



# ABSTRACT BOOK

## NAACCR Annual Conference

**June 20 - 22, 2023**

Resilience and Recovery: Charting the Path  
Forward for Cancer Surveillance



[www.naaccr23nola.org](http://www.naaccr23nola.org)

# PLENARY PRESENTATIONS

## Plenary #1 - Highlighting Local Research and COVID-19

### Social Determinants of Triple Negative Breast Cancer Disparities

**Dr. Lucio Miele**

*Cancer Crusaders Professor and Chair, Department of Genetics, Assistant Dean for Translational Science, LSU School of Medicine*

### Cancer Screening in the United States following the COVID-19 Pandemic

**Dr. Ahmedin Jemal**

*Senior Vice President Surveillance & Health Equity Science Department, American Cancer Society (ACS)*

The emergence of the Coronavirus 2019 (COVID-19) pandemic in the second quarter of disrupted delivery and receipt of routine preventive services, including cancer screening. In this talk, I will discuss changes in the receipt of screening for breast, cervix, prostate, and colon and rectum cancers during the second year following the COVID-19 pandemic overall and by sociodemographic characteristics using the 2019 and 2021 National Health Interview Survey.

Learning Objectives:

The audience will learn whether cancer screening rates in the United States returned to the pre-pandemic level during the second year of the pandemic (2020) after screening rates declined by as much as 80% during the first three months of the pandemic (March through May 2019).

### COVID-19 and Cancer: Inception, Methods, and Outcomes

**Dr. Suki Subbiah**

*Associate Professor, LSU School of Medicine*

# Plenary #2 - Cancer Surveillance Roundtable and A Day in the Life of a Registrar.

## Cancer Surveillance Roundtable

### Dr. Vicki Benard

*Chief of Cancer Surveillance Branch, Centers for Disease Control and Prevention*

### Dr. Heidi Nelson

*Medical Director of Cancer Programs for the American College of Surgeons*

### Dr. Lynne Penberthy

*Associate Director Surveillance Research Program (SRP), National Cancer Institute (NCI)*

### Betsy Kohler

*NAACCR Executive Director, NAACCR, Inc.*

This session will bring together leaders of cancer surveillance in the US for an informal discussion of challenges related to capturing data from electronic health records, artificial intelligence, changes in cancer care as it relates to surveillance, patient privacy concerns and the complexities of data sharing, to name a few. The panel will reflect on the past and look forward to the future of cancer surveillance. How should the cancer surveillance system adapt to the ever-changing needs of public health and clinical care?

#### Learning Objectives:

To better understand the National Program of Cancer Registries including our current priorities and future direction

## A Day in the Life of a Hospital Registrar

### Mr. Jim Hofferkamp

*Program Manager, NAACCR, Inc.*

During this presentation we will discuss case finding, suspense file, and abstracting. Three professional cancer registrars will discuss how they conduct these activities at their facility.

#### Learning Objectives:

1. Have a better understanding of how case finding is conducted in CoC accredited facilities.
2. Have a better understanding of how registrars use a suspense file to determine which cases need to be abstracted.
3. Have a better understanding of how abstracting is done in a CoC facility.

## Plenary #3 – National Childhood Cancer Registry

### Overview National Childhood Cancer Registry

#### Stephanie Hill

*Associate Director, NAACCR, Inc.*

The National Childhood Cancer Registry is a collaborative initiative of the National Cancer Institute's Surveillance Research Program, NAACCR, and central cancer registries. The goal is to establish an infrastructure for population-based data to support important research on cancer in children, adolescent, and young adults.

Learning Objectives:

1. Provide an overview of the NCCR initiative.
2. Describe accomplishments of the NCCR over the past year.

### Data Release Protections

#### Johanna Goderre

*Health Data Scientist of Surveillance Informatics Branch (SIB), National Cancer Institute (NCI)*

The goal of the NCI's Childhood Cancer Data Initiative (CCDI) is to improve data sharing from a broad community of groups. As part of the CCDI, the NCCR will support childhood cancer research and provide a population-level dataset on all childhood and AYA cancer patients. Data release protections are a critical component of this interconnected data ecosystem.

Learning Objectives:

1. Discuss the current and planned data uses for the NCCR.
2. Understand the strategies used to ensure data privacy and protection in the NCCR.

### National Childhood Cancer Registry Data Platform

#### Dr. Radu Robotin

*Technical Advisor, National Cancer Institute*

The NCCR Data Platform is designed to meet the needs of researchers and investigators who require access to vast amounts of data in a secure, anonymized, and de-identified manner. The platform allows users to build cohorts and request access to data, which is managed and reviewed by the platform. Reviewers can approve or reject data requests, and once a request is approved, the dataset is automatically cut, packaged, and delivered to the workspace, where it is available for a limited time. One of the key features of the platform is its ability to provide users with an analytical layer over the data. Users can apply pre-built reports and spin up cloud-based analytical environments that are isolated and unique to each project. The platform supports R code in an R-studio environment, Python scripts in a Jupyter notebook, and even SAS code using

an existing NIH SAS VYIA project. The goal of the data platform team is to create a one-stop-shop for all data processing and analytical needs. By minimizing the need for data to be downloaded or extracted for processing, the platform helps ensure that data privacy and security are maintained at all times.

Learning Objectives:

My goal in this presentation is to provide a comprehensive overview of the various features of the NCCR Data platform, which is an innovative solution for the research community. I will begin by discussing the platform's key features, including its user-friendly interface and advanced data analytics capabilities.

I will also delve into the platform's unique timelines and schedules for releasing new features, which are designed to ensure that researchers have access to the latest and most up-to-date data.

## Real World Application of ExtractEHR

**Kevin Ward**

*Director, Georgia Center for Cancer Statistics*

ExtractEHR is an automated data extraction software tool written in the R programming language and deployed using the R Studio integrated development environment. The purpose of ExtractEHR is to standardize the methods used to extract and format Electronic Health Record (EHR) derived data across multiple institutions, EHR systems, and vendors for the purpose of academic research.

Learning Objectives:

1. Define ExtractEHR, its importance and how it has been used.
2. Discuss what has been learned from pulling data during the ExtractEHR process.

# Plenary #4 – Updates on Cancer Surveillance in North America

## Update on CDC's National Program of Cancer Registries

### Dr. Vicki Benard

*Chief of Cancer Surveillance Branch, Centers for Disease Control and Prevention*

This session will provide an update on the innovative work of the National Program of Cancer Registries

Learning Objectives:

To better understand the National Program of Cancer Registries including our current priorities and future direction.

## SEER Program Updates

### Dr. Serban Negoita

*Branch Chief, National Cancer Institute*

This session will provide an update on the SEER program and new initiatives.

## North of the 49th parallel: The National Perspective of Canadian Cancer Registration

### Dr. Lorraine Shack

*Cancer Advanced Analytics, Alberta Health Services, Canada*

One in two Canadians will be diagnosed with cancer with significant improvements in survival over time. The Canadian Cancer Registry system is a network of 13 central cancer registries: one for each province and territory with central submission to the Canadian Central Cancer Registry for national epidemiological analysis. This robust system provides complete coverage for all cancers diagnosed in Canada and enables epidemiologic analysis and research. Cancer diagnosis and outcomes are impacted by the publicly funded health care health system which is universally available in each province and territory though with regional differences in the implementation of this. The COVID pandemic highlighted the different approaches to managing public health and impacted cancer diagnosis in varying ways across the country. This presentation will provide an overview of the Canadian Cancer registry landscape with t a focus on the epidemiological variations and the impact of COVID all in the context of a public health system.

Learning Objectives:

1. Understand the cancer registry system and health system in Canada including the role of Canadian Central Cancer Registry.
2. Understand some of the epidemiologic variations in cancer in Canada.
3. Summarize impact of COVID on cancer registrations in Canada.

# High-Level Strategic Group Update

## Dr. Loria Pollack

*Medical Director of National Program of Cancer Registries, Center for Disease Control and Prevention* This presentation will provide an overview of NAACCR's High-Level Strategic Group (HLSG), highlight its engagement in shared initiatives that advance the field, and summarize recent strategic planning, including future priorities.

### Learning Objectives:

Understand who comprises the of NAACCR's High-Level Strategic Group (HLSG) and what are its role and priorities in advancing cancer surveillance.

## Plenary #5 – Structural Racism and Cancer Surveillance



# Assessing Structural Racism and Cancer Surveillance Research

**Dr. Salma Shariff-Marco**

*Associate Professor/Co-Investigator, UCSF, Greater Bay Area Cancer Registry*

Structural racism is a fundamental cause of health inequities including those across the cancer continuum. This talk will share work the DREAM Lab at UCSF is leading to investigate the impact of structural racism on cancer inequities, leveraging registry data.

Learning Objectives:

This presentation will share: Conceptual frameworks for understanding how structural racism impacts cancer outcomes and inequities; Operationalization of structural racism measures for cancer surveillance research; Analytic approaches for investigating impact of structural racism on cancer outcomes.

# Historical Structural Racism and Current Breast Cancer Outcomes in New Jersey

**Dr. Jesse Plascak**

*Assistant Professor, The Ohio State University*

Transmission of socioeconomic factors across generations and social networks, persistence of residential segregation, and practices and policies affecting built environment factors, are a few ways in which structural racism occurring decades in the past may ultimately impact present-day cancer outcomes. 1930's Home Owner's Loan Corporation (HOLC) redlining maps were originally intended to estimate the risk level of insuring home mortgages. These maps were shaded red if, in part, residents in an area were identified as African American or immigrants to the U.S., a practice made illegal by the Fair Housing Act within the Civil Rights Act of 1968. This talk will present evidence from empirical investigations of associations between current residence in historical HOLC areas and cancer risk factors and outcomes. Focus will be placed on results of a linkage with breast cancer cases within the New Jersey State Cancer Registry.

Learning Objectives:

1. Recognize how historical mortgage lending discrimination might impact present-day cancer outcomes through the neighborhoods where people live.
2. Describe how high-quality residential address and cancer outcome data from central cancer registries can motivate cancer epidemiologic investigations involving measures of historical structural racism.
3. Summarize evidence of studies investigating associations between historical mortgage lending discrimination and cancer risk factors and outcomes.



# Place, Race, and Racism: Leveraging Surveillance Data to Achieve Justice in Breast Cancer Outcomes

**Dr. Lauren McCullough**

*Associate Professor, Rollins School of Public Health, Emory University*

This talk will share our work in the BRIDGE research group which leverages Georgia Cancer Registry data to understand multi-level drivers of cancer inequities.



# CONCURRENT ORAL PRESENTATIONS

## 50 Years of Pathology Reporting: From Paper to Electronic Data Capture

[Mrs. Andrea Sipin-Baliwas<sup>1</sup>](#), Mr. Omar Moncayo<sup>1</sup>, Mr. Lenard Berglund<sup>1</sup>, Mr. Kin Leung<sup>1</sup>, Mrs. Denise Alcantara<sup>1</sup>, Dr. Lihua Liu<sup>1</sup>

<sup>1</sup>Los Angeles Cancer Surveillance Program, Keck School of Medicine, University of Southern California, Los Angeles, USA

**Topic Area:** 6 - Data Collection, Tools and Operations

**Sub-Topic:** 4a. Technologic and scientific advances and innovations

**Background:** The Los Angeles Cancer Surveillance Program (CSP) became population-based in 1972 after having the good fortune of establishing voluntary agreements with all 184 hospitals in Los Angeles County. Hospital pathology departments were the key facilitators in helping the registry establish these relationships and we have relied heavily on pathology partners ever since. The CSP started off in the early days having a large team of Field Technicians who collected paper pathology reports on site, a practice that continued through 2018. The shift to receiving nearly 100% electronic pathology reports (ePath) directly in house happened almost abruptly, with some exceptions. Purpose: To describe how the pathology reporting infrastructure at the CSP changed over time and our continued reliance on this source document for cancer casefinding.

**Methods:** Historically, CSP accessed pathology reports at hospitals after establishing relationships on site to ensure continuous and complete data capture. Field Technicians reviewed all pathology reports available to them, sorting through and selecting only those positive for cancer to bring back to CSP. In recent years, the importance shifted away from in-person connections with health information and medical records departments to a heavy reliance on pathology labs and remote IT teams in order to keep the ePath data flowing.

**Results:** We will discuss the nature of pathology report repositories at the CSP and describe data systems used to support casefinding and related operational activities.

**Conclusion:** Learning from our past and assessing our current practices will allow us to keep moving forward into the next 50 years of CSP data collection.

# A Discussion of Best Practices on Data Release for the NAACCR Community

[Lauren Maniscalco](#)

*Louisiana Tumor Registry, New Orleans, Louisiana, USA*

[Dr. Bozena Morawski](#)

*Cancer Data Registry of Idaho, USA*

A Discussion of Best Practices on Data Release for the NAACCR Community

Objectives:

1. Overview of current environment surrounding release of cancer surveillance data for research
2. Present NAACCR draft best practices on release of cancer surveillance data for research
3. Compile recommendations from attendees regarding three focus areas (participation in research studies and patient selection/recruitment, release of restricted data in linkages vs research vs surveillance data, suppression guidelines)

# Accuracy of Patient Race and Ethnicity Data in a Central Cancer Registry

Ms. Rachel R. Codden<sup>1,2</sup>, Dr. Carol Sweeney<sup>1,2</sup>, Ms. Kimberly A. Herget<sup>1</sup>, Ms. Blessing S. Ofori-Atta<sup>2</sup>, Ms. Kacey Wigren<sup>1</sup>, Ms. Marjorie Carter<sup>1</sup>, Dr. Jennifer A. Doherty<sup>1,2,3</sup>, **Dr. Morgan Millar<sup>1,2,3</sup>**

<sup>1</sup>Utah Cancer Registry, Salt Lake City, USA, <sup>2</sup>University of Utah, Salt Lake City, USA, <sup>3</sup>Huntsman Cancer Institute, Salt Lake City, USA

**Topic Area:** 6 - Data Collection, Tools and Operations

**Sub-Topic:** 6a. Data quality control and standards

Race and Hispanic ethnicity data important for monitoring overall trends and disparities in cancer across populations. However, obtaining high-quality information for these variables has been a challenge for central cancer registries. The purpose of this analysis was to evaluate the accuracy of the race and ethnicity variables as currently collected by the Utah Cancer Registry (UCR) by comparing them to self-reported data. Participants were 3,260 Utah cancer survivors who responded to questionnaires administered by UCR for research projects conducted 2015-2022. We treated self-reported race and Hispanic ethnicity as the gold standard, comparing these values to registry-collected race and Hispanic ethnicity variables for the same individuals. We separately calculated sensitivity and specificity for each race category and for Hispanic ethnicity. We evaluated the accuracy of Hispanic ethnicity before and after application of the NAACCR Hispanic Identification Algorithm (NHIA). Surveyed participants included 323 (10.3%) survivors who reported Hispanic ethnicity, a somewhat lower proportion Hispanic than the 12.2% indicated by the registry Hispanic variable. Sensitivity and specificity of registry classification of Hispanic ethnicity were 88.2% and 96.5%, respectively; these values were essentially the same before and after application of the NHIA algorithm. Twenty-three participants (0.7%) identified as Black or African American, 32 (1.0%) as Asian, 16 (0.5%) Pacific Islander (PI), and 43 (1.4%) American Indian or Alaska Native (AIAN). The registry race variable indicated a smaller proportion of survivors to be members of these race groups: 0.5%, 0.6%, 0.2%, and 0.4%, respectively. Sensitivity for classification of race as Black was 60.9%, Asian 40.6%, PI 25.0%, and AIAN 9.3%; specificity for each of these groups was 99%. Sensitivity for AIAN classification did not improve appreciably when estimated only among individuals not identifying as Hispanic. Sensitivity and specificity for White participants were 98.8%, 47.4%. We found that categorization of race and ethnicity by a cancer registry, which is based primarily on race and ethnicity reported by hospitals, often did not match the individuals self-reported identification. Of particular concern is the high proportion of AIAN individuals whose race is misclassified. Continued attention should be directed to the accurate capture of race and ethnicity data.

# Addressing Missingness of Nativity (US-Born, Foreign-Born) Data in Cancer Registries: Important for Understanding Cancer Disparities in the US

[Dr. Salma Shariff-Marco](#)<sup>1,2,3</sup>, [Dr. Aniruddha Bhadresh](#)<sup>4</sup>, [Dr. Francis Boscoe](#)<sup>6</sup>, [Ms. Alison J. Canchola](#)<sup>1,2</sup>, [Dr. Scarlett Gomez](#)<sup>1,2,3</sup>, [Dr. Kevin Henry](#)<sup>7</sup>, [Dr. Robert Hiatt](#)<sup>1,3</sup>, [Dr. Debora Oh](#)<sup>1,2</sup>, [Prof. Paulo Pinheiro](#)<sup>8,9</sup>, [Ms. Kathryn Shahan](#)<sup>4</sup>, [Dr. Antoinette Stroup](#)<sup>10,11</sup>, [Dr. Hong Zhu](#)<sup>12</sup>, [Dr. Sandi Pruitt](#)<sup>4,5</sup>

<sup>1</sup>Department of Epidemiology, University of California, San Francisco, San Francisco, USA, <sup>2</sup>Greater Bay Area Cancer Registry, UCSF, San Francisco, USA, <sup>3</sup>Helen Diller Family Comprehensive Cancer Center, UCSF, San Francisco, USA, <sup>4</sup>Peter O'Donnell Jr. School of Public Health, University of Texas Southwestern Medical Center, Dallas, USA, <sup>5</sup>Harold C. Simmons Comprehensive Cancer Center, University of Texas Southwestern Medical Center, Dallas, USA, <sup>6</sup>Pumphandle LLC, Camden, ME, USA, <sup>7</sup>Department of Geography, Temple University, Philadelphia, USA, <sup>8</sup>Department of Public Health Sciences, University of Miami, Miami, USA, <sup>9</sup>Sylvester Comprehensive Cancer Center, University of Miami, Miami, USA, <sup>10</sup>Rutgers Cancer Institute of New Jersey, Newark, NJ, USA, <sup>11</sup>New Jersey State Cancer Registry, Newark, NJ, USA, <sup>12</sup>Division of Biostatistics, Department of Public Health Sciences, University of Virginia School of Medicine, Charlottesville, USA

**Topic Area:** 3 - Epidemiologic Studies using Cancer Surveillance Data

**Sub-Topic:** 3b. Social determinants and cancer disparities

Where a person is born is an important social driver of health. Research indicates disparities by nativity for outcomes across the cancer continuum, but findings are mixed and vary by outcomes and specific racial and ethnic groups. Birthplace data, which is used to derive nativity (US-born vs. Foreign-born) is not consistently reported to cancer registries from hospitals and other facilities; therefore, the missingness of birthplace data has increased over time. We apply multiple imputation to improve the ascertainment of nativity among Asian American and Hispanic persons using registry data and publicly available neighborhood data from the American Community Survey. Using registry data from 4 states (CA, NJ, NY, and TX) for Asian American and Hispanic cases with breast, cervical, and colorectal cancer, information on birthplace was missing for 32.5% to 52.1 % of cases diagnosed 2000-2017, with much higher proportions since 2012. Among Asian American and Hispanic patients with non-missing birthplace, 88.3% and 56.2%, respectively, were foreign-born. Using multiple imputation with fully conditional specification, we imputed nativity separately for Asian American and Hispanic cases. We will describe the overall percent missing birthplace data, by disaggregated racial and ethnic groups, state, and over time. We will evaluate the accuracy of our multiple imputation and report on sensitivity, specificity, misclassification rate, and agreement between true and imputed values, by comparing its performance to a sample of cases with available birthplace data and to a validated algorithm to impute birthplace data using patient social security numbers. We will discuss pros and cons of our multiple imputation approach and describe how patterns of missing data are associated with several patient and census tract level factors, including vital status. We will also discuss the potential for SEER registries to work with NCI to validate against Social Security Administration linked data. Given the increasing proportions of missing birthplace data for nativity classifications, strategies are needed to improve data collection and methods for imputing this variable. This is critical to understand and ultimately address cancer burden in the US, especially among Asian American and Hispanic populations, two of the fastest growing.

# After Meaningful Use: How Can Outpatient Providers Report to Cancer Registries?

*Ms. Valerie Yoder<sup>1</sup>, Ms. Loretta Huston<sup>1</sup>, Ms. Heather Cheney<sup>1</sup>, Ms. Carrie Bateman<sup>1</sup>, Dr. Morgan Millar<sup>1, 2</sup>* <sup>1</sup>Utah Cancer Registry, Salt Lake City, USA, <sup>2</sup>University of Utah, Salt Lake City, USA

**Topic Area:** 4 - New Directions and IT Solutions

**Sub-Topic:** 4b. New and emerging methods of data collection

Central cancer registries have found it challenging to improve electronic reporting from outpatient health care providers. Utah Cancer Registry (UCR) has explored multiple avenues for routine outpatient reporting, including the Promoting Interoperability (formerly Meaningful Use) Program (PI). When introduced, PI offered a promising new standard for outpatient health care providers to report to cancer registries. However, widespread utilization of this option was hampered by software implementation challenges and the discontinuation of incentive payments for cancer reporting under PI as of 2019. Several small to large specialty practices/provider groups reported to UCR through the PI mechanism for several years. UCR identified a significant number of cancer cases solely from PI and obtained treatment and site-specific data items, demonstrating that outpatient providers are a critical data source. However, due to the implementation challenges UCR cannot expand this route to providers who use electronic health record software (EHR) that lacks the cancer reporting capability. Further, two large provider groups that previously reported through PI have switched to EHR software that does not support this functionality. Alternatives are needed to ensure ongoing outpatient reporting to UCR. Initiatives such as MedMorph are underway and expected to create a more widely applicable standard for public health data reporting, but it will take time for EHR software to implement new standards. Therefore, there is an interim need to continue obtaining cancer reports from outpatient health care providers but limited electronic reporting options to offer. UCR requests low-volume outpatient providers to complete manual data entry forms, but this is not efficient for mid and high-volume providers to complete or for UCR to receive. In collaboration with four large outpatient providers, UCR is developing semi-automated or fully automated electronic reporting. Two are implementing a custom solution based on the cancer services they provide and their IT structure. The other two are testing a basic capability in all modern electronic health record software: creating C-CDA and CCD records. However, these documents are typically used for exchange between healthcare providers and lack a cancer diagnosis section. In this presentation, UCR will evaluate these alternative record types for cancer reporting.

# An Application of Using Cancer Reporting Zones in Disseminating Cancer Surveillance Data in Nebraska

*Ms. Lifeng Li<sup>1</sup>, Mr. Christophe Irumva<sup>1</sup>, Dr. Qianru "Amie" Wu<sup>1,2</sup>, Mr. Mark Watson<sup>1</sup>, Mrs. Marissa Ayotte<sup>1</sup>, Mrs. Diane Ng<sup>3</sup>, Mr. David Stinchcomb<sup>3</sup>*

*<sup>1</sup>Nebraska Department of Human and Health Services, Lincoln, USA, <sup>2</sup>University of Nebraska-Lincoln, Lincoln, USA, <sup>3</sup>Westat, Rockville, USA*

**Topic Area:** 6 - Data Collection, Tools and Operations

**Sub-Topic:** 6c. Overcoming issues with data sharing

**Background:** The data governance policy of the Nebraska Department of Health and Human Services requires suppression of cancer data when the population size is less than 20,000 or when the case/death count is less than 6, leading to compromised geographic estimates of cancer burden. In 2020, we collaborated with the NCI/NAACCR Zone Design Project team to create zones in Nebraska. Our objective is to examine the suppression rate of cancer data by different geographic regions and to assess the potential of new zoning strategies in alleviating the issue of data suppression and addressing the geographic disparities of cancer.

**Methods:** Based on a minimum population size of 50,000, sociodemographic homogeneity (percentage of urbanicity, minority, and poverty), and compactness, 31 zones were created, including a combination of small- and medium-sized counties (populations less than 100,000) or census tracts for large counties (populations over 100,000). We compared the suppression rates of cancer incidence and mortality by county, Local Health Department (LHD), and zones using 2019 and 2014-2019 data, respectively. The data suppression rules of Nebraska (fewer than 6 cases) and CDC (fewer than 16 cases) were used for comparison.

**Results:** Out of 93 counties, 19 local health departments, and 31 zones, the suppression rate of the overall cancer incidence in 2019 has reduced from 8.6% (Nebraska rule) and 20.4% (CDC rule) by county level to 0% by zones. For overall cancer mortality in 2019, the suppression rate was reduced even more with the county (15.1%, Nebraska and 49.5%, CDC) and zone data (0%). Using the data from 2014 to 2019, the results are consistent but with a lower reduction rate. The results of different types of cancers varied between the most common and rare cancers. The reporting zones also enabled us to examine the cancer burden at the sub-county level for heavily populated counties in Nebraska.

**Conclusions:** Cancer reporting zones broaden the data sharing methods by reducing the geographic suppression rate, particularly for the common types of cancers, and increasing the capabilities of utilizing the sub-county level cancer surveillance data in evaluating cancer disparities and planning for cancer prevention and control.

# An Explainability Module for Analysis of ML Model Extraction from Cancer Pathology Reports

[Sayera Dhaubhadel](#)<sup>1</sup>, [Mr. Jamaludin Mohd-Yusof](#)<sup>1</sup>, [Dr. Kumkum Ganguly](#)<sup>1</sup>, [Dr. Benjamin McMahon](#)<sup>1</sup>,  
[Dr. Tanmoy Bhattacharya](#)<sup>1</sup>

<sup>1</sup>Los Alamos National Laboratory, Los Alamos, USA

**Topic Area:** 2 - Big Ideas in Cancer Surveillance

**Sub-Topic:** 2a. How to modernize the Cancer Surveillance System

The Modeling Outcomes using Surveillance data and Scalable AI for Cancer (MOSSAIC) project is an NCI-DOE collaboration to develop scalable natural language processing (NLP) and machine learning (ML) tools for extracting reportable cancer surveillance data. This includes methods for pathology coding, reportability, biomarkers, recurrence, and metastasis. As part of the uncertainty quantification of this effort, we use our deep abstaining classifier (DAC) multi-task model as a use case to develop an explainability module that highlights the words, in context, contributing both for and against a given prediction. We apply explainable AI techniques to identify several hundred words most responsible for affecting classification choices and use data-driven analysis to subgroup reports according to common reasons for misclassification, which can then be identified by reading representative reports for questions of interest. We place the information extracted from the pathology report on a hierarchy, starting with the site of cancer, then assessing other attributes, including subsite and histology, contingent on correct answers to previous classification tasks. For cancer site, these include confusing anatomy, multiple samples analyzed in a single report, and metastatic spread of cancer. For subsite, these include information missing from reports, which may occur for example when treatment decisions do not depend on the specific subsite. For histology, these include the hierarchical nature of the histology coding scheme and the time dependence of histology nomenclature and coding rules. Incorporation of the abstention category and the use of ML explainability techniques facilitates quantitative conclusions regarding the sources of error, and these insights suggest concrete workflows for iteratively improving classifier accuracy in the deployed system. We present an explainable AI workflow to enable systematic characterization of reasons for the misclassification of cancer pathology reports with our DAC, which can be applied to millions of reports and suggest strategies for improving DAC and its incorporation into practical workflows. Our workflow is not specific to the details of the classification methodology but can be used with other classifiers as a modular tool.



# Approach and Success Factors to Participation in the CDC STAR Project's National Oncology Rapid Ascertainment Hub, a Cloud-Based Infrastructure Developed to Improve the Timeliness of Reporting Childhood Cancer

Ms. Christina Hiller<sup>2</sup>, Dr. Loria Pollack<sup>1</sup>, Mr. Richard Batson<sup>2</sup>, Mrs. Kasey Diebold<sup>1</sup>, Mr. David Butterworth, Ms. Kimiko Sanders<sup>1</sup>, Dr. Erin Stair<sup>2</sup>

<sup>1</sup>Centers for Disease Control and Prevention, Atlanta, USA, <sup>2</sup>Tanaq Support Services, LLC, Anchorage, USA

**Topic Area:** 5 - Childhood Cancers

**Sub-Topic:** 5b. Childhood Cancer Data Initiative, National Childhood Cancer Registry and STAR Projects

**Background:** The Survivorship, Treatment, Access, and Research (STAR) Act empowered the Centers for Disease Control and Prevention (CDC) to improve early identification and track the epidemiology of childhood cancer. In 2018, National Program of Cancer Registries (NPCR) began to develop a secure, cloud-based informatics system, called National Oncology rapid Ascertainment Hub (NPCR-NOAH), to electronically receive and report newly diagnosed cancer in children, adolescents, and young adults to state-based central cancer registries. An early focus and critical success factor of the CDC STAR Project was to recruit potential reporting sources and central cancer registries (CCRs) interested in electronic transmission of newly diagnosed childhood cancer in children using NPCR-NOAH. Purpose: We will describe the approach used to identify, evaluate, and onboard interested laboratories and registries to pilot NPCR-NOAH.

**Methods:** Five key phases of engagement with reporting CCRs and facilities were: 1) Outreach by email or phone to identify leaders; 2) Contact meeting to gather information and recruit for participation; 3) Interest confirmation; 4) Analysis of fit and feasibility using an assessment checklist; and 5) Implementation of CDC STAR project pilot in CCRs/facilities.

**Results:** After outreach to 19 CCRs and 28 facilities, 5 CCRs and 18 facilities confirmed interest to participate in the CDC STAR project. Key barriers to further interest were resource costs, lack of mandate to use NOAH-NPCR, competing priorities, and interstate data exchange. Three CCRs and four facilities progressed to implementation. Success factors were state reporting timeliness mandates, alignment between facilities and their laboratories, and strong technical knowledge at the CCR.

**Discussion:** The lessons learned in the recruitment and evaluation of potential electronic reporting sources offer a useful example to other public health data modernization efforts. The CDC STAR Project and participating CCRs are laying groundwork and developing procedures to implement and expand the use of rapid, secure electronic reporting.]

# Assessing the Completeness of Data Items for Deriving Toronto Staging in the SEER Program

[Dr. Fernanda Silva Michels](#)<sup>1</sup>, [Dr. Gonçalo Forjaz](#)<sup>2</sup>, Ms. Jennifer Ruhl<sup>3</sup>, Mrs. Stephanie Hill<sup>1</sup>, Mrs. Betsy Kohler<sup>1</sup>

<sup>1</sup>North American Association of Central Cancer Registries, Springfield, USA, <sup>2</sup>Westat, Rockville, USA,

<sup>3</sup>National Cancer Institute, Bethesda, USA

**Topic Area:** 5 - Childhood Cancers

**Sub-Topic:** 5b. Childhood Cancer Data Initiative, National Childhood Cancer Registry and STAR Projects

**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. One goal of this project is to adopt the Toronto Staging Guidelines\* and implement new data items to get the Toronto Stage and other relevant clinical factors. For ages 0-19 years, new data items are being proposed and existing Extent of Disease (EOD) data items in EOD Primary Tumor, EOD Regional Nodes, and EOD Mets were identified in order to derive Toronto Staging. Methods: We used the Median/Multiple Outlier Testing

**Method** (MMOT), a quality control tool recently developed by the NCI's Surveillance Research Program, to assess the completeness of EOD fields (EOD Primary Tumor, EOD Regional Nodes and EOD Mets) needed to derive the Toronto stage and identify outliers. We used SEER data from the November 2021 submission for patients aged 0-19 years diagnosed in 2018-2020 with one of the following cancers: Hodgkin Lymphoma, Hepatoblastoma, Rhabdomyosarcoma, Non-Rhabdomyosarcoma, Testicular Germ Cell Tumors, and Ovarian Germ Cell Tumors. Only SEER registries data were included because NPCR registries do not collect EOD fields.

**Conclusion:** With the increased focus on pediatric staging brought about by the National Childhood Cancer Registry initiative, our results will help to assess the feasibility of deriving Toronto Stage from existing data items in the registry abstract and to identify areas in need of enhanced data collection efforts. \* The Toronto Pediatric Cancer Stage Guidelines were developed by consensus and published in The Lancet Oncology in 2016. In fact, that same year the Guidelines were presented at the NAACCR Annual Conference in St. Louis, MO.

# Assessment of Rural-Urban Differences in Geographic Access to Commission on Cancer-Accredited Hospitals within the Continental United States

Ms. Madison Wahlen<sup>1</sup>, Dr. Mary Schroeder<sup>2</sup>, Dr. Ingrid Lizarraga<sup>3</sup>, Ms. Amanda Kahl<sup>1,4</sup>, Dr. Jacklyn Engelbart<sup>3</sup>, Dr. Erin Johnson<sup>5</sup>, Dr. Aaron Seaman<sup>6</sup>, Dr. Sarah Birken<sup>7</sup>, Dr. Mary Charlton<sup>1,4</sup>

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**Topic Area:** 3 - Epidemiologic Studies using Cancer Surveillance Data

**Sub-Topic:** 3c. Using real-world data from cancer registries to improve cancer outcomes

**Background:** Rural patients face greater barriers to cancer care. The American College of Surgeons Commission on Cancer (CoC) offers accreditation to hospitals that meet standards demonstrating achievement of high-quality, comprehensive cancer care. These standards, and the data collection necessary to document progress toward meeting them, are challenging for most rural hospitals to meet, likely resulting in limited access to CoC-accredited programs among rural patients. Purpose: Investigate the relationship between patient and hospital rurality and distance to CoC-accredited facilities to enhance understanding of rural access to high-quality, comprehensive cancer care across the continental US.

**Methods:** Population data were extracted from 2010 US census data. Hospital names and location were obtained from Homeland Infrastructure Foundation-Level Data merged with accreditation data from the CoC. Hospital and patient rurality were defined at the county level and classified using US Department of Agriculture Rural-Urban Continuum Codes as either metropolitan (1-3), large rural (4-6), or small rural (7-9). Geographic access to CoC-accredited facilities was measured from county centroid and hospital coordinates using Great Circle Distance in ArcGIS.

**Results:** Large and small rural counties account for 11% and 4% of the continental US population, and 21% and 15% of hospitals, respectively. Over a third (35%) of metropolitan hospitals were CoC-accredited, compared with 11% and 4% of large and small rural hospitals. Almost all metropolitan residents (92%) resided within 25 miles of a CoC-accredited hospital, versus 41% and 23% of large and small rural residents. Most (85%) non-accredited hospitals in metropolitan counties were located within 25 miles of a CoC-accredited hospital, versus 27% and 11% of non-accredited hospitals in large and small rural counties.

**Conclusion/Implications:** Compared to metropolitan counties, both rural patients and rural non-accredited hospitals have significantly limited geographic access to CoC-accredited facilities. The Iowa Cancer Registry is piloting approaches to assist rural hospitals in developing the data collection infrastructure necessary for accreditation, including the provision of abstracting, quality control and analytic/reporting support on a contractual basis. Further research should investigate models and opportunities for central cancer registries in providing resources and support needed to improve and facilitate high-quality cancer care in rural hospitals.

# Association of First Primary Cancer with Risk of Subsequent Primary Cancer Among Survivors of Adult-Onset Cancers in Kentucky and Appalachian Kentucky

Dr. Quan Chen<sup>1</sup>, [Dr. Bin Huang](#)<sup>1,3,4</sup>, Dr. Abigail Anderson<sup>1</sup>, Dr. Eric Durbin<sup>1,4</sup>, Dr. Jill Kolesar<sup>1,2</sup>  
<sup>1</sup>Markey Cancer Center, University of Kentucky, Lexington, USA, <sup>2</sup>Department of Pharmacy Practice, University of Kentucky and Science, Lexington, USA, <sup>3</sup>Division of Cancer Biostatistics, University of Kentucky, Lexington, USA, <sup>4</sup>Kentucky Cancer Registry, Lexington, USA

**Topic Area:** 3 - Epidemiologic Studies using Cancer Surveillance Data

**Sub-Topic:** 3c. Using real-world data from cancer registries to improve cancer outcomes

**Background:** The study aims to assess the risk of subsequent primary cancers (SPCs) among adult-onset cancer survivors by first primary cancer (FPC) type, sex, and Appalachia residence, a region with significant cancer disparities.

**Methods:** The study is based on a retrospective cohort of 148,509 cancer survivors diagnosed with FPCs in Kentucky Cancer Registry (KCR) from 2000-2014 and followed up until December 31, 2019. The incidence of SPCs per 10,000 person-years and the standardized incidence ratio (SIR) were calculated and compared with the general Kentucky population.

**Results:** Results showed that 12.1% of cancer survivors in KCR developed a SPC, were at increased risk compared to the general population. 20 out of 30 FPC types in men and 20 out of 31 FPC types in women were associated with a statistically significant increased risk of developing SPCs. The highest SIR was estimated among survivors of oral and laryngeal cancers, both of which have known associations with smoking and other lifestyle factors. Survivors living in Appalachian regions had a higher risk of overall SPC and site-specific SPC than non-Appalachian survivors, suggesting a possible link between regional environmental and lifestyle factors and cancer risk.

**Conclusion:** The study highlights the need for ongoing surveillance and prevention efforts to reduce the burden of SPCs among cancer survivors, particularly among those living in Appalachian regions. Addressing these disparities will require not only the development of effective treatments and interventions but also the creation of supportive and empowering environments that promote healthy lifestyles and access to care.

# Availability of High-Resolution Data for Breast Cancer in the North American Cancer Registries – the VENUSCANCER Project

Prof. Claudia Allemani<sup>1</sup>, Ms. Veronica Di Carlo<sup>1</sup>, Dr. Bozena Morawski<sup>2</sup>, Dr. Donna Turner<sup>3</sup>, Mr. Chris Johnson<sup>2</sup>, Dr. Lorraine Shack<sup>4</sup>, Dr. Pamela Minicozzi<sup>1</sup>, on behalf of the North American VENUSCANCER Working Group

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**Topic Area:** 2 - Big Ideas in Cancer Surveillance

**Sub-Topic:** 3c. Using real-world data from cancer registries to improve cancer outcomes

**Background:** The CONCORD programme documented wide global differences in survival trends for women diagnosed with breast cancer. Age-standardised 5-year net survival approached 90% in both Canada and the United States during 2010-2014. The VENUSCANCER project, embedded in the CONCORD programme, will examine whether global differences in survival are attributable to differences in disease biology between populations, or to differences in patterns or care, or to socio-economic status. Aims: To examine the availability of data on stage, staging procedures, biomarkers and treatment (high-resolution variables) for women with breast cancer in North America during 2015-2018. To assess adherence to international guidelines for treatment.

**Methods:** Cancer registries were invited to submit data for the most recent year of incidence during 2015-2018 for which incidence and high-resolution variables are complete. We have been collaborating with the Idaho Cancer Registry to develop a SAS program to map the NAACCR to the VENUSCANCER data specification. This program will hugely facilitate data submission from additional cancer registries, expected before summer 2023. We will examine the distribution of the main prognostic factors for breast cancer, such as age, stage, biomarkers and treatment, and where possible, socio-economic status and insurance status, in the North American registries participating in VENUSCANCER. We will estimate the odds of women being treated according to the most up-to-date clinical guidelines, adjusted by age, stage and other prognostic factors.

**Results:** Twenty US registries and all Canadian registries have expressed their interest in participating in VENUSCANCER. So far, we have received data on 2,024 women, 1,124 diagnosed with breast cancer in Idaho in 2016, and 900 Montana in 2017. Stage was known for 98% of the women. About 90% of women received cancer-directed surgery, 58% received radiotherapy and 67% received endocrine treatment. Results for more North American registries will be presented.

**Conclusions:** The preliminary analyses show an excellent completeness of data on stage. Information on the type of treatment for breast cancer will be crucial to assess adherence to clinical guidelines. Similar analyses will be conducted for women diagnosed with cervical or ovarian cancer. The NAACCR conference will offer an opportunity for further discussion.

