targeting specific neighborhoods.

Purpose

To demonstrate the utility of a regionalization method that consolidates geographic areas, balancing the need to present late-stage colorectal cancer (LSCRC) incidence rates at a fine geographic scale with the need to protect patient privacy.

Methods

Using 2011-2020 data from the Ohio Cancer Incidence Surveillance System, we calculated age-adjusted LSCRC incidence rates at the census tract level, masking areas with <11 patients per data use agreement. In comparison, we applied the Max-P regionalization method to aggregate the minimum number of adjacent, homogeneous census tracts into the smallest geographic areas to satisfy the threshold constraint of 11 patients and called these areas “MaxTract”. We then calculated age-adjusted LSCRC incidence rates at the MaxTract level. Using census tract-level data from CDC PLACES, we re-estimated the colorectal screening rates at the pre-defined MaxTract level weighted by census tract population. Finally, we identified neighborhoods (or MaxTracts) with high LSCRC incidence rates and low colorectal screening rates for future interventions.

Results

The census tract-level map of LSCRC has 98% of its areas masked due to <11 patients. In comparison, we identified 783 MaxTracts with LSCRC incidence rates varying between 4.1 and 40.4 per 100,000 people. The overlay of the MaxTract-level LSCRC map and the colorectal screening map highlights areas with high LSCRC rates and low screening rates, where target intervention is mostly needed.

Conclusion

This novel regionalization method increases geographic resolution in displaying cancer statistics, broadening our understanding of cancer disparities at the neighborhood level. Federal agencies, cancer registries, and researchers should consider these more targeted and actionable geographic areas to have better resource utilization in designing interventions to reduce cancer disparities.

Anonymizing Cancer Pathology Reports: A Three-Tiered Approach

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Background

Cancer pathology reports contain identifiable information, such as the patients' name, health number, physician's name, etc. With advances in natural language processing, cancer registries are considering automated data collection and curation using deep-learning approaches, with the state-of-the-art being transformer-based large language models.

Purpose

Multiple studies have shown that such models are capable of memorizing training data and can leak sensitive information. This limits the ability to share models across institutions or openly due to the risk of information leakage. There are two approaches to ensure that the machine learning models do not leak sensitive information from the training data. First, training models using differential privacy and second, training on data that does not have any sensitive information. The first approach is in its infancy where differentially private models tend to provide subpar utility, which is unacceptable in a healthcare setting.

Methods

At the British Columbia Cancer Registry (BCCR), we have focused on developing a three-tiered approach for the second paradigm, which automatically identifies and removes sensitive information from the pathology reports before they are used for training language models.

In the BCCR's approach, the first tier uses a regular expression-based method to identify names and patient health numbers from the header (HL7 PID segment) that can often be matched and removed from the report body, followed by removal of the header. Header is where most of the identifiable information resides and it does not provide useful information for machine learning models, hence it can be completely removed. After the first step, unmatched names still remain in multiple places within the report. The second tier uses Presidio, an open-source anonymization library to remove any identifiable names. However, Presidio struggles to identify and remove long names or names of ethnic origins. The third tier uses a deep learning based named entity recognition model called piistar.

Results

Our initial evaluation via manual audit on 100 randomly chosen reports shows that our approach accomplishes 99% and 95% complete or partial removal of patient and physician identifiers respectively.

Conclusion

This provides evidence that we can successfully leverage pre-trained models for anonymization, lowering the barriers for collaborative ML research.

Assessing Risk Factors for Invasive Breast Cancer Patients with Ductal Carcinoma In Situ (DCIS) Diagnosis

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Background

The incidence of ductal carcinoma in situ (DCIS), a noninvasive form of breast cancer, has increased markedly in recent decades. In Virginia, DCIS cases accounted for approximately 20% of all breast cancer diagnosis during 2016-2020. Many DCIS cancers later progress to invasive breast cancer, with or without treatment. However, it is not possible to accurately predict which DCIS would be more likely to progress to invasive breast cancer. Thus, assessing risk factors for DCIS-invasive breast cancer (IBC) progression is very important.

Purpose

The purpose was to understand risk factors for female DCIS patients who later developed invasive female breast cancer.

Methods

We extracted all female breast DCIS patients diagnosed between 2007 and 2011 and followed them up to 2021 from the Virginia Cancer Registry (VCR). After data cleaning and manipulation, there were N=7347 patients in the study. Among those patients, 581 (7.9%) were diagnosed with an invasive female breast cancer after six months or more. We applied a logistic model to examine the association between smoking status, alcohol status, age, race, and family history and the invasive cancer diagnosis after the DCIS diagnosis. The analysis was conducted using SAS 9.4.

Results

We found that the odds of developing invasive breast cancer in a DCIS patient are 3.4 (95% CI 2.2-5.3) times higher for patients with a breast cancer family history compared with those without a family history of cancer. In addition, black women were found to have a higher rate (1.6 times, 95% CI 1.4-2.0) of progressing to invasive breast cancer compared with white women.

Conclusion

Women with a family history of breast cancer and black women are disproportionately affected. This may require additional access to screenings to prevent the development of invasive breast cancer. However, expanded racial categories and improved data quality from self-reported variables (alcohol, smoking status, and family history) are needed to further inform prevention efforts.

Bayesian Mediation Analysis for Time-to-Event Outcome: Investigating Racial Disparity in TNBC Survival

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Background

Among women in the United States, breast cancer is not only the most common malignancy but also the second leading cause of death. Triple-negative breast cancer (TNBC) has a higher recurrence rate and poorer overall mortality than other subtypes of breast cancer. Studies have shown that African American (AA) women are genetically more likely to develop advanced TNBC than Caucasian American (CA) women. In Louisiana (LA), there were 3,790 TNBC cases from 2010 to 2017, of which 1,861 (49.1%) were from the AA population versus 1,900 (50.1%) were from the CA population, while 32.8% of the LA population were AA and 62.8% were CA. Notably, 43.5% of the AA patients were diagnosed with regional or distant metastasis, compared with 36.6% of CA patients. Thus, TNBC represents a significant challenge to racial health disparities in Louisiana.

Purpose

To identify environmental risk factors and quantify their effects that explain the racial disparities in survival among TNBC patients in LA.

Methods

Our research is based on data collected by a CDC project entitled “Enhancing Cancer Registry Data for Comparative Effectiveness Research” (CER). In addition to the routinely collected standard data items, the funded cancer registries also collected variables on patient socio-demographic information, area-based (census tract) socioeconomic status, the detailed first course of treatment information, and tumor biomarkers of prognostic significance listed under CSv2 site-specific factors (SSFs, e.g. estrogen receptor (ER) status, progesterone receptor (PR) status and human epidermal growth factor receptor 2 (HER2)) for cancer cases diagnosed in 2011 for the CER project. Patients diagnosed with TNBC were followed-up for more than 8 years. We also developed a Bayesian Mediation Analysis method to explore the observed disparity in survival.

Results

The observed disparity was completely explained by the included variables. We found that variables age of diagnosis, insurance status, AJCC stage, breast cancer subtypes, poverty, and completion of the first course of chemotherapy were significant mediators.

Conclusion

We proposed three methods for Bayesian mediation analysis with time-to-event outcomes. All methods are shown to be effective in identifying important mediators and confounders. The disparity was completely explained using the currently collected mediators.

Cancer Incidence in Persistent Poverty Areas of California by Race/Ethnicity

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Background

While several studies have examined the relationship between living in persistent poverty areas (PPAs) and adverse cancer outcomes, the relationship between PPAs in California and disparities in specific cancer incidence rates and trends by race/ethnicity are unknown.

Purpose

To understand the differential impact of poverty on the cancer burden in California.

Methods

PPAs are defined as census tract of residence at time of diagnosis with a poverty rate of at least 20 percent for approximately 30 years. Using California Cancer Registry data, we identified patients diagnosed with 16 common cancers between 2006-2020. We calculated age-adjusted incidence rates (AAIRs), rate ratios (RRs), average annual percent changes (AAPCs), and associated p-values to facilitate comparisons between incidence rates and trends among patients living in PPAs and non-PPAs in California by race/ethnicity. Incidence rates per 100,000 persons each year were age-adjusted to the 2000 United States standard population.

Results

Of the 2,493,936 patients, 162,538 (6.5%) lived in persistent poverty areas. The largest proportion (41%) of the cancer patient population in PPAs was of Hispanic/Latino race/ethnicity. Across all racial/ethnic groups, AAIRs of cervical and liver cancers were significantly higher among patients in PPAs versus non-PPAs. Significantly lower incidence of female breast cancer was observed in PPAs versus non-PPAs across all racial/ethnic groups. Among non-Hispanic/Latina Whites, cervical cancer significantly decreased only in non-PPAs (AAPC=-2.0). Incidence of colorectal cancer and non-Hodgkin lymphoma among Hispanic/Latinos increased significantly in PPAs (AAPC=0.4, 1.2) and decreased in non-PPAs (AAPC=-1.4, -0.3). Thyroid cancer incidence among Black/African Americans significantly increased only in PPAs (AAPC=4.7). Cervical cancer incidence among Asian/Pacific Islanders decreased in both groups. Among American Indian patients, significant increases were observed for most cancers in non-PPAs, although trends for many cancers could not be calculated in PPAs due to small numbers and unstable AAIRs.

Conclusion

Populations living in PPAs of California would benefit from public health interventions. Our findings of significantly higher AAIRs of cervical and liver cancers across all racial/ethnic groups among patients in PPAs versus non-PPAs call for additional research to understand the etiology of these cancers in PPAs and appropriately distribute cancer prevention resources to reduce the observed disparities.

Cervical Cancer Survival in a Northeastern Brazilian State, 1996-2017

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Background

Trends in the burden of cervical cancer have been influenced by the availability of preventive measures, early detection, access to high-quality healthcare, and the implementation of effective treatment.

Purpose

Population-based survival is a pivotal metric for assessing the effectiveness of health systems in cancer management. Our objective was to describe temporal trends in cervical cancer survival in Sergipe, Brazil, by histological group.

Methods

We analyzed individual data from the Aracaju Cancer Registry on women (15-99 years) diagnosed with an invasive primary cancer of the cervix in Sergipe, Brazil, over five periods (1996-1999, 2000-2004, 2005-2009, 2010-2014, 2015-2017), with follow-up to 31 December 2022. Of 10,482 registrations, 6,095 (58.1%) in situ neoplasms were excluded. After application of the quality control procedures developed for the VENUSCANCER project, 3,977 (90.7%) of 4,387 invasive malignancies were included in survival analyses. One- and five-year net survival were estimated with the Pohar-Perme estimator, by histological group, and age-standardized with the International Cancer Survival Standard weights. To account for background mortality, complete life tables (single year of age 0-99 years) of all-cause mortality rates among women in Sergipe were constructed for each year 1996-2022.

Results

One-year net survival declined from 84.6% (1996-1999) to 73.4% (2015-2017), while five-year survival fell from 60.8% to 49.3% during the same timeframe. Squamous cell carcinomas comprised 85.1% of cases. Age-standardized survival proved comparable for squamous cell carcinomas and adenocarcinomas, approximately 80% at one year of diagnosis and 55-58% at five years. For other specified morphologies, age-standardized survival was 70.8% at one year and 46.1% at five years. Between 1996-1999 and 2015-2017, net survival for squamous cell carcinoma fell from 85.7% to 74.5% at one year and from 62.5% to 51.4% at five years.

Conclusion

We observed a modest decline in survival over the years, possibly suggesting improvements in cervical cancer screening programs. Treating and curing in situ tumors found during screenings can reduce the occurrence of invasive cancer. However, aggressive tumors, harder to detect due to faster growth, pose challenges in treatment, possibly leading to a decrease in survival. Additionally, there was no difference in survival between squamous cell carcinoma and adenocarcinoma.

Contemporary Cancer Mortality Disparities among Asian/Asian American, Native Hawaiian, and Other Pacific Islander Individuals

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Background

Although the Office of Management and Budget (OMB) disaggregated Asian/Asian American (AA) from Native Hawaiian/Other Pacific Islander (NHPI) in 1997, cancer statistics for NHPI individuals are typically grouped with AA individuals, masking likely existing disparities between populations.

Purpose

This study examines contemporary cancer mortality among AA and NHPI populations compared to the non-Hispanic White population.

Methods

We conducted a retrospective cohort study comparing age-standardized cancer death rates (with 95% confidence intervals) from 2018 through 2021 in AA and NHPI individuals to those in White individuals for 23 cancer sites stratified by sex using the underlying cause of death data provided by the National Center for Health Statistics and population estimates based on single race postcensal estimates of the July 1 provided by the CDC. Estimates excluded individuals of Hispanic ethnicity to reduce misclassification.

