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Letter from the Guest Editor

I am pleased to present the fourth annual North American Association of Central Cancer Registries (NAACCR) special edition of the *Journal of Registry Management (JRM)*. Each year, this edition provides opportunities for NAACCR members to publish their cancer surveillance work, experience, and ideas. As is evident in this issue, we are interested in research articles as well as short reports, editorials, and registry-specific experiences. We will begin accepting submissions for next year's issue this fall.

This issue contains 2 editorials, 5 original articles, 1 short report, and the 3 winning posters from the NAACCR 2023 Annual Conference that was held in New Orleans in June. As in prior years, articles published underwent a peer-review process overseen by members of the NAACCR Research and Data Use Steering Committee. The posters underwent a peer-review process to be accepted at the NAACCR Annual Conference, met the criteria to be judged as part of the annual conference proceedings, and won their respective categories.

This volume contains articles that cover a range of topics, including a description of the Panama mortality-based cancer registry (Quintana et al) and assessment of a new site recode to identify rare cancers (Hofer et al). The rare cancer site recode paper is the subject of this issue's continuing education quiz. There is also a collaborative paper led by the Centers for Disease Control and Prevention that assesses the role of HPV in a race cancer, scrotal squamous cell carcinoma. There are 2 papers out of the New York State Cancer Registry, one focused on improving Social Security number information in cancer registries (Qiao et al) and one using residential history to inform life-course exposure to toxic air among mesothelioma patients (Liu et al). Finally, we have a short report on the California Cancer Registry's Patient Contact Database (Movsisyan Vernon et al).

The 2 editorials are equally wide-ranging. One is focused on the ethical issues involved with data collection, use, and disclosure (Hill). The other discusses the need to capture screening methods to better inform breast cancer research (Eby).

The winning posters were presented and judged at NAACCR's first in-person conference in 4 years. The winning poster in the Research and Data Use category was from the Puerto Rico Cancer Registry and explored the association of a premalignant condition, monoclonal gammopathy of undetermined significance, with multiple myeloma survival (Castañeda-Avila et al). The Standards and Registry Operations winning poster was out of the Rhode Island Cancer Registry on a template to improve early case reporting for pediatric and young adult cases (Zinkann et al). Finally, the UNCOV-MBD (Uncovering International Disparities in Metastatic Breast Cancer Outcomes) project poster focused on collection of cancer recurrence for breast cancer patients and received an honorable mention (Morgan et al).

As always, I value our collaboration with NCRA and the *JRM* on the special publication of NAACCR-focused articles. Please note that the findings and conclusions in these reports are those of the authors and do not necessarily represent the views of the NAACCR, NCRA, or *JRM*.

Be well,

Recinda Sherman, MPH, PhD, ODS-C

JRM Guest Editor

Letter to the Editor

Who Owns My Identity?

T. Patrick Hill, PhD

Cancer registries routinely collect a constellation of identifiers derived from individuals that, when combined, result in personal individuation. Significantly, this collection is considered justified even without formal consent because it is undertaken for the purposes of public health surveillance and clinical and social research. This, in turn, is thought to constitute a transfer of ownership of the identifiers to registries as an agency of the state. But since such a transfer is, on its face, both unnecessary and unethical, we have to ask: what might justify it?

The question is unavoidable if we wish to determine who does own the identifiers. Consider the nature of the information involved: name, sex, gender, genetics, birth date, nationality, location, occupation, etc. Combined, this is the very stuff of personal individuation, without which name alone does not convey a person's identity fully. As such, the information is reduced to data only in the subsequent process of aggregation required for the identification of populations. Data are to the identity of populations what individuating information is to the identity of persons. The concept of personal identity constituted in such information is not to be confused with the concept of population identity as constituted in data. Doing so is, in logic, a category mistake and, in this case, leads to the mistaken inference that, in owning population data, registries or research institutions consequently own individuating information.

Avoiding this mistake requires understanding the social nature and purpose of the cancer registry agenda, a transaction involving mutual interests between individual members and their society. If so, why would a transfer of ownership and members' loss of control over their interests be acceptable when a custodial deposit, much like a bank deposit, would be no less effective and would not result in a loss of control? It isn't, unless we consider society to consist merely in what American philosopher, John Dewey,[1] decried as "a numerical aggregate of individual units," urging us instead to view it as an organism constituted in members who are social beings. "A State represents men [*sic*] so far as they have become organically related to one another," in recognition of certain common interests that require this relationship, if they are to be realized. From the premise that the individual and society are organically related, Dewey concluded that, to the extent society embodies a common good, to that extent each individual member does not merely participate in it proportionately to individual interest but is its very embodiment. Analogically speaking, according to Dewey, just as the "eye is the body organized for seeing," so the individual is society organized for pursuing the common good.

There can be little doubt that Dewey regards the interdependence of society and its members as a moral enterprise in which, according to Alan Gewirth,[2] the identity of the individual consists in their role in a society whose public policies and institutions are designed to combine common goods with individual good as their primary moral purpose. One, that is, in which the individual member is responsible for the well-being of society, and society is responsible for the well-being of the individual member. It is this mutual responsibility that assumes the two ought to be reconciled, and, consequently, as a moral imperative requires appropriate behavior from both for its realization.

If then we consider individual health a good, can we consider it also a common good? Both questions are etiological. As Geoffrey Rose[3] observed, etiology addresses two distinct but complementary questions. The first, addressed by medical care, has to do with the particular cause of disease in an individual patient's case, which requires determining the level of risk for disease based on susceptibility. The second, the focus of public health, has to do with the cause of the incidence rate for a disease in a given population, such as "diet and its association with the mean distribution of heart disease across the population." Knowing disease cause may eventually lead to knowing disease prevention, which is ideally the goal of both medical care and public health. But since determining individual susceptibility is likely inadequate for identifying the root causes of incidence, that must, as Rose concludes, remain the overriding goal, since once known, "susceptibility ceases to matter."

This, precisely, is what justifies cancer registries routinely collecting individuating medical information. The systematic posing of the first question by health care professionals of individual patients enables public health professionals to ask the second question of a population, now identifiable from the aggregated data resulting from the first question. It also justifies inferring that if we consider individual health a good, we must also consider it a common good. If, for the individual, as organically related to society, that means being organized for pursuing the common good, then, when pursuing their personal health interests, they do so with due regard for the health interests of others. And if the public's health is a necessary condition for the individual's health, then, since collecting individuating information by cancer registries is integral to securing conditions conducive to a population's health, the individual must expect to collaborate with the cancer registries to ensure their success. And if the moral nature of this human societal organism is recognized as a transaction involving mutual interests, then the idea that individuals

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lose ownership of their individuating information, participation in the transaction would amount to acting against self-interest and consequently be unethical.

If the individual should be considered as society organized for pursuing the common good, here a population's health, then cancer registries are acting in the name of the individual so that they can do for them what they cannot do in their self-interest. And, since individuals should not be expected to act against their best interests, so should they consent to the collection of individuating medical information. Ideally, this is best secured by means of explicit consent from the individual. However, practically speaking, since requiring explicit consent could prevent cancer registries from acting in the individual's best interests, they can function on the basis of an assumed tacit consent. As long as an individual remains freely a member of society, enjoying the benefits of membership, that signals a willingness to be considered as reciprocally organized for pursuing the common good, which should include individual good or at least prevent individual harm.

If the moral argument for the individual's continuing ownership of individuating information in the wake of its collection by cancer registries is compelling, the legal argument to the contrary in favor of state ownership is not, as is acknowledged by the US Health Insurance Portability and Accountability Act (HIPAA).[4] Left standing, it violates the integrity of persons and the indispensable organic nature of their relationship to society as its members. It results, regrettably, in what Dewey thought of as a society of two classes, those that govern and those that are governed, rather than ideally "two aspects of the same fact—the fact of the possession by society of a unified and articulate will." It would be hard to think of anything more desirable morally for the success of the working relations between health care and public health. It would be hard to think of anything more unacceptable morally than laws undermining this collaboration and, as a consequence, the very possibility of its success.

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Letter to the Editor

Patients Will Benefit if We Expand Cancer Registries to Capture Method of Detection

Peter R. Eby, MD, FACR; for American College of Radiology Screening and Emerging Technology Committee of the American College of Radiology Breast Commission

Key words: *breast, cancer, screening, mammography*

Introduction

Controversies related to screening for breast cancer persist in the United States despite cutting-edge tools for diagnosis and treatment. Patients continue to receive conflicting recommendations from providers and specialty societies who rely on models and historic clinical trial data that may no longer accurately represent the diversity of the screening-eligible population or advances in screening technologies. One challenge to conducting population-based breast cancer research is the lack of a direct link between cancer outcomes and the initial method of detection (MOD) for each registrant. Inclusion of this valuable data element would facilitate assessment of linkage between screening and cancer stage, treatment received, patient outcomes, sociodemographics, geography, access to health care, and molecular signatures, for example.

The results of randomized controlled trials (RCTs) conducted between 1963 and 1990 from multiple international sources provide robust evidence that screening mammography significantly reduces breast cancer mortality.[1] The American College of Radiology (ACR), US Preventive Services Task Force (USPSTF), and American Cancer Society (ACS) agree that annual screening mammography beginning at age 40 years will save the most lives.[2-5] However, the same organizations disagree over the balance of risks and benefits of screening mammography and recommend different frequencies and ages to initiate early detection of breast cancer in the United States.[1] In the decades since the RCTs concluded, the technology, health care systems, and racial diversity in the United States have drastically changed. The ACR, USPSTF, ACS, and other organizations advocate for new research of technologic efficacy inclusive of Black, Hispanic, Latina, Asian, Pacific Islander, Native American, and Alaska Native women in the United States but lack the national population data to do so.

Shortly after the data from RCTs confirmed the benefits of early detection, many nations instituted population-wide breast cancer screening programs.[6] Administrators of those programs had the foresight to include the initial MOD, such as mammography screening or clinical examination, in cancer registries for every patient with a new diagnosis of breast cancer. Using these data, which were acquired annually for decades, administrators and physicians can actively review contemporary patient-specific links between MOD and outcomes to understand and continuously adapt breast cancer care to the local and evolving populations in those countries.[6] The United States, lacking a centralized screening program or an ability to link MOD to individual patients, cannot. Our understanding of the impact of screening on minority and vulnerable and underinsured populations in screening remains low while barriers to participation remain high.

Knowledge Gaps

The Surveillance, Epidemiology, and End Results (SEER) program, the National Program of Cancer Registries (NPCR), the National Cancer Database (NCDB), and the ACR's National Mammography Database collect specific data for every patient with a new diagnosis of breast cancer, but MOD has never been included. The North American Association of Central Cancer Registries (NAACCR) maintains the data dictionary for all state and regional registries. Neither NAACCR nor NPCR nor NCDB nor SEER require registries to assign or collect MOD.

Thus, among nations with high rates of breast cancer and state-of-the-art screening facilities and cutting-edge technology, the United States lacks the fundamental ability to directly link breast cancer outcomes to MOD and scientifically address ongoing controversies over screening. This is compounded by continuously evolving population demographics of the United States. National organizations such as the USPSTF, ACS, and the American College of Physicians must rely on observational data from the Breast Cancer Surveillance Consortium, SEER, and other sources and simulation models that employ nonuniform assumptions. These assumptions may be subject to bias when examining the impact of screening.[2,5,7,8] The lack of a consistent, patient-specific link between MOD and outcomes has permitted ongoing speculation and fostered disagreement about the risks and benefits of screening in the United States.[9] Ultimately, the conflicting recommendations confuse patients and providers and disrupt clear and critical opportunities to save lives.

Defining and Determining MOD

The initial MOD of breast cancer is defined as the first test or clinical event to trigger the work-up leading to the histologic diagnosis of breast cancer. When national service-screening programs and registries were built in the 1980s and 1990s, the choices for initial MOD were limited. Originally, film-screen mammography was the only image-based test. Today, initial MOD can include multiple other image-based screening modalities (Table 1). Screening with 2-dimensional digital mammography, digital breast tomosynthesis (DBT), ultrasound, magnetic resonance imaging (MRI), and other tests can now provide the earliest evidence of breast cancer. Self-examination and

Table 1. The Proposed Categories of Initial MOD Designed to Capture Information Relevant to Contemporary Technology and the Impact of Self Breast Examination and Clinical Breast Examination
Category S: Initially detected with image-based screening.
Sdbt: Screening DBT, with synthetic or full field 2D
Sma: Screening 2D mammogram without any DBT
Sus: Screening ultrasound (automated or handheld)
Smri: Screening MRI
Scem: Screening contrast enhanced mammogram
Snuc: Screening nuclear medicine breast examination
So: Other screening modality such as screening breast CT, etc
Category P: initially detected by patient or provider.
Pat: Patient first detected by self-examination or symptom such as pain
Pro: Provider first detected by clinical examination
Ppp: Not possible to determine if patient or provider detected
Category N: Not detected by patient or provider or with image-based screening. Example: liver metastasis detected by abdominal ultrasound prompted by abdominal pain and abnormal liver function tests.

DBT, digital breast tomosynthesis; MRI, magnetic resonance imaging.

clinical breast examination, which detect lumps, thickening, or tenderness, can also be the initial MOD leading to a diagnosis. Patients may also trigger detection of breast cancer when they seek care for nipple discharge, erythema, pain, dimpling, or skin ulceration. In addition, other imaging or laboratory tests not designed to evaluate the breast, such as abdominal computed tomography or brain MRI, may detect metastases that lead to a diagnosis of breast cancer.

Benefits of Collecting MOD

If MOD could be assigned and collected accurately and without bias for each patient, providers from multiple specialties could access new primary data that capture the diversity of our screening-eligible population and advances in screening technologies. Concrete, patient-specific data could bring the ACR, USPSTF, and ACS to consensus recommendations for screening. MOD-inclusive data can contribute to collaborative, multispecialty assessment of efficacy, equity, treatment, and outcomes for breast cancer, such as:

1. What are the relative contributions of screening mammography and treatment to reducing breast cancer mortality?
2. Are the outcomes for patients with stage 1 breast cancers different for different initial methods of detection?
3. Do patients with image-detected cancers have different treatment or mortality outcomes compared to patients with clinically detected cancers?
4. Do image-detected tumors have different molecular signatures compared to clinically detected tumors?
5. What are the relationships between race, demographics, social determinants of health and MOD and outcomes?
6. What percentage of breast cancers are not initially screen-detected, and how does this vary by personal risk, breast density, age, or other factors?
7. Are there differences in initial staging for breast cancers initially detected with image-based screening vs clinical or self-examination?
8. Which specific geographic locations have below average outcomes and below average fractions of image-detected cancer, and can we use that information to improve access to screening at the local level?
9. Are supplemental image-based screening modalities (MRI, ultrasound, etc) providing the same reductions in morbidity and mortality as screening mammography?

Barriers To National Collection of MOD

The US health care system provides cutting-edge care with comparatively brief wait times and less regard to societal cost. However, data collection is a patchwork of public and private entities funded by numerous private and public payors competing at the local and regional levels. This data is stitched together with different electronic medical records of heterogeneous patient populations. Every state has a tumor registry responsible for tracking valuable information such as incidence, stage, race, and mortality for every case of cancer diagnosed. However, there is no state or nationally standardized process for collecting MOD.

Assigning MOD Accurately

Abstractors employed by state, local and hospital registries currently gather information related to a new cancer diagnosis from clinical reports. Most of the information regarding cancer type, size, grade, and receptor status is quickly abstracted from succinct and standardized pathology reports. However, abstractors frequently revert to the tedious and time-consuming strategy of sifting through other clinical notes for details regarding the treatment plan, for example. Abstractors could attempt to assign MOD through retrospective review, but if abstractors already know the patient has breast cancer, the assignment of MOD could be skewed by unconscious bias. It is imperative that the assignment of initial MOD be accurate, prospective, unbiased, easily discoverable, and correctly transferred to registries for future scientific investigation.

The Screening and Emerging Technology Committee of the ACR Breast Commission recommends that radiologists prospectively assign the MOD for each patient with suspicious imaging findings at the time of the diagnostic work-up prior to a new diagnosis of breast cancer. We cannot expect abstractors to retrospectively read multiple radiology and pathology reports to recreate the clinical history and accurately determine the MOD. The diagnostic radiologist has the necessary expertise to understand the subtle nuances of the imaging, history, and clinical information and is uniquely suited to accurately assign the initial MOD. Indeed, in the standard course of imaging work-up when recommending tissue sampling to a patient, the diagnostic radiologist will have the most complete understanding of the clinical scenario and an unbiased prospective opportunity to assign a single, initial, highly accurate MOD.

Summary

Controversies related to screening for breast cancer persist in the United States despite cutting-edge tools for diagnosis and treatment. This is because outcomes cannot be directly related to the initial MOD at the state or national levels. Inclusion of MOD in state and regional cancer registries and national databases is long overdue. In addition to requiring registries to capture MOD, methods to increase MOD reliability and abstraction ease, such as mandating inclusion of MOD in radiology reporting, are necessary. Inclusion of MOD for breast cancer registries may serve as a model for image-detected cancers such as lung and colon cancers and their respective registries. Radiologists have an opportunity to directly facilitate the capture of MOD and contribute to a new critical linkage in our national registries to dramatically improve our understanding of breast cancer and screening and reduce the burden of disease on our patients.

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Original Article

Human Papillomavirus Detection in Scrotal Squamous Cell Carcinoma: Case Series from a Population-Based Cancer Registry

Jacqueline M. Mix, PhD, MPH[a,b]; Maureen J. Miller, MD, MPH[a]; Troy D. Querec, PhD[a]; Teresa M. Darragh, MD[c]; Mona Saraiya, MD, MPH[a]; Sameer V. Gopalani, PhD, MPH[a,b]; Charles F. Lynch, MD, PhD[d]; Trevor D. Thompson, BS[a]; April Greek, PhD[e]; Thomas C. Tucker, PhD, MPH[f]; Edward S. Peters, DMD, ScD[g]; Elizabeth R. Unger[a]

Abstract: Introduction: Scrotal squamous cell carcinomas (SCCs) are rare malignancies that are not considered to be associated with the human papillomavirus (HPV) by the International Agency for Research on Cancer. However, recent studies have detected HPV in these cancers. We sought to determine the presence of HPV types among scrotal cancer cases identified through population-based cancer registries. Methods: Primary scrotal SCCs diagnosed from 2014 to 2015 were identified, and tissue sections from formalin-fixed, paraffin-embedded tissue blocks were obtained for laboratory testing. A pathology review was performed to confirm morphology. HPV testing was performed using L1 consensus polymerase chain reaction analysis. Immunohistochemistry was used to evaluate p16INK4a (p16) expression. Results: Five cases of scrotal SCC were identified from 1 cancer registry. Age at diagnosis ranged from 34 to 75 years (median, 56 years). Four cases were non-Hispanic White, and 1 was non-Hispanic Black. The morphologic subtype of 4 cases was keratinizing (usual), and 1 case was verrucous (warty) histologic subtype. Two of the usual cases of SCC were HPV-negative and p16-negative, and 2 were positive for HPV16 and p16. The verrucous (warty) SCC subtype case was HPV6-positive and p16-negative. Conclusions: The presence of HPV16 and p16 overexpression in the examined tissue specimens lends additional support for the role of HPV in the etiology of scrotal SCC.

Key words: *HPV16, human papillomavirus, scrotal cancer, squamous cell carcinoma*

Introduction

Oncogenic types of human papillomavirus (HPV) are known to cause cancers of the cervix, vagina, vulva, anus, penis, and oropharynx.[1] Studies with small sample sizes have reported detection of oncogenic HPV DNA in scrotal squamous cell carcinomas (SCCs)[2-5]; however, scrotal SCCs are not currently considered an HPV-associated cancer by the International Agency for Research on Cancer.[6]

Scrotal cancers are rare malignancies. From 2015 to 2019, an average of approximately 260 cases per year were reported in the United States.[7] From 1973 to 2002, scrotal cancer incidence rates nearly doubled from 0.049 to 0.095 per 100,000.[8] Although scrotal cancer incidence rates have remained stable in recent years, the magnitude of rates is higher than previously reported, with an incidence rate of 0.21 per 100,000 in 2019.

Routine population-based tracking of HPV types among HPV-associated cancers is not currently conducted in the United States. Most studies of HPV type prevalence in HPV-associated cancers have been performed in limited geographic areas without population-based sampling strategies. The Centers for Disease Control and Prevention (CDC) has supported 2 special studies covering data from 2004 and 2005 (study 1) and 2014 and 2015 (study 2) that facilitated the development of the Cancer Registry Sentinel Surveillance System (CRSSS), which used central cancer registries to obtain tissue samples from HPV-associated cancers to determine HPV type prevalence.[1,9] CDC's CRSSS provides a novel framework for population-based sampling of HPV-associated tissue for genotyping and monitoring HPV prevalence. By using data collected from scrotal SCC cases identified in the second study during 2014 and 2015, our objectives were to: (1) identify the HPV types present in scrotal SCC cancers derived from cancer registries; (2) determine the p16INK4a (p16) overexpression in the same scrotal tissues by using immunohistochemistry; and (3) confirm the histologic subtypes of the scrotal SCC cases. This report will add information to the limited data on the etiologic role of HPV in scrotal cancers.

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The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

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Materials and Methods

Study Population and Design

We analyzed data from CDC's CRSSS, which included data from 3 central cancer registries: Iowa, Kentucky, and Louisiana. Scrotal SCC cancers diagnosed in 2014 and 2015 (years covered by the CRSSS) were identified by the cancer registries using the *International Classification of Diseases for Oncology, Third Edition* (ICD-O-3) site (C63.2) and histology codes. All malignant cases (with behavior code 3) were included, except for melanomas (8720–8790), sarcomas (8800–8991), mesotheliomas (9050–9055), Kaposi sarcomas (9140), and leukemias and lymphomas (9590–9992). Eligible cases were tracked back to the pathology laboratories where the tumor tissues were stored. Eleven histologically eligible cases were identified from 2 cancer registries: 1 case from Kentucky and 10 cases from Louisiana. No eligible cases were identified in Iowa. The case from Kentucky could not be retrieved from the pathology laboratory. Among the remaining 10 eligible cases, 3 cases could not be shared by the pathology laboratories, and 1 case was ineligible because of out-of-state residence. Paraffin-embedded tissue from the remaining 6 samples was sent to the CDC HPV laboratory for slide preparation and HPV typing. One of the samples sent to the CDC HPV laboratory contained the wrong tissue type and was therefore excluded. All protocols were reviewed and approved by the institutional review boards (IRBs) of all participating organizations and CDC. Tissue collection was performed as part of cancer registry operations with all patient identifiers removed; therefore, no written informed consent was required by the IRBs.

Pathology and Laboratory Methods

Tissue processing, histology review, and laboratory methods have been described previously.[1,10] Briefly, central pathology laboratories associated with the cancer registries were asked to select 1 representative-archived, formalin-fixed, paraffin-embedded (FFPE) tissue block from each scrotal cancer case. Tissue sections were prepared by taking eight 5-µm sections from each block and performing hematoxylin and eosin staining on the first and last sections. Two unstained sections were placed in each of 2 tubes for DNA extraction, and 2 unstained slides were prepared for immunohistochemistry. All tissue blocks were processed with a standardized protocol to prevent contamination of samples.

Both high-risk (including HPV 16 and 18) and low-risk (including HPV 6 and 11) HPV types were tested. Primary testing was conducted with Linear Array (LA, Roche Diagnostics), which detects 37 HPV types (6, 11, 16, 18, 26, 31, 33, 35, 39, 40, 42, 45, 51, 52 [XR], 53, 54, 55, 56, 58, 59, 61, 62, 64, 66, 67, 68, 69, 70, 71, 72, 73, 81, 82, 83, 84, 89, IS39) and human β-globin. HPV negative and inadequate (HPV negative and β-globin negative) tissues were retested with the RHA kit HPV SPF-10-LiPA25, version 1 (Labo Biomedical Products B.V.) that detects 25 types (HPV 6, 11, 16, 18, 31, 33, 34, 35, 39, 40, 42, 43, 44, 45, 51, 52, 53, 54, 56, 58, 59, 66, 68, 70, 74). P16 immunohistochemistry was performed by using Ventana BenchMark XT automated system with monoclonal anti-p16INK4a (clone E6H4 in CINtec p16 assay, Ventana/Roche) and ultraView Universal DAB Detection kit (Ventana/Roche). A positive tissue control (FFPE cell pellet of HPV-positive cancer cell line) was included with each assay.

All HPV typing and p16 immunohistochemistry were conducted at the CDC HPV laboratory using standardized procedures. Cancer registries provided demographic and clinical data about each case, including age at diagnosis, race and ethnicity, and SEER Summary tumor stage at diagnosis. Interpretation of p16 results (p16 positive, p16 negative, or inadequate) was performed by a pathologist using light microscopic examination of slides processed with and without primary antibody using established criteria.[11]

The original pathology review was performed by pathology laboratories and hospitals associated with the cancer registries. Two additional board-certified anatomic pathologists examined the tissue samples collected by the central pathology laboratory to confirm the reporting facility's tumor histology diagnosis. The reviewers also reached consensus and further classified SCCs into 1 of 3 common histologic subtypes (usual, warty, or basaloid).

Results

A total of 5 scrotal cancer tissue samples were analyzed. Patient age ranged from 34 to 75 years, with a median age of 56 years. Four cases were in non-Hispanic White men, and 1 was in a non-Hispanic Black man (Table 1).

Table 1. Characteristics of Scrotal Squamous Cell Carcinoma Cases (n = 5), Centers for Disease Control and Prevention Cancer Registry Sentinel Surveillance System, 2014–2015

	Scrotal SCC cases				
Characteristic	**1**	**2**	**3**	**4**	**5**
Age, y	30–39	40–49	50–59	70–79	70–79
Race/ethnicity	NH White	NH Black	NH White	NH White	NH White
Histologic classification	Keratinizing SCC, usual	Keratinizing SCC, usual	Verrucous SCC, warty	Keratinizing SCC, usual	Keratinizing SCC, usual
HPV genotype	HPV16	HPV16	HPV6	HPV-negative	HPV-negative
p16 overexpression	Positive	Positive	p16 negative	p16 negative	p16 negative

HPV, human papillomavirus; NH, non-Hispanic; SCC, squamous cell carcinoma

Representative images of histopathology and immunohistochemistry are presented in Figure 1 (A–E). Two of the scrotal SCCs were given morphologic code 8070 (SCC, not otherwise specified [NOS]) by the central pathology laboratory. These cases were reclassified by our study reviewers as SCC, keratinizing type (ICD-0-3 code, 8071). Review by the central pathology laboratory resulted in classification of 4 of the 5 scrotal SCCs as keratinizing SCC, usual type and 1 as warty/ verrucous.

HPV-Positive Cases

Three SCCs (60%) were positive for HPV DNA. All had single-type infections. Of the cases positive for HPV, 2 were positive for HPV16 and 1 was positive for HPV6. Both cases positive for HPV16 were keratinizing SCCs and had p16 overexpression with diffuse nuclear and cytoplasmic p16 staining (cases 1 and 2). Of note, these 2 HPV16 SCC cases occurred in men aged younger than 50 years. The SCC classified as warty/verrucous was positive for HPV6 and was p16 negative.

HPV-Negative Cases

Two keratinizing SCCs, usual type were negative for HPV DNA (cases 4 and 5). Both cases were negative for p16 overexpression.