# Barriers and Facilitators to Effective Cancer Surveillance Program Implementation: A Mixed-Methods Program Evaluation

[Ms. Sofia Huster](#)<sup>1</sup>, Dr. Paran Pordell<sup>1</sup>, Ms. Corinne Fukayama<sup>1</sup>, Ms. Emily Nethercott<sup>1</sup>, Ms. Trevia Brooks<sup>1</sup>, Dr. Vicki Benard<sup>1</sup>

<sup>1</sup>Centers for Disease Control and Prevention, Atlanta, USA

**Topic Area:** 6 - Data Collection, Tools and Operations

**Introduction:** In November 2022, the Centers for Disease Control and Prevention (CDC) compiled a State of Evaluation Report of completed evaluation activities during the National Program of Cancer Registries (NPCR) funding cycle (2017-2022). Evaluation goals were to increase completeness, timeliness, and quality of 12- and 24-month data and understand promising practices, facilitators, and barriers to cancer surveillance program implementation.

**Methods:** As part of a mixed-methods program evaluation, four CDC evaluators conducted an extensive document review over a 3-month period of completed evaluation reports. These reports included the North American Association of Central Cancer Registries (NAACCR) and the National Association of Chronic Disease Directors (NACDD) Best Practices Report; CDC and Research Triangle Institutes (RTIs) Feasibility Assessment of E-Reporting; and CDC-led evaluation reports. These reports involved primary and secondary mixed-methods data collection and analysis to better understand cancer registry operations, management, and program implementation.

**Results:** Throughout all assessments, several common barriers and facilitators to cancer surveillance program implementation were identified. The single most important barrier was a critical shortage of trained, experienced, and available personnel. Other areas where challenges were found across evaluation reports consisted of legislation and regulation, case volume, funding, and IT systems, infrastructure, and support. Additional evaluation reports reinforced a lack of technical expertise and weak IT systems and infrastructure as key barriers. Common facilitators across reports included successful partnerships, implementation of routine quality assurance (QA) activities, funding availability, strong IT systems/infrastructure, and management support.

**Conclusion:** CDC was able to answer key evaluation questions about barriers and facilitators to cancer registry implementation outlined in the evaluation plan. These findings suggest that staffing, infrastructure, and software often pose the greatest barriers to registry operations. However, some registries have been able to implement promising practices that address these barriers and enhance their programs.

**Program Implementation:** Recipients suggested CDC: establish a platform to share promising practices between registries; create workgroups to discuss challenges; improve CDC training materials; and provide funds for innovative studies. These suggestions are being implemented in the current NPCR funding cycle (2022-2027) and are informing future program evaluation efforts.

# Building Census Tract-Level Life Tables for Idaho, 2010-2020

[Dr. Bozena Morawski](#)<sup>1</sup>, Ms. Pam Harder<sup>2</sup>, Mr. Chris Johnson<sup>1</sup>

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**Topic Area:** 3 - Epidemiologic Studies using Cancer Surveillance Data

**Sub-Topic:** 3b. Social determinants and cancer disparities

**Background:** Life tables can be used to characterize the health experience of a population and illuminate health disparities, e.g., via life expectancy at birth (LEB). Life tables with increased specificity, e.g., census tract versus county, age- and race-specific estimates versus age-specific only, provide more accurate estimates. The National Center for Health Statistics (NCHS) publishes census tract-level estimates (2010-2015). However, because Idaho's local mortality geocoding offers higher accuracy than nationally geocoded mortality data and because of recent changes in mortality patterns in Idaho and elsewhere, the Cancer Data Registry of Idaho (CDRI) created census-tract specific life tables for the period 2010-2020.

**Methods:** CDRI geocoded Bureau of Vital Records Health Statistics mortality data to 2010 census tract geography. We used NCI (Woods Poole, 2010-2020) population estimates to calculate sex- and age-specific mortality rates from over 100 models for 298 tracts. We evaluated the utility of including numerous sociodemographic covariates, interaction terms of age group and socioeconomic covariates, and census tract random effects. Final model selection was based on the smallest average absolute differences between crude and model-based estimates (number of deaths). We also calculated LEB as the mean of the sex-specific estimates for each tract. We plan to use these mortality rates to generate life tables for use in SEER\*Stat and compare survival estimates using the census tract and county-based life tables.

**Results:** The hierarchical Poisson model with a random effect for overdispersion produced the smallest absolute differences in predicted versus observed deaths (3%). Final model included Rural Urban Commuting Area code, percent population with greater than high school education, percent population with incomes below federal poverty guidelines, and estimates of current smoking as covariates. Mean LEB values from raw data were 79.0 (SD = 2.76) and 79.2 (SD = 2.28) from the final model. Results of differences in survival will be shown in the presentation.

**Conclusions:** Idaho-specific modeling of mortality produced representative estimates at the census tract level. The inclusion of a census tract random intercept and interactions by age and socioeconomic covariates were instrumental in calculating more accurate small area estimates.

# Cancer Path: CHART-Edits

[Mr. Jim Hofferkamp<sup>1</sup>](#)

<sup>1</sup>NAACCR, Springfield, USA

**Topic Area:** 7 - Other Relevant Topics

During this presentation we will see the how the changes made by the Cancer PathCHART review impact the site/type histology tables and how those changes impact edits.



# Cancer PathCHART: CTR Review

Ms. Lois Dickie<sup>1</sup>, [Dr. Goncalo Forjaz](#),

<sup>1</sup>National Cancer Institute, Rio Rancho, USA

**Topic Area:** 7 - Other Relevant Topics

The Cancer PathCHART project involves specialty pathologists who bring their expertise to the project; however, they have a focused view of current terminology and practices. CTR's have a global knowledge of terminology used in pathology reports, ICD-O codes, and coding rules. We'll present an overview of the CTR review process and their significant contributions to Cancer PathCHART.

# Collaborative to TNM Staging: Implications in a Canadian Central Cancer Registry

[Miss Oluwaseun Ikuomola](#)<sup>1</sup>, Mr. Lung Fung Tsang<sup>1</sup>, Mrs. Grace Musto<sup>1</sup>, Mr. Oliver Bucher<sup>1</sup>, Ms. Sheila Fukumura<sup>1</sup>

<sup>1</sup>Department of Epidemiology and Cancer Registry, CancerCare Manitoba, Winnipeg, Canada

**Topic Area:** 3 - Epidemiologic Studies using Cancer Surveillance Data

**Sub-Topic:** 2c. Visions for the future

**Background:** The Collaborative Staging (CS) methodology recommended by the Canadian Council of Cancer Registries has been used by Provincial/Territorial Cancer Registries to support standardized stage data collection since 2004. Following the release of the AJCC8th edition TNM Staging manual, Manitoba transitioned from calculating tumour stage using the CS system to AJCC8th TNM staging for cases diagnosed January 1, 2018, forward. We compared solid tumour staging and summarized the impact of changing staging schemas from 2010 to 2020 in Manitoba.

**Methods:** Stage data for all invasive, solid tumours recorded between 2010 and 2020 was retrieved from the Manitoba Cancer Registry and analyzed. Proportions of each stage group were calculated for each schema to examine shifts in stage over time. AJCC8 clinical and pathological stages were converted to the previous AJCC7 stage to determine the degree of overlap, if any, that existed between the two staging editions.

**Results:** From 2018-2020, 17,492 cases were recorded for all solid tumour sites in Manitoba. The change in staging schema resulted in varying proportions of up- and down-staging and increased the proportion of unknown-stage for most solid tumour sites. For the top 4 cancer sites, lung had almost no change in stage I-IV but an increased proportion (1.5 to 6.6%) of unknown-stage; breast had more stage I, fewer stage II and III, and an increased proportion (1.31 to 7.8%) of unknown-stage; prostate had fewer stage I and II, more stage III, and an increased proportion (2 to 26.9%) of unknown-stage; while colorectal had fewer stage I and an increased proportion (3.5 to 16.2%) of unknown-stage.

**Conclusion:** The impact of transitioning from CS to AJCC8 staging varied by tumour site. Particularly, prostate and breast cancers now having a larger proportion of unknown-stage tumours. The periodic revision of cancer staging schemas is essential for oncology and cancer research as new knowledge is incorporated into practice. As new staging schemas are released, it is important to investigate the impact and develop a methodology to harmonize with existing stage data if important differences emerge so that the impact of these differences on surveillance and research efforts can be minimized.

# Creating Data Reports Using Cancer Registry Data for Hospitals' Cancer Control Initiatives

Ms. Amanda Kahl<sup>1,2</sup>, Dr. Suzanne Bentler<sup>1,2</sup>, Dr. Sarah Nash<sup>1,2</sup>, Dr. Mary Schroeder<sup>3</sup>, Dr. Ingrid Lizarraga<sup>4</sup>, Dr. Mary Charlton<sup>1,2</sup>

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**Topic Area:** 3 - Epidemiologic Studies using Cancer Surveillance Data

**Sub-Topic:** 3c. Using real-world data from cancer registries to improve cancer outcomes

**Background:** Rural, non-Commission on Cancer (CoC) accredited hospitals may have limited capacity to analyze data and identify where cancer control efforts may be needed. Even if a hospital has the data and resources to analyze who is utilizing their services, they will not have data on cancer patients in their community who do not seek care at their facilities. Cancer registries are a unique data source that can help hospitals understand the cancer control and prevention needs of their communities.

**Objective:** Develop and test report templates to help hospitals understand the service needs of their cancer patient population, as well as the characteristics and service needs of the other cancer patients living in their communities and assess the perceived value of these data to hospital administration and providers.

**Methods:** The Iowa Cancer Registry developed multiple reports to share with hospitals that include information on patients abstracted at their facility and cancer patients that reside in their catchment area. The reports contained information on patient and tumor characteristics, treatment, survival outcomes, patients travel distance, and a hospital's market share of cancer patients by county in their catchment area. Also included are county-level estimates for cancer screening and health behavior data. Acceptability and value of the report was initially tested on six rural critical access hospitals (CAHs).

**Results:** During initial testing, CAH leadership was very satisfied with the reports and stated they had not received similar cancer information before. They were interested in incorporating the data into their needs assessment process. Since the initial version, we have received feedback from facilities including small CAHs to large CoC-accredited hospitals. We have used this feedback to adapt the reports to their data needs. Between 2019 and 2022, 66 reports were created for 35 unique hospitals.

**Conclusions:** Many hospitals, especially rural non-CoC accredited ones, have not previously received detailed cancer information at the hospital or community level. These reports empower hospitals with data they can use to inform resource allocation and cancer control and prevention initiatives in their communities.

# Critical Informatics Use Cases for Cancer Surveillance

[Mr. Joseph Rogers](#)<sup>1</sup>, Mrs. Sandy Jones<sup>1</sup>, Mrs. Kasey Diebold<sup>1</sup>, Ms. Caitlin Kennedy<sup>1</sup>, Mr. Sean Porter<sup>1</sup>, Mr. Pradeep Podila<sup>1</sup>, Dr. Vicki Benard<sup>1</sup>, Mr. Sanjeev Baral<sup>2</sup>, Mrs. Michelle Esterly<sup>2</sup>, Ms. Jen Wike<sup>2</sup>, Mr. Ian McClendon<sup>2</sup>

<sup>1</sup>CDC, Atlanta, GA, USA, <sup>2</sup>Katmai Government Services, Anchorage, AK, USA

**Topic Area:** 6 - Data Collection, Tools and Operations

**Sub-Topic:** 2a. How to modernize the Cancer Surveillance System

**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 and state, tribal, local, and territorial (STLT) public health landscape. This effort is known as the Data Modernization Initiative (DMI). CDC/National Program of Cancer Registries (CDC/NPCR) has made significant progress in implementing key priority objectives aligned with the overall CDC DMI strategic implementation plan for FY20-26.

**Purpose:** This presentation will provide an update on the CDC DMI strategy, progress to date, roadmap, and expected outcomes. Consistent with the CDC DMI strategy, CDC/NPCR has prioritized resources to help STLT reporters achieve real-time reporting, developed FHIR standards for interoperability, create innovative solutions to automate data collection/processing, and define data governance standards to break down siloed data systems. Finally, this presentation will explore how these activities align with CDC DMI public health use cases and how they can be used as common building blocks by other programs looking to achieve similar functionality.

**Methods/Approach:** Over the past six years, CDC/NPCR has developed new and innovative methods to improve data exchange methods, timeliness, quality, and completeness. These methods are implemented based on best practices gathered from subject matter experts (SMEs) and existing CDC/NPCR DMI workgroup members. Furthermore, these approaches align with industry expectations, such as those outlined for Health IT certification criteria.

**Results:** The presentation will detail the CDC/NPCR DMI efforts and use cases. These projects increase cancer surveillance interoperability and improve data quality for public health action.

**Conclusion:** By modernizing cancer surveillance, a fully integrated approach to data collection and processing can be achieved. This approach has the potential to break down barriers that inherently exist within traditional systems used for data collection, processing, and analysis. These barriers exist because systems are siloed, fragmented, require manual intervention, and need consistent, enforced standards to exchange data between systems seamlessly. Leveraging interoperability initiatives has the potential to overcome barriers by modernizing and improving electronic data exchange and the timeliness and quality of data reporting.

# Data Collection for an Efficient Cancer Control Program in Nunavut: Improving Case Management and Reducing Psychosocial and Economic Impacts.

Mrs. Selina Khatun, Ms. Michelle Doucette, Mr. Sean Waites  
*<sup>1</sup>Health Information Unit, Government of Nunavut, Iqaluit, Canada*

**Topic Area:** 6 - Data Collection, Tools and Operations

**Sub-Topic:** 2b. How to make cancer data more timely

**Introduction:** Nunavut, a northern territory of Canada, is socially, culturally, and economically incomparable to other parts of Canada. Due to the limited availability of health care services in the territory, cancer patients are referred to three other provinces for treatment, follow-up, palliative care, and psychosocial support. These referral processes result in delayed data entry and higher chances of unrecorded cancer cases. Presently, there is an assisted cancer registry, a collaboration with the Government of Nunavut, Department of Health and Cancer Care Ontario. Due to delayed data entry, and as a result of rigorous and ongoing case reviews, a recent analysis showed that 60 of 229 deaths from 2016 to 2020 were not currently found in the Nunavut cancer registry, these cases are identified through other data triangulation and the repatriation of records from outside of the territory.

**Objectives:** To strengthen and establish an independent cancer registry including the possible risk factor and psychosocial information of the corresponding cases and to provide this information to relevant stakeholders to elucidate the complete context of the cancer burden for Nunavummiut. Improving the efficiency of the Nunavut cancer registry will also support improved data output which will contribute to modernizing Nunavut's cancer control efforts.

**Methods:** Surveillance sites, and data sharing agreements, are planned in phases by identifying each hospital where cancer patients receive out of territory care, each laboratory where the tests were done, and each family physician who suspected or referred a cancer case. A near real-time (at the end of the week), electronic transfer of information of cases is planned to the In-Charge cancer registry as a suspected case / confirmed for review and case follow-up. The data are collected and repatriated include patient details and detailed data about the type of cancer, stage/grade, and the treatment the patient receives.

**Conclusion/ Expected results:** An independently operated cancer registry of Nunavut with near real-time validated information for efficient implementation of a cancer control plan is expected.

# Deep Learning Approach to Predict Recurrence or Second Breast Cancer Event Using Claims Linked Population-Based Registry Data

Dr. Qi Qiao<sup>1</sup>, Dr. Quan Chen<sup>1</sup>, Mr. Lucas Liu<sup>1</sup>, Dr. Eric Durbin<sup>1</sup>, Dr. Val Adams<sup>1</sup>, Dr. Steve Schwartz<sup>2</sup>, Dr. Jessica Chubak<sup>3</sup>, Dr. Ruth Etzinoi<sup>2</sup>, Dr. Jin Chen<sup>1</sup>, [Dr. Bin Huang<sup>1</sup>](#)

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**Topic Area:** 2 - Big Ideas in Cancer Surveillance

**Sub-Topic:** 3c. Using real-world data from cancer registries to improve cancer outcomes

**Background:** Cancer recurrence is an important feature in patient care and cancer outcome research, but it is not well captured in US population-based cancer registries. Previously, using health claims-linked registry data, we utilized an XGBoost machine learning approach to develop algorithms predicting the occurrence and timing of second breast cancer events (SBCE) (i.e., recurrences and new primaries). We sought to improve the accuracy of the algorithms using an array of deep learning approaches.

**Methods:** Stage I-III female first primary breast cancer patients diagnosed in Kentucky 2004-2015 and linked with Medicaid and Medicare claims data were obtained from the Kentucky Cancer Registry (n=18,239). Key features including demographic characteristics, tumor characteristics and engineered features based on diagnosis, procedure and medication claims grouping were used for the patient-level classification of SBCE. We adopted a Bidirectional long-short term memory (Bi-LSTM) with attention, which takes into account of longitudinal structure of the study data. We also explored Multiview and Contrastive Learning approaches, which utilized top features from several developed algorithms, to further improve the performance of the prediction algorithm.

**Results:** Compared to the results from the XGBoost approach, the deep learning approach had much improved patient level performance in accuracy (0.91 vs. 0.85), sensitivity (0.70 vs. 0.60), specificity (0.93 vs. 0.88), precision (0.45 vs. 0.29), and F1 (0.55 vs. 0.34). Our results show that a carry-over feature Secondary Malignancy plays a significant role in the performance of the developed algorithm.

**Discussion:** The Bi-LSTM algorithm developed using the deep learning approach showed improved predictive performance of SBCE in a population-based large dataset. Data sparsity and imbalance are critical issues in population-based claims-linked data. The performance of the developed algorithm needs to be further evaluated in other datasets.

# Dramatic Variations in Causes of Death Over Time Among Adolescent and Young Adult Cancer Survivors by Cancer Type and Number of Cancer Diagnoses

[Dr. Lihua Liu](#)<sup>1,2</sup>, Ms. Ziwei Song<sup>1</sup>

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**Topic Area:** 3 - Epidemiologic Studies using Cancer Surveillance Data

**Sub-Topic:** 3a. Epidemiologic studies

**Background:** Adolescent and young adult (AYA) cancer patients refer to those who were diagnosed with cancer during ages 15 to 39 and have been recognized as a special patient population due to the many unique challenges they face from treatment to survivorship issues, follow up care, and psychosocial needs, that are distinctly different from their younger and older counterparts. Cancer incidence among AYAs has been rising in recent decade. With the overall 5-year survival for AYA cancer patients exceeds 80%, the number of AYA cancer survivors is steadily increasing. Monitoring the cause-specific mortality among AYA cancer survivors by cancer type and subsequent cancers will provide important information for evaluating the late effects of treatment and improving AYA cancer outcomes.

**Methods:** Using consolidated research data from the California Cancer Registry (CCR), we identified AYA cancer patients aged 15-39 years old diagnosed during 1988-2019 by AYA Site Grouping (female breast, thyroid, melanoma, testicular germ cell tumor, cervical/uterine, non-Hodgkin lymphoma, Hodgkin Lymphoma, bone/soft tissue sarcoma, and the remaining cancer types combined) and Cause of Death Grouping (primary cancer, other cause of death, cardiovascular/cerebrovascular, subsequent cancers\_other, subsequent cancers\_lung). Cancer-specific cumulative mortality was estimated and plotted by Kaplan-Meier estimator separately for those who had only one cancer diagnosis vs. those who had more than one cancer diagnoses.

**Results:** A total of 241,576 AYA cancer patients were identified during the study period, of which 92% had only one primary diagnosis and 8% had more than one diagnoses. Both groups demonstrated very different cumulative mortality patterns by cause of death over time, with death due to the (first) primary cancer having a much larger share of cause of death for those with only one primary cancer, and death due to subsequent cancers is more prominent cause of death for those with more than one cancer diagnosis. These differences between the two groups also vary by cancer type.

**Conclusions:** Population-based cancer registry data have a lot to offer for better understanding AYA cancers and for improving the quality of life for AYA cancer survivors.

# Effect of Underlying Health Conditions on Racial Differences in COVID-19 Hospitalization Among Cancer Patients

[Dr. Xiao-Cheng Wu](#)<sup>1</sup>, Dr. Qingzhao Yu<sup>1</sup>, Dr. Yong Yi<sup>1</sup>, Lauren Maniscalco<sup>1</sup>, Mei-chin Hsieh<sup>1</sup>, Dr. Vivien Chen<sup>1</sup>, Dr. Augusto Ochoa<sup>1</sup>

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**Topic Area:** 3 - Epidemiologic Studies using Cancer Surveillance Data

**Sub-Topic:** 3b. Social determinants and cancer disparities

**Background.** Research has indicated Black cancer patients have higher COVID-19 hospitalization than their White counterparts. This observed disparity may be related to racial differences in underlying health conditions (UHCs). However, the mediation effect of UHC on the above racial disparity has not been studied using population-based data. This study aimed to assess the mediation effect of UHCs on racial differences in COVID-19 hospitalization.

**Methods.** We linked Louisiana Tumor Registry (LTR) cancer cases diagnosed in 2015-2019 with the state COVID-19 data to identify cancer patients who tested COVID-19 positive in 2020. COVID-19 hospitalization was determined using the state hospital in-patient discharge data (HIDD). UHCs were obtained from LTR and the 2012-2020 HIDD. We assessed the mediation effect of UHCs using the multivariable logistic regression, adjusting for age, sex, insurance, poverty, and cancer type as confounders or covariates. First, we assessed the effect of UHCs using the number of UHCs (0, 1, 2+). Then, we evaluated the effect of individual types of UHCs (i.e., congestive heart failure, diabetes, hypertension, hyperlipidemia, liver disease, myocardial infarction, peripheral vascular/cerebrovascular diseases, pulmonary disease, renal disease, and all other UHC combined).

**Results.** Of 6,318 cancer patients with COVID-19, 31.6% were Black, and 68.4% were White. COVID-19 hospitalization was higher ( $p < 0.01$ ) among Blacks than Whites (28.4% vs. 17.3%). The multivariable mediation analysis showed that overall, the odds of COVID-19 hospitalization were 1.80 times in Blacks as in Whites, and the number of UHCs explained 41% of the racial difference in COVID-19 hospitalization; the top 4 contributing UHCs to the racial disparity in COVID-19 hospitalization were hypertension (10.0%), diabetes (9.6%), renal disease (8.2%), and chronic heart failure (1.7%). Age and cancer type explained 1% of the racial difference. Poverty and insurance were not associated with COVID-19 hospitalization after adjusting for other risk factors.

**Conclusion.** UHCs, especially hypertension, diabetes, and renal disease, explained most racial differences in COVID-19 hospitalization. This study provides quantified population-based evidence about the association of enduring racial health disparities with COVID-19 hospitalization. Multi-dimensional actions shall be taken to address the root cause of racial inequality and improve health across all races and ethnic populations.



# EHR-Based Epidemiologic Cohorts for Studies of Cancer Risk and Etiology: Examining Factors that Contribute to Racial and Ethnic Disparities in Liver Cancer

**Dr. Mindy Hebert-DeRouen**<sup>1,2,3</sup>, Ms. Alison J. Canchola<sup>1,2</sup>, Dr. Janet Chu<sup>1,3</sup>, Ms. Alyssa Cortella<sup>1</sup>, Dr. Pushkar Inamdar<sup>1</sup>, Mr. Sixiang Nie<sup>4</sup>, Ms. Mai Vu<sup>5</sup>, Dr. Ma Somsouk<sup>1,3</sup>, Dr. Michele Tana<sup>1,3</sup>, Dr. Caroline A. Thompson<sup>6</sup>, Dr. Scarlett Gomez<sup>1,2,3</sup>, Dr. Hashem B. El-Serag<sup>7</sup>, Dr. Mi-Ok Kim<sup>1,3</sup>, Dr. Mark Segal<sup>1</sup>, Dr. Chanda Ho<sup>8</sup>, Dr. Yihe G. Daida<sup>4</sup>, Dr. Su-Ying Liang<sup>5</sup>, Dr. Salma Shariff-Marco<sup>1,2,3</sup>

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**Topic Area:** 3 - Epidemiologic Studies using Cancer Surveillance Data

**Sub-Topic:** 3b. Social determinants and cancer disparities

**Background:** Linkage of EHR-based cohorts to population-based cancer registries leverages readily available data to study cancer risk and etiology. However, operationalization of EHR data to meaningfully define social determinants is essential to advance understanding of cancer health disparities. We assembled an EHR-based cohort linked to cancer registry data to study disparities in risk of hepatocellular carcinoma (HCC) among detailed racial and ethnic groups and to examine the contribution of known and putative HCC risk factors to disparities in risk.

**Methods:** Adults with at least one in-person encounter 2000-2017 within the San Francisco Health Network, Sutter Health Northern California, and Kaiser Permanente Hawaii were linked to state cancer registries for data on incident HCC. We used EHR data to define sociodemographic and clinical factors; neighborhood-level data were appended to geocoded patient addresses. We used Cox proportional hazards regression with age as the timescale to examine racial and ethnic disparities in HCC risk, stratified by sex. Models were adjusted for site, birth cohort, baseline year, number of encounters, and length of follow-up. We are calculating population attributable fractions of HCC risk factors (e.g., infections, metabolic syndrome, neighborhood environment) among racial and ethnic groups.

**Results:** The pooled cohort contains data on 4,249,671 individuals across fifteen detailed racial and ethnic groups; 55% were female, 2,916 had an incident HCC diagnosis. Compared to non-Hispanic White males, Vietnamese males had the highest risk of HCC (HR: 7.42; 95% CI: 4.25, 12.96); followed by American Indian/Alaska Native, Black, Chinese American, Hispanic, Native Hawaiian, and Pacific Islander males, and those of multiple races or ethnicities. Among females, every group except for American Indian/Alaska Native, Asian Indian American, and Pacific Islander females had higher risk of HCC compared to the non-Hispanic White group; HRs ranged from 1.68 (1.01, 2.78) among Filipino to 6.38 (2.79, 14.55) among Vietnamese females.

**Conclusions:** Thoughtful operationalization of EHR data to study health inequities assures that EHR-based cohorts benefit efforts to understand and intervene upon cancer disparities. Our results highlight racial and ethnic disparities in HCC risk. Ongoing work is examining the relative contribution of known and putative HCC risk factors within groups.

# Environmental Scan of Electronic Reporting of Pathology Information Across Cancer Registries in Canada.

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**Topic Area:** 6 - Data Collection, Tools and Operations

**Sub-Topic:** 6b. Innovative operations and procedures

**Background:** To facilitate complete ascertainment of pathology confirmed cases, improvements in electronic reporting from pathology laboratories continue in Canada and the United States. However, cancer registries often rely on manual processes including filtering electronic reports for reportability status. In response to these challenges, the Canadian Council of Cancer Registries struck a Task Force to lead an environmental scan of electronic reporting of pathology information across Canadian provincial and territorial cancer registries (PTCRs). This effort aimed to (1) describe the current state of electronic pathology reporting in Canada, (2) enable comparison of data sources, systems, processes and tools across PTCRs and (3) contribute towards Pan-Canadian solutions, registry practices and data standards.

**Methods:** A questionnaire was developed by the Task Force and cancer registry experts to gather key information about electronic pathology reporting. Topic areas covered data sources, transmission and ingestion practices, and case ascertainment. Semi-structured follow up interviews were held with PTCRs to discuss questionnaire responses and develop outputs: (1) a data metrics table and (2) process map flow diagrams. The data metrics table compares high-level information on systems, processes, and data on electronic reporting of pathology across PTCRs. The visual process maps incorporated information on cancer registry systems and processes, areas that rely on manual work, challenges, and opportunities.

**Results:** All Canadian PTCRs (13) participated. Many PTCRs are in early phases of transitioning or just transitioned to electronic reporting. In most cases, electronic reporting includes complete coverage of pathology information. PTCRs showed significant variation in the way reports are fed into the system, report format, and technical solutions to process information. Many PTCRs are exploring data science methods to support demands associated with volumes, timeliness, and human resource (registrar) shortages.

**Conclusion:** This work provides the current state of electronic reporting of pathology information to cancer registries in Canada. This work highlights successes, common challenges, and emerging methods and informs modernization of cancer registry systems to make full use of electronic reporting of pathology information. A second phase of this initiative is underway focusing on the processing, consolidation, and integration of pathology data into the cancer registry dataset.

# Evaluation of Breast Cancer Hormone Receptor Status Information and Incidence of Breast Cancer Subtypes in the District of Columbia, 2010-2019

Ms. Claudine Samanic<sup>1</sup>, Ms. Maria Leuchert<sup>1</sup>, Mr. Ian Quan<sup>1</sup>, Ms. Alfreda Woods<sup>1</sup>  
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**Topic Area:** 3 - Epidemiologic Studies using Cancer Surveillance Data

**Background:** Breast cancer is the most commonly diagnosed cancer among women in the District of Columbia (DC), and mortality from breast cancer is highest among African American women in DC. One potential driver of this disparity may be a higher incidence of triple-negative breast cancer (TNBC) among African American women, which are negative for estrogen receptors (ER), progesterone receptors (PR), and human epidermal growth factor type 2 receptors (HER2).

**Methods:** We examined the completeness of ER/PR/HER2 data reported to the District of Columbia Cancer Registry (DCCR) among women diagnosed with breast cancer between 2010-2019. Analysis included breast cancer subtype in relation to demographic and clinical characteristics, age-adjusted incidence, and overall and cause-specific survival by race and breast cancer subtype. Breast cancer subtype was categorized as Luminal A (ER+ and/or PR+/HER2-), Luminal B (ER+ and/or PR+/HER2+), TNBC (ER-/PR-/HER2-), and HER2 positive (HER2+/ER/PR).

**Results:** Among 4,811 White and African American female residents diagnosed with breast cancer between 2010-2019, coding of the relevant cancer registry data fields for breast cancer hormone status was nearly 100% complete; 21 cases (0.44%) were missing/blank for the relevant fields. Results from ER/PR/HER2 testing were available for 84.6% (4,072 out of 4,811) of women. Subtype distributions varied by age, race/ethnicity, SEER summary stage, and grade. Overall incidence of breast cancer was similar for African American women relative to White women (incidence rate ratio (IRR)=0.96; 95%CI=0.90-1.02, p=0.21). However, when examining by subtype, incidence of TNBC was higher among African American women compared to White women (IRR=1.93; 95%CI=1.60-2.33; p 0.001), whereas incidence of Luminal A, the most commonly diagnosed subtype, was lower among African American relative to White women (IRR=0.81; 95%CI=0.75-0.87; p 0.001). African American women with TNBC had worse overall and cause-specific survival than African American women with ER+/PR+ tumors, or White women with either ER+/PR+ or TNBC.

**Conclusion:** In DC, similar to overall US trends, there were differences in incidence of breast cancer subtype by race. DCCR data are complete enough to monitor outcomes among DC women by breast cancer subtype.

# Expanding Casefinding Audits to Assess Reporting Facility Completeness

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**Topic Area:** 6 - Data Collection, Tools and Operations

**Sub-Topic:** 6b. Innovative operations and procedures

In the past, the Cancer Registry of Greater California (CRGC) conducted casefinding audits at reporting facilities by requesting the Medical Record Disease Indices (MRDI) for specific months, based on the facility annual cancer caseload, using the ICD-10 CM Casefinding Codes. This was a sample assessment only of how well the reporting facility was able to identify reportable cancers for a 2 to 4 month period, depending on the annual cancer caseload. While this approach was fine for conducting casefinding efforts based on a small sampling of cases, it did not identify potential casefinding gaps, assess overall casefinding efforts, or identify the impact of casefinding on case completeness. To enhance the audit process and to make the results more meaningful, CRGC changed the casefinding audit approach to request the MRDI for an entire calendar year, based on the ICD-10-CM Casefinding Codes, regardless of annual cancer caseload. A utility developed by our CRGC Business Analyst is used to match cases from the MRDI to the cases in our central database management system from the reporting facility audited. This comprehensive approach not only assesses the reporting facility's casefinding efforts and practices, but the audit also assesses the facility's completeness for the year being audited. This presentation will review the process of this new casefinding and completeness audit, share the results of 8 casefinding audits conducted in 2022, as well as the missed case profile information provided back to the reporting facility to assist in identifying casefinding gaps and our plans for enhancing these audits in the future. The presentation will also review the benefits of maximizing the casefinding audit in this manner, for both the reporting facility and central registry.

# Extending NAACCR XML for Non-Standard Pediatric Cancer Data: Strategies and Considerations

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<sup>1</sup>Kentucky Cancer Registry, Lexington, USA

**Topic Area:** 6 - Data Collection, Tools and Operations

**Sub-Topic:** 6c. Overcoming issues with data sharing

**Background** The introduction of the NAACCR XML standard allows central registries more flexibility when defining registry-specific items. Further capabilities are available for registries who may wish to transmit other data, such as genomic or clinical reports, experimental data items, or even entire data files. Recently, the Kentucky Cancer Registry (KCR) collaborated with the SEER program to pilot the collection of pediatric cancer staging data, and with the National Childhood Cancer Registry (NCCR) to collect molecular and genomic data related to pediatric cancers. These collaborations required extending NAACCR XML to transmit data. Purpose To examine three strategies for exchanging pediatric cancer data using NAACCR XML and the benefits and considerations of each strategy.

**Methods** The Toronto staging system pilot program tested a new staging system to assess the extent and burden of pediatric cancers. We modified our hospital-based registry software to collect several data items specific to this staging system. A user defined dictionary was created as part of the project and was used for transmission. Due to the higher complexity of data items sent to NCCR, we utilized a custom namespace. Some data were highly structured and could be directly translated into an XML tree. Other data were too complex, so we included entire data files as character data (CDATA).

**Results** We were able to easily update our existing data flow to accommodate the new structured data for Toronto staging pilot data since it was collected alongside the existing data used to generate NAACCR XML files. The data being transmitted to NCCR needed a linkage step to be integrated with registry data, requiring several programs to be written. These programs were easy to develop, in large part because of the existence of many useful tools to manipulate XML files.

**Conclusions** NAACCR XML provides a great amount of flexibility and helped us to reduce limitations and complexity when exchanging non-standard data items with NCCR and SEER. The main challenge we observed in linking external data to registry data. Overall, we found that data with any degree of structure could be easily integrated with existing cancer registry data using NAACCR XML.

# Factors Associated with Treatment and Survival Disparities in Metastatic Renal Cell Carcinoma, CA: 2010-2019

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**Topic Area:** 3 - Epidemiologic Studies using Cancer Surveillance Data

**Sub-Topic:** 3b. Social determinants and cancer disparities

**Background:** Treatment underutilization has previously been reported in minority groups with renal cell carcinoma, particularly localized disease. Few have examined treatment disparities in advanced RCC, particularly timing of treatment. Both adequate and timely treatment may contribute to survival outcomes. Purpose: To examine if sociodemographic characteristics and insurance status at time of diagnosis are associated with treatment delays and survival in patients diagnosed with metastatic RCC (mRCC).

**Methods:** California Cancer Registry data from 2010-2019 was used to identify adults (age 20) with mRCC. Sample was further restricted to first primary cases with microscopic confirmation who lived beyond 30 days of diagnosis. Time to treatment was defined as duration between diagnosis and treatment initiation dates, and categorized as follows: no treatment, received treatment 30 days, between 31-60 days, and 60+ days from diagnosis. Summary statistics (e.g. frequency, percentage) were used to describe sample characteristics and summarize key variables of interest. Association between patient characteristics including race/ethnicity, neighborhood socioeconomic status (nSES), insurance and timing of treatment was assessed using multinomial regression model. Overall survival (OS) was assessed using Cox proportional hazard model. All models were adjusted for sociodemographic and baseline clinical characteristics.

**Results:** A total of 5,193 eligible cases were identified. Most cases were male (70.8%), non-Hispanic white (NHW, 51.5%), between ages 50-79 (81.0%), and had private insurance or Medicare with supplement (55.7%). NH black had significantly higher odds of being untreated (OR[95%CI]: 1.58[1.09, 2.28] and trends for receiving treatment 31+ days from diagnosis (ORs: 1.38-1.42, p: 0.05-0.08) compared to NHW. Those with Medicaid or residing in poorer areas had higher odds of being untreated (OR range: 1.77-2.05, p0.02) or treated beyond 60 days (OR range: 1.46-2.08, p0.01). These groups, except for NHB, also had increased risk of dying (HR range: 1.12-1.13, p0.05). For NHB, poorer OS was observed in unadjusted model, but not after adjusting for other factors including treatment status.

**Conclusion:** Disparity exists in treatment utilization and survival, particularly in poorer neighborhoods and among Medicaid beneficiaries. More studies are needed to determine key underlying factors leading to treatment disparity and poorer survival.

# Feasibility and Limitations of Using Commercial Databases to Evaluate Residential Mobility Prior to Latency Period in Registry-Based Research on Childhood Cancers

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**Topic Area:** 6 - Data Collection, Tools and Operations

**Sub-Topic:** 6b. Innovative operations and procedures

Case-control studies on childhood cancers and environmental exposures often select controls from birth registries and assign exposures based on residential address on the birth certificate. This approach is limited by exposure misclassification because residential location may change from conception to birth and prior to the latency period. Our objective was to evaluate the feasibility and limitations of using address data from LexisNexis Accurint for Government data systems, a commercially available credit reporting company, to capture residential mobility from conception through the start of the latency period. Our study population consists of 520 children in the Colorado Central Cancer Registry (CCCR) diagnosed with acute lymphocytic leukemia between 2002 and 2016, aged 2-9 years at diagnosis, and born in Colorado (1993-2014) as well as 3120 randomly selected controls (i.e., children not diagnosed with any cancer) drawn from the Colorado Birth Registry and matched to cases based on race/ethnicity, birth year, and month. Each control was assigned a reference date equal to the diagnosis date of their matched case. Using the name, birth date, and social security number of the mother listed on the birth certificate, LexisNexis provided us a batch file of up to 20 addresses from the conception date through the latency period with first and last date the address appeared for each case and control. We evaluated whether completeness of residential information differed by ethnicity, age, birth year, and case-control status. We also evaluated LexisNexis ability to provide residential addresses and date ranges consistent with the birth certificate address for cases and controls and CCCR diagnosis address for cases. We then evaluated whether accuracy differed by ethnicity, age, birth year, and case-control status.

# FrESCO: Framework for Exploring Scalable Computational Oncology

[Mr. Adam Spannaus](#)<sup>1</sup>, Dr. John Gounley<sup>1</sup>, Dr. Mayanka Chandra Shekar<sup>1</sup>, Dr. Zach Fox<sup>1</sup>, Mr. Dakota Murdock<sup>1</sup>, Mr. Jamaludin Mohd-Yusof<sup>2</sup>, Mr. Noah Schaefferkoetter<sup>1</sup>, Dr. Heidi Hanson<sup>1</sup>

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**Topic Area:** 2 - Big Ideas in Cancer Surveillance

**Sub-Topic:** 2a. How to modernize the Cancer Surveillance System

The Modeling Outcomes using Surveillance data and Scalable AI for Cancer (MOSSAIC) project is an NCI-DOE collaboration to develop scalable natural language processing (NLP) and machine learning (ML) tools for extracting reportable cancer surveillance data. This includes methods for pathology coding, reportability, biomarkers, recurrence, and metastasis. The National Cancer Institute (NCI) Surveillance, Epidemiology, and End Results (SEER) program collects, analyzes, and annotates cancer pathology reports for population-level cancer monitoring of cancer incidence and mortality. Due to the technical and dense language used in the reports, there is nearly a two-year lag between time of diagnosis and published report. Collective AI efforts aimed at extracting information from unstructured medical text may transform the cancer surveillance over the next decade and improve our ability to rapidly identify patients for clinical trials, identify individuals at high risk for cancer, and create targeted public health interventions. Here we present our modular deep-learning NLP library for extracting phenotype information from clinical text. Our project codebase provides a deep-learning Python library based on PyTorch for extracting information from clinical text. Our flexible and modular codebase provides independent modules for: (1) loading text data and creating the required data structures for model training, (2) building and training deep-learning models, (3) scoring and evaluating trained models, and (4) incorporating abstention into these models. We will detail our workflow and give examples of present use cases of our software library deployed in different environments by the NCI.