Results

From 2018 to 2021, there were 72,495 cancer deaths among AA individuals and 3,084 among NHPI individuals. The overall age-adjusted cancer mortality rate for AA (91.1 per 100,000) and NHPI (142.2 per 100,000) individuals was 40% and 7% lower, respectively, compared to White (152.8 per 100,000) individuals; however, there were striking disparities by cancer type. For example, the death rate in AA individuals in comparison to White individuals was 37% higher for liver cancer (8.2 vs. 6 per 100,000) and 2-fold higher for stomach cancer (4.2 vs. 2.1 per 100,000). The death rate among NHPI compared to White individuals was 30% higher for female breast cancer (25.5 vs. 19.6 per 100,000), approximately 2-fold higher for liver, thyroid, and cervical cancers, and 3-fold higher for stomach (5.9 vs. 2.1 per 100,000) and uterine corpus (15.5 vs. 4.7 per 100,000) cancers.

Conclusion

Despite lower overall cancer mortality in AA and NHPI individuals compared to White individuals, there are alarming disparities for cancers with known interventions, especially among NHPI individuals. These findings highlight the need for increased cancer prevention strategies in Asian and Pacific Islander communities, including H. Pylori and viral hepatitis infection control and screening interventions, as well as etiologic research to uncover reasons for the extraordinary burden of uterine corpus cancer in Pacific Islander women.

Data Quality for Gastrointestinal Cancers in Brazilian Population-Based Cancer Registries

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Background

Population-Based Cancer Registries (PBCR) are important sources for cancer surveillance, in Brazil there are currently 30 PBCRs. Governmental and non-governmental cancer institutions and research groups use registry data to generate incidence estimates, which, in turn, are influenced by the coverage and quality of the data.

Purpose

This study aimed to assess the data quality of five gastrointestinal cancers in Brazilian cancer registries according to the international criteria of comparability, validity, completeness, and timeliness.

Methods

A cross-sectional study included data from Brazilian PBCRs available at National Cancer Institute (INCA) on Jan. 08, 2023, last updated on 25 Nov. 2022, with over ten years of historical series from 2000, regardless of the geographic coverage (state, metropolitan region, or capital). The Brazilian PBCRs were evaluated according to comparability, validity (accuracy), completeness and timeliness. We analyzed all cancer cases, excluding non-melanoma skin cancer (NMSC), and five gastrointestinal tumors (esophagus, stomach, colon and rectum, liver, and pancreas) by cancer registries and sex, within the available period.

Results

Sixteen Brazilian PBCRs included in this study cover 17% of the national population (36 million inhabitants in 2021) with data spanning 2000 and 2018, around 1.3 million cases, excluding NMSC, and around 300,000 NMSC cases. The historical series varied between 12 and 19 years of incidence. Morphologically verified cases (MV%) ranged from 74.3% (Manaus) to 94.8% (Aracaju), while death certificate-only (DCO%) ranged from 3.0% (São Paulo) to 23.9% (Espírito Santo). Highly lethal cancers like liver and pancreas showed DCO% above 30% in most PBCRs. All sixteen registries showed delays of more than 36 months in data disclosure relative to the calendar year 2022.

Conclusion

While Brazilian cancer registries meeting international comparability criteria, half of the studied exhibited lower-than-expected indexes for validity and completeness in highly lethal tumors such as the liver and pancreas. In addition, the prolonged delay in the timely incidence data dissemination underscores the need to ensure the activity and stability of PBCRs in Brazil, maintaining their role as essential tools for monitoring cancer incidence and informing national cancer control policies.

Do More Abstracts Equal Better Quality?

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Background

Cancer registries are experiencing rapid advancements in technology while experiencing cancer registrar workforce shortages. This combination has motivated the Iowa Cancer Registry to evaluate operations to increase efficiency and maximize limited resources. Iowa's catchment includes 184 facilities, of which 26% (n=47) have <30 abstracts annually and see a small fraction of Iowa's cancer cases. Yet, staff devote similar effort abstracting cases at these hospitals as at larger facilities. This led us to the question of what information do we gain from completing a full abstract from these small facilities?

Purpose

Evaluate the numbers of duplicate abstracts across catchment area facilities and understand the information gained from complete abstracts from small volume facilities.

Methods

Iowa Cancer Registry abstracts with an admission year between 2018 and 2022 were included. It was determined if tumors had single or multiple abstracts. Reporting facilities (Iowa and non-Iowa) were categorized based on the volume of new primary abstracts each year; low- (<30 abstracts, n=47), medium- (30-124, n=40), high-volume (125+, CoC, n=50), other non-hospital (n=47) facilities. Treatment data from abstracts for surgery, systemic therapies, and radiation variables were categorized as yes/no and values were reviewed to determine which facility categories reported the information.

Results

Eighty-three percent of abstracts were from a high-volume facility. Low-volume facilities accounted for 2% of abstracts and 0.5% were a single abstract. Of cases that had an abstract from a low-volume facility (n=3,660), the low-volume hospital was the only facility to report receipt of treatment for 36% (n=314) of surgery cases, 25% (n=136) of systemic therapy cases, and 14% (n=31) of radiation cases.

Conclusion

The majority of cancer treatment information comes from high-volume facilities. In an era of limited resources, it is important to design registry operational workflow to account for this. Strategies could include prioritizing abstraction from high-volume facilities, identifying duplication at low-volume hospitals, and implementing a limited abstract to reduce staff time spent abstracting low-volume hospitals. Future work will explore these strategies.

Emerging Cancer Trends by Birth Cohort in the USA

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Background

Cancer trends in recent birth cohorts reflect changes in exposures during early life and foreshadow the future disease burden. Herein, we examined trends in cancer incidence by birth cohort for 34 cancer types in the USA.

Purpose

Examine trends in cancer incidence rates by birth cohort for 34 cancers in the USA.

Methods

Incidence data for invasive cancers diagnosed in individuals aged 25-84 years from 2000-2019 were identified from the North American Association of Central Cancer Registries. The cohort-specific incidence rate ratio (IRR), adjusted for age and period effects, was calculated for each birth cohort born from 1920 to 1990 (10-year overlapping birth cohorts, designated by the mid-year of birth).

Results

The cohort-specific incidence rate increased in successive birth cohorts born since circa 1920 for eleven of the 34 cancer types. For example, cancer risk was approximately 2-3 times higher in the 1990 birth cohort than in the 1955 cohort for cancers of the small intestine (IRR=3.56; 95%CI=2.96-4.27), pancreas (IRR=2.61; 95%CI=2.22-3.07), and gastric cardia (IRR=1.46; 95%CI=1.07-2.00) in both sexes; and for liver (IRR=2.05, 95%CI=1.23 to 3.44) and esophageal adenocarcinoma (IRR=1.72; 95%CI=1.14-2.61) in females. In contrast, the cohort-specific rate increased in the younger birth cohorts after either stabilizing or declining in the older birth cohorts for 9 of the remaining cancers, including estrogen-receptor-positive breast cancer, uterine corpus, colorectum, gastric non-cardia, gallbladder, ovary, testis, anus (males), and Kaposi sarcoma (males). For these cancers, the risk in the 1990 birth cohort was 12% (CRR1990 versus 1975=1.12; 95%CI=1.03-1.21 for ovary) to 169% (CRR1990 versus 1930=2.69; 95%CI=2.34-3.08 for uterine corpus) higher than the risk in the older birth cohort, which had the lowest risk.

Conclusion

Twenty of 34 cancers examined had increasing risk in younger birth cohorts, including some that followed previously declining trends. The findings add to growing evidence of elevated cancer risk in younger generations and highlight the need for etiologic research to identify underlying risk factors.

Emergency Dispatch Address Points as Geocoding Candidates to Quantify Delimited Confidence in Residential Geolocation

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Background

Publication of cancer incidence rates at sub-county (compared to county) scales may impact citizens' sense of well-being and/or property values. If such negative impacts occur, citizens naturally pay attention to the quality of data used for calculating cancer incidence. This in turn brings a need for a simple metric to quantify confidence in residential geolocation as a key constraint of geospatial analysis.

Purpose

We repurpose emergency dispatch (ED) address point data to quantify delimited confidence in residential geolocation.

Methods

During geocoding record linkage, a patient address may have more than one ED address point candidate with equal likelihood (CEL) of being the correct match. The discriminant power of residential geolocation depends on the number of CEL, with a higher CEL number signifying lower confidence in residential geolocation. We propose a simple metric based on residential geolocation discriminant power (RGDP) calculated for each case as $1/\text{CEL}$, thus ranging between >0 and 1. Using 5807 new cancer cases reported to the North Carolina Central Cancer Registry in January of 2022, we calculate summary RGDP (sRGDP) for a set of cases from each county to show variation in the quality of residential geolocation.

Results

74 NC counties reported new cancer cases, among them 54 were rural and 20 were urban. Cases matched to a unique best ED address (CEL=1) constituted 86%, demonstrating the importance of residential geolocation for sub-county incidence results. While current standards ensure that ~97% of cases are identified within the county boundaries, within the counties, confidence in residential geolocation is lower. Overall, between counties, sRGDP varied 1.6-fold (0.62–1.00), with 1.00 indicating the highest discriminant power of matched addresses. We demonstrate significant differences in sRGDP for cases identified in urban vs. rural counties: mean sRGDP 0.948 vs. 0.896 ($p < 0.05$).

Conclusion

Variability in sRGDP between counties informs confidence in the quality of geospatial analysis, with low sRGDP helping to manage expectations for the uncertainty in cancer incidence data. The overall quality of residential geolocation is lower in rural vs. urban counties, likely reflecting the lack of resources in the rural areas.

Estimating the Uninsured Cancer Rate: Unraveling the Indelible Link Between Insurance, Age, and the Accessibility of Cancer Treatment

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Background

Patients without insurance often wait until their symptoms become severe before seeking treatment. While done to avoid the cost of preventative care, this decision often leads to uninsured patients presenting with more advanced diseases. This trend can be clearly seen in cancer care. Research has shown that uninsured adults are less likely to receive cancer screenings than their insured counterparts, more likely to be diagnosed with cancer at a later stage, hence, have an increased risk for death for certain types of cancer.

Purpose

We aim to calculate the overall uninsured rate for cancer patients across The University of Kansas Cancer Center's (KUCC) catchment area and estimate the uninsured rate for patients treated within a large health system in the state of Kansas.

Methods

We conducted a literature review to collect data related to the uninsured rates for Kansas and Missouri by age group. Three datasets were used to generate an overall uninsured rate for both states for the age groups of 0-19, 20-64, and 65 or older. The cancer incidence was derived using the 2020 estimated number of KUCC cases and the mean percentage of 2015-2019 cases for the corresponding age groups. The estimated uninsured and cancer incidence rates were then used to calculate the overall uninsured cancer rate.

Results

The total number of estimated 2020 KUCC cases was 24,412, with 0.86%, 42.56%, and 56.58% being the percentage per the age groups 0-19, 20-64, and 65 or older. The estimated uninsured rate per age group was 5.33%, 13.49%, and 0.40%. Based on these results, there were an estimated 11 uninsured cancer patients in the MCA area between the ages of 0-19, 1,401 between the ages of 20-64, and 55 uninsured cancer patients over the age of 65. This yielded an overall uninsured cancer rate of 6.01%.

Conclusion

With the estimate of uninsured cancer patients, we could do future projections and plan on how to solicit funds through philanthropic and state administrators to provide care to these uninsured cancer patients.

Evaluating Impacts of the COVID-19 Pandemic on Cancer Outcomes

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Background

Previous assessment of the COVID-19 pandemic's impact on 2020 cancer incidence data showed a significant decrease in case counts and age-adjusted rates (AARs) in 2020 compared to 2005–2019. Much of the decrease in 2020 occurred during March–May when a public health emergency response was implemented.

Purpose

Evaluate the impact of the COVID-19 pandemic on cancer incidence, late-stage diagnoses, survival, and death trends.

Methods

U.S. Cancer Statistics (USCS) data were used to evaluate trends in AARs and stage at diagnosis during 2012–2021 for all cancer sites combined and selected sites. Rates from 2020 were calculated but excluded from the trend. We used Merged Summary Stage to define stage at diagnosis and analyzed data for leading cancer sites and screening-amenable cancers. We used National Center for Health Statistics death data to assess cancer death rates during 2012–2021. NPCR data from the 2023-submission will be used to measure survival in three- and five-year cohorts across geographic areas. NPCR recipients meeting USCS publication standards for the 2022- and 2023-data submissions will be included.

Results

Across all sites, incidence trends remained stable during 2012–2019 with a decrease in 2020 to 450.7 per 100,000 population. There were differences in the stage distribution for several cancers. For breast cancers diagnosed in 2020, there was a 10.0% drop in cases diagnosed at the localized stage, and an 8.4% drop in cases diagnosed at the regional stage when compared to 2019. Death trends decreased over the period from 2012 to 2021. Additional results, including survival and 2021 data, will be presented after analyses are completed.