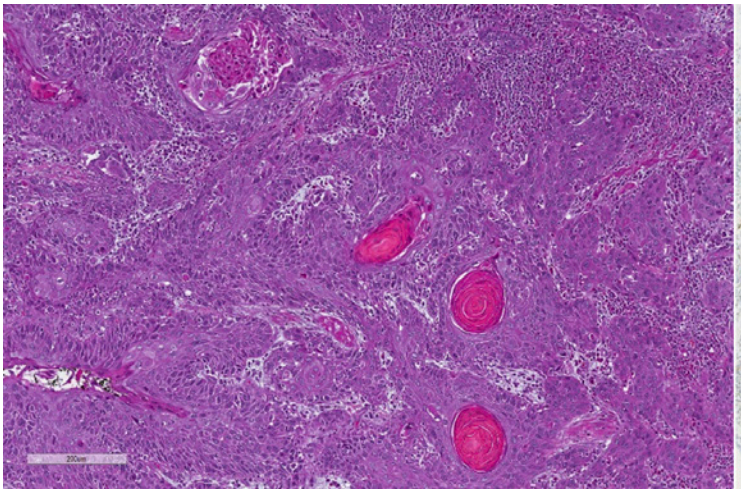
Discussion

HPV has been previously detected in scrotal SCC tissue, but its rarity among the population limits most studies to small sample sizes or case series. In our study of 5 scrotal SCCs, 2 cases of keratinizing SCC with usual histological subtype tested positive for HPV16 and demonstrated p16 overexpression. Although a small sample, our findings add further support for considering scrotal SCCs as HPV-associated cancers, similar to HPV-associated vulvar cancer.[12]

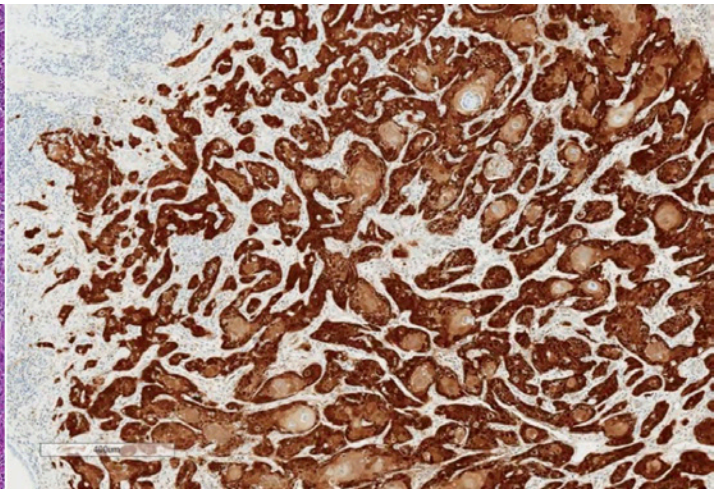
Figure 1. Scrotal Squamous Cell Carcinoma Cases Hematoxylin and Eosin (H&E) Histological Images with Associated p16INK4a (p16) Expression Pattern on Immunohistochemistry, Centers for Disease Control and Prevention Cancer Registry Sentinel Surveillance System, 2014–2015

A. Case 1: SCC HPV16-positive, p16 overexpression positive

A1: H&E

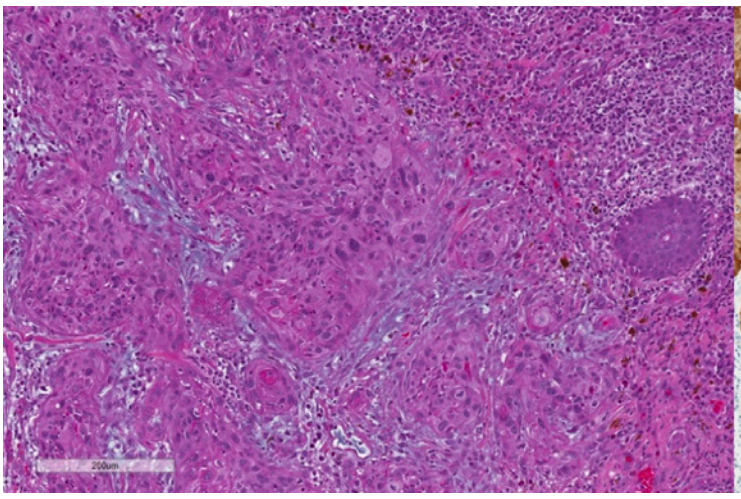


A2: p16 expression

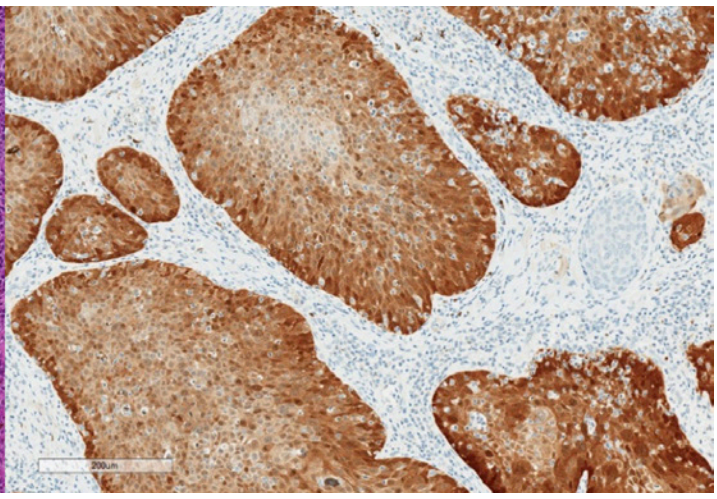


B. Case 2: SCC HPV16-positive, p16 overexpression positive

B1: H&E

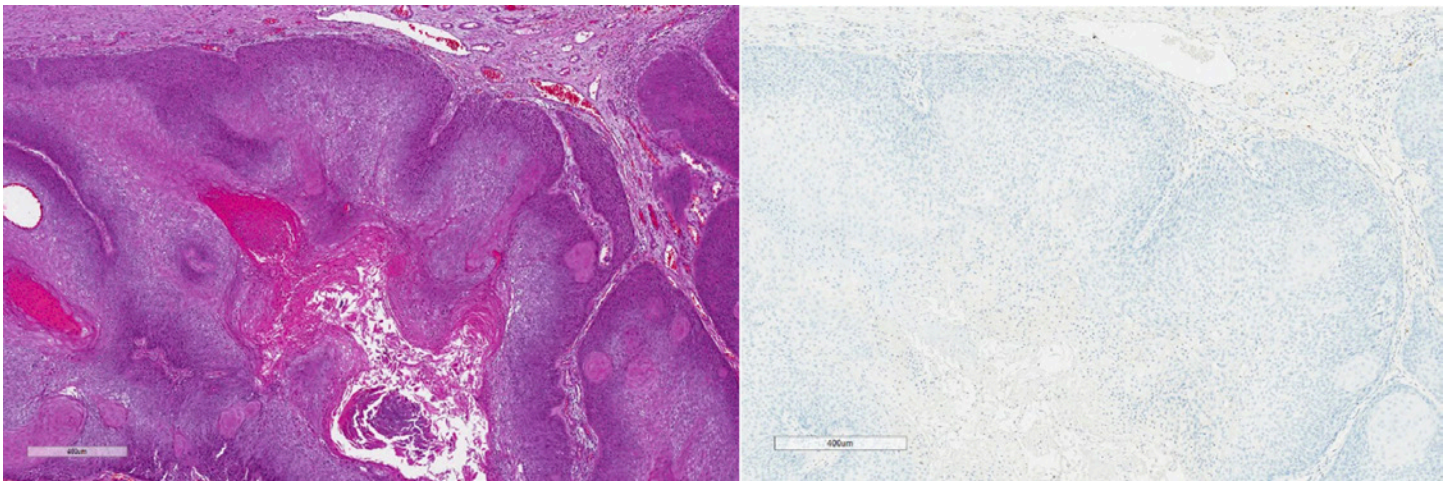


B2: p16 expression



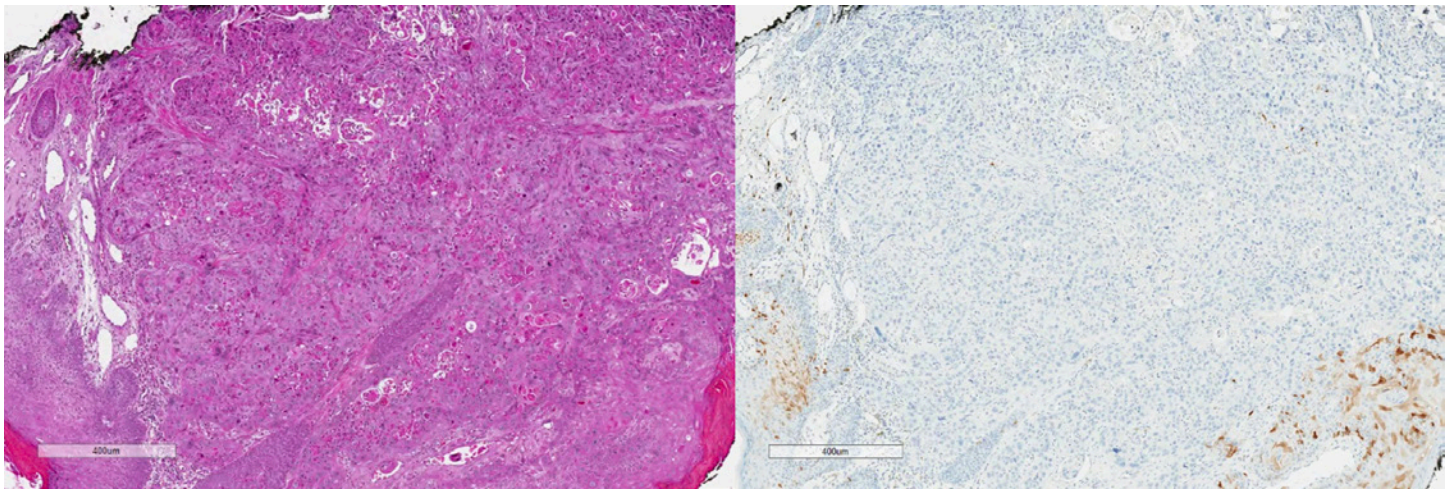
C. Case 3: Verrucous carcinoma, HPV16-negative (HPV6-positive), negative for p16 overexpression

C1: H&E **C2:** p16 expression



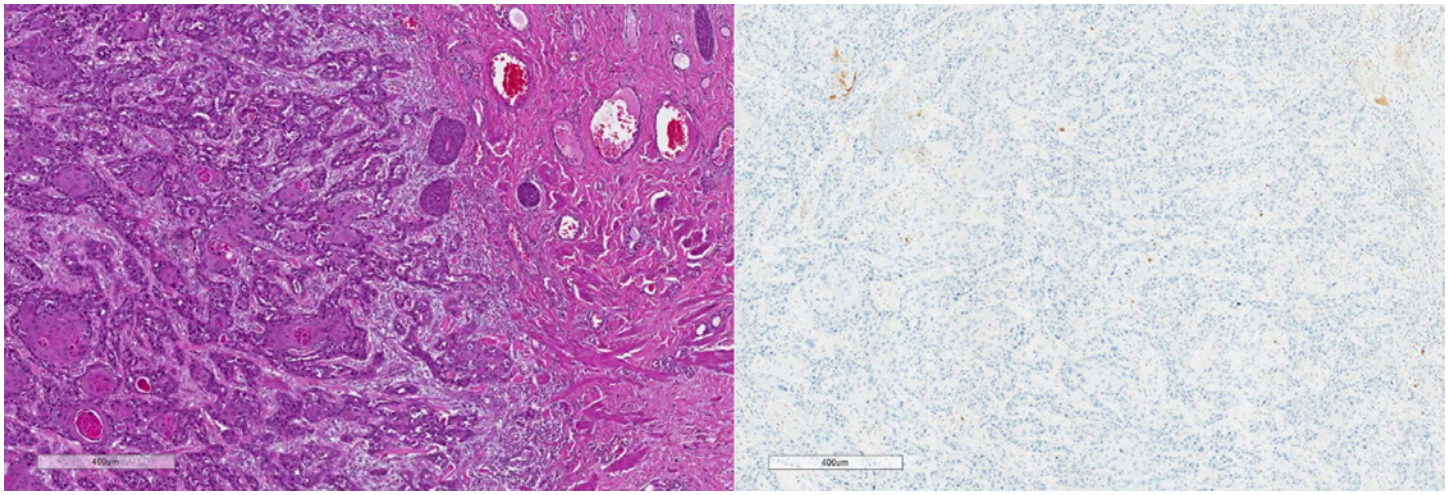
D. Case 4: SCC HPV16-negative (negative for all HPV types), negative for p16 overexpression

D1: H&E **D2:** p16 expression



E. Case 5: SCC HPV16-negative (negative for all HPV types), negative for p16 overexpression

E1: H&E **E2:** p16 expression



H&E, hematoxylin and eosin; HPV, human papillomavirus; SCC, squamous cell carcinoma.

A retrospective chart review conducted in 3 Rhode Island institutions identified 10 invasive scrotal SCC cases diagnosed during 1993 to 2003 and detected oncogenic HPV in 3 of the samples, all with p16 overexpression.[5] The same authors conducted a follow-up study to determine the specific HPV types present. They found that 5 in 10 cases of invasive scrotal SCCs were positive for oncogenic HPV, 2 of whom were positive for HPV16.[4] In another series of 6 scrotal SCCs from various geographic locations (Australia, Nigeria, and Spain), HPV16 was detected in basaloid and warty scrotal SCCs, but not usual SCC.[2] The authors hypothesized that usual SCC appeared to be associated with a p53 mutation—the protein associated with the TP53 tumor suppressor gene—where warty and basaloid subtypes were related to HPV infection.[2]

In our case series, we found that 1 case with verrucous (warty) carcinoma tested positive for HPV6, an HPV type associated with genital warts. HPV6 has been found in some anogenital SCCs, and its potential oncogenic role requires further study.[13-15] In addition, it is possible that some of the tumors gave false-negative HPV results due to inadequate preservation, nonrepresentative sampling, copy number below the limit of detection, or HPV types not included in the assay. Similar to vulvar cancer, HPV-negative scrotal cases could originate from alternative etiologic pathways.

Scrotal SCC was once most commonly associated with occupational exposure to carcinogens, including oil, soot, tar, and paraffin.[16] More recently, scrotal SCC is less associated with occupational hazards. Instead, scrotal SCC is linked with HPV exposure, immunocompromised states, and chronic skin infections.[16] The pathobiology of scrotal SCC is not well described, but the etiology of scrotal SCC is thought to resemble penile and vulvar SCC. According to the 2022 World Health Organization Classification of Tumors for Urinary System and Male Genital Organs, the skin of the penis and scrotum share similar skin histology and potential risk factors for skin damage or cancer.[17] The possible dual pathway of oncogenesis via (1) HPV16-related carcinogenesis, by which the viral proteins E6 and E7 alter normal tumor suppression by the TP53 and retinoblastoma genes (RB), or (2) via direct p53 mutation, would align with observed pathologic characteristics of penile cancers, perhaps reflecting unique skin histology in this anatomic region. Both HPV16-positive and HPV-negative cancers of the scrotum have been associated with overexpression of p53, indicating dysregulation of normal tumor suppression and possibly serving as a prognostic marker.[3] Some researchers have posited a potential association between HPV16 infection and these cancer subtypes, speculating that the squamous epithelium in the scrotal region has unique histological characteristics that may predispose to high-risk HPV infection (ie, stem cell-like or genital-like embryology despite the anatomic location on the skin).[2,17]

The introduction of the HPV vaccine has had an impact on the occurrence of cervical precancers[18] as well as vulvar, vaginal, and anal precancers.[19] Since 2006, the 4-valent vaccine, which protects against HPV types 6/11/16/18, has been available in the United States. As of 2015, the 9-valent vaccine is the only vaccine being distributed in the United States, which includes the types included in the 4-valent vaccine, plus 5 additional oncogenic types. In 2006, routine vaccination with the HPV vaccine among girls aged 11 to 12 years was recommended to prevent infection from HPV16 and HPV18, which cause nearly 70% of cervical cancers and 90% of HPV-associated anogenital cancers.[20] Current recommendations include routine vaccination with the 9-valent HPV vaccine for all persons aged 11 to 12 years, and catch-up vaccination for those who have not been adequately vaccinated through age 26 years.[21] Shared clinical decision-making is recommended for persons aged 26 to 45 years.[21] HPV vaccination coverage in the United States has gradually increased since its introduction. The percentage of adolescents aged 13 to 17 years receiving at least 1 dose of HPV vaccine increased from approximately 30% in 2011 to 76% in 2022.[22] Given its rarity, there are no currently accepted screening methods for scrotal cancer at the population level, so primary prevention with HPV vaccine is particularly important.

Although the International Agency for Research on Cancer does not currently consider scrotal SCC an HPV-associated cancer,[6] experts have confirmed that it plays a role,[2] but larger studies are needed to replicate findings. Currently, there is no systematic effort to routinely determine the HPV types in HPV-associated cancer cases in the United States. In this study, CDC used a novel methodology to obtain HPV-associated cancer tissue, leveraging partnerships with population-based cancer registries to obtain cancer tissue for HPV typing. A major limitation of our study was the small number of scrotal cancer cases from whom we were able to obtain tissue. Although our ability to obtain more samples and additional prior years of data was limited in the current study, this framework could be applied to future studies. In addition, we were limited to sociodemographic data available in the cancer registry, which does not include information on other relevant factors, including occupational exposures, sexual history, or immunocompromising conditions, such as HIV infection. There may be future opportunities to improve the data through linkages, such as links to immunization registries. In addition, we focused on only 2 markers most related to HPV-associated cancers, HPV DNA, and p16 overexpression. Other studies have used additional markers to help determine true cancer etiology, which would be helpful in a future iteration of this study. These markers include mRNA, which can confirm HPV is present and the demonstration of viral integration.

In our case series of 5 scrotal SCCs, 3 were HPV-positive, providing further evidence supporting a potential causal link between HPV and this rare cancer. With the reduction in environmental exposures that have traditionally caused SCC, HPV infection may become a more important etiologic factor in scrotal SCC. Currently, scrotal SCC is not captured in HPV-associated cancer surveillance summaries, given its low frequency and the evolving but limited data to support a causal role of HPV. Additional studies with larger sample sizes will be crucial to elucidate the role that HPV plays in the development of scrotal cancer. Continued monitoring of scrotal cancer incidence rates will be important in evaluating the potential effects of the HPV vaccine on this cancer.

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Original Article

The Burden of Rare Cancers in North America

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Abstract: Background: Rare cancers are difficult to study owing to their infrequent diagnosis. Using aggregate incidence data from population-based cancer registries in Europe, the Surveillance of Rare Cancers in Europe project compiled a list of clinically relevant, topography and morphology defined rare cancers operationally defined as having a crude annual incidence rate of <6 per 100,000 persons. In 2020, this list of rare cancers was updated. The objective of this study was to assess the utility of a rare cancer recode variable for use in the Cancer in North America (CiNA) dataset and to provide a first look at the burden of rare cancers in Canada and the United States. Methods: Data were obtained from 62 registries in Canada and the United States that met North American Association of Central Cancer Registries (NAACCR) high-quality data standards. The list of rare cancers was programmed as a Rare Cancer Classification variable within SEER*Stat. SEER*Stat was used to estimate case counts and crude and age-specific incidence rates per 100,000 for cancers diagnosed 2015–2019 by age at diagnosis, country, and country-specific geographic regions in Canada and the United States, and by race/ethnicity in the United States. Results: In Canada and the United States, 21% and 22% of all invasive cancers were classified as rare, respectively. The percentage of rare cancers ranged between 18% to 21% across geographic regions in Canada and the United States. Children (aged 0–14 years) had the highest percentage and lowest incidence rates of rare cancers. The percentage of rare cancers decreased, and incidence increased with increasing age. In the United States, Hispanics had the highest percentage (27%) and non-Hispanic Whites and non-Hispanic Blacks the lowest percentage (21%) of rare cancers. Conclusions: While individual rare cancers are infrequently diagnosed, in aggregate, they account for a substantial percentage of all cancers diagnosed in the population and pose a substantial public health burden. We report variations in percentage of rare cancers by age, and race/ethnicity (United States only). Such variations in the burden of these cancers may suggest possible areas for public health research.

Key words: *cancer registries, North American Association of Central Cancer Registries (NAACCR), rare cancers, surveillance*

Introduction

Rare cancers comprise a group of heterogenous cancers defined as having a low frequency of diagnosis in the general population. However, these cancers, in aggregate, comprise a substantial percentage of all cancers.[1-5]

To standardize the definition of rare cancers, the Surveillance of Rare Cancers in Europe (RARECARE) project, in consultation with pathologists, hematologists, clinicians, and epidemiologists, used aggregate incidence data from population-based cancer registries in Europe to compile a list of clinically relevant topography- and morphology-defined rare cancers. An operational definition was proposed for rare cancers as those having an annual crude incidence rate of less than 6 cases per 100,000.[2] In 2020, the Joint Action on Rare Cancers (JARC), consisting of partners from health ministries, universities, public health agencies, oncological institutes, cancer registries, and patient organizations, reviewed and slightly revised the list of rare cancers and reaffirmed the operational definition of rare cancers based on a crude annual incidence rate of less than 6 cases per 100,000 population.[6]

Experts from RARECARE and JARC released a list of rare cancers grouped into 3 tiers.[2,6] The bottom tier (tier 3) comprised individual cancer entities and their corresponding ICD-O-3 topography and morphology codes.[7] These cancer entities were then rolled up into an additional 2 tiers that grouped cancers related to medical decision-making and management. Tier 2 contained clinically distinct categories of cancers having similar diagnostic and treatment approaches that could be used as eligibility criteria for a clinical trial. Tier 2 cancers were further grouped into 68 tier 1 major cancer categories of organizational importance (eg, patient referral).[2] For example, the more general tier 1 category, *epithelial tumors of breast,* includes tier 2 category *mammary Paget's disease of breast* (ICD-O topography C50 and ICD-O morphology codes 8540–8541, 8543) and tier 2 category *salivary gland type tumor of breast* (ICD-O topography C50 and ICD-O morphology codes 8200, 8430, 8550, and 8982). This standardized definition of rare cancers that are diagnostic and clinically related for decision-making allows for consistent categorization and comparisons of rare cancers across jurisdictions such as was recently reported between the United States and the European Union.[8]

In North America, population-based cancer registries operate in all 50 states, Puerto Rico, the District of Columbia, and select regional and metropolitan areas in the

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United States, as well as in all 13 provinces and territories in Canada. These registries collect information on all invasive cancers diagnosed in their jurisdiction. Invasive cancers collected by the registries includes in situ bladder cancers, which are considered invasive for the purpose of incidence reporting, and excludes basal and squamous cell skin cancers. All Canadian and US registries are members of the North American Association of Central Cancer Registries (NAACCR). Each year, NAACCR compiles incidence data from member registries whose data meet high quality data standards for inclusion in the Cancer Incidence in North America (CiNA) database.[9] CiNA data provide a unique opportunity to describe the burden of rare cancers in North America using high quality incidence data and the Rare Cancer Classification variable.

Methods

Data Source

CiNA incidence data for patients diagnosed with an invasive cancer between 2015 and 2019 were obtained from 51 registries covering 99% of the US population and 11 registries covering 74% of the Canadian population.[9] Topography and morphology information were coded according to the third edition of the *International Classification of Diseases for Oncology* (ICD-O-3).[6]

Using the 2020 updated list of rare cancers, the Surveillance, Epidemiology, and End Results (SEER) Program introduced a Rare Cancer Classification variable into SEER*Stat[10] that includes tier 1 and tier 2 cancer groups (**https://seer.cancer.gov/seerstat/variables/seer/raresiterecode/**). It should be noted that the Rare Cancer Classification variable includes recodes for all invasive cancers including rare, common, and other and not otherwise specified (NOS), including other morphology classifications not sufficient in number to warrant their own category or to be meaningfully grouped in separate clinically relevant categories. These classifications were applied to microscopically confirmed cases.

Statistical Analysis

CiNA data, available in SEER*Stat (version 8.4.2)[10], was used to generate case counts and crude and age-specific incidence rates per 100,000 for cancers diagnosed in Canada and the United States between 2015 and 2019. Rare cancer groups (tier 1 or tier 2) were further combined into an all-rare-cancers combined group.

Incidence rates were based on corresponding country- and age-specific population estimates. The US population estimates are curated by the National Cancer Institute for the purpose of cancer surveillance and made available in SEER*Stat (**https://seer.cancer.gov/data-software/uspopulations.html**). Population estimates for Canada were obtained directly from Statistics Canada. For sex-specific rare cancers, incidence rates were also based on corresponding sex-specific population estimates. The percentage of rare cancers were estimated by age, geographic region within country, and, in the United States only (because Canadian registries do not collect race information), by race and ethnicity, including Hispanic, non-Hispanic White (NHW), non-Hispanic Black (NHB), non-Hispanic Asian and Pacific Islander (NHAPI), and non-Hispanic American Indian/Alaskan Native (NHAIAN). NHAIAN estimates were restricted to residents of geographic areas within which Indian Health Service care is made available to members of an identified Indian community that resides in the area.[9] The percentage of rare cancers were expressed as the total number of microscopically confirmed rare cancers among all invasive cancers.

Results

Between 2015 and 2019, a total of 8,716,138 invasive cancer cases were diagnosed in the United States and 770,340 in Canada (Table 1). Of these cases, 8,123,869 (93.2%) were microscopically confirmed in the United States and 699,120 (90.8%) were microscopically confirmed in Canada. The majority of invasive cancer cases were identified as common (64.5% in the United States and 63.1% in Canada), followed by rare (21.5% in the United States and 20.6% in Canada), and other and NOS (5.8% in the United States and 6.0% in Canada). An additional 1.4% of cases in the United States and 1.1% of cases in Canada could not be classified as tier 1 or tier 2 cancers.

Approximately 375,545 and 31,713 rare cancers were diagnosed annually in the United States and Canada, respectively. Cases of rare cancers were distributed among 68 tier 1 and 234 tier 2 groups in both Canada and the United States (Table 2). Similar results were observed in both countries with one exception. Among these groups, two tier 2 groups were either rare in the United States or Canada but not in both countries based on crude annual incidence rates: squamous cell carcinoma with variants of oropharynx (6.3 and 5.1 per 100,000, respectively) and adenocarcinoma with variants of stomach (5.6 and 7.7 per 100,000, respectively).

In North America, children under the age of 5 years had the highest percentage of rare cancers (Figure 1). For each increasing 5-year age group, the percentage of rare cancers decreased until it stabilized at approximately 20% at age ≥55 years. Age-specific incidence of rare cancers increased with age for both all invasive cancers and all rare cancers, although the incidence of all invasive cancers was nearly 5-fold higher than that for rare cancers in the older age groups.

The percentage of rare cancers among all invasive cancers ranged from 18.4% in the Atlantic region of Canada to 20.9% in the western region of the United States (Figure 2).

In the United States, Hispanics of any race had the highest percentage of rare cancers (26.9%), followed by NHAPI (24.9%), NHAIAN (23.4%), NHB (21.1%), and NHW (20.9%) (Figure 3).

Discussion

While individual rare cancers are infrequently diagnosed, in aggregate, rare cancers account for a substantial percentage of all cancers diagnosed. These cancers pose a substantial public health burden in the United States and Canada. Patients are often diagnosed at a later stage of

Table 1. Number and Percent of Invasive Cancer Cases in the United States and Canada by Rare Cancer Classification, 2015–2019

	United States		*Canada*	
	n	**%**	**n**	**%**
Total invasive cases	8,716,138		770,340	
Microscopically confirmed	8,123,869	93.2%	699,120	90.8%
Common	5,622,673	64.5%	485,911	63.1%
Rare	1,877,726	21.5%	158,567	20.6%
Other and not otherwise specified	503,297	5.8%	46,191	6.0%
Not classified	120,173	1.4%	8,451	1.1%

Source of data: SEER*Stat Database: NAACCR Incidence Data—CiNA Research Data, 1995–2019, for Expanded Races, Standard File, Hofer—Rare cancer in North America (which includes data from CDC's National Program of Cancer Registries (NPCR), CCR's Provincial and Territorial Registries, and the NCI's Surveillance, Epidemiology and End Results (SEER) Registries), certified by the North American Association of Central Cancer Registries (NAACCR) as meeting high-quality incidence data standards for the specified time periods, submitted December 2021. ***United States:*** Alabama, Alaska, Arizona, Arkansas, California, Colorado, Connecticut, Delaware, District of Columbia, Florida, Georgia, Hawaii, Idaho, Illinois, Indiana, Iowa, Kansas, Kentucky, Louisiana, Maine, Maryland, Massachusetts, Michigan, Mississippi, Minnesota, Missouri, Montana, Nebraska, New Hampshire, New Jersey, New Mexico, New York, North Carolina, North Dakota, Ohio, Oklahoma, Oregon, Pennsylvania, Puerto Rico, Rhode Island, South Carolina, South Dakota, Tennessee, Texas, Utah, Vermont, Virginia, Washington, West Virginia, Wisconsin, Wyoming. ***Canada:*** Alberta, British Columbia, Manitoba, New Brunswick, Newfoundland and Labrador, Northwest Territory, Nunavut, Ontario, Prince Edward Island, Saskatchewan, Yukon. ***Note:*** These registries cover 99% and 74% of the United States and Canadian population, respectively.