# Future Enhancements of the Virtual Pooled Registry Cancer - Linkage System and Match\*Pro Software

Mr. Don Green<sup>1</sup>

<sup>1</sup>Information Management Services, Inc., Calverton, MD, USA

**Topic Area:** 4 - New Directions and IT Solutions

**Sub-Topic:** 2c. Visions for the future

**Background:** The Virtual Pooled Registry Cancer Linkage System (VPR-CLS) was created to address challenges associated with linking study data with multiple central cancer registries. Funded by NCI and managed by NAACCR, the VPR-CLS provides a single portal through which researchers apply to link their data with participating U.S. registries. The VPR-CLS leverages various efficiencies, including use of Match\*Pro to link and identify matches between the two data sources. These linkages are performed at each registry for all VPR-CLS studies. To date, the VPR has facilitated 15 study linkages with the volume increasing every year. The challenge has now shifted to managing resources to perform linkages and monitoring the status of numerous studies across the 45 participating registries.

**Purpose:** The author will provide an update on future VPR-CLS portal enhancements and projected Match\*Pro changes to address the new challenges. The update will focus on automation of encrypted linkages within the VPR-CLS, data and information visualizations to monitor progress across studies and registries, and the addition of a privacy preserving linkage component to Match\*Pro.

**Results/Conclusion:** With the increasing number of studies that want to use the VPR-CLS and the current process of registries running their linkages locally, the option to upload encrypted registry files to the VPR-CLS for automated linkage will be offered. Linkages can be run quickly and efficiently, with the results immediately provided to each registry and the associated workload reduced. For registries unable to submit encrypted PII to the VPR-CLS, a privacy-preserving record linkage (PPRL) module will be added to Match\*Pro. The module will create a set of hash tokens and provide an even greater level of security than the encrypted data linkages currently provide, but at the cost of some accuracy. By adding visualizations to the VPR-CLS, various metrics can be produced and viewed by users. Metrics can convey how workflows are functioning and identify areas where improvements can be made. They can also measure and display key efficiencies gained through use of the VPR-CLS, such as timeliness of registry, IRB, and Central IRB reviews and data release.

# Getting to Know You: NAACCR, Our Plan, Activities and How to Get Involved

## **Betsy Kohler**

*NAACCR Executive Director, NAACCR, Inc., Springfield, USA*

## **Coleen Sherman**

*New York State Cancer Registry, USA*

## **Dr. Sarah Nash**

*Assistant Professor, University of Iowa, USA*

## **Deirdre Rogers**

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## **Dr. Antoinette Stroup**

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## **Mrs. Andrea Sipin-Baliwas**

*Director Of Registry Operations, Los Angeles Cancer Surveillance Program - University of Southern California, USA*

## **Heather Stabinsky**

*New Jersey State Cancer Registry, USA*

This session will provide an overview of NAACCR, preview our Steering Committees and current projects, as well as introducing two new groups to aid in volunteerism and professional development.

# Godzilla Meets King Kong: How the Manitoba Cancer Registry Helped Understand the Impact of COVID-19 on Cancer in Real-Time and the Long-Term

Dr. Donna Turner<sup>1,2,3</sup>, Dr. Kathleen Decker<sup>1,2,3</sup>, Mr. Pascal Lambert<sup>1,2</sup>, Mr. Oliver Bucher<sup>1</sup>, Ms. Allison Feely<sup>1</sup>, Ms. Katie Galloway<sup>1,3</sup>, Mrs. Carrie O'connell<sup>1,3</sup>, Mr. Erik Campbell<sup>1</sup>, Miss Munayie Wakie<sup>1</sup>, Mr. David Phillips<sup>1</sup>, Ms. Sheila Fukumura<sup>1</sup>

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**Topic Area:** 1 - Effects of Covid-19 on Cancer Surveillance and Operations

**Sub-Topic:** 3c. Using real-world data from cancer registries to improve cancer outcomes

**Background.** The COVID-19 pandemic brought abrupt changes to the healthcare system, including the delivery of cancer services. In Manitoba, Canada, this included a shift to virtual visits, prioritization of surgeries and diagnostics, and temporary suspension of cancer screening. Along with these changes, the demand for data accelerated as decision-makers needed quick answers about the impact of COVID-19 on cancer patients, cancer services, and staff.

**Methods.** The Manitoba Cancer Registry (MCR) was a key data resource for determining the impact of COVID-19 on cancer in our province, along with data from other information systems and audits. We produced weekly dashboards, including reports from the cancer registry's electronic pathology (e-path) system as an early warning indicator of effects on diagnostics, adding to other measures like COVID-19 positivity in patients, staff sick time, clinic visit volumes by type (virtual vs in-person), treatments and personal protective equipment compliance. The MCR was also featured in more fulsome analyses of COVID-19's impact on cancer, using Interrupted Time Series (ITS) techniques to assess the impact of the pandemic on the number and stage of cancers diagnosed over time along with volumes of e-path, screening, clinic visits and treatments.

**Results.** Dashboard data provided real-time information and allowed monitoring of services during the pandemic's ebbs and flows. For example, weekly e-path decreased from 1100 reports to 600 in the week following the declaration of the pandemic, followed by a recovery to normal levels within 3 months. While many services returned to typical levels quite rapidly, ITS analyses showed that by December 2021, 6.9% fewer e-path reports had been received by the MCR since the beginning of the pandemic compared to what was expected, and 5.2% fewer total cancers were diagnosed (ranging from 2.8% for colorectal cancer to 13.6% for breast cancer).

**Conclusions.** Our analysis demonstrated that cancer registry data can be used for quick turnaround needs to provide decision-makers and healthcare operators with key information, in addition to longer term evaluations. This highlighted the utility of the cancer registry and raised its profile and is an important lesson from the COVID-19 pandemic that has implications for future registry operations.

# Impact of COVID-19 on Cancer Incidence and Mortality in Kentucky

Dr. Quan Chen<sup>1</sup>, [Dr. Thomas Tucker<sup>1,2</sup>](#), Dr. Eric Durbin<sup>1,2</sup>, Dr. Bin Huang<sup>1,2</sup>

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**Topic Area:** 1 - Effects of Covid-19 on Cancer Surveillance and Operations

**Background:** The COVID-19 pandemic had a significant impact on health access and cancer patient care. Kentucky had one of the highest cancer incidences and mortality in the nation. Potentially COVID-19 had a large impact on cancer incidence and mortality in this rural state. This study was to examine the cancer incidence and mortality in the year 2020 and gain an understanding of how COVID-19 has impacted the cancer burden in Kentucky.

**Method:** Using the Kentucky Cancer Registry (KCR) data, the age-adjusted rates for all cancer sites combined and individual sites were calculated for both incidence and mortality for patients diagnosed in 2004-2020. Data was further stratified and evaluated by sex, age, stage, and Appalachia status groups. Trend analyses were performed using the JoinPoint regression.

**Results:** The cancer incidence for the year 2020 in Kentucky is 463.4 per 100,000, which dropped by more than 10% compared to the previous year. The mortality rate is 176.8, which is comparable to the previous years. Based on the joint regression model, the estimated incidence rate for all sites combined in 2020 was 11% higher than the observed value. Overall, both males and females, and Appalachian and non-Appalachian residents experienced a similar drop in incidence. However, the incidence of cancers diagnosed at early stage dropped by more than 15% in the year 2020, while only 7.7% for late stages. The decreases in rates for the early stage were primarily found among those screening-able cancer sites. And the Appalachia population had a higher decrease than the non-Appalachia in early-stage screening able cancer sites like female breast and colorectal.

**Conclusion:** the study observed a significant decrease in cancer incidence in Kentucky in the first year of the pandemic, primarily among early-stage cancer. The screening able cancer sites had the highest impact, and the Appalachia population also had the bigger impact. These findings provide valuable insights and can inform decision-making in the future.

**Key Words:** COVID-19, Cancer Incidence, Appalachia, Cancer Screening

# Impact of Weight on Breast and Cervical Cancer Treatment Quality

[Dr. Sarah Nash](#)<sup>1</sup>, Ms. Amanda Kahl<sup>1</sup>, Ms. Jamie Sorensen<sup>1</sup>, Dr. Ingrid Lizarraga<sup>1</sup>, Dr. Keely Ulmer<sup>1</sup>, Dr. Kathleen Robinson<sup>1</sup>, Dr. Mary Charlton<sup>1</sup>

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**Topic Area:** 3 - Epidemiologic Studies using Cancer Surveillance Data

**Sub-Topic:** 3a. Epidemiologic studies

**Background:** Obesity is associated with increased cancer-specific mortality, and lower cancer survival. Timely access to high quality, evidence-based cancer treatment is known to impact outcomes; however, we do not know whether these vary by weight.

**Methods:** We used data from the Iowa Cancer Registry (2006-2015), linked with drivers license data for height and weight, to examine whether treatment type, and time from cancer diagnosis to treatment initiation varied by BMI category. We evaluated whether adherence to Commission on Cancer treatment guidelines varied by BMI. Finally, we assessed associations of BMI with cancer survival, and explored whether timely or guideline concordant care modified associations between BMI and survival outcomes.

**Results:** During the period 2006-2015, there were 19,102 breast cancer patients, and 911 cervical cancer patients with drivers license-linked data in the Iowa Cancer Registry. Breast cancer patients with obesity were less likely to receive a contralateral prophylactic mastectomy or breast reconstruction, and more likely to receive hormonal and radiation therapies than patients with a BMI of 18.5-24.9 kg/m<sup>2</sup>. Time from diagnosis to receipt of surgery and chemotherapy therapy increased with BMI. Cervical cancer patients with obesity were less likely to receive surgery, and more likely to receive chemotherapy than patients with a BMI of 18.5-24.9 kg/m<sup>2</sup>. They also had a shorter time to chemotherapy; however, time to radiation and surgical treatment was higher among those with a BMI of 25-29 and 30-35 kg/m<sup>2</sup>.

**Conclusions:** This study is the first to use cancer registry data to investigate whether receipt of timely or guideline-concordant cancer treatment was associated with obesity among breast and cervical cancer patients. Our preliminary results indicate that there may be differences in cancer treatment by weight that require further investigation. Ongoing work by our group is exploring the potential role of weight stigma in receipt of timely and guideline-concordant cancer care.

# Impacts of the Affordable Care Act (ACA) Implementation on Insurance Coverage, Treatment Utilization and Receipt of Guidelines-Based Treatment Among Bladder Cancer Patients in California, 2011-2019

Mr. Eric Stewart, MPH<sup>1,2</sup>, Ms. Dimitra Fellman, BS<sup>1</sup>, Dr. Alain Monnereau, MD, PhD<sup>1</sup>, [Dr. Anshu Shrestha, MPH, PhD<sup>1</sup>](#)

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**Topic Area:** 3 - Epidemiologic Studies using Cancer Surveillance Data

**Sub-Topic:** 3a. Epidemiologic studies

**Background:** Since the implementation of the ACA in 2014, many studies have assessed the policy's impact on cancer care, mainly in screenable cancers. However, ACAs impact on bladder cancer care, which is not screenable and requires frequent interaction with the healthcare system for treatment, has not been well studied. Purpose: To describe the impact of ACA on bladder cancer insurance coverage, treatment received, and use of guidelines-based treatment (GBT) across the last decade.

**Methods:** The California Cancer Registry was used to identify patients diagnosed with a first primary bladder cancer between 2011-2019. Descriptive statistics and chi-square tests were calculated to understand patterns across pre- and post-ACA implementation (Pre-ACA: 2011-2013; Post-ACA: 2014-2016; and ACA Premium Increase: 2017-2019). We examined changes in insurance coverage and treatment received by patient and tumor characteristics. Sub-analysis was conducted to assess utilization of guidelines-based treatment by stage and grade at diagnosis.

**Results:** A total of 43,549 eligible patients were identified, of which most were male (77%), non-Hispanic White (72%), and had non-invasive disease at diagnosis (72%), with a median age of 71 years. Medicare and Medicaid coverage increased across the policy periods by 2% and 7%, respectively. Among those aged 65, there was an observed 6.5% increase in Medicaid coverage. Both patients with low- and high-grade non-invasive bladder cancer saw an increase in receipt of GBT in the Post-ACA period (6-10% increase). Among all age groups of muscle invasive and metastatic disease there was minimal difference in receipt of GBT, however, the age-stratified groups saw a marginal increase. Patients aged 65 with muscle invasive disease and patients 65 years or older with metastatic disease saw a 5% and 4% increase in receipt of GBT, respectively.

**Implications:** These results indicate that the ACA provided better access to health care for bladder cancer patients in California. Guidelines-based treatment utilization increased for those with NMIBC, however, only a marginal impact was observed on treatment utilization for those with later stage disease. Future analysis on the impact of ACA on bladder cancer survival is warranted and will be conducted as a follow-up to this investigation.

# Implementation of Standardized Cancer Pathology Reporting to a Cloud Platform

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**Topic Area:** 4 - New Directions and IT Solutions

**Sub-Topic:** 4b. New and emerging methods of data collection

**Background:** Challenges facing the cancer surveillance community include interoperability and timeliness. Central cancer registries have difficulty establishing connectivity to pathology laboratories for electronic reporting of cancer cases, even though the cancer surveillance community has developed a standard for this data exchange. Central cancer registries also spend a significant amount of time collecting and abstracting data for cancer cases due to manual intervention throughout the process including data linkage, identification/abstraction of data elements in clinical notes within a pathology report, and/or gathering missing information through follow-back procedures. These interoperability challenges and manual processes can possibly reduce the effectiveness of public health policy and interventions to address the incidence of cancer in the community.

**Purpose:** This presentation will describe an innovative approach that has been implemented, as part of the Data Modernization Initiative, to use the APL Informatics Messaging Services (AIMS) Platform to improve the data exchange infrastructure between laboratories and cancer registries. The registries have been integrated into the APL AIMS infrastructure and provided with technical assistance to support real-time data exchange of standards-based cancer pathology data to meet mandated cancer reporting. This project demonstrates how standardized reporting can be implemented using a cloud platform to improve reporting for public health surveillance purposes.

**Methods/Approach:** Central cancer registries have indicated the need for streamlining the data collection and processing tasks in cancer surveillance. To overcome interoperability challenges and delays caused by manual intervention, the National Program of Cancer Registries is working with the Association of Public Health Laboratories (APHL) to expand reporting to the AIMS Platform to include cancer pathology reporting.

**Results:** As of the end of 2022, four laboratories (Quest Diagnostics, QDX, PathGroup, and ICM Diagnostics) are in production to report cancer pathology data electronically via the AIMS Platform to all applicable central cancer registries. Seven additional laboratories and/or laboratory information systems are in the process of onboarding and/or implementation.

**Conclusion:** Implementation of cancer pathology reporting through the AIMS Platform demonstrates how the use of a cloud platform to streamline public health reporting from healthcare systems can improve cancer surveillance processes and achieve real-time reporting.

# Improvements in the Loss in Expectation of Life Due to a Cancer Diagnosis in the United States

[Dr. Theresa Devasia](#)<sup>1</sup>, Dr. Nadia Howlader<sup>1</sup>, Mr. Ron Dewar<sup>2</sup>, Ms. Jennifer Stevens<sup>3</sup>, Ms. Karen Mittu<sup>3</sup>, Dr. Angela Mariotto<sup>1</sup>

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**Topic Area:** 3 - Epidemiologic Studies using Cancer Surveillance Data

**Sub-Topic:** 3a. Epidemiologic studies

**Introduction:** Cancer is becoming more of a chronic disease, largely due to improvements in treatment for multiple cancer sites. Life expectancy is a popular measure for the general population, but it has had limited use in the cancer survival literature. The loss in expectation of life (LEL) due to cancer is defined as the difference between the general population life expectancy and the life expectancy among cancer patients. To gain insight on how much longer cancer patients are living due to improved treatment, we quantified trends in the LEL due to a cancer diagnosis for five cancer sites from 1975 through 2018.

**Methods:** We used data for patients diagnosed with female breast cancer, chronic myeloid leukemia (CML), colon and rectum cancer (CRC), diffuse large B-cell lymphoma (DLBCL), or melanoma between 1975 and 2018 from nine Surveillance, Epidemiology, and End Results (SEER) cancer registries. Cancer and general population life expectancies for individuals aged 50+ were modeled by sex using flexible parametric survival models. LEL was calculated as the difference in area underneath the general population expected survival and cancer patient overall survival curves.

**Results:** Over 1.3 million patients were diagnosed with female breast cancer, CML, CRC, DLBCL, or melanoma in nine SEER registries between 1975 and 2018. Large decreases in LEL were observed between 1990 and 2010 for female breast cancer, DLBCL, and CML. Patients with CRC and melanoma exhibited more gradual improvements in life expectancy.

**Conclusions:** The gains in life expectancy reported in this study largely correlate with progress in the management and treatment of these five cancers since 1975. LEL provides an important public health perspective on how improvements in treatment and their impact on survival translate into changes in the life expectancy of cancer patients.



# Incidence of Etiology-Specific Hepatocellular Carcinoma: Results of a Linkage with Discharge and Viral Hepatitis Data in Florida.

[Prof. Paulo Pinheiro](#)<sup>1</sup>, Dr. Patricia Jones<sup>1</sup>, Dr. Heidy Medina<sup>1</sup>, Ms. Hannah Cranford<sup>1</sup>, Dr. Katherine McGlynn<sup>2</sup>, Dr. Tulay Koru-sengul<sup>1</sup>

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**Topic Area:** 3 - Epidemiologic Studies using Cancer Surveillance Data

**Sub-Topic:** 3c. Using real-world data from cancer registries to improve cancer outcomes

**Background/Aims:** The main causes of hepatocellular carcinoma (HCC) include chronic hepatitis C and B viral infections (HCV, HBV), NAFLD, alcohol-related disease (ALD). Etiology-specific HCC incidence rates and temporal trends on a population-basis are needed to improve HCC control and prevention.

**Approach/Results:** All 14,420 HCC cases from the Florida statewide cancer registry were individually linked to data from the hospital discharge agency and the viral hepatitis department to determine the predominant etiology of each case diagnosed during 2010-2018. Age-adjusted incidence rates (AAIR) were used to assess the intersection between etiology and detailed race-ethnicity. Etiology-specific temporal trends based on diagnosis year were assessed using Joinpoint regression. HCV remains the leading cause of HCC among men, but since 2017 NAFLD-HCC is the leading cause among women. HCV-HCC rates experienced a rapid decline since 2015 (-9.6% annually), while ALD-HCC (+6.0%) and NAFLD-HCC (+4.3%) are rising ( $p < 0.05$ ). HCV-HCC AAIRs are particularly high among US-born minority men, including Puerto Rican (10.9 per 100,000), African American (8.0 per 100,000), and US-born Mexican American men (7.6 per 100,000). NAFLD is more common among all Hispanics and Filipinos, HBV-HCC among Asian and Haitian Black men. HCV-HCC surpasses HBV-HCC in Asian women. ALD-HCC is high among specific Hispanic male groups.

**Conclusions:** New directly acting anti-viral drugs have impacted rates of HCV-HCC, offsetting important increases in both ALD- and NAFLD-HCC. Hispanics may be a group of concern due to higher rates for ALD- and NAFLD-HCC. HCC etiology varies remarkably and may warrant specific interventions by detailed race-ethnicity.

# Incidence Rates Stratified by CoC Accreditation Flag

[Ms. Reda Wilson](#)<sup>1</sup>, Ms. Mary Elizabeth O'Neil<sup>1</sup>

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**Topic Area:** 3 - Epidemiologic Studies using Cancer Surveillance Data

**Sub-Topic:** 6a. Data quality control and standards

**Background:** The CoC Accreditation Flag, identifying at least one cancer registry abstract prepared at a CoC-accredited facility, became a standard data item in 2018. This data item primarily serves to validate required information is received from CoC facilities. Analyses can be stratified to identify potential disparities. A previous evaluation illustrated data were high-quality, complete, and data collection rules were applied correctly.

**Methods:** This analysis used the NPCR and SEER Quality Control SEER\*Stat dataset, 2021-submission, and was limited to NPCR registries, malignant behavior, and diagnosis years 2018-2019. Cases were excluded when the data item was blank. The data was grouped as non-CoC and CoC. Age-adjusted incidence rates and RR were generated by CoC status for primary site, age, race, sex, stage, and economic status. For demonstration purposes only, rates were considered statistically different if the RR was 1.00. Confidence intervals and p-values were not calculated for this demonstration project. Proportions were generated for treatment.

**Results:** For all sites combined, cases with an unknown stage were more likely to be reported by a non-CoC facility. Less difference in RRs was seen among the 0-14 age groups, increasing through age group 40-44, and again becoming less different for age groups 45. For all sites combined, treatment was more likely (three to four times higher proportion) at CoC facilities. All patients were more likely to be seen at a COC facility, regardless of economic status. But those in the higher economic status groups were much more likely to be seen at a COC facility. Results for the top five primary sites and cases with an unknown stage will be presented.

**Conclusion:** A previous evaluation showed 70% of cancer cases were reported to the central cancer registry by a CoC facility with 1% missing information. In the current analysis, RRs were higher for cases reported from a CoC facility for all analyses. This analysis demonstrates how the CoC Accreditation Flag can be used to evaluate potential differences in cancer care and outcomes. Including a p-value and/or confidence intervals would thoroughly document statistical significance in future analyses using the CoC Accreditation Flag.

# Inner Workings of Cancer PathCHART: Impact Analyses

[Dr. Gonçalo Forjaz](#)<sup>1</sup>, Dr. Huann-Sheng Chen<sup>2</sup>, Dr. Manxia Wu<sup>3</sup>, Dr. Alison Van Dyke<sup>2</sup>, Dr. Brian Rous<sup>4</sup>, Dr. Loria Pollack<sup>3</sup>

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**Topic Area:** 7 - Other Relevant Topics

**Background:** The Cancer PathCHART initiative is a collaboration between 11 national and global organizations that aims to update validated standards for tumor site-histology combinations recorded by tumor registrars from the medical record. One critical step in this enterprise is an independent pathologist review of tumor histology types by site group. The primary outcome of this review is to determine if a specific site/histology combination is Biologically Valid, Biologically Unlikely, or Biologically Impossible. Site/histology combinations falling within one of these three categories will be placed (if not already there) into, respectively, the SEER Site/Type Validation List, an Override category, and the Impossible List. This study aims to assess the potential impact of significant changes in site/histology combinations on U.S. incidence rates and counts.

**Methods:** We used data from the U.S. Cancer Statistics Database for patients of all ages diagnosed in 2001-2019. We calculated age-adjusted incidence rates by reviewed site and fitted a Joinpoint model to the observed data to estimate the impact on incidence trends if a specific site-histology combination is included vs. excluded. The selected cancer sites underwent a complete pathologist review for epithelial, mesenchymal, and germ cell tumor histologies.

**Results:** Results will be presented by reviewed cancer site and assuming that an alternative site-histology code will not be assigned. We will focus on the most significant change: when a specific site-histology combination moves from the current Site/Type Validation List or Override category to the Impossible List.

**Discussion:** The end goal of the Cancer PathCHART pathologist review is to have the SEER Site/Type Validation List, the Override categories, and the SEER Impossible Combinations List reviewed, vetted, and updated. This process may have varying impacts on U.S. incidence counts and rates depending on the proportion of histologies being excluded (i.e., deemed Biologically Impossible in the pathologist review) for a given site. Our analyses will help quantify these changes on reported statistics.

# Inner Workings of Cancer PathCHART: Process and Workflow

[Ms. Annelie Landgren](#)<sup>1</sup>, Dr. Gonçalo Forjaz<sup>2</sup>, Ms. Camille Goff<sup>3</sup>, Ms. Kathleen Loomis<sup>3</sup>, Ms. Peggy Adamo<sup>4</sup>, Ms. Lois Dickie<sup>4</sup>, Dr. Serban Negoita<sup>4</sup>, Dr. Brian Rous<sup>5</sup>, Dr. Alison Van Dyke<sup>4</sup>  
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**Topic Area:** 6 - Data Collection, Tools and Operations

**Sub-Topic:** 6a. Data quality control and standards

**Background:** The Cancer Pathology Coding Histology And Registration Terminology (Cancer PathCHART) initiative is a collaboration of 11 U.S., North American, and global registrar (NAACCR, NCRA, IACR), registry (SEER, NPCR, CoC), clinical (ACS, AJCC, WHO/IARC), and pathology (CAP, ICCR) organizations that aims to validate and update standards for tumor site-histology code combinations recorded by tumor registrars from the medical record. This ongoing work involves: 1) Content review by expert pathologist and CTRs of tumor histology/behavior types by site group, 2) Impact analyses of the updates, 3) Database generation based on review results and current standards 4) Implementation preparation with stakeholder meetings with registries and registrars as well as Cancer Registry software vendors, and 5) Release of updated standards.

**Aims:** We will illustrate how the CTRs and wider cancer registration community will benefit from the Cancer PathCHART updated standards, and describe the steps of this multilevel review and release processes, as well as the methods we used to monitor decisions and track progress.

**Review methodology and processes:** Multilevel reviews are conducted by subspecialty matter expert pathologists and CTRs to update tumor site-histology standards for cancer registration. A statistical evaluation is performed to evaluate impact of the changes. Registrars, registries, cancer researchers, and public health officials will benefit from the updated, uniform tumor site-histology combination standards that will be used as the source of truth for cancer registration software vendors and products by member organizations. In parallel with the content reviews, meetings with CTRs, and cancer registry managers in different types of registries (SEER, other central, COC-accredited hospital, other hospital, and Canadian) were held to inform the project regarding differing needs for implementation of Cancer PathCHART products and coordination with other standards. During the Spring 2023, we will work closely with cancer registration software vendors to ensure that released information is in file formats specifically requested (Excel, JSON, CSV, etc.) to easily incorporate for implementation in January 2024. We will also discuss some of the challenges encountered and solutions identified for coordinating this complex, international collaboration of vital importance for data quality.

# Interoperability: Key Concepts and Initiatives

## Mrs. Sandy Jones

Public Health Advisor, Centers for Disease Control and Prevention, DCPC, Cancer Surveillance Branch

## Mr. Sean Porter

Health Scientist – Informatics, Centers for Disease Control and Prevention

## Mr. Joseph Rogers

Team Lead, Centers for Disease Control and Prevention

## Ms. Caitlin Kennedy

Health Scientist (informatics), Centers for Disease Control and Prevention

## Mrs. Kasey Diebold

Health informatics, Centers for Disease Control and Prevention

Initiatives in public health interoperability are emerging and changing at a rapid pace. This workshop will provide an up-to-date overview of key interoperability terms and current initiatives that will impact public health and cancer surveillance in particular. These initiatives are intended to improve health data exchange across healthcare. Benefits and potential implications for registries will be discussed. There will be time for questions and answers throughout the session.

# Leveraging Electronic Laboratory Reporting to Inform Cancer Surveillance by Obtaining Results of Tumor Tissue Assays

Ms. Marjorie Carter<sup>1</sup>, Ms. Valerie Yoder<sup>1</sup>, Ms. Camille Roundy<sup>2</sup>, Mr. Theron Jeppson<sup>2</sup>, Ms. Sandra Edwards<sup>1</sup>, Dr. Carol Sweeney<sup>1</sup>

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**Topic Area:** 4 - New Directions and IT Solutions

**Sub-Topic:** 4b. New and emerging methods of data collection

The Centers for Disease Control and Prevention has supported implementation of electronic lab reporting (ELR) infrastructure for clinical laboratories reporting to public health agencies. The primary use case for ELR has been infectious disease surveillance. ELR infrastructure has recently been applied to electronic reporting of pathology reports for cancer surveillance. Utah Cancer Registry (UCR), in partnership with the Utah Department of Health and Human Services (DHHS) Cancer Genomics Program, piloted use of ELR for transmitting structured data describing results of lab tests performed on tumor tissue. We focused on assays related to Lynch syndrome (LS), an inherited genetic disorder associated with increased risk for colorectal, endometrial, and other cancers. UCR identified lab assays of interest for LS: microsatellite instability, mismatch repair, MLH1 promoter methylation, and BRAF mutation. We met with compliance and technical staff from DHHS and a clinical reference laboratory to discuss the data and procedures. Test files were used to ensure the processes of transmitting data from the lab to DHHS, filtering cancer assay results at DHHS, and relay by DHHS to UCR were working as expected. After successful testing and troubleshooting, the lab added the selected cancer assay results to their regular ELR feed to DHHS. UCR linked the results to cancer records using SEER\*DMS automatic matching, with no restriction on diagnosis year. Of 501 results received from assays performed 2017 to present, 403 (80%) link to any cancer record. The largest number of results received from a clinical reference lab, 351 (70%), were for BRAF mutation. Collection of structured data items through ELR has potential to improve completeness of cancer site specific data items (SSDI) and reduce the coding and data entry burden on cancer registrars. Unlinked lab records likely represent recently diagnosed cancer cases not yet reported to the registry. Good communication with laboratory informatics personnel was important because query processes for reportable cancer data are different from infectious disease reporting. Additional work is needed to assess the quality of linkages to known cancers, integrate results with cancer registry SSDI variables, and explore use of ELR infrastructure to obtain SSDI data for additional cancers.

# Linking Registry and Community Data: The Ohio Cancer Assessment and Surveillance Engine (OH-CASE)

[Dr. Johnie Rose](#)<sup>1</sup>, Dr. Weichuan Dong<sup>1</sup>, Dr. Uriel Kim<sup>1</sup>, Mr. Joseph Hnath<sup>1</sup>, Dr. Abby Statler<sup>1</sup>, Dr. Paola Saroufim<sup>1</sup>, Ms. Sunah Song<sup>1</sup>, Dr. Mustafa Ascha<sup>1</sup>, Mr. Harry Menegay<sup>1</sup>, Mr. Ye Tian<sup>1</sup>, Mr. Mark Beno<sup>1</sup>, Dr. Siran Koroukian<sup>1</sup>

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**Topic Area:** 4 - New Directions and IT Solutions

**Sub-Topic:** 3b. Social determinants and cancer disparities

**Background:** The comprehensive, individual-level case data housed in central cancer registries can provide valuable insight into the spatial, temporal, and demographic distribution of cancer burden. Linking registry data with data sources describing the communities where cancer patients live presents the opportunity to gain additional understanding of the relationships between social determinants of health (SDOH) and population cancer burden.

**Methods:** We developed a relational database, the Ohio Cancer Assessment and Surveillance Engine (OH-CASE), by spatially joining (by patient residential address at diagnosis) Ohio Cancer Incidence Surveillance System (OCISS) cancer registry data (2006-2019) with U.S. Census five-year American Community Survey data (2013-2017), a Food and Drug Administration (FDA) database of certified mammography facilities, and a database of Health Resources and Services Administration (HRSA) Health Professional Shortage Area census tracts. With input from research, community outreach and engagement, public health, and advocacy stakeholders, we developed a user interface in an open-source visualization platform called R Shiny.

**Results:** OH-CASE contains 791,786 cancer cases from across Ohio (88 counties, 1215 municipalities and 1197 zip codes). The user interface allows searching by demographic, disease, or geographic characteristics. Results may be reported by county, municipality, or zip code and include case counts, age-adjusted incidence and mortality rates, stage distribution, time to treatment, proportion uninsured, as well as community demographics and socioeconomic indicators. Results are stratifiable by sex, age, race, and ethnicity; and these may be viewed in HTML format or exported as comma separated value files. The data has so far been used for research, assessment of study feasibility, cancer center catchment area report generation, and analyses to assist community partners.

**Conclusions:** We have developed a multi-level population cancer data infrastructure with the goal of helping researchers and other stakeholders better understand and address the impacts of SDOH on the distribution of cancer burden. To ensure scalability, a central design principle for this infrastructure has been the use of data sources which are available in standard formats nationwide. Next steps include expansion of data sources and output features and development of tools to enable others to set up similar infrastructures using central cancer registries from other locations.

# Making Population-Based Whole Slide Imaging Feasible for Cancer Research

Dr. James A. Mays<sup>1</sup>, Dr. Anna Fernandez<sup>2</sup>, Mr. Sheshadri Mudiyanur<sup>2</sup>, Mr. David Manthey<sup>3</sup>, Mr. Rusty Shields<sup>4</sup>, Ms. Suzanne Adams<sup>4</sup>, Mr. David Roney<sup>4</sup>, [Dr. Alison Van Dyke](#)<sup>1</sup>

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**Topic Area:** 4 - New Directions and IT Solutions

**Sub-Topic:** 4a. Technologic and scientific advances and innovations

Cancer researchers use whole slide images (WSIs) of digitally scanned glass slides, generated through clinical care, to yield prognostic data, such as immune cell infiltrates, that are more important than stage in predicting disease outcome at some tumor sites. However, slides need to be deidentified before they are shared for research. The Surveillance Research Program (SRP) of the Division of Cancer Control and Population Sciences (DCCPS) with the National Cancer Institute (NCI); Kitware, Inc.; and Information Management Services, Inc. (IMS) developed an open-source, WSI deidentification tool, the Digital Slide Archive WSI De-identification (DSA WSI DeID) software. Between August 2020 and March 2022 and with support from the Childhood Cancer Data Initiative, SRP tested the validity of this tool and the feasibility of a WSI Program through the SEER-Linked Pediatric Cancer WSI Pilot (Pilot) that involved six SEER registries (Greater Bay, Hawaii, Kentucky, Louisiana, New Mexico, and Utah). Up to 20 slides for each pediatric cancer case, diagnosed in 2016 in the registry's catchment area, were digitally scanned by Leica/Aperio slide scanners. Each registry used the DSA WSI DeID tool to deidentify WSIs and transferred them to IMS for confirmation of deidentification along with the corresponding deidentified pathology reports. Of 1,045 eligible subjects, 731 (70%) had WSIs deidentified and transferred to IMS, yielding 3,935 deidentified WSIs. The most time-consuming step of the WSI deidentification process was the matching of WSIs with cancer cases in the registry's database prior to deidentification for future linkage with National Childhood Cancer Registry (NCCCR) data. Subsequently, SRP and its partners at Kitware and IMS are developing a next-generation of the DSA WSI DeID tool (<https://github.com/DigitalSlideArchive/DSA-WSI-DeID>) that auto-extracts and parses text from the WSI label image, calls to a database or an upload file, and matches WSIs to the corresponding cancer case in an automated fashion. In the next two years, this version of the tool will be tested on a large scale using WSIs from the three major slide scanner makers (Leica/Aperio, Philips, and Hamamatsu). The future of digital WSIs in cancer registration and associated population-based cancer research will be discussed.



# Massachusetts Cancer Registry/COVID-19 Linkage

[Dr. Susan Gershman](#)<sup>1</sup>, Ms. Megan Hatch<sup>2</sup>, Dr. Monina Klevens<sup>2</sup>, Ms. Annie MacMillan<sup>1</sup>

<sup>1</sup>Massachusetts Cancer Registry, Boston, USA, <sup>2</sup>Bureau of Infectious Disease and Laboratory Sciences, Boston, USA

**Topic Area:** 1 - Effects of Covid-19 on Cancer Surveillance and Operations

**Background:** The COVID-19 pandemic has been associated with delays in cancer diagnosis, interruption of treatment and follow-up care, and increases in premature mortality[i]. Patients with cancer represent a vulnerable population as they are often immunocompromised and are at an increased risk of experiencing COVID-19-associated complications. We aimed to describe the Massachusetts population that has both a cancer and a COVID-19 diagnosis.

**Methods:** Using Match\*Pro software, COVID-19 diagnoses in 2020 from the Massachusetts Virtual Epidemiologic Network (MAVEN) were linked with the Massachusetts Cancer Registry. This resulted in a total of 27,813 matches between MA residents who had or have cancer and COVID-19.

**Results:** Of the 27,813 matches of unique patients, 56% were females and 44% were males. The percent distribution by race/ethnicity was as follows: White NH 80%, Hispanic 8.2%, Black NH 7.4%, Asian NH 2.2%, American Indian NH 0.1%, and unknown race/ethnicity 2.4%. The most common cancer types among females were breast (invasive and in situ), thyroid, corpus uteri and uterus NOS, colorectal, bronchus and lung. Among males, the most common cancers were prostate, colorectal, urinary bladder, melanoma, and kidney. Overall, 15.3% of individuals with cancer had a COVID-19 associated death. In people with COVID-19 but not cancer, 1.97% of people had a COVID-19 associated death. For those with cancer and a COVID-19 associated death, the range of mortality rates was 4.1% (invasive thyroid cancer) to 27.2% (invasive lung and bronchus cancer).

**Conclusion:** Of cancer patients who also had a COVID-19 diagnosis in public health databases, people with invasive lung and bronchus cancer had the highest mortality rate. As COVID-19 is known to affect lung function[ii], further study could be useful to understand any interaction between these diagnoses. Additional study is needed to understand mortality factors within this vulnerable population, which may have implications for future COVID-19 vaccination recommendations. [i] Desai A, Sachdeva S, Parekh T, Desai R. COVID-19 and Cancer: Lessons From a Pooled Meta-Analysis. *JCO Glob Oncol.* 2020;6:557-559. doi:10.1200/GO.20.00097 [ii] Thomas M, Price OJ, Hull JH. Pulmonary function and COVID-19. *Curr Opin Physiol.* 2021 Jun;21:29-35. doi: 10.1016/j.cophys.2021.03.005. Epub 2021 Mar 26. PMID: 33817453; PMCID: PMC7997144.

# Medical Financial Hardship Among Young Adult Cancer Survivors

Ms. Lihua Li<sup>1,2,3,4</sup>, Ms. Mayuri Jain<sup>1,2,3</sup>, Ms. Xingyu Lin<sup>5</sup>, Ms. Rebecca Hu<sup>6</sup>, Dr. Junxiu Liu<sup>1</sup>, Dr. Janani Thapa<sup>7</sup>, Dr. Lan Mu<sup>8</sup>, Dr. Zhuo Chen<sup>7</sup>, Dr. Donglan Zhang<sup>8</sup>, Dr. Yan Li<sup>1,10</sup>, Dr. Bian Liu<sup>1,3,11</sup>, Dr. José A. Pagán<sup>12</sup>

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**Topic Area:** 7 - Other Relevant Topics

**Sub-Topic:** 3b. Social determinants and cancer disparities

**Background** Due to the high costs of cancer treatment and care, many cancer survivors experience medical financial hardship including having trouble paying medical bills (material financial hardship), worrying about paying medical bills (psychological financial hardship), and cannot afford or forgo medical care (behavioral financial hardship). This study describes the medical financial difficulties experienced by young adult cancer survivors in the United States.

**Methods** Our sample included young adults 18-39 years of age from the National Health Interview Survey 2015-2020. We defined young adults with a self-reported history of physician diagnosed cancer as cancer survivors and young adults without a cancer history as controls. We matched up to three controls to every cancer survivor using nearest neighbor matching. Conditional logistic regressions were used to examine the association between cancer history and financial hardship (defined as material, psychological, and behavioral financial hardship). Sensitivity analyses were conducted to assess whether this association varied by age, sex, race/ethnicity, residential region, and cancer type.

**Results** We identified 898 young adult cancer survivors and matched 805 (90%) to 2,301 controls of young adults without a cancer history. Compared to young adults without a cancer history, young adult cancer survivors were more likely to report material (21.6% vs 16.7%; odds ratio (OR) 1.37, 95% confidence interval (CI), 1.26-1.49), behavioral (34.4% vs 23.6%; OR 1.70, 95% CI, 1.57-1.83), but not psychological financial hardship (51.0% vs 50.5%; OR 1.01, 95% CI, 0.95-1.10). Young adult cancer survivors who were non-Hispanic Black or Hispanic, lived in the Midwest and South, or had a history of cervical cancer were more likely to report psychological financial hardship than their counterparts.

**Conclusion** Based on a nationally representative sample, we found that young adult cancer survivors were more likely to experience material and behavioral medical financial hardship than young adults without a cancer history. We also identified specific subgroups of young adult cancer survivors that call for targeted policies and interventions to alleviate their financial hardship challenges.