Conclusion

The decrease in 2020 incidence rates for all sites is presumed to be from missed cases resulting from screening delays and interruptions to care. It is yet to be seen if these missed cases were caught during 2021 through return to screening and care efforts. Cancer death rates continue to decrease, primarily driven by reductions in deaths among the common screening-amenable cancers. Preliminary analysis shows that among breast cancer cases, there was a decrease in early-stage diagnoses in 2020. This could be a result of declines in breast cancer screening during the pandemic.

Evaluating the Burden of Lung Cancer among Arkansans

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Background

Arkansas historically grades poorly for lung cancer measures ranking bottom tier for 3.7% screenings performed among high-risk groups and low 5-year overall survival rate of 22.6%.^{1–3} In 2021, the state had the 5th highest lung cancer mortality rate in the US with 44.0 deaths per 100,000.⁴

Purpose

The purpose of this study is to examine the latest lung cancer incidence rates and trends for Arkansas.

Methods

NCI's SEER*Stat program was used to calculate percentages of risk factors and lung cancer age-adjusted incidence rates (AAIR) diagnosed as the only primary tumor using Arkansas Central Cancer Registry data between 2011-2020. Data was stratified by sex, race/ethnicity for early and late-stage and 2 main lung cancer subtypes, Non-Small Cell Lung Cancer (NSCLC) and Small Cell Lung Cancer (SCLC).^{5,6} Joinpoint software was used to assess average annual percent change (AAPC) for Arkansas and by sex, race/ethnicity among late-stage cases.

Results

In Arkansas, 19,432 lung cancer cases were diagnosed. At the time of diagnosis, 44.6% previously used tobacco, 30.3% currently used tobacco, 40.4% had a family history of cancer. Among males, Black, Non-Hispanic (NH) had the highest overall lung cancer incidence rate (AAIR=100.9, 95%CI: 95.5-106.6), late-stage diagnosis rate (AAIR=74.0, 95%CI: 69.5-78.8) and NSCLC rate (AAIR=56.3, 95%CI: 52.8-60.0), but White, NH males had the highest SCLC rate (AAIR=8.4, 95%CI: 8.0-8.9). Among females, White, NH had the highest overall lung cancer incidence rate (AAIR=61.6, 95%CI: 60.3-63.0), late-stage diagnosis rate (AAIR=42.8, 95%CI: 41.7-44.0), NSCLC rate (AAIR=32.8, 95%CI: 31.9-33.7), and SCLC rate (AAIR=8.5, 95%CI: 8.0-8.9). Arkansas had an estimated 2.2% AAPC decrease for lung cancer incidence (95% CI: -2.8, -1.3), but an overall trendline higher than the US. White, NH males had the most AAPC decrease for late-stage diagnosis (AAPC=-3.3, 95% CI: -4.08, -2.6), followed by Black, NH males (AAPC=-2.9, 95% CI: -3.6, -2.2), White, NH females (AAPC=-1.5, 95% CI: -1.9, -1.1), and Black, NH females (AAPC=-0.8, 95% CI: -2.6, 1.1).

Conclusion

This study is consistent with national findings with Black males experiencing a higher burden of lung cancer incidence.^{7,8} These findings may provide statewide cancer programs with data-driven information to promote lung cancer services such as screening and/or genomic testing among subgroups.



Evaluation of Cancer Incidence Rates among American Indians/Alaska Natives in the California Cancer Registry Using Two Different Classification Methods

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Background

Accurately assessing the cancer burden among different populations is imperative to identifying health disparities. Population-based cancer registries continue to face challenges in assessing the cancer burden among American Indians/Alaska Natives (AIANs) including: the misclassification of AIANs as another race or ethnicity, the effect of calculating incidence rates only for AIANs living in Purchased/Referred Care Delivery Areas (PRCDA), and small numerators and denominators which may require suppression of data and lead to unstable rates. Furthermore, in California, a large number of people identify as both AIAN and Hispanic/Latino ethnicity, requiring further consideration of how to accurately define AIANs in cancer registry and population data.

Purpose

To evaluate how two different methods of classifying AIANs in California Cancer Registry (CCR) data impacts cancer incidence rates.

Methods

Individuals with cancer diagnosed from 2000 through 2019 were obtained from the CCR. Patients were classified as AIAN when Race 1, 2, 3, 4, or 5 (NAACCR Data Items 160-164) had a value of 3, or the patient linked to the Indian Health Service patient registration database (Method 1). Method 2 excluded AIANs from Method 1 who also identified as Hispanic/Latino ethnicity. Hispanic/Latino ethnicity was determined using NHIA Derived Hispanic Origin (NAACCR Data Item 191). Population data for AIANs, used in the denominators, were obtained from the National Center for Health Statistics. Using both classifications of AIANs, we will calculate and compare age-adjusted incidence rates (AAIR) and trends by cancer type, sex, age at diagnosis, and PRCDA designation.

Results

16,870 Hispanic/Latino AIANs versus 15,120 non-Hispanic/Latino AIANs were identified in the CCR. Regardless of the classification method used, the incidence of all cancers combined among AIANs significantly increased over the study period. The average annual percent change was 3.25% among Hispanic/Latino AIANs and 2.25% among non-Hispanic/Latino AIANs. Comparison of AAIR and trends by cancer type, sex, age, and PRCDA are forthcoming.

Conclusion

Despite limitations, cancer registries must provide information to the AIAN community on their cancer burden. Cancer registries should continue to evaluate the best methods for accurately assessing the cancer burden in this population and engage with the AIAN community to understand their needs.



Examining the Impact of the COVID-19 Pandemic on Survival Rates for Breast, Colon, Lung, Prostate, and Rectal Cancers in Manitoba, Canada

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Background

We previously examined the impact of the COVID-19 pandemic on cancer survival up to September 2021 using an interrupted time series analysis. One-year survival rates were similar to expected values except for individuals 50 to 74 years of age diagnosed with lung cancer from April to June 2021. However, these analyses did not include the Omicron wave. Although the Omicron variant caused less severe disease than previous variants, it was more transmissible and resulted in significant increases in COVID-19 incidence, hospitalizations, and deaths in Manitoba. Consequently, this wave of the COVID-19 pandemic may have had a significant impact on cancer survival.

Purpose

To investigate differences in cancer survival due to the Omicron wave of the COVID-19 pandemic in Manitoba, Canada.

Methods

We will use an interrupted time series analysis with quarterly survival rates to examine cancer survival rates prior to COVID-19 (January 2015 to December 2019) and after the start of COVID-19 (April 2020 to June 2022). Royston-Parmar models will be used to account for time-varying effects. Kaplan Meier (KM) estimates at 1-year will be calculated to describe observed survival. Restricted mean survival times (RMST) will be produced at 1-year for COVID-19 fitted values and counterfactual values during the COVID-19 period. The delta between these two values will represent the mean survival time lost or gained during the COVID-19 period. Models will be adjusted for age, stage, and sex.

Results

The delta RMST results will be presented in forest plots for each quarter in the COVID-19 period for both the unadjusted and adjusted analyses. Plots of the KM estimates will be used to describe the observed and expected survival in each quarter of COVID-19. The results will be presented for breast, colon, lung, prostate, and rectal cancers.

Conclusion

By extending the analyses to include individuals where the predominant strain of COVID-19 during the diagnosis and follow-up periods was Omicron, this study will examine the impact of the Omicron wave on cancer survival. Cancer survival during the Omicron wave will be compared to pre-pandemic cancer survival and survival during the previous COVID-19 waves.

Exploring Knowledge Sharing and Boundary Spanning Leadership in Cancer Surveillance: The Cancer Surveillance High Level Strategic Group (HLSG)

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Background

The Cancer Surveillance High-Level Strategic Group (HLSG) collaborates on decisions affecting the cancer surveillance community that support cancer research, prevention, control and patient care. The collective goal is to enhance the future timeliness, responsiveness, and adaptability of cancer surveillance systems. This involves overseeing the maintenance and improvement of consensus data standards and supporting shared initiatives that advance the field.

Purpose

The goal of this project is to identify potential opportunities for HLSG to engage in boundary spanning, which refers to alignment and commitment at individual, group, and system levels to improve partnership and collaboration across boundaries while providing new opportunities to advance cancer surveillance.

Methods

A modified Delphi process prioritized 22 HLSG activities. In the first round, member organizations decided on retention or removal for each activity. In the second round, using a Likert scale, HLSG members rated the 15 retained activities based on importance and feasibility.

Results

Four HLSG priorities were identified, with a combined feasibility and importance score exceeding 17. The priorities include aligning priority data items with other U.S. data standards, promoting increased adoption of synoptic reporting over text, exploring the role of diagnostic and treatment partial records in early case capture and processing, and developing a value proposition for data harmonization and interoperability.

Two HLSG operations priorities were identified, with a combined feasibility and importance score exceeding 18. Those priorities include reviewing HLSG meeting cadence, agenda creation, and status reports, and developing a standard process and timeline with Mid-Level Tactical Group for communicating vital information to central registries, hospitals registries, and partners.

Conclusion

The findings serve as a roadmap for enhancing boundary spanning and knowledge sharing within complex systems like the HLSG, and across cancer surveillance and broader public health communities.

Final Results of the Evaluation of Melanoma and Bladder Cancers in New Hampshire After Follow-Back Efforts

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Background

A Data Quality Evaluation (DQE) by the National Program of Cancer Registries (NPCR) is performed every five years to assess quality of data from central cancer registries and to determine training needs. Following the NPCR protocol, the New Hampshire State Cancer Registry (NHSCR) evaluated a sample of melanomas of skin and urinary bladder cancers diagnosed in 2018 to identify challenges and implement training for hospital registrars. Following our initial audit reported last year, we now present findings on this evaluation after follow-back efforts to reporting sources.

Purpose

The DQE can help determine whether central registries need to incorporate additional training for their reporters.

Methods

The NHSCR performed a recoding audit on random samples of melanomas of skin and urinary bladder cancers diagnosed in 2018. The audit included a review of data items with the lowest accuracy found on the national DQE and three additional data items recommended for review based on the DQE findings. Discrepancies that were identified were sent to hospital registries for reconciliation. Responses from hospital registries will be reviewed, and cases will be finalized.

Results

Accuracy rates were calculated on the quality of data items. Data items for melanomas of skin include Tumor Size Summary, Date of First Course Treatment, and Treatment Summary – Surgery of Primary Site. Data items for urinary bladder cancers include Grade Clinical and Grade Pathological. The three additional data items include Diagnosis Date, Histology, and Date of First Surgical Procedure.

Conclusion

Results from the recoding audit will be used to address training needs for New Hampshire registrars.

Follow-up and Evaluation of Cancer Patients Who Were Over 100 Years Old and Not Known to be Dead in the New York State Cancer Registry

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Background

State vital records and the National Death Index (NDI) are two primary data sources used by the New York State Cancer Registry (NYSCR) to ascertain deaths among cancer patients. For various reasons, but mainly due to issues with demographic data quality, a small number of matches were missed during the initial linkages, causing some patients to become immortal in our database. Data linkage could be improved with updated demographic information available since the initial linkage attempt. The current study aimed to identify immortal patients in the NYSCR, then conducted additional death record linkages to improve follow-up information.

Methods

Patients in the NYSCR diagnosed with an invasive cancer during the years 1995-2020 were included. We calculated expected ages as of 12/31/2021 for all patients, to identify those who were 100 years or older and not known to be dead. We re-linked those patients to state vital records and NDI with a broader death year range (1995-2021). Patients with newly identified deaths were examined by demographic and tumor characteristics. Percentage of patients lost to follow-up was evaluated before and after these linkages.

Results

We identified 2,405 patients not known to be dead who would be 100 years or older (ranging from 100 to 130) on 12/31/2021. Compared to patients younger than 100 and alive, those elder/alive patients were more likely to be female, Black, Asian/Pacific Islander, of unknown race, Hispanic, foreign born, living in NYC, diagnosed in early years. A total of 194 new deaths were identified, 56.2% of which occurred in 1995-2001 and 91.8% died in NYS. The percentage lost to follow-up among those elder/alive patients was reduced from 62.6% to 54.6% after the linkages.

Conclusion

This study identified 194 new deaths that had been missed previously, the majority of which were identified through the vital records linkage. Many of those patients had certain data quality issues (such as missing SSN or incorrect birth date), thus, requiring more time and work in determining their match status. Periodically identifying potential immortal patients and conducting additional death follow-up could help reduce the loss to follow-up rate in registries.