Table 2. Average Annual Cancer Cases and Crude Incidence Rates Classified According to Rare Cancer Site Recode Variable, Canada and the United States, 2015–2019

	United States			*Canada*		
	Averaged annual			**Averaged annual**		
Rare Cancer Site Recode	**Rate**	**No.**	**Class.***	**Rate**	**No.**	**Class.**
1 EPITHELIAL TUMORS OF NASAL CAVITY AND SINUSES						
1.1 Squamous cell carcinoma with variants of nasal cavity and sinuses	0.396	6,436	R	0.421	575	R
1.2 Lymphoepithelial carcinoma of nasal cavity and sinuses	0.001	19	R	0.001	1	R
1.3 Undifferentiated carcinoma of nasal cavity and sinuses	0.027	440	R	0.031	42	R
1.4 Intestinal type adenocarcinoma of nasal cavity and sinuses	0.006	104	R	0.015	20	R
1.5 Other epithelial tumors of nasal cavity and sinuses	0.032	513	O	0.041	56	O
2 EPITHELIAL TUMORS OF NASOPHARYNX						
2.1 Squamous cell carcinoma with variants of nasopharynx	0.450	7,304	R	0.636	869	R
2.2 Papillary adenocarcinoma of nasopharynx	0.001	24	R	0.001	1	R
2.3 Other epithelial tumors of nasopharynx	0.081	1,312	O	0.122	167	O
3 EPITHELIAL TUMORS OF MAJOR SALIVARY GLANDS AND SALIVARY-GLAND TYPE TUMORS						
3.1 Epithelial tumor of major salivary glands	1.400	22,744	R	1.434	1,960	R
3.2 Salivary gland type tumor of head and neck	0.450	7,310	R	0.471	643	R
4 EPITHELIAL TUMORS OF HYPOPHARYNX AND LARYNX						
4.1 Squamous cell carcinoma with variants of hypopharynx	0.674	10,953	R	0.536	732	R
4.2 Squamous cell carcinoma with variants of larynx	3.625	58,868	R	2.500	3,416	R
4.3 Other epithelial tumors of hypopharynx and larynx	0.053	867	O	0.040	54	O
5 EPITHELIAL TUMORS OF OROPHARYNX						
5.1 Squamous cell carcinoma with variants of oropharynx	6.276	101,932	C	5.119	6,996	R
5.2 Other epithelial tumors of oropharynx	0.056	911	O	0.054	74	O
6 EPITHELIAL TUMORS OF ORAL CAVITY AND LIP						
6.1 Squamous cell carcinoma with variants of oral cavity	3.888	63,148	R	4.235	5,787	R
6.2 Squamous cell carcinoma with variants of lip	0.551	8,950	R	0.858	1,173	R
6.3 Other epithelial tumors of oral cavity and lip	0.046	742	O	0.070	96	O

Table 2, cont. Average Annual Cancer Cases and Crude Incidence Rates Classified According to Rare Cancer Site Recode Variable, Canada and the United States, 2015–2019

Rare Cancer Site Recode	*United States*			*Canada*		
	Averaged annual			Averaged annual		
	Rate	No.	Class.*	Rate	No.	Class.
7 EPITHELIAL TUMORS OF ESOPHAGUS						
7.1 Squamous cell carcinoma with variants of esophagus	1.499	24,342	R	1.767	2,415	R
7.2 Adenocarcinoma with variants of esophagus	3.592	58,340	R	3.677	5,025	R
7.3 Salivary gland type tumor of esophagus	0.001	18	R	0.000	0	R
7.4 Undifferentiated carcinoma of esophagus	0.005	78	R	0.016	22	R
7.5 Other epithelial tumors of esophagus	0.154	2,508	O	0.169	231	O
8 EPITHELIAL TUMORS OF STOMACH						
8.1 Adenocarcinoma with variants of stomach	5.608	91,076	R	7.697	10,518	C
8.2 Squamous cell carcinoma with variants of stomach	0.079	1,283	R	0.128	175	R
8.3 Salivary gland-type tumor of stomach	0.000	4	R	0.000	0	R
8.4 Undifferentiated carcinoma of stomach	0.005	76	R	0.020	28	R
8.5 Other epithelial tumors of stomach	0.179	2,901	O	0.283	387	O
9 EPITHELIAL TUMORS OF SMALL INTESTINE						
9.1 Adenocarcinoma with variants of small intestine	0.855	13,892	R	1.086	1,484	R
9.2 Squamous cell carcinoma with variants of small intestine	0.006	97	R	0.017	23	R
9.3 Other epithelial tumors of small intestine	0.038	617	O	0.085	116	O
10 EPITHELIAL TUMORS OF COLON (including appendix)						
10.1 Adenocarcinoma with variants of colon	30.313	492,333	C	40.299	55,071	C
10.2 Squamous cell carcinoma with variants of colon	0.023	372	R	0.018	25	R
10.3 Fibromixoma and low grade mucinous adenocarcinoma of the appendix	0.344	5,593	R	0.345	471	R
10.4 Other epithelial tumors of colon (including appendix)	0.469	7,621	O	0.431	589	O
11 EPITHELIAL TUMORS OF RECTUM						
11.1 Adenocarcinoma with variants of rectum	8.284	134,538	C	13.886	18,976	C
11.2 Squamous cell carcinoma with variants of rectum	0.295	4,792	R	0.138	188	R
11.3 Other epithelial tumors of rectum	0.132	2,144	O	0.162	222	O
12 EPITHELIAL TUMORS OF ANAL CANAL						
12.1 Squamous cell carcinoma with variants of anal canal	2.046	33,232	R	1.766	2,413	R
12.2 Adenocarcinoma with variants of anal canal	0.214	3,477	R	0.263	359	R
12.3 Pagets disease of anal canal	0.006	102	R	0.020	27	R
12.4 Other epithelial tumors of anal canal	0.027	446	O	0.022	30	O
13 EPITHELIAL TUMORS OF PANCREAS						
13.1 Adenocarcinoma with variants of pancreas	11.865	192,699	C	8.975	12,265	C
13.2 Squamous cell carcinoma with variants of pancreas	0.036	591	R	0.029	40	R
13.3 Acinar cell carcinoma of pancreas	0.044	720	R	0.031	42	R
13.4 Mucinous cystadenocarcinoma of pancreas (invasive)	0.008	128	R	0.006	8	R
13.5 Intraductal papillary mucinous carcinoma invasive of pancreas	0.047	759	R	0.070	96	R
13.6 Solid pseudopapillary carcinoma of pancreas	0.053	867	R	0.027	37	R
13.7 Serous cystadenocarcinoma of pancreas	0.000	8	R	0.000	0	R
13.8 Carcinoma with osteoclast-like giant cells of pancreas	0.008	123	R	0.007	9	R
13.9 Other epithelial tumors of pancreas	0.221	3,589	O	0.164	224	O

Table 2, cont. Average Annual Cancer Cases and Crude Incidence Rates Classified According to Rare Cancer Site Recode Variable, Canada and the United States, 2015–2019

Rare Cancer Site Recode	*United States*			*Canada*		
	Averaged annual			Averaged annual		
	Rate	No.	Class.*	Rate	No.	Class.
14 EPITHELIAL TUMORS OF LIVER AND INTRAHEPATIC BILE TRACT (IBT)						
14.1 Hepatocellular carcinoma of Liver and IBT	4.241	68,874	R	3.117	4,259	R
14.2 Hepatocellular carcinoma, fibrolamellar	0.019	307	R	0.013	18	R
14.3 Cholangiocarcinoma of IBT	1.546	25,115	R	1.290	1,763	R
14.4 Adenocarcinoma with variants of liver and IBT	0.336	5,460	R	0.411	562	R
14.5 Undifferentiated carcinoma of liver and IBT	0.002	26	R	0.004	6	R
14.6 Squamous cell carcinoma with variants of liver and IBT	0.007	110	R	0.007	10	R
14.7 Bile duct cystadenocarcinoma of IBT	0.001	18	R	0.001	1	R
14.8 Other epithelial tumors of liver and intrahepatic bile tract (IBT)	0.114	1,844	O	0.083	114	O
15 EPITHELIAL TUMORS OF GALLBLADDER AND EXTRAHEPATIC BILIARY TRACT (EBT)						
15.1 Adenocarcinoma with variants of gallbladder	1.085	17,623	R	1.024	1,399	R
15.2 Adenocarcinoma with variants of EBT	1.761	28,607	R	2.645	3,615	R
15.3 Squamous cell carcinoma of gallbladder and EBT	0.025	412	R	0.019	26	R
15.4 Oth epithelial tumors of gallbladder and extrahepatic biliary tract (EBT)	0.099	1,600	O	0.207	283	O
16 EPITHELIAL TUMORS OF TRACHEA						
16.1 Squamous cell carcinoma with variants of trachea	0.036	580	R	0.047	64	R
16.2 Adenocarcinoma with variants of trachea	0.002	39	R	0.013	18	R
16.3 Salivary gland type tumor of trachea	0.010	165	R	0.014	19	R
16.4 Other epithelial tumors of trachea	0.002	35	O	0.013	18	O
17 EPITHELIAL TUMORS OF LUNG						
17.1 Squamous cell carcinoma with variants of lung	14.625	237,529	C	11.668	15,945	C
17.2 Adenocarcinoma with variants of lung	29.404	477,557	C	31.231	42,680	C
17.3 Adenosquamous carcinoma of lung	0.679	11,035	R	0.421	576	R
17.4 Large cell carcinoma of lung	0.239	3,879	R	0.239	327	R
17.5 Poorly differentiated endocrine carcinoma of lung	9.496	154,225	C	7.999	10,931	C
17.6 Salivary gland type tumor of lung	0.053	868	R	0.043	59	R
17.7 Sarcomatoid carcinoma of lung	0.413	6,710	R	0.327	447	R
17.8 Other epithelial tumors of lung	4.482	72,792	O	5.354	7,317	O
18 EPITHELIAL TUMORS OF THYMUS						
18.1 Malignant thymoma	0.301	4,892	R	0.334	457	R
18.2 Squamous cell carcinoma of thymus	0.044	720	R	0.060	82	R
18.3 Adenocarcinoma with variants of thymus	0.007	113	R	0.012	17	R
18.4 Other epithelial tumors of thymus	0.013	205	O	0.011	15	O
19 EPITHELIAL TUMORS OF BREAST						
19.1 Inv carcinoma of no special type-NST (obs Invasive ductal carc of breast)	65.047	1,056,462	C	63.746	87,114	C
19.2 Invasive lobular carcinoma of breast	8.053	130,798	C	6.929	9,469	C
19.3 Mammary Pagets disease of breast	0.177	2,876	R	0.376	514	R
19.4 Special types of adenocarcinoma of breast	2.536	41,183	R	2.661	3,637	R
19.5 Metaplastic carcinoma of breast	0.448	7,283	R	0.544	743	R
19.6 Salivary gland type tumor of breast	0.076	1,229	R	0.053	73	R
19.7 Other epithelial tumors of breast	1.703	27,658	O	1.603	2,191	O

Table 2, cont. Average Annual Cancer Cases and Crude Incidence Rates Classified According to Rare Cancer Site Recode Variable, Canada and the United States, 2015–2019

	United States			*Canada*		
	Averaged annual			Averaged annual		
Rare Cancer Site Recode	Rate	No.	Class.*	Rate	No.	Class.
20 EPITHELIAL TUMORS OF CORPUS UTERI (female cases)						
20.1 Adenocarcinoma with variants of corpus uteri	27.419	226,143	C	30.333	20,889	C
20.2 Squamous cell carcinoma with variants of corpus uteri	0.081	672	R	0.049	34	R
20.3 Adenoid cystic carcinoma of corpus uteri	0.000	0	R	0.000	0	R
20.4 Clear cell adenocarcinoma, NOS	0.483	3,986	R	0.508	350	R
20.5 Serous (papillary) carcinoma	2.755	22,721	R	2.814	1,938	R
20.6 Mullerian mixed tumor	1.642	13,544	R	1.342	924	R
20.7 Other epithelial tumors of corpus uteri	0.396	3,267	O	0.556	383	O
21 EPITHELIAL TUMORS OF CERVIX UTERI (female cases)						
21.1 Squamous cell carcinoma with variants of cervix uteri	5.096	42,027	R	5.564	3,832	R
21.2 Adenocarcinoma with variants of cervix uteri	1.967	16,226	R	2.139	1,473	R
21.3 Undifferentiated carcinoma of cervix uteri	0.008	67	R	0.003	2	R
21.4 Mullerian mixed tumor of cervix uteri	0.048	392	R	0.023	16	R
21.5 Other epithelial tumors of cervix uteri	0.452	3,725	O	0.369	254	O
22 EPITHELIAL TUMORS OF OVARY AND FALLOPPIAN TUBE (female cases)						
22.1 Adenocarcinoma with variants of ovary	8.425	69,488	C	10.085	6,945	C
22.2 Mucinous adenocarcinoma of ovary	0.654	5,390	R	0.754	519	R
22.3 Clear cell adenocarcinoma of ovary	0.683	5,629	R	1.000	689	R
22.4 Primary peritoneal serous/papillary carcinoma	0.679	5,604	R	0.378	260	R
22.5 Mullerian mixed tumor of ovary and falloppian tube	0.466	3,846	R	0.392	270	R
22.6 Adenocarcinoma with variants of fallopian tube	1.489	12,283	R	1.208	832	R
22.7 Other epithelial tumors of ovary and falloppian tube	0.756	6,239	O	0.575	396	O
23 NON EPITHELIAL TUMORS OF OVARY (female cases)						
23.1 Sex cord tumor of ovary	0.303	2,499	R	0.177	122	R
23.2 Malignant/Immature teratoma of ovary	0.115	947	R	0.154	106	R
23.3 Germ cell tumor of ovary	0.188	1,552	R	0.163	112	R
23.4 Other non epithelial tumors of ovary	0.000	1	O	0.000	0	O
24 EPITHELIAL TUMORS OF VULVA AND VAGINA (female cases)						
24.1 Squamous cell carcinoma with variants of vulva and vagina	3.321	27,394	R	4.213	2,901	R
24.2 Adenocarcinoma with variants of vulva and vagina	0.183	1,507	R	0.331	228	R
24.3 Pagets disease of vulva and vagina	0.167	1,376	R	0.274	189	R
24.4 Undifferentiated carcinoma of vulva and vagina	0.001	9	R	0.001	1	R
24.5 Mullerian mixed tumor of vulva and vagina	0.012	99	R	0.015	10	R
24.6 Other epithelial tumors of vulva and vagina	0.078	644	O	0.102	70	O
25 TROPHOBLASTIC TUMORS OF PLACENTA (female cases)						
25.1 Choriocarcinoma of placenta	0.045	372	R	0.036	25	R
25.2 Other trophoblastic tumors of placenta	0.011	89	O	0.006	4	O

Table 2, cont. Average Annual Cancer Cases and Crude Incidence Rates Classified According to Rare Cancer Site Recode Variable, Canada and the United States, 2015–2019

	United States			*Canada*		
	Averaged annual			Averaged annual		
Rare Cancer Site Recode	Rate	No.	Class.*	Rate	No.	Class.
26 EPITHELIAL TUMORS OF PROSTATE (male cases)						
26.1 Adenocarcinoma with variants of prostate	127.317	1,017,764	C	117.777	79,843	C
26.2 Squamous cell carcinoma with variants of prostate	0.014	113	R	0.022	15	R
26.3 Infiltrating duct carcinoma of prostate	0.258	2,060	R	0.353	239	R
26.4 Transitional cell carcinoma of prostate	0.017	139	R	0.022	15	R
26.5 Basal cell adenocarcinoma of prostate	0.004	34	R	0.004	3	R
26.6 Other epithelial tumors of prostate	1.380	11,032	O	0.850	576	O
27 TESTICULAR AND PARATESTICULAR CANCERS (male cases)						
27.1 Paratesticular adenocarcinoma with variants	0.001	9	R	0.004	3	R
27.2 Non seminomatous testicular cancer	2.385	19,063	R	2.548	1,727	R
27.3 Seminomatous testicular cancer	2.877	22,995	R	3.543	2,402	R
27.4 Spermatocytic seminoma	0.021	247	R	0.066	45	R
27.5 Teratoma with malignant transformation	0.003	23	R	0.009	6	R
27.6 Testicular sex cord cancer	0.042	332	R	0.038	26	R
27.7 Other testicular and paratesticular cancers	0.129	1,035	O	0.068	46	O
28 EPITHELIAL TUMORS OF PENIS (male case)						
28.1 Squamous cell carcinoma with variants of penis	0.890	7,115	R	1.242	842	R
28.2 Adenocarcinoma with variants of penis	0.008	63	R	0.024	16	R
28.3 Other epithelial tumors of penis	0.014	110	O	0.024	16	O
29 EPITHELIAL TUMORS OF KIDNEY						
29.1 Renal cell carcinoma with variants	16.895	274,398	C	14.882	20,338	C
29.2 Squamous cell carcinoma spindle cell type of kidney	0.005	81	R	0.010	14	R
29.3 Squamous cell carcinoma with variants of kidney	0.012	192	R	0.024	33	R
29.4 Other epithelial tumors of the kidney	0.145	2,355	O	0.244	334	O
30 EPITHELIAL TUMORS OF PELVIS AND URETER						
30.1 Transitional cell carcinoma of pelvis and ureter	1.666	27,062	R	1.455	1,989	R
30.2 Squamous cell carcinoma with variants of pelvis and ureter	0.022	354	R	0.017	23	R
30.3 Adenocarcinoma with variants of pelvis and ureter	0.018	289	R	0.032	44	R
30.4 Other epithelial tumors of pelvis and ureter	0.028	455	O	0.044	60	O
31 EPITHELIAL TUMORS OF URETHRA				0.138		
31.1 Transitional cell carcinoma of urethra	0.084	1,365	R	0.072	98	R
31.2 Squamous cell carcinoma with variants of urethra	0.045	724	R	0.039	53	R
31.3 Adenocarcinoma with variants of urethra	0.033	532	R	0.016	22	R
31.4 Other epithelial tumors of urethra	0.008	124	O	0.011	15	O
32 EPITHELIAL TUMORS OF BLADDER						
32.1 Transitional cell carcinoma of bladder	21.720	352,767	C	26.809	36,637	C
32.2 Squamous cell carcinoma with variants of bladder	0.296	4,807	R	0.234	320	R
32.3 Adenocarcinoma with variants of bladder	0.196	3,183	R	0.217	296	R
32.4 Salivary gland type tumor of bladder	0.000	0	R	0.000	0	R
32.5 Other epithelial tumors of bladder	0.344	5,584	O	0.263	359	O

Table 2, cont. Average Annual Cancer Cases and Crude Incidence Rates Classified According to Rare Cancer Site Recode Variable, Canada and the United States, 2015–2019

	United States			*Canada*		
	Averaged annual			Averaged annual		
Rare Cancer Site Recode	Rate	No.	Class.*	Rate	No.	Class.
33 EPITHELIAL TUMORS OF EYE AND ADNEXA						
33.1 Squamous cell carcinoma with variants of eye and adnexa	0.087	1,418	R	0.111	152	R
33.2 Adenocarcinoma with variants of eye and adnexa	0.021	339	R	0.029	39	R
33.3 Other epithelial tumors of eye and adnexa	0.013	204	O	0.013	18	O
34 EPITHELIAL TUMORS OF MIDDLE EAR						
34.1 Squamous cell carcinoma with variants middle ear	0.008	134	R	0.010	14	R
34.2 Adenocarcinoma with variants of middle ear	0.003	56	R	0.000	0	R
34.3 Other Adenocarcinoma with variants of middle ear	0.001	11	O	0.000	0	O
35 MALIGNANT MESOTHELIOMA						
35.1 Mesothelioma of pleura and pericardium	0.724	11,760	R	1.220	1,667	R
35.2 Mesothelioma of peritoneum and tunica vaginalis	0.112	1,822	R	0.152	208	R
35.3 Other malignant mesothelioma	0.052	846	O	0.020	28	O
36 MALIGNANT SKIN MELANOMA						
36.1 Superficial spreading melanoma	9.489	154,123	C	8.397	11,475	C
36.2 Nodular melanoma	2.007	32,599	R	2.705	3,697	R
36.3 Lentigo maligna melanoma	1.975	32,083	R	1.768	2,416	R
36.4 Acral lentiginous melanoma malignant	0.274	4,451	R	0.310	424	R
36.5 Other malignant skin melanoma	12.508	203,145	O	11.587	15,834	O
37 MALIGNANT MELANOMA OF MUCOSA AND EXTRACUTANEOUS	0.200	3,251	R	0.258	353	R
38 MALIGNANT MELANOMA OF EYE						
38.1 Malignant melanoma of conjunctiva	0.037	599	R	0.050	68	R
38.2 Malignant melanoma of uvea	0.330	5,353	R	0.251	343	R
38.3 Other malignant melanoma of eye	0.025	400	O	0.023	31	O
39 EPITHELIAL TUMORS OF SKIN						
39.1 Basal cell carcinoma of skin	0.011	178	R	0.021	29	R
39.2 Squamous cell carcinoma with variants of skin	0.035	566	R	0.031	43	R
39.3 Other epithelial tumors of skin	0.006	104	O	0.009	12	O
40 ADNEXAL CARCINOMAS OF SKIN						
40.1 Nodular hidradenoma, malignant	0.023	370	R	0.020	27	R
40.2 Sebaceous adenocarcinoma	0.244	3,970	R	0.279	381	R
40.3 Adenoid cystic carcinoma	0.018	293	R	0.053	73	R
40.4 Pagets disease extramammary	0.058	946	R	0.107	146	R
40.5 Apocrine adenocarcinoma	0.013	211	R	0.026	35	R
40.6 Mucinous adenocarcinoma	0.035	561	R	0.031	43	R
40.7 Pilomatrix carcinoma	0.000	0	R	0.000	0	R
40.8 Eccrine poroma, malignant	0.061	986	R	0.106	145	R
40.9 Mixed tumor malignant, NOS	0.003	56	R	0.006	8	R
40.10 Sclerosing sweat duct carcinoma	0.034	550	R	0.081	111	R
40.11 Malignant eccrine spiradenoma	0.006	97	R	0.013	18	R
40.12 Tubular adenocarcinoma	0.000	0	R	0.000	0	R
40.13 Eccrine papillary adenocarcinoma	0.014	229	R	0.023	31	R
40.14 Other adnexal carcinomas of skin	0.141	2,295	O	0.247	338	O

Table 2, cont. Average Annual Cancer Cases and Crude Incidence Rates Classified According to Rare Cancer Site Recode Variable, Canada and the United States, 2015–2019

Rare Cancer Site Recode	*United States*			*Canada*		
	Averaged annual			Averaged annual		
	Rate	No.	Class.*	Rate	No.	Class.
41 NEUROBLASTOMA AND GANGLIONEUROBLASTOMA	0.205	3,323	R	0.173	236	R
42 NEPHROBLASTOMA	0.147	2,383	R	0.120	164	R
43 EMBRYONAL TUMORS OF EYE						
43.1 Retinoblastoma	0.046	742	R	0.020	28	R
43.2 Medulloepithelioma	0.000	4	R	0.000	0	R
44 HEPATOBLASTOMA	0.049	798	R	0.036	49	R
45 PLEUROPULMONARY BLASTOMA	0.007	113	R	0.005	7	R
46 PANCREATOBLASTOMA	0.002	36	R	0.002	3	R
47 OLFACTORY NEUROBLASTOMA	0.054	869	R	0.048	65	R
48 ODONTOGENIC MALIGNANT TUMORS						
48.1 Odontogenic tumor, malignant	0.008	130	R	0.009	12	R
48.2 Clear cell odontogenic carcinoma	0.001	12	R	0.002	3	R
48.3 Ghost cell odontogenic carcinoma	0.000	5	R	0.000	0	R
48.4 Other odontogenic malignant tumors	0.015	238	O	0.010	13	O
49 EXTRAGONADAL GERM CELL TUMORS						
49.1 Non seminomatous germ cell tumor	0.092	1,494	R	0.088	120	R
49.2 Seminomatous germ cell tumor	0.018	285	R	0.016	22	R
49.3 Germ cell tumor of Central Nervous System (CNS)	0.061	985	R	0.069	94	R
49.4 Other extragonadal germ cell tumors	0.018	288	O	0.015	20	O
50 SOFT TISSUE SARCOMA						
50.1 Soft tissue sarcoma of head and neck	0.328	5,332	R	0.327	447	R
50.2 Soft tissue sarcoma of limbs	1.607	26,095	R	1.698	2,321	R
50.3 Soft tissue sarcoma of superficial trunk	0.785	12,743	R	0.757	1,035	R
50.4 Soft tissue sarcoma of mediastinum	0.031	498	R	0.031	42	R
50.5 Soft tissue sarcoma of heart	0.025	414	R	0.020	28	R
50.6 Soft tissue sarcoma of breast	0.208	3,375	R	0.279	381	R
50.7 Soft tissue sarcoma of uterus	0.678	11,018	R	0.658	899	R
50.8 Soft tissue sarcoma of paratestis	0.047	763	R	0.073	100	R
50.9 Soft tissue sarcomas of other genitourinary tract	0.165	2,677	R	0.196	268	R
50.10 Soft tissue sarcoma of viscera	0.259	4,212	R	0.222	304	R
50.11 Soft tissue sarcoma of retroperitoneum and peritoneum	0.409	6,646	R	0.501	684	R
50.12 Soft tissue sarcoma of pelvis	0.338	5,497	R	0.351	480	R
50.13 Soft tissue sarcoma of skin	0.544	8,830	R	0.914	1,249	R
50.14 Soft tissue sarcoma of paraorbit	0.007	114	R	0.008	11	R
50.15 Soft tissue sarcoma of brain and other parts of the nervous system	0.123	2,001	R	0.121	166	R
50.16 Embryonal rhabdomyosarcoma of soft tissue	0.076	1,231	R	0.072	98	R
50.17 Alveolar rhabdomyosarcoma of soft tissue	0.048	773	R	0.051	70	R
50.18 Ewings sarcoma of soft tissue	0.086	1,397	R	0.093	127	R
50.19 Other soft tissue sarcoma	0.249	4,045	O	0.165	225	O

Table 2, cont. Average Annual Cancer Cases and Crude Incidence Rates Classified According to Rare Cancer Site Recode Variable, Canada and the United States, 2015–2019

	United States			*Canada*		
	Averaged annual			Averaged annual		
Rare Cancer Site Recode	Rate	No.	Class.*	Rate	No.	Class.
51 BONE SARCOMA						
51.1 Osteogenic sarcoma	0.290	4,707	R	0.276	377	R
51.2 Chondrogenic sarcoma	0.281	4,562	R	0.330	451	R
51.3 Notochordal sarcoma, chordoma	0.112	1,812	R	0.124	170	R
51.4 Vascular sarcoma	0.015	245	R	0.019	26	R
51.5 Ewings sarcoma	0.133	2,160	R	0.112	153	R
51.6 Other high grade sarcomas (fibrosarcoma, malignant fibrous histiocytoma)	0.010	162	R	0.004	6	R
51.7 Other bone sarcoma	0.102	1,649	O	0.074	101	O
52 GASTROINTESTINAL STROMAL SARCOMA	1.215	19,733	R	0.895	1,223	R
53 KAPOSIS SARCOMA	0.318	5,159	R	0.252	344	R
54 NET GEP						
54.1 Well diff not functioning endocrine carc of pancreas and digestive tract	5.406	87,809	R	4.813	6,578	R
54.2 Well diff functioning endocrine carc of pancreas and digestive tract	0.013	219	R	0.029	40	R
54.3 Poorly differentiated endocrine carcinoma of pancreas and digestive tract	1.419	23,048	R	1.630	2,228	R
54.4 Malignant mixed pancreatic endocrine and exocrine tumor	0.011	173	R	0.005	7	R
54.5 Other NET GEP	0.000	0	O	0.000	0	O
55 NET LUNG/TYPICAL AND ATYPICAL CARCINOID OF THE LUNG	1.290	20,949	R	1.191	1,627	R
56 NET OTHER SITES						
56.1 Pheochromocytoma, malignant	0.034	548	R	0.032	44	R
56.2 Paraganglioma	0.031	509	R	0.026	36	R
56.3 Endocrine carcinoma of thyroid gland	0.282	4,578	R	0.250	341	R
56.4 Neuroendocrine carcinoma of skin	0.839	13,629	R	0.833	1,139	R
56.5 Neuroendocrine carcinoma of other sites	1.559	25,325	R	1.013	1,385	R
57 CARCINOMAS OF PITUITARY GLAND						
57.1 Pituitary carcinoma	0.004	58	R	0.004	5	R
57.2 Other carcinomas of pituitary gland	0.002	30	O	0.004	5	O
58 CARCINOMAS OF THYROID GLAND						
58.1 Papillary adenocarcinoma, NOS	8.753	142,164	C	8.571	11,713	C
58.2 Follicular carcinoma, NOS	0.495	8,045	R	0.254	347	R
58.3 Undifferentiated/anaplastic carcinoma	0.141	2,285	R	0.135	185	R
58.4 Mucoepidermoid carcinoma	0.002	36	R	0.001	2	R
58.5 Mucinous carcinoma	0.000	1	R	0.000	0	R
58.6 Spindle cell tumor with thymus-like differentiation (SETTLE)	0.000	6	R	0.001	2	R
58.7 Carcinoma showing thymus-like differentiation (CASTLE)	0.000	3	R	0.001	1	R
58.8 Other carcinomas of thyroid gland	4.967	80,671	O	7.245	9,901	O
59 CARCINOMAS OF PARATHYROID GLAND	0.027	445	R	0.032	44	R
60 CARCINOMAS OF ADRENAL CORTEX						
60.1 Adrenal cortical carcinoma	0.120	1,943	R	0.147	201	R
60.2 Other carcinomas of adrenal cortex	0.021	341	O	0.045	62	O

Table 2, cont. Average Annual Cancer Cases and Crude Incidence Rates Classified According to Rare Cancer Site Recode Variable, Canada and the United States, 2015–2019

Rare Cancer Site Recode	*United States*			*Canada*		
	Averaged annual			Averaged annual		
	Rate	No.	Class.*	Rate	No.	Class.
61 TUMORS OF CENTRAL NERVOUS SYSTEM (CNS)						
61.1 Astrocytic tumors of CNS	4.803	78,015	R	5.002	6,835	R
61.2 Oligodendroglial tumors of CNS	0.335	5,442	R	0.448	612	R
61.3 Ependymal tumors of CNS	0.216	3,514	R	0.192	263	R
61.4 Neuronal and mixed neuronal-glial tumors	0.009	145	R	0.016	22	R
61.5 Choroid plexus carcinoma of CNS	0.007	118	R	0.003	4	R
61.6 Malignant meningiomas	0.078	1,262	R	0.080	110	R
61.7 Tumors of the pineal gland	0.027	440	R	0.026	36	R
61.8 Other tumors of central nervous system (CNS)	0.031	509	O	0.023	31	O
62 EMBRYONAL TUMORS OF CNS						
62.1 Medulloblastoma	0.090	1,456	R	0.088	120	R
62.2 Desmoplastic nodular medulloblastoma	0.027	431	R	0.024	33	R
62.3 Medulloblastoma, large cell/anaplastic	0.010	169	R	0.010	13	R
62.4 Medulloblastoma, WNT-activated	0.002	30	R	0.003	4	R
62.5 Medulloblastoma, SHH-activated and TP53-mutant	0.001	15	R	0.000	0	R
62.6 Medulloblastoma, non-WNT/non-SHH	0.008	138	R	0.004	6	R
62.7 CNS Embryonal tumor, NOS	0.014	235	R	0.014	19	R
62.8 CNS ganglioneuroblastoma	0.002	34	R	0.004	5	R
62.9 CNS neuroblastoma	0.009	152	R	0.010	13	R
62.10 CNS embryonal tumor with rhabdoid features	0.024	393	R	0.021	29	R
62.11 Medulloepithelioma, NOS	0.001	10	R	0.000	0	R
62.12 Embryonal tumor with multilayered rosettes, C19MC-related/NOS	0.002	29	R	0.001	2	R
62.13 Other embryonal tumors of CNS	0.003	56	O	0.001	1	O
63 LYMPHOID DISEASES						
63.1 Hodgkin lymphoma, classical	2.581	41,922	R	2.537	3,467	R
63.2 Hodgkin lymphoma nodular lymphocyte predominance	0.231	3,753	R	0.259	354	R
63.3 Precursor B/T lymphoblastic leukemia/lymphoblastic lymphoma (and Burkitt)	2.126	34,537	R	1.645	2,248	R
63.4 T cutaneous lymphoma (Sezary syn, Mycosis fung)	0.858	13,936	R	0.979	1,338	R
63.5 Other T cell lymphomas and NK cell neoplasms	1.297	21,061	R	1.464	2,000	R
63.6 Diffuse B lymphoma	8.108	131,678	C	8.849	12,093	C
63.7 Follicular B lymphoma	4.012	65,162	R	5.109	6,982	R
63.8 Hairy cell leukemia	0.302	4,901	R	0.350	478	R
63.9 Plasmacytoma/Multiple Myeloma (and Heavy chain diseases)	7.691	124,906	C	6.759	9,237	C
63.10 Other non Hodgkin, Mature B cell lymphoma	9.308	151,169	C	10.078	13,772	C
63.11 Mantle cell lymphoma	1.033	16,777	R	1.016	1,389	R
63.12 Prolymphocytic leukemia, B cell	0.032	513	R	0.024	33	R
63.13 Other lymphoid diseases	2.120	34,431	O	2.072	2,832	O
64 ACUTE MYELOID LEUKEMIA AND RELATED PRECURSOR NEOPLASMS						
64.1 Acute promyelocytic leukemia (AML with t(15;17) with variants	0.345	5,603	R	0.242	331	R
64.2 AML	4.767	77,422	R	4.491	6,137	R

Table 2, cont. Average Annual Cancer Cases and Crude Incidence Rates Classified According to Rare Cancer Site Recode Variable, Canada and the United States, 2015–2019

Rare Cancer Site Recode	*United States*			*Canada*		
	Averaged annual			Averaged annual		
	Rate	No.	Class.*	Rate	No.	Class.
65 MYELOID AND LYMPHOID NEOPLASMS	0.133	2,168	R	0.091	125	R
66 MYELOPROLIFERATIVE NEOPLASMS						
66.1 Chronic myeloid leukemia	1.447	23,499	R	1.182	1,615	R
66.2 Other myeloproliferative neoplasms	2.856	46,382	R	2.847	3,891	R
66.3 Mast cell tumor	0.063	1,025	R	0.134	183	R
67 MYELODYSPLASTIC SYNDROME AND MYELODYSPLASTIC/MYELOPROLIFERATIVE DISEASES						
67.1 Myelodysplastic syndrome with 5q syndrome	0.191	3,098	R	0.083	113	R
67.2 Other myelodysplastic syndrome	3.786	61,497	R	3.419	4,672	R
67.3 Chronic Myelomonocytic leukemia	0.554	8,995	R	0.727	993	R
67.4 Atypical chronic myeloid leukemia BCR/ABL negative	0.028	448	R	0.025	34	R
67.5 Other myelodysplastic syn and myelodysplastic/myeloproliferative diseases	0.682	11,069	O	1.494	2,042	O
68 HISTIOCYTIC AND DENDRITIC CELL NEOPLASMS						
68.1 Histiocytic malignancies	0.200	3,241	R	0.147	201	R
68.2 Lymph node accessory cell tumors	0.038	618	R	0.039	53	R
69 Not Classified	7.399	120,173		6.184	8,451	

Rates are per 100,000. *C, common; R, rare; O, other and not otherwise specified.