# Minimum Data Set for Cancer Incidence Reporting – A National Standard to Speed Up Incidence Reporting of Cancer Cases

Mr. Sean Porter<sup>1</sup>, Mr. Joseph Rogers<sup>1</sup>, Mrs. Sandy Jones<sup>1</sup>, Dr. Vicki Benard<sup>1</sup>, Ms. Jennifer Seiffert<sup>2</sup>, Mrs. Michelle Esterly<sup>2</sup>, Ms. Jen Wike<sup>2</sup>

<sup>1</sup>Centers for Disease Control and Prevention, Atlanta, USA, <sup>2</sup>Katmai Government Services, Anchorage, USA

**Topic Area:** 6 - Data Collection, Tools and Operations

**Sub-Topic:** 2b. How to make cancer data more timely

**Background:** Thirty years ago, the U.S. Congress supported a vision of more accurate and complete national and local cancer data when they passed the Cancer Registries Amendment Act. It created CDC's National Program of Cancer Registries (NPCR) to collect data on cancer occurrence, including the type, extent, and initial treatment. Systems to collect these data and report them to CDC have become outdated. It currently takes 24-36 months for a cancer diagnosis to be processed for publication at CDC, limiting utility for and timeliness in decision-making for cancer control.

**Purpose:** At present, a six-month delay in cases being reported to an NPCR central cancer registry (CCR) is built in to allow inclusion of treatment and other details required for a complete abstract. A newly defined standard Minimum Data Set would reduce the data required for an initial incidence report and encourage immediate reporting to an NPCR CCR, reducing the time needed for an NPCR CCR to report the initial incidence to CDC.

**Methods:** First, NPCR is working with a NAACCR Task Force to develop a standard Minimum Data Set. Second, NPCR is modernizing its IT system with the Cancer Surveillance Cloud-Based Computing Platform (CS-CBCP). The CS-CBCP intends to, in real time, receive, process, and visualize standardized Minimum Data Set reports from facilities and providers and route them to the appropriate NPCR CCR. This platform is described in detail in other presentations at this conference.

**Results:** Several use cases for this Minimum Data Set will be discussed during the presentation. Once a Minimum Data Set national standard is in place the NPCR CS-CBCP can begin to receive this new data set.

**Conclusions:** The NPCR cancer data collected has allowed researchers, doctors, policy makers, public health professionals, and members of the public to monitor cancer, evaluate prevention and control programs, and identify needs for additional efforts. We can reduce the timeframe for data collection from 36 months to days after the close of a reporting period, allowing public health professionals to see patterns in various populations and act more quickly, potentially saving more lives.

# Modernizing Public Health Cancer Surveillance Interoperability with Standardized, Electronic HL7 FHIR Implementation Guides

Ms. Caitlin Kennedy<sup>1</sup>, Mrs. Sandy Jones<sup>1</sup>, Ms. Maria Michaels<sup>1</sup>, Mr. Alex Goel<sup>2</sup>, Mr. David DeRoode<sup>3</sup>, Mrs. Kasey Diebold<sup>1</sup>, Mr. Richard Moldwin<sup>2</sup>, Mr. Joseph Rogers<sup>1</sup>

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**Topic Area:** 4 - New Directions and IT Solutions

**Sub-Topic:** 4b. New and emerging methods of data collection

**Background:** As part of its interoperability strategy, the CDC's National Program of Cancer Registries (NPCR) worked with partners to develop cancer content HL7 FHIR implementation guides (IGs). The goal of implementing these IGs is to facilitate more standardized, timely, actionable, and complete cancer information for public health surveillance.

**Purpose:** The discussion will provide an update on several cancer content FHIR IGs, focusing on two related to structured data capture of cancer pathology data. The development and impact of the cancer pathology FHIR IGs will be discussed as well as how these IGs have been tested at HL7 FHIR Connectathons and demonstrated at HIMSS Interoperability Showcases.

**Methods:** The HL7 FHIR IGs discussed are: the Central Cancer Registry Reporting Content IG for ambulatory provider EHR systems, the IHE SDC on FHIR IG, and the Cancer Pathology Data Sharing IG for laboratory reporting. These IGs leverage the Making Electronic Data More Available for Research and Public Health (MedMorph) reference architecture (RA) and HL7 FHIR approaches. These IGs align with these terminologies or standards: College of American Pathologists (CAP), North American Association of Central Cancer Registries (NAACCR), Minimal Common Oncology Data Elements (mCODE), and United States Core Data for Interoperability (USCDI).

**Results:** Based on multiple cycles of successful Connectathon testing, these FHIR IGs are ready for trials of real-world implementations. These IGs are the best available standards specifically for FHIR-based exchange of cancer data and can be leveraged for mandatory cancer registry reporting.

**Conclusions:** The IGs and the incorporated data standards are fundamental to CDC/NPCRs data modernization and interoperability strategy. Informatics systems may be more interoperable because of implementing these HL7 FHIR cancer content IGs. Additionally leveraging these HL7 FHIR cancer content IG may reduce reporting burden on implementers and will hopefully improve data quality and health equity in applied cancer surveillance.

# Molecularly-Defined Medulloblastoma: Population-Level Patterns in the United States, 2018-2019

Dr. Quinn T. Ostrom<sup>1,2,3,4</sup>, Mrs. Mackenzie Price<sup>1,2</sup>, Mr. Corey Neff<sup>1,2</sup>, Mr. Gino Cioffi<sup>1,5</sup>, Dr. Kristin A. Waite<sup>1,5</sup>, Mrs. Carol Kruchko<sup>1</sup>, Dr. Jill S. Barnholtz-Sloan<sup>1,5,6</sup>

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**Topic Area:** 5 - Childhood Cancers

**Sub-Topic:** 5c. Pediatric epidemiology

**Background:** Medulloblastoma is one of the most common types of brain and other central nervous system (CNS) tumors occurring in the pediatric population in the United States (US). Molecularly-defined brain tumor histopathologies including medulloblastoma subtypes were incorporated into US cancer registry reporting for individuals with brain tumors beginning in 2018. We, therefore, assessed the epidemiology and overall survival (OS) patterns for medulloblastoma in children and adolescents, highlighting molecularly-defined subtypes.

**Methods:** Children and adolescents (0-19 years) that were histopathologically diagnosed with medulloblastoma from 2018-2019 and had brain molecular marker data were identified within the Commission on Cancers National Cancer Database (NCDB) and Central Brain Tumor Registry of the United States databases, which combines data from CDC's National Program of Cancer Registries (NPCR) and NCI's Surveillance, Epidemiology, and End Results (SEER) Programs. Incidence rates per 100,000 population with 95% confidence intervals (95CI) were estimated for histopathologies with 16 cases diagnosed in 2018-2019. One-year OS was estimated using NCDB data for histopathologies with 50 cases diagnosed in 2018-2019 with follow-up through 2020 using Kaplan-Meier methods.

**Results:** There were 601 cases of histopathologically-confirmed medulloblastoma diagnosed in children and adolescents from 2018-2019, 39.6% of which had available molecular subtype information. Overall incidence of medulloblastoma was 0.37 per 100,000 (95CI=0.34-0.40). Incidence of medulloblastoma subtypes was 0.05 (95CI=0.04-0.06) for SHH-activated TP53wt, 0.02 (95CI=0.01-0.02) for WNT-activated, 0.08 (95CI=0.06-0.09) for nonWNT/nonSHH, while SHH-activated TP53mut was too rare to calculate incidence. Overall, one-year OS for medulloblastoma was 96.6% (95CI=92.1%-100.0%). One-year OS for nonWNT/nonSHH was 96.6% (95CI=92.8%-100.0%), and for SHH-activated TP53wt was 93.7% (95CI=87.1%-100.0%). Other subtypes occurred too rarely to calculate survival.

**Conclusions:** Our findings provide the initial US epidemiological estimates for molecularly-defined medulloblastoma histopathologies in children and adolescents. As improvements in collection completeness lead to higher levels of molecular subtype availability, the robustness of these estimates will increase. Collection of these data are essential for understanding the epidemiology of this important childhood and adolescent brain tumor, which now can also be molecularly defined.

# NAACCR XML – Future Directions

Mr. Rich Pinder<sup>1</sup>, Mr. Fabian Depry<sup>2</sup>, Mr. Isaac Hands<sup>3</sup>, Ms. Valerie Yoder<sup>4</sup>

<sup>1</sup>Los Angeles Cancer Surveillance Program, Sherman Oaks, USA, <sup>2</sup>Information Management Services, Inc., Rockville, MD, USA, <sup>3</sup>Kentucky Cancer Registry, Lexington, KY, USA, <sup>4</sup>Utah Cancer Registry, Salt Lake City, UT, USA

**Topic Area:** 4 - New Directions and IT Solutions

**Sub-Topic:** 4b. New and emerging methods of data collection

From a small group of NAACCR members brainstorming 7 years ago, the NAACCR XML Data Exchange work group now has over 30 dedicated volunteers, contributing all areas of registry expertise. This expertise has made possible our transition from the old Flat File transport format, over to the NAACCR XML standard. This presentation will discuss future directions the XML standard might take, highlighting the benefits and features of each. Topics covered will include: Modify the NAACCR XML standard to expand the cancer record hierarchy, which would enhance our current model of Patient and Tumor information. Adding new tiers could support multiple hospital admissions, specific treatment procedures, different demographics and other enhanced information. Registries often need to transmit complex cancer data from sources other than traditionally required by NAACCR integrating these data is an important feature of the NAACCR XML framework. The session is designed to provide ample time for discussion, suggestions and ideas from the audience to help formulate the direction forward for the NAACCR XML standard. Learn all about NAACCR XML at [www.naacccr.org/xml-data-exchange-standard/](http://www.naacccr.org/xml-data-exchange-standard/) and we hope to see you at our session!

# NAACCR XML: How Far We've Come

[Mr. Isaac Hands](#)<sup>1</sup>, [Mr. Fabian Depry](#)<sup>2</sup>, Ms. Jenna Deniaud<sup>3</sup>, Ms. Valerie Yoder<sup>4</sup>

<sup>1</sup>Kentucky Cancer Registry, Lexington, USA, <sup>2</sup>Information Management Services, Inc., Calverton, USA, <sup>3</sup>Wisconsin Cancer Reporting System, Madison, USA, <sup>4</sup>Utah Cancer Registry, Salt Lake City, USA

**Topic Area:** 4 - New Directions and IT Solutions

**Sub-Topic:** 4b. New and emerging methods of data collection

NAACCRs fixed-width standard for cancer data exchange was not easily adaptable to meet emerging needs in cancer surveillance and research. The NAACCR XML data exchange standard was fully implemented, and the legacy fixed-width format retired, when NAACCR version 21 was released. Although the file size in XML may be larger and require more processing power, there are many benefits to the structure that will be described. A summary of the XML standard and recent improvements will be given then an exploration of challenges and opportunities that have arisen after fully adopting XML. Software that supports central registry operations such as surveillance submission software has been updated to handle NAACCR XML. Several software tools have been developed to assist with handling XML files, including resources for SAS. The user dictionaries feature of NAACCR XML highlighted a long-standing need of the cancer registry vendor community to obtain information about customizations of hospital registry software for specific central registry requirements. The NAACCR XML Workgroup tackled this need and developed a clearinghouse for user dictionaries. This model has also been adopted by NAACCR for custom Edits metafiles. A survey of published user dictionaries will be presented.

# NCCR Virtual-Pooled Registry Linkage Results

[Ms. Nicola Schussler](#)

Assistant Project Manager/Task Manager, Information Management Services, Inc.

The National Childhood Cancer Registry (NCCR) and Virtual Pooled Registries participated in a linkage in order to obtain information about subsequent cancers for patients in the NCCR. This linkage involved 22 central cancer registries and 9 additional VPR registries and was performed by IMS in their role as data custodian of the NCCR PII. Indicators of subsequent cancers will be available on the NCCR data platforms. Methods for the linkage, as well as challenges involved in combining data across 22 registries to create the NCCR linkage file will be discussed. After matching at the patient level as completed, matching of tumors for the matched patients was performed. Match results at both the patient and cancer level will be discussed. Please note that while this identified duplicate cancers across registries, dealing with such cancers is outside the scope of this discussion.





# NCCR-Childrens Oncology Group Linkage Results

[Ms. Nicola Schussler](#)

Assistant Project Manager/Task Manager, Information Management Services, Inc.

The National Childhood Cancer Registry (NCCR) and Children's Oncology Group (COG) participated in a linkage in order to obtain information about the protocols that patients in NCCR have been enrolled in. This linkage involved 22 central cancer registries and was performed by IMS in their role as data custodian of the NCCR PII. The protocols have been categorized and high-level indicators of enrollment will be available on the NCCR data platforms. Methods for the linkage and match results will be discussed.

# New Directions and Opportunities for Advanced Computing for Cancer Surveillance and Epidemiology at Scale

[Dr. Heidi Hanson<sup>1</sup>](#)

<sup>1</sup>*Oak Ridge National Laboratory, Oak Ridge, USA*

**Topic Area:** 2 - Big Ideas in Cancer Surveillance

**Sub-Topic:** 2a. How to modernize the Cancer Surveillance System

The Modeling Outcomes using Surveillance data and Scalable AI for Cancer (MOSSAIC) project is an NCI-DOE collaboration to develop scalable natural language processing (NLP) and machine learning (ML) tools for extracting reportable cancer surveillance data. This includes methods for pathology coding, reportability, biomarkers, recurrence, and metastasis. Over the next five years, AI will revolutionize cancer surveillance and epidemiological related research. The field is on the cusp of exciting research breakthroughs that will change the way we collect, process, and analyze data. The focus of this session will be to provide a broad overview of the landscape of AI for cancer surveillance and precision public health will be presented as well as suggestions for priority areas that have potential to significantly advance population-based cancer surveillance and research within 5-10 years. A targeted review of how development of the new foundational models, privacy preserving AI, and privacy enabled health data sharing can be utilized to push the field forward will be presented. Followed by an interactive discussion with session attendees aimed at identifying unsolved challenges that impede large scale epidemiological research and discussing computational approaches that may adequately address them.

# Non-Asbestos Exposure Associated Cancer Risk Among Mesothelioma Patients: A Latent Class Mixed Modeling Approach

[Dr. Bian Liu](#)<sup>1</sup>, Dr. Furrina Lee<sup>2</sup>

<sup>1</sup>Icahn School of Medicine at Mount Sinai, New York, USA, <sup>2</sup>Bureau of Cancer Epidemiology, Division of Chronic Disease Prevention, New York State Department of Health, Menands, USA

**Topic Area:** 3 - Epidemiologic Studies using Cancer Surveillance Data

**Sub-Topic:** 3b. Social determinants and cancer disparities

**Background:** While asbestos exposure is the dominant contributor to mesothelioma, little is known about other non-asbestos exposures among mesothelioma patients. We examined the heterogeneous trajectories of non-asbestos air toxic exposure for mesothelioma patients.

**Methods:** Patients residential histories were obtained by linking mesothelioma cases diagnosed during 2011-2015 from the New York State Cancer Registry to LexisNexis administrative data and inpatient claims data. Percentile ranking of lifetime cancer risk from inhalation of non-asbestos air toxics was based on the National Air Toxic Assessment. To compare data across years during patients residential history, yearly excess risk was calculated by dividing exposures at individual census tracts by the state-level average and subtracting one. We used a latent class mixed model to identify distinct risk trajectories among patients with a 15-year residential history prior to cancer diagnosis (n=909). We further examined differences in trajectory groups by patient characteristics (age at cancer diagnosis, sex, race/ethnicity, cancer stage, tobacco use, and the total number of addresses lived) using bi-variate analysis and a multinomial logistic regression model.

**Results:** The majority of the patients were non-Hispanic White (89.7%), male (75.5%), and with distant stage at diagnosis (64.8%). Patients lived on average 3 (SD 2.2) addresses, and the mean age at diagnosis was 72.8 (SD 11.4) years. We identified 5 distinct trajectories of cancer risk: Persistent low-risk (24.8%), Increased low-risk (24.1%), Increased high-risk (22.2%), Tempered low-risk (16.2%), and Persistent moderate-risk (12.8%). Patient characteristics did not differ across trajectory groups, except for race and Hispanic ethnicity (p<0.0001). The proportion of non-Hispanic White patients was the highest in the Persistent low-risk (99.6%) while the lowest in the Increased high-risk (75.2%). Compared to their counterparts, non-Hispanic White patients had a significantly lower odds of being in trajectory groups other than the Persistent low-risk group (all adjusted OR 0.1, all upper 95% confidence intervals 0.7).

**Conclusion:** We quantified the heterogeneous experiences of cancer risks associated with ambient air toxics among a cohort of mesothelioma patients. In addition, we found patients race and ethnicity differed across the identified trajectories, likely a reflection of disparities in patients residential mobility prior to their cancer diagnoses.

# Novel Methods for Clinical Text Abstraction

Mr. Jamaludin Mohd-Yusof<sup>1</sup>

<sup>1</sup>Los Alamos National Laboratory, Los Alamos, USA

**Topic Area:** 2 - Big Ideas in Cancer Surveillance

**Sub-Topic:** 2a. How to modernize the Cancer Surveillance System

The Modeling Outcomes using Surveillance data and Scalable AI for Cancer (MOSSAIC) project is an NCI-DOE collaboration to develop scalable natural language processing (NLP) and machine learning (ML) tools for extracting reportable cancer surveillance data. This includes methods for pathology coding, reportability, biomarkers, recurrence and metastasis. Safe deployment of deep learning systems in critical real-world applications requires models to make very few mistakes, and only under predictable circumstances. Abstraction of important elements like site, subsite, histology, laterality and behavior of the cancer from ePath reports is one such critical use case. Traditional ML classifiers require the model to attempt to categorize all samples, even if they may have missing or ambiguous information. In addition, because of the training requirements of deep learning (DL) methods, some classes (e.g., rare histology types) may not have enough samples for adequate training to the accuracy required. In order to enable the model to perform with accuracy similar to human registrars, we have developed a novel deep abstaining classifier (DAC) which allows the model to learn features which may be predictive of low accuracy and abstain (decline to provide a prediction) for some tasks on those samples. Since the five tasks each have widely varying numbers of classes, and disparate distributions across those classes, the degree of abstention is similarly disparate. The combined accuracy across all tasks is dependent on the correlation between all the tasks in question. In order to maximize coverage across each task, as well as simplify autocoding of reports where all tasks can be predicted with high accuracy, we have developed a method to separately classify those reports where all aspects are predictable, dubbed Ntask. We present the derivation of the DAC methodology and discuss the performance improvements compared to traditional methods. We also show performance (accuracy and coverage) of the DAC on ePath reports and describe the Ntask classification method.

# Numerators, Denominators, and ABSMs - Critical Issues with Calculating Cancer Statistics

**Ms. Jane Henley**

Epidemiologist, CDC

**Dr. Mandi Yu**

Statistician, National Cancer Institute

**Mr. Steve Scoppa**

Senior Systems Analyst, IMS, Inc.

This session will provide an overview of potential issues in calculating cancer statistics such as rates and area-based social measures due to recent changes in numerators and denominators. We will present current work on developing best practices with regards to large-scale issues with denominator data, i.e. 2020 census issues as well as changing race categories.

# Online Tools to Visualize Cancer Registry and Other Geospatial Data

[Dr. Debora Oh](#)<sup>1,2</sup>, Dr. Salma Shariff-Marco<sup>1,2</sup>, Ms. Katherine Lin<sup>1,2</sup>, Mr. Dan Meltzer<sup>1</sup>, Dr. Mindy Hebert-Derouen<sup>1,2</sup>, Dr. Courtney Lyles<sup>1,3</sup>, Dr. Scarlett Gomez<sup>1,2</sup>

<sup>1</sup>University of California, San Francisco, San Francisco, USA, <sup>2</sup>Greater Bay Area Cancer Registry, San Francisco, USA, <sup>3</sup>Zuckerberg San Francisco General Hospital, San Francisco, USA

**Topic Area:** 6 - Data Collection, Tools and Operations

**Sub-Topic:** 2b. How to make cancer data more timely

**Background:** Cancer registry data are a public resource, but often accessing the data is challenging or it is difficult to explore. For researchers, having a straightforward way to visualize cancer rates and neighborhood-level data can give a fuller picture of what contributes to health inequities, and what can be done to address them.

**Methods:** We developed two web-based dashboards to visualize cancer incidence and mortality rates for California. Data for the tools was pulled from SEER\*Stat and the dashboard was developed in Tableau. In addition, we integrated two geospatial tools into the dashboards, California Health Maps and Health Atlas; data for these tools was obtained from the California Cancer Registry, the American Community Survey, CDC PLACES, and CalEnviroscreen.

**Results:** The Greater Bay Area Cancer Registry dashboard ([cancerregistry.ucsf.edu](http://cancerregistry.ucsf.edu)) is a tool to query and visualize population-based cancer incidence and mortality rates for the 9-county region. The UCSF Helen Diller Family Comprehensive Cancer Center dashboard ([cancer.ucsf.edu/catchment-area-dashboard](http://cancer.ucsf.edu/catchment-area-dashboard)) is a similar tool for the 25-county cancer center catchment area. The dashboards provide 5-year rates for the 19 most common cancer sites as well as more specific information on county-level rates, disparities over time, pediatric cancers, and comparisons to regional and state-level data. California Health Maps ([californiahealthmaps.org](http://californiahealthmaps.org)) is an interactive mapping tool of health data for several different geographies in California. Users can map cancer incidence for the 12 most common cancer sites and filter by sex and/or race and ethnicity. The UCSF Health Atlas ([healthatlas.ucsf.edu](http://healthatlas.ucsf.edu)) is an interactive mapping tool to explore how neighborhood-level social determinants of health, health behaviors, and health outcomes are distributed at a population level. Health Atlas includes over 100 variables at the census tract, zip code, and county level; the site provides user-friendly options to view and export data.

**Conclusion:** These data visualization tools can be used to better serve cancer control, public health, and policy efforts to improve cancer outcomes and cancer inequities.

# Precision Cancer Registries as Critical Infrastructure for Precision Oncology

[Mrs. Kasey Diebold<sup>1</sup>](#), [Dr. Jon Patrick<sup>2</sup>](#), Mr. Joseph Rogers<sup>1</sup>, Mrs. Sandy Jones<sup>1</sup>, Dr. Juan Rodriguez<sup>1</sup>  
<sup>1</sup>Centers for Disease Control and Prevention, Atlanta, USA, <sup>2</sup>Health Language Analytics Global LLC, Helena, USA

**Topic Area:** 2 - Big Ideas in Cancer Surveillance  
**Sub-Topic:** 2c. Visions for the future

**Background:** With the current exploration of precision oncology and the abundance of new tests to capture genomic data, cancer registries face pressure to keep up with this rapid expansion in content. Central Cancer Registries (CCRs) currently collect information that is more consequential to diagnosis, but precision oncology also requires the collection of information important for treatment planning, treatment quality, and assessing future risk of cancer. Cancer Tumor Registrars (CTRs) must now learn the meaningfulness of hundreds of new biomarker and genomic data items to correctly extract it into the structured abstract needed for precision cancer surveillance. A lack of reporting standards and unstructured formatting of reporting from pathology laboratories have been a major barrier. This creates a challenge for registrars to abstract relevant genomic information into the cancer record, potentially increases mistakes during the manual abstraction process, and results in a long delay in data availability. Existing biorepositories are largely used for research and have been shown to lack diversity, potentially perpetuating health disparities in precision oncology research findings. These challenges limit the use of genomic information in clinical care evaluation and public health application.

**Purpose:** This presentation will describe a potential cancer registry future state to support precision cancer surveillance and epidemiology and discuss barriers and solutions to collecting necessary data to support precision oncology in a rapidly changing environment. Methods: Informatics solutions that enable standardized reporting of cancer genomic data and leverage methodological advancements in clinical Natural Language Processing (NLP) are essential to support CCRs without adding additional burden.

**Results:** Innovative methods to integrate the needs of precision oncology into cancer registries better position registries to collect cancer data to measure progress, drive actions, prevent cancers, and improve treatment for all people.

**Conclusions:** The era of precision oncology requires as its source of information the precision cancer registry. CCRs can become precision registries while reducing burden to their workforce by utilizing technologies to provide better identification and extraction of cancer information from reporting sources.

# Prediction of Risk of Metastatic Recurrence for Female Breast Cancer Patients in the Presence of Competing Causes of Death

[Dr. Angela Mariotto](#), Dr. Laura Botta<sup>2</sup>, Dr. Alice Bernasconi<sup>2</sup>, Mr. Zhaohui Zou<sup>3</sup>, Dr. Gemma Gatta<sup>2</sup>, Dr. Riccardo Capocaccia<sup>2</sup>

<sup>1</sup>National Cancer Institute, Bethesda, USA, <sup>2</sup>Evaluative Epidemiology Unit, Fondazione IRCCS Istituto Nazionale Tumori, Milan, Italy, <sup>3</sup>Information Management Services Inc., Calverton, USA

**Topic Area:** 3 - Epidemiologic Studies using Cancer Surveillance Data

**Sub-Topic:** 3a. Epidemiologic studies

**Background:** The objective of this study is to extend a previous method to estimate recurrence-free survival for women diagnosed with non-metastatic breast cancer by including the risks of dying of other causes, as cancer patients live

**Methods:** The method is based on the diagnosis metastasis death pathway and allows patients to die from competing causes of death. It estimates four probabilities of being: a) alive and recurrence-free, b) alive and in recurrence, c) died-cancer cause and d) died-competing cause at any point in time after diagnosis. We apply the method to female breast cancer relative survival from the Surveillance, Epidemiology and End Results (SEER) registries (2000-2018) data. We compare recurrence-free survival estimates in the presence and absence of competing causes of death.

**Results:** Under competing causes of death, the 5-year recurrence-free survival estimates were very similar for women diagnosed at ages 15-59 and 60-74 but lower for older women diagnosed at ages 75-84. For women diagnosed with stages I, II and III breast cancer, the percent recurrence-free were respectively, 95.0%, 85.9%, and 59.8% for women ages 60-74 and 82.1%, 71.3%, and 44.4%, for women ages 75-84. Under competing causes of death recurrence-free estimates were very similar to estimates in the absence of competing causes of death, for younger women especially at 5 years from diagnosis, however they were lower for older women or longer time since diagnosis.

**Conclusions:** This work provides recurrence-free survival estimates that include risks of dying of other causes representing the real survival experiences of cancer patients, as they are amenable to die of other causes. Impact: The estimates are likely to add to the net estimate and provide a more complete picture of the risks of recurrence and useful to inform clinical decisions for monitoring patients for recurrence.



# Proportions of Metastatic Recurrence in Women with an Initial Diagnosis of Non-Metastatic Breast Cancer: A Systematic Review and Meta-Analysis

[Dr. Eileen Morgan](#)<sup>1</sup>, Dr. Colette O'Neill<sup>2</sup>, Ms. Aude Bardot<sup>1</sup>, Dr. Paul Walsh<sup>2</sup>, Dr. Isabelle Soerjomataram<sup>1</sup>, Dr. Melina Arnold<sup>1</sup>

<sup>1</sup>International Agency for Research on Cancer, Lyon, France, <sup>2</sup>National Cancer Registry Ireland, Cork, Ireland

**Topic Area:** 3 - Epidemiologic Studies using Cancer Surveillance Data

**Sub-Topic:** 3a. Epidemiologic studies

**Background:** The prevalence of metastatic breast cancer (MBC), including women with metastatic disease at initial diagnosis and those who develop MBC as a recurrence, remains largely unknown. The aim of this systematic literature review and meta-analysis was to consolidate proportion of metastatic recurrence estimates in women initially diagnosed with non-metastatic breast cancer.

**Methods:** Studies that reported proportions of metastatic recurrence in women with non-metastatic breast cancer published between January 2010-May 2022 were identified from a systematic search of MEDLINE and Web of Science. Clinical trials or studies that included other cancer sites/diseases, in-situ breast cancer or second primaries were excluded. Random-effects meta-analyses were used to estimate pooled proportions and 95% confidence intervals (CIs) by age at diagnosis, stage at diagnosis, subtype, and follow-up time.

**Results:** In total, 194 studies on almost 280,000 patients were included in the analysis including 172 hospital-based studies, 15 population-based cancer registries and 7 from other settings (eg. claims data). Proportions of patients diagnosed with metastatic recurrences increased with longer follow-up time from 12.5% (95% CI 10.7-14.3%) at 5 years after diagnosis to 20.4% (95% CI 17.6-23.2%) at 10 years or more from initial diagnosis. Regional variation was observed with pooled proportions ranging from 10.9% (95% CI 8.7, 13.3%) in Europe to 26.4% (95% CI 16.7, 37.4%) in African studies (5 years follow-up). Proportions of metastatic recurrence were higher in women with hormone receptor negative compared with receptor positive disease (15.2% vs. 9.9%), locally advanced compared with early stage at initial diagnosis (33.2% vs. 4.8%), and in younger (50 years) compared with older (70+ years) age groups at diagnosis (18.4% vs. 13.3%). High heterogeneity was evident in all meta-analyses and results should be interpreted with caution.

**Conclusions:** The higher proportions of metastatic recurrences in patients initially diagnosed at more advanced stage emphasises the importance of follow-up, early detection, and management to reduce the risk of MBC. As the number of breast cancer survivors continues to increase, it is pertinent that researchers and policy makers focus on timely diagnosis and access to adequate treatments and care.

**Funding:** Susan G Komen

# Racial Disparities in Receipt of Curative Surgery for Early-Stage Non-Small Cell Lung Cancer

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**Topic Area:** 3 - Epidemiologic Studies using Cancer Surveillance Data

**Sub-Topic:** 3b. Social determinants and cancer disparities

**Background** Studies on racial/ethnic disparities for early-stage non-small cell lung carcinoma (NSCLC) have not considered the increasing use of alternative curative-intent radiotherapy in recent years. Here, we examine trends and disparities in receipt of curative-intent surgery and/or radiotherapy in a large and diverse population-based cohort.

**Study Design and Methods** Data for early-stage NSCLC (2005-2017) from the Florida statewide cancer registry were individually linked to discharge data (94% match rate) containing patient-level comorbidities and treatment-specific information. Joinpoint and multivariable logistic regression were used to assess trends in receipt of curative-intent surgery and radiotherapy and the association between race/ethnicity and receipt of curative-intent treatment type.

**Results** Among 63,872 early-stage NSCLC patients, 72.2% received curative-intent treatment (surgery and/or radiotherapy). Hispanic patients (71.0%) had the highest prevalence of curative-intent surgery, followed by Whites (66.3%) and Blacks (56.0%) ( $p < 0.01$ ). Overall, receipt of curative-intent radiotherapy increased by 8.1% annually ( $p = 0.04$ ) from 2007-2017, while curative-intent surgery declined (-6.3%) during 2014-2017 ( $p < 0.01$ ). After considering sociodemographic and clinical factors (including receipt of curative-intent radiotherapy), Blacks had 31% lower odds of receiving curative-intent surgery (OR: 0.69; 95% CI, 0.64 to 0.75) compared to Whites, whereas Hispanics surpassed Whites with 12% (OR: 1.12; 95% CI, 1.04 to 1.21) higher odds. Patients with 3 comorbidities had 36% lower odds of having curative-intent surgery (0.64; 95% CI, 0.50 to 0.68) compared to patients with no comorbidities. Disparities between Blacks and Whites for receipt of any curative treatment (surgery and/or radiotherapy) were also present (OR: 0.65; 95% CI: 0.60 to 0.71). Interpretation Racial disparities in receipt of curative-intent surgery for early-stage NSCLC persist despite increasing rates of alternative curative-intent radiotherapy. More research on the treatment decision-making process, patient-provider communication, and treatment compliance/refusal among early-stage NSCLC Black patients is warranted.

# Real World Data on Oral Drugs for Cancer Treatment: Lessons Learned from Combining Cancer Registry and Pharmacy Dispensing Data in the US

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**Topic Area:** 2 - Big Ideas in Cancer Surveillance

**Sub-Topic:** 3c. Using real-world data from cancer registries to improve cancer outcomes

**Background:** With recent advances in cancer care and lack of detailed treatment information in population-based registries, there are few resources to support broad investigations of the uptake, adherence, and outcomes of novel therapies. Objective: To evaluate the representativeness and completeness of a linkage between SEER cancer registry data and dispensing data for cancer drugs from two large retail pharmacy chains, covering approximately 50% of the market in the United States.

**Methods:** A probabilistic data linkage between 11 SEER cancer registries and dispensing data from retail pharmacy chains was conducted for individuals diagnosed with cancer from 2013-2017 and followed through 2019. Medicare Part D event data, which contains outpatient prescription drug dispensing information for Medicare beneficiaries regardless of the pharmacy source, was obtained to further validate this linkage. As a test setting, women aged 65 years and older with a first, primary breast cancer and a claim or dispensing for tamoxifen, a hormonal therapy, in either data source were included. Agreement between initial and longitudinal tamoxifen claims and dispensing were compared between the Part D event and retail pharmacy data.

**Results:** Among 5963 older women with breast cancer identified as receiving tamoxifen in Part D data, 1490 (25%) cases were identified as receiving tamoxifen using the retail pharmacy data. Of these 1490 women, about half (n=749) had complete longitudinal information (i.e., agreement in total number of days supplied) from the retail pharmacy data on tamoxifen dispensing. Most of these women with complete information were white and presented with higher SES.

**Conclusion:** Coverage of retail pharmacy dispensing data for oral cancer therapies may not track with overall pharmacy market share. We provide a framework for evaluating these real-world data, discuss lessons learned from this linkage effort and introduce potential uses cases for this resource going forward.

# Real-World Implementation of Natural Language Processing to Process Electronic Pathology Reports at the British Columbia Cancer Registry

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**Topic Area:** 2 - Big Ideas in Cancer Surveillance

**Sub-Topic:** 2c. Visions for the future

**Background:** The British Columbia Cancer Registry (BCCR) is a Canadian provincial population-based cancer registry that collects information on all reportable tumours among British Columbian (BC) residents. Pathology reports are the major source for cancer registrations. BCCR receives all provincial pathology (including non-cancer) electronically in HL7, and eMaRC (developed by the National Program of Cancer Registries) is used to identify reportable cancer pathology reports (N=80,000/year) through rule-based text mining. However, rule-based approaches are not robust enough in classifying non-melanoma skin cancers accurately as non-reportable, resulting in a large volume of false positives (N=38,000/year). This complicates registry processes and requires manual review to filter out. This study demonstrates the utility of Natural Language Processing (NLP) with a pre-trained language model to analyze post-eMaRC pathology to improve classification of pathology report tumour reportability status.

**Methods:** Our NLP pipeline uses the pre-trained language model PubMedBERT, trained on biomedical text. Natural Language Inference (NLI) was used to quantify the relationship between the unstructured text within post-eMaRC pathology and fields-of-interests (Fol). Fols represent site-histology combinations for non-reportable cancers curated. A Random Forest Classifier classified reportability based on NLI output and was optimized to maintain a 99% or higher true-positive rate. To demonstrate the effectiveness of the NLI pipeline (NLP-NLI), a second Question-Answering model (NLP-QA) was developed for comparison. Both approaches are highly interpretable as they implement logic used by tumour registrars.

**Results:** Using post-eMaRC pathology reports, the training set consisted of 8,484 non-reportable and 14,036 reportable reports for both NLP approaches. Models were evaluated with an unseen dataset of 11,000 non-reportable and 19,542 reportable reports. The NLP-NLI pipeline identified 75.5% (8,302 of 11,000) of non-reportable and 99.3% (19,403 of 19,542) of true reportable cancer reports. For NLP-QA, the accuracies on non-reportables and reportables were 50.2% and 99.1% respectively.

**Conclusion:** This project highlights how NLP advances can improve cancer registry operations by leveraging expert knowledge from tumour registrars and data scientists. The NLP pipeline builds on top of eMaRC to detect false positives. Automation of manual review improves data timeliness and enables a more efficient use of the tumour registrar skillsets on downstream operational tasks.

# Responding to the Changing Needs of Caribbean Cancer Registries through International Collaborations and Electronic Innovation

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**Topic Area:** 4 - New Directions and IT Solutions

**Sub-Topic:** 4b. New and emerging methods of data collection

IT improvements benefit cancer registries worldwide. In the Caribbean, a system that allows for remote data reporting to a centralized database would facilitate data entry from multiple sites in larger countries and is needed to support a proposed multi-country cancer registry for small island developing states within the OECS region. In 2020, in response to these needs, the International Agency for Research on Cancer (IARC) Caribbean Cancer Registry Hub, based at the Caribbean Public Health Agency (CARPHA), began investigating IT solutions. This resulted in a collaborative project between IARC, CARPHA, the University of Oslo, OECS and the Rwanda National Cancer Registry to develop linkages between health information systems and cancer registries that could be made available as a global tool. The Rwanda National Cancer Registry has developed an oncology module using the open-source, web-based health information management platform District Health Information Software version 2 (DHIS2) (1). The module allows users to enter oncology-related patient data including patient information, tumour diagnosis and treatment information, using a web browser. The module incorporates IARC logic checks to validate records before being uploaded to a database housed in secure application servers. From March October 2022, the DHIS2 Oncology Module was pilot tested at CARPHA. The project Executive Committee was formalized and the DHIS2 Metadata files were imported onto a CARPHA server. The variable list was customized to the core dataset recommended for Caribbean cancer registries (2) and usability testing to assess fit for purpose and ease of use was completed. DHIS2 Oncology module was successfully installed and customized for use in Caribbean cancer registries. User-testing participants expressed satisfaction with the application, with the exception that internal-consistency validation rules were not included in the tested application. Additionally, participants reported issues due to a lack of experience using the DHIS2 platform. The DHIS2 Oncology Module can be installed and customized for use in Caribbean cancer registries, demonstrating wider applicability for global implementation. Work to develop appropriate training materials to support its installation, customization, and use is underway. 1. DHIS2. <https://dhis2.org/>. 2. CARPHA. Caribbean Registry Manual: Data Collection and Operating Procedures Module. 2018.

# Risks of Premature Mortality Among Survivors of Childhood Cancer

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**Topic Area:** 5 - Childhood Cancers

**Sub-Topic:** 5c. Pediatric epidemiology

**Background:** Due to remarkable achievements in childhood cancer treatments, childhood cancer patients have 80% chance of achieving 5-year survival. However, overcoming cancer at a young age comes with significant adverse consequences from their treatment. These young patients experience significant risks of life-threatening conditions and mortality for decades. Using individual-level linkages between California Cancer Registry (CCR) and California Center for Health Statistics and Informatics, we built a retrospective cohort, Multi-ethnic Survivors of Childhood Cancer (MESCA) to assess types and magnitude of cancer burden in childhood cancer survivors and impact of racial/ethnic disparities. Purpose: We examined excess risks of premature mortality for childhood cancer survivors after achieving 5-year survival using population-based approach.

**Methods:** Patients diagnosed with cancer before or at age 20 from 1988 to 2010 and survived 5+ years were identified from the CCR and individually linked to death certificates data from 1993 to 2016 to assess risks of premature mortality. The death certificates data from the California population of same age who have never been diagnosed with childhood cancer was used as reference group. We estimated age adjusted mortality rates and standardized mortality ratio (SMR) for cancer survivors in comparison to the California's general population by race/ethnicity, sex, age, time period and cancer diagnosis. We will further examine cause specific mortality risks among the childhood cancer survivors.

**Results:** The MESCA cohort consists of 34,502 5-year survivors of childhood cancers. Of these, 1,948 patients linked to death certificate data with recorded mortality before age 50. Childhood cancer survivors experienced significantly higher risks of premature mortality compared to the general population. These excess risks varied by race/ethnicity (SMR for Non-Hispanic whites =5.1, 95% CI:4.8-5.5; Non-Hispanic Blacks =4.1, 95% CI:3.5-4.7; Hispanics =5.8, 95% CI:5.4-6.2; Asians/Pacific Islanders =9.8, 95% CI:8.4-11.3; and American Indian =3.9, 95% CI:1.7-6.1) After adjusting for race/ethnicity, sex, calendar years and age, childhood cancer survivors were 6.2 times (95% CI: 5.9-6.5) as likely to die prematurely. We will present cause specific mortality risks to help understand the severe burden of cancer among this vulnerable population.

**Conclusion:** Childhood cancer survivors experience significant excess risks of premature mortality.

# SPARC – A New Integrated Platform to Assess Racial/Ethnic and Nativity Disparities in US Cancer Mortality

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**Topic Area:** 3 - Epidemiologic Studies using Cancer Surveillance Data

**Sub-Topic:** 3b. Social determinants and cancer disparities

**Background:** The size and share of foreign-born populations have grown substantially in the US, so does its impact on advancing cancer mortality equity. The racial/ethnic heterogeneity of foreign-born populations adds further complexities. To make improvements on tracking the progress towards health equity, the National Cancer Institute developed the Survey-Based Population-Adjusted Rate Calculator (SPARC) for calculating nativity stratified age-standardized mortality rates (ASMR).