Guideline-Based Treatment Utilization in Treatment of Bladder Cancer in California: 2011-2020

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Background

Bladder cancer is a highly recurring cancer occurring three times more frequently in men than women, with expected incidence of over 83,000 and approximately 16,840 deaths in 2024.¹ Timely and appropriate treatment is critical for better management of disease. Guideline-based treatments (GBT) are recommended for this purpose. However, underutilization of such treatments for varying stages of disease have been reported before.

Purpose

To describe utilization of GBT in patients diagnosed with bladder cancer in California in the past decade and identify factors associated with GBT utilization.

Methods

California Cancer Registry (CCR) data from 2011-2020 were used to identify first primary bladder cancer cases. The cohort included adults (age ≥ 20) with microscopically confirmed diagnosis, who had a known stage and grade (for non-muscle invasive disease) at diagnosis. Receipt of GBT (Yes/No) was assigned by comparing first course treatment to American Urological Association (AUA) and National Comprehensive Cancer Network (NCCN) guidelines relevant for the study period. Distribution of GBT by sociodemographic characteristics were assessed using frequencies, percentages, and chi-square tests. Logistic regression analysis, adjusted for relevant covariates, will be conducted to assess factors associated with receipt of GBT.

Results

A total of 44,553 cases were identified. Of them, nearly 40% received GBT. Fewer patients in the following groups received GBT as initial treatment: 75+ age group (33.6% vs 43 – 44.7% in <75 age groups), Hispanic (35.9%) and other racial/ethnic groups (22.8%) compared to non-Hispanic white (41.1%), those without partner (36.7% vs 42.9% with partner), residing in the lowest socioeconomic (SES) quintile areas (32.5% vs 45.4% in the highest SES areas), and those on Medicaid or Medicaid/Medicare dual program (30.5% - 32.9% vs 42.6% for Private insurance). Over time, a gradual increase in reception of GBT was observed (33% in 2011 to 47% in 2020). However, the degree of increase and patterns varied across groups. Results from regression analysis will be presented at the conference.

Conclusion

GBT utilization continues to be underutilized in California. Lower use of GBT in poorer neighborhoods and in Hispanic/other racial/ethnic groups suggest some disparities exist. Further studies are needed to better understand of its underlying mechanisms and potential effects on survival.

Health Behaviors and Beliefs about Cancer among Cancer Survivors in the United States: A SEER-HINTS study

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Background

Data on health behaviors among cancer survivors have largely come from studies with limited generalizability.

Purpose

To describe demographic factors, beliefs about health behaviors and cancer risk, and health behaviors among a population-based sample of cancer survivors from 3 US regions.

Methods

Data for this analysis came from a Health Information National Trends Survey (HINTS) study that sampled cancer survivors from 3 Surveillance, Epidemiology and End Results (SEER) registries (Greater Bay Area, Iowa, New Mexico) in 2021. We used weighted logistic regression to examine whether age, sex, education, income, financial stability, occupation, marital status, rurality, or time since diagnosis were associated with alcohol use, tobacco use, adherence to aerobic exercise and resistance training guidelines, or beliefs about health behaviors and cancer risk.

Results

Of 1,195 cancer survivors, the median age was 72 y; 55% were female; 72% were Non-Hispanic White and 11% were Hispanic or Latino; 40% had less than a college education; 35% reported some financial instability; and 18% lived in a rural area. Participants had 56 cancer types; 23% had breast and 21% had prostate cancer. 42% reported no alcohol use and 59% were never smokers; 43% met aerobic exercise, and 31% met resistance training, guidelines. Male cancer survivors and survivors with higher incomes were more likely to drink alcohol. Cancer survivors 75+ y, male, with less education, or with financial instability were more likely to ever have smoked. Survivors with less education, not employed or retired (e.g., disabled, unemployed), lower income, or residing in rural areas were less likely to meet aerobic exercise guidelines. Cancer survivors <65 y, with less education, and <5 y since diagnosis were more likely to agree that “everything causes cancer.” Cancer survivors with less education were more likely to agree that there are “too many [cancer prevention] recommendations.” Lastly, cancer survivors with less education, lower income, and those residing in rural areas were more likely to agree that there is “nothing one can do to lower their [cancer] risk.”

Conclusion

Behavioral interventions need to be tailored to cancer survivors with lower education and income, and address survivors’ beliefs that health behaviors do not impact cancer risk.

Hematopoietic Cell Transplantation Trends and Outcomes in Manitoba

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Background

Hematopoietic cell transplantation (HCT) is an established therapy for hematologic malignancies and certain blood disorders. Effective HCT delivery requires complex hospital-based care. Therefore, monitoring HCT trends in a population is essential to track disease burden for healthcare resource planning and utilization.

Purpose

We assessed HCT trends and outcomes [overall survival (OS) and non-relapse mortality (NRM)] in Manitoba from 2005 to 2019 using data obtained from the Cell Therapy Transplant Canada (CTTC) registry - a clinical database of HCTs in Canada.

Methods

Data on patients' first HCTs was stratified by transplant type (allogeneic vs autologous) and age group (pediatrics: 00-17yrs, young adults: 18-39yrs, middle-aged adults: 40-64yrs, older adults: ≥65yrs). Rates are based on the number of HCTs performed among the Manitoba population and standardized to the 2011 Manitoba population. Time trends were analyzed using Joinpoint regression software. 5-year OS probabilities were estimated using the Kaplan-Meier method with curves compared using the log-rank test. 100-day NRM was analyzed using cumulative incidence and Gray's test to accommodate competing risks of relapse and death from other causes.

Results

Of the 1049 transplants, 51.7% were autologous and 17% were for pediatrics. Generally, transplant rates increased across all types and age groups with notable increases in older adults [annual percent change (APC) = 20.7%]. The 5-year OS was similar between both transplant types (allogeneic: 58%, autologous: 62%, $p=0.2057$), but differed by age group with the highest among pediatrics (71%), but comparable between young, middle-aged, and older adults [58%, 58%, and 56% respectively, $p=0.0041$]. 100-day NRM differed by transplant type [6% for allogeneic and 1% for autologous HCT ($p<0.0001$)] but was similar between age groups [4% each for pediatrics, young adults, and older adults but 3% for middle-aged adults ($p=0.8666$)].

Conclusion

The rate of allogeneic and autologous HCT increased over the 15-year time period. In particular, the rate of HCT in older adults increased significantly over time and showed similar 5-year OS and 100-day NRM compared to other adult age groups. This marks a significant increase in transplant accessibility and underscores the importance of ongoing monitoring and surveillance to plan for resource allocation appropriately as our population ages.

Identify Cancer Recurrence or Metastasis Events using Radiology Report and Natural Language Processing

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Background

Cancer recurrence and metastasis are critical events following primary treatment with profound effect on patient outcomes. Population cancer registries do not include these events. Currently, the identification of these events relies on manual chart review, which is time consuming and costly. Clinical narratives, such as radiology reports, contain information about the presence and timing of cancer recurrence and metastasis. By extracting data from these narratives, we could potentially automate the identification of recurrence or metastasis events.

Purpose

To develop AI algorithms for detecting recurrence/metastasis in population-based radiology reports

Methods

Data consists of 2,404 radiology reports from 1,752 patients linked with SEER data. We include patients with breast, colorectal, and lung primary cancer who were diagnosed between 2011 and 2018, with images that were taken at least six months after the primary diagnosis. We adopt a pre-trained deep learning model “stanza” with rule-based negation detection algorithm to identify recurrence or metastasis instances from each report. The data are split into training sets (80%) and testing sets (20%) at the patient level. The training data are used to develop the negation rules to exclude unqualified terms. We compared our model with a traditional keyword-searching algorithm (i.e., searching for recurrence/metastasis-related words). The model performances were evaluated by randomly selected 32 cases for independent manual validation.

Results

Using a pre-trained model with negation detection in our approach has demonstrated enhanced results compared to the traditional keyword searching approach. The results indicate that our approach significantly improved accuracy (0.94 vs. 0.62), specificity (0.96 vs. 0.57), precision (0.75 vs. 0.25), and F1 (0.75 vs. 0.40). However, our approach has modestly lower sensitivity (0.75 vs. 1.00); to be verified in a larger validation set.

Conclusion

This study shows the potential of using deep learning algorithms to identify recurrence and metastasis events from radiology reports. Model performance will be further evaluated on larger validation sets by using secondary and salvage treatment information from linked claims data as the gold-standard labels.

Impact of Residence on Survival of Lung Cancer Patients in Saskatchewan

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Background

Lung cancer is the common malignancy among Canadian. It remains a leading cause of cancer-related death and responsible for about 25% of cancer death among Canadians. Lung cancer death rates may be varied by the place of residence due to access to care and high turnover of primary care providers. Geographical distributions of healthcare resources have become critical areas of inquiry, especially in regions with diverse landscapes and populations. We hypothesized that patients with lung cancer living in Rural area have inferior survival compared to their urban counterpart.

Purpose

To compared the stage distribution and survival of lung cancer patients by rural vs. urban in Saskatchewan.

Methods

This retrospective cohort study will use data from the Saskatchewan Cancer Agency Registry from 1995-2017 for patient diagnosed with lung cancer (ICD-O-3 C34). Place of residence will be identified at the time of diagnosis and will be defined as urban/rural using available Statistics Canada definition. The baseline demographic and clinical information of eligible patients will be obtained from the Cancer Registry. Net survival will be obtained for both rural and urban patients. Overall survival for the two groups will be compared by Long Rank Test. For the multivariable analysis, this study will use the Cox proportional hazard model.

Results and Conclusion

Outcomes from this study will be helpful for the healthcare provider, policy maker, government, and stakeholder to determine and plan, how to minimize the survival disparities among lung cancer patients impacted by the place of residence. This research is expected to result in valuable insights into healthcare disparities within Saskatchewan. In this study, residence and lung cancer survival based on disease stage will be investigated to develop targeted interventions that take into account the challenges faced by patients living in different geographical locations. Healthcare policies and resource allocation can be shaped in a more equitable and efficient manner when these disparities are understood.

Improvements in Conditional Survival for Childhood Cancer Survivors

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Background

Considerable progress has been made in the treatment of childhood cancers over the past five decades. However, many survivors of childhood cancer experience continuing adverse effects from the disease or treatment. Conditional survival is a novel measure that can elucidate the long-term survivorship of childhood cancer patients.

Purpose

The aim was to quantify improvements in conditional survival for children diagnosed with cancer using data from the Surveillance, Epidemiology, and End Results (SEER) program.

Methods

Relative survival data on first primary tumors from nine SEER registries for children diagnosed between ages 0 and 19 from 1975 to 2017 were used for analysis. Generally, conditional survival is defined as the probability of surviving to time $t+s$, given survival to time t . Conditional relative survival at 10 years, given survival to 5 years, was calculated for all cancers combined and 15 childhood cancer sites identified using the ICCC site recode 3rd edition/IARC 2017 variable. Trends in 10-year conditional relative survival were assessed using the joinpoint survival model with a maximum of two joinpoints.

Results

10-year conditional survival was predicted to increase or remain constant for all childhood cancers examined. The largest increases in 10-year conditional relative survival were observed for lymphoid leukemia and acute myeloid leukemia (AML). For lymphoid leukemia, 10-year conditional survival was estimated to increase from 84.4% in 1975 to 98.0% in 2007, corresponding to an increase of 0.38 percentage points (pp) annually (95% CI 0.31-0.46). For AML, conditional survival was predicted to increase from 90.5% in 1975 to 97.2% by 2007, equivalent to a 0.08 pp yearly increase (95% CI 0.03-0.35). For all cancers combined, 10-year conditional survival was estimated to increase from 92.9% in 1975 to 97.2% in 2007, with a significant annual increase of 0.20 pp (95% CI 0.16-0.24) between 1975 and 1996.

Conclusion

For most childhood cancers, 10-year conditional survival was high, capturing advancements in treatment and improvements in survival. Conditional survival is a measure that is more pertinent to cancer survivors as it contextualizes future survival in terms of current survival, and it can serve as an alternative to the 5-year survival benchmark commonly used in childhood cancer.

Incidence of Uveal Melanoma in the US: Age-, Sex-, and Race-Based Analysis and Forecast

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Background

Uveal melanoma (UM) is a rare cancer but is the most common ocular malignancy. Although risk factors are not well known, advanced age and White/Caucasian race are known to be associated with greater rates of disease. Despite recent advancements in diagnosis and treatment options, morbidity and mortality associated with UM has not significantly improved. As the US population ages and changes, a greater understanding of the burden of the disease is critical to providing proper diagnosis and care.

Purpose

To estimate and forecast the age-, sex-, and race-specific incidence of UM in the US from 2022-2035 using historical data.