Figure 1. Percent of All Rare Cancers Among All Invasive Cancers and Age-Specific Incidence Rates of Rare Cancers by Age Group, North America, 2015–2019

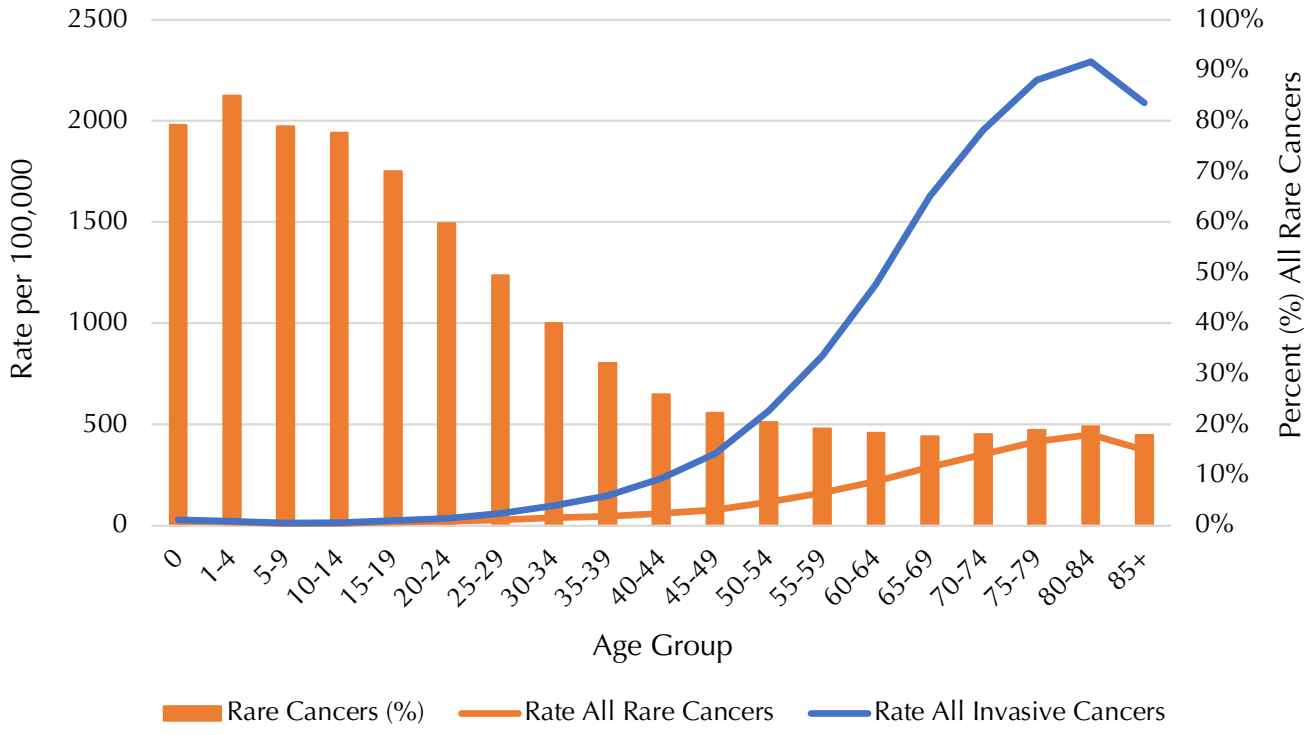


Figure 2. Percent of Rare Cancers Among All Invasive Cancers by Geographic Region, North America, 2015–2019

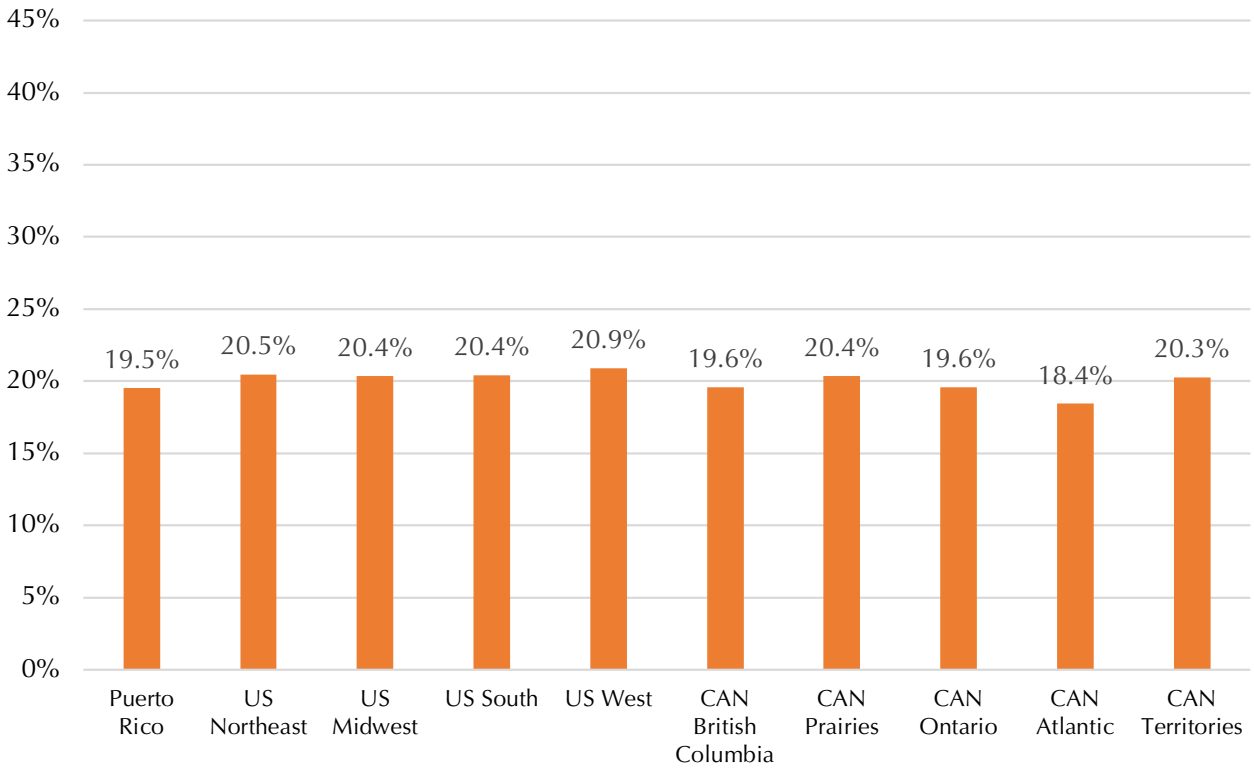
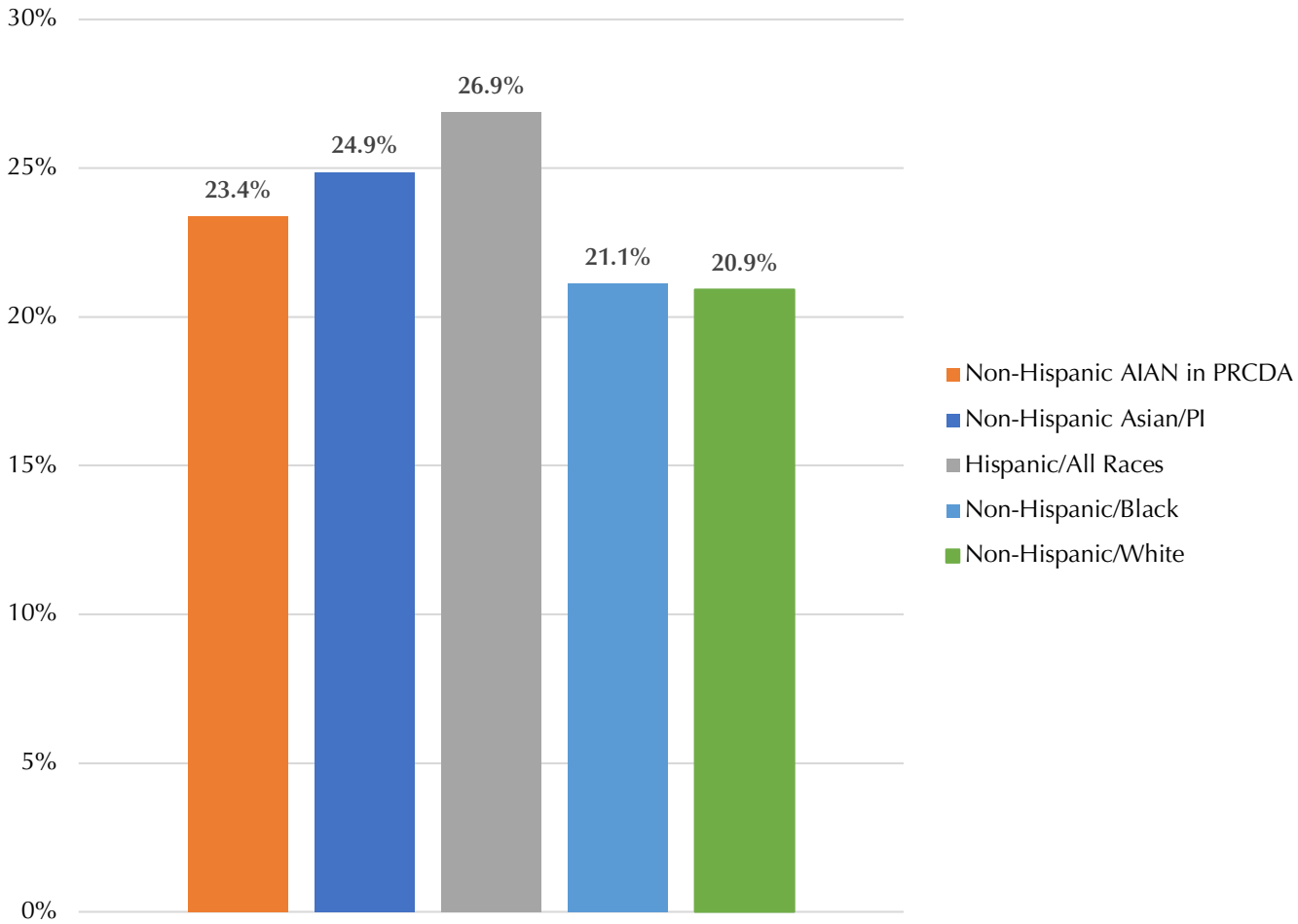


Figure 3. Percent of Rare Cancers Among All Invasive Cancers by Race/Ethnicity, United States, 2015–2019



disease and have worse outcomes than patients diagnosed with many of the more common cancers.[2,3,5] This is likely due to delays in accurate diagnosis, inadequate treatments, and fewer opportunities for patients to participate in clinical trials.[11,12] And the burden of rare cancers will likely increase as more molecular subsets of common cancers are identified and differentiated clinically.[13]

Using the operational definition and list of rare cancers proposed by RARECARE and updated by JARC as a standard definition, the percentage of rare cancers among all invasive cases in Canada and the United States was 21% and 22%, respectively, and comparable to that previously reported in the United States[1,3], Europe[2], and Australia.[5] The consistency of the percentages of rare cancers in different populations worldwide, including geographic areas within Canada and the United States, and the relatively low overall incidence of these cancers across all age groups does not support a strong role for exogenous factors in elevating a patient's risk for developing a rare cancer. The fact that rare cancers disproportionately impact younger ages may indicate more of a genetic component that would benefit from clinically relevant genomic assessments.[13]

Differences seen in the percentage of rare cancers by race and ethnicity in the United States is consistent with that reported by DeSantis.[3] However, caution is advised when interpreting population-based proportional differences. A higher percentage of rare cancers may result when there is a higher incidence of these cancers or when there is a lower incidence of common cancers. For instance, the incidence of common cancers of the colon, breast, prostate, lung, and bladder increases with increasing age and varies by race and ethnicity in the United States.[9] Variation in the incidence of common cancers may contribute to the disproportionate percentage of rare cancer observed in different racial and ethnic populations.

CiNA data is a comprehensive source of high-quality cancer incidence data covering 99% of the US population and 74% of the Canadian population. Incidence data from NAACCR member registries is comparable because all registries use standardized procedures for the collection and reporting of incidence data.[14] Each year, incidence data from member registries are evaluated to assess the quality, accuracy, and completeness of their data. Unusual topography and morphology combinations are flagged for manual review and verified by registry staff prior to data submission. Only data meeting high quality standards are pooled for inclusion in the CiNA research file. The low percentage of death-certificate only cases (1.8% in the United States and 1.0% in Canada, data not shown), the high level of microscopically confirmed cases (93% in the United States and 90% in Canada), and low percentage of cases not able to be classified (Table 1 and Table 2) attest to the quality and completeness of CiNA data.

However, our case counts likely reflect undercounts of the true burden of rare cancers in the population. The identification of rare cancers requires accurate and specific morphology information. The *other and NOS* group within the tier 1 cancer groups included nonspecific morphology codes (ie, ICD-O-3 8000-8001) that resulted in the cancer case not being assigned to a common or rare cancer group. The absence of specific morphology information may be due to a lack of such information being available or collected in the clinical setting, or because this information was not transmitted to the cancer registry. The inclusion of even a small number of additional cases could result in some tier 2 rare cancer groups being reassigned as common cancers. The threshold of less than 6 per 100,000 for defining rare cancers is arbitrary as demonstrated: two tier 2 groups were rare in either Canada or the United States, but not in both countries. However, the incidence of these cancers was similar in both countries. The cancer registry community should continue efforts to obtain detailed pathology information as available and to limit the use of nonspecific codes as much as possible

Furthermore, this study only included microscopically confirmed invasive cancer cases. Additional assessment is needed to describe the burden of rare cancers in non–microscopically confirmed cases as well as nonmalignant cancers. About 3% of all malignant cancers were excluded from this analysis as they were radiologically confirmed without microscopic confirmation (data not shown). Cancer registries collect some nonmalignant cancers, which include most in situ cancers and, beginning in 2004, benign, borderline, and in situ brain cancers. Radiologic confirmation is an important diagnosis tool for brain cancers, accounting for about 10% of all malignant and nearly 60% of all nonmalignant brain cancers in the CiNA dataset during this time period. Further evaluation for all cancers is needed for a more comprehensive understanding of the burden of rare cancers in North America. Also, future research in North America aimed at examining differences in stage distributions and survival among patients with rare cancer compared to common cancers is needed to understand their cumulative burden due to these unique challenges.

Cancer registries will continue to play a critical role in describing and monitoring the burden of rare cancers in the population and can serve as an important resource in the conduct of public health research. For example, cohort studies of rare cancers require complete and accurate diagnosis and follow-up information which is often not available through self-reported data and active follow-up.[15] The Virtual Pooled Registry Cancer Linkage System (VPR-CLS), which is coordinated through NAACCR (**https://www.naaccr.org/about-vpr-cls/),** could be leveraged to help provide this information. The VPR-CLS could also be used to link cancer outcomes data to tissue repositories to support genomic research.

Many factors have been linked to poorer outcomes in rare cancers, including accuracy and timeliness of diagnosis, lack of standard of care guidelines, or delayed and limited treatment options, including clinical trials.[2,3,5,11,16,17] Recent advances in precision medicine have allowed for novel approaches in clinical trials to accelerate progress in development of treatment and timeliness of updated standard of care guidelines for rare tumors.[17]

Next Steps

The Rare Cancer Classification variable will be available to approved researchers with the 1995–2021 CiNA research datasets in Spring of 2024 (**https://www.naaccr.org/cina-data-products-overview/**). We encourage additional evaluation of the variable and wider assessment of the burden of rare cancers using the CiNA dataset. NAACCR will develop resources to assist researchers in applying the rare cancer variable in their studies.

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Original Article

Using LexisNexis to Improve Social Security Number Information in the New York State Cancer Registry

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Abstract: Background: Social Security numbers (SSNs) collected by cancer surveillance registries in the United States are used for patient matching, deduplication, follow-up, and linkage studies. However, due to various reasons, a small proportion of patient records have missing or inaccurate SSNs. Recently, New York State Cancer Registry (NYSCR) data have been linked to LexisNexis data to obtain patient demographic information, including SSNs. The current study evaluated the feasibility of using LexisNexis to improve SSN information in the NYSCR. Materials and Methods: Patients diagnosed during the years 2005–2016, aged 21 or older, in the NYSCR were linked to LexisNexis data. For the matched patients, LexisNexis returned demographic information, including SSNs as available. Percentages of patients without LexisNexis matches or without LexisNexis SSNs were examined by demographic characteristics. We used multivariate logistic regression analyses to further evaluate how patient demographic characteristics affected the likelihood of no LexisNexis matches or of no SSNs returned. For patients with SSNs returned, LexisNexis SSNs were compared with registry SSNs. If patients had prior missing registry SSNs or if LexisNexis SSNs were inconsistent with registry SSNs, we used Match*Pro to review and verify match status. Registry SSNs were updated for those confirmed to be true matches. Improvement of SSNs was assessed based on percentage reduction of missingness. Results: Of 1,396,078 patient records submitted for LexisNexis linkage, 1.6% were not matched. Among those matched, 1.5% did not have SSNs returned. Multivariate logistic regression analyses indicated that patients who were female, Black, Asian Pacific Islander (API), Hispanic, born outside the United States, deceased, or living in poorer census tracts were more likely to not have LexisNexis matches, or to not have SSNs returned. Among 47,271 patients with missing registry SSNs (3.4%), 26,895 had SSNs returned from LexisNexis, and 24,919 were confirmed to be true matches. After registry SSNs updates, the percentage of SSN missingness was reduced to 1.7%, with a larger absolute reduction observed among those who were younger than 60 years, API, or alive. For 33,057 patients with inconsistent SSNs, 11,474 were due to incorrect consolidations of SSNs in the registry, and those SSNs were subsequently fixed. Conclusions: LexisNexis is a valuable resource for improving the quality of SSN information in registries. Our results showed that the overall percentage of patients with missing SSNs was reduced from 3.4% to 1.7% after LexisNexis linkage, and SSNs that were initially incorrectly consolidated for some patients were also identified and subsequently fixed. However, the magnitude of SSN improvement varied by patient demographic characteristics. Data quality improvements often require resources, and this evaluation can assist registries with decisions related to similar efforts.

Key words: *LexisNexis, Social Security number*

Introduction

Population-based central cancer registries in the United States collect data on patient demographics, cancer diagnosis, staging, treatment, and follow-up information for cancer patients diagnosed in their catchment areas.[1] Social Security number (SSN) is a standard data item that has been routinely collected. SSN is an important data element that is used for patient matching, deduplication, follow-up, and linkage studies.[2,3] However, a small proportion of patient records have missing or inaccurate SSNs in registries.

The NYSCR, funded by the Centers for Disease Control and Prevention's National Program of Cancer Registries (NPCR) since 1995 and by the National Cancer Institute's Surveillance, Epidemiology, and End Results (SEER) program since 2018, is one of the largest registries in the nation, collecting data on more than 120,000 newly diagnosed cancer cases each year. As one of the SEER registries, the NYSCR recently had the opportunity to participate in linkages of registry and LexisNexis data. LexisNexis is a commercial database containing public and proprietary information for over 276 million individuals in the United States.[4] Even though the NYSCR had previously used LexisNexis batch searches to obtain or verify birth date, SSN, and address for patients with missing, incomplete, or conflicting information, those linkages included limited patient records.[5] For example, in Pradhan and Boscoe's study,[5] only 5,958 patients diagnosed during 2003–2010 (representing 0.7% of all cases diagnosed in that time period) were selected for assessment of SSN improvement using LexisNexis. However, this new SEER-sponsored large-scale linkage allowed us to systematically evaluate the usefulness of LexisNexis for improving data quality on

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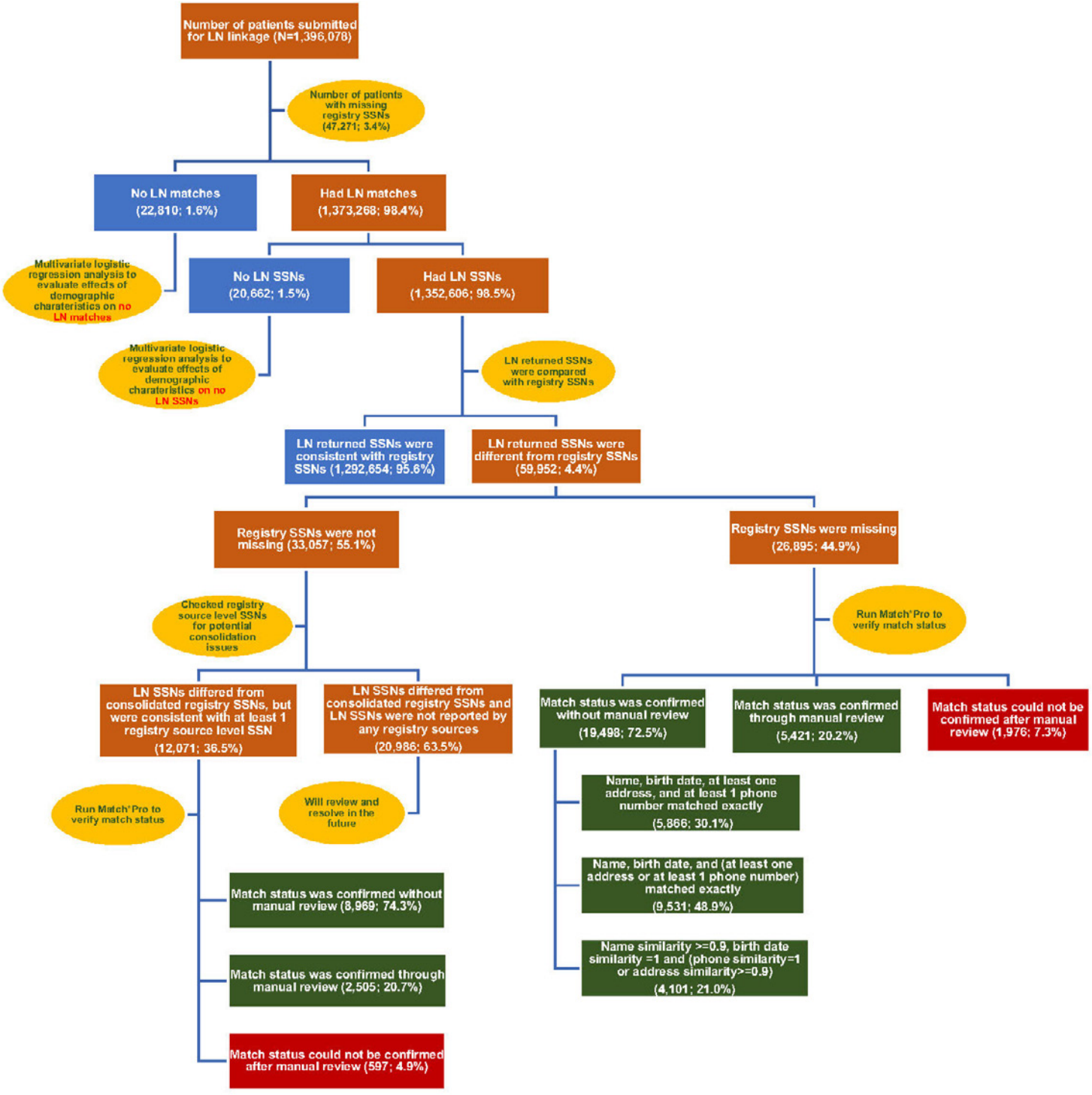
demographic information of cancer patients. The purpose of the current study was to evaluate the feasibility of using LexisNexis to improve SSN information in the NYSCR.

Materials and Methods

A total of 1,396,078 cancer patients diagnosed during 2005–2016 at age 21 years or older in the NYSCR were submitted for LexisNexis linkages. For the matched patients, LexisNexis returned first name, last name, middle name, birth date, SSN, up to 3 phone numbers, and 20 addresses, as available.

We first examined the patients who had missing registry SSNs prior to LexisNexis linkages by the following patient demographic characteristics: sex (male or female), age at linkage (<60, 60–<70, 70–<80, 80–<90, or ≥90 years), race (White, Black, American Indian/Alaska Native, Asian/Pacific Islander [API], or unknown), ethnicity (non-Hispanic or Hispanic), birthplace (United States, non–United States, or unknown), census tract poverty level (assigned based on address at cancer diagnosis: 0%–<5%, 5%–<10%, 10%–<20%, 20%–100%, or unknown), and vital status (deceased or

Figure 1. Steps for Evaluation of Social Security Numbers (SSNs) Returned from LexisNexis (LN) Linkage



alive). Then, based on the linkage results, we calculated percentage of patients who had no LexisNexis matches and the percentage who had LexisNexis matches, but no SSNs were returned, by patient demographic characteristics. We used multivariate logistic regression analyses to further evaluate how patient demographic characteristics affected the likelihood of no LexisNexis matches or of no SSNs returned.