**Methods:** Using SPARC, the most recent 3-year (2016-2018) bias-corrected ASMRs and bias-corrected rate ratios were calculated based on newly developed statistical methods for most common causes of cancer deaths by sex, age-group, nativity (foreign-born vs. US-born), and major racial/ethnic groups in the US. The bias-correction accounts for sampling errors in population denominators as nativity-stratified populations are estimated from American Community Survey samples. Mortality counts are derived from the National Vital Statistics Systems. For the first time, mortality trends by nativity for a 12-year period spanning 2006-2018 were also examined.

**Results:** US-born Americans have higher mortality rates than their foreign-born counterparts across almost all cancers, by sex and racial/ethnic group with the largest difference being in lung cancer among non-Hispanic blacks where the rates are 3-fold higher for US-born. One exception is liver cancer, where the reverse is true among non-Hispanic API. The well-documented White-Black differences in breast cancer mortality is mainly driven by US-born women. For all cancers combined, the descending trends are more accelerated for US-born compared to foreign-born (AAPCs: -1.78 vs. -1.30 for NH white respectively, -2.62 vs. -1.66 for NH black, -2.14 vs. -1.30 for NH API, and -1.53 vs. -0.73 for Hispanic). Pancreas and liver cancers are exceptions in that trends are increasing, stable or decreasing (liver cancer in foreign-born APIs), depending on nativity and race-ethnicity. For screen-detectable colorectal cancer, foreign-born Black and Hispanic males are the only groups without a favorable descending trend.

**Conclusions:** SPARC is a user-friendly tool that integrates high quality data and rigorous statistical methods for evaluating the intertwined relationships between race/ethnicity and nativity in cancer mortality. Future state-specific analyses, also supported by SPARC, will shed light on state demographic profiles for understanding disparities in cancer mortality.

# Staging Childhood Cancer Using CanStaging+ in Population-Based Cancer Registries

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**Topic Area:** 4 - New Directions and IT Solutions

**Sub-Topic:** 4a. Technologic and scientific advances and innovations

**Background:** In 2018 the World Health Organization launched the Global Initiative for Childhood Cancer to address global inequality in childhood cancer survival. Cancer staging is important for treatment planning and discussion with patients, it is also important to monitor and evaluate cancer actions and outcomes at population level. Population based cancer registries (PBCRs) are key partners in assigning stage at diagnosis yet it is complex and required adherence to international standards and regularly updates.

**Methods:** In a collaborative international collaboration, we developed a user-friendly electronic staging tool, CanStaging+, for PBCRs based on UICC TNM classifications for adult cancers and on Toronto Paediatric Cancer Stage guidelines for childhood cancers, publicly available both online and as an offline tool, which will be demonstrated during the presentation.

**Results:** CanStaging+ with anatomical drawings is designed to help maximise availability, standardisation and comparability of cancer staging internationally. The tool provides automatic calculation of the international TNM staging classification editions 7 and 8 for a variety of tumour sites. CanStaging+ also provides the two-tiered approach of Toronto childhood cancer staging for fifteen cancer types including the complete guideline of the Toronto Paediatric Cancer Stage. A batch function also exists to allow registries to stage or derive stage groups of each case recorded. In addition it also hosts guideline for the Essential TNM including its diagram. Today the tool is available in English, and an expansion to include translation to Spanish, French, Italian, Turkish and Japan is ongoing, with a view to expand this to other languages in the future.

**Conclusions:** We present an electronic staging tool for cancer registries available on and offline to enhance the completeness and comparability of cancer staging internationally. Specifically, for this conference we will present the new updates in particular on the childhood cancer staging tool. The project has been a true international collaborative effort, and continued collaboration is seek to join different sub-works of CanStaging+ e.g., expansion, implementation or capacity building.



# Staging Over Time: A Process to Stabilize Staging Data

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**Topic Area:** 6 - Data Collection, Tools and Operations

**Sub-Topic:** 6a. Data quality control and standards

Over the years, the criteria/definitions for staging has changed. A majority of the changes are due to changes in the American Joint Committee on Cancer (AJCC) staging manuals, which historically have changed every 6-8 years, with rolling updates being done starting in 2021. The Surveillance Research Program (SRP) that oversees the Surveillance, Epidemiology and End Results (SEER) registries, has changed how stage is collected based on the AJCC changes and these changes are reflected in the public use dataset and the research file. These changes can cause differences in the stage distribution, survival and trends over time. Researchers have been requesting to look at stage over time (covering multiple AJCC editions), but until now, this capability has either been limited, or very complex to determine. In conjunction with related projects examining changes in SEER-based coding practices, the Staging Over Time project will 1. Provide staging over time for all sites that have a TNM and/or Summary Stage chapter. 2. Provide clear descriptions for the T, N, M, TNM Stage Group and Summary Stage definitions. 3. Summarize these changes and associated time periods. 4. Develop a SEER internet-based educational resource summarizing these changes over time. 5. Analyze the impact of selected changes on stage distribution, survival statistics and their associated trends. 6. Explore options for and develop a tool for informing end users of SEER data of such changes that references the SEER web-based interface.

# Streamlining IRB Review of Studies Submitted to the Virtual Pooled Registry - Cancer Linkage System

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**Topic Area:** 4 - New Directions and IT Solutions

**Sub-Topic:** 2c. Visions for the future

**Background:** Historically, studies wanting to link with multiple cancer registries and receive cancer outcome data had to undergo duplicative, time-intensive registry and IRB review. To streamline the IRB review process and align with changes to the Common Rule, the National Cancer Institute (NCI) contracted with Biomedical Research Alliance of New York (BRANY) to serve as the Central IRB (CIRB) for review of minimal-risk multi-site linkage requests submitted through the Virtual Pooled Registry Cancer Linkage System (VPR-CLS).

**Methods:** BRANY, NCI, and NAACCR staff met with registry and local IRB staff to describe the CIRB review process, understand the local review process, and determine whether registry IRBs could cede review to BRANY. When possible, local IRBs signed reliance agreements with BRANY CIRB and completed a Local Research Context form outlining laws, regulations, and policies that BRANY would account for in their review. A streamlined CIRB workflow was added to the VPR-CLS and leveraged the existing templated application and supporting documents submitted by the researcher. BRANY also developed standard operating procedures and a website (<https://www.brany.com/forms-downloads-vpr-cls-cirb/>) to document their process and activities.

**Results:** Efforts to establish a CIRB review process have been successful. Among the 45 registries participating in the VPR-CLS, 16 did have a local IRB requirement and five determined that IRB review was not needed for VPR-CLS linkage requests. Of the remaining 25 registries, 13 have ceded review to BRANY, 2 are unable to cede, and 10 are in various stages of exploring the BRANY CIRB processes and benefits. Prior to adoption of the BRANY CIRB, the average IRB review time in these registries was 212 days for three of the initial VPR-CLS studies. BRANY has reviewed VPR-CLS linkage requests for seven studies, six of which underwent expedited review and one was considered not human subjects research. The average timeframe for BRANY CIRB expedited review was 2.2 business days.

**Conclusions:** Implementation of the CIRB has significantly reduced the IRB review time and eliminated redundant reviews across 13 registry IRBs. Leveraging an automated CIRB workflow and existing application materials in the VPR-CLS, BRANY CIRB review is a streamlined, efficient process.

# The COVID-CANCER Surveillance Data Repository in New Jersey: Description and Lessons Learned

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**Topic Area:** 3 - Epidemiologic Studies using Cancer Surveillance Data

**Sub-Topic:** 3a. Epidemiologic studies

**Background:** Cancer patients may have weakened immune systems due to the cancer itself or certain treatments, thus being at increased risk for severe COVID-19 outcomes. Cancer patients diagnosed with COVID-19 have a higher case fatality rate than the general population. Purpose: (1) To describe the COVID-Cancer data linkage process, (2) to characterize demographics, tumor surveillance data, and covid surveillance data among cancer patients diagnosed with COVID-19 (the linked individuals), and (3) identify challenges in linking the data.

**Methods:** Recognizing the need for research on the associations between COVID-19 and cancer, New Jersey State Cancer Registry (NJSCR) data were linked to New Jersey Communicable Disease Reporting and Surveillance System (CDRSS) data to create a data repository for COVID-Cancer research using Match\*Pro. NJSCR data consisted of cancer cases diagnosed from 1979-2022 (n=1,454,733). CDRSS data consisted of PCR-confirmed COVID-19 cases diagnosed among New Jersey residents in 2020 or 2021 (n=1,526,213). To reduce the amount of resource-intensive manual review, we developed automatic classification rules that maximized the number of matches while preventing false matches. Accurint was used to validate match status of a subset of pairs captured by the rules and for adjudication of uncertain pairs. Descriptive statistics were generated using SAS.

**Results:** The linkage process was impacted by the lack of SSN in the provided CDRSS data and other data quality issues, resulting in a large number of potential matches needing manual review. A total of 70,895 matches were identified by Match\*Pro rules, representing 69,137 individuals. The rules captured approximately 90% of all potential pairs (including matches and non-matches), leaving about 10% for manual review. Over half (56%) of matched individuals were female and 67% were non-Hispanic White. The five most common cancers were breast, prostate, melanoma, thyroid, and lung; 53% of all cancers were diagnosed between 2010-2019. The mean age at COVID-19 diagnosis was 66.4 for females and 68.6 for males.

**Conclusions:** The linkage process was streamlined and standardized by using Match\*Pro rules and will undoubtedly improve future linkages. The COVID-CANCER Surveillance Data Repository is a rich resource for research elucidating the associations between COVID-19 and cancer outcomes.

# The Effect of the COVID-19 Pandemic on 2020 Cancer Diagnosis, Screening, and Stage in Alaska

[Dr. David O'Brien<sup>1</sup>](#)

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**Topic Area:** 1 - Effects of Covid-19 on Cancer Surveillance and Operations

**Background:** The COVID-19 pandemic greatly affected how cancer is normally diagnosed, with reduced number of cases during the first half of 2020. Delayed cancer diagnosis could result in a poorer prognosis such as cancers being reported at a late stage.

**Purpose:** To assess the effect of the pandemic on cancer diagnosis in Alaska.

**Methods:** The Alaska Cancer Registry (ACR) reviewed its data for screening-amendable cancers (SACs) and non-screening-amenable cancers (NSACs). The 2020 monthly case count was compared to the average of the previous 5 years monthly case count.

**Results:** The number of 2020 cases was less than the previous 5-years average for the first few months of the pandemic, especially for SACs. For SACs as a group for March, April, May, and June, the decrease was 4%, 32%, 27%, and 10% respectively. For NSACs as a group for March, April, and May, the decrease was 9%, 22%, and 6% respectively. The various SACs had different maximum decreases at different months. The maximum decrease for colorectal was 33% and lung 24% in April. The maximum decrease for breast was 54% and prostate 46% in May. The case count in other months of the year tended to be slightly higher than the 5-year average for both groups. ACR also reviewed stage at diagnosis over time for SACs and NSACs. Surprisingly, both SACs and NSACs as groups had an average of about 40% late-stage cases over time with very little variation prior to the pandemics start. This trend was not necessarily consistent for the individual SACs. Although there was an increase in percentage late-stage cases in 2020 for both SACs (2%) and NSACs (6%), this increase was relatively small, followed by a small decrease in late-stage cases in 2021.

**Conclusions:** Fewer cancers were diagnosed during the start of the pandemic, especially for SACs. A large uptick of late-stage diagnoses was not observed for 2020 or 2021, and some of the diagnoses missed during the beginning of the pandemic were probably diagnosed later in the year. However, the total number of 2020 cases is still unusually low and well below the expected case count.

# The NAACCR Mentorship Program

[Dr. Monique N. Hernandez](#)

Florida Cancer Data System

The NAACCR Mentorship program is a new initiative to engage members in learning from each other. The program provides a platform to connect mentors and mentees in a one-on-one professional relationship. The Program will also provide roundtable discussion forums for a more dynamic and interactive space for sharing.



# The NUMIDENT Project on Birthplace Data Augmentation in SEER Cancer Datasets

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**Topic Area:** 6 - Data Collection, Tools and Operations

**Sub-Topic:** 6b. Innovative operations and procedures

**Introduction:** Knowledge of birthplace in cancer registration is crucial to study incidence and survival in US and foreign-born populations, and potentially allows for detailed studies on Black, Hispanic and Asian and Pacific Islander (API) subgroups. Birthplace is currently incomplete in SEER especially for cancer survivors, thus causing biases especially in estimating survival statistics. Because of this, birthplace has been removed from public use datasets released by SEER. To augment SEER birthplace data, a linkage with the Social Security Administration Numerical Identification System (NUMIDENT) was performed under strict legal conditions and with limitations of data use. As a legal requirement for determining employment eligibility, NUMIDENT data has strong quality, high completeness and therefore was categorized as the gold standard in this analysis. Here we show preliminary results of this linkage and discuss potential uses and limitations of this data addition.

**Methods:** SSA performed a deterministic-type linkage using the variables: name, social security number, gender, and date of birth. The information returned to NCI/SEER consisted of country of birth for people born out of the US and state/territory of birth for people born in the US.

**Results:** Of 16 million people in the SEER dataset (November-2021 submission), 4.8% lacked information, 3.4% did not match with NUMIDENT while 91.8% matched. The matched proportions varied by racial-ethnic group, from 93.8% among American Indians to 83.7% in Hispanics. Current SEER birthplace data was highly incomplete (35%). SEER data sensitivity and specificity for US-birth were 98.8% and 90.9% respectively; as many as 9% of all foreign-born were misclassified. Gains from unspecified racial-ethnic categories using NUMIDENT data could reach 13% for Koreans and Vietnamese in Asians and 30%-65% for all Hispanic ethnic groups in SEER.

**Discussion:** Biases related to non-matched records and unavailable data will persist for incidence and survival studies with an impact primarily among API and Hispanic populations. Moreover, NUMIDENT will not help in determining subgroup in the large US-born Hispanic and API populations since the data does not specify region of origin. Regardless, NUMIDENT, within its legal limitations, may constitute an important tool for more accurate and more complete data on birthplace.

# The Virtual Pooled Registry Cancer Linkage System: Expanding Cancer Registry Research Impact

Mr. Chris Johnson<sup>1</sup>, Ms. Annelie Landgren<sup>2</sup>, Dr. Dennis Deapen<sup>5</sup>, Mrs. Betsy Kohler<sup>1</sup>, Mr. Don Green<sup>3</sup>, Dr. Lynne Penberthy<sup>2</sup>, [Chris Johnson](#)<sup>4</sup>

<sup>1</sup>North American Association of Central Cancer Registries, Springfield, USA, <sup>2</sup>National Cancer Institute, Bethesda, USA, <sup>3</sup>Information Management Services, Inc, Calverton, USA, <sup>4</sup>Cancer Data Registry of Idaho, Boise, USA, <sup>5</sup>Keck School of Medicine, Los Angeles, USA

**Topic Area:** 4 - New Directions and IT Solutions

**Sub-Topic:** 2c. Visions for the future

The Virtual Pooled Registry Cancer Linkage System (VPR-CLS) is an NCI-sponsored online service that efficiently connects existing researcher studies with U.S. cancer registries to facilitate minimal risk linkages and identify incident cancers among study participants. The VPR-CLS uses a two-phase process. Phase I supports a secure, standardized linkage and provision of de-identified aggregate match counts to researchers, while Phase II streamlines the ensuing application process, including necessary agreements, to allow release of individual-level data on the matched cases. The VPR-CLS was officially launched in February 2022 and is now in its second year of production. The authors will provide an update on the VPR status, registry adoption of VPR efficiencies, number and type of linkage studies being processed, and significant outcomes from the linkages. New and proposed enhancements to the system, such as a recurring linkage workflow and additional templated forms, will be discussed. We will also highlight efforts to understand, protect, and facilitate the secondary sharing of de-identified registry data by VPR-CLS linkage studies in accordance with National Institutes of Health Data Management and Sharing Policy.

# Toronto Stage for Pediatric Cancer Surveillance

## Mrs. Betsy Kohler

NAACCR Executive Director, NAACCR, Inc., Springfield, USA

## Dr. Fernanda Silva Michels

Program Manager of Data Quality and Integration, NAACCR, Inc., Springfield, USA

Toronto Pediatric Cancer Stage Guidelines have been in use internationally by population-based registries for several years. We will provide an introduction to the Guidelines and discuss the importance of collecting staging for pediatric cancers as part of the National Childhood Cancer Registry.



# Translating and Mapping Data Using Exchange Plus: Another Tool in the Toolkit!

[Mrs. Michelle Esterly<sup>1</sup>](#), [Mr. Sanjeev Baral<sup>1</sup>](#), Mr. Joseph Rogers<sup>2</sup>

<sup>1</sup>Katmai Government Services, Orlando, USA, <sup>2</sup>Centers for Disease Control and Prevention, Atlanta, USA

**Topic Area:** 6 - Data Collection, Tools and Operations

**Sub-Topic:** 6b. Innovative operations and procedures

**Background:** Exchange Plus, formerly XML Exchange Plus, has transformed into a useful tool to assist central cancer registries in several registry operation activities. While Exchange Plus continues to support XML by providing a tool to create valid NAACCR XML dictionaries, several enhanced features have been added to the application. The latest innovative feature provides a tool to convert and map data items from any fixed width or delimited file to the current NAACCR XML standard.

**Purpose:** To demonstrate the innovative mapping features of Exchange Plus including converting delimited or fixed width files to the NAACCR standard, translating data in non-NAACCR format to NAACCR standard codes and definitions, and illustrating writing custom mapping functions in the applications code editor.

**Approach:** An overview of new mapping features in Exchange Plus will be provided. These advancements have been identified from specific use cases and needs within the community with the purpose of translating data to the NAACCR standard as effortlessly as possible.

**Results:** This presentation will illustrate mapping features and custom mapping capabilities to assist registry staff in converting and mapping data. Terminology and concepts introduced in Exchange Plus will be reviewed as well as the process of creating mapping configurations and translation tables that can be saved for future use and shared with others. A feature is available for those familiar with writing programming code to generate custom mapping. The code editor is meant to write simple code to do mapping when built-in functions are inadequate for certain use cases. Custom code can be saved as a user function by adding it to a Mapping Functions library and these functions can be shared with other users at a different site using export/import features.

**Conclusion:** This presentation will highlight key mapping features and capabilities of Exchange Plus and demonstrate how the application can facilitate central registry operations as the need for data linkages to supplement data is expanding. These enhanced features provide users with a comprehensive mapping tool to streamline complex registry tasks.

# Transparent and Adaptable Natural Language Processing for Cancer Surveillance

[Mrs. Kasey Diebold](#)<sup>1</sup>, Mrs. Sandy Jones<sup>1</sup>, Mr. Joseph Rogers<sup>1</sup>

<sup>1</sup>Centers for Disease Control and Prevention, Atlanta, USA

**Topic Area:** 2 - Big Ideas in Cancer Surveillance

**Sub-Topic:** 2b. How to make cancer data more timely

**Background:** CDC/National Program of Cancer Registries (NPCR) has been a leader in developing Natural Language Processing (NLP) solutions to process anatomic pathology reports. These solutions focus on the extraction of information that can aid in case ascertainment and automated coding of key cancer data elements for abstraction. Building off successes, lessons learned, and new developments in AI methodology and cloud computing, CDC/NPCR has developed a strategy to maximize the benefits of both rule-based and statistical NLP solutions.

**Purpose:** The CDC/NPCR NLP strategy aims to improve timeliness, completeness, and quality of cancer surveillance data by utilizing multiple NLP methods for rapid case ascertainment and auto-coding and developing an efficient cloud-based informatics pipeline for data processing and reporting.

**Methods/Approach:** CDC/NPCR plans to establish a data pipeline that incorporates a rule-based NLP reportability classifier within the laboratory information system (LIS) combined with a cloud-based statistical NLP service to provide reportability and auto-coding of key data elements at CCRs. To maximize model performance and ensure continuous improvements, an auditing feedback loop will be incorporated to analyze NLP results for discrepancies. Results will be used to update knowledge artifacts for rule-based methods and retrain models for statistical methods.

**Results:** The presentation will provide an overview of CDC/NPCR's NLP efforts and detail the strategy for implementing scalable, transparent, and adaptable NLP solutions to address major challenges faced by laboratories, CTRs, and CCRs in the collection, processing, and reporting of cancer data.

**Conclusion:** Public health has been challenged to develop new strategies to incorporate the benefits of machine learning while maintaining maximum transparency. Applications of a single NLP method have resulted in inconsistent model performance and gaps in adaptability to specific laboratory/registry needs. Utilizing multi-method approaches has the potential to overcome these barriers leading to transparent improvements in the efficiency and quality of data abstraction and processing while reducing the manual coding burden on laboratories and CTRs.

# Two-Tiered Hospital Reporting of Abstracts: Implementation and Lessons Learned

[Ms. Carrie Bateman](#)<sup>1</sup>, Ms. Valerie Yoder<sup>1</sup>, Ms. Kacey Wigren<sup>1</sup>, Dr. Morgan Millar<sup>1</sup>, Dr. Jennifer A. Doherty<sup>1</sup>

<sup>1</sup>University of Utah, Salt Lake City, USA

**Topic Area:** 2 - Big Ideas in Cancer Surveillance

**Sub-Topic:** 2b. How to make cancer data more timely

The Utah Cancer Registry sought to identify ways to enable more timely creation of cancer cases to promote earlier release of incidence data. Hospital cancer registries are required to report complete abstracts following SEER, NPCR, and CoC standards, including complete first course treatment. First course treatment varies and can take more than a year to complete, which delays abstract submission. In turn this delays the creation of cases in our database management system. We therefore developed a two-stage submission process for each case, with an initial abstract due within six months followed later by a complete abstract. The initial abstract did not need to pass edits but had to contain a minimum set of data items for creating a cancer case. Then the completed abstract was submitted to us again when finalized by the hospital. We began implementing this two-stage submission process for diagnosis year 2020. In 2022, when we consolidated initial abstracts, we identified several challenges caused by the process, including that: 1) it created extra tasks which required revisiting the case multiple times; 2) initial abstract information was not always accurate causing additional work to clarify; and 3) the initial and complete abstracts needed to be reconciled to ensure complete casefinding. Additionally, this process created extra work for reporting hospitals during both the submission and reconciliation processes. Our project demonstrated that receiving an early, incomplete abstract followed by a complete abstract for cancer cases is not the optimal way to increase timely reporting of cancer surveillance data. After implementation of the two-stage submission process, SEER presented information about a new real-time reporting project to create cases from pathology reports, with the goal of allowing for earlier reporting of incident cases. Given the issues identified during our project and SEERs upcoming project, we decided to discontinue requiring initial abstracts from hospitals. By participating in the SEER project, we look forward to sharing our lessons learned with other registries.

# Use Natural Language Processing (NLP) to Identify Reportability of Cancer Reports

Dr. Qianru "Amie" Wu<sup>1,2</sup>, Ms. Lifeng Li<sup>1</sup>, Ms. Bhavana Srinivas<sup>1</sup>, Mr. Remy Poudel<sup>1</sup>, Dr. Yi Du<sup>1,3</sup>, Ms. Elaine Flores<sup>4</sup>, Ms. Raquel Brown<sup>4</sup>, Mr. Patric Prado<sup>5</sup>, Dr. Ming Qu<sup>1</sup>

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**Topic Area:** 4 - New Directions and IT Solutions

**Sub-Topic:** 4a. Technologic and scientific advances and innovations

**Background:** Identifying reportability of cancer from ePath reports is a manual, time-consuming process. CTRs manually review each report and identify reportability using the SEER ICD-10-CM codes list as a reference, combining evaluation of diagnostic text, which frequently takes one to five minutes. Among more than 7,000 ePath reports received by the Nebraska Cancer Registry (NCR) every year, approximately 1/3 are non-reportable. In 2022, as one of the CSTE Data Science Team Training Programs, we developed an automated pipeline using NLP to facilitate reportable cancer identifications.

**Methods:** We used 4,295 HL7 formatted ePath reports from four pathology laboratories. We summarized the frequency of ICD-10-CM codes in ePath reports and evaluated the hypothesis that stated a report was reportable if it contained reportable code(s). Then CTRs manually labeled reportability for each report, as a gold standard, to build a training and testing datasets. We used only OBX-5 data fields, where the diagnostic text located, to train our model. We employed Scikit-learn (sklearn) and Natural Language Toolkit (nltk) modules in Python. We deployed three text classification models: the Nave Bayes model, Logistic Regression, and Linear Support Vector Machine (SVM), with two vectorization methods: Frequency Vector, and Term Frequency-Inverse Document Frequency (TF-IDF) vector. We used an 80%:20% of training and testing datasets split for model runs.

**Results:** Approximately 72% of reports had ICD-10-CM codes. We obtained only 58% accuracy when using the reportable ICD-10-CM codes to identify reportable reports, mainly because many reportable reports contained other health conditions codes rather than cancer codes. Among model runs, the Linear SVM model with TF-IDF performed the best, with 87% accuracy, 81% sensitivity, and 89% specificity for the overall prediction. Once the model and vector were chosen, processing 4,295 ePath reports took less than 10 minutes, including text preprocessing and model run.

**Conclusion:** Using NLP significantly improved the efficiency of reportable cancer identifications. The accuracy of classification results from the NLP experiments underscores the potential to incorporate this technique as a standard of practice. We will continue to evaluate this process by optimizing each step for improved accuracy by identifying where manual review might be necessary.

# Using the New Survey-Based Population-Adjusted Rate Calculator (SPARC) to Calculate Mortality Rates by Nativity

Mr. Steve Scoppa<sup>1</sup>, Dr. Mandi Yu<sup>3</sup>, Dr. Eric (Rocky) Feuer<sup>2</sup>, Mr. David Campbell<sup>1</sup>

<sup>1</sup>Senior Systems Analyst, IMS, Inc., Calverton, MD, USA, <sup>2</sup>Mathematical Statistician and Program Director, Division of Cancer Prevention and Population Sciences, National Cancer Institute, Rockville, Maryland, USA, <sup>3</sup>Chief, Statistical Research and Applications Branch, Surveillance Research Program, Division of Cancer Prevention and Population Sciences, Rockville, Maryland, USA

**Topic Area:** 3 - Epidemiologic Studies using Cancer Surveillance Data

**Background:** Most incidence and mortality rates produced by cancer researchers are produced using census populations for the denominator of the rates. These populations are generally available by year, race/ethnicity, sex, age, and geography and are considered complete without error. There are many applications where a researcher wants to calculate rates for a subpopulation, for example nativity, for which census populations are not available. For these rates, probability-based sample survey data is available, such as the American Community Survey (ACS), but these populations are subject to sampling error and uncertainty. The NCI, in collaboration with researchers at the University of California at Davis, have developed a new inference method for estimating age-adjusted rates while incorporating sampling errors in the population denominators. Multiple papers have been published on the new method and it is now implemented in the new SPARC web-based tool.

**Purpose:** The author will present the new SPARC tool for the first time. The SPARC tool initially includes U.S. mortality by U.S.- versus foreign-born status. The presentation will include a live demonstration generating rates and rate ratios (RR) by state and total U.S. The RR of cancer incidence or mortality is an essential measure for identifying and characterizing subpopulations that are associated with higher risks of developing cancers (incidence) or dying from cancers (mortality).

**Conclusion:** The SPARC tool will be made publicly available soon with the mortality data by nativity. Additional applications will be added to the tool over time.

# Utilizing Delaware Cancer Registry Data to Improve Breast and Cervical Cancer Outcomes in Delaware

Ms. Dawn Hollinger, Ms. Sumitha Nagarajan, Ms. Stephanie Belinske, Mr. Maxwell Amoako, Ms. Helen Arthur, Mrs. Diane Ng

*<sup>1</sup>Delaware Division of Public Health, Dover, USA*

**Topic Area:** 3 - Epidemiologic Studies using Cancer Surveillance Data

**Sub-Topic:** 3c. Using real-world data from cancer registries to improve cancer outcomes

The state of Delaware consists of three counties and historically presented cancer rates by census tract in order to report sub-county cancer data. However, there are several limitations to reporting cancer data by census tract, including small counts that only allowed for all-site cancer reporting. In February 2022, Delaware began to participate in the NCI/NAACCR Zone Design Project. The project aims to work with central cancer registries to create cancer reporting zones that 1) have a minimum and target population of 50,000; 2) are socio-demographically homogenous; and 3) are compact. Reporting by cancer reporting zones will allow for more meaningful and targeted outreach and reporting of data that previously could only be done at the county level, which did not have high spatial resolution, or by areas such as ZIP codes that do not allow for convenient rate calculation. In January 2023, a survey was distributed to state-employed epidemiologists, members of the Delaware Cancer Consortium, and other stakeholders that introduced several zone layouts to rank. The results of the survey were used to adopt the Delaware zone designations. The survey responses provided valuable feedback that identified the best cancer reporting zones for Delaware. The newly established zones were applied to a data analysis project using Delaware Cancer Registry (DCR) information to create ArcGIS maps showing locations of late-stage breast cancer diagnoses. Additional maps use data pulled from the Screening for Life (SFL) program to show locations of enrolled clients eligible for breast cancer screenings, sub-analysis by race, in relation to SFL-contracted health care provider sites. Project outcomes will guide future SFL outreach to ensure Delaware is focusing breast cancer screening programs in areas of increased need. Additionally, the maps will identify service gaps where the SFL program should recruit more breast cancer screening providers. This same data analysis process using the zone designations, DCR data, and SFL information will be applied to colorectal, lung, and prostate cancers. Presentations of each project will be delivered at quarterly meetings of the Delaware Cancer Consortium and included in data briefs issued by the Delaware Department of Public Health.

# World-Wide Comparison of Age-Specific Net Survival from Non-Epithelial Ovarian Tumours (CONCORD-3)

[Dr. Melissa Matz](#)<sup>1</sup>, Prof. Michel Coleman<sup>1</sup>, Prof. Claudia Allemani<sup>1</sup>, on behalf of the CONCORD-VENUSCANCER Working Group

<sup>1</sup>London School of Hygiene and Tropical Medicine, London, United Kingdom

**Topic Area:** 3 - Epidemiologic Studies using Cancer Surveillance Data

**Sub-Topic:** 3a. Epidemiologic studies

**Background** Age-standardised survival estimates are useful for international comparisons of trends in cancer survival. However, age standardisation requires survival estimates for each age group. With rare tumour sub-types, such as germ cell and sex cord-stromal tumours, comparison of age-standardised estimates is often impossible. Comparing age-specific estimates can allow for more informative international comparisons.

**Purpose** The CONCORD programme is the largest population-based study of global trends in cancer survival. CONCORD-3 included data on 53,970 women (aged 15-99 years) from 57 countries who were diagnosed with non-epithelial ovarian cancer during 2000-2014. We examined whether international differences exist in age-specific survival for germ cell, sex-cord stromal and other non-epithelial ovarian cancers.

**Methods** Germ cell and sex-cord stromal tumours were defined with morphology codes from the International Classification of Diseases for Oncology 3rd edition (ICD-O-3). Only microscopically verified tumours were included. Tumours with a borderline, non-specific or unknown morphology were excluded. We categorised age into 5-year age groups (15-19, 20-24 years, etc.). We estimated one- and five-year net survival by age, country and sub-type for women diagnosed during 2000-2014. Net survival was estimated using the Pohar Perme estimator.

**Results** Age-specific one-year net survival from germ cell tumours ranged from 67% in Russia to 100% in several countries in Europe and Oceania. Age-specific five-year survival was higher, reaching 100% in several countries in Asia, Europe and Oceania. Survival from germ cell tumours generally decreased with increasing age, with the highest survival in women aged 15-29 years. Age-specific one-year survival from sex cord-stromal tumours ranged from 80.0% in Bulgaria to 100% in Canada, Korea, Taiwan and several countries in Europe. Age-specific five-year survival from sex cord-stromal tumours ranged from 39.4% for women aged 15-19 years in Australia to 100% for women aged 25-39 years in Korea, Taiwan and Sweden. Unlike germ cell tumours, survival from sex cord stromal tumours generally increased with increasing age.

**Conclusions** Age-specific survival from germ cell and sex cord-stromal tumours is generally higher than that from more common epithelial ovarian tumours, but international variations are also wide.

## POSTER PRESENTATIONS

### 50 Years of Cancer Surveillance in Los Angeles County: A Look at the Evolution of the Cancer Reporting Community

Mrs. Andrea Sipin-Baliwas<sup>1</sup>, Mrs. Melissa Dimacali<sup>1</sup>, Mr. Kin Leung<sup>1</sup>, Mrs. Randi Chavez<sup>1</sup>, Ms. Denise Alcantara<sup>1</sup>, Mrs. Juanjuan Zhang<sup>1</sup>, Mrs. Lihua Liu<sup>1</sup>

<sup>1</sup>Los Angeles Cancer Surveillance Program, Keck School of Medicine, University of Southern California, Los Angeles, USA

**Topic Area:** 6 - Data Collection, Tools and Operations

**Sub-Topic:** 2c. Visions for the future

**Background:** In the last 50 years, it is no surprise that our cancer reporting landscape in Los Angeles County has changed dramatically. In the recent 10 years, we have tracked over 140 facility closures. While majority were the disappearance of physician offices, nursing homes, hospices, and other free-standing facilities, nearly 7% were community hospitals who served diverse patient populations. Since some hospitals housed well-known cancer care specialists, we will explore the movement of cases to the extent possible.

**Purpose:** We aim to describe the changing demographics of our reporting facilities, specifically capturing impact of organizational mergers, closures, and emergence of new facilities which shifted cancer rates across, and in some cases, out of the county.

**Methods:** CSP maintains a reporting source database of all facilities in our catchment area, identifying facility type, maintaining contact information, physician associations, and tracking annual caseload. In particular, we will review case information from facilities who have permanently closed and determine what shifts occurred among the patient population.

**Results:** We will present the evolution of facility and patient characteristics over time.

**Conclusion:** We discuss the importance of facility monitoring and how the fluid nature of our reporting community has impacted cancer surveillance and registry operations in Los Angeles County.



# A Comprehensive Usability Engineering Framework for Cancer Registry Information Systems

Mr. Ian McClendon<sup>2</sup>, Ms. Michelle Esterly<sup>2</sup>, Mr. Sanjeev Baral<sup>2</sup>, Mr. Joe Rogers<sup>1</sup>

<sup>1</sup>Centers for Disease Control and Prevention, Atlanta, USA, <sup>2</sup>Katmai Government Services, Orlando, USA

**Topic Area:** 6 - Data Collection, Tools and Operations

**Sub-Topic:** 2a. How to modernize the Cancer Surveillance System

**Background:** Cancer registry software provides a platform for cancer surveillance data collection, management, and analysis. Poor usability reduces the usefulness of cancer registry information systems and hinders the acceptance of system changes by users. Currently, there are no standards or widely adopted usability frameworks for cancer registry software. Several studies have shown that increasing software usability is strongly correlated with user productivity, user satisfaction, and lower error rates. A domain-specific, usability model that considers the complex workflows, and dynamic interaction of a cancer registrar can improve cancer registry software usefulness and acceptance.

**Purpose:** This presentation demonstrates a real-world approach to evaluating the usability of cancer registry applications as well as gauging the impact of annual changes on users of these applications. Finally, a distribution model is proposed for conveying user testing results and analysis among cancer surveillance stakeholders, to facilitate research-based design, and to aid in more-informed, user-oriented application changes.

**Methods/Approach:** The framework employs a multistep approach for user testing and heuristic evaluations. For the redesign of an existing system, the framework provides a model for: 1) providing a reference domain ontology; 2) employing a sequential task analysis and usability metrics; 3) analyzing feedback and identifying usability problems; 4) implementing changes to usability problems; and 5) evaluating the implemented changes.

**Results:** The presentation will detail a case study that employs the framework to increase application usability through user error messaging, improved tooltips related to new features, and a chatbot to help users quickly answer questions. The framework measures quantitative and qualitative data among five user traits: 1) ease to learn; 2) ease of use; 3) memorability; 4) error rate; and 5) overall user satisfaction.

**Conclusion:** The cancer surveillance community would benefit from a standardized usability framework to improve usability, assess the impact of new features and standards changes, and have a repository for user research data that is easily accessible among cancer surveillance community members.

# Analysis of Cancer Incidence During COVID-19 Onset Compared to Pre-COVID-19 Years

Ms. Abby Holt<sup>1</sup>, Ms. Olga Galin<sup>1</sup>, Dr. Yuan Ren<sup>1</sup>, Ms. Ji Li<sup>1</sup>, Mr. Jonathan Stanger<sup>1</sup>, Ms. Reda Wilson<sup>2</sup>, Ms. Mary Elizabeth O'Neil<sup>2</sup>, Ms. Jane Henley<sup>2</sup>, Dr. Manxia Wu<sup>2</sup>  
<sup>1</sup>ICF, Fairfax, VA, USA, <sup>2</sup>Centers for Disease Control and Prevention, Atlanta, Georgia

**Topic Area:** 1 - Effects of Covid-19 on Cancer Surveillance and Operations

**Sub-Topic:** 3c. Using real-world data from cancer registries to improve cancer outcomes

**Background:** During the initial phase of the COVID-19 pandemic cancer screening and care were affected because many facilities paused elective procedures in order to treat infected patients, preserve medical supplies, and reduce the transmission of COVID-19. Additionally, stay-at-home orders were implemented in many states and people did not go to hospitals and other medical facilities for fear of contracting COVID-19. This caused a delay in cancer diagnoses, as evidenced by a community level study in 5 states that observed a decrease of weekly cancer diagnoses for 10 weeks following the onset of the pandemic. The purpose of this project is to assess case counts and characteristics among CDC's National Program of Cancer Registries (NPCR) award recipients during the pre-COVID-19 time period, 2005-2019, compared to data during the onset of COVID-19 in 2020.

**Methods:** NPCR Cancer Surveillance System compliance reports from the 2021 and 2022 data submissions were used to assess case counts between diagnosis years and temporal trends. The U.S. Cancer Statistics public use database will be used to analyze age-adjusted incidence rate (AAR) trends. Descriptive analyses will be used to evaluate differences between historic trends and current data submission. Data will be further analyzed by sex, race/ethnicity, age, and cancer site.

**Results:** From 2005-2019, annual counts for all cancer cases combined increased while AARs decreased due to a growing aging population. Compared to 2019, when case counts were highest, overall reported central cancer registry-level case counts in 2020 dropped by 7.42%, ranging from a reduction of 17.43% to 0.22% by central cancer registry. Case counts decreased from 2019 to 2020 with the greatest monthly decrease in March through May 2020. Additional trend results will be presented after analyses are completed.

**Conclusions:** NPCR Cancer Surveillance System compliance reports are useful in evaluating the impact of COVID-19 on cancer registry operations and trends in cancer diagnoses. U.S. Cancer Statistics and NPCR data can be used to continue to monitor the longer-term impacts of COVID-19 on cancer outcomes such as staging, treatment, and survivorship across the United States.

# An Analysis of Meningioma Incidence and Surgical Treatment by County-Level Socioeconomic Status (SES) in the United States

Ms. Sangami Pugazenthi<sup>1</sup>, [Mrs. Mackenzie Price<sup>2,3</sup>](#), Mrs. Carol Kruchko<sup>2</sup>, Dr. Kristin A. Waite<sup>2,6</sup>, Mr. Gino Cioffi<sup>2,6</sup>, Dr. Jill S. Barnholtz-Sloan<sup>2,6,7</sup>, Dr. Quinn T. Ostrom<sup>2,3,4,5</sup>

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**Topic Area:** 3 - Epidemiologic Studies using Cancer Surveillance Data

**Sub-Topic:** 3b. Social determinants and cancer disparities

**Background:** Prior literature suggests that individual socioeconomic status (SES) may influence incidence of brain tumors, as well as access to treatment and patient outcomes. However, there is no population-level study assessing the correlation between meningioma incidence and county-level SES. We aim to conduct a national study of meningioma cases in the United States (US) to evaluate the association between county-level SES, stratified by sex, race, ethnicity, and incidence in meningioma cases.