Methods

The NAACR CiNA Use Public Dataset and the SEER Research dataset were used to obtain data for incidence rates of UM from 2012-2020. Incidence analysis was done for sex, race, and age and historical data were used to inform forecast rates for 2022-2035. Averages of the rates observed across datasets were used to inform forecast rates.

Results

The age-, sex-, and race-adjusted incidence of UM was estimated to be 0.69 per 100,000 [95% CI = 0.53,0.80] in 2022, corresponding to approximately 2,400 cases, and was forecast to grow modestly to 0.70 [95% CI = 0.55, 0.87] by 2035. White males have the highest rate of disease, growing from 1.15 per 100,000 in 2022 to 1.28 per 100,000 in 2035. Incidence of UM was highest among those 65 and older (2.18 per 100,000 in 2022), particularly for 75–84-year-olds (2.47 per 100,000 in 2022). However, these rates are estimated to decline by nearly 6% by 2035.

Conclusion

In this study, we analyzed the historical rate of uveal melanoma utilizing cancer registry data from NAACR CiNA Use Public Dataset. Despite an aging population and greater rate of disease among older Americans, the incidence of UM is forecast to remain relatively stable through 2035, due in part to demographic changes and differences in race- and sex-specific rates.

Interfacing with the CDC Guidelines for Unusual Patterns of Cancer and Environmental Concerns: A 2023 Wisconsin Case Study

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Background

Interfacing with the CDC Guidelines for Unusual Patterns of Cancer and Environmental Concerns (Guidelines) remains a challenge for many state and territorial public health agencies. We use a Wisconsin community concern reported in 2023 as a case study to highlight the importance of strong working relationships between an environmental and occupational health bureau and a population-based central cancer registry in responding to community cancer cluster concerns.

Purpose

To showcase one population-based central cancer registry's experience interacting with the CDC Guidelines.

Methods

The Wisconsin Cancer Reporting System received notice of a community-initiated cancer cluster concern about per- and polyfluoroalkyl substances contaminated drinking water from the Bureau of Environmental and Occupational Health in late February 2023. We applied the CDC Guidelines to design a series of county-level aggregate data tables as well as review and select record-level cases for use in spatial assessment within one month's time.

Results

We experienced significant challenges applying Criteria 1-5 in Phase 2 of the CDC Guidelines—specifically: selecting appropriate reference population(s) for the community of concern for standardized incidence ratio calculations; communicating the many nuances of registry operations and data release policies (e.g. reporting schedules, release of only non-DCO cases, exclusion of cases solely reported by the VA); validating statistical models, and reviewing geocoding quality for data used in mapping the geographic distribution of cancer cases.

Conclusion

Strong working relationships between registry and environmental health staff are imperative to responsibly applying the CDC Guidelines at state and territorial public health agencies. Decisions in operationalizing the CDC Guidelines should include registry staff throughout a cancer cluster response as study populations in Phase 2 will most often be created from our data.



International Prostate Cancer Mortality Trends

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Background

Prostate cancer, the fifth leading cause of cancer death globally among men in 2020, is estimated to cause approximately 740,000 deaths by 2040. Despite this growing burden, comprehensive data on international trends in prostate cancer mortality rates is limited.

Purpose

Analyze international prostate cancer mortality trends using up-to-date data from the World Health Organization (WHO).

Methods

Population-based death registry data from 50 countries with available data between 1950 to 2019 were obtained from the WHO database, as compiled by the International Agency for Research on Cancer. Age-standardized mortality rates based on the 1966 Segi-Doll world standard population, were calculated for the most recent 5-year period of available data for each country. Trends, expressed as annual percent change (APC) and average APC (AAPC), were described as increasing or decreasing when the APC or AAPC was statistically significantly different from a two-sided p-value of <0.05, otherwise expressed as stable.

Results

Rates varied 6-fold, from 4.03 per 100,000 men in Kyrgyzstan (2012-2016) to 24.25 in Cuba (2014-2018), with the lowest rates found in most countries throughout Asia and the highest in Latin America and the Caribbean and Northern Europe. Rates began to decrease in many countries around the late 1990s to early 2000s, and stabilized in Singapore, Canada, Poland, Estonia, Croatia, Greece, and Austria around the late 2000s to early 2010s. In contrast, rates began to increase in Bulgaria, Romania, and Cuba since 1982 and in the Kyrgyzstan and Slovakia since the mid-to-late 2010s. During the most recent 5-year period, mortality rates decreased, on average, for 37 of the 50 countries analyzed, ranging from 3.5% per year in Israel to 0.4% per year in Mexico. In contrast, rates increased in 5 countries, from 4.7% per year in Slovakia to 0.8% per year in Ecuador, and stabilized in 8 countries.

Conclusion

While many countries experienced decreasing mortality rates during the most recent 5-year period, rates in 13 countries increased or stabilized. This variation may be due to heterogeneity in the introduction and dissemination of Prostate-Specific Antigen (PSA)-based testing and early diagnosis, prevalence of certain risk factors such as genetic susceptibility, and access to care and treatments.

Key Findings from the NCRA-UCSF Hospital Workload Study

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Background

Cancer registrars (CRs) are vital to cancer surveillance and monitoring. Foundational CR work includes collecting, coding, and reporting national cancer data. However, cancer registry work extends far beyond these processes. Previous research and staffing guidelines have been used to inform staffing decisions and advocate for staffing needs.

Purpose

The purpose of this study is to update guidelines by documenting and quantifying the workload of hospital-based CRs and to collect qualitative data about the role and skills required for future activities.

Methods

Two surveys were conducted: the Registry Lead Survey (RLS) and the Cancer Registrar Survey (CRS). Survey development was informed by cancer registry experts, and both surveys were pretested. The RLS was sent to all self-identified registry managers/leads working at hospital-based registries in the National Cancer Registrars Association's membership database. RLs were asked to send the CRS to their CR staff. Post-survey interviews were conducted with experts and leaders in the cancer registry industry.

Results

RLs were most concerned with recruiting well-trained staff (87.6%), compensating staff well enough to retain them (82.3%), and funding additional positions (77%). About 25% of registries reported that they had vacant positions and expressed concern about filling them. About 28% of CRs had 1-5 years of experience in the profession and nearly 25% of CRs had more than 20 years' experience, with about 28% planning to leave the profession in the next five years. Reported case completion times are about 1 hour for simpler cases and 1.5 hours for more complex cases. A model using data from the RLS survey indicated that caseload is the dominant consideration when determining staffing. An additional consideration is the type of institution served, multi- or single. Post-survey interviewees opined that myriad artificial intelligence (AI) based technologies will automate certain tasks and can help to recover some of registrars' time.

Conclusion

AI will shift the responsibilities of CRs, but it will not eliminate the role. Attracting new people to the field and training them in the appropriate areas is more critical than ever given existing shortages. RLs can use these results to develop their own workload and productivity standards and staffing guidelines.



Minimized Data Set for Early Reporting in Rhode Island

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Background

In 2018, the RI Cancer Registry changed their Rules and Regulations to include “Each health care facility and/or health care provider shall submit a set of available information on reportable cases within thirty (30) to forty-five (45) days from the date of a case first seen by provider” (RI DOH Rules and Regulations). After numerous meetings with hospital registry staff members, RICR has agreed to change the Rules and Regulations to sixty (60) days from the date of first contact. This change is currently in the process of being updated.

Purpose

Changing the time to report will give the central registry more complete information within each abstract with the minimized data set. These abstracts will be incorporated into the registry system quicker so that the information can be used for data requests or other purposes in the state of RI. This could also assist in casefinding audits.

Methods

- Provide facilities with a minimized data set.
- Ask that they send the ‘suspense’ cases from the 2 months prior (example: current month is April, they will send suspense cases from February).
- Ensure that all facilities are sending a complete minimized data set.

Results

Changing from 30-45 days to 60 days in reporting yielded great results. With most RI reporting facilities using the minimized data set, they can provide a more complete minimal abstract that the registry will be able to use.

Conclusion

Getting data quicker can be completed using a minimized data set. Currently, we are receiving the minimized data set through Excel. In the future, we will be asking all reporting facilities to report the minimized data set through XML format. The central registry will then incorporate these cases into the registry system for complete use.

Misclassification of Adult T-cell Lymphoma/Leukemia Deaths in Florida

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Background

Adult T-cell lymphoma/leukemia (ATLL) (ICD-O-3 code 9827.3) is a rare cancer with low 5-year survival (28%) caused by human T-cell lymphotropic virus type 1 (HTLV-1). US HTLV-1 prevalence is low, but infection is endemic in areas of the Caribbean, South America, and Africa, leading to a seemingly higher ATLL risk among specific US populations including Afro-Caribbean people, who make up a considerable portion of the Florida population. ATLL is preventable through control of HTLV-1 vertical transmission.

Purpose

To help inform ATLL public health measures among high-risk groups in the US [as birth country is more complete in mortality Vital Statistics (VS) than in registry data], a validity study is needed to measure the extent of misclassification present for ATLL deaths among hematological cancers in relation to the respective cancer registry incident case.

Methods

All decedents by hematological causes (ICD-10 codes C81-C96) with incident cancer during 2005-2018 were collected from the Florida Cancer Data System (FCDS) inclusive of ATLL deaths (ICD-10 C91.5). Validity of cause of death ATLL was estimated by sensitivity and specificity calculations using FCDS data as the gold standard.

Results

Of 58,244 total hematological cancer deaths, there were 159 ATLL deaths documented in Florida VS, and 271 deaths among 381 FCDS ATLL cases. The sensitivity of VS ICD-10 ATLL was 19.2% (95%CI: 18.9%-19.5%), while the specificity was 99.8% (95%CI: 99.8%-99.8%). Over two thirds of VS ATLL deaths were false positives (67.3%, 107/159) with a low positive predictive value of 32.7%. Of the 159 VS ATLL deaths, FCDS had 8.8% recorded as peripheral T-cell lymphoma, 10.1% T-cell prolymphocytic leukemia, 7.5% T-cell lymphoblastic leukemia/lymphoma, 5.0% chronic lymphocytic leukemia, 5.7% T-cell large granular lymphocytic leukemia, and 30.2% other diseases.

Conclusion

Accuracy of ICD-10 mortality coding for ATLL is very poor (sensitivity <20%), with extensive misclassification across hematological cancers and other diseases. Two major issues which hinder ATLL population-based research: 1) the lack of validity among ATLL mortality data, and 2) the lack of specific racial-ethnic data among incidence registry data precluding the study of the groups most affected by this preventable disease.



Ohio Melanoma Reporting System

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Background

The Ohio Partners for Cancer Control (OPCC) Skin Cancer and UV Protection Workgroup, in collaboration with the state central cancer registry (Ohio Cancer Incidence Surveillance System, "OCISS"), developed goals to improve skin cancer case reporting in Ohio. The group developed a system for increasing the number of dermatology practices submitting skin cancer cases to OCISS, which involved a diverse group of partners and stakeholders.

Purpose

To improve skin cancer data collection accuracy in Ohio; to provide real-world abstracting experience for graduating Health Information Management (HIM) students; to increase awareness of and compliance in cancer reporting for physicians in Ohio; saving physician office staff time and resources.

Methods

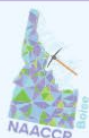
The system requires four (4) fundamental partners: the dermatology partner, the university partner, the central registry partner, and the individual dermatology offices. The dermatology partner and university partner are responsible for the secure transmission of health records needed for abstracting by the students. To do this, the dermatology partner established a secure HIPAA fax line for use by all dermatology offices to securely transmit relevant patient information to the university partner. Once received, the university partner stores the records in the appropriate provider's secure folder and assigns that folder to a student. Students can access the secure folders within the secure school software. Students then abstract the cases based on the information provided by the dermatology offices and upload them directly to OCISS via WebPlus. Once reporting is complete, folders are destroyed for security purposes.

Results

Currently there are seventeen providers reporting to OCISS through the Ohio Melanoma Reporting System; none of these providers were previously reporting to OCISS. Four graduating classes of students have successfully abstracted skin cancer cases in real time, earning valuable, practical cancer case abstraction experience.

Conclusion

The Ohio Melanoma Reporting System has been a success and has increased melanoma case reporting to OCISS from the previous year. HIM students receive valuable work skills to use after graduation. Dermatology offices are now in compliance with state cancer reporting requirements, without the need to reallocate staff. This system allows dermatology offices to save time and resources that would otherwise be devoted to cancer reporting.



Opportunities and Challenges Linking Central Cancer Registry and Clinical Databases Data

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Background

The Manitoba Cancer Registry (MCR) is legally mandated to collect, organize and analyze data for all individuals in Manitoba with a cancer diagnosis. The CAISIS Chronic Lymphocytic Leukemia (CLL) database is a clinical database at CancerCare Manitoba that collects detailed clinical information from individuals seen at CCMB. Linkage between these two data sources offers great potential to answer many epidemiologic, health services, clinical and translational research questions. We report on our experience linking these two data sources for a multidisciplinary translational research study.