For patients with SSNs returned, we compared LexisNexis SSNs with registry SSNs to determine their consistency. If patients had prior missing registry SSNs or the returned LexisNexis SSNs were different from the registry SSNs, patients' names, birth dates, phone numbers, and addresses were further compared using Match*Pro software[6] to verify match status. Based on the similarity scores of the data fields in comparison, we determined whether manual review was needed (Figure 1). If the SSNs returned from LexisNexis were different from registry SSNs (consolidated values), registry source level SSNs were reviewed to determine whether there were any consolidation issues. Registry SSNs were updated for those confirmed to be true matches. Improvement of registry SSNs was assessed using

Table 1. Characteristics of Patients Without LexisNexis Matches or With LexisNexis Matches but Without LexisNexis SSNs, and Odds Ratios With 95% CIs from Multivariate Logistic Regression Analyses

Demographic characteristics	*Patients without LexisNexis matches*			*Patients with LexisNexis matches but without SSNs*		
	n	**%**	**Adjusted OR (95% CI)**	**n**	**%**	**Adjusted OR (95% CI)**
Total	22,810	1.6	NA	20,662	1.5	NA
Sex [a]						
Male	10,311	1.5	Reference	8,725	1.3	Reference
Female	12,493	1.7	1.05 (1.03–1.08)	11,929	1.7	1.22 (1.19–1.26)
Age at LexisNexis linkage (y)						
<60	4,705	1.9	Reference	3,914	1.6	Reference
60–<70	4,904	1.7	1.04 (1.00–1.08)	3,236	1.1	0.79 (0.75–0.83)
70–<80	5,532	1.5	1.11 (1.07–1.16)	4,133	1.2	0.91 (0.87–0.96)
80–<90	4,806	1.7	1.47 (1.40–1.53)	4,811	1.7	1.46 (1.39–1.53)
≥90	2,863	1.3	1.59 (1.51–1.68)	4,568	2.1	2.13 (2.02–2.24)
Race						
White	10,370	0.9	Reference	12,525	1.1	Reference
Black	6,100	3.1	2.34 (2.26–2.42)	3,976	2.1	1.25 (1.21–1.30)
American Indian/Alaska Native	15	0.7	0.86 (0.51–1.43)	16	0.7	0.73 (0.45–1.20)
Asian and Pacific Islander	5,111	7.8	3.58 (3.44–3.73)	3,628	6.0	2.45 (2.34–2.56)
Unknown	1,214	10.1	7.28 (6.81–7.79)	517	4.8	3.10 (2.82–3.40)
Ethnicity						
Non-Hispanic	17,007	1.3	Reference	15,622	1.2	Reference
Hispanic	5,803	4.9	1.70 (1.64–1.76)	5,040	4.1	1.55 (1.49–1.61)
Birthplace						
United States	3,377	0.4	Reference	4,936	0.6	Reference
Outside the United States	13,659	5.8	8.00 (7.67–8.35)	11,166	5.0	5.42 (5.22–5.64)
Unknown	5,774	1.7	2.36 (2.25–2.47)	4,560	1.3	1.95 (1.87–2.04)
Census tract poverty level (%)						
0–<5	2,657	0.7	Reference	2,123	0.6	Reference
5–<10	3,931	1.1	1.29 (1.22–1.35)	3,483	1.0	1.53 (1.45–1.61)
10–<20	7,114	1.9	1.75 (1.68–1.84)	6,402	1.7	2.36 (2.25–2.48)
20–100	8,808	3.1	1.96 (1.87–2.05)	8,598	3.1	3.26 (3.10–3.43)
Unknown	300	7.8	12.59 (11.02–14.39)	56	1.6	3.30 (2.52–4.33)
Vital status						
Deceased	7,995	1.2	Reference	10,212	1.5	Reference
Alive	14,815	2.1	0.55 (0.53–0.57)	10,450	1.5	0.84 (0.81–0.87)

NA, not applicable; OR, odds ratio; SSN, Social Security number. [a] Patients with unknown sex are not shown in the table.

absolute and relative reductions in percentage missing SSN overall and by demographic characteristics.

Results

The detailed steps taken for this evaluation (both automated and manual effort) are illustrated in Figure 1. Of 1,396,078 patient records submitted for LexisNexis linkages, 22,810 (1.6%) were not matched. Among 1,373,268 (98.4%) with matches, 1.5% had no SSNs returned. Demographic characteristics of patients without LexisNexis matches or with LexisNexis matches but without SSNs are shown in Table 1. Notably, percentages of patients who had no LexisNexis matches were higher among Black (3.1%), API (7.8%), and Hispanic (4.9%) individuals, as well as those born outside the United States (5.8%). Among those with LexisNexis matches, patients who were API (6.0%),

Table 2. Characteristics of Patients with Missing Registry Social Security Number (SSN) Prior to or Post LexisNexis Linkage, and Registry SSN Improvement after LexisNexis Linkage

Demographic characteristics	*Patients submitted for LexisNexis linkage, n (%)*	*Patients with missing registry SSN prior to LexisNexis linkage*		*Patients with missing registry SSN post LexisNexis linkage*		*Reduction of missing registry SSN*	
		n	%	n	%	Absolute (%)	Relative (%)
Total	1,396,078 (100)	47,271	3.4	23,294	1.7	1.7	50.7
Sex [a]							
Male	665,376 (47.7)	22,409	3.4	10,342	1.6	1.8	54.0
Female	730,538 (52.3)	24,846	3.4	12,946	1.8	1.6	47.9
Age at LexisNexis linkage (y)							
<60	241,203 (17.3)	18,185	7.5	8,253	3.4	4.1	54.6
60–<70	292,091 (20.9)	13,001	4.5	5,861	2.0	2.4	54.8
70–<80	355,974 (25.5)	9,496	2.7	4,879	1.4	1.3	48.7
80–<90	283,022 (20.3)	4,913	1.7	3,039	1.1	0.7	38.5
≥90	223,788 (16.0)	1,676	0.8	1,262	0.6	0.2	25.3
Race							
White	1,119,033 (80.2)	27,499	2.5	11,222	1.0	1.5	59.3
Black	197,210 (14.1)	9,771	5.0	6,210	3.2	1.8	36.4
American Indian/Alaska Native	2,203 (0.2)	45	2.0	23	1.0	1.0	49.0
Asian and Pacific Islander	65,559 (4.7)	6,756	10.3	4,175	6.4	3.9	38.2
Unknown	12,073 (0.9)	3,200	26.5	1,664	13.8	12.7	48.0
Ethnicity							
Non-Hispanic	1,266,467 (90.7)	37,079	2.9	16,268	1.3	1.7	56.3
Hispanic	129,611 (9.3)	10,192	7.9	7,026	5.4	2.4	31.0
Birthplace							
United States	816,561 (58.5)	5,612	0.7	2,366	0.3	0.4	58.0
Outside the United States	236,176 (16.9)	17,097	7.2	13,760	5.8	1.4	19.5
Unknown	343,341 (24.6)	24,562	7.2	7,168	2.1	5.1	70.8
Census tract poverty level (%)							
0–<5	361,050 (25.9)	8,279	2.3	2,714	0.8	1.5	67.2
5–<10	368,475 (26.4)	10,469	2.8	4,111	1.1	1.7	60.6
10–<20	376,573 (27.0)	14,204	3.8	7,394	2.0	1.8	48.0
20–100	286,121 (20.5)	13,962	4.9	8,769	3.1	1.8	37.3
Unknown	3,859 (0.3)	357	9.3	306	7.9	1.3	14.3
Vital status							
Deceased	682,217 (48.9)	5,940	0.9	5345	0.8	0.1	10.3
Alive	713,861 (51.1)	41,331	5.8	17,949	2.5	3.3	56.6

SSN, Social Security number. [a]Patients with unknown sex are not shown in the table.

Hispanic (4.1%), or born outside the United States (5.0%) also had higher percentages of no LexisNexis SSNs.

Multivariate logistic regression analyses indicated that patients who were female, Black, API, Hispanic, born outside the United States, deceased, or living in poorer census tracts were more likely to not have LexisNexis matches, and also to not have SSNs returned (Table 1). Compared to patients younger than 60 years, patients aged 60–<80 years were more likely to have no LexisNexis matches and less likely to have no LexisNexis SSNs returned when matches were found. Patients aged ≥80 years were at increased likelihoods of both no LexisNexis matches and no LexisNexis SSNs. Patients with unknown race, birthplace, or poverty level were also more likely to have no LexisNexis matches and no LexisNexis SSNs returned.

Prior to LexisNexis linkage, 47,271 (3.4%) patients had missing registry SSNs, with higher percentages observed among those who were younger than 60 years at the time of linkage (7.5%), Black (5.0%), API (10.3%), of unknown race (26.5%), Hispanic (7.9%), born outside the United States (7.2%), with unknown birthplace (7.2%), living in the poorest or unknown census tracts (4.9%), and alive (5.8%) (Table 2). 26,895 patients with missing registry SSNs had SSNs returned from LexisNexis (56.9%). Using Match*Pro, 19,498 (72.5%) were determined to be true matches without manual review, and 5,421 (20.2%) were confirmed to be true matches through manual review. Match status could not be verified for 1,976 (7.3%) patient records.

Registry missing SSNs were updated with LexisNexis SSNs for 23,977 patient records, resulting in an overall percentage of missingness reduced to 1.7%. A larger absolute percentage reduction was observed among those who were younger than 60 years (4.1%), API (3.9%), alive (3.3%), or with unknown race (12.7%) or birthplace (5.1%) (Table 2). Returned LexisNexis SSNs for 942 individuals were thought to be Individual Tax Identification Numbers rather than SSNs and therefore, were not added to the registry.

For 33,057 patients who had known registry SSNs but had different SSNs returned from LexisNexis (Figure 1), source level SSNs reported to the registry were further examined. A total of 12,071 (36.5%) had at least 1 source record that reported the same SSN as LexisNexis. After review, 11,474 (95.0%) matches were confirmed, and registry SSNs were subsequently reconsolidated using the correct source-level SSNs for those patients. The 20,986 patients who did not have the same SSNs as LexisNexis reported by any registry sources will be reviewed in the future. To resolve conflicting SSNs for those patients, we might need to use another independent data source, such as hospital discharge administrative data, to help us determine which SSNs are correct.

Discussion

The NYSCR had the opportunity to participate in the project of linking registry data with the LexisNexis database during 2019–2021 as part of the SEER program. Per the SEER linkage protocol, all cancer patients diagnosed during 2005–2016 at age 21 years or older were selected for LexisNexis linkage. Even though the primary objective of the project was to obtain residential history of cancer patients, LexisNexis also returned other demographic information including SSN for the matched patient records. Based on the results of this large-scale linkage, the current study evaluated the feasibility of using LexisNexis to improve SSNs in the NYSCR.

Our results showed that the overall LexisNexis matching rate was remarkably high. Among nearly 1.4 million cases submitted for linkage, matching records were found in LexisNexis for 98.4%. However, the match rate varied considerably by patient demographic characteristics. For example, the match rates were significantly lower for individuals who identified as Black, API, or Hispanic, or those who were born outside the United States or with an unknown race or birthplace, compared to the reference groups. These findings were consistent with previous reports. Woolpert et. al[7] studied the validity of LexisNexis in identifying state of residence at death using the Georgia Cancer Registry's Cancer Recurrence and Information Surveillance cohort, and they found that cohort members who were Black, API, or Hispanic had higher odds of being missed by linkage to LexisNexis compared to White and non-Hispanic members. Lower LexisNexis match rates among API and Hispanic cancer patients have also been reported by Tatalvich et al.[8] The lower LexisNexis match rates observed among minority race/ethnicity groups and those born outside the United States are likely due to missing or incomplete information in the LexisNexis database for those individuals. Our study also found that similar patient demographic characteristics determined the likelihood of obtaining SSNs from LexisNexis among patients with matches.

Prior to the LexisNexis linkages, about 3.4% of patients had missing SSNs in the NYSCR. After updating SSNs using information obtained from LexisNexis, the overall percentage of SSN missingness was reduced to 1.7%. Although patients who identified as API or who had unknown race or birthplace were less likely to have LexisNexis matches or SSNs returned, a large absolute reduction of SSN missingness was still achieved for these groups because the percentages of missing SSNs were much higher prior to linkage. A larger SSN improvement was also seen for patients who were younger than 60 years at linkage or who were still alive.

The NYSCR has a history of using LexisNexis for data quality improvement. About a decade ago, Pradhan and Boscoe[5] used LexisNexis Batch searches to obtain or verify birth date, SSN, and address for patients with missing or conflicting information in the NYSCR and found that LexisNexis was a cost-effective solution for resolving data quality issues. Since then, LexisNexis has been regularly used by NYSCR geocoding staff for obtaining and verifying patient demographic information. Recently, the Michigan State Cancer Registry also highlighted its success in using LexisNexis linkage to improve SSN and vital status information.[9] LexisNexis, however, has some known limitations. LexisNexis contains public and proprietary records of individuals, but such information is usually not available for minors. Therefore, linkage with LexisNexis for pediatric

cancer patients would be less helpful than it is for adult patients. Thus, the SEER–LexisNexis linkage only included cancer patients aged 21 years or older.

The current study has 2 notable strengths compared to the previous evaluations. First, this SEER-sponsored LexisNexis linkage included a much larger number of patient records, allowing us to conduct more systematic and comprehensive evaluations of LexisNexis' usefulness in improving SSNs. For example, we were able to assess SSN improvement overall, as well as by detailed patient demographic characteristics. In addition, the effects of demographic characteristics on LexisNexis match rate and SSNs returned were also thoroughly examined. Second, the match records returned from LexisNexis have been reviewed and verified using Match*Pro. Through this process, we identified a small number of incorrect LexisNexis matches, then subsequently excluded them from SSNs updates. Some of those matches appeared to be for relatives of the patients rather than for the patients themselves. The LexisNexis database contains billions of records collected from vast and diverse data sources, and thus may contain some errors. Furthermore, as in all linkages, particularly ones at such a large scale, mismatches cannot be totally prevented. Therefore, it is necessary to conduct additional review and match verification before making any updates to a registry database.

In our evaluation, about 75% of matches returned from LexisNexis could be confirmed automatically, but the remaining 25% of matches required manual review. Two staff members were involved in match verifications using Match*Pro and it took us approximately 1 week to complete the process. However, it is worth noting that the similarity scores we set for no manual review in the current evaluation were relatively high, and we believe the number of patient records requiring manual review could be further reduced through adjusting the review criteria. In addition, we found that appropriate use of the filter function in Match*Pro could speed up the review process. Data quality improvements often require resources. Our results could provide some insights for other registries that are interested in conducting a similar evaluation.

In conclusion, our study demonstrated that LexisNexis can be a valuable resource for improving the quality of SSN information in cancer registries. However, because LexisNexis occasionally returns incorrect patient matches, additional review and verification of LexisNexis matches are recommended to avoid updating registry SSNs with results from incorrect matches. This evaluation can assist registries with decisions related to similar improvement efforts.

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Original Article

Utilizing Residential History to Examine Heterogeneous Exposure Trajectories: A Latent Class Mixed Modeling Approach Applied to Mesothelioma Patients

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Abstract: Background: Life-course exposure assessment, as opposed to a one-time snapshot assessment based on the address at cancer diagnosis, has become increasingly possible with available cancer patients' residential history data. To demonstrate a novel application of residential history data, we examined the heterogeneous trajectories of the nonasbestos air toxic exposures among mesothelioma patients, and compared the patients' residential locations with the spatiotemporal clusters estimated from the National Air Toxic Assessment (NATA) data. Methods: Patients' residential histories were obtained by linking mesothelioma cases diagnosed during 2011–2015 in the New York State (NYS) Cancer Registry to LexisNexis administrative data and inpatient claims data. To compare cancer risks over time, yearly relative exposure (RE) was calculated by dividing the NATA cancer risk at individual census tracts by the NYS average and subtracting 1. We used a latent class mixed model to identify distinct exposure trajectories among patients with a 15-year residential history prior to cancer diagnosis (n = 909). We further examined patient characteristics by the latent trajectory groups using bivariate comparisons and a logistic regression model. The spatiotemporal clusters of RE were generated based on all NATA data (n = 72,079) across the contiguous United States and using the SaTScan software. Results: The median number of addresses lived was 2 (IQR, 1–4), with a median residential duration of 8 years (IQR, 4.7–13.2 years). We identified 3 distinct exposure trajectories: *persistent low exposure* (27%), *decreased low exposure* (41%), and *increased high exposure* (32%). Patient characteristics did not differ across trajectory groups, except for race and Hispanic ethnicity ($P < .0001$) and residential duration ($P = .03$). Compared to their counterparts, non-Hispanic White patients had a significantly lower odds of belonging to the increased high exposure group (adjusted odds ratio, 0.14; 95% CI, 0.09–0.23) than the persistent low exposure and decreased low exposure groups. Patients in the increased high exposure group tended to reside in New York City (NYC), which was covered by one of the high-RE clusters. On the other hand, patients in the persistent low exposure group tended to reside outside of NYC within NYS, which was largely covered by 2 low-RE clusters. Conclusion: Using mesothelioma as an example, we quantified the heterogeneous trajectories of nonasbestos air toxic exposure based on patients' residential histories. We found that patients' race and ethnicity differed across the latent groups, likely reflecting the differences in patients' residential mobility before their cancer diagnoses. Our method can be used to study cancer types that do not have a clear etiology and may have a higher attributable risk due to environmental exposures as well as socioeconomic conditions.

Key words: *exposure trajectories, heterogeneity, hot/cold spots, National Air Toxic Assessment (NATA), SaTScan*

Introduction

Using residential history to assess life-course environmental exposure, as opposed to a one-time snapshot exposure assessment (eg, exposure information at cancer diagnosis or at study baseline enrollment), has long been advocated in cancer epidemiology.[1-3] In the United States, previous studies have largely used self-reported residential history data to study the risk of developing cancer from exposures to air and water pollutants in the physical environment.[4-6] Obtaining residential history and incorporating such information into cancer epidemiological studies at scale (eg, using population-based data, such as those collected by the central cancer registries) has been a slow process in the United States, with a renewed interest in recent years.[7-15] For example, the recent linkage of address information from the LexisNexis administrative data with 11 cancer registries within the Surveillance, Epidemiology, and End Results (SEER) program of the National Cancer Institute (NCI) yielded a residential history data set for over 3 million cancer cases throughout the country.[13] These encouraging developments have opened opportunities, such as applying innovative methods to examine the impact of physical and social environments across the cancer continuum by using residential history information.

Previously, we developed a method to construct the chronological profile of cancer risk from inhalation of

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ambient air toxics as well as risk associated with disadvantaged socioeconomic status (SES).[16] We applied generalized linear regression models to compare the relative exposure in the past with that at cancer diagnosis, and explored the direction and the magnitude of exposure misclassification using mesothelioma patients as an example. Mesothelioma is a rare type of cancer with about 3,000 new cases diagnosed annually in the United States.[17-19] It is also an aggressive disease with a poor prognosis, as reflected by the late stage at diagnosis, a long latency period of 20 to 30 years, and a poor survival rate.[19-21] Malignant pleural mesothelioma, which represents over 80% of all mesothelioma cases, has a median diagnosis age of 72 years, and a 5-year relative survival rate of only 12%.[17,22]

In this study, we continued to explore new ways of using these residential history data from the same group of mesothelioma patients. In particular, we applied a case-only design and a novel statistical method (ie, a latent class mixed modeling approach[23-27]) to the reconstructed cancer risk profile for exposure to ambient air toxics. It is not our intention to identify nonasbestos related exposure as a potential risk factor for mesothelioma, as mesothelioma is one of the few cancers with a known etiology, where asbestos exposure, especially in occupational settings, is the primary risk factor for the disease.[18,20,21,28,29] Instead, we aimed to demonstrate a new approach to explore hidden exposure heterogeneities associated with patients' residential histories. As a side note, by using mesothelioma cases as an example, we provided some new insights into the heterogeneity of environmental exposures among these patients other than the commonly known patterns. Existing studies have been mainly focused on examining workplace asbestos exposure histories of mesothelioma patients.[19-21] Researchers have also used mesothelioma registries and questionnaires to incorporate residential history information into their analyses, hoping to understand the impact of known and unknown asbestos exposures among mesothelioma patients.[30-33] In contrast, only a few studies have examined nonasbestos exposures, such as air pollution and tobacco smoking, among mesothelioma patients.[18,34-36] No study has assessed the residential histories of mesothelioma patients and estimated nonasbestos exposure trajectories. Moreover, we also investigated whether patients' residential locations tended to be within spatiotemporal clusters (ie, hot or cold spots), which were estimated by using the National Air Toxic Assessment (NATA) data and the commonly used spatial epidemiologic methods implemented in the SaTScan software.[37] Findings from the current study can provide insights into applying novel methods to residential history data and studying other types of cancer with potentially a large contribution from physical environment exposures and social risks.

Methods

Data Sources and Study Population

Through an NCI-funded exploratory research project, we demonstrated the feasibility of reconstructing the residential history of 1,015 mesothelioma patients diagnosed between 2011 and 2015 and reported to the New York State (NYS) Cancer Registry.[16] The sample size (and the proportion of the full sample) was 974 (96.0%), 952 (93.8%), 913 (90.0%), 839 (82.7%), and 444 (43.7%) for patients with available 5-year, 10-year, 15-year, 20-year, and 30-year residential histories prior to their cancer diagnoses, respectively. In the current study, we analyzed 913 patients with a 15-year residential history before their mesothelioma diagnoses. The choice of this subset was to strike a balance between having a sufficient number of patients from the original cohort and capturing a sufficient length of residential history. The study was approved by the institutional review boards at the NYS Department of Health (#1498055-1) and at the Icahn School of Medicine at Mount Sinai (IRB-19-02514).

Patient residential histories were constructed based on the address information from 3 data sources: (1) patient's street-level address at the time of cancer diagnosis collected in the NYS cancer registry database, (2) patient's street-level address at the time of hospitalization collected in the health insurance claims for the years 1982–2019 available in the New York Statewide Planning and Research Cooperative System (SPARCS) database,[38] and (3) patient's addresses provided by the LexisNexis, a commercial database that has been used in other studies.[10,12,39,40] The majority (5,696 of 5,795; 98.3%) of the unique address texts were valid and thus were successfully geocoded using 3 geocoders: the Automated Geospatial Geocoding Interface Environment system, which is a powerful geocoding platform for open use by US cancer registries[41,42]; Google Maps; and the Census Geocoder. As the focus of the current analysis was to estimate the exposure history up to the time of cancer diagnosis, we included only geolocations where patients had resided prior to and at the time of their cancer diagnoses. Because the exposure data (details below) were only available at the census tract level, we mapped each address location to the corresponding census tract.

To assess patients' environmental exposures, we used estimates from the NATA data provided by the United States Environmental Protection Agency. The NATA estimate is a modeled lifetime cancer risk from inhalation of nonasbestos air toxins, which takes into account emission source types, meteorological conditions, and human activity patterns.[43] The national percentile ranking was available at census tract level for the calendar years 1996, 1999, 2002, 2005, 2011, and 2014. We matched the time of census tracts lived with the closest NATA years available. For example, for a census tract lived before 1997, we used the 1996 NATA estimate, and if a census tract was lived in 2015, then we used the 2014 NATA data.

Relative Exposure (RE)

Patient's cancer risk from exposure to nonasbestos air toxics was measured by a relative exposure (RE) with the NYS average as the reference. It was calculated by dividing the NATA percentile ranking of an individual census tract by the average percentile ranking for NYS and subtracting 1. The reason for using the RE was to overcome the inherent limitation of the NATA data. That is, it does not allow for a direct comparison of the NATA estimates (including the

metric of cancer risk) across years due to methods changes (eg, the number and types of pollutants and models used) over time.[43] As the NATA's lifetime cancer risk estimate is based on ambient levels of a mixture of air toxics, the RE served as a composite indicator of the overall exposure to nonasbestos air toxics, rather than a specific type of air pollutant.

RE Across Patient's Residential History

We calculated the yearly time-weighted-average (TWA) RE during the 15-year look-back window up to the year of cancer diagnosis. Patients who lived at a single address during an entire year were given the weight value of 1 for the yearly TWA measure. For patients who lived in multiple addresses in a year, the weights from these addresses summed to 1, with a higher weight assigned to addresses with a longer residential duration. To be consistent with the method used by other studies to calculate the duration of each address lived,[10-12,39,40] we used the first known date associated with a unique address as the starting time of this address, and used the start date of the next address in chronologically order as the end of the previous address. When we lacked any duration information for an address, we assumed a duration of 2.2 years, which was the median length of residency at an address among the original study population.[16]

Statistical Analyses

The main analysis was a 2-stage process. In the first stage, we identified the exposure trajectories and grouped patients with similar exposure histories into their own classes using a latent class linear mixed model. In the second stage, the identified trajectory class membership was used as the outcome variable in a logistic regression model to examine its associated patient-level characteristics.

We used a latent class linear mixed model to estimate the RE trajectories during the 15-year observation window. Linear mixed models are commonly used for longitudinal data with continuous outcomes (eg, RE in the current study) to account for within-subject correlations arise from repeated measures by incorporating random effects, which are assumed to be sampled from a single multivariate Gaussian distribution.[23,24,27] This homogenous assumption is relaxed in latent class linear models, which can incorporate non-normal random effects (eg, through a finite mixture of normal distributions rather than a single normal distribution).[23-27] In our model, RE was explained by time (a variable which indicated RE was at 1-, 2-, …, and 15-year prior to cancer diagnosis), squared time divided by 10 (for a potentially nonlinear time trend),[23] and age at cancer diagnosis, which was centered to 65 years (calculated as age at diagnosis minus 65). The random effects were grouped by unique participants. This model offered a way to account for the unobserved (latent) heterogeneity in the data and provided insights into how patients might have experienced different exposure trajectories, while the traditional linear mixed model assumed no presence of hidden subgroups. We tested 1- to 6-trajectory solutions, and chose the optimal number of trajectories based on commonly used measures, such as the Akaike information criterion (AIC; the lower the better), the Bayesian Information Criterion (BIC; the lower the better), entropy (the closer to 1 the better), the integrated complete-data likelihood (ICL; the lower the better), the number of patients in each trajectory group, and the class-membership posterior probabilities. In addition, we considered the optimal number of classes based on the stable "elbow" point of diminishing returns in model fit measures.[44]

Once the trajectory class membership was established, we summarized descriptive statistics (eg, frequency, proportion, mean, standard deviation, median, and interquartile range) of the patient characteristics, most of which were collected at cancer diagnosis as a part of the routine cancer surveillance, including patient's age at cancer diagnosis, sex, race/ethnicity, cancer stage, and tobacco use status. We also summarized the characteristics related to patients' residential mobility, including the number of unique addresses lived, residential duration, and the Euclidean distance moved between addresses. We compared these patient characteristics by the trajectory group membership using χ^2 tests for categorical variables and Kruskal–Wallis tests for continuous variables. The same set of variables were used as explanatory variables in the logistic regression model. To minimize issues resulted from small cell sizes, we combined all patients whose race/ethnicity were not non-Hispanic White (NHW) into 1 aggregated group, "not NHW." Thus, the not-NHW category included non-Hispanic Black, Hispanic, and patients in other race/ethnicity groups combined. This not-NHW group was then used as the reference to compare with the NHW group in the regression model. We also combined the persistent low exposure and decreased low exposure classes, since their REs were all below 0 (ie, lower than the NYS average), to avoid small cell size issues. We reported the adjusted odds ratio (aORs) and their 95% CIs. We implemented the trajectory modeling using the hlme function in the lcmm package[23] using R (version 4.0.2) with Rstudio (version 2022.02.03), and the logistic regression was implemented using SAS (version 9.4).

We also mapped the residential locations by the identified trajectory groups and assessed whether patients belonging to different trajectory groups tended to reside in different spatial clusters of high RE *(hot spots)* or low RE *(cold spots)* levels. The hot/cold spots were identified using a commonly used spatial epidemiological software, SaTScan (version 10.0.2).[37,45] Specifically, we first calculated the REs of cancer risk using all census tracts in the contiguous United States available in the NATA data (n = 72,079), similar to the RE estimates used for the mesothelioma sample. As such, the RE at each census tract was a relative measure in reference to the NYS average in a given year. We then used the space–time detection method with a normal probability model to identify clusters of high or low REs with the default settings, such as using a circular search window, a 999-random replication to obtain *P* values, and a Monte Carlo hypothesis testing approach.[37,45]

Results

As shown in Table 1, the majority of the patients were NHW (89.6%), male (75.6%), and with a distant-stage tumor at the time of cancer diagnosis (65.0%). The mean age at diagnosis was 73.0 (SD, 11.9) years. On average, patients resided at 3 (SD, 2.3) addresses, with an average residential duration of 10.4 (SD, 8.4) years. The median distance moved among the entire study population was 8.2 (IQR, 1.6–133.2) miles. The time-weighted average REs had a median value of –0.16 (IQR, –0.43 to 0.18).

We selected a 3-trajectory model as the optimal solution from models with 1 to 6 latent trajectories (Table 2). When choosing the optimal number of trajectories, we considered a combination of factors, including the best values on multiple model fit measures, the elbow point of diminishing returns in the model fit, the interpretability of the latent

Table 1. Characteristics of the Study Population Overall and by the 3 Exposure Trajectory Groups

Variables	*Persistent low exposure (n = 245; 27%)*	*Decreased low exposure (n = 373; (1%)*	*Increased high exposure (n = 295; 32%)*	*Overall (n = 913)*
Age (y)				
Mean (SD)	72.8 (11.6)	73.2 (12.0)	73.0 (11.9)	73.0 (11.9)
Median (IQR)	74 (67–81)	76 (66–82)	75 (66–82)	75 (66–82)
Sex				
Male	190 (77.6%)	280 (75.1%)	220 (74.6%)	690 (75.6%)
Female	55 (22.4%)	93 (24.9%)	75 (25.4%)	223 (24.4%)
Race/ethnicity*				
Non-Hispanic Black	NR	NR	29 (9.8%)	37 (4.1%)
Non-Hispanic White	244 (99.6%)	347 (93.0%)	227 (76.9%)	818 (89.6%)
Hispanic	NR	13 (3.5%)	28 (9.5%)	41 (4.5%)
Other	NR	NR	11 (3.7%)	17 (1.9%)
Cancer stage				
Local	18 (7.3%)	37 (9.9%)	32 (10.8%)	87 (9.5%)
Regional	45 (18.4%)	50 (13.4%)	50 (16.9%)	145 (15.9%)
Distant	158 (64.5%)	248 (66.5%)	187 ((63.4%)	593 (65.0%)
Unknown	24 (9.8%)	38 (10.2%)	26 (8.8%)	88 (9.6%)
Tobacco use				
Current	26 (10.6%)	41 (11.0%)	32 (10.8%)	95 (10.4%)
Former	129 (52.7%)	178 (47.7%)	50 (16.9%)	446 (48.9%)
Never	69 (28.2%)	130 (34.9%)	187 (63.4%)	298 (32.6%)
Unknown	21 (8.6%)	24 (6.4%)	26 (8.8%)	74 (8.1%)
Number of addresses lived				
Mean (SD)	3.1 (2.2)	3.0 (2.3)	3.1 (2.2)	3.0 (2.3)
Median (IQR)	3 (1–4)	2 (1–4)	3 (1–4)	2 (1–4)
Average residential duration (years)*				
Mean (SD)	9.4 (7.4)	11.1 (9.2)	10.6 (8.2)	10.4 (8.4)
Median (IQR)	6.9 (4.2–12.3)	8.2 (5.2–13.3)	8.3 (4.8–13.6)	8.0 (4.7–13.2)
Average Euclidean distance (miles) moved between addresses lived				
Mean (SD)	146.4 (262.9)	130.3 (282.6)	93.9 (185.9)	122.9 (250.3)
Median (IQR)	8.7 (0.9–202.0)	8.9 (1.9–125.7)	7.1 (1.5–88.2)	8.2 (1.6–133.2)
Time-weighted-average relative exposure*				
Mean (SD)	–0.60 (0.21)	–0.18 (0.20)	0.27 (0.19)	–0.15 (0.39)
Median (IQR)	–0.61 (–0.75 to –0.46)	–0.20 (–0.31 to –0.04)	0.30 (0.15–0.40)	–0.16 (–0.43 to 0.18)

IQR, interquartile range (25th–75th percentile); NR, not reportable due to cell size suppression of n<11.