**Methods:** Data from the Central Brain Tumor Registry of the United States (2006-2019), a combined dataset including both CDC's National Program of Cancer Registries and NCI's Surveillance, Epidemiology, and End Results Program data was analyzed representing approximately 97% of the population excluding Kansas and Minnesota. SES quintiles were created using 2010-2015 American Community Survey data, and average annual age-adjusted incidence rates (AAAIR) were compared between county-level SES quintiles to calculate incidence rate ratios (IRR) compared to the lowest SES quintile. Logistic regression was used to assess surgical treatment among cases adjusting for race and ethnicity, sex, SES quintile, urbanicity, age group quintiles, and grade.

**Results:** 411,963 cases were analyzed. The median age at diagnosis was 66 years and 73.5% were female. The majority (74.0%) of cases were White non-Hispanic (NH). Overall, meningioma AAAIR increased with increased SES even when stratified by sex. Among White NH individuals, higher SES was associated with increased meningioma incidence ( $P < 0.001$ ). However, among Black NH individuals, lower SES was associated with increased meningioma incidence ( $P < 0.001$ ). Interestingly, compared to cases with lowest SES, those in the highest quintile were less likely to receive surgical treatment (OR: 0.89, 0.81-0.99). Overall, the odds of receiving surgery decreased with increased age.

**Conclusions:** In the US, meningioma incidence was correlated with higher SES, even when stratified by sex. Increased meningioma incidence was associated with higher SES in White NH individuals, but with lower SES in Black NH individuals. Cases in higher SES counties were less likely to receive surgical treatment than those in the lowest SES counties. These findings have significant implications for the effects of SES on meningioma disease burden and treatment access in the US.

# An Assessment of Obesity Attributable Cancers for Implementation of New Data Items in Cancer Surveillance in Arkansas

Miss Daniela Ramirez Aguilar<sup>1</sup>, Mr. Clint Lemons<sup>1</sup>, Mrs. Lindsay Collins<sup>1</sup>, Dr. Bala Simon<sup>1,2,3</sup>

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**Topic Area:** 4 - New Directions and IT Solutions

**Sub-Topic:** 2c. Visions for the future

**Background:** In 2021, Arkansas ranked 6<sup>th</sup> in the nation with the highest obesity prevalence at 38.9%. Obesity was found to have sufficient evidence for its attribution in 13 different cancers among humans by the International Agency for Research on Cancer (IARC). As part of Arkansas Central Cancer Registry (ACCR) initiative in implementing the collection of height and weight data items for cancer surveillance, we assessed the burden due to obesity attributable cancers in Arkansas.

**Method:** We calculated the age-adjusted incidence rates (IR) of obesity associated cancers in Arkansas for the period 1996-2020 among adults aged 30 years or older by using the published population attributable fraction (PAF). A separate qualitative analysis was performed to assess the number of overall obesity-associated cancer cases with 'height' and 'weight' information within cancer report text field in ACCR.

**Result:** Of the 135,247 obesity associated cancer cases, approximately 15.85% were attributable to obesity (n=21,452) during the study period. Females had a higher obesity attributable cancer incidence rate (IR= 21.35, 95%CI: 20.00-22.52) compared to males (IR= 5.85, 95%CI:5.32-6.27). Corpus uteri, NOS, had the highest obesity attributable cancer incidence rates (IR= 5.68, 95%CI: 5.11-6.26) followed by postmenopausal female breast (IR= 5.08, 95%CI: 4.50-5.72), kidney cancer (IR= 4.97, 95%CI: 4.38-5.62), liver/gallbladder (IR= 3.09, 95%CI: 2.61-3.61), colorectal (IR= 2.29, 95%CI: 1.85-2.69), pancreas (IR= 1.81, 95%CI: 1.46-2.14), thyroid (IR= 0.84, 95%CI: 0.64-1.04), esophageal adenocarcinoma (IR= 0.78, 95%CI: 0.66-0.92), multiple myeloma (IR= 0.63, 95%CI: 0.45-0.83), ovary (IR= 0.57, 95%CI: 0.43-0.72), and gastric cardia (IR= 0.35, 95%CI: 0.28-0.43). Additionally, among overall obesity-associated cancer cases (N= 135,247), only 0.58% (n= 789) contained height and weight information within the cancer report text field in ACCR.

**Conclusion:** With obesity and its associated cancers on the rise in Arkansas, ACCR aims to incorporate height and weight as state-specific required data items as part of its effort to expand cancer surveillance in the state, and to address the growing public health burden due to obesity.

The views expressed in this abstract are not necessarily those of Arkansas Department of Health.

# An Examination of Liver Cancer Incidence in California

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**Topic Area:** 3 - Epidemiologic Studies using Cancer Surveillance Data

**Sub-Topic:** 3b. Social determinants and cancer disparities

**Background:** Liver cancer is composed of two main types, hepatocellular carcinoma (HCC) and cholangiocarcinoma (CCA). After years of increasing HCC incidence in the United States, declines have been noted in recent years, but CCA incidence has been increasing. Given these variable trends, documented disparities by sex, age, and race/ethnicity, and shifting risk factors from viral infection (hepatitis B and C) to metabolic causes (obesity, diabetes, non-alcoholic fatty liver disease), a current evaluation of liver cancer incidence by histologic subtype and demographic characteristics is warranted to identify at-risk groups that may benefit from targeted intervention.

**Purpose:** To examine incidence trends by sex, age group, and race/ethnicity in California

**Methods:** Using SEER\*Stat software, we calculated age-adjusted incidence rates (AAIR) by sex, age group, and race/ethnicity for patients diagnosed with HCC and CCA from 2010 to 2019 identified in the California Cancer Registry. We assessed the average annual percent change (AAPC) over the time period for each subgroup using Joinpoint software.

**Results:** For HCC, the AAPC of the AAIR significantly decreased for men (-6.5%) and women (-5.7%) ages 40-64 years since 2014. But for men ages 65-74 (3.3%) and ≥75 (1.4%), AAIR significantly increased over the ten-year period; no increases were observed among women. For CCA, the AAPC of the AAIR significantly increased for men ≥75 (2.6%), and for women in the following age groups: 40-64 (4.2%), 65-74 (2.1%), and ≥75 (5.2%). Significant increases by race/ethnicity were observed for men ≥65 with HCC who were non-Hispanic White (4.0%), non-Hispanic Black (6.3%), and Hispanic (1.4%). The AAPC for Asian/Pacific Islander men significantly decreased (-2.8%). For CCA, the AAPCs for non-Hispanic White women ≥40 (4.4%) and men ≥75 (3.2%) significantly increased.

**Conclusion:** We observed increasing liver cancer incidence trends among older men and women. For HCC the increasing trends were confined to older non-Hispanic White, non-Hispanic Black, and Hispanic men, while older non-Hispanic White patients of both sexes experienced increasing incidence trends for CCA. Future research should focus on evaluating risk factors by liver cancer subtype in these populations; regular screening of individuals with risk factors should be considered.

# A New Focus on Older Patients: Harnessing Cancer Registry Data to Inform Planning and Decision-Making Related to Older Adults Living with Cancer in Manitoba, Canada

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**Topic Area:** 3 - Epidemiologic Studies using Cancer Surveillance Data

**Sub-Topic:** 3b. Social determinants and cancer disparities

Total cancer cases are expected to rise considerably over the next decade in Canada, driven by our ageing population. In 2018, 141,200 adults aged 70+ years ("older adults") resided in Manitoba (11% of our overall population), yet this population made up 46% of new cancer diagnoses and 71% of cancer deaths. The older adult population is heterogeneous, as many live with multiple chronic diseases, each requiring its own treatment plan. Multimorbidity and polypharmacy complicate cancer care delivery, resulting in higher rates of health service utilization and mortality. Here, harnessing Manitoba Cancer Registry data and other routinely collected data sources, we provide insights into the population of older adults living with cancer in Manitoba. We describe regional variability across our province; showing that regions with the oldest populations have the highest proportion of cancer in older adults (up to 53% in a single region). We observe no difference in the type of cancers diagnosed overall, but greater proportions of lung and colorectal cancer in female older adults and kidney cancer in male older adults compared to younger patients. Furthermore, we found that 22% of all older adults were diagnosed with stage IV cancer. The greatest differences in stage were observed in the proportion of unknown stage, which increased with age from 10% (50-59 years old) to 20% (80+ years old). Our data show older adults had lower utilization of cancer treatment for all cancers combined compared to younger adults (systemic therapy: 33% vs. 50%; radiation: 27% vs. 36%; surgery: 41% vs. 63%). While we've provided a snapshot of our findings, this presentation will guide the audience through our detailed report in an effort to better describe cancer system performance for older adults in Manitoba. As our population ages, the healthcare system will face increasing demand for cancer services. We must be able to plan for and deliver high quality services to this unique population. Understanding the cancer experience for older adults is the first step to informed decision-making and planning.

# A Scoping Review Exploring the Use and Reporting of Caribbean Cancer Registry Data

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**Topic Area:** 3 - Epidemiologic Studies using Cancer Surveillance Data

**Sub-Topic:** 3c. Using real-world data from cancer registries to improve cancer outcomes

Cancer registries collect the information necessary to generate key cancer statistics including incidence, mortality, survival, and prevalence. Quality of life, cancer risk factor, and screening information may also be collected as part of registry special studies, including linkage with other public health data. Understanding the use of statistics generated by cancer registries in the Caribbean region can help identify impact and reach, gaps, and generate new ideas regarding the use and dissemination of this essential information.

We are conducting a scoping review to explore publications that used Caribbean cancer registry or registry special studies data for cancer research or public health policy. We are following the JBI methodology and will use the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) Scoping Review extension for review writing. A biomedical librarian will search CINAHL Plus, Embase, LILACS/BIREME, PubMed, Scopus, and Web of Science: Core and Scielo databases. Searches will be limited to Dutch, English, French, and Spanish. Two reviewers will screen each citation in Covidence by title and abstract followed by full text using the eligibility criteria. Articles published 2003 to present and using data from a Caribbean-domiciled registry will be included. Two reviewers will extract the following from each article using Covidence: cancer registry type (population-based, hospital-based, other), statistic type (incidence, prevalence, mortality, survival, quality of life, morbidity, risk factor, screening measure), statistic characteristic (ratio/rate/proportion, unit of measure, type of risk factor or screening measure), population type (open field), year of publication, year(s) of diagnosis, cancer registry domicile (country/territory, region). As a secondary objective, all reports listed on known Caribbean regional websites (e.g. cancer registries, ministries of health, departments of health) will be characterized and quantified.

Sound planning for public health activities depends on the availability of evidence-based, high-quality statistics. Cancer statistics are essential for conducting disease surveillance, generating research hypotheses to better understand cancer causes, and identifying the best cancer control measures. The findings of this scoping review will inform the reach of Caribbean regional cancer statistics for essential public health activities and highlight any gaps in the collection, reporting, or use of this information.

# Assessing the Feasibility of a U.S. Mesothelioma Patient Registry

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**Topic Area:** 6 - Data Collection, Tools and Operations

**Sub-Topic:** 3c. Using real-world data from cancer registries to improve cancer outcomes

**Background:** Mesothelioma is caused by asbestos exposure. Asbestos use has declined in the U.S. since the 1970s, but mesothelioma cases continue to occur, and prognosis remains poor. In 2019, Congress noted there was no registry "...that could help develop and improve standards of care" and instructed CDC to conduct a feasibility study for a patient registry.

**Methods:** Activities have included an expert workshop, public comments via the Federal Register, and pilot testing a risk factor-focused questionnaire, rapid case ascertainment and outreach, and electronic case reporting (eCR).

**Results:** Ten experts presented at the workshop on mesothelioma surveillance, registry best practices, and the potential utility of a registry. Moderated discussion focused on functionality, recruitment, and confidentiality. Twenty-six comments were submitted by organizations and individuals to the Federal Register; 19 stated that a registry could improve patient care and there was strong agreement that a registry would benefit research. Some commenters stated that protecting confidentiality and not allowing participation to affect compensation proceedings would be vital. Eleven mesothelioma patients served as key informants for initial questionnaire development; online data collection is feasible if staff are available to assist participants. Timing is also critical for recruitment and collaboration with clinicians is needed to determine when to contact patients. Collection of standardized work information using a modified questionnaire is ongoing. Rapid case ascertainment using electronic pathology reports and natural language processing software is feasible but labor-intensive because it involves steps beyond routine reporting. Patient outreach to gather supplemental information is feasible but alternatives to telephone should be considered. The eCR pilot is ongoing and involves adapting trigger codes for cancer to filter for mesothelioma cases.

**Discussion:** Stakeholder feedback highlights priorities including rapidly identifying and connecting patients with clinical trials, facilitating data access, and ensuring confidentiality. Rapid case ascertainment and recruitment are feasible but require dedicated staff and funding. Additional work is needed to examine how a registry could effectively connect patients with resources including clinical research opportunities. Findings could inform implementation of a regional or state pilot, perhaps as a supplement to an existing registry or network, to evaluate methods for identifying and enrolling patients.



# Association between Hispanic Melanoma Survival and Physician Volume

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**Topic Area:** 3 - Epidemiologic Studies using Cancer Surveillance Data

**Sub-Topic:** 3b. Social determinants and cancer disparities

Melanoma is the most lethal form of skin cancer. Hispanics are less likely to be diagnosed with melanoma, but they are diagnosed at later stages and have lower survival rates than their non-Hispanic white counterparts. Reasons for the later stage at diagnosis among Hispanics are unknown, and could be related to patient, clinician, or healthcare systems issues.

To investigate the possible role of physician expertise in later stage diagnosis among Hispanics, we used data from the Los Angeles Cancer Surveillance Program (the LA-SEER registry) and compared melanoma survival among Hispanics and non-Hispanic whites, considering the experience level of the treating physician. Physicians who had diagnosed 15 or fewer melanomas (i.e. 1 case per year or fewer) were classified as low volume, while those who had diagnosed more than 15 melanomas were classified as high volume. We included all melanomas (all races) to determine “volume”.

Our preliminary results show that physicians with low volume treat Hispanic patients more often than physicians with high volume (11.8% vs. 6.5%). Physicians with low volume report a higher proportion of late-stage melanomas; this applies to non-Hispanic whites and Hispanics. Nevertheless, it is more marked in the Hispanic population.

After adjusting for stage, survival was worst for patients seen by low-volume physicians. The difference was more pronounced for late-stage disease in both groups, although smaller for Hispanics (36.2% v 23.4% 5-year survival for high- and low-volume respectively) than non-Hispanic whites (53.4% v 24.8% 5-year survival for high- and low-volume respectively). Current analyses include multivariate estimation of hazard ratios and the addition of information about physician specialty.

We conclude that the volume of patients seen by physicians appears to affect survival, especially for late-stage melanomas in non-Hispanic whites, but does not seem to impact outcomes for Hispanics. Hispanics continue to have worse outcomes no matter who they are getting diagnosed by. This study suggests that interventions to improve stage at diagnosis among Hispanics should be uniformly applied to all physicians, but that interventions targeted to low volume physicians might improve survival for non-Hispanic whites.

# Bayesian Mediation Analysis for Time-to-Event Outcome – Investigating Racial Disparity in Breast Cancer Survival

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**Topic Area:** 3 - Epidemiologic Studies using Cancer Surveillance Data

**Sub-Topic:** 3b. Social determinants and cancer disparities

**Background:** It has been long observed that African American patients were suffered disproportionately with more disadvantaged outcomes (e.g., higher incidence, recurrence, and mortality rate). The risk factors that may explain the racial disparities are from multilevel resources. It is important to identify and quantify the effects or risk factors that may explain the racial disparity, therefore inform caregivers and policy makers to design interventions to optimally reduce the disparities.

**Methods:** Mediation analysis is conducted to make inferences on effects of third-variables (e.g. mediators or confounders) that intervene the relationship between an exposure variable and an outcome. Bayesian mediation analysis (BMA) naturally considers the hierarchical structure of the effects from the exposure variable to third-variables and then to the outcome. We propose three BMA methods on survival outcomes, where third-variable effects are measured in terms of hazard rate, survival time, or log of survival time respectively. In addition, we set a limit to the survival time where infinite survival time is impossible. We validate the methods using simulations and check the precision of estimates at different scenarios. The three methods all give effective estimates. The methods are applied to the Surveillance, Epidemiology, and End Results Program (SEER) supported special studies to explore the racial disparity in breast cancer survival among Louisiana patients.

**Results:** The included variable completely explained the racial disparity in breast cancer survival. The 95% confidence intervals of the direct effect of race after adjusting for other risk factors from the three methods all include 0. Significant third-variables include age of diagnosis, insurance status, AJCC stage, breast cancer subtypes, poverty and completion of the first course of chemotherapy. We provide visual aids to help with the result interpretations.

**Conclusion:** The disproportional impact of breast cancer on AA patients can be partially reduced by providing more accessible screenings and adjuvant cares to AA patients.

# Breast Cancer Survival by Stage at Diagnosis in Countries in Transition: A Population-Based Study

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**Topic Area:** 3 - Epidemiologic Studies using Cancer Surveillance Data

**Sub-Topic:** 3b. Social determinants and cancer disparities

**Background:** Breast cancer is the most common cancer worldwide. Stage at diagnosis is an important prognostic factor for cancer survival. Yet, few benchmarking studies that include lower-income countries have investigated breast cancer survival by stage at diagnosis. The aim of this study is to explore variations in breast cancer survival by stage at diagnosis in transitioning countries.

**Methods:** This study used data from the SURVCAN-3 project which collects population-based cancer registry data from Africa, central and south America and Asia. Data were collected at patient-level, including stage information, vital status, date of death or end of follow-up on patients diagnosed between 2008-2012 from 65 jurisdictions in 31 countries. Registries that had 50% or more of staged breast cancer cases were included. Age-standardized 1-, 3- and 5-year net survival for non-metastatic, metastatic, and missing stage were calculated for each included registry (n=6). Additionally, based on data quality assessment and if the registry had more than 30 cases in each stage category, multiple imputation was used to reassign missing stage data. For these registries, age-standardized 1-, 3- and 5-year net survival were calculated by stage and country.

**Results:** Large variation in proportions of advanced disease across countries was seen, ranging from 4% (Algeria) to 18% (Bahrain) with metastatic breast cancer. Variation in survival across countries was less apparent in patients with early stage at diagnosis. Variation in breast cancer survival by stage at diagnosis and across countries was observed although differences were less apparent in patients with early stage at diagnosis. Across countries, consistently lower survival in India (Trivandrum) and higher survival in Ecuador (Quito) and Puerto Rico in patients with late stage at diagnosis was observed.

**Conclusion:** Survival from breast cancer varied across transitioning countries and was apparent within stage groups. These disparities can be due to earlier diagnosis contributing to earlier stage distributions in some countries. Differences in treatment could also impact variation in survival across countries. Stage information is an important prognostic indicator that cancer registries should be supported to collect to inform cancer control actions in countries.

# Cancer Among Maine Adolescent and Young Adult Population

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**Topic Area:** 3 - Epidemiologic Studies using Cancer Surveillance Data

**Sub-Topic:** 3a. Epidemiologic studies

**Background:** Cancers among the adolescent and young adult (AYA) populations are generally understudied, creating prevention, treatment, and outcome challenges. Risk-factors such as tobacco use, alcohol consumption, obesity, and physical activity among AYA may contribute to increased cancer risk in young adulthood and later in life. Understanding trends in cancer incidence, including for risk-factor associated cancers, among AYAs can help cancer prevention and control programs identify intervention opportunities.

**Methods:** Using 2001-2019 Maine Cancer Registry data, SEER\*Stat 8.4.01., and Joinpoint 4.9.1.0, we examined patterns and trends in Maine AYA cancer incidence rates by sex, age (15-39, 15-19, 20-29, and 30-39 years), and year. We examined cancer incidence overall as well as by site-specific (SEER AYA site recode, 2020 revision) and risk-associated cancer groupings.

**Results:** Overall cancer incidence rates among AYA have not significantly increased in Maine over the last two decades (2001-2019), however, sex-specific analyses show a different pattern. Male incidence rates among the 15-39 age group increased significantly from 2001-2011 but have remained relatively unchanged from 2011 to 2019. Female rates among the 15-39 group have increased, though only significantly among females 30-39. Trends in female AYA cancer incidence rates appear to be driven by breast and thyroid cancer. Rates among females 15-39 were nearly two times higher than those among males each year during this time period. Overall the most common cancers among Maine AYA were thyroid, female breast cancer, and lymphoma. Among adolescents and young adults, Maine has a higher rate of obesity, physical inactivity, alcohol, and tobacco-associated cancers than the U.S.

**Conclusion:** Cancer incidence rates were nearly twice as high among Maine AYA females than males, and rates among 30-39-year-old females significantly increased over the past two decades. Cancers associated with modifiable risk factors were higher among Maine AYA than the US. Information on risk-associated cancers may provide an opportunity for cancer prevention programs to educate and engage AYA in Maine.

# Cancer Cluster Investigation Concerning a Facility using Ethylene Oxide (EtO) in Shelby County, TN

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**Topic Area:** 2 - Big Ideas in Cancer Surveillance

**Sub-Topic:** 3a. Epidemiologic studies

A cancer cluster investigation was carried out by the Tennessee Department of Health in collaboration with the Shelby County Health Department to explore a potential cluster in Shelby County, TN, concerning a sterilization facility that uses Ethylene Oxide (EtO), a known carcinogen (International Agency for Research on Cancer (IARC), 2022; National Toxicology Program (NTP), 2021). The purpose of this cluster investigation was to evaluate if incidence rates were higher around the EtO facility. Age-adjusted incidence rates were calculated for cases diagnosed during two periods of time (2010-2019 and 2000-2009) with cancers that are associated with EtO exposure; Leukemia, Non-Hodgkin Lymphoma (NHL), Breast, or Stomach cancers (NTP, 2021). Spatial analyses in ArcGIS (spatial autocorrelations and hot spot analyses) and statistical group comparison analyses (Mann Whitney U tests) were performed to compare the age-adjusted incidence rates of the two groups of census tracts. The geospatial analyses and the group comparison statistical tests did not provide evidence that the EtO facility in Shelby County is associated with an increase in for Leukemia, NHL, Breast, or Stomach cancer incidence rates from 2010-2019 in a group of census tracts close in proximity to the facility when compared to a group of census tracts away from the facility. Although this study did not reveal evidence of higher cancer incidence rates associated with the facility, Memphis has historically experienced and continues to experience environmental injustices (Broshears & Bradley, 1992; Greene, et al., 2006; Johnson, 1996; Lee, 2019; Padilla, 2020). Stricter EPA regulations regarding EtO, which are currently being drafted, are necessary and will help better protect the health of individuals living and working near facilities using EtO (Blackman, 2022). The more quickly the regulations are updated to correspond with the new studies that reveal the true harmfulness of EtO, the closer Shelby County and other communities in the nation come to achieving environmental justice. Cancer cluster investigations face many challenges, but with CDC's 2022 publication of "Guidelines for Examining Unusual Patterns of Cancer and Environmental Concerns," and with the more regular practice of publishing cancer cluster investigations, the methodology and results of this type of study is improving.

# Cancer Distribution among Asian, Native Hawaiian, and Pacific Islander Subgroups — United States, 2015-2019

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**Topic Area:** 3 - Epidemiologic Studies using Cancer Surveillance Data

**Sub-Topic:** 3a. Epidemiologic studies

**Background:** Asian persons and Native Hawaiian and Pacific Islander (NHPI) persons represent growing segments of the U.S. population. Although revisions to the standards for the classification of Federal Data on Race and Ethnicity includes separate categories for “Asian” and “Native Hawaiian or Other Pacific Islander” persons, epidemiologic cancer studies have often aggregated Asian and NHPI people into one racial group. Cancer distribution may be different among culturally, geographically, and linguistically diverse people and subgroup data might be useful in addressing these health disparities.

**Purpose:** To examine the frequency and percentage of cancer incidence among non-Hispanic Asian and NHPI subgroups.

**Methods:** Using U.S. Cancer Statistics incidence data from 2015-2019, this study reports the frequency and percentages of invasive cancers among 25 non-Hispanic Asian and NHPI subgroups by: sex and age; the ten most common cancer types; and stage for four screenable cancer types.

**Results:** This report found distribution of cancers among non-Hispanic Asians and NHPI subgroups varied by sex, age, cancer type, and stage at diagnosis.

More than half of cancer cases among non-Hispanic Asian (56.2%) and NHPI (56.5%) persons were diagnosed in females and almost 10% of the cases occurred among those younger than 40 years (8.5% and 9.6%). Across subgroups, the highest percentages of new cancer cases among non-Hispanic females were seen in Tahitian (68.2%), Thai (65.5%), and Fiji Islander (65.1%) women. New cancer cases in non-Hispanic persons younger than 40 years were highest among Hmong (20.2%), Micronesian, not otherwise specified (NOS) (18.1%), and Melanesian, NOS persons (15.7%). Non-Hispanic Japanese persons accounted for the lowest percentage of new cancer cases for those under 40 (3.1%).

Breast cancer made up the highest proportion of new cancer diagnoses among 19 of the 25 non-Hispanic Asian and NHPI subgroups.

Late-stage cancer diagnoses among 7 out of the 10 non-Hispanic Asian and NHPI subgroups were reported in approximately at least a third of female breast, half of cervical, and three-fifths of colorectal cancers.

**Conclusions:** Understanding cancer distribution among non-Hispanic Asian and NHPI subgroups can guide development and implementation of culturally and linguistically relevant programs addressing health disparities and social determinants of health.

# Cancer Surveillance Data Modernization: Pilot Testing Cancer Registry Reporting Form EHRs

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**Topic Area:** 4 - New Directions and IT Solutions

**Sub-Topic:** 4b. New and emerging methods of data collection

**Background:** Making Electronic Data More Available for Research and Public Health (MedMorph), is a multi-partner effort to create a standard common framework and methodology for automated electronic reporting. It builds on modern health IT standards such as HL7® FHIR®. MedMorph provides a standard resource, the Reference Architecture Implementation Guide (RA IG), addressing data exchange needs with a common, streamlined approach.

The MedMorph Cancer Use Case focuses on transmission of cancer information from EHRs to Central Cancer Registries (CCRs). Cancer-specific data elements meeting NAACCR Volume II cancer reporting requirements are defined in the Central Cancer Registry Reporting IG (CCRR IG). The CCRR IG aligns with US Core, US Public Health Library, and mCODE profiles. The MedMorph RA IG, together with the CCRR IG can be used to facilitate automated, electronic reporting of cancer information.

**Purpose:** This project conducts pilot implementations of cancer reporting from healthcare organization EHRs to CCRs using the MedMorph RA and CCRR IGs to report cancer information automatically to CCRs.

**Methods:** The pilot will consist of three ambulatory clinical sites with different EHRs to implement the MedMorph architecture in their EHR system and two CCRs to receive and process the cancer reports. System actors and workflows that will be tested in the pilot are detailed in the MedMorph RA IG, and cancer reporting requirements are detailed in the CCRR IG. The pilot includes implementation, testing, and refinement of the workflows and actors listed in these IGs.

**Results:** The presentation will detail the CDC/NPCR data modernization effort to increase cancer surveillance interoperability and automated data exchange between EHRs and CCRs.

**Conclusions:** Automated, electronic reporting from EHRs in clinical settings can be captured and exchanged in real-time, with the potential to speed up the CCR process of creating cancer abstracts and provide more timely incidence data to public health. More timely and complete data enable public health to better measure successes in prevention, screening, and survivorship.

# Can You Reduce DCO Cases with Follow-Back to Hospice?

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**Topic Area:** 6 - Data Collection, Tools and Operations

**Sub-Topic:** 6b. Innovative operations and procedures

**Background:** The CDC NPCR and NAACCR have specific data requirements for meeting Registry of Excellence (CDC NPCR) and Gold Standard (NAACCR). One of the requirements pertains to Death Clearance Only (DCO) cases. Both agencies require DCO only cases be below 3%. Routinely, RI's DCO percent ranges from 1.74%-2.48%. Although we are under the 3%, we would like to be closer to 1.5% or lower. After reviewing the NAACCR Death Clearance Manual, we have changed some methods of follow-back, specifically when a resident dies in the state catchment area but was a resident from another catchment area.

**Purpose:** Decrease the percent of DCO only cases in RI

## Method:

1. Review all cases linked with state vitals from death years 2016-2020.
2. Provide the number of abstracts RI reviews at the state vitals office yearly.
3. Provide the number of abstracts that we send to reporting facilities in RI and the hospice facility for follow-back information.
4. After reviewing the follow-back information from noted facilities, specifically hospice, the decrease in DCO only percentage per year will be calculated again.

**Results:** After thoroughly reviewing the NAACCR Death Clearance Manual and performing follow-back to hospice, RI Central Registry was able to remove many residents that passed in RI but lived outside the catchment area. RI was also able to update information from follow-back to hospitals and the hospice facility. During our review of all DCO cases in RI, we have found that, on average, 20% of these cases were noted as deceased at our hospice facility or hospice at home. The RI central registry plans to show how conducting follow-back to hospice, our DCO only percentage will be well under 3% and closer to the 1.5% we are targeting.



# Causes of Death Among Massachusetts Cancer Registry Cases in 2019 and 2020

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**Topic Area:** 3 - Epidemiologic Studies using Cancer Surveillance Data

**Sub-Topic:** 3a. Epidemiologic studies

**Objectives:** To examine differences in causes of death among Massachusetts residents in the Massachusetts Cancer Registry (MCR) who died from 2019-2020.

**Methods:** Differences in all causes of deaths in 2019 and 2020 for all cancer sites and selected cancers in the MCR were examined by total cases and by race/ethnicity. Comparisons between 2019 and 2020 were made by looking at time from diagnosis to death and mean age at death for all cancer sites and the selected cancers. The distribution of cancer types who died of COVID-19 in 2020 was compared with those who died of other causes.

**Results:** There was an increase in deaths among MCR cancer cases from 25,963 in 2019 to 27,888 in 2020. While there was a decrease in cancer as an underlying cause of death (-308 deaths), this was offset by COVID-19 deaths (2,026) and smaller increases in influenza/pneumonia deaths (68) and other causes. Increases in death occurred across race/ethnicity groups. The percentages of the 2,026 COVID deaths in the MCR with a history of prostate and breast cancer (20% and 15%, respectively) were higher than the non COVID deaths in the MCR (12% and 11%), likely the result of older people diagnosed with these cancers for many years. The mean age of COVID deaths in the MCR was 83, while for prostate and breast it was 82 and 80, respectively. There were no significant differences in the mean age at death from 2019-2020 for the selected cancers. There was a slight increase in deaths for cases diagnosed more than 5 years before death, likely related to these cases being older on average (81) than cases diagnosed within 5 years of death (75).

**Conclusions:** The mortality increase among cancer cases from 2019-2020 is mostly attributed to COVID-19. Since cancer cases are older and COVID-19 mortality was related to advanced age, this likely affected the rise in deaths, but other factors may be present. Further analyses will be done to examine specific cancers, age groups, race/ethnic groups, and time since diagnosis and chemotherapy treatment and their association with increased death from 2019-2020.

# Changes in Lung Cancer Stage at Diagnosis by Age, Sex, Race, and Ethnicity Following 2013 Recommendations for Low-Dose Spiral Computed Tomography Screening

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**Topic Area:** 3 - Epidemiologic Studies using Cancer Surveillance Data

**Sub-Topic:** 3a. Epidemiologic studies

**Background:** Increased incidence of early-stage lung cancer is partly attributed to uptake of screening, first recommended in 2013 for high-risk individuals ages 55-79 years. How this stage shift differs by major demographic characteristics is unknown.

**Purpose:** Examine temporal patterns in lung cancer stage at diagnosis by age, sex, and race/ethnicity.

**Methods:** Age- and delay-adjusted incidence rates during 2004-2019 were obtained from a custom NAACCR database and stratified by stage at diagnosis (localized, regional, distant, unknown); sex; age (20-54, 55-79, 80+ years); and race/ethnicity (non-Hispanic [NH] White, NH Black, NH American Indian and Alaska Native [AIAN], NH Asian American and Pacific Islander [AAPI], Hispanic). Changes in stage at diagnosis during 2007-2013 and 2013-2019 were quantified using incidence rate ratios (IRR) with 95% confidence intervals (CI).

**Results:** Localized stage lung cancer incidence decreased from 2007-2013 (IRR[2013 versus 2007] 0.97, 95%CI, 0.95-0.98), then increased from 2013-2019 (IRR[2019 versus 2013] 1.22, 95%CI, 1.21-1.24). The increase was confined to ages 55+ years and of similar magnitude in ages 55-79 (IRR 1.25, 95%CI, 1.23-1.27) and 80+ (IRR 1.22, 95%CI, 1.19-1.26). IRRs were larger among women than men in both age groups (e.g., 1.29 versus 1.20 in ages 55-79) and all racial/ethnic groups (some differences not statistically significant). These increases perpetuate the higher percent of localized disease among women (22% and 30% in 2013 and 2019, respectively, versus 18% and 25% for men). IRRs were statistically similar by racial and ethnic group except for stable rates among Hispanic men ages 55+ years, Hispanic women ages 80+, and NHAIAN men ages 55-79. Data were insufficient to analyze NHAIAN individuals ages 80+.

**Conclusions/Implications:** After previously decreasing, localized stage lung cancer incidence increased from 2013-2019 similarly among those who met screening guideline age criteria and among older individuals, likely reflecting screening exposure beyond the recommended age. Larger increases among women compared to men may reflect greater access to care and/or exposure to screening. Increasing screening uptake, particularly for under-resourced populations, will further improve stage at diagnosis.

# Clinical and Demographic Predictors of New Jersey Participation in the RESPOND Study, A Population-Based Prostate Cancer Study

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**Topic Area:** 3 - Epidemiologic Studies using Cancer Surveillance Data

**Sub-Topic:** 3b. Social determinants and cancer disparities

**Background:** The Research on Prostate Cancer in Men of African Ancestry: Defining the Roles of Genetics, Tumor Markers and Social Stress (RESPOND) Study is an ongoing large population-based study designed to evaluate risk factors for prostate cancer in African American men throughout the United States, including New Jersey. Participation in the initial phase involves completing a paper-based or online web-based survey.

**Purpose:** To evaluate predictors of participation in the initial phase of the RESPOND study in New Jersey, and to compare paper-based survey participants to those who completed their surveys online.

**Methods:** Eligible cases were identified and recruited through the New Jersey State Cancer Registry. To compare demographic and clinical factors of patients who completed the survey with refusers and to compare patients who completed online surveys to those who completed paper surveys, logistic regression models in SAS were used to calculate odds ratios (OR) and 95% confidence intervals (CI).

**Results:** A total of 675 patients have completed surveys (585 paper and 90 online), and 836 refused (442 active, 365 passive, and 29 gatekeeper refusals). The participants did not differ significantly from the refusers by age, stage at diagnosis, or census tract poverty level. Patients diagnosed with grade 1 prostate cancer were 36% more likely to complete the survey than those with grades 2 or 3 cancer (OR=1.36, 95%CI: 1.03-1.79). Younger participants diagnosed at age 40-49 were 8.34 times more likely to complete online surveys than older participants diagnosed at age 70+ (95%CI: 2.48-28.09). Participants residing in census tracts with higher poverty levels were less likely to select the online option than those in wealthier census tracts (poverty level 20%+: OR=0.46, 95% CI: 0.22-0.94; poverty level 10-19%: OR=0.47, 95%CI: 0.25-0.90).

**Conclusions:** Though a considerable amount of resources are invested into conducting population-based studies, recruitment remains a challenge. These findings may help to formulate better recruitment and survey design strategies in future research studies.

# Contribution of Hormone Receptor Status and Stage at Diagnosis to the Black-White Breast Cancer Mortality Disparity, US

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**Topic Area:** 3 - Epidemiologic Studies using Cancer Surveillance Data

**Sub-Topic:** 3a. Epidemiologic studies

**Background:** Over the past decade, breast cancer mortality has remained 40% higher in Black than White women despite similarly declining trends and comparable incidence rates. Approximately 60% of the death rate disparity has been attributed to hormone receptor (HR) negative breast cancer, however, the contribution of HR status and stage at diagnosis is unknown. We estimated the contribution of HR status and stage to the contemporary Black-White breast cancer mortality disparity among women.

**Methods:** We used the Surveillance, Epidemiology, and End Results (SEER) program incidence-based mortality database to analyze Black and White adult women in 17 SEER areas diagnosed with breast cancer during 2000-2019 and died during 2017-2019. HR status, positive or negative, was assigned for approximately 10% of White women and 8% of Black women with missing HR status using a simple two-step imputation. Incidence-based breast cancer death rates were calculated by race, hormone receptor (HR) status, and stage at diagnosis. The contribution to disparity was estimated as the proportion of the absolute difference between the Black and White incidence-based mortality rates for each combination of HR status and stage.

**Results:** Among women diagnosed during 2000-2019, the incidence-based breast cancer mortality rate during 2017-2019 was 10.5 per 100,000 higher in Black women (35.3) than White women (24.8). Separately, the largest contribution to this disparity were for HR-negative (7.2 per 100,000 higher in Black women, 68.0% of total disparity) and regional-stage disease (5.0 per 100,000 higher in Black women, 47.6% of total disparity). Combined, HR-negative breast cancers diagnosed at a regional-stage contributed the most to the total Black-White disparity (3.5 per 100,000 higher in Black women, 32.8% of total disparity) followed by distant stage HR-negative disease (1.9 per 100,000 higher in Black women, 17.8% of total disparity). There was no significant difference for HR-positive breast cancer diagnosed at a localized stage.

**Conclusion:** Overall, the largest contributor to the absolute difference between Black and White breast cancer mortality were HR-negative breast cancers diagnosed at regional-stage. More efforts are needed to understand the underlying factors of why disparities remain between Black and White women diagnosed with similar breast cancers and stages.

# Cryptogenic Stroke Patients with Active Cancer: Characteristics, Treatment and Outcomes Using Population Based Registries

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**Topic Area:** 3 - Epidemiologic Studies using Cancer Surveillance Data

**Sub-Topic:** 3a. Epidemiologic studies

**Background:** The objective of our study was to evaluate the frequency, predictors, and outcomes of cryptogenic stroke (CS) patients with malignancy.

**Methods:** We linked data from the Georgia Coverdell Acute Stroke Registry from 2017-2019 and the Georgia Cancer Registry from 2016-2019 for a population based cross-sectional study; to determine the frequency, treatment, and outcomes of CS patients who were newly diagnosed with active cancer within one year before and after the CS. We compared baseline characteristics and outcomes of patients with active cancer (CS+) versus patients without active cancer (CS-).

**Results:** Of the 3,686 CS patients, 145 (4%) were CS+ of which 90 (62%) were diagnosed with stroke after cancer diagnosis (median 79 days). The top 3 cancers among patients with cryptogenic strokes were lung (37/145, 26%), pancreas (16/145, 11%), and other malignancies (14/145, 10%). Compared with CS- patients, CS+ had more venous thromboembolism (VTE) history (6% vs 1%,  $p = 0.0001$ ), less hypertension (68% vs 77%,  $p = 0.009$ ) and diabetes (28% vs 37%,  $p = 0.028$ ). Also, CS+ patients were less likely to receive IV tPA (9.7% vs 15.6%,  $p=0.059$ ); more likely to undergo Mechanical Thrombectomy (9% vs 4%,  $p=0.004$ ); less likely to be discharged with antiplatelets (84% vs 95%,  $p < 0.001$ ); more likely to be discharged with anticoagulants (23% vs 11%,  $p < 0.001$ ); and more likely to be discharged on both antiplatelet and anticoagulant therapies (13% vs 6%,  $p = 0.006$ ) than CS- patients. CS+ patients were less likely to be discharged home (49% vs 61%) and skilled nursing or rehabilitation facilities (26% vs 33%) but more likely to be sent to hospice or expire (23% vs 4%,  $p < 0.001$ ).