Purpose

To review and highlight key considerations when linking central cancer registries with clinical databases.

Methods

The MCR and CAISIS databases were both used to identify individuals diagnosed with CLL from 2006 to 2019 in Manitoba, Canada. The MCR contributed demographic, diagnosis, staging and high-level treatment information. CAISIS contributed demographic, diagnosis, progression, disease-specific staging, detailed treatment and diagnostic testing information. As part of the linkage process, concordance in diagnosed malignancy and diagnosis date was measured. Malignancies and dates of diagnosis were noted to exist in either or both datasets, and a review of diagnoses with a different malignancy or diagnosis date was completed.

Results

A total of 1808 diagnoses were identified, sixty-six percent (n=1204) of diagnoses were found in both data sources, 28% (n=516) were only in the MCR, and 5% (n=88) were only in CAISIS. Of those found in both datasets, 4% (n=50) had different malignancies, 8% (n=99) differed by diagnosis date, and 3%(n=33) differed by both malignancy and diagnosis date.

Conclusion

Differences between the two data sources are expected given inclusion, and data collection/coding practices differ. The MCR is a province-wide registry that registers all cancer cases regardless of treatment location, but follows strict coding rules that are not as flexible to incorporating new knowledge compared to a clinically-managed database. Due to discordance likely caused by different methods of data acquisition, it is important to verify the linkage, harmonize variables collected and resolve differences prior to analyses. Ongoing communication between registry and clinic personnel to review case registrations and update disease and treatment details is an essential component to ensure data are useable and accurate before use.

Ovarian Cancer Survival in a Brazilian State with Medium Human Development Index (1996-2017)

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Background

Ovarian cancer survival in low- and middle-income countries tend to be lower compared to high-income countries. Access to quality healthcare and socioeconomic factors contribute to this disparity.

Purpose

Our objective was to describe trends in ovarian cancer in Sergipe, Brazil, by histological group.

Methods

We analysed individual data from the Aracaju Cancer Registry on women aged 15 to 99 years diagnosed with a cancer of the ovary, fallopian tube, uterine ligaments and adnexa, peritoneum or retroperitoneum, other specific and unspecified female genital organs, in Sergipe, Brazil, over five periods (1996-1999, 2000-2004, 2005-2009, 2010-2014, 2015-2017), with follow-up to 31 December 2022. After application of the quality control procedures developed for the VENUSCANCER project, of 1,131 registrations, 948 eligible patients were included in survival analyses. We determined one- and five-year net survival using the Pohar-Perme estimator and age-standardised with the International Cancer Survival Standard weights. These estimates were stratified by histological group. To adjust for background mortality, complete life tables (single year of age 0-99 years) of all-cause mortality rates among women in Sergipe were constructed for each calendar year 1996-2022.

Results

One-year net survival ranged from around 60-70% during 1996-2017, while five-year survival varied from 31-47%. Epithelial type I tumours accounted for approximately a quarter (24.9%) of cases, whereas type II constitutes over half (56.1%) of the cases. One-year survival for type I and type II were comparable, at around 67-68.5% in 1996-2017. However, five-year net survival for type II tumours was 32.5%, in contrast to a higher survival of 52% for type I. Over time, there was an increase in survival for type II tumours, going up from 55.4% (2000-2004) to 69% (2015-2017) at one year, and from 22.3% (2000-2004) to 37.4% (2015-2017) at five years.

Conclusion

Survival trend for ovarian cancer remained relatively stable over time. Notably, type II epithelial tumours, accounting for over half of the cases, presented a lower five-year survival rate compared to type I tumours. The observed disparities in healthcare infrastructure and resources in regions with a medium Human Development Index could potentially impact the survival outcomes for patients with ovarian cancer.

Overall Cancer Survival: A Decade-Long Analysis at Cancer Center in Brazil, from 2000 to 2017

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Background

Hospital Cancer Registries (HCR) are sources of information about cancer, including diagnoses, clinical characteristics, treatment, and short- and long-term outcomes. The HCR at A.C.Camargo Cancer Center (ACCCC) has been active since 2000, recording new cases diagnosed and/or treated at the institution.

Purpose

This study aimed to analyze the overall survival of the ten most common cancer types within the institution, by sex and period, between 2000 to 2017.

Methods

Survival analysis utilized HCR data extracted on August 10, 2022, focusing on cases diagnosed from 2000 and 2017. Overall survival was calculated for ten most common cancer by sex (oropharynx, oral cavity, stomach, colorectal, lung, melanoma of skin, kidney, bladder, thyroid, Hodgkin's lymphoma; and tumors exclusive to a single sex as prostate, female breast, cervix and uterine corpus) across three five-year periods (2000-2004, 2005-2009, and 2010-2014) and one three-year period (2015-2017) applying the log-rank test with a significance level of $p < 0.05$ was applied using IBM® SPSS Statistics (version 23).

Results

More than 33,000 cases were analyzed, an increasing five-year survival probability for the top ten cancers in both sexes from 2000 to 2017 was observed principally in females. For adenocarcinoma of the lung (C34), the survival rate rose from 10.4% (2000-2004) to 51.1% (2015-2017) in males and from 18.8% (2000-2004) to 59.0% (2015-2017) in females. For adenocarcinoma of the stomach, the probability of five-year overall survival increased from 25.2% (2000-2004) to 51.0% (2015-2017) in males and from 31.3% (2000-2004) to 58.5% (2015-2017) in females. Increases in survival occurred for papillary thyroid adenocarcinoma in males and Hodgkin's lymphoma in both sexes, although with no difference among periods. Survival decreased for bladder carcinoma in females during the period 2015-2017.

Conclusion

The overall survival rates for the analyzed cancers increased in periods analyzed, with better survival observed in the most recent period (2015-2017) in females. These observed increases in survival from 2000 to 2017 reflect the ACCCC's commitment to embracing innovations in oncological diagnosis and treatment, providing patients with improved resources for therapeutic success.

Pancreatic Cancer in Manitoba: An Assessment of Incidence, Mortality and Net Survival

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Background: Recent findings from the Canadian Cancer Society's 2023 report show that pancreatic cancer mortality is on the rise and is projected to be the third leading cause of cancer death in Canada for both sexes and Canadians 60 years of age and older.

Purpose

We evaluated pancreatic cancer incidence trends from 2007 to 2021, mortality trends from 2018 to 2021, and 5-year net survival in Manitoba using the Manitoba Cancer Registry data.

Methods

Data obtained on individuals diagnosed with invasive pancreatic cancer was stratified by sex, stage at diagnosis, age group (≤ 69 yrs, 70-79 yrs, and ≥ 80 yrs), and residence type (rural or urban). Rates were based on the number of cases and deaths among the Manitoba population and standardized to the 2011 Manitoba population. Time trends were analyzed using Joinpoint regression software and 5-year net survival was estimated using the cohort method for cases diagnosed from 2007 to 2016 and the period approach for cases diagnosed from 2017 to 2021.

Results

2,677 cases of invasive pancreatic cancer were diagnosed over the 15-year period with rates increasing from 2007 to 2010 but remaining relatively stable from 2011 onwards. Most cases were diagnosed at Stage IV, higher in males, and primarily among people aged 70 and above. Urban residents had higher rates of pancreatic cancer from 2007 to 2016 but declined from 2016 to 2021. For mortality, 667 deaths occurred between 2018 and 2021 but demonstrated an annual decline. Mortality rates are higher for unknown-staged tumours, in males, among people aged 70 years and above, and urban residents. 5-year net survival is generally low, but a 5% increase occurred between the 2007-2016 period and the 2017-2021 time period.

Conclusion

This study is a preliminary assessment of the pancreatic cancer landscape in Manitoba. These results serve as a baseline for further investigation that can highlight gaps and opportunities for pancreatic cancer control strategies, identify priority areas for clinical and health services research, and inform prevention and screening initiatives for early detection of pancreatic cancer in Manitoba.

Patient Compliance with Recommended Cancer-Directed Therapy in Hawaii

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Background

Cancer-directed treatment plays a critical role in cancer outcomes. There is limited population-based information on patient compliance with recommended treatment regimens.

Purpose

Our objective was to evaluate cancer patient treatment compliance, including variation by demographic and clinical factors and its impact on survival.

Methods

We evaluated treatment compliance among Hawaii residents diagnosed with cancer in 2006-2019 using statewide registry data.

Results

Overall, among all patients for whom cancer-directed treatment was recommended, receipt of treatment was highest (93%) for surgery and lowest (79%) for chemotherapy. Significant differences were observed by stage, age, sex, race/ethnicity, and Yost socioeconomic index ($p < 0.0001$). Treatment refusal was higher for patients with localized compared to those with advanced cancers for chemotherapy (20% vs. 13%) and hormonal therapy (7% vs. 5%). Treatment refusal was higher for patients aged 60+ compared to those <60 years for surgery (4% vs. 1%), radiation (5% vs. 3%), chemotherapy (18% vs. 8%), hormonal therapy (7% vs. 5%), and biological response modifiers (9% vs. 4%). Refusal of chemotherapy was 16% among females compared to 13% among males. Refusal of radiation ranged from 3% for Filipinos to 6% for Whites and refusal of chemotherapy ranged from 11% for Filipinos to 16% for Whites. Comparing the lowest to the highest SES levels, treatment refusal varied for chemotherapy (16% vs. 14%) and radiation (6% vs. 3%).

Five-year cancer-specific survival significantly varied by treatment compliance. Among surgery-recommended patients, survival was 85.7% (95% CI 85.4 - 86.1) for treatment receipt, 53.4% (51.6 - 55.2) for treatment not given/unknown, and 42.2% (39.3 - 45.0) for treatment refusal. For radiation, survival was 72.4% (71.8 - 73.0) for treatment receipt, 71.7% (68.4-74.7) for treatment not given/unknown, and 53.5% (50.1-57.0) for treatment refused. For chemotherapy, survival was 56.3% (55.7 - 57.0) for treatment receipt, 39.0% (36.6-41.3) for treatment not given/unknown, and 42.5% (40.9-44.0) for treatment refused. Survival differences were also observed for hormonal and biological response modifier therapies.

Conclusion

Treatment compliance, including refusal of therapy, varies by patient and clinical characteristics. Treatment refusal is associated with poor survival outcomes. The reasons for treatment refusal warrant further investigation.

Population-Based Survival from Advanced Melanoma among Adolescents and Young Adults since the Widespread Use of Immunotherapy Treatments: Is it Getting Better?

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Background

Melanoma survival remains understudied among the adolescent and young adult population (AYA; ages 15-39 at time of diagnosis). Advanced melanoma outcomes were historically poor. Since immunotherapy was first approved in 2010, advanced melanoma survival has improved greatly, increasing from a median of about 6 months to 6 years for stage IV melanoma, based on data from clinical trials with long-term follow-up data. It is unclear if gains in survival from advanced melanoma are observable in population-based data, and whether improvements are similar across age groups, specifically for AYA patients with advanced melanoma.

Purpose

This population-based study aims to examine age-group-specific survival to determine if disparities in survival from advanced melanoma are observable in the era after immunotherapy usage became available.

Methods

Cutaneous cases of AYA melanoma in 2010-2021 from the California Cancer Registry will be included. Frequencies/percents of melanoma by sociodemographic and clinical characteristics, including sex, age group (15-39y, 40-64y), race/ethnicity, socioeconomic status (SES), insurance type, and stage at diagnosis, along with immunotherapy as a first course of treatment for advanced stages, will be described. Kaplan-Meier estimates will be used to examine the probability of survival by sex, stage, and age group. Cox proportional hazard regressions with adjustment for confounding will be used to evaluate survival from late-stage vs early-stage melanoma.

Results

Age-group-specific survival from advanced melanoma by sex, race/ethnicity, SES, insurance type, and stage at diagnosis will be presented using Kaplan-Meier graphs and hazard ratio estimates with 95% confidence intervals.

Conclusion

Immunotherapy use has led to dramatic improvements in survival from advanced melanoma. However, the literature largely reflects older adults, remaining less well-examined among AYAs, who may not have equal access, impacting their survival. In our prior study, we observed worse survival from advanced melanoma for AYAs vs older adults, during a period prior to widespread use of immunotherapy. In this study, we will report whether evidence of improved AYA survival from advanced melanoma may be observable by using data from the period after immunotherapy was first approved. Should a sustained disparity in AYA survival from advanced melanoma be observed, further study of AYA melanoma would be needed.