*Patient characteristics did not differ across the trajectory groups, except for race/ethnicity ($P < .0001$), average residential duration ($P = .03$), and time-weighted relative exposure (RE) ($P < .0001$). The duration, distance moved, and RE associated with each address were averaged within individual patients, respectively, before deriving the summary statistics shown.

Table 2. Measures Used to Identify the Optimal Trajectory Groups

A. Model fit measures

Number of classes	loglik	AIC	BIC	SABIC	entropy	ICL
1	899.084	–1776.170	–1723.180	–1758.120	1.000	–1723.180
2	1009.231	–1990.460	–1923.030	–1967.490	0.835	–3665.170
3	1116.696	–2199.390	–2117.510	–2171.500	0.834	–3804.880
4	1150.770	–2261.540	–2165.210	–2228.720	0.819	–3802.420
5	1178.634	–2311.270	–2200.480	–2273.530	0.808	–3797.400
6	1184.910	–2317.820	–2192.580	–2275.160	0.804	–3757.740

B. Mean of posterior probabilities in each class in the optimal model with 3 trajectory classes

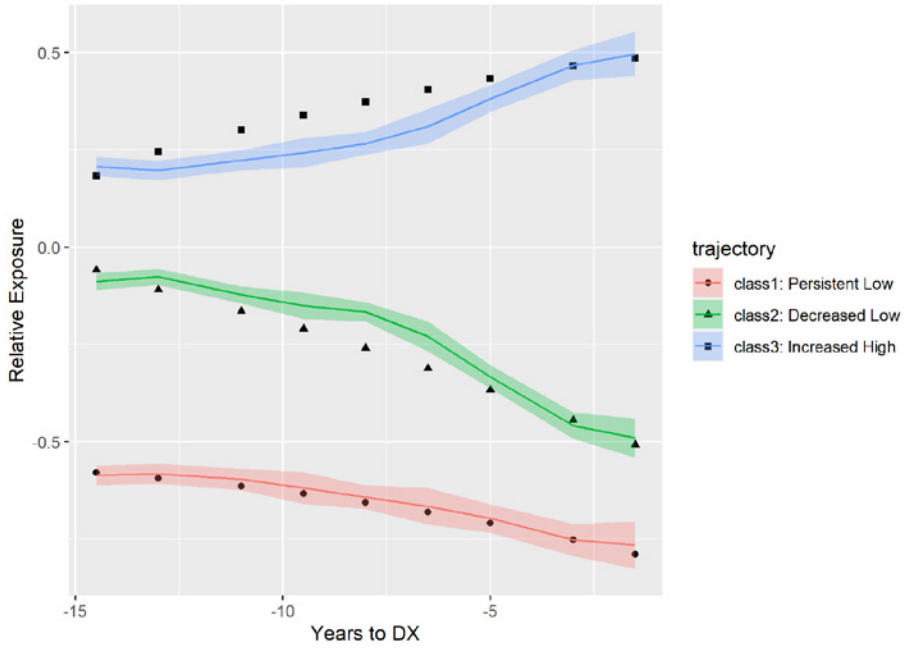
	%class1 (PLE)	%class2 (DLE)	%class3 (IHE)
	PLE	DLE	IHE
class1 (PLE)	91	9	0
class2 (DLE)	6	91	3
class3 (IHE)	0	4	96

C. Posterior probabilities of being above a threshold (%) in the optimal model with 3 trajectory classes

Threshold	class1 (PLE)	class2 (DLE)	class3 (IHE)
prob>0.7	88.57	88.20	94.58
prob>0.8	78.78	82.84	92.20
prob>0.9	70.20	71.85	87.80

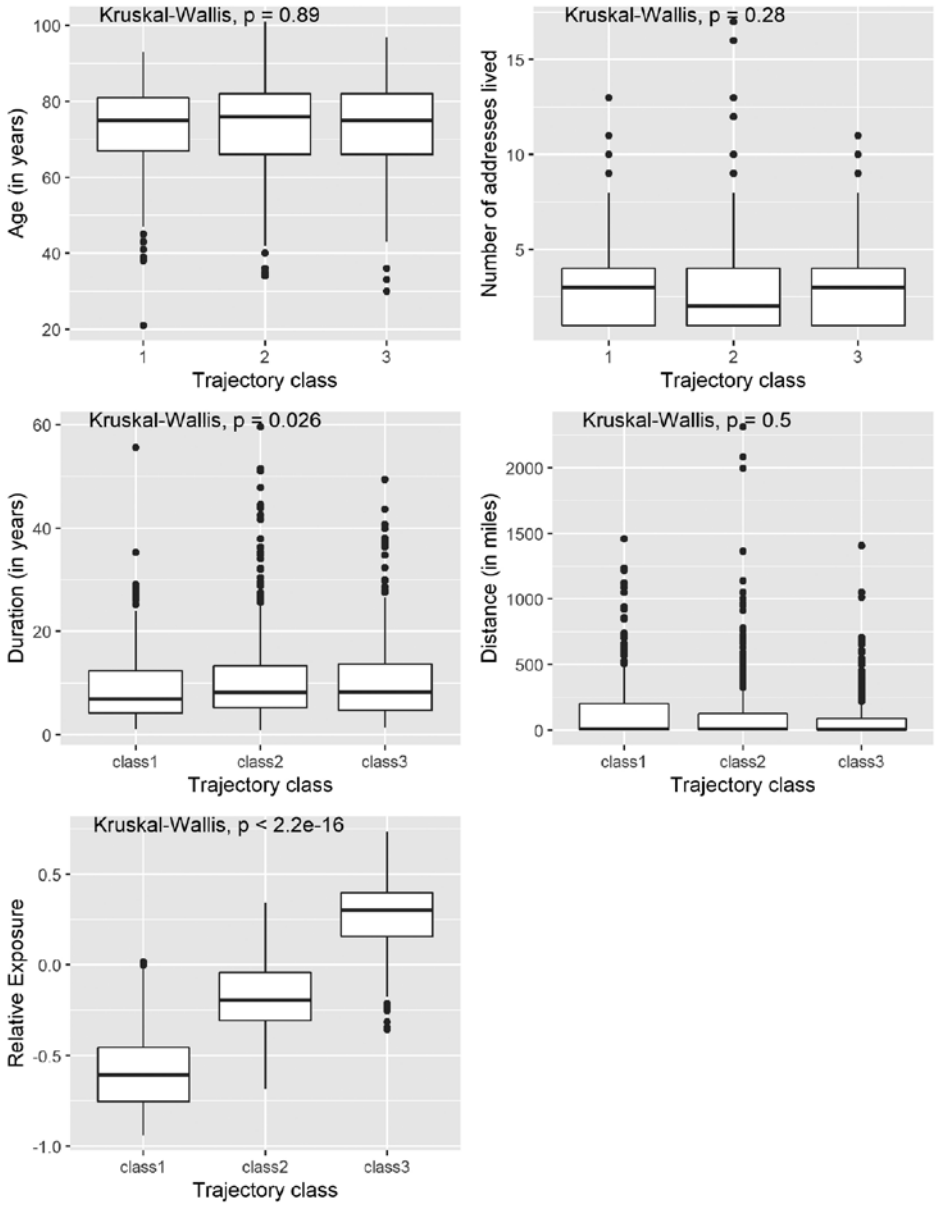
AIC, Akaike information criterion (the lower the better); BIC, Bayesian information criterion (the lower the better); DLE, decreased low exposure; entropy (the closer to 1 the better); ICL, integrated complete-data likelihood (the lower the better); IHE, increased high exposure; Loglik, maximum log-likelihood (the higher the better); PLE, persistent low exposure; SABIC, sample-size-adjusted BIC (the lower the better); prob, probability. *Class1, class2,* and *class3* represent persistent low exposure, decreased low exposure, and increased high exposure, respectively.

Figure 1. Weighted Marginal Prediction of Exposure Trajectory Classes



We interpreted these 3 distinct trajectories of relative exposure as "persistent low exposure" for class 1, "decreased low exposure" for class 2, and "increased high exposure" for class 3.The dots in the figure show the fitted values of class-specific marginal and subject-specific mean relative exposure (RE) evolution over time. The line and the shaded band showed the observed class-specific mean RE evolutions with time and its 95% confidence bounds, respectively. The class-specific mean evolutions were weighted by the class-membership probabilities. The "low" and "high" designations in the naming of the trajectory groups reflected that the RE values of addresses in class 1 and class 2 were both below 0 (lower than the New York State average), while those in class 3 were above 0 (higher that the state average). The terms "increased" and "decreased" in the trajectory names reflected the trend over time.

Figure 2. Bivariate Comparisons of Patient Characteristics (Continuous Variables) by the Exposure Trajectory Classes



Trajectory classes 1, 2, and 3 represent "persistent low exposure," "decreased low exposure," "increased high exposure," respectively.

trajectories, the posterior probabilities of the class memberships, and the adequate sample size of different trajectory groups. The mean posterior probabilities for trajectory classes 1 to 3 were 91%, 91%, and 96%, respectively, which meant that, on average, the probability of patients belonging to the corresponding trajectory group was above 90%. The posterior probabilities of being above the 80% threshold for trajectories 1 to 3 were 79%, 83%, and 92%, respectively, which meant that the proportion of patients not ambiguously classified into their corresponding trajectory groups was greater than 79%.

We interpreted these 3 distinct trajectories of REs as *persistent low exposure* (n = 245; 27%), *decreased low exposure* (n = 373; 41%), and *increased high exposure* (n = 295; 32%) (Figure 1, Table 1). Unsurprisingly, RE values differed significantly by exposure trajectory groups ($P < .0001$), with the highest RE found in the increased high exposure group (Table 1, Figure 2). In addition, levels of RE by the trajectory groups in Figure 1 show that the lowest REs were among patients in the persistent low exposure group, while the highest REs were among patients in the increased high exposure group.

Patient characteristics did not differ across the 3 trajectory groups, except for race/ethnicity ($P < .0001$) and the average residential duration ($P = .03$; Table 1, Figure 2). The proportion of NHW patients was the highest in the persistent low exposure group (99.6%) and lowest in the increased high exposure group (76.9%). Consistent with the bivariate comparison result, the logistic regression model also showed a significant association between the race/ethnicity variable and the trajectory class membership (Table 3). NHW patients (vs the aggregated group of the remaining patients who were not NHW) had lower odds (aOR, 0.14; 95% CI, 0.09–0.23) of belonging to the increased

Table 3. Factors Associated with Belonging to the Increased High Exposure Trajectory Class Compared to the Persistent Low and Decreased Low Exposure Classes

Variable	*Adjusted OR (95% CI)*
Age	1.01 (0.995–1.02)
Sex (female vs male)	1.11 (0.78–1.58)
Race/ethnicity (NHW vs not NHW)	0.14 (0.09–0.23)
Cancer stage	
Local vs distant	1.33 (0.81–2.17)
Regional vs distant	0.76 (0.44–1.30)
Other vs distant	1.12 (0.75–1.68)
Tobacco use	
Former vs current	1.20 (0.71–2.02)
Never vs current	1.05 (0.61–1.80)
Other vs current	1.69 (0.84–3.40)
Number of tracts lived	1.06 (0.98–1.15)
Average duration lived	1.01 (0.99–1.03)
Average distance moved	0.998 (0.999–1.000)

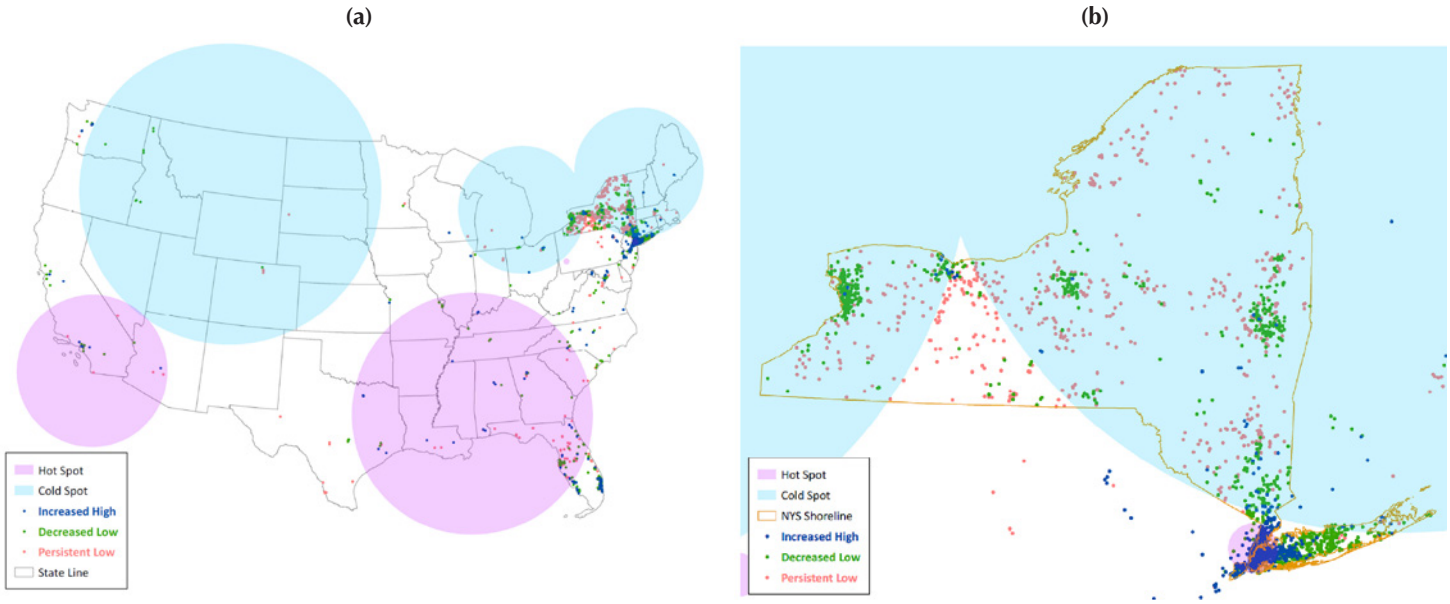
NHW, non-Hispanic White; not NHW, individuals whose race/ethnicity are not non-Hispanic White (eg, Hispanic, non-Hispanic Black, Asian, Pacific Islander, and American Indian/Alaskan Native persons, as well as those of unknown of mixed races); OR, odds ratio. $P < .0001$ for race/ethnicity comparison; $P = .01$ for average distance moved. $P > .05$ for all the remaining variables.

high exposure trajectory group than in the reference group (ie, combined persistent low exposure and decreased low exposure trajectory groups).

Of 2,782 unique addresses, 2,317 (83.3%) were in NYS, spanning 1,493 census tracts. The proportion of New York City (NYC) addresses was 0.5%, 6.6%, and 74.8% for the trajectory classes 1, 2, and 3, respectively. Among the 818 NHW patients, 207 (25.3%) resided in NYC at one time, including 94 (11.5%) who resided exclusively in NYC within the 15 years prior to cancer diagnosis. In comparison, of the remaining 95 not-NHW patients, 71 (74.8%) resided in NYC at one time and 41 (43.1%) resided exclusively in NYC. These results were consistent with the distribution of patient residential locations and hot/cold spots of REs across the contiguous United States as shown in Figure 3a. Furthermore, NYS-focused distribution in Figure 3b shows that patients in the increased high exposure group tended to live in NYC, while patients in the persistent low exposure group tended to live outside of NYC.

Also shown in Figure 3, the SaTScan analysis found a total of 7 significant clusters (all $P < .001$), which included 4 high-RE clusters (ie, hot spots) and 3 low-RE clusters (ie, cold spots). One of the high-RE clusters centered in NYC (40.774858 N, 73.980666 W, cluster III), with a radius of 24.18 kilometers. The mean RE within this particular hot spot was 0.61, while areas outside of NYC had a mean RE of -0.19 (Table 4). The mean RE of this NYC hot spot was also higher than the mean REs found in the other 2 hot spots (0.25 and 0.32 in clusters II and III, respectively). On the other hand, a large portion of NYS excluding NYC tended to be covered by 2 low-RE clusters, one (cluster IV) over the Great Lakes region and the other (cluster VI) over the New England region (Figure 3, Table 4). Therefore, areas within

Figure 3. The Distribution of Patient Residential Locations (Dots) by the 3 Relative Exposure (RE) Trajectory Classes (Persistent Low, Decreased Low, and Increased High Exposure) in Relation to the Distribution of Hot/Cold Spots of High/Low RE Clusters Across the Continuous United States (a), and in New York State (b)



Hot/cold spot RE clusters were identified using a SaTScan space-time analysis based on data from all census tracts (n = 72,079) in the National Air Toxics Assessment (NATA) for the contiguous United States. Details of the hot/cold spots were shown in Table 4. To protect confidentiality, points in the map are not shown at the exact locations.

Table 4. Details of the 7 Spatial Clusters of Relative Exposure (RE) Identified from the SaTScan Analysis Based on All Census Tract in the National Air Toxics Assessment (NATA) Data (n = 72,079) for the Contiguous United States

	Cluster type	*General regions covered*	*Cluster centroid*	*Cluster radius (km)*	*Mean RE inside the cluster*	*Mean RE outside of the cluster*	*Time frame*
Cluster I	High	Southeast region	31.667244 N, 88.650140 W	842.20	0.25	–0.23	2011/1/1 to 2014/12/31
Cluster II	High	West region	32.664751 N, 117.147814 W	528.22	0.32	–0.20	2011/1/1 to 2014/12/31
Cluster III	High	New York City area	40.774858 N, 73.980666 W	24.18	0.61	–0.19	2011/1/1 to 2014/12/31
Cluster IV	Low	Great Lakes region	44.042897 N, 82.941870 W	443.61	–0.52	–0.16	2011/1/1 to 2014/12/31
Cluster V	Low	Northwest region	45.173773 N, 108.711004 W	1054.14	–0.61	–0.17	1999/1/1 to 2005/12/31
Cluster VI	Low	New England region	44.941764 N, 72.219544 W	450.32	–0.52	–0.17	2011/1/1 to 2014/12/31
Cluster VII	High	Pittsburg area	40.417762 N, 79.892146 W	21.38	0.56	–0.18	2011/1/1 to 2014/12/31

RE at each census tract was a relative measure in reference to the New York State average in 1996, 1999, 2002, 2005, 2011, and 2014, which were the years of corresponding available NATA data.

Table 5. Proportions of Addresses from the 3 Relative Exposure (RE) Trajectory Groups by Hot/Cold Spot RE Clusters

	Trajectory groups	*Overall (%)*	*Cold spots (%)*	*Hot spots (%)*	*Neither (%)*
All addresses within the contiguous United States	Increased high exposure	33.3	7.0	67.2	25.8
	Decreased low exposure	39.4	52.2	10.1	37.6
	Persistent low exposure	27.4	71.0	7.9	21.1
All addresses within New York State	Increased high exposure	33.5	6.5	74.6	18.9
	Decreased low exposure	39.8	59.6	5.1	35.4
	Persistent low exposure	26.7	82.6	0.5	16.9

Hot/cold spot RE clusters were based on all census tracts (n=72,079) in the National Air Toxics Assessment (NATA) data for the contiguous United States. Details of the hot/cold spots were shown in Table 4.

NYC tended to have a higher air toxic exposure than the non-NYC area in the state.

Table 5 shows the proportion of addresses within each of the 3 RE trajectory groups by the hot/cold spot RE clusters identified from the SaTScan analysis. At the national level, 67.2% of the addresses in the increased high exposure group were located within hot-spot clusters. In contrast, 71.0% of the addresses in the persistent low exposure group were covered by cold-spot clusters. Within NYS, 74.6% of the increased high exposure addresses were in the NYC hot spot, while 82.6% of the persistent low exposure addresses were within cold spots.

Discussion

When analyzing mesothelioma patients' residential histories spanning 15 years prior to their cancer diagnoses, we found that the trajectory pattern of exposures to nonasbestos air toxics was not homogeneous. In addition, patients' residential histories, their related exposures, and exposure trajectories differed by race and ethnicity. The identified nonasbestos exposure patterns were not intended for studying the disease etiology of mesothelioma. Rather, our findings provide some new insights into the heterogeneity of environmental exposures among mesothelioma patients other than the commonly known asbestos exposure patterns. More importantly, this study demonstrated an innovative approach that can be used to study cancer types that do not have a clear etiology and may have a higher risk from environmental exposures. This method can also be applied to examine exposure heterogeneity in social risks, such as low SES, and their impact on patient outcomes across the cancer continuum.

We identified 3 clear trajectory patterns of exposure histories to nonasbestos air toxics: *persistent low exposure, decreased low exposure,* and *increased high exposure*. They corresponded to lateral, downward, and upward changes of exposures over time. In addition, we found patients' race and ethnicity differed across the 3 trajectory groups, with NHW patients being less likely to be in the increased high exposure group than patients of other races/ethnicities. To

further elucidate the identified heterogeneity, we compared our mesothelioma patients' residential locations with the hot/cold spots of REs identified using the national NATA data. We found that patients within the persistent low exposure class tended to live outside of NYC, the largest metropolitan urban city in the United States, which also tends to have a higher air toxic exposure than the non-NYC area in NYS. The opposite was seen for patients belonging to the increased high exposure group. These results are consistent with the general demographic distributions of NHW and not-NHW groups, where a higher proportion of not-NHW individuals tend to concentrate in NYC than in the rest of NYS. We also found that, compared to patients in the other 2 trajectory groups, patients in the persistent low exposure trajectory group had a significantly shorter residential duration, suggesting that these patients may move more frequently. However, comparisons of patients across the 3 trajectory groups shows that these patients were similar in other characteristics, including the number of unique addresses lived. Taken together, the observed differences in the proportion of race/ethnicity and residential durations by exposure trajectory groups are likely reflecting the differences in patients' residential mobility. For instance, patients in the persistent low exposure group tend to have a lateral mobility (ie, moving among places with similar levels of low exposure levels to nonasbestos air toxics). While investigating the reasons of moving is beyond the scope of the current paper, future studies should examine factors (eg, family, job, housing, SES, and health related factors) associated with the moves that occurred both before and after cancer diagnosis, as well as how these moves impact patient's cancer care delivery and health outcomes.

The current study also suggests that the extent of exposure misclassification may vary by trajectory groups when using the exposure at cancer diagnosis for past exposures. For example, our mesothelioma patients in the persistent low exposure group experienced a lower variability in their exposure levels than those in the increased high exposure and decreased low exposure groups. Consequently, using the exposure level at cancer diagnosis and assuming a constant exposure history may be more reasonable for patients in the persistent low exposure group than patients in the other 2 groups. Nevertheless, regardless of the trajectory assignment, all 3 groups showed some variations during the 15-year look-back window and thus all patients would be susceptible to exposure misclassification. In particular, using the snapshot of exposure level at cancer diagnosis is likely to overestimate patients' past exposures for those in the increased high exposure group and underestimate them for patients in the other 2 trajectory groups.

Our previous study of mesothelioma patients with varied residential history lengths, which assumed no heterogeneity in exposure trajectories among patients, showed a difference of up to 15 percentage points in the yearly RE associated with air toxics between earlier addresses and the address at cancer diagnosis.[16] The method we used in the previous study was a traditional general estimated equation model, which is commonly used for longitudinal data, such as ours where the yearly RE estimate was available for the same mesothelioma patient over multiple time points during the 15-year period prior to cancer diagnosis. The focus there was to capture the average RE variation over time assuming a homogeneous RE profile among all patients. In the current study, we used a latent class mixed modeling approach, which belongs to a family of latent process methods that have been increasingly used to capture the heterogeneity in treatment responses and behavioral development in clinical and psychosocial studies.[23-26] Here, we focused on the relationship between REs and the underlying latent trend among subgroups. This method allowed us to capture the variability in the shape and level of REs across trajectory groups. The finding of 3 class trajectories over 1 class trajectory suggests that individuals may follow distinctive exposure trajectories or belong to different subgroups rather than all belonged to 1 homogeneous group.

Expanding from our previous work, the current study suggests that there exist heterogeneous exposure misclassification patterns tied to different exposure trajectories as well. These findings may have important implications in examining cancer risks when comparing cancer patients and their noncancer counterparts, such as those in a case-control or a cohort study. For example, if more cases are from an increased high exposure trajectory group while more controls are from a decreased low exposure or a persistent low exposure trajectory group, then the relative risk or odds ratio based on the exposure at cancer diagnosis may be overestimated. On the other hand, if more cases were from a decreased low exposure group or a persistent low exposure group while more controls are from an increased high exposure trajectory group, then the relative outcome–exposure association based on the snapshot exposure at cancer diagnosis would be underestimated. Therefore, future studies should consider the heterogeneity in exposure trajectories when estimating exposure-outcome associations.

The study has a few limitations. First, our findings may be unique to the mesothelioma patients studied, as these patients were likely to have different occupational, socioeconomic, and demographic factors, as well as residential mobility patterns from patients diagnosed with other types of cancer. For example, the predominant majority of mesothelioma patients in our study were NHW. This also contributed to the uncommon magnitude of aOR and their relatively wide 95% CIs seen in the regression model results. In addition, patients in NYS may also differ from patients in other states, as NYS is a large populous state with dynamic migration patterns. For example, a recent study on all cancer patients from 11 registries (representing 11 states) in the NCI's SEER program showed that cancer patients in NYS had the highest state-to-state move rates within the most recent 5-year period.[13] Future examinations using different patient populations, particularly those with cancer types that are more germane to nonasbestos air toxics, are needed. Second, our exposure estimate was based on the NATA data at the census tract level for 6 specific years, which did not consider border (or overflow) effects. Incorporating environmental exposure data with refined geographic and time resolutions and applying spatial disaggregation or downscaling methods should improve the

quality of exposure estimates. Finally, the patient residential history included may be incomplete and the missingness of the address information may differ by patients characteristics, including race and ethnicity, as previous studies using LexisNexis have shown.[10,14,39] On the other hand, we were able to identify the patient residential history information from 3 data sources, which may have mitigated this problem to a certain degree, though the cancer registry data only contained patients' address information at the time of cancer diagnosis, and the SPARCS data were only for those who had inpatient admissions in NYS during the study period. Additional analysis using those with a 20-year residential history also yielded a 3-class solution and supported the main finding that NHW patients were more likely to be in the persistent low exposure and decreased low exposure groups (data not shown). Finally, while we were able to identify 3 trajectory groups in the first stage of the analysis, the uncertainty of the class membership was not incorporated in the second stage of the analysis, which warrants further exploration with more advanced statistical models. The current model also assumed a linear relationship between the outcome (RE) and a Gaussian latent variable, which may be a strong assumption.[46] Future studies should also explore the differences between linear and nonlinear latent models in estimating trajectory groups and the impact of different group membership assignments in the second stage analysis. Along the same vein, the hot/cold spots were identified using a circular search window (default settings and computationally efficient), while the true hot/cold spots may be irregularly shaped.

Conclusions

As residential history information becomes more and more readily available, there is a growing interest in using this information to facilitate cancer surveillance and epidemiological studies. We quantified the heterogeneous experiences of cancer risks associated with exposures to ambient air toxics among a cohort of NYS mesothelioma patients, and found that patient race and ethnicity differed across the identified exposure trajectories. Comparisons of the patient residential locations to the spatiotemporal hot/cold spots of exposures, identified based on the NATA data, revealed that the observed differential trajectory patterns were likely a reflection of differences in patients' residential mobility prior to their cancer diagnoses. We used mesothelioma patients for illustrative purposes, acknowledging that the method was not developed for the purposes of identifying the etiology of mesothelioma. Overall, we demonstrated an innovative method of combining latent class mixed modeling and spatiotemporal scan statistics. This method can be applied to all cancer types to understand patient exposure history to pollutants and social risks, as well as their relationships with cancer incidence, treatment, and survival.

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Original Article

Description of the National Mortality Register of Panama

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Abstract: Introduction: The National Mortality Register (NMR) of Panama is a key element in demographic analysis and in acquiring an updated picture of population health in Panama. The main objectives of this study are to characterize the NMR and to enumerate its strengths and weaknesses. Methods: We describe the history, processes, and structure of the Vital Statistics Section of the National Institute of Statistics and Census (the curator of the NMR database). In addition, we discuss publication punctuality, underregistration of the data, the proportion of registered deaths certified by medical doctors, and the top 5 causes of death according to the 80 groups of the *International Classification of Diseases, Tenth Revision*. We also examine works derived from the register's data, from the first publication on its website (2002) until 2019. Results: The NMR procedures were described. The web reports of the NMR were performed with a delay of between 1 to 2 years. The underregistration of deaths in 2002–2019 was 14.7%, and the national yearly proportion of deaths certified by medical doctors was always above 90%. Hard-to-reach areas had higher underregistration proportions and fewer deaths certified by medical doctors. Information extracted from the NMR supports several national and international reports, geographic information systems, and studies. The most common causes of death between 2002 and 2019 were noncommunicable diseases. Conclusions: The NMR is a robust official information system. However, hard-to-reach areas require improvement in terms of the NMR. The NMR is used for publishing official reports, writing studies, and updating reports on the current health status of Panama in a timely fashion following international guidelines.