**Conclusions:** Only 4% of CS patients had active malignancy and were more likely to have a history of VTE. Active malignancy patients were less likely to receive IV tPA but more likely to undergo thrombectomy. Given nearly half of CS+ patients were discharged home, further study is needed to refine recommendations on antithrombotic and revascularization therapy in these patients.

# Did COVID-19 Impact how Caregivers Received Cancer Screening? Results from a National Level Study in 2018 and 2020

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**Topic Area:** 1 - Effects of Covid-19 on Cancer Surveillance and Operations

**Purpose:** Informal caregiving is the underrecognized backbone to healthcare with 1/5 Americans falling into the category. With an aging population on the rise and healthcare worker shortages, it is important to uncover the challenges caregivers face. This study examines the relationship between caregiver status and their screening for cervical, colorectal, female breast, and prostate cancer using data from the BRFSS 2018&2020 study. The purpose is to investigate whether Covid-19 impacted caregiver behavior as to whether cancer screening was utilized in accordance with USPSTF recommendations in comparison to a pre-pandemic year.

**Methods:** Data from the BRFSS 2018&2020 study was used to perform weighted multivariable logistic regression analyses to investigate the association between being a caregiver for a friend/family member who has a health problem/disability, and getting screened for cancer, by corresponding screening age recommendations. US adults ages 18-79, without a prior cancer diagnosis, were included in the study. A subgroup analysis was performed by year of study, to investigate this association before and during the COVID-19 pandemic. After a DAG evaluation, adjustment was made for age, race, education, employment, income, health insurance, marital status, smoking, heavy drinking, obesity, and depression.

**Results:** In 2020, among females, the weighted and adjusted odds (WAO) of screening for cervical cancer were 2.25x significantly greater (95%CI: 1.38-3.64) and for colorectal cancer were 1.32x significantly greater (95%CI: 1.01-1.71) in those who were caregivers compared to those who were not. In 2020, among males, the WAO of screening for prostate cancer were 1.27x marginally significantly greater (95%CI: 0.94-1.70) in those who were caregivers compared to those who were not. These associations were not significant in 2018. There were no significant associations between caregiver status and their screening for male colorectal and female breast cancer, in either 2018 or 2020.

**Conclusion:** Despite the burden caregivers face, their screening odds for cancer in 2020 - the COVID-19 pandemic year, were significantly higher than those of non-caregivers regarding female colorectal, cervical, and prostate cancer. These associations were non-significant in the pre-pandemic year 2018. This COVID-19 pandemic significantly impacted how caregivers addressed the importance of cancer screening.

# Differences in Lung Cancer Incidence by U.S. Sociodemographic and Geographic Characteristics

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**Topic Area:** 3 - Epidemiologic Studies using Cancer Surveillance Data

**Sub-Topic:** 3b. Social determinants and cancer disparities

**Background:** Most lung cancers can be attributed to modifiable exposures, such as tobacco use, secondhand smoke, radon, and asbestos. Some groups have more exposure to these risk factors than others, which in turn might affect lung cancer rates. This study provides recent estimates of lung cancer incidence by sociodemographic and geographic characteristics.

**Methods:** Using high-quality data from U.S. Cancer Statistics, covering 99% of the U.S. population, we calculated age-adjusted lung cancer incidence rates in 2019. We examined differences in lung cancer incidence by individual demographic characteristics (sex, race and ethnicity [Hispanic, non-Hispanic (NH) American and Indian Alaska Native, NH Asian and Pacific Islander, NH Black, and NH White]), county-level sociodemographic characteristics (poverty, income, and educational attainment; categorizing county using estimates from the American Community Survey), and geographic characteristics (state and urbanicity [categorizing county as metropolitan or nonmetropolitan using U.S. Department of Agriculture 2013 rural-urban continuum codes]).

**Results:** In 2019, lung cancer incidence was higher among males (59 cases per standard 100,000 population) than females (48) and among non-Hispanic White persons (57) than other racial and ethnic groups (ranging from 28 to 55 cases/100,000). At the county level, lung cancer incidence was highest in counties with the largest percentage of families living in poverty (58 vs 49 in lowest group), largest percentage of residents without a 4-year college degree (62 vs 47 in lowest group), lowest household income (61 vs 46 in highest group), and in nonmetropolitan areas (63 vs 51 in metropolitan areas). By state, lung cancer incidence varied 3-fold from 26 to 83 cases/100,000.

**Conclusions:** Our data suggest that absolute differences in lung cancer incidence by state were larger than differences by individual or county-level sociodemographic characteristics. These differences correspond to differences in cigarette smoking prevalence and cessation rates, which are influenced by state-wide policies such as tobacco excise taxes and comprehensive coverage of proven cessation treatments. Lung cancer incidence can be reduced by ensuring that cancer prevention and control policies reach all population groups equally, and disparities in incidence may be diminished by working with communities with high burden to implement focused interventions.

# Disparities in Liver Cancer Incidence and Mortality in Massachusetts, 2015-2019

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**Topic Area:** 3 - Epidemiologic Studies using Cancer Surveillance Data

**Sub-Topic:** 3a. Epidemiologic studies

**Purpose:** To produce a data report that describes disparities in liver cancer incidence and mortality in Massachusetts with a focus on Asian non-Hispanics (NHs). The report will also highlight current prevention efforts to address the high incidence and mortality of liver cancer in Massachusetts.

**Methods:** Descriptive statistics on liver cancer in Massachusetts were summarized for 2015-2019 by the following: 1) incidence and mortality rates by race/ethnicity, sex, and age; 2) joinpoint regression for long term trends (2000-2019), and comparisons to national rates.

**Results:** Although overall cancer incidence and mortality rates in Massachusetts are generally significantly lower among Asian NHs compared to White NHs, liver cancer incidence and mortality were significantly higher among Asian NHs than White NHs. Between 2015 and 2019, the liver cancer incidence rate in Asian NHs was 15.9 per 100,000 compared to 7.7 per 100,000 among White NHs. Liver cancer mortality was also significantly elevated among Asian NHs compared to White NHs (9.3 per 100,000 vs. 5.8 per 100,000). Liver cancer incidence rates were over 3 times higher in males than in females, with incidence rates of 14.1 and 4.3 per 100,000 in males and females respectively. Similarly, liver cancer mortality rates were significantly higher among males compared to females (9.7 per 100,000 vs. 3.6 per 100,000). Overall liver cancer incidence and mortality rates were similar between Massachusetts and the United States during this period. Liver cancer incidence rates increased while mortality rates remained unchanged in Massachusetts between 2015-2019.

**Implications:** Producing an in-depth data report on liver cancer disparities helps to identify and highlight specific liver cancer related issues such as high incidence and mortality rates among males in Massachusetts that may not be obvious when focusing on the usual leading causes of cancer. The report will include liver cancer risk factors such as hepatitis B and C, alcohol and tobacco use, and being overweight. In addition, the report will highlight possible ways of addressing liver cancer disparities in Massachusetts.



# Early Ascertainment of Breast Cancer Diagnoses Comparing Self-Reported Questionnaires and Electronic Health Record Data Warehouse: The WISDOM Study

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**Topic Area:** 6 - Data Collection, Tools and Operations

**Sub-Topic:** 2b. How to make cancer data more timely

**Purpose:** The study goal was to use real-world data sources that may be faster and more complete than self-reported data alone, and timelier than cancer registries, to ascertain breast cancer cases in the national, ongoing screening trial, the WISDOM Study, to best inform bi-annual study safety monitoring analyses.

**Methods:** We developed a data warehouse procedural process (DWPP) to identify breast cancer cases from a subgroup of WISDOM participants (N=11,314) who received breast-related care from a University of California Health Center in the period 2012-2021 by searching electronic health records in the University of California Data Warehouse. Incident breast cancer diagnoses identified by the DWPP were compared to those identified by self-report via annual follow-up online questionnaires.

**Results:** This cohort included 11,314 enrolled WISDOM participants who self-reported care at a UC and had at least one diagnostic or procedural breast care code. Among these participants, 160 had an ICD10CM C50 breast cancer diagnostic code of which 132 breast cancer cases were confirmed: 111 were already self-reported through WISDOM and 21 additional confirmed breast cancer cases were identified through the UCDW. As a standard process, only WISDOM self-reported cancer cases confirmed by chart review are entered into the study database. The percentage of confirmed UCDW-identified cases that were not also self-reported was greater for recent diagnoses (16% overall and 6% for period prior to June 2020).

**Discussion/Conclusion:** Self-reported data provides quick ascertainment with relative accuracy compared to cancer registry. Cancer ascertainment can be further improved by combining self-reported data with EHR data from a health system data warehouse registry, particularly for self-reported questionnaire issues such as timing and lack of response. Accuracy of self-reported cancer diagnosis from annually distributed questionnaires improves over time. While cancer registry reporting often is not as timely, it does not require verification as does the DWPP or self-report from annual questionnaires. While the purpose of this data warehouse linkage was rapid cancer case ascertainment, WISDOM is one of the first studies selected to link to the NAACCR registry, which will support our critical study objective to capture all breast cancer diagnoses among WISDOM participants nationally.

# Evaluation of Excess Cancer Incidence in Long Beach Port Area

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**Topic Area:** 3 - Epidemiologic Studies using Cancer Surveillance Data

**Sub-Topic:** 3a. Epidemiologic studies

**Background:** Outdoor air pollution is an established carcinogen and has been associated with increased cancer incidence and mortality. Residents near the port of Long Beach have been exposed to elevated levels of carcinogenic diesel exhaust and particulate matters. Since the Los Angeles Cancer Surveillance Program (CSP) documented elevated incidence of certain cancers in census tracts along the I-710 freeway near the port of Long Beach, scientific research studies and subsequent policy changes resulted in improvement in air quality in this area. However, updated cancer statistics taking into account racial-ethnic differences in this area have not been published.

**Purpose:** We aim to evaluate secular trends in risks of site-specific cancer in the census tracts near the port of Long Beach compared to the general population of the Los Angeles County (LAC).

**Methods:** We will use the CSP data (1990-2019) and calculate the standardized incidence ratio (SIR) and age-adjusted incidence rates for each cancer site by sex, racial/ethnic group, and time periods between 1990-2019. To describe any changes in demographic and health-related characteristics of the residents during this time period, we will analyze the data from publicly available community survey data such as the American Community Survey and the California Health Interview Survey.

**Results:** We will generate graphs and summary tables reporting on the SIR and incidence rates over time and population characteristics.

**Conclusion:** We will discuss the updated cancer incidence trends in the areas near the port of Long Beach by sex, racial/ethnic subgroup, and time period.

# Evaluation of Melanoma and Bladder Cancers in New Hampshire to Identify Registrar Training Needs

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**Topic Area:** 6 - Data Collection, Tools and Operations

**Sub-Topic:** 6a. Data quality control and standards

**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.

**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.

**Results.** Accuracy rates will be 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*.

**Discussion.** Results from the recoding audit will be used to address training needs for New Hampshire registrar.

# Exploration of Electronic Pathology for 12-Month Cancer Incident Reporting

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**Topic Area:** 2 - Big Ideas in Cancer Surveillance

**Sub-Topic:** 2b. How to make cancer data more timely

Recent efforts to make better use of 12-month cancer incident reporting have been made by the National Program of Cancer Registries (NPCR), so that cancer data are available to the public earlier than the conventional 2-year timeframe. In New Hampshire (NH), brief rapid reports are required by state law within 45 days of diagnosis for every case. We have previously assessed the reliability of these rapid reports when compared to definitive reports but have not assessed the utility of electronic pathology reports as a source of rapid casefinding. Potential limitations of 12-month data include lack of completeness. In recent years, completeness is even lower than usual due to national delays in implementing NAACCR v18 and the COVID-19 pandemic. The American College of Surgeons Commission on Cancer (CoC) has recently implemented rapid reporting, but CoC only covers 70% of hospitals nationwide. However, with the rise in electronic-Pathology (ePath) transmissions and their increased reporting capabilities, ePath may represent a resource that could generate data on cancer incidence within 12 months. Within the scope of NAACCR cancer records, the following variables are needed to meet the basic requirements for NH rapid case reporting: histology & behavior; primary tumor site; patient demographics including age, gender, race; and date and place of diagnosis. In this poster presentation, we will explore the feasibility of identifying the critical core variables in a timely manner using only ePath relative to standard NH rapid and definitive reports using samples of data from several hospital laboratories and cancer registries. Our approach will a) consider data structure and database capacity to meet 12-month reporting using the ePath database and processing tool known as eMaRC, and b) assess ePath data completeness with respect to the critical core variables, necessary to meet the reporting goals outlined above.

# Florida Trends in Melanoma Cancer 2015-2019

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**Topic Area:** 7 - Other Relevant Topics

**Sub-Topic:** 3b. Social determinants and cancer disparities

**Background:** Skin cancer is the most common form of cancer in the United States (U.S.). Melanoma is a type of skin cancer that develops when melanocytes grow out of control. From 2015-2019, 427,935 new cases of Melanomas of the skin were reported in the U.S. Melanoma rates have been rapidly increasing over the past few decades, perhaps due to an aging population. The exact cause of all melanomas is not known, although exposure to ultraviolet (UV) radiation from sunlight or tanning lamps is likely to increase risk of developing this specific cancer. Melanoma rates have been rapidly increasing over the past few decades, especially in Non-Hispanic Whites over the age of 50.

**Methods:** Using 2015-2019 data from the Florida Cancer Data System (FCDS), age-adjusted rates of melanoma were compared by race, sex and age to examine disparities in incidence and identify trends at diagnosis. Analyses were limited to Non-Hispanic Whites, Non-Hispanic Blacks, and Hispanics of all ages for 2015-2019. Statical analyses were done using Microsoft Excel and JoinPoint Regression Program 4.9 to look at Annual Percent of Change (APC). Statistically significant differences ( $p < 0.05$ ) are presented below.

**Results:** Between 2015-2019, 35,434 Floridians were diagnosed with melanoma. This population included 32,587 (92%) Non-Hispanic Whites, 197 (1%) Non-Hispanic Blacks, 938 (2%) Hispanics, 1534 (4%) Unknown, and 178 (1%) other. Non-Hispanic White men and Non-Hispanic White women 50 and older made up 82% of Melanoma cases in Florida. Non-Hispanic White males 50 and older had the highest incidence of 140.6 per 100,000 compared to Non-Hispanic White women, with an incidence of 65.8 per 100,000. Based on the JoinPoint analysis, Non-Hispanic White women have a higher APC (4.8%) than Non-Hispanic White men (2.4%). APC over the 5-year range is significant.

**Conclusions:** Consistent with national findings, Non-Hispanic Whites in Florida were more frequently diagnosed with Melanoma compared to any other demographic (especially for men over age 50). These findings provide important information to state partners working to reduce barriers to screenings and to provide educational outreach with the intent of improving early detection of melanoma cancer and decreasing mortality among Non-Hispanic White men and women.

# HPV Vaccination Utilization in Patients Diagnosed with Pre-Invasive Cervical Lesions (CIN3) in Louisiana

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**Topic Area:** 6 - Data Collection, Tools and Operations

**Background:** Central cancer registries stopped routine collection of pre-invasive cervical lesions (CIN3) in 1996, The Louisiana Tumor Registry (LTR) was funded for the CDC-NPCR CIN-3 Surveillance Pilot Project in 2011-2022, aiming to assess the impact of HPV vaccination programs on cervical cancer diagnoses. Although LTR has utilized the Louisiana statewide vaccination database (LINKS) since 2015, vaccination status was never a required data item for this project.

**Purpose:** To test the feasibility of assessing vaccination utilization in the cohort of individuals diagnosed with CIN3 in Louisiana by linking LTR data with LINKS and to begin evaluating the effectiveness of HPV vaccination programs within Louisiana.

**Approach:** The Louisiana Dept. of Health (LDH) provided LTR view-only access to the web-based LINKS in 2015. Due to limited resources, an additional file for linkage was unavailable. LTR staff manually searched women born after 1979 diagnosed with CIN3 in 2016 through 2020 using name, date of birth, and social security number, to coincide with dosing guidelines for Gardasil Quadrivalent when released in 2006. HPV vaccination-specific data items were added to the LTR database. These included if the patient was found in LINKS as well as brand name of vaccine and up to 3 vaccine administered dates. A system to record two separate HPV vaccinations was included in the event that two series were administered.

**Results:** LTR identified n=5,472 vaccine age women with a diagnosis of CIN3 in 2016-2020 and 86.3% were found to have a patient profile in LINKS. An HPV vaccine was received in n=1,107 (20.23%) of these women. Further, individuals that began the quadrivalent series at least a year prior to diagnosis increased from 9.66% in 2016 to 18.25% in 2020. Gardasil 9 replaced the quadrivalent in 2017, and we observed n=168 (15%) of the vaccinated receiving HPV vaccine in the year of CIN diagnosis. It will require more time to collect and analyze the effects of vaccination on our patient population due to this overlap.

**Conclusion:** This endeavor was successful, and future analysis will examine the differences in CIN3 diagnosis in individuals who received the quadrivalent vs. the newer 9-valent HPV vaccine as well as explore the effects of adherence to dosing and timing guidelines.

# Impact of Hispanic Ethnicity Text Literals from Death Certificate Records on Hispanic Subpopulation Classification and Mortality Rates in New York State

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**Topic Area:** 6 - Data Collection, Tools and Operations

**Sub-Topic:** 6b. Innovative operations and procedures

**Background:** New York State's (NYS) Hispanic population is both large, representing approximately 19% of the state's population, and diverse, reflecting changes in immigration patterns over time. Ethnicity data are often used by cancer registries to identify and seek to reduce cancer burden disparities across population groups. However, registry data on ethnicity are often incomplete. To help address this issue, the NYS Cancer Registry (NYSCR) uses death certificate information to reclassify individuals with unknown or unspecified Hispanic ethnicity. The standard U.S. death certificate includes data elements for non-Hispanic, Mexican, Puerto Rican, Cuban, and other Hispanic, but also includes space to specify text for other Hispanic individuals, which had not previously been used for Hispanic origin coding in the NYSCR. In this project, we explored the use of these Hispanic text literals to improve NYSCR data on Hispanic ethnicity and mortality rates by Hispanic subpopulation.

**Methods:** We collected all available Hispanic text literals from 519,971 NYS death certificates from 2018-2020 and manually assigned a NAACCR standard Hispanic origin code value to each literal. We used this crosswalk table to incorporate the Hispanic literals into our existing Hispanic coding rules, and iteratively tested and finalized the crosswalk table. Using SAS 9.4 and American Community Survey 2019 one-year population data, we calculated crude mortality rates by Hispanic subpopulation before and after incorporating the Hispanic literals, and calculated the percent change in mortality rate for all cancers combined and for several common cancer sites.

**Results:** Of 99,840 deaths attributed to cancer, 4,756 had a Hispanic literal and 478 (10.1%) of these resulted in a change to Hispanic origin. Incorporating the Hispanic literals resulted in increases in the all-cancer mortality rate of 14.6% for Dominican, 7.2% for South/Central American, and 0.1% for Puerto Rican subpopulations, decreases in the mortality rate of 41% for other Hispanic/Latino and 0.5% for Mexican subpopulations, and no change for the Cuban subpopulation.

**Conclusion:** By improving the accuracy of this data item, we are better able to identify differences in cancer mortality across Hispanic subpopulations, which can help inform programs to reduce the cancer burden and cancer disparities in NYS.

# Impact of COVID-19 Pandemic on Cancer Incidence in California in 2020

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**Topic Area:** 1 - Effects of Covid-19 on Cancer Surveillance and Operations

**Sub-Topic:** 3a. Epidemiologic studies

**Background:** Early cancer diagnosis improves treatment outcomes and reduces morbidity and mortality. However, during the COVID-19 pandemic beginning in 2020, access to cancer screening and in-person healthcare dropped precipitously, leaving many individuals vulnerable to later-stage cancer diagnosis. It is imperative to characterize the gap between observed and expected cancer incidence, identify potential disparities in pandemic-related underdiagnosis, and identify those most vulnerable to delayed diagnosis.

**Purpose:** To quantify the reduction of cancers diagnosed in California in 2020 and to identify characteristics of subgroups most vulnerable to pandemic-related underdiagnosis for screening-detectable cancer sites.

**Methods:** Using California Cancer Registry (CCR) data and estimated cancer counts from the American Cancer Society, we calculated observed-to-expected (O/E) ratios, with associated 95% confidence intervals, for 21 common cancer sites. Among screening-detectable cancer sites, including cervical, breast, colorectal, and melanoma, trends in incidence and mortality from 2006-2020 will be assessed by sociodemographic characteristics.

**Results:** Among 21 common cancer sites, 18 had lower incidence than expected, with significantly lower O/E ratios ranging from 44.6% to 94.5%. Cancer sites with the lowest O/E ratios included colorectal (44.6%, CI: 43.6, 45.7), urinary bladder (46.3%, CI: 44.8, 47.9), and oral cavity and pharynx (54.3%, CI: 52.8, 55.9). Sites for which incidence was not significantly different than expected included larynx, esophagus, and prostate.

**Conclusions:** The incidence of many cancers was significantly lower than expected in California in 2020. The sites with the greatest reduction in cancer incidence included colorectal, urinary bladder, and oral cavity and pharynx, where 46%-55% of diagnoses were missed in 2020. Our findings highlight the need to identify those most at risk of missed early-stage diagnosis during the pandemic to reduce morbidity and mortality from these diseases. Strategies to address unmet cancer screening and treatment needs should be developed.



# Impact of COVID-19 Pandemic on the Types of Cancers Diagnosed among Adolescents and Young Adults in Los Angeles County, 2010-2019 vs 2020

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**Topic Area:** 1 - Effects of Covid-19 on Cancer Surveillance and Operations

**Sub-Topic:** 3a. Epidemiologic studies

**Background:** Delays to cancer diagnosis and disruptions to cancer-related treatment and follow-up care are known to have occurred due to the COVID19 pandemic. This has been more widely examined among adults over age 65. Very little population-based information on the impact of COVID19 among the adolescent and young adult population (AYA; ages 15-39 at time of cancer diagnosis) is available in the literature. To better understand potential impacts, we will describe the top 10 cancers diagnosed in the decade prior to the start of COVID19 (2010-2019) for comparison to diagnoses in 2020 (the first year of the pandemic).

**Methods:** The most commonly diagnosed AYA cancers will be identified for the decade prior to the pandemic (2010-2019) and over the first year of the pandemic (2020) using data from the Los Angeles County Cancer Surveillance Program. Frequencies and percents will be used to describe the top 10 cancer types in each time period for all cases and by detailed sociodemographic and clinical characteristics, including sex at birth, age group (15-24, 25-34, 35-39), race/ethnicity, socioeconomic status (SES), insurance type, and stage at diagnosis. Age-adjusted incidence rates (AAIR) rates (2010-2014, 2015-2019 vs 2020) will be used to identify differences in the top 10 cancers diagnosed during this time frame.

**Results:** TBD – differences in types of cancers diagnosed among males and females will be described, along with any differences observed by age group, race/ethnicity, SES, insurance type, and stage at diagnosis.

**Limitations:** Registry data was complete through the year 2020, thus potential continued impact due to the ongoing pandemic could not be evaluated at this time. Information on gender is not routinely collected by the registry.

**Conclusions:** As the COVID-19 pandemic continues to unfold, it will be important to identify subgroups as greatest risk of falling out of cancer screening and diagnosis, which can exacerbate disparities and lead to poorer cancer-related outcomes. Future studies using more years of data as they become available, and examining any impact on survival, can enhance these findings and provide a fuller picture of the impact on cancer surveillance and outcomes for the AYA patient population.

# Implementation and Evaluation of the California Cancer Registry Patient Contact Database

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**Topic Area:** 6 - Data Collection, Tools and Operations

**Sub-Topic:** 6b. Innovative operations and procedures

**Introduction:** Timely delivery of patient contact data by population-based cancer registries is vital to cancer-related research participation and representation of diverse patient groups in epidemiological cancer research studies. The California Cancer Registry (CCR) Patient Contact Database (PCDB) is an internal tracking system for cancer cases released to researchers for patient contact studies and is used at the state and regional registry levels. The PCDB tracks the following: 1) availability for patient contact, 2) cases released for patient contact, and 3) outcomes after patient contact. We provide an evaluation of the PCDB implemented at the statewide CCR in June 2021, with a focus on workflow efficiency and timeliness.

**Methods:** We compared the number of individual steps required to prepare a patient contact dataset before and after the implementation of the PCDB. We estimated net business workdays between patient contact study start and completion for 38 studies, with 19 studies pre- and 19 studies post-PCDB implementation. Net workday averages of the pre- and post-PCDB studies were compared using an unpaired *t*-test.

**Results:** The workflow pre-PCDB implementation consisted of 10 steps between study start and completion, while the workflow post-PCDB implementation consisted of 5 steps. The 5 steps removed were: 1) create files for regional registry patient contact availability check; 2) secure transfer of files to regional registries; 3) regional registry check for availability; 4) return of available cases by regional registry; and 5) merge of available cases from regional registries. The 5 remaining steps were 1) select list of records meeting study criteria; 2) upload list to PCDB for patient contact availability check; 3) download list of available cases from the PCDB; 4) secure transfer of patient contact dataset to researcher; and 5) upload released list of Patient IDs to the PCDB. We observed a statistically significant difference ( $p=0.0004$ ) in average net workdays between study start and completion pre- ( $N=19$ , Mean=51.16, SD=35.27) and post- ( $N=19$ , Mean=16.84, SD=14.59) PCDB implementation.

**Conclusion:** The implementation of the PCDB at the central registry led to reductions in the number of steps and net workdays required to release data for patient contact studies, improving timeliness of data for researchers.

# Implementation of a Standardized Template to Improve the Timeliness and Consistency of Early Case Reporting of Pediatric, Adolescent and Young Adult Cancer Cases to the Rhode Island Central Registry (RICR).

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**Topic Area:** 5 - Childhood Cancers

**Sub-Topic:** 5b. Childhood Cancer Data Initiative, National Childhood Cancer Registry and STAR Projects

**Background:** The 2018 Surveillance, Treatment, Access, and Research Act (STAR) required data collection and early reporting of pediatric, adolescent, and young adult cancers ages 0 through 29 within thirty days of first contact with a physician. Rhode Island (RI) is one of 4 states to work with the CDC on this project. RI enacted a state mandate that all cancer incidences be reported to the state central cancer registry within 30 to 45 days of first contact with a physician. To improve the reporting process, Certified Tumor Registrars (CTR) working on the STAR project developed a data dictionary that could be used by facilities when submitting reports to RICR.

**Purpose:** Develop a standardized template of minimally required data fields to streamline the process and improve the timeliness of monthly reports submitted to RICR.

**Methods:** 1) Create a standardized template to submit monthly reports using elements from the data dictionary and information gathered from widely used rapid case reporting systems. 2) Introduce to all facilities reporting Early Case Reporting of Pediatric, Adolescent and Young Adult Cancer Cases. 3) Over the six-months RICR offered certificate of participation to encourage adoption of template. 4) Evaluate success rate and barriers to implementation.

**Results:** When the template was first introduced in May 2022, 56% of all facilities reporting cancer cases in the 0 to 29 age group used the template. By December 2022, 89% of facilities used the template. Some of the barriers documented were staffing, software, and workload.

**Conclusion:** Over a 6-month period, there was a 33% increase in the number of facilities using the template. This demonstrates that reporting facilities can successfully implement use of a new template. Future studies will evaluate how usage of this new template impacts reporting timeliness.

# Inaugural Project to Assess and Report on the Burden of Cancer in the Caribbean: Processes, Challenges and Lessons Learned

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**Topic Area:** 2 - Big Ideas in Cancer Surveillance

**Sub-Topic:** 2b. How to make cancer data more timely

The Caribbean region consists of 31 island countries and territories, and the mainland countries of Belize, Guyana, and Suriname. Of the twelve countries and territories covered by population-based cancer registries (PBCRs) in 2020 (1), only three have high-quality cancer incidence data accessible in the most recent Cancer Incidence in Five Continents publication from the International Association for Research on Cancer (IARC) (2). To address the need for more high-quality cancer incidence data in the Caribbean, the IARC Caribbean Cancer Registry Hub, based at the Caribbean Public Health Agency (CARPHA), commenced a surveillance project to assess and report on the burden of cancer in the Caribbean.

The research ethics committee approved the project and ten Caribbean countries and territories with operational PBCRs in 2022 were invited by the IARC Caribbean Cancer Registry Hub to submit official documentation and incidence data for diagnosis years during the period 2000-2020. Data specifications were provided to registries, and a secure data submission portal was established. The IARC Caribbean Cancer Registry Hub is assessing the quality of the submitted data, generating standardized cancer incidence rates, and producing and disseminating a report on cancer incidence in the Caribbean.

To date, nine PBCRs verbally agreed to participate. One cancer registry submitted the required documentation and cancer incidence data. Four cancer registries have submitted partial documentation and data are pending. Official documentation and data for the remaining registries are underway.

Positive feedback from Caribbean PBCRs on the project concept and invitation indicates a general awareness of the importance and need for high-quality reports on cancer in the Caribbean. Administrative requirements for official documentation surrounding PBCR participation and data sharing have required more time than expected. File preparation, data cleaning, and submission can be supported by on going PBCR staff engagement and capacity building. Lessons learned regarding administrative requirements, timeline, and type of technical support required have been informative and can help the Hub identify ways to support Caribbean PBCRs better.

1. Quesnel-Crooks, S, et al. 2020. *Cancer Registration in the Caribbean*. *J Registry Manag.*

2. Bray, F, et al. *Cancer Incidence in Five Continents, Vol. XI*. <https://ci5.iarc.fr>.

# Initial Impacts of Lung Cancer Screening on Incidence Rates and Stage Distribution

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**Topic Area:** 3 - Epidemiologic Studies using Cancer Surveillance Data

**Sub-Topic:** 3a. Epidemiologic studies

**Background:** Despite a demonstrated reduction in lung cancer mortality from screening, uptake of low dose computed tomography (LDCT) has been estimated to be approximately 5% among eligible smokers, with considerable variation by state. While the percentage of eligible adults being screened is small, screening may still identify enough lung cancer cases to impact stage distribution and incidence rates at the state level, especially in states with greater uptake. There is currently limited data on the impact of lung cancer screening in the general population but more information is needed to help predict future impacts as screening increase. Using previous estimates of LDCT uptake and SEER cancer incidence data, we assessed if changes in stage distribution and incidence rates, particularly for early staged tumors, correlated with levels of LDCT uptake.

**Methods:** We used SEER data to calculate incidence rates of lung cancer in 2013 and 2018. Rates were calculated among adults aged 55-79 years in 10 states (CA, CT, GA, HI, IA, KY, LA, NJ, NM, UT.). Data for screening rates were pulled from a previous publication (Fedewa et al. 2021). We analyzed the correlation for uptake of lung cancer screening and the absolute and relative percent change in AJCC stage I/II (early) and stage III/IV (advanced) distributions and rates between 2013 and 2018. A secondary analysis examined correlations with predicted rates based on pre-LDCT years.

**Results:** The change in early-stage incidence rates was highly correlated with LDCT use by state. KY had the largest actual change in rates (17.5% points) while NJ had the smallest (-0.1) ( $R=0.87$   $p=0.001$ ). The same was true for stage distribution, with increased LDCT use correlated with a greater percent increase in early tumors from 2013 to 2018 ( $R=0.79$   $p=0.006$ ). There was no significant correlation with rates or distribution of advanced staged tumors.

**Conclusions:** Even with low uptake of LDCT screening in the US, we found evidence that modest uptake can impact rates of early staged tumors at the state level. With decreasing lung cancer rates overall, it will be important to assess and model the impact increased screening will have on future trends.

# Innovative Ways to Monitor Electronic Reporting at the Central Cancer Registry

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**Topic Area:** 6 - Data Collection, Tools and Operations

**Sub-Topic:** 4a. Technologic and scientific advances and innovations

**Background:** Data visualization is an essential tool in supporting decision making dealing with complex datasets. It helps to identify patterns, trends, and insights that might be difficult to recognize through textual or tabular data. In the healthcare industry, data visualization can be used in areas such as population health surveillance, clinical research, and quality improvement. However, it is still in its early stages compared to the development of the EHR.

**Purpose:** To provide creative methods for tracking and monitoring case reporting timeliness and completeness utilizing visualization tools. Our goal is to determine whether data visualization aids in the efficiency of data collection for the central cancer registry (CCR).

**Methods:** For the data collection, A SAS SQL query retrieved abstract level data from the registry database to generate a completeness report which is then presented by the primary site and reporting facility as annual counts (%) with comparison to three-year average. A SQL query pulls abstract files with NAACCR options from Web Plus that show facilities' self-reported cases and submission dates. Dashboards are created using tableau.

**Results:** Data visuals show facility name, registry and EMR software, along with number of cases reported in a specific diagnosis year for all registry and non-registry hospitals plotted on the map of SC. Another graph demonstrates total number of cases reported and 3-year averages for SC's top five primary cancer sites. Onboarding and submission dates are displayed in the Facility Self Reporting dashboard which differentiates between compliant and non-compliant facilities along with overall number of cases.

**Conclusion:** We seek to improve the effectiveness of the CCR's data collection through this ongoing project. These graphics examine and compare data among diagnosis years and the 3-year averages, as well as discover trends in case reporting for each facility and the top five primary cancer sites in SC. These graphics will allow for easier monitoring and interpretation of case reporting compliance.

# Investigating Disparities in Histology of Testicular Germ Cell Tumors According to Race, Ethnicity, Nativity, and Neighborhood SES.

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**Topic Area:** 3 - Epidemiologic Studies using Cancer Surveillance Data

**Sub-Topic:** 3b. Social determinants and cancer disparities

**Background:** Non-Hispanic White (White) males have the highest incidence of testicular germ cell tumors (TGCT). However, TGCT is increasing among other racial and ethnic groups, particularly the Hispanic population. TGCT occurs in two main histologic types, nonseminoma and seminoma, which are diagnosed in approximately equal proportions in the overall population. However, previous descriptive studies indicate that while 51%-56% of Hispanic males are diagnosed with nonseminoma, 38%-48% of other groups are diagnosed with this histologic type. This study examined whether Hispanic males have higher odds of being diagnosed with nonseminoma TGCT when age and year of diagnosis are considered. We also examined whether neighborhood socioeconomic status (SES) and nativity associate with histologic type of TGCT jointly with Hispanic ethnicity.

**Methods:** Data on 24,511 adult males diagnosed with TGCT between 1988-2015 were obtained from the California Cancer Registry. We used logistic regression adjusted for age and year of diagnosis to determine relative odds of diagnosis of a nonseminoma versus seminoma TGCT across groups jointly defined by race, ethnicity, and nativity (U.S.-born Asian American/Pacific Islander [AAPI], foreign-born AAPI, U.S.-born Hispanic, foreign-born Hispanic, non-Hispanic Black, and non-Hispanic White). Among Hispanic and White males, we also examined odds of diagnosis of nonseminoma according to neighborhood SES.

**Results:** Compared to White males, U.S.-born Hispanic males had lower odds of nonseminoma versus seminoma TGCT (OR: 0.89; 95% CI: 0.82, 0.95), whereas no difference was observed for foreign-born Hispanic males. Males residing in lower SES neighborhoods had higher odds of diagnosis with nonseminoma TGCT compared to those residing in high SES neighborhoods (OR: 1.10; 95% CI: 1.01, 1.21). In stratified analyses, the lower odds of nonseminoma diagnosis for U.S.-born Hispanic males compared to White males was only observable in lower SES neighborhoods.

**Conclusions:** Among Hispanic males, U.S.-born nativity and lower neighborhood SES distinguish those at lower odds of diagnosis of nonseminoma TGCT. Our results suggest that prior observations that Hispanic males had a higher proportion of nonseminoma diagnoses compared to other groups was not due to greater risk of developing nonseminoma among the Hispanic population but rather other population factors relevant to risk of nonseminoma TGCT.

# Keeping Data in Check: Comparing Results of Validating Caribbean Cancer Incidence Data using the IARC/IACR Check Program and the NAACCR Data Edits Application

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**Topic Area:** 6 - Data Collection, Tools and Operations

**Sub-Topic:** 6a. Data quality control and standards

International and regional standards and guidelines are available to ensure comparable data are generated from population-based cancer registries (PBCRs) worldwide. Recommendations for monitoring and assessing PBCR data quality are also available, which include the periodic assessment of internal data consistency using software applications. This involves review of: (1) intra-record accuracy, validity and consistency; and (2) inter-record edits to assure proper record consolidation and consistency of information from multiple reports. Several software applications or "Data Edits" programs exist to detect data inconsistencies. Two examples are the International Agency for Research on Cancer (IARC)/International Association of Cancer Registries (IACR) Tools for Cancer Registries (IARCcrgTools) package [1] and the NAACCR International Data Edits.

IARCcrgTools is based on ICD-O-3 [2] and checks the validity of the variables, the consistency between them, and identifies duplicate records for the same patient and multiple primary tumors following the IARC/IACR rules. The NAACCR International Data Edits were developed from data validation programs used in NAACCR quality assessments based on North American standards. The NAACCR International Data Edits software incorporates updates to ICD-O-3 and includes checks on all coded variables as well as consistency checks between variables. Both of these programs were adapted by identifying NAACCR data items that were comparable to Caribbean registries' data items and mapping them to a data dictionary, then adjusting as necessary to accommodate IARC/IACR rules.

Evaluating the quality of data submitted is critical as part of regular PBCR activities and for special surveillance projects. The IARC Caribbean Cancer Registry Hub is currently working to assess the burden of cancer in the Caribbean by analyzing the data collected by PBCRs in the Caribbean. To assess internal data consistency, cancer incidence data from participating countries will be validated using the adapted version of IARCcrgTools and the NAACCR International Data Edits. The results will be compared and presented to each respective registry as a capacity-building activity and before data are published.+

1. Ferlay J, et al. 2005. IARC/IACR. Check and Conversion Programs for Cancer Registries (IARC/IACR Tools for Cancer Registries).

2. WHO. ICD-O-3. <https://www.who.int/standards/classifications/other-classifications/international-classification-of-diseases-for-oncology>



# Liver Cancer Incidence Disparities in California, 1999-2019

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**Topic Area:** 3 - Epidemiologic Studies using Cancer Surveillance Data

**Sub-Topic:** 3b. Social determinants and cancer disparities

**Background:** Liver cancer disparities may reflect differences in liver cancer risk factors, including infection with hepatitis B virus (HBV) and/or hepatitis C virus (HCV), alcohol consumption, tobacco smoking, and excess body weight. Mitigating exposure to these potentially modifiable risk factors can reduce the morbidity and mortality related to liver cancer.

**Methods:** We used data from the California Cancer Registry to describe liver cancer incidence in California. We included all males and females diagnosed between January 1999 and December 2019 with hepatocellular carcinoma (HCC). We report incidence trends comparing San Francisco County to California overall as well as to other counties in California with similar proportion of Asian American residents, population density, and chronic HBV/HCV infections. Data on HBV, HCV, current smoking, binge drinking, diabetes, and obesity were taken from the California Department of Public Health and the California Health Interview Survey.

**Results:** Three-year HCC incidence for males in San Francisco was 19.9 per 100,000 (95% CI (17.4, 22.7)) in 1999-2001, and 25.8 (95% CI (23.2, 28.6)) in 2011-2013, and 16.5 (14.5, 18.7) in 2017-2019. In comparison, HCC incidence in California was 8.2 (95% CI (8.0, 8.5)) in 1999-2001, and 12.4 (95% CI (12.4, 12.7)) in 2011-2013, and 11.4 (11.1, 11.6) in 2017-2019. HCC incidence in females was relatively stable from 1999 to 2019 in both San Francisco and California. In 2016, the rate of HBV was of 82.1 per 100,000 in San Francisco compared to 46.9 per 100,000 in Los Angeles, the county with the second highest rate in California. While Hepatitis B rates decreased by 20% in San Francisco from 2012 to 2016, rates increased by 106% in Los Angeles. In the same time period, rates of HCV, current smoking, binge drinking, diabetes, and obesity have remained relatively stable.