Regional Differences in Lung Cancer Survival: The Tennessee Story

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Background

In Tennessee, lung cancer was the first leading cause of cancer incidence and death by numbers of cases with 5530 diagnoses and 3974 deaths recorded in 2020. Studies suggest that new cases of and deaths from lung cancer are more common in rural areas. Recent studies suggest overall lung cancer survival is poorer in more rural areas compared to urban areas.

Purpose

To analyze Tennessee-based regional differences in overall lung cancer survival and factors associated with poor survival using Kaplan-Meier and Cox Proportional Hazards analysis

Methods

The lung cancer dataset includes 40797 cases diagnosed during 2010-2016. Univariate and bivariate analyses were conducted using the Kaplan-Meier method. The dependent variable in all analyses was follow up time in days, which was determined by calculating the difference between the Date of Last Contact variable and the Diagnosis Date variable. The chief covariate of interest was TN Department of Health region, which was stratified into 8 separate regions: Northwest, Southwest, Mid-Cumberland, South Central, Upper Cumberland, Southeast, East, and Northeast. Analyses were adjusted using sex, age at diagnosis, race, stage, primary payer at diagnosis, and tumor histology. Sex was classified into males and females. Age at diagnosis was a continuous variable. Race was classified into Black, Other, and White. Stage was classified using SEER Summary Stage 2000 as early stage (in situ and localized) and late stage (regional and distant stage). Primary Payer at Diagnosis was classified into insured and uninsured. Tumor histology was classified as Squamous Cell Carcinoma, Small Cell Carcinoma, Adenocarcinoma, Large Cell Carcinoma, and Other. The event of interest in all analyses was death due to lung cancer, and censoring was employed for non-events.

Results

Univariate and bivariate analyses using the Kaplan-Meier method revealed the poorest overall survival occurred in the Northwest region of Tennessee. Multivariate Cox Proportional Hazards analysis demonstrated the Northwest region continued to display a marked survival disparity compared to all other Tennessee regions, with an average hazard ratio for the other regions of 0.90.

Conclusion

The Northwest region of Tennessee, a highly rural region, displayed significant lung cancer survival geographic disparities. These results confirm the findings of other recent studies.



Reviewing of GenEDITS on Cancer Data Collected in New Hampshire

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Background

GenEDITS is an application developed by the National Program of Cancer Registries (NPCR) to identify errors in cancer data collected by cancer registries. Raw cancer data received by reporting facilities at the New Hampshire Cancer Registry (NHSCR) are run through GenEDITS before they are processed into the main system. Feedback on errors is sent to individual reporting facilities in an effort to improve data quality at the reporting source.

Purpose

We will utilize the findings of this assessment for data quality improvement and to identify areas of opportunity for training.

Methods and Results

The NHSCR runs GenEDITS every month and generates reports for each reporting facility to identify common errors using pivot tables. We will tabulate the type and number of errors seen in the raw data received in calendar years 2022 and 2023. We will assess if the top errors are reduced with the monthly feedback to the reporting facilities. Repetitive cases will be selected and analyzed to identify the root causes of errors and determine where training is needed.

Conclusion

Findings will be shared with the reporting facilities and will be used to address training needs.

Spatio-temporal Modeling Approach to Mapping Geographic Variation in Cancer Incidence Rates for U.S. Subnational Areas

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Background

Mapping plays a crucial role in spatially analyzing and visualizing cancer incidence distribution within specific geographic areas. While previous literature has predominantly focused on reporting and mapping variations in cancer incidence by state, limited information is publicly available at the county level especially for less common cancer sites. Counties with sparse data often face masking due to instability and confidentiality concerns.

Purpose

This research aims to explore suitable spatio-temporal small area models for estimating age-adjusted cancer incidence rates for all U.S. counties, with the objective to create maps that identify patterns and hotspots through comprehensive mapping.

Methods

U.S. cancer counts for 16 cancer sites ranged from common to rare cancers from 15 diagnosis years, specially 2005-2019, were obtained from NAACCR's CiNA Research Dataset. County-level hierarchical spatio-temporal models incorporating ecological covariates obtained from alternative sources, assuming a standard Poisson distribution and several extensions to address sparseness and zero inflation were implemented using R-INLA. Rigorous model selection and diagnosis processes were carried out to identify the best models.

Results

This presentation will include a summary of the model selection and evaluation results. Modeled age-adjusted rates for 3,142 counties for each year from 2005-2019, based on the ultimately selected models, will be generated. Maps derived from modeled estimates will be created to discern trends and patterns, allowing for a comparison with maps based on observed data with suppression.

Conclusion

The spatio-temporal modeling approach proves useful in smoothing and estimating age-adjusted rates for all the U.S. counties. These modeled estimates serve as a useful resource for studying trends, patterns, and disparities in cancer incidence among U.S. counties. The product offers insights for identifying focus areas in cancer intervention and guides further research.

Statewide Linkage Study of Salmonella Infection and Colorectal Cancer Incidence in Michigan, United States

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Background

Non-typhoidal Salmonella infection is one of the most common foodborne illnesses and its oncogenic potential has been documented in animal models. This study is the first to attempt linking two statewide public health surveillance registries (communicable disease and cancer) to assess the feasibility of addressing epidemiologic association between laboratory-confirmed salmonellosis and the subsequent risk of colorectal cancer. Further, we established an efficient method of linking two public health registry systems under the condition of lacking pivot unique identifiers (Social Security Number, SSN).

Methods

Records with positive laboratory test for enteric Salmonella between 01/01/1992 to 12/31/2020 were linked to LexisNexis database for the period of January 1992 to February using address, date of birth (DOB) and names. Information such as SSN, address history, deaths in Michigan or other states were obtained through this linkage. Second linkage occurred by using SSN, names and DOB to link records in Michigan Cancer Surveillance Program. the standardized incidence ratio (SIR) was calculated with the consideration of age, sex and specific calendar year with the assumption of Poisson distribution.

Results

93% of the initially identified Salmonellosis records diagnosed between 1992 and 2020 (n=16,179) were sent to LexisNexis linkage, which returned address history, death, and social security number for 97% of these records (N=15,734). Further linkage to the statewide cancer registry identified 98 incident colorectal cancer cases from diagnosed of infections till 12/31/2020. Overall, the standardized incidence ratio compared with general population was not different from unity (0.833 with 95% confidence interval 0.627-1.003).

Conclusion

While the new linkage strategy was found effective, we cannot rule out bias due to incomplete/under reporting in estimating the risk associated with Salmonellosis.



The Burden of High-Risk Hereditary Breast and Ovarian Cancers (HBOC) in New Jersey

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Background

Hereditary breast and ovarian cancer syndrome (HBOCS) increases the risk of developing breast, ovarian, and other cancers; however, the true burden of HBOCS-related cancers remains unclear at the population level.

Purpose

To estimate the age-adjusted incidence rate of high-risk HBOCS (HR-HBOCS) related breast and ovarian cancers in New Jersey (NJ) and compare racial/ethnic and stage patterns between HR-HBOCS cancers and all breast and ovarian cancers statewide.

Methods

We used 2015-2019 breast and ovarian cancer data from the New Jersey State Cancer Registry. The HR-HBOCS cancer definition was based on diagnostic criteria from the 2021 National Comprehensive Cancer Network® guidelines. Age-adjusted incidence rates (AAIR) per 100,000, rate ratios (RR), and 95% confidence intervals (CI) were generated in SEER*Stat.

Results

The AAIR of HR-HBOCS-related cancers in NJ women was 50.6. Among Hispanic women, the rate was significantly higher in Hunterdon County (AAIR 115, 95%CI: 68.4-181.1) compared to statewide (AAIR 40.6, 95%CI: 38.7-42.6). Compared to non-Hispanic Whites, the AAIR was significantly lower for non-Hispanic Asian/Pacific Islanders (RR 0.85, 95%CI: 0.80-0.91), Hispanics (RR 0.74, 95%CI: 0.70-0.79), and non-Hispanic Blacks (RR 0.90, 95%CI: 0.85-0.95). Compared to local-stage ovarian cancer, the AAIR of distant-stage was significantly higher statewide (RR 2.59, 95%CI: 2.37-2.83) and among those with HR-HBOCS (RR 3.22, 95%CI: 2.93-3.55). The AAIR of regional-stage ovarian cancer was only significantly higher for the HR-HBOCS group (RR 1.21, 95%CI: 1.08-1.36).

Conclusion

We uncovered potential racial/ethnic and county-level differences and a greater burden of late-stage cancers related to HBOCS. Quantifying population-level HR-HBOCS cancers and identifying high-incidence areas represent the first steps toward understanding the true burden in affected populations. Policies supporting the collection of genetic data at the population level are needed to accurately quantify the population at risk.

The Effect of Major Events on Breast Cancer Incidence Trends in Puerto Rico: An Interrupted Time Series Analysis

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Background

During 2016 to 2020, breast cancer was the most common diagnosed cancer among Puerto Rican women. During this period, PR was affected by two major events that disrupted its health system.

Purpose

This study aims to assess the effects of the Hurricanes (Irma and Maria), post-hurricanes recovery peak, and the COVID-19 lockdown restrictions on the breast cancer cases in PR.

Methods

PR Central Cancer Registry database was used to obtain the breast cancer counts diagnosed from 2012 to 2021. An interrupted time-series analysis was used to assess the following: 1) estimate the changes in the breast cancer counts after each event, 2) determine trends in each time period, and 3) to estimate the difference between the observed cases count and the expected count without the event. We analyzed four time periods: 1) prior major events (January 2012 to August 2017), 2) after the hurricanes (September 2017 to March 2018), 3) after post-hurricane recovery peak (April 2018 to March 2020), and 4) start of COVID-19 restrictions (April 2020 to December 2021). To accomplish our aims, we used Prais-Winsten AR (1) regression to fit our data using first-order autoregression.

Results

A steady trend in the monthly breast cancer cases was observed from January 2012 to August 2017. Immediately after the hurricanes, the breast cancer cases count dropped 53% of the estimated count, followed by an upward trend of 24.8 cases per month. Case counts similar to the pre-hurricane period were observed at the end of this period. A second major drop was observed immediately after COVID-19 restrictions, reaching only 35.7% of the estimated counts, followed by a positive trend of 4.55 cases per month until the end of 2021.

Conclusion

Our analysis supports that these major events had great impact on the breast cancer incidence in PR. After the major events, the case count drops substantially but gradually returns close to the estimated count. Further research is needed to understand the different factors that could be additionally associated with the changes in the breast cancer incidence in PR.

The Impact of COVID-19 on Cancer Incidence Projections in Manitoba, Canada

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Background

Cancer projections inform capital planning and service delivery, provide a basis for risk reduction strategies, and give an indication of time trends. Anomalous data points in Manitoba cancer surveillance data due to the COVID-19 pandemic have made it unclear if, or how, these disruptions should be handled when estimating cancer projections. The National Cancer Institute has proposed the exclusion of 2020 incidence data from trends estimates and to observe a wait-and-see approach going forward to determine if 2020 data should continue to be excluded or reincorporated into analyses. The Manitoba Cancer Registry has begun the process of updating its cancer projections for its next 5-year cycle and is investigating if, and how, data points impacted by COVID-19 should be handled.

Purpose

To investigate the impact of excluding or replacing pandemic period estimates with expected incidence counts and age-standardized incidence rates (ASIRs) on cancer incidence projections.

Methods

To investigate the impact of the COVID-19 period (2020 to 2021) on projected cancer incidence, the number and ASIR for all invasive cancer diagnoses will be estimated (1) without adjustment for the COVID-19 period, (2) by replacing the 2020 and 2021 incidence counts and ASIRs with counts and ASIRs expected in the absence of COVID-19, and (3) by excluding the 2020 and 2021 counts and ASIRs. Within these scenarios, additional sensitivity analyses comparing the impact of using low-, medium-, and high-level population growth projections will be investigated. Expected counts/ASIRs will be estimated using generalized linear models within an interrupted-time series analysis to account for baseline trends in the historical data. Projected counts and ASIRs will be estimated over a 25-year period using the CanProj package in R. Joinpoint regression models will be used to visualize incidence trends throughout the observed data period.

Results

Line and scatterplots, in combination with Joinpoint, will be used to visualize the historical and projected incidence trends. The results will be presented for the province overall, by sex (female/male), and region.

Conclusion

This work will examine the impact of COVID-19 on projected incidence in Manitoba and provide the basis for selecting appropriately fit projection models.

Trends in Breast Cancer Incidence Rates by Estrogen Receptor Status in the United States, 2004-2020

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Background

Prior studies have shown a rising incidence of estrogen receptor (ER)-positive breast cancer but falling ER-negative breast cancer in the United States. Whether this trend has continued, however, is unknown.

Purpose

To examine the most recent trends in breast cancer incidence trends by ER status in the United States.