Key words: *mortality register, Panama, vital statistics*

Introduction

Vital records, including the mortality register, are used to perform a series of demographic analyses to calculate rates and projections to assess the current and future growth of a population. A mortality register is an essential component of a health information system.[1] Mortality statistics contribute to assessment of the current picture of population health and the planning, execution, and evaluation of national development programs. The main objective of the National Mortality Register (NMR) of Panama is to compile, review, and publish mortality statistics using data from every person who died in Panama.

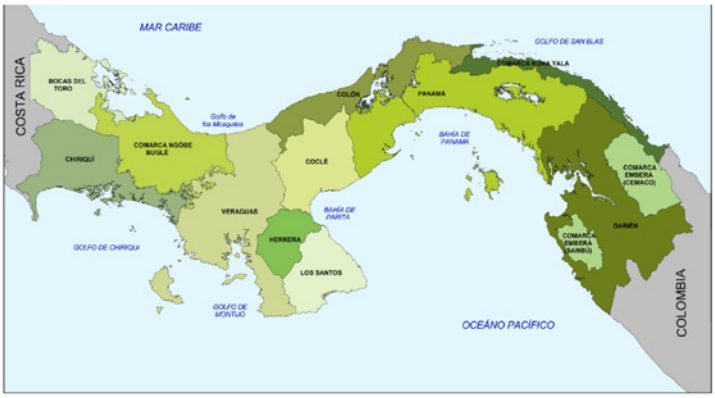
Panama is a tropical country located in the southern part of the Central American Isthmus with an estimated population of 4,445,505. Panama became a republic in 1903.[2] Panama first had 12 administrative divisions (9 provinces and 3 indigenous territories) (Figure 1). In December 2013, the area within the province of Panama west of the Panama Canal was declared a new province named "Panama Oeste."[3] However, for the current report, we use the original geographic divisions.

The main objectives of this study were to characterize the NMR of Panama and to enumerate its strengths and weaknesses.

Materials and Methods

Using interviews with the officer of the Vital Statistics Section (VSS) of the National Institute of Census and Statistics (INEC, acronym in Spanish) and from the official documentation, we described the history and procedures of the NMR.

Figure 1. First-Level Administrative Divisions (Provinces and Indigenous Territories) of the Republic of Panama, 2014



Source: DIVISIÓN POLÍTICA DE LA REPÚBLICA DE PANAMÁ POR PROVINCIAS Y COMARCAS, AÑO 2010 (28). Ngäbe-Bugle, Emberá and Guna-Yala are Indigenous Territories (Comarca in Spanish).

Strengths and Weaknesses of the Register

The punctuality of the NMR was assessed using the time between data generation and the published report extracted from the NMR website between 2002 (when the first report was uploaded online) and 2019. Although the

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website also shows reports from 2020 onwards, such information will be evaluated in future studies because of the unique impact of the COVID-19 pandemic.

Using the observed deaths and the census population as of July 1, a mortality table was prepared to evaluate life expectancy at birth. A hypothesis of expected life expectancy at birth in the year 2050 was formulated via Coale and Demeny model tables, and logit West Brass was used to obtain expected deaths, since this is the model used for the behavior of mortality in the countries of the Latin American region. The yearly national underregistration rates were calculated using the number of yearly registered deaths extracted from the reports from the NMR website and corresponding estimated deaths, which were calculated by the INEC Demographic Analysis Unit between 2002 and 2019.

The underregistration rate was calculated using the following formula:

$$\textit{Underregistration} = 1 - \frac{\text{Registered deaths}}{\text{Estimated deaths}}$$

The national and provincial proportions of underregistration are reported for 2002–2019 in a similar fashion.

The national yearly proportions of deaths certified by medical doctors were assessed using official reports between 2002 and 2019. The national and provincial proportions of deaths certified by medical doctors are reported for 2002–2019 in a similar fashion.

We report the top 5 most common causes of death according to the Mortality Tabulation List 2 (80 groups) of the *International Classification of Diseases, Tenth Revision* (ICD-10)[4] extracted from the most recent VSS official reports between 2002 and 2019 on its webpage.[5]

Routine official report information was described by VSS officers (FG/FI/AR). Other reports were also mentioned. A search of the latest literature using NMR data was performed using the Medline and Web of Science databases.

Ethical Statement

Anonymous secondary data were taken from the Mortality Registrars and from the publicly available web page; therefore, no ethics approval was required.

Results

NMR Characterization

Official national death statistics in the Republic of Panama have been published since 1907. Starting in 1942, official death statistics were published by the Directorate of Biostatistics and Health Education of the Ministry of Health and Public Works. Since 1952, these statistics have been published by the Subsection of Vital Statistics as a dependency of the Social Statistics Subdirectorate of the Direction of Census and Statistics within the Direction of Biostatistics and Health Education. Since 1964, the Subsection of Vital Statistics has been named the VSS. Since 1952, the VSS has published national official vital statistics tables in printed form.

In 2009, a new law (10/2009) was introduced with the aim of modernizing the National Statistics System and officially implementing the INEC as a dependency of the Contraloría General de la República (in English: *National Comptroller General of Panama*).[6] The main aims of the VSS are as follows:

1. To establish the principles and rules that govern statistics-related activities in the Panamanian government.
2. To implement the INEC, the National Statistics System, the National Council of Statistics, and the Technical Consulting Committees and to rule regarding the National Statistics Plan to articulate its activities.
3. To establish the principles and to improve the duties of the National Statistics System for coordination regarding the participation and collaboration of governmental institutions. The National Statistics System, when needed, shall foster cooperation from private institutions and the public.
4. To foster the integration and development of the National Statistics System to satisfy citizens' rights to grant them access to public official information.

The VSS is within the INEC. The VSS and 8 INEC regional offices code death certificates. Table 1 shows the regional offices and their respective geographic areas covered by the NMR (Figure 1). There is an INEC regional office per province except for the Herrera/Los Santos regional office, which covers 2 provinces, mainly due to

Table 1. The Vital Statistics Section (VSS), the National Institute of Statistics and Census (INEC, Spanish Acronym) Regional Offices and Their Respective Geographic Areas Related to the National Mortality Register (NMR) of Panama

Office	*Geographic area covered*
VSS (in Panama City)	Panama Province and Guna-Yala Indigenous Territory
INEC regional office	
Bocas del Toro	Bocas del Toro Province and the following Ngäbe-Bugle districts: Kankintú, Kusapin, Jirondai, and Santa Catalina
Coclé	Cocle Province
Colón	Colon Province
Chiriquí	Chiriqui Province and the following Ngäbe-Bugle districts: Besikó, Mironó, and Nole Düima
Darién	Darien Province and Emberá-Wounnan Indigenous Territory
Herrera/Los Santos	Herrera and Los Santos provinces
Veraguas	Veraguas Province and the following Ngäbe-Bugle districts: Müna and Ñürúm
Panama Oeste	Panama Oeste Province

their geographic proximity. Coding of death certificates in the Province of Panama is performed by the VSS. The Ngäbe-Buglé Indigenous Territory districts are covered by the closest INEC regional office, the Emberá-Wounnan Indigenous Territory is covered by Darién, and the Guna-Yala Indigenous Territory is covered by the VSS (Table 1). The VSS is financed by public funds, with 20 people working full-time.

The procedures of the NMR performed by the VSS closely follow the Principles and Recommendations for a Vital Statistics System, Revision 3 (PRVSS)[7] and the Code of Good Practice in Statistics for Latin America and the Caribbean.[8] Both are international standards to foster high-quality vital statistics systems.

Death registration is possible nationwide due to interinstitutional coordination and collaboration among the Ministry of Health, the Civil Records Department of the Electoral Tribunal, the Legal Medicine and Forensics Sciences Institute, and the VSS.

Until 2008, each death was independently recorded by 2 institutions, the VSS and the Civil Records Department of the Electoral Tribunal, using 2 different forms. Currently, the Unique Clinical Death Report Form, a standard form, is used by every institution for recording deaths and related information. To point out the historical relevance of this standard form, we extracted information from official reports preceding 2008, shortly after 2008, and the most recent information.

The original paper form of the Unique Clinical Death Report Form is collected by the Civil Records Department of the Electoral Tribunal within a week after the event. A hard copy of the form is also collected by either the corresponding INEC regional office or by the VSS within a 15-day period. Then, the Unique Clinical Death Report Form is coded and sent via the web to the Death Subsection of the VSS. Since 2015, the INEC regional offices and the VSS have validated the coded data from the form using other sources (described below). Then, the hard copies of the standard form stored in each INEC regional office are sent monthly to the Control and Promotion Subsection of the VSS.

The main cause of death is classified according to book I of the ICD-10 and according to 4 shortened lists of ICD-10 codes of the 103, 80, 6/67, and 51 death groups since 1998.[4] Contributory causes of death are also classified according to the ICD-10 codes since 2016.

The Control and Promotion Unit of the VSS receives, reviews, validates, and cross-checks the coded web data sent by each INEC regional office. Every 6 months, a report is produced to assess delayed death certificates. Delayed death certificates (less than 1%) are archived for a monthly in-depth review.

The information that feeds the NMR is stored in 3 databases: (1) as hard copies of the death certificates stored in the Civil Records Department of the Electoral Tribunal; (2) in crude electronic form stored in the National Information Technology (IT) Department of Contraloría; and (3) as a clean database curated by the VSS. Before 1996, the VSS published mortality statistics using paper-based death certificates and mortality aggregated data provided by the National IT Department of Contraloría. Since 1996, the VSS has published mortality statistics using data extracted from the database they curate. Between 1996 and 2000, the clean database was stored in Visual Basic FoxPro format. Currently, the clean database is stored in a Microsoft SQL Server version 06.01.7601. The other 2 databases are backups of the NMR.

As shown in Table 2, the NMR contains variables that correspond to the direct and indirect themes of the deceased person and the death event according to the PRVSS. For example, the death date is recorded as the day, month, and year.[7] The report of the direct themes of the PRVSS in the death certificate is also required under articles 58 to 70 of

Table 2. List of Variables Included in the National Mortality Register

Variable	*Description*
Name	Name of the deceased
Day of death	Date of death
Month of death	Month of death
Year of death	Year of death
Sex	Sex of the deceased
Age	Age of the deceased
ID number	Identification number of the deceased (Panamanian ID or passport if the deceased was born outside Panama)
Security Number	Security number of the deceased
Main cause of death	ICD-10 code of the main cause of death
Main cause of death description	Main cause of death text description
Cause of death A Part I	ICD-10 code of the cause of death A Part I
Cause of death A Part I description	Cause of death A Part I description
Cause of death B Part I	ICD-10 code of the cause of death B Part I
Cause of death B Part I description	Cause of death B Part I description

Table 2, *cont*. List of Variables Included in the National Mortality Register	
Variable	***Description***
Cause of death C Part I	ICD-10 code of the cause of death C Part I
Cause of death C Part I description	Cause of death C Part I description
Cause of death Part II	ICD-10 code of the cause of death Part II
Cause of death Part II description	Cause of death Part II description
List 80	80 group list of ICD codes for the main cause of death
List 51	51 group list of ICD codes for the main cause of death
List 667	6/67 group list of ICD codes for the main cause of death
List 103	103 group list of ICD codes for the main cause of death
Occupation	Eleven occupation groups of the deceased: • Directors and managers in the public and private sectors and their social interest organizations • Professionals, scientists, and intellectuals • Technicians and midlevel professionals • Office employees • Service workers, store and market salespersons • Farmers and agricultural, forestry, fishing and hunting workers • Craftsmen and workers in mining, construction, manufacturing, mechanics, and related occupations • Stationary plant and machine operators; assemblers, drivers and mobile machine operators • Unclassified workers in service, mining, construction, manufacturing, transportation, and other elementary occupations • Members of the armed forces and workers in unidentifiable or undeclared occupations.
Civil Status	Civil status of the deceased: • Single • Common-law married • Married • Separated/divorced • Widow/er • Younger than 15 years
Deathplace Province	Province where death took place
Deathplace District	District where death took place
Deathplace Corregimiento	Corregimiento where death took place
Geographical area	Geographical area where the death took place: • Urban • Rural
Death in hospital	Whether the death occurred in a hospital or not
Residence Province	Province where the deceased lived
Residence District	District where the deceased lived
Residence Corregimiento	Corregimiento where the deceased lived
Certification code	Person who certified the death: • Attending physician (at least a day attending the deceased) • Medical examiner • Nonattending physician • Registrar (deceased received medical attention) • Registrar (deceased did not receive medical attention)
Medical certification	Death certified by a medical doctor (physician or medical examiner)
Medical details	The name of the medical institution where the death took place, if available

ICD-10, International Classification of Diseases, Tenth Revision.

Law 31/2006.[9] Among these variables, the name, unique personal identification number (assigned to each person who is living or who has lived in Panama), birth date, and sex are considered direct themes of the deceased person.[7]

There are several quality parameters of a death register. According to the PRVSS, it is recommended to cross-validate the data derived from the NMR with independent sources that also document the death event.[7] Since 2016, the VSS regional offices and the VSS have carefully cross-validated the age, sex, and unique identification number of the deceased person using the Identification Verification System curated by the Civil Records Direction of the Electoral Tribunal. However, if the deceased person was not a Panama national and did not have a Panamanian identification number, the passport number is used instead. Data stored in the NMR are also cross-checked yearly with the National Integrated System of Criminal Statistics curated by the Panamanian Ministry of Public Security.[10]

Strengths and Weaknesses of the Panama NMR

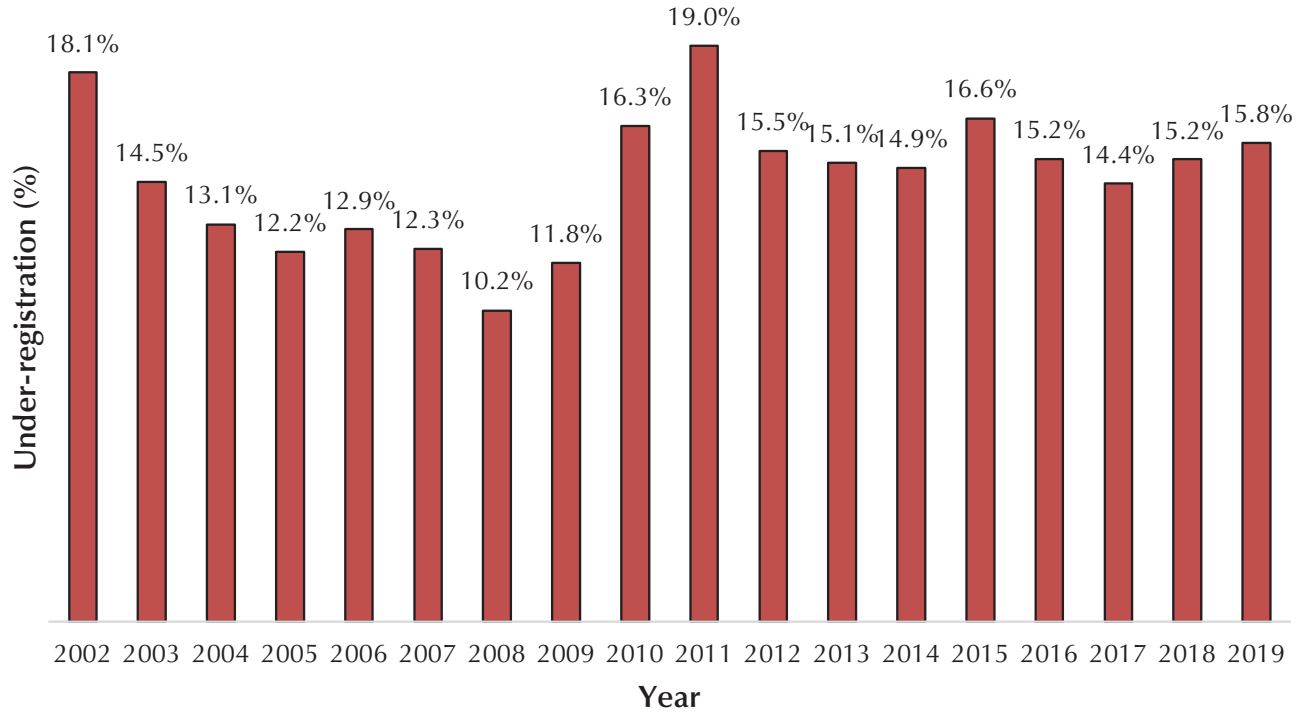
The time between the generation of the data and the web-based reports in the study period was a year, except for the following reports that took 2 years: 2002 and from 2007 up to 2012 (Table 3).

The yearly national underregistration rate reached a maximum of 19.0% in 2011 and a minimum of 10.2% in 2008 (Figure 2).

Table 3. Publication Year of the Panamanian National Mortality Register (NMR) Reports on its Website, 2002–2019

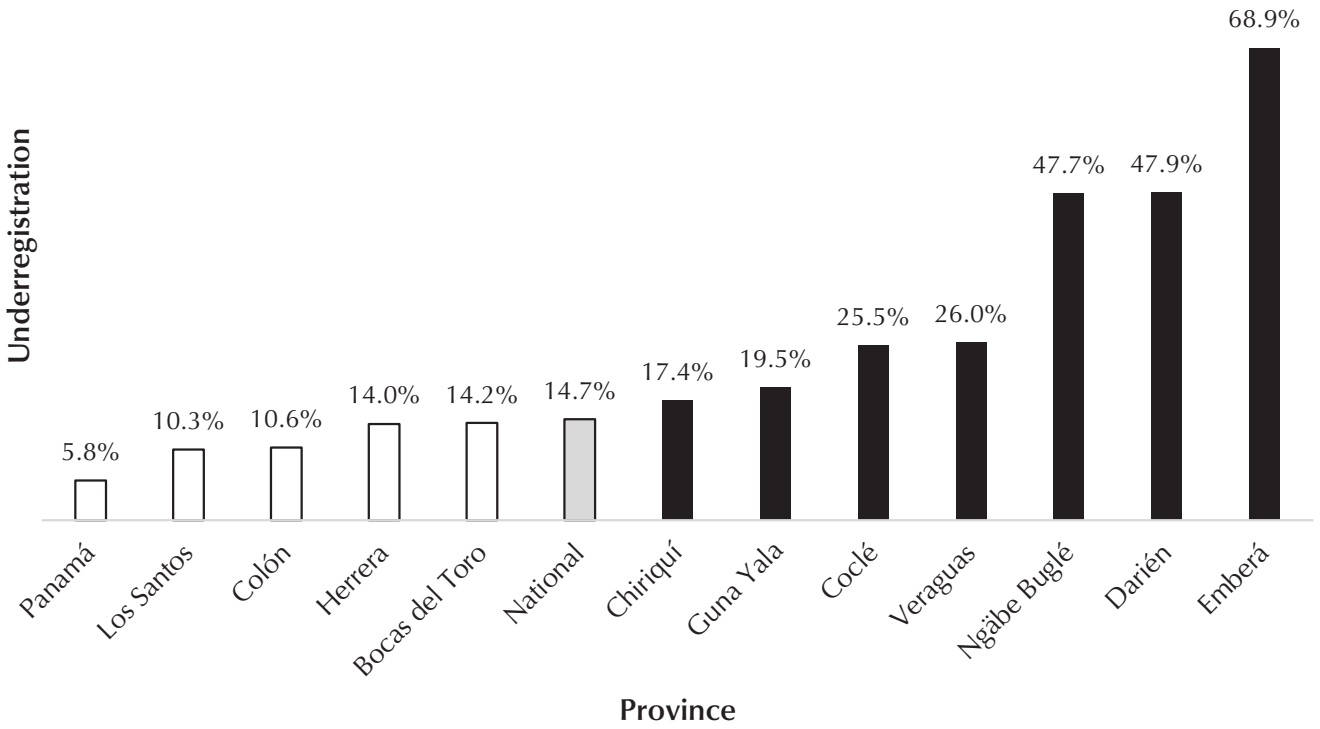
NMR report	*Publication year*
2002	2004
2003	2004
2004	2005
2005	2006
2006	2007
2007	2009
2008	2010
2009	2011
2010	2012
2011	2013
2012	2014
2013	2014
2014	2015
2015	2016
2016	2017
2017	2018
2018	2019
2019	2020

Figure 2. Yearly Underregistration of Deaths of the Panamanian National Mortality Register (NMR), 2002–2019



Sources: Registered deaths are shown on the National Mortality Register website; yearly expected deaths were provided by the Demographic Analysis Unit of the Panamanian National Institute of Statistics and Census (INEC) as described in the main text.

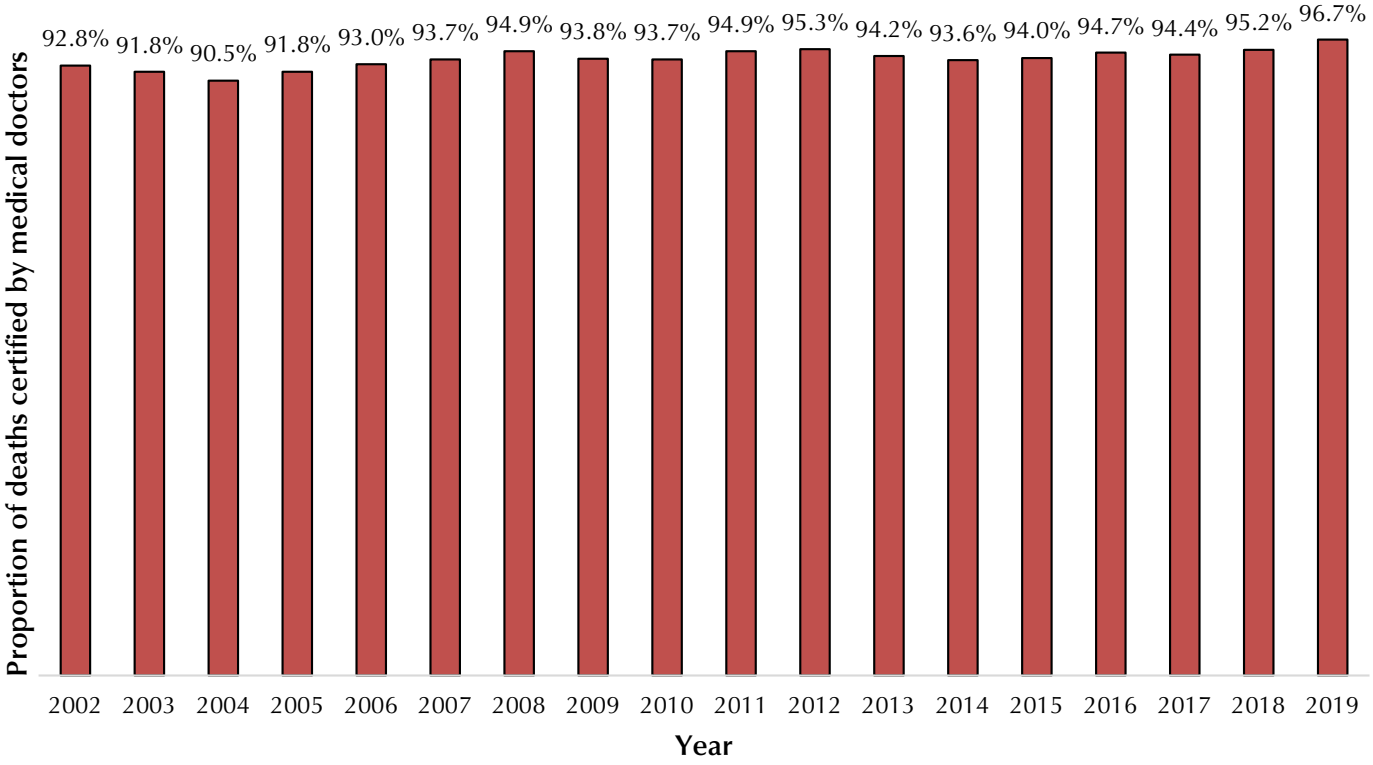
Figure 3. Underregistration of Deaths in the Panamanian National Mortality Register by Province, 2002–2019



The underregistration of deaths in Panama Oeste is shown together with that of the province of Panama between 2014 and 2019.

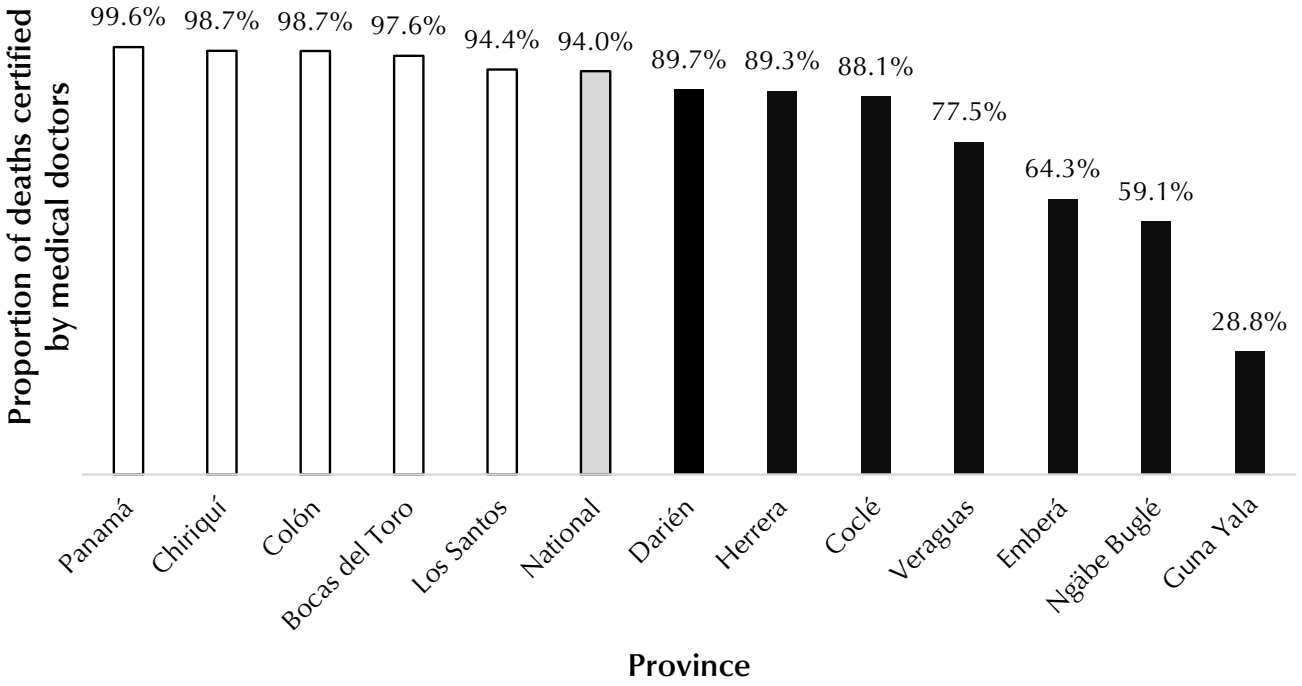
Sources: Registered deaths are shown on the National Mortality Register website; yearly expected deaths were provided by the Demographic Analysis Unit of the Panamanian National Institute of Statistics and Census (INEC) as described in the main text.

Figure 4. Yearly Proportion of Deaths Certified by Medical Doctors in the Panamanian National Mortality Register (NMR), 2002–2019



Sources: The proportion of registered deaths certified by medical doctors was extracted from the Panamanian National Mortality Register website.

Figure 5. Proportion of Deaths Certified by Medical Doctors in the Panamanian National Mortality Register by Province, 2002–2019



The proportions of deaths certified by medical doctors in Panama Oeste and Panama are shown together between 2014 and 2019. Sources: Registered deaths are shown on the Panamanian National Mortality Register website; yearly expected deaths were provided by the Demographic Analysis Unit of the Panamanian National Institute of Statistics and Census (INEC) as described in the main text.

The national underregistration rate from 2002–2019 was 14.7% (Figure 3). The provinces with proportions of underregistered deaths during 2002–2019 higher than the national value were Chiriquí (17.8%), Comarca Guna Yala (17.4%), Coclé (25.5%), Veraguas (26.0%), Comarca Ngäbe-Buglé (47.7%), Darién (47.9%), and Comarca Emberá (68.9%). The yearly national proportion of deaths certified by medical doctors was higher than 90%, with a maximum value of 96.7% in 2019 (Figure 4).

The proportion of deaths certified by medical doctors from 2002–2019 was 94.0% (Figure 5). The provinces that had proportions of deaths certified by medical doctors during 2002–2019 lower than the national value were Darién (89.7%), Herrera (88.3%), Coclé (88.1%), Veraguas (77.5%), Comarca Emberá (64.3%), Comarca Ngäbe-Buglé (59.1%), and Comarca Guna-Yala (28.8%).The VSS generates a monthly report to the Statistics Division of the United Nations (UN) with the national number of deaths and the

Table 4. Yearly Ranking of the Top Causes of Deaths According to the 80-Groups of ICD-10 in the Panamanian National Mortality Register, 2002–2019

Ranking	*2002*	*2003*	*2004*	*2005*	*2006*	*2007*
1	Malignant neoplastic diseases	Malignant neoplastic diseases	Malignant neoplastic diseases	Malignant neoplastic diseases	Malignant neoplastic diseases	Malignant neoplastic diseases
2	Accidents, self-inflicted injuries, assault and other violence	Accidents, self-inflicted injuries, assault and other violence	Stroke	Ischemic heart diseases	Accidents, self-inflicted injuries, assault and other violence	Ischemic heart diseases
3	Stroke	Stroke	Ischemic heart diseases	Stroke	Ischemic heart diseases	Accidents, self-inflicted injuries, assault and other violence
4	Ischemic heart diseases	Ischemic heart diseases	Accidents, self-inflicted injuries, assault and other violence	Accidents, self-inflicted injuries, assault and other violence	Stroke	Stroke
5	Diabetes mellitus	Diabetes mellitus	Diabetes mellitus	Diabetes mellitus	Diabetes mellitus	Diabetes mellitus

Table 4, *cont.* Yearly Ranking of the Top Causes of Deaths According to the 80-Groups of ICD-10 in the Panamanian National Mortality Register, 2002–2019

Ranking	*2008*	*2009*	*2010*	*2011*	*2012*	*2013*
1	Malignant neoplastic diseases	Malignant neoplastic diseases	Malignant neoplastic diseases	Malignant neoplastic diseases	Malignant neoplastic diseases	Malignant neoplastic diseases
2	Ischemic heart diseases	Ischemic heart diseases	Accidents, self-inflicted injuries, assault and other violence	Accidents, self-inflicted injuries, assault and other violence	Accidents, self-inflicted injuries, assault and other violence	Ischemic heart diseases
3	Accidents, self-inflicted injuries, assault and other violence	Accidents, self-inflicted injuries, assault and other violence	Ischemic heart diseases	Ischemic heart diseases	Ischemic heart diseases	Accidents, self-inflicted injuries, assault and other violence
4	Stroke	Stroke	Stroke	Stroke	Stroke	Stroke
5	Diabetes mellitus	Diabetes mellitus	Diabetes mellitus	Diabetes mellitus	Diabetes mellitus	Diabetes mellitus

Table 4, *cont.* Yearly Ranking of the Top Causes of Deaths According to the 80-Groups of ICD-10 in the Panamanian National Mortality Register, 2002–2019

Ranking	*2014*	*2015*	*2016*	*2017*	*2018*	*2019*
1	Malignant neoplastic diseases	Malignant neoplastic diseases	Malignant neoplastic diseases	Malignant neoplastic diseases	Malignant neoplastic diseases	Malignant neoplastic diseases
2	Accidents, self-inflicted injuries, assault and other violence	Accidents, self-inflicted injuries, assault and other violence	Accidents, self-inflicted injuries, assault and other violence	Enfermedades cerebrovasculares	Ischemic heart diseases	Enfermedades cerebrovasculares
3	Ischemic heart diseases	Ischemic heart diseases	Enfermedades cerebrovasculares	Ischemic heart diseases	Enfermedades cerebrovasculares	Ischemic heart diseases
4	Stroke	Stroke	Ischemic heart diseases	Accidents, self-inflicted injuries, assault and other violence	Accidents, self-inflicted injuries, assault and other violence	Accidents, self-inflicted injuries, assault and other violence
5	Diabetes mellitus	Diabetes mellitus	Diabetes mellitus	Diabetes mellitus	Diabetes mellitus	Diabetes mellitus

ICD-10, International Classification of Diseases, Tenth Revision.

national death rate. The VSS responds to a yearly questionnaire regarding detailed vital statistics by the same division of the UN. The Pan American Health Organization receives a copy of the NMR database curated by the VSS yearly.

The VSS publishes an annual web-based report of the NMR called *Vital Statistics Volume III: Deaths*.[11] This report includes mortality statistics published in at least 22 tables as suggested in the PRVSS.[7]

The NMR provides data for several health-related governmental institutions. For example, the Ministry of Health periodically publishes a report called "Analysis of Health Status" using data from the NMR and comparing with other sources.[12] In addition, the Gorgas Memorial Institute for Health Studies has 2 geographic information systems to visualize malignancies and cardiovascular-related mortality using NMR data.[13,14] Furthermore, several studies have used NMR data to assess the mortality and sociodemographic variables of several diseases.[15-21] Others have used information extracted from the NMR to compare the Panamanian death rates with those of other countries.[22-26] Panamanian insurance companies offering life insurance require actuarial technical notes that support their products using data extracted from official reports published by the VSS.[27]

During the study period, the annual leading cause of death nationally was malignant neoplastic diseases. The following second, third, and fourth yearly leading causes of death nationally varied among the following 3 groups: "accidents, self-inflicted injuries, physical assault and other violence," "heart ischemic disease," and "cerebrovascular disease." The fifth leading annual cause of death in Panama was diabetes mellitus (Table 4).

Discussion

Herein, we provided a detailed overview of the current registration practices of the NMR. Eight INEC regional offices and the VSS code data from death certificates. All data received are carefully revised before adding them to the curated NMR database to produce official mortality statistics reports in a timely fashion.

Data extracted from the NMR have been used in several reports and studies. The leading cause of death between 2002 and 2019 was noncommunicable diseases, with small changes in the ranking of diseases.

The completeness of death registration data, accurate coding of the cause of death, and identification of the underlying cause of death are key issues for any national mortality registry.[7] There is a lack of studies describing the NMR at a subnational level. Notably, other studies have compared the performance of the NMR with those of other countries, ranking it as *good*.[23,24,26] One of the publications of the Global Burden of Diseases collaboration estimated that the NMR had >95% completeness in 2014.[23]

One of the advances of the NMR is recording the contributory causes of deaths since 2016. This novel advance might help researchers use the NMR database to clearly understand the chain of events leading to death when needed and to identify an outcome that might not be captured by the main cause of death.

Since 2014, the NMR results from the prior year have been published regularly. This follows the "timeliness and punctuality" principle of the Code of Good Practice in Statistics for Latin America and the Caribbean.[8]

One of the strengths of the NMR is that the VSS closely follows the PRVSS[6] when it inputs and revises the data of the NMR database, which provides high-quality mortality statistics in Panama in a timely manner. The Panamanian identification number is unique, making it easy to link to other national registers. The VSS together with INEC regional offices review and crosscheck the information of each registered death event that occurs in Panama with independent information systems before adding the deceased person and the death information to the NMR and publishing a high-quality official mortality statistics report. The comprehensive PRVSS parameters of the NMR are a consequence of a close interinstitutional collaboration of the INEC, the Panamanian Health Ministry, the Tribunal Electorate, and Institute of Legal Medicine and Forensics Sciences in the last 10 years. Unfortunately, previous studies have shown that in a few other countries in the Americas, most deaths are not registered, particularly in Honduras, Haiti, and Bolivia.[23,24] However, some weaknesses of the NMR include underregistration and the low proportion of deaths certified by medical doctors in hard-to-reach provinces.

Conclusion

The NMR is a robust official information system. The NMR provides high-quality information supporting reports, geographic information systems, and studies in a timely fashion. Although the NMR needs improvements in the data collected from provinces and indigenous territories that are difficult to reach, it plays a unique and critical role in providing health metrics for Panama.

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Short Report

Implementation and Evaluation of the California Cancer Registry Patient Contact Database

Ani S. Movsisyan Vernon, MS; Brenda M. Hofer, MA; Arti Parikh-Patel, PhD, MPH; Theresa H.M. Keegan, PhD, MS

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 availability for patient contact, cases released for patient contact, and outcomes after patient contact (Figure 1). All patient contact studies at the central registry begin after administrative review and approval of respective patient contact study protocol, including the patient consent process and

Figure 1. Three Main Functions of the Patient Contact Database

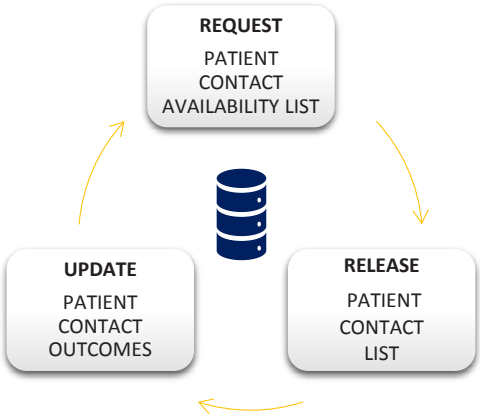
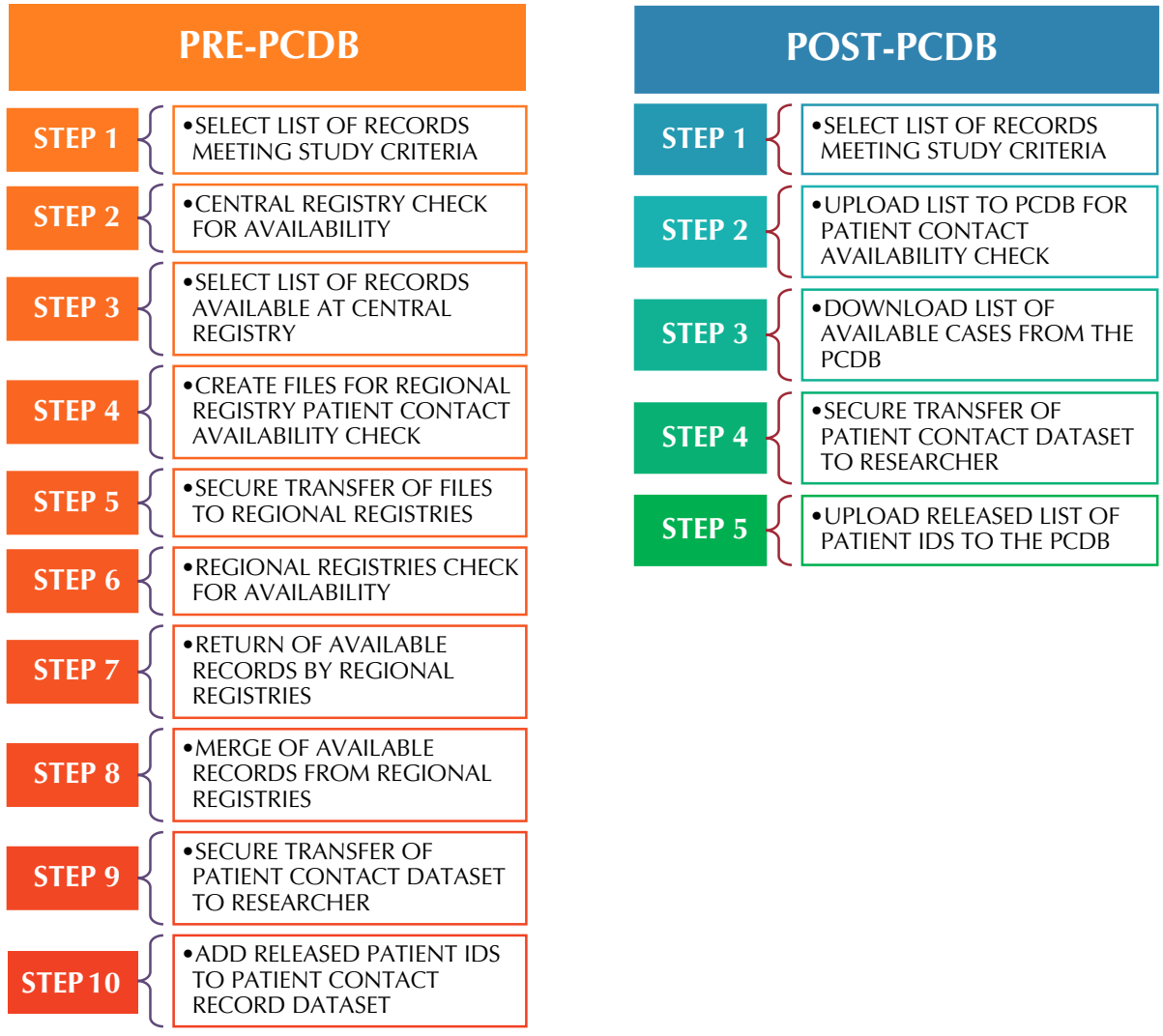


Figure 2. Patient Contact Data Release Workflow Pre– and Post–Patient Contact Database (PCDB) Implementation



an application for CCR data, including patient selection criteria. As such, for the purposes of this study, start and completion dates of patient contact studies occur after completion of all administrative reviews. Therefore, the time required for administrative review is not considered in this study. 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 conducted before PCDB implementation and 19 studies conducted after implementation. Net workday averages of the pre- and post-PCDB studies were compared using an unpaired *t* test.

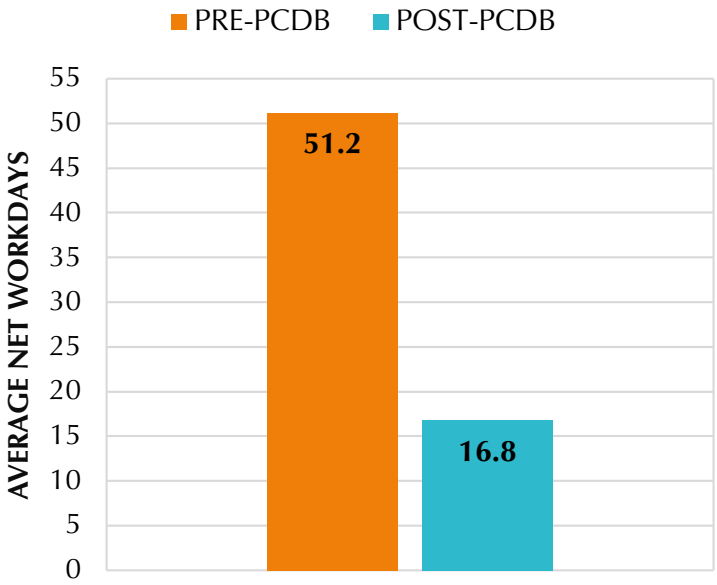
Results

The workflow pre-PCDB implementation consisted of 10 steps between study start and completion, while the workflow post-PCDB implementation consisted of 5 steps (Figure 2). 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 identifiers to the PCDB. We observed a statistically significant difference (P = .0004) in average net workdays between study start and completion before PCDB implementation (n = 19; mean, 51.16; SD, 35.27) and after (n = 19; mean, 16.84; SD,14.59) (Figure 3).

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.

Figure 3. Average Net Workdays Between Patient Contact Study Start and Completion Pre– and Post–PCDB Implementation



Research and Data Use Winner

Monoclonal Gammopathy of Undetermined Significance and Multiple Myeloma Survival Among Hispanics Living in Puerto Rico

Maira A. Castañeda-Avila[a]; Tonatiuh Suárez Ramos[b]; Carlos R. Torres-Cintrón[b]; Axel Gierbolini-Bermúdez[b]; Guillermo Tortolero-Luna[b]; Karen J. Ortiz-Ortiz[b]

Background

Monoclonal gammopathy of undetermined significance (MGUS) is a premalignant condition that may progress to multiple myeloma (MM). Understanding the progression of MGUS to MM is crucial for identifying those at high risk and developing early detection and treatment strategies.

Objective

The aim of this study was to investigate the effect of previous MGUS diagnosis on MM survival in Puerto Rico.

Methods

The study included incident cases of MM diagnosed between 2010 and 2016 coming from the Puerto Rico Central Cancer Registry Health Insurance Linkage Database (PRCCR-HILD). Patients with MM who had a previous MGUS diagnosis at any point in their health history were identified by applying a previously validated algorithm to health claims data.

Competing-risk modeling was used to estimate the impact of previous MGUS on MM survival, adjusting for sex, age group, National Cancer Institute Comorbidity Index, and insurance status at diagnosis. Survival differences were compared by MGUS status using Kaplan–Meier survival curves and the log-rank test.

Main Findings

Of the 1,183 cases with MM diagnosis identified in the PRCCR-HILD, 117 (9.9%) had at least 1 MGUS diagnosis code 30 days before MM diagnosis (Figure 1). Patients with a previous MGUS were found to be older, have a higher comorbidity index, and more likely to have Medicare compared to those without a previous MGUS diagnosis (Table 1).

After adjusting for sex, age at diagnosis, comorbidity index, and insurance, patients with a previous MGUS diagnosis had an overall 53% lower risk of dying from MM than patients without a previous MGUS diagnosis (subdistribution hazard ratio [SHR], 0.47; 95% CI, 0.32–0.70).

Figure 1. Study Flow

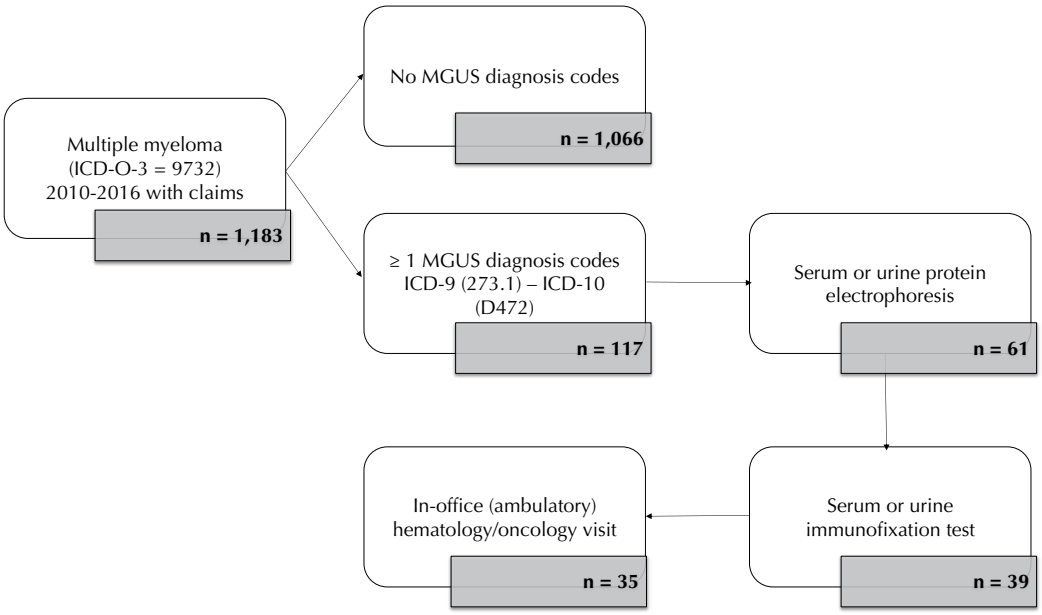


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Table 1. Clinical and Sociodemographic Characteristics Among MM Patients With and Without MGUS (n = 1,183)

Characteristics	*Previous MGUS*	
	Yes	**No**
	117	1,066
Sex		
Male	52 (44.4)	536 (49.3)
Female	65 (55.6)	552 (50.7)
Age group (y)*		
40–69	50 (42.7)	578 (54.2)
70–79	38 (32.5)	334 (31.3)
≥80	29 (24.8)	154 (14.5)
NCI Comorbidity Index*		
0–1	76 (65.0)	807 (74.2)
≥2	41 (35.0)	281 (25.8)
Insurance at diagnosis*		
Private	25 (21.4)	235 (22.2)
Medicare	62 (53.0)	381 (36.1)
Medicare–Medicaid†	30 (25.6)	440 (41.7)

MGUS, monoclonal gammopathy of undetermined significance; MM, multiple myeloma; NCI, National Cancer Institute. *χ^2 $P < .05$.
†Includes only Medicaid and dual eligible.

In a stratified analysis, after adjusting for all other covariables, males with prior MGUS had a 60% lower risk of dying from MM compared to males without MGUS (SHR, 0.40; 95% CI, 0.22–0.74). In addition, adults aged 40–69 years with MGUS had a 77% lower risk of dying from MM compared to adults aged 40–69 years without MGUS (SHR, 0.23; 95% CI, 0.09–0.61) (Table 2).

Adults with a comorbidity index score of 0 or 1 and prior MGUS had a 70% lower risk of dying from MM than adults without MGUS (SHR, 0.30; 95% CI, 0.17–0.54). Also, people with both Medicare and MGUS had a 57% lower risk of dying from MM compared to people with Medicare without MGUS (SHR, 0.43; 95% CI, 0.25–0.74). No statistical difference was found among those with private or Medicaid–Medicare dual insurance (Table 2).

Probabilities of survival were lower in patients without previous MGUS compared to patients with MGUS diagnosis ($P < .05$) (Figure 2).

Conclusion

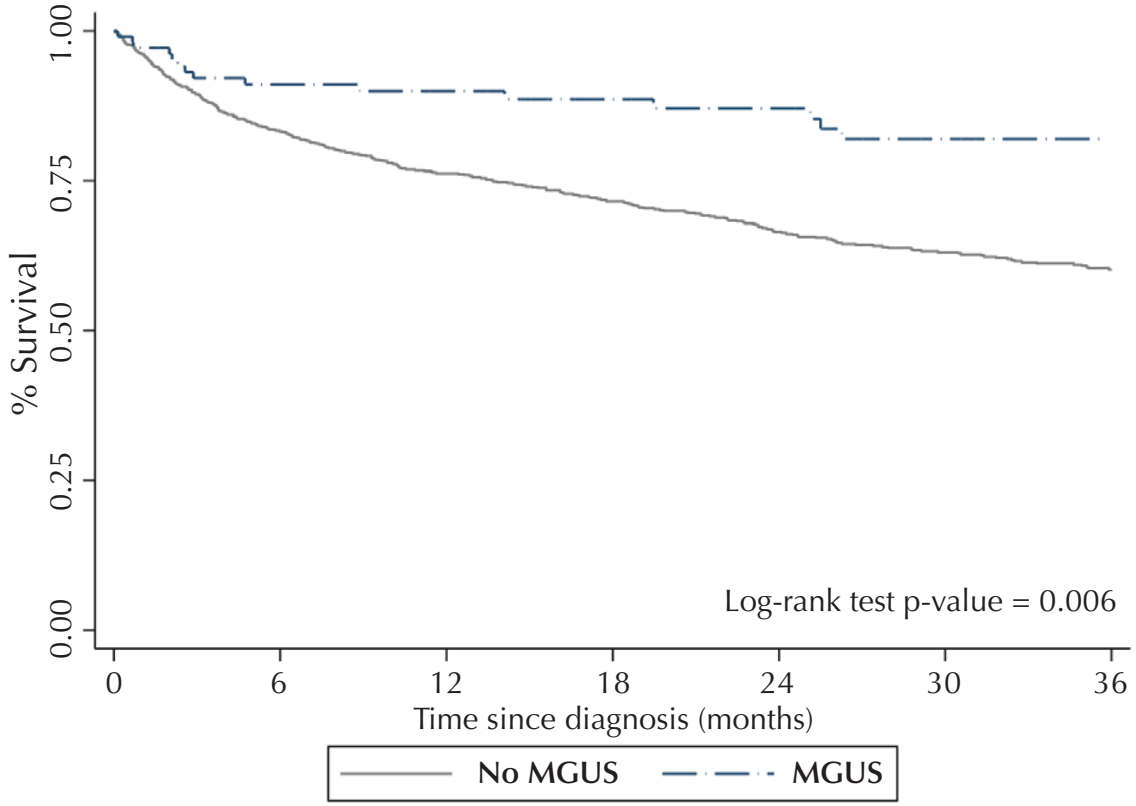
Our study suggests that for patients diagnosed with MM, having a previous diagnosis of MGUS may be associated with a lower risk of dying from MM. This association was stronger among males, younger adults, and those with low comorbidity. Patients with a previous MGUS diagnosis may have improved survival due to more frequent access to health care or earlier access to more effective treatments for MM. Further research is necessary to gain a comprehensive understanding of the underlying mechanisms.

Table 2. The Magnitude of the Association Between Having a Previous Diagnosis of MGUS and MM-Specific Risks of Death by Different Characteristics

	Crude SHR (95% CI)	*Adjusted SHR (95% CI)*
Overall		
Non-MGUS	1.00	1.00
MGUS	0.51 (0.34–0.75)	0.47 (0.32–0.70)
Sex		
Males		
Non-MGUS	1.00	1.00
MGUS	0.41 (0.22–0.76)	0.40 (0.22–0.74)
Females		
Non-MGUS	1.00	1.00
MGUS	0.63 (0.38–1.03)	0.58 (0.36–0.94)
Age group (y)		
40–69		
Non-MGUS	1.00	1.00
MGUS	0.23 (0.09–0.61)	0.23 (0.09–0.61)
70–79		
Non-MGUS	1.00	1.00
MGUS	0.50 (0.27–0.94)	0.50 (0.27–0.92)
≥80		
Non-MGUS	1.00	1.00
MGUS	0.76 (0.42–1.36)	0.71 (0.39–1.29)
NCI Comorbidity Index		
0-1		
Non-MGUS	1.00	1.00
MGUS	0.33 (0.19–0.59)	0.30 (0.17–0.54)
≥2		
Non-MGUS	1.00	1.00
MGUS	0.84 (0.49–1.43)	0.83 (0.49–1.41)
Insurance at diagnosis		
Private		
Non-MGUS	1.00	1.00
MGUS	0.65 (0.25–1.70)	0.55 (0.25–1.22)
Medicare		
Non-MGUS	1.00	1.00
MGUS	0.44 (0.24–0.74)	0.43 (0.25–0.74)
Medicaid–Medicare		
Non-MGUS	1.00	1.00
MGUS	0.52 (0.26–1.05)	0.51 (0.26–1.03)

MGUS, monoclonal gammopathy of undetermined significance; MM, multiple myeloma; NCI, National Cancer Institute; SHR, subdistribution hazard ratio.

Figure 2. Kaplan–Meier Survival Estimates Among Adults with Multiple Myeloma by MGUS Status



MGUS, monoclonal gammopathy of undetermined significance. Log-rank test *P* = .006.

Standards and Registry Operations Winner

Implementation of a Standardized Template to Improve the Timeliness and Consistency of Early Case Reporting for Pediatric, Adolescent, and Young Adult Cancer Cases to the Rhode Island Cancer Registry

Paulette Zinkann, Kioka Jenkins, Nancy Lebrun, Lisa Garcia, Christina Hiller, Erin Stair

History and Background

The 2018 Surveillance, Treatment, Access, and Research (STAR) Act required data collection and early reporting for pediatric, adolescent and young adult cancers ages 0 through 29 years. Rhode Island is 1 of 4 states to work with the Centers for Disease Control and Prevention (CDC) on this project. Rhode Island enacted a mandate requiring all cancer incidences be reported to the Rhode Island Central Registry (RICR) within 30 to 45 days of the date of first contact with a physician. To improve this reporting process, certified cancer registrars (ODS-Cs) working on the STAR Project developed a data dictionary that could be used by facilities when submitting reports to RICR (Table 1).

Objective

The study objective was to develop a standardized template of minimally required data fields to streamline the process and improve the timeliness of monthly reports submitted to RICR.

Results

When the template was introduced in May 2022, 56% of all facilities reporting cancer cases in the 0–29-year age group used the template. By December 2022, 89% of facilities were using the template (Figures 1 and 2).

Methods

The following methods were implemented:

- Create a standardized template containing minimum data variables that were selected from information gathered from widely used rapid case reporting systems.
- Introduce all facilities reporting of pediatric, adolescent, and young adult cancer cases to the template.
- Offer certificates of participation to encourage template adoption over a 6-month period.
- Evaluate the adoption rate of the data dictionary template and discuss the barriers to implementation.

Conclusions

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 without additional burden on the part of the hospital registry. Future studies will evaluate how usage of this new template may impact reporting timeliness and data quality.

Author affiliations: Peers-Partners, Rhode Island Cancer Registry, Tanaq Support Services, LLC.

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For more information on the STAR Project or the research on this abstract contact STAR@Tanaq.com.

The findings and conclusions are those of the authors and do not necessarily represent the official position of Tanaq Support Services, Peer-Partners, or the Rhode Island Department of Health.

Table 1. Data Dictionary for the 2018 Surveillance, Treatment, Access, and Research (STAR) Act Project

Variable Label	Description
Registry ID	A unique code representing the data transmission source.
Reporting Facility	The Reporting Facility ID number or FIN is used to identify a reporting facility in the central registry database.
Accession Number - Hospital	A unique identifier for the patient consisting of the year in which the person was first seen at the reporting facility & the consecutive order in which the patient was abstracted.
Medical Record Number	A unique patient identifier in a facility.
Social Security Number	The patient's social security number.
Name - Last	The patient's last name.
Name - First	The patient's first name.
Address DX - Street	The patient's street address at the time the reportable tumor was diagnosed.
Address DX - City	Name of the city in which the patient resides at the time the reportable tumor was diagnosed.
Addr at DX - State	The state of residence in which the patient resides at the time the reportable tumor was diagnosed.
Addr at DX - Postal Code	The postal code in which the patient resides at the time the reportable tumor was diagnosed.
County at DX	This data item may be used for epidemiological purposes. It identifies the cancer incidence in a geographic region.
Race 1	Racial origin captures information used in research and cancer control activities comparing stage at diagnosis and/or treatment by race.
Spanish/Hispanic Origin	This code is used by hospital and cancer registries to identify whether the person should be classified as "Hispanic" for purposes of calculating cancer rates.
Sex	This data item is used to compare cancer rates and outcomes by site.
Age at Diagnosis	This data is useful for patient identification.
Birth Date	Date of birth of the patient.
Sequence Number - Hospital	Sequencing is done to identify the people that only had one malignant primary in their lifetime for survival analysis.
Date of 1st Contact	This data item is used to measure the time between first contact and the date that the case was abstracted.
Date of Diagnosis	The time for staging and treatment of cancer begins with the date of initial diagnosis for cancer.
Primary Site (ICD-O-3)	Primary site is a basis for staging and the determination of treatment options.
Laterality	Laterality supplements staging and extent of disease information and defines the number of primaries involved.
Diagnostic Confirmation	This item is an indicator of the precision of diagnosis.
Type of Reporting Source	This variable codes the source documents used to abstract most of the information on the tumor being reported.
Histology (ICD-O-3)	Histology is a basis for staging and the determination of treatment options. It also affects the prognosis and course of the disease.
Behavior (ICD-O-3)	The behavior code is used by pathologists to describe whether tissue samples are benign, borderline, in-situ, or invasive.
Grade Clinical	Records the grade of a solid primary tumor before treatment.
Grade Pathological	Records the grade of a solid primary tumor that has been resected and for which no neo-adjuvant therapy has been administered.

= Demographic Data Elements

= Cancer Identification Data Elements

Figure