**Conclusion:** San Francisco has had unique HCC incidence trends over the past two decades. There have been a number of integrated cross-sector collaborative efforts to reduce HBV and HCV across San Francisco, which may contribute to the improvement in HCC burden. Future studies should examine whether broader implementation of similar multi-stakeholder, community-engaged efforts can address HCC disparities more broadly.

# Lung Cancer Incidence by Detailed Race-Ethnicity.

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**Topic Area:** 3 - Epidemiologic Studies using Cancer Surveillance Data

**Sub-Topic:** 3b. Social determinants and cancer disparities

**Background:** Despite recent incidence and mortality declines, lung cancer (LC) is still the second most common and deadliest cancer in the US. Yet, LC incidence rates and tumor characteristics among (non-Hispanic) Black and Hispanic specific groups, normally characterized in aggregate, have been overlooked in the US.

**Methods:** We used LC data from the Florida state cancer registry, 2012–2018, to compute first-ever LC age-adjusted incidence rates (AAIR) for US-born Black, Caribbean-born Black, Mexican, Puerto Rican, Cuban, Dominican, Central American, and South American populations. For comparisons, we computed Fay and Feuer incidence rate ratios (IRR), 95% confidence intervals (CI). Multiple imputation of detailed ethnic (for Hispanics) and nativity group (for Blacks) was performed for missingness within 34.5% of Hispanic cases (n=2,427 of 7,038) and 23.9% of Black cases (n=1,325 of 5,553). We also assess the proportions of LCs that occurred among never smokers by sex and detailed race-ethnicity.

**Results:** We analyzed 120,550 total LC cases. Women [16.8%] had a higher proportion of LC among never smokers compared to men [10.4%] ( $p < 0.05$ ). Among Hispanics, Cuban males had the highest AAIR [65.6 per 100,000; 95%CI:63.6-67.6], only 8% [Incidence Rate Ratio (IRR):0.92; 95%CI:0.89-0.95] lower than Whites, but 2.7 times higher than Central Americans. Among Blacks, the AAIR for US-born Black males was over three times that of those Caribbean-born [IRR:3.12; 95%CI:2.80-3.40] and 14% higher than White males [IRR:1.14; 95%CI:1.11-1.18]. Among women, US-born Blacks (46.4 per 100,000) and foreign-born Mexicans (12.2 per 100,000) had the highest and lowest rates.

**Discussion:** This novel analysis of Florida LC incidence and never-smoker proportions by detailed race-ethnicity furthers knowledge, characterizing LC patterns across US minority populations. Larger LC proportions in never-smokers among minority groups and particularly among women warrant further research. Aggregation of non-Hispanic Blacks or Hispanics obscures inherent disparities within groups. Understanding the distinct LC rates in US populations is crucial for targeting public health measures for LC diagnosis, prevention, and treatments.

# Melanoma of the Skin Cancer Survival Among Male Florida Firefighters

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**Topic Area:** 3 - Epidemiologic Studies using Cancer Surveillance Data

**Sub-Topic:** 3a. Epidemiologic studies

**Background:** The incidence rates of melanoma of the skin continue to increase worldwide. Although advances in treatment are reflecting a decrease in mortality rates, survival is still highly dependent on stage at diagnosis. Occupational and epidemiologic studies suggest that firefighters have increased risk for different types of cancer, including melanoma when compared to the general population. Although there has been progress in screening, diagnosis and treatment, epidemiologic studies on melanoma-related mortality for firefighters and non-firefighting occupational groups are lacking.

**Methods:** Data from the Florida Cancer Data System (FCDS) (1981-2014) were linked with firefighter certification records from the Florida State Fire Marshal's Office to identify all patients of this occupational group, in addition to from FCDS records of the longest held job. Melanoma-specific mortality was compared between firefighters and non-firefighting occupational groups using multivariable Cox regression models adjusting for demographics and clinical characteristics. Adjusted hazard ratios (aHR) and 95% confidence intervals (95%CI) were calculated.

**Results:** Out of 48,632 male melanoma cases diagnosed in Florida (1981-2014), there were 388 firefighters (331 career, 57 volunteer). Melanoma-mortality was lower among firefighters (all 14.9%; career-only 13.3%; volunteer-only 24.6%) than non-firefighters (23.7%). Five-year survival was higher among firefighters (all 90.2%; career-only 91.5%; volunteer-only 82.5%) than non-firefighters (83.1%). In a multivariable model, compared to non-firefighters, all firefighters have significantly lower melanoma-specific mortality (aHR:0.67; 95%CI: 0.51-0.86; p=0.002). Compared to volunteer-firefighters, career-firefighters have significantly lower melanoma-specific mortality (0.54; 0.30-0.99; p=0.047). In a separate multivariable model with firefighters as the comparator, other broad occupational groups had significantly higher melanoma-specific mortality (white collar: 1.49 (1.14-1.94); blue collar: 1.74 (1.33-2.29); service: 1.65 (1.21-2.25); others/unknown: 1.48 (1.14-1.92); all p-values<0.004).

**Conclusion:** Melanoma survival is significantly higher among firefighters compared to non-firefighters where career-firefighters had significantly higher survival rates than volunteer-firefighters. Compared to firefighters, broad occupational groups had significantly lower melanoma survival. Improved survival among firefighters might be possibly multifactorial, including superior treatment compliance, increased medical knowledge, performance of more self-skin exams, better treatment engagement/surveillance and better navigation of cancer care. Additional epidemiological studies are needed to determine and link occupational and environmental exposure data to cancer cohort studies.

# Minnesota Prostate Cancer Occurrence Before and After US Preventive Services Task Force Recommendations Against Screening

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**Topic Area:** 7 - Other Relevant Topics

**Sub-Topic:** 3a. Epidemiologic studies

**Background:** Prostate cancer (PC) is the second-leading cause of cancer death in US men. Previous studies called the effectiveness of prostate-specific antigen (PSA) screening into question. In 2008 the US Preventive Services Task Force (USPSTF) changed its PC screening guideline, recommending against PSA screening in men over 75 years, and extended this recommendation to all men in 2012. Nationally, incidence of local stage PC began a steep decline in 2007, but subsequently the rates for regional and distant stage PC have begun trending upward.

**Methods:** We described patterns in PC incidence, mortality, and survival in Minnesota before and after the USPSTF guideline changes. We compared and contrasted incidence and mortality rates over two time periods: 2003-2007 versus 2015-2019. Inclusion criteria included microscopically diagnosed malignant PC and age 50+ years at diagnosis for incidence, and age 50+ at death for mortality. Rates were age-adjusted and reported per 100,000. We compared 5-year relative PC survival for men diagnosed from 2001-2007 with survival in men diagnosed from 2013-2019. Rate ratios were considered statistically significant if  $p < 0.05$ , and survival differences if non-overlapping 95% confidence intervals.

**Results:** Between 2003-2007 and 2015-2019, PC incidence in Minnesota among men 50+ years of age decreased from 646 to 400 new diagnoses/100,000 men/year (-38%). Local and regional stage incidence decreased by 49% and 13% respectively, whereas distant stage incidence increased by 40%. As a result, the percentage of cases diagnosed at distant stage increased from 4% to 8%. PC mortality declined from 92 to 70 deaths/100,000 men/year (-22%). Between 2001-2007 and 2013-2019, 5-year relative survival of PC for all stages combined decreased from 98% to 94%. Paradoxically, regional stage survival improved by 4.5% and distant stage survival by 8%. All results were statistically significant except for distant stage survival (borderline).

**Conclusion:** The PC picture in Minnesota is mixed. The decline in incidence in recent years means fewer men are exposed to potential harms of treatment. Further, survival of distant and regional stage PC has improved. On the other hand, both incidence and the percentage of cases diagnosed with distant stage PC have increased.

# Neighborhood Segregation Contextual Impacts on Treatment and Outcomes in Women with Ductal Carcinoma In Situ of the Breast

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**Topic Area:** 3 - Epidemiologic Studies using Cancer Surveillance Data

**Sub-Topic:** 3b. Social determinants and cancer disparities

**Background:** While racial and racialized economic segregation (RES) have been associated with survival outcomes in women with invasive breast cancer (IBC), the impact of integrated racial and economic segregation on clinical treatment for ductal carcinoma in situ (DCIS) and outcomes remained unclear.

**Methods:** This study included women aged 18 and older with unilateral DCIS diagnosed between January 1990 and December 2015, followed through December 2016, and identified from the Surveillance, Epidemiology, and End Results (SEER) database. Exposure to the RES was defined at the county level using Index of Concentration at the Extremes metrics. Using multilevel logistic regression and multilevel Cox proportional hazards regression, we estimated the odds ratios (ORs) of receipt of local treatment (surgical resection and radiation therapy) and hazard ratios (HRs) of subsequent IBC, breast cancer-specific mortality, and overall mortality for RES, adjusted for sociodemographic and clinical factors and rural residence.

**Results:** Of 103,898 participants, 13005 (12.5%) were non-Hispanic African American and 90893 (87.5%) were non-Hispanic white. In counties with the least compared to the most privileged quintile of RES, odds of undergoing surgical treatment was lower (OR=0.74, 95% CI 0.58-0.94; Ptrend=0.01) and odds of receiving radiation therapy following breast-conserving surgery were higher (OR=1.25, 95% CI 1.05-1.47; Ptrend=0.01). Despite no significant differences in subsequent IBC, contralateral IBC, or breast cancer-specific mortality across quintiles of RES, we observed significantly higher risks of ipsilateral IBC (HR=1.20, 95% CI 1.05-1.37; Ptrend=0.01) and overall mortality (HR=1.19, 95% CI 1.11-1.27; Ptrend<.0001) for the least privileged quintile of RES compared with the most privileged quintile.

**Conclusion:** The results provide evidence for disparities in local treatment for DCIS and prognostic outcomes between women in counties with a high concentration of low-income non-Hispanic African American residents and those in counties with a high concentration of high-income non-Hispanic white residents. Our findings can inform multilevel interventions (geographically prioritizing) to improve the clinical care and outcomes of DCIS.

# Neoadjuvant Therapy and Gastric Cancer Clinical Stage Using a Mid-Atlantic Institution Tumor Registry

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**Topic Area:** 3 - Epidemiologic Studies using Cancer Surveillance Data

**Sub-Topic:** 3c. Using real-world data from cancer registries to improve cancer outcomes

**Introduction:** Patients with locally advanced gastric cancer (clinical stage (cs) 1B, 1C, II, III) are recommended neoadjuvant chemotherapy based on National Comprehensive Cancer Network (NCCN) recommendations. However, not all patients undergo pre-operative treatment and instead undergo surgery first (prior to any chemotherapy). The goal of this pilot study was to determine compliance with NCCN recommendations at an integrated health care system.

**Methods:** We selected reportable gastric cancer cases, age 18 or older at diagnosis, from the Kaiser Permanente Mid-Atlantic States (KPMAS) tumor registry from 1/1/2015 through 12/31/2021, excluding cancer at the cardia or gastro-esophageal junction and lymphomas, leukemia, squamous cell, neuroendocrine, sarcomas, and medullary carcinoma. After determining eligible patients for surgery and neoadjuvant therapy, or palliative care, we defined the clinical characteristics (including Eastern Cooperative Oncology Group (ECOG) performance status and Charlson Comorbidity Index (CCI)), surgical and neoadjuvant treatments that were NCCN non-compliant.

**Results:** After excluding 144 C16.\* cases for histology and treatment location, 177 cases remained (26 cs 1/1A; 8 cs 1B/1C; 36 cs II, 18 cs III, 77 cs IV and 12 cs unknown). There were 16 non-locally advanced patients (median age 63, median ECOG 1 and median CCI 0.5) who received neoadjuvant therapy with surgery. Of the 62 locally advanced cases: 7 had a biopsy only, 6 had biopsy and palliative treatment, 1 aborted surgery, 9 had surgery first and 39 (62.9%) had the recommended neoadjuvant therapy with surgery. Of the 13 (21%) patients not receiving neoadjuvant therapy or surgery, 4 patients were later found to have metastatic disease and 2 were referred to hospice. The 39 locally advanced patients with neoadjuvant therapy had a median age 68, median ECOG 1 and median CCI 1, compared to the 9 with surgery first (median age 64, median ECOG 1 and median CCI 1).

**Conclusions:** There were 21% of patients who would otherwise be recommended to have neoadjuvant treatment that actually received it. Limitations on accurate and evolving clinical stage may impact assessment of appropriate care. Further research is needed on the impact of neoadjuvant therapy on survival and other outcomes.

# Prostate Cancer Study in Manitoba

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**Topic Area:** 3 - Epidemiologic Studies using Cancer Surveillance Data

**Sub-Topic:** 3c. Using real-world data from cancer registries to improve cancer outcomes

**Background/Objective:** Prostate cancer incidence is lower in Manitoba compared to other provinces, but mortality is higher. A closer look at population subgroups within Manitoba was undertaken to determine if differences in incidence, and survival exist between regions in the province, time period, and prostate cancer risk category.

**Methods:** The Manitoba Cancer Registry was used to identify individuals diagnosed from 2005 to 2019 with invasive prostate cancer in Manitoba, Canada. Manitoba cancer registry data, life tables from Statistics Canada, and risk categories based on the Genitourinary Radiation Oncologists of Canada (GUROC) Consensus Risk Categories were used to determine cancer characteristics, treatment history, relative survival, and risk category. Age standardized incidence rate (ASIR) and 5-year relative survival were examined by region of residence, time period, and risk category.

**Results:** 10,819 individuals were diagnosed with invasive prostate cancer from 2005 to 2019. Overall, the ASIR decreased over time, dropping in 2010-2014 then stabilizing in the 2015-2019 time period. There was variation in incidence between RHAs and over time. Within the major urban center, incidence decreased, while fluctuations were observed within different rural regions in the province. One rural region was consistently higher than the Manitoba rate. A shift from low/intermediate risk to high-risk was observed in all RHAs except for one rural region. Generally, survival remained consistent across the province over time except for two rural regions that saw a decrease and increase in 5-year relative survival, respectively. In particular, the rural region with the observed decrease was significantly lower than the provincial estimate in the 2015-2019 period.

**Conclusion:** Incidence and 5-year relative survival varied within the province by RHA, and over time. A shift in risk category was also observed due to the change in staging scheme. Further investigations into potential differences in mortality and patient-specific characteristics are planned for the future.

# Racial and Ethnic Disparities in Survival Among Persons with Second Primary Lung Cancer

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**Topic Area:** 3 - Epidemiologic Studies using Cancer Surveillance Data

**Sub-Topic:** 3b. Social determinants and cancer disparities

**Background:** About 25% of newly diagnosed lung cancer occur among persons with prior cancer. But data are limited on second primary lung cancer outcomes, especially regarding racial and ethnic disparities.

**Methods:** This study included 48,066 persons who developed second primary lung cancer at ages  $\geq 20$  years during 2000-2013 and recorded in 18 Surveillance, Epidemiology, and End Results registries. Cause-specific proportional hazards models were used to estimate HR (hazard ratio), comparing the risk of cancer or cardiovascular death in Hispanic, non-Hispanic Asian or Pacific Islander (API), or non-Hispanic Black (Black) persons to that in non-Hispanic White (White) persons. HRs were adjusted for sex, prior cancer type, prior cancer stage, age and year of second lung cancer diagnosis, household income, urbanity as well as stage, subtype, and treatment receipt (surgery, radiotherapy, chemotherapy) for second lung cancer.

**Results:** During 12 months of median follow-up (10<sup>th</sup>-90<sup>th</sup>, 1 month to 86 months), 36,124 cancer deaths and 2,587 cardiovascular deaths occurred. Five-year age-standardized relative survival was highest among API (25.5%), followed by White (20.8%), Hispanic (20.4%), and Black (18.0%) persons. In multivariable models, compared with White persons, the risk of cancer death was 16% lower (95%CI=0.80-0.89) among API persons and was comparable among Black (HR=0.98; 95%CI=0.94-1.01) and Hispanic (HR=0.95; 95%CI=0.90-1.00) persons. In contrast, the risk of cardiovascular death was 19% (95%CI=1.05-1.36) higher among Black persons but the association was not statistically significant among API (HR=0.86; 95%CI=0.69-1.06) and Hispanic (HR=0.84, 95%CI=0.68-1.03). The increased HR for CVD death among Black persons was more pronounced among younger (HR=1.46, 95%CI=1.10-1.94 for 20-64 years vs HR=1.13, 95%CI=0.98-1.31 for 65+ years) and female (HR=1.30, 95%CI=1.03-1.65 for women vs HR=1.15, 95%CI=0.98-1.32 for male) persons and persons with lower household income (HR=1.28, 95%CI=1.11-1.48 for <\$75,000 vs HR=0.91, 95%CI=0.65-1.27 for \$75,000+).

**Conclusions:** Among persons with second primary lung cancer, the risk of cardiovascular death was significantly higher among Black persons than White persons with the magnitude of elevated risks varying by sociodemographic characteristics. Future studies are needed to identify factors that contribute to the higher risk of cardiovascular death among Black persons to inform survivorship care planning and improve health in this population.



# Results of Data Quality Evaluation: Completeness Follow-back of CDC's National Program of Cancer Registries

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**Topic Area:** 7 - Other Relevant Topics

**Sub-Topic:** 6a. Data quality control and standards

**Background:** CDC monitors the National Program of Cancer Registries (NPCR) data quality by routinely auditing each registry's data. In the last three years, CDC contracted with Westat to assess completeness of some data items for selected cancer sites. Forty-eight NPCR-funded central cancer registries (CCRs) participated (14 in year 1, 17 in year 2, and 17 in year 3).

**Methods:** Westat analyzed the NPCR data using SEER\*Stat to evaluate completeness of selected tumor and treatment information for colorectal and female breast cases diagnosed in 2017, and for ovary, pancreas, urinary bladder, brain, esophagus, and liver and intrahepatic bile duct cases diagnosed in 2018. A sample of cases with unknown values were randomly selected for each CCR to perform follow-back to recode items to a value other than unknown. For each selected cancer site, over one-thousand cases across data items and CCRs were reviewed for follow-back.

**Results:** Across all evaluation years, 40% of data items with unknown values were updated after follow-back.

By site, data items with highest and lowest percentages for being updated were: colorectal (RX summary radiation and radiation regional RX modality, both 59%) vs. grade, 17%); female breast (RX hormone, 61% vs. estrogen and progesterone receptors, both 28%); ovary (RX summary primary site, RX summary chemotherapy, and grade post therapy, all 53% vs. grade pathological, 19%); pancreas (grade post therapy, 48% vs. tumor size summary, 28%); urinary bladder (RX summary BRM, 59% vs. grade pathological, 20%); brain (summary stage 2018, 83% vs. grade post therapy, 21%); esophagus (phase I radiation treatment modality, 47% vs. grade clinical, 12%); and liver and intrahepatic bile duct (RX summary chemotherapy, 52% vs. grade clinical, 12%).

The majority of the updates were based on internal CCR review alone and not through follow-back to the reporting facility. The most common reasons for unknown values were that having an unknown value was correct, reporter's coding error, or consolidation being incomplete or completed with errors.

**Conclusion:** Results from the evaluation will allow CDC to make decisions on the collection of data items and to inform procedures and training that may improve the completeness of data items.

# Rurality Impacts Mammography Screening Adherence Among Mid-Life Women in the Kansas Region

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**Topic Area:** 7 - Other Relevant Topics

**Sub-Topic:** 3b. Social determinants and cancer disparities

**Objective:** The gold standard for breast cancer screening and prevention is regular mammography; thus, understanding what impacts adherence to this standard is essential in limiting cancer-associated costs. We assessed the impact of various understudied sociodemographic factors of interest on adherence to the receipt of regular mammograms.

**Methods:** A total = 14,553 mammography-related claims from N = 6,336 female Kansas aged between 45 and 54 were utilized from insurance claim databases furnished by multiple providers. Adherence to regular mammography was quantified continuously via a compliance ratio, used to capture the number of eligible years in which at least one mammogram was received, as well as categorically. The relationship between race, ethnicity, rurality, insurance (public/private), screening facility type, and distance to nearest screening facility with both continuous and categorically defined compliance were individually assessed via Kruskal-Wallis one-way ANOVAs, Chi-squared tests, multiple linear regression models, and multiple logistic regression, as appropriate. Findings from these individual models were used to inform the construction of a basic, multifaceted prediction model.

**Results:** Model results demonstrated that all factors, but race and ethnicity had at least some bearing on compliance with screening guidelines among mid-life female Kansans. The strongest signal was observed in the rurality variable, which demonstrated a significant relationship with compliance regardless of how it was defined.

**Conclusion:** Understudied factors that are associated with regular mammography adherence, such as rurality and distance to nearest facility, may serve as important considerations when developing intervention strategies for ensuring that female patients stick to prescribed screening regimens.

# Screenable Cancer Incidence Rates Before and During the Start of the COVID-19 Pandemic, 2017-2020, New Jersey

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**Topic Area:** 1 - Effects of Covid-19 on Cancer Surveillance and Operations

**Background:** Cancer screenings declined during the COVID-19 pandemic due to facility closures and fear of going to medical facilities for non-emergency procedures.

**Purpose:** To examine breast, cervical, melanoma of the skin, lung, and colorectal cancer (CRC) incidence rates before and during the start of the COVID-19 pandemic.

**Methods:** New Jersey State Cancer Registry data were used to capture the change in screenable cancers diagnosed among screening age NJ residents from 2017 to 2020. Screening age is defined as ages 45-74 for CRC, 50-79 for lung cancer, 40-74 for breast cancer, 20-64 for cervical cancer, and 20+ for melanoma per American Cancer Society guidelines. Age-adjusted cancer incidence rates, rate ratios (RR) comparing 2020 rates to 2017-2019 rates, and 95% confidence intervals (CI) were generated using SEER\*Stat.

**Results:** There was a statistically significant decrease in cancer incidence rates for screening-aged adults from pre-COVID-19 (2017-2019) to the start of COVID-19 (2020), particularly in invasive cervical cancer (RR=0.85, 95% CI: 0.73-0.99), male lung (RR=0.87, 95% CI: 0.83-0.92), female lung (RR=0.87, 95% CI: 0.83-0.92), female breast cancer (RR=0.90, 95% CI: 0.87-0.92), and male and female melanoma (RR=0.81, 95% CI: 0.77-0.85). Most notable were the gender differences in early-stage CRC, which showed a more pronounced decline in men (RR= 0.74, 95%CI: 0.66-0.82) than in women (RR= 0.85, 95%CI: 0.76-0.96). We also saw a significant decline in **early stage** of the following cancers: invasive cervical cancer (RR=0.74, 95% CI: 0.58-0.94), female breast cancer (RR=0.88, 95%CI: 0.86-0.91), male lung (RR=0.84, 95% CI: 0.76-0.93), female lung (RR=0.80, 95% CI: 0.73-0.88), male melanoma (RR=0.81, 95% CI: 0.77-0.85), and female melanoma (RR=0.81, 95% CI: 0.76-0.86).

**Conclusions:** The decline in guideline-concordant screening can lead to a decrease in early-stage diagnoses and increase in advanced stage diagnoses and cancer mortality. It is important to close the cancer screening gap that has been caused by COVID-19 and return to pre-pandemic screening rates to increase early detection and decrease cancer mortality.

# Sex Disparities in Contemporary Liver Cancer Incidence Trends in the United States: An Age-Period-Cohort Analysis.

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**Topic Area:** 3 - Epidemiologic Studies using Cancer Surveillance Data

**Sub-Topic:** 3a. Epidemiologic studies

**Background:** Liver cancer incidence in the US has stabilized in men but continues to increase in women. A comprehensive examination of contemporary sex disparities is needed. We evaluated sex-specific age and birth cohort patterns in liver cancer incidence.

**Methods:** We conducted a retrospective cohort study of individuals aged  $\geq 25$  years diagnosed with liver and intrahepatic bile duct cancer (liver cancer) from 2000 through 2019 in 17 Surveillance, Epidemiology, and End Results Program registries. Joinpoint regression and age-period-cohort modeling were used to quantify incidence trends in men and women by age, calendar period, and birth cohort. The relative risk of liver cancer was analyzed across 16 generations from 1915 through 1990.

**Results:** During 2000-2019, 100,353 males and 40,532 females were diagnosed with liver cancer. Although overall age-standardized incidence rates increased by a similar magnitude in males (59%, from 13.6 to 21.6) and females (64%, from 5.0 to 8.2), birth cohort patterns differed. The age-specific risk of liver cancer in men peaked in generations born circa 1955, with the incidence rate ratio being 4 times higher than in men born in 1920, then decreased in successive generations until 1970 and thereafter stabilized. Among women, the risk did not peak but increased steadily across successive generations evaluated in this study. Compared to people born in 1920, the risk among people born circa 1990 was 2.6 times higher in men and 5.2 times higher in women. Incidence rates during 2015-2019 among men were stable in ages  $< 40$ , declining in ages 40-64, and increasing in ages  $\geq 65$  years, consistent with birth cohort trends; among women, patterns were less clear, with declines confined to ages 50-54 and increases in ages 35-44 and  $\geq 65$  years of approximately 2%-5% annually.

**Conclusion:** Liver cancer risk peaked in men born circa 1955 but continued to increase in women, with the youngest generations experiencing 6-fold higher rates compared to women born in the early 20<sup>th</sup> century. These findings may reflect sex differences in patterns of risk factor exposure (e.g., smoking, alcohol, viral hepatitis) and highlight the need for improved prevention (including treatment of viral hepatitis), and early detection, especially among women.

# The Challenges of Collecting Long-Term Outcomes in Cancer Patients on the Population-Level: The Case of Metastatic Breast Cancer

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**Topic Area:** 3 - Epidemiologic Studies using Cancer Surveillance Data

**Sub-Topic:** 3a. Epidemiologic studies

**Background:** Cancer recurrence is an important long-term outcome of cancer survivors that is often not collected and recorded by population-based registries. In this narrative review, we examine the current availability, landscape and infrastructure of data collection of long-term outcomes in population-based setting, specifically metastatic recurrence in women initially diagnosed with non-metastatic breast cancer.

**Methods:** We reviewed the literature to identify studies that used population-based registry data reporting metastatic recurrence in women who had an initial diagnosis of non-metastatic breast cancer. Information on outcomes, methods of ascertainment and definitions of recurrence from each study were extracted. Registry infrastructure including sources and funding were also reviewed.

**Results:** A total of 23 studies from 11 registries in 8 countries spanning Europe, North America and Oceania were identified and included in the review. Most studies were retrospective in nature and collected recurrence data only for ad-hoc studies. Definitions of recurrence and data sources varied considerably across studies: the minimum cancer-free interval between the start of follow-up and risk window ranged from none (n=4) to 6 months (n=1); the start of follow-up ranged from follow-up from the initial date of diagnosis (n=17) to date of treatment (n=6).

**Conclusions:** Cancer surveillance should take step-wise expansion to include outcomes and statistics among survivors. International standards and local support for cancer registries to routinely collect recurrence data are needed for benchmarking and to evaluate prevalence and outcomes of metastatic breast cancer and provide information of the impact of recurrence on breast cancer patients.

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# The Role of Physicians in Hispanic Melanoma Survival.

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**Topic Area:** 3 - Epidemiologic Studies using Cancer Surveillance Data

**Sub-Topic:** 3b. Social determinants and cancer disparities

Melanoma is the most lethal form of skin cancer. Hispanics are less likely to be diagnosed with melanoma, but they are diagnosed at later stages and have lower survival rates than their non-Hispanic white counterparts. Reasons for the later stage at diagnosis among Hispanics are unknown, and could be related to patient, clinician, or healthcare systems issues.

To investigate the possible role of physician expertise in later stage diagnosis among Hispanics, we used data from the Los Angeles Cancer Surveillance Program (the LA-SEER registry) and compared melanoma survival among Hispanics and non-Hispanic whites, considering the experience level of the treating physician. Physicians who had diagnosed 15 or fewer melanomas (i.e., 1 case per year or fewer) were classified as low volume, while those who had diagnosed more than 15 melanomas were classified as high volume. We included all melanomas (all races) to determine "volume".

Our preliminary results show that physicians with low volume treat Hispanic patients more often than physicians with high volume (11.8% vs. 6.5%). Physicians with low volume report a higher proportion of late-stage melanomas; this applies to non-Hispanic whites and Hispanics. Nevertheless, it is more marked in the Hispanic population.

After adjusting for stage, survival was worst for patients seen by low-volume physicians. The difference was more pronounced for late-stage disease in both groups, although smaller for Hispanics (36.2% v 23.4% 5-year survival for high- and low-volume respectively) than non-Hispanic whites (53.4% v 24.8% 5-year survival for high- and low-volume respectively). Current analyses include multivariate estimation of hazard ratios and the addition of information about physician specialty.

We conclude that the volume of patients seen by physicians appears to affect survival, especially for late-stage melanomas in non-Hispanic whites but does not seem to impact outcomes for Hispanics. Hispanics continue to have worse outcomes no matter who they are getting diagnosed by. This study suggests that interventions to improve stage at diagnosis among Hispanics should be uniformly applied to all physicians, but that interventions targeted to low volume physicians might improve survival for non-Hispanic whites.

# Trends in Colorectal Cancer Incidence Among Young Adults by Metropolitan Status in the US, 2000 to 2019

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**Topic Area:** 3 - Epidemiologic Studies using Cancer Surveillance Data

**Sub-Topic:** 3a. Epidemiologic studies

**Background:** Colorectal cancer (CRC) incidence rates among young adults aged 20 to 54 years are increasing in the US. Research examining disparities in CRC trends among rural and urban areas is limited. We examined trends in CRC incidence rates from 2000 to 2019 among adults aged 20 to 54 years by metropolitan status in the US.

**Methods:** Data on persons aged 20 to 54 years diagnosed with CRC from 2000 to 2019, stratified by metropolitan (urban) and nonmetropolitan (rural) residency, were obtained for 22 registries in the National Cancer Institute's Surveillance, Epidemiology and End Results (SEER) program. Incidence rates were age-standardized and adjusted for delays in reporting using SEER\*Stat software. Trends were analyzed using Joinpoint regression and described as increasing or decreasing when statistically significantly different from 0 ( $p < 0.05$ ). In addition, we calculated incidence rate ratios (RRs), with 95% confidence intervals (CIs), comparing cross-sectional rates in nonmetropolitan areas versus metropolitan areas for 2000-2001 and 2018-2019.

**Results:** Incidence rates per 100,000 persons increased from 16.5 (95% CI: 15.9-17.2) in 2000-2001 to 23.9 (95% CI: 23.0-24.7) in 2018-2019 in rural areas, and from 15.3 (95% CI: 15.0-15.5) to 20.0 (95% CI: 19.8-20.3) in urban areas. Rates increased approximately by 2% annually (average annual percent change [AAPC]: 1.98%; 95% CI: 1.65-2.31%) in rural areas and by 1.5% (AAPC: 1.50%; 95% CI: 1.16-1.84%) in urban areas. As a result, the disparity in incidence rates in rural versus urban areas increased from 8% (RR: 1.08; 95% CI: 1.04-1.13) higher during 2000-2001 to 19% (RR: 1.19; 95% CI: 1.15-1.24) higher during 2018-2019.

**Conclusion:** Colorectal cancer incidence rates among adults aged 20 to 54 years are increasing more rapidly in rural areas than urban areas, leading to widening disparities. These findings may reflect differences in the prevalence of modifiable risk factors, such as obesity and unhealthy dietary patterns. Future studies should examine reasons for this rising trend. In the meantime, increasing access to care and cancer prevention interventions that promote age-eligible screening, physical activity, and healthy dietary behaviors in both urban and rural communities are needed to mitigate the rising burden of the disease.

# Use of Immunosuppression and Subsequent Cancer Incidence

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**Topic Area:** 3 - Epidemiologic Studies using Cancer Surveillance Data

**Sub-Topic:** 3a. Epidemiologic studies

**Objective:** To evaluate the incidence of any cancer and of putatively immunosuppression-related cancers after immunosuppressive treatment compared to persons unexposed to immunosuppression.

**Design:** Retrospective cohort study of the Systemic Immunosuppressive Therapy for Eye Diseases (SITE) Cohort.

**Setting:** United States ocular inflammatory disease subspecialty practices where approximately one-fourth of patients were managed with immunosuppression.

**Participants:** Patients with non-infectious ocular inflammatory disease; patients known to have HIV infection were excluded.

**Interventions:** Immunosuppressive drugs including: antimetabolites (primarily methotrexate, azathioprine, and mycophenolate mofetil), calcineurin inhibitors (cyclosporine and tacrolimus), alkylating agents (primarily cyclophosphamide and chlorambucil), and Tumor Necrosis Factor (TNF) inhibitors (primarily infliximab, adalimumab, and etanercept) were examined.

**Main outcomes measures:** Cancer incidence was ascertained by linkage to twelve state cancer registries from 1996-2015. Cancer incidence was analyzed using Cox regression survival analysis, using 0-, 3- and 5-year lags after immunosuppression began.

**Results:** The cancer incidence cohort comprised 10,872 individuals who were at risk of incident cancer and resided in one of the 12 states covered; 812 primary cancers were identified through cancer incidence tracing. Neither TNF inhibitor, antimetabolite, calcineurin inhibitor nor alkylating agent classes were associated with statistically significant increases in cancer incidence. Methotrexate was associated with significantly lower overall cancer incidence in the systemic inflammatory diseases (SID)-including cohort (adjusted hazard ratio (aHR)= 0.77, 95% confidence interval (CI):0.61 to 0.98) and similarly lower incidence in the smaller non-SID cohort (aHR=0.73, 95%CI:0.53 to 1.002). We found statistically significant reduced hazards in the SID-including cohort for adalimumab and chlorambucil and increased hazards for tacrolimus and etanercept in the non-SID cohort.

**Conclusions:** We found no increased risk of overall or site-specific cancer incidence associated with the most commonly used immunosuppressive drug classes and many specific drugs. Further research may clarify potentially protective or harmful effects of specific agents that were not consistently associated with reduced or increased cancer incidence.



# Using LexisNexis to Improve Social Security Number Information in the New York State Cancer Registry

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**Topic Area:** 6 - Data Collection, Tools and Operations

**Sub-Topic:** 6b. Innovative operations and procedures

**Background/Introduction:** Social security numbers (SSNs) collected by cancer surveillance registries are used for patient matching, deduplication, follow-up, and linkage studies. However, small proportions of patient records have missing or inaccurate SSNs. New York State Cancer Registry (NYSCR) data have been linked to LexisNexis (LN) data to obtain SSNs. The current study evaluated the feasibility of using LN to improve SSN information in the NYSCR.

**Materials and Methods:** NYSCR patients diagnosed 2009-2017 at age 21 or older were linked to LN. For the matched patients, LN returned SSNs as available. Percentages of patients with: 1) missing SSN prior to LN linkage, 2) no LN match, or 3) LN match but without LN SSN, were evaluated by demographic characteristics (sex, age at linkage, race, ethnicity, birth country and vital status). For those with LN SSN, the SSNs were compared to the NYSCR to determine consistency. Patients with prior missing or inconsistent SSNs were reviewed using Match\*Pro to verify match status. NYSCR SSNs were updated for those confirmed to be true matches. Improvement of SSN completeness was assessed by demographic characteristics.

**Results:** Of 1,396,078 patient records linked to LN, 1.6% were not matched. Among those matched, 1.5% did not have LN SSNs. Prior to LN linkage, 47,271 (3.4%) of patients had missing SSN, with higher percentages among younger age groups, black, Asian Pacific Islander (API), Hispanic, and foreign born. Percentages with no LN match or matched without LN SSNs tended to be higher for the same sub-groups of patients. Preliminary evaluation indicated that 19,524 missing and 8,969 inaccurate SSNs could be replaced, resulting in a decrease in the overall percentage of patients missing SSNs to 2.0%. A larger absolute reduction of SSN missingness was observed for younger age groups, API, and alive patients.

**Conclusions:** LN is a valuable resource for improving the quality of SSN information in registries. Preliminary results show that the percentage of patients missing SSNs were reduced from 3.4% to 2.0%. Some SSNs that were incorrectly consolidated were identified and subsequently fixed. SSNs are expected to be improved even further after completion of this project.

# Using Chart Abstractions to Improve Risk Factor Case Definitions in Michigan

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**Topic Area:** 6 - Data Collection, Tools and Operations

**Sub-Topic:** 2a. How to modernize the Cancer Surveillance System

For nearly forty years, the State of Michigan has monitored cancer burden within its communities by maintaining a population-based cancer registry. As cancer risk becomes better understood, establishing collection of case-level risk factor data in the registry has become a key priority. The goal of this project was to evaluate current registry fields regarding alcohol and tobacco use, family history of cancer, and genomics, in order to explore the feasibility of collecting more descriptive data on these topics.

Ten Michigan facilities with Commission on Cancer accreditation were selected to each retrospectively abstract twenty cases of early-onset breast cancer, early-onset colorectal cancer, endometrial cancer, or ovarian cancer they had diagnosed in 2019. Two abstraction tools were developed for the facilities to provide case-level risk factor data and send back to the cancer registry.

Smoking history was deemed complete for 77.2% of collected abstractions. Of cases who had smoked, sufficient data to calculate pack-years was provided for approximately half. Incorporating smokeless tobacco and e-cigarette use (78.9% and 52.8% complete, respectively) brought overall tobacco use history down to 47.2% complete. Alcohol use history was 55.0% complete but improved to 65.6% complete when the type of alcohol used was not included in calculations.

Overall, 85.0% of charts had complete information on family history variables including family history of cancer, cancer in a first or second degree relative and cancer diagnosed at the same site as a family member. Of those with a family history of cancer, almost all patients (99.1%) had recorded whether cancer diagnosis was in a first or second degree relative. Genetic counseling status was specified in 71.1% of patient charts, and among patients who received genetic testing, 95.4% of charts documented testing results.

These initial findings demonstrate feasibility in expanding what case-level cancer risk factor data is collected in Michigan's cancer registry. More descriptive fields regarding alcohol and tobacco use history, family history of cancer among first and second degree relatives, and genetic counseling and testing information would be beneficial to Michigan's efforts in preventing and controlling cancer.

# U.S. Cancer Statistics and Talk to Nathan: CDC Tools to Monitor Prostate Cancer Incidence and Survival and Address Health Disparities

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**Topic Area:** 3 - Epidemiologic Studies using Cancer Surveillance Data

**Sub-Topic:** 3b. Social determinants and cancer disparities

**Background:** In the United States, prostate cancer is the most common cancer in men among reportable cancers and is the second leading cancer-related cause of death. Prostate cancer ranges from a non-aggressive, slow-growing disease that may not require treatment to metastatic disease.

**Methods:** U.S. Cancer Statistics (USCS) data, which includes incidence data from CDC's National Program of Cancer Registries (NPCR) and NCI's Surveillance, Epidemiology, and End Results Program and cover 99% of the U.S. population, were used to calculate age-adjusted prostate cancer incidence rates in 2019. Five-year relative survival and survival by stage were calculated using NPCR survival data, which cover 88% of the U.S. population. Race and ethnicity characteristics were examined.

**Results:** In 2019, approximately 225,000 new prostate cancer cases were reported. For every 100,000 men, 112 new prostate cases were reported. Prostate cancer incidence was higher among Non-Hispanic (NH) Black men (174 cases/100,000) than other racial and ethnic groups (ranging from 58 in NH Asian and Pacific Islander (API) men to 105 in NH White men). The estimated 5-year relative survival was 96.4%, ranging from 96.2% among both NH White and NH Black men to 93.6% among NH API men. The estimated 5-year relative survival for men diagnosed with distant prostate cancer ranged from 30.8% among NH White men to 44.1% for NH API men.

**Conclusions:** USCS incidence and NPCR survival data can be used at the population level to monitor cancer burden. They can also be used to evaluate programs, such as ones addressing health disparities through education and outreach to African American men and men with increased risk of prostate cancer due to a family history. Several professional organizations recommend a discussion between men and their providers about the benefits and risk of prostate cancer screening. CDC's Talk to Nathan (<https://www.cdc.gov/cancer/prostate/talk-to-nathan>) is an interactive online decision aid that facilitates this discussion.

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