Methods

Female malignant breast cancer cases of ages 20 to 84, diagnosed from 2004 to 2020, were identified in the U.S Cancer Statistics database. Unknown ER status was corrected using a simple imputation that incorporated age and year of diagnosis and race and ethnicity. Trends in incidence rates were quantified with joinpoint regression model and estimated annual percent change (APC) in age-standardized incidence rate per 100,000 woman-years were calculated overall and by race and ethnicity (non-Hispanic American Indian or Alaska Native (AIAN), non-Hispanic Asian or Pacific Islander (API), non-Hispanic Black (Black), Hispanic, or non-Hispanic White (White)).

Results

A total of 3,081,142 breast cancer cases were identified. After correcting unknown ER status (N=170,405, 5.5%), 81.6% of women had ER-positive cancer, while 18.4% had ER-negative cancer. From 2004-2009, the incidence rate of ER-positive cancer increased by 1.75% annually (95%CI=1.26%-3.15%), and the increase decelerated to 0.87% per year (95%CI=0.41%-1.03%) from 2009-2019. The increase in ER-positive cancer was steady among API (APC=2.27%; 95%CI=2.05%-2.52%) and Hispanic (APC=1.47%; 95%CI=1.21%-1.78%) women, while the increase slowed down among White women and stabilized among Black and AIAN women since around 2010. Meanwhile, the incidence rate of ER-negative cancer decreased by 3.13% annually (95% CI= -4.2% to -2.55%) from 2004-2012 and then flattened (APC=0.55%; 95%CI= -1.30% to 0.92%) with generally similar trends were observed across all racial and ethnic groups.

Conclusion

The contemporary rise in breast cancer incidence in the US is due to a continuous increase in ER-positive cancer, coupled with the recent plateauing of the rapid decline in ER-negative cancer. These trends align with the slowdown in the decline of breast cancer death rates, potentially halting the progress made against breast cancer death rate. Further research is imperative to identify risk factors responsible for the observed trend to inform preventive strategies.

Trends in Lung Cancer Incidence in Maine by Sex and Age Group

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Background

While lung cancer rates have declined over the last twenty years, Maine's lung cancer incidence rate remains significantly higher than the United States; Maine's lung cancer incidence rate is the fifth highest in the nation. Lung cancer is the most common cancer in Maine overall and among Maine males. It is the second most common cancer among Maine females after breast cancer.

Purpose

To assess whether Maine data reflect recently published national trends where rates of lung cancer among women under 50 years of age are higher than rates of lung cancer among men under 50 years of age.

Methods

Using SEERStat software, we assessed Maine's overall and age-specific trends in lung cancer incidence by sex between 2000 and 2019. We used Joinpoint software to analyze overall trends. For age-specific analyses, we analyzed five-year age groups for ages 35 to 54 and non-overlapping five-year aggregate rates estimates for 2000-2004 through 2015-2019 to improve statistical reliability due to small numbers.

Results

In 2000, the age-adjusted lung cancer incidence rate was substantially higher among Maine males than females. Over the last 20 years, rates among Maine males declined significantly, while rates among females remained stable. The overall age-adjusted incidence rates converged over time, though the rate among males remains significantly higher than among females. In the most recent 5-year time period (2015-2019), the age-specific rates among those 35-54 were higher among females than males in each age group. Age-specific trends appear similar for males and females in each age group among those 35-49, but rates among males are decreasing while those among females are increasing among those 50-54. Above age 55, male incidence rates remain higher than female rates.

Conclusion

There has been a greater decline in lung cancer incidence rates among men in Maine compared with women from 2000-2020. In the most recent five years, women ages 35-54 years of age have higher age-specific rates of lung cancer than men, though the differences were not statistically significant. Currently only 1 in 5 Mainers who are eligible for lung cancer screening have been screened; screening rates by age and sex should be assessed.

Two Breast Cancer Risk Prediction Models Based on the Universal Mammography Screening Program of Taiwan

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Background

Breast cancer incidence rates in Taiwan have been increasing rapidly in the past three decades, and it is the most common cancer among Taiwanese women. Based on some exploratory studies, the Taiwan Health Promotion Administration has implemented a universal biennial mammography screening (UBMS) program since 2004. However, it is essential to use a validated absolute risk model for breast cancer for individualized risk assessment regarding mammography screening.

Purpose

Developing and validating the breast cancer risk prediction models for the Taiwanese population.

Methods

Based on the linkage of datasets from the UBMS from 2004 to 2019, Taiwan Cancer Registry (TCR) from 1979 to 2019, Taiwan Cause of Death Database (TCOD) from 1985 to 2019, and Taiwan National Health Insurance Research Database from 2000 to 2019, we developed and validated absolute risk prediction models for breast cancer among Taiwanese women aged 50–69. In fact, the linked dataset had a total of 1,746,580 women and was randomly divided into three disjoint datasets: one-half as the training set, one-quarter as the validation set, and the remaining quarter as the test set. Eventually, we obtained two models: one included mammography density, called the Taiwan Breast Cancer Model with mammography density (TBCM-M), and the other didn't, called the Taiwan Breast Cancer Model (TBCM). The other risk factors used included age at screening, age at menarche, age at menopause, parity, age at first birth, height, interaction between BMI and hormone replacement therapy (HRT) use, education, breast cancer family history in first-degree relatives, and breastfeeding.

Results

Both models were well-calibrated, and TBCM-M (TBCM) had an AUC of 0.60 (0.58) for predicting breast cancer occurrence in the upcoming 5 years.

Conclusion

Both models could be used to improve the early detection of breast cancer. TBCM is applicable to women without any mammography screening record, and TBCM-M is suitable for women had mammography screening results.

U.S. Cancer Statistics and Cancer Screening Change Packages: CDC Tools to Monitor Screening-Detectable Cancers and Support Delivery of Cancer Screening Services

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Background

For some cancers, regular screening tests can find cancers early, when treatment is likely to work best. CDC supports screening for breast, cervical, colorectal, and lung cancers as recommended by the U.S. Preventive Services Task Force (USPSTF).

Purpose

Assess trends from 2011 to 2020 in 4 screening-detectable cancers by stage: female breast, cervical, colorectal, and lung.

Methods

Using U.S. Cancer Statistics data, the annual percent change (APC) in age-adjusted incidence rates by stage from 2011 to 2019 was calculated with joinpoint regression. Rates were considered to increase or decrease if the APC was statistically significantly different from zero ($P < 0.05$). Rates from 2020 were calculated but were excluded from the regression models.

Results

Localized female breast cancer incidence rates increased from 77.8 to 82.6 per 100,000 women in 2011-2017 and then were stable through 2019; distant stage diagnoses were stable over the 9-year period. Localized cervical cancers were stable across the 9-year period and decreased slightly for distant diagnoses in 2014-2019 (1.1 to 1.0 per 100,000 women). Both localized and distant colorectal cancers decreased over the 9-years (localized: 15.5 to 11.8 per 100,000 persons; distant: 8.3 to 8.0). Localized lung cancers increased in 2011-2019 (11.9 to 14.7 per 100,000 persons); distant stage decreased over the 9-years (31.0 to 21.0). Across the 4 sites, rates of localized and distant diagnoses decreased by an average of 15% and 6%, respectively, between 2019 and 2020.

Conclusion

Differences were seen in the 4 screening-detectable cancers' incidence trends by stage, which may reflect variations in risk factors, shifts in screening test usage, and changes in screening recommendations. Delays in cancer screenings during the COVID-19 pandemic may have attributed to declines in localized cancer diagnoses. To improve cancer screening, CDC developed Cancer Screening Change Packages (<https://www.cdc.gov/cancer/dcpc/resources/change-packages>), which provide clinic staff and public health organizations with evidence- and practice-based strategies, tools, and resources for implementing and scaling effective screening services. The actionable strategies span the screening process, including social determinants of health, community-clinical linkages, and follow-up and referrals. U.S. Cancer Statistics data can be used to monitor population-level cancer burden and to evaluate the effectiveness of cancer screening programs.

Using AI Technology via Atlas to Streamline Clinical Documentation and Enable Data-Driven Improvement Through Analysis of Patient Data

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Background

Using AI technology, via Carta Healthcare Atlas, to streamline clinical documentation and enable data-driven improvement through analysis of patient data. Atlas uses human expertise and the power of AI to automate and simplify the resource-consuming task of finding and interpreting patient data for clinical registries.

Purpose

To streamline clinical documentation and enable data-driven improvement through analysis of patient data.

Methods

Atlas automates and simplify the resource-consuming task of finding and interpreting patient data for clinical registries. This allows clinicians to focus on what's most important — caring for patients.

Results

Atlas allows your staff to focus on other tasks while increasing data availability for your organization to access deeper data insight.

Conclusion

Atlas implementation leads to more accurate clinical registry completion and the opportunity to drive greater value from your data.

Using Available Resources to Streamline the Casefinding Audit Process

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Background

Performing a casefinding audit poses significant challenges, involving manual review for every patient listed on the medical record disease index (MRDI), visually comparing diagnosis codes to the ICD-10-CM casefinding list, and ensuring accuracy in patient details. Prior to changing the process, time spent completing an audit process ranged from several weeks to several months prompting us to identify crucial modifications in the MRDI format. Through this undertaking we discovered a change in the MRDI format was essential to make this goal achievable. Facilities were submitting their MRDI in non-standardized as a PDFs, hindering seamless conversion to Excel with no formal structure. This made it difficult when converting the PDF to Excel.

Purpose

Our objective was to streamline the audit process by leveraging Excel and Match*Pro software and shorten the audit process time.

Methods

A sample MRDI using Excel was created, placed on our website, and distributed to low volume facilities throughout the state. The process involved exporting MRDIs to Excel and utilizing the Excel match function to compare ICD-10 codes in the MRDI to the ICD-10 case finding list. This yielded a list of potential cases for review. The list of potentially reportable cases was then analyzed in Match*Pro and compared against our database. The results were consolidated, and any MRDI cases missing in the database were flagged for facility review.

Results

Recognizing the need for a modified MRDI format and process, the implementation of Excel and Match*Pro software significantly reduced the case finding audit timeline from weeks to days.

Conclusion

Utilizing Excel, Match*Pro software, and requesting MRDIs in Excel format, allowed the MCR QA staff to substantially diminish the time spent on case finding audits, transforming a lengthy process into a more streamlined process for MCR and facilities.

Utilization of First-line Targeted and Immunotherapy-Based Treatments for Stage IV Non-Small Cell Lung Cancer

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Background

Lung cancer, the third most common cancer, is often diagnosed late-stage when prognosis is poor (8.2% 5-year survival). In the past decade, an expanding array of targeted and immunotherapy-based treatments have become available for late-stage non-small cell lung cancer (NSCLC), the most common subtype.

Purpose

To quantify the utilization of targeted and immunotherapy-based treatments among patients with stage IV NSCLC and to investigate disparities by race/ethnicity, insurance type, and neighborhood socioeconomic status (SES).

Methods

We obtained data for 33,875 patients diagnosed 2016 to 2021 with stage IV NSCLC from the California Cancer Registry (CCR). We summarized first-line treatments into targeted therapy, immunotherapy, chemotherapy, and no systemic treatments using text fields from the CCR. We used multivariable logistic regression models to examine characteristics associated with treatment utilization and treatment type.

Results

Patient median age was 71 years, slightly more were male (51.7%), most were non-Hispanic White (NHW, 57.5%), and approximately half had private insurance (48.3%). The most common treatment was immunotherapy (18.2%), followed by chemotherapy (14.0%), targeted treatment (13.4%), targeted treatment and immunotherapy (2.3%), and unknown (1.8%). However, the greatest proportion of patients received no systemic treatment (50.4%). Characteristics associated with not receiving systemic treatment included older age (≥ 80 years, odds ratio (OR)=9.27, 95% confidence interval (CI) 7.90-10.88), male sex (OR=1.18, CI 1.13-1.24), American Indian race/ethnicity (vs. NHW) (OR=1.37, 95% CI 1.02-1.83), low SES (OR=1.57, CI 1.47-1.68), increasing comorbidity, non-private insurance, and treatment at non-NCI designated cancer center (OR=2.14, CI 1.99-2.30). Among patients receiving treatment, characteristics associated with receipt of targeted therapy or immunotherapy included more recent year of diagnosis, Asian/Pacific Islander race/ethnicity, high SES (OR=1.58, CI 1.43-1.75), being married, and treatment at NCI-designated cancer centers (OR=1.61, CI 1.45-1.77).

Conclusion

In this population-based study, we found low utilization of each category of systemic treatments and significant disparities by race/ethnicity, insurance type, treatment facility, and SES. The decreased likelihood of treatment for patients residing in low SES neighborhoods and with non-private insurance suggests possible financial and educational barriers. More research is needed to better understand reasons for non-treatment and efforts should be made to improve uptake among vulnerable populations.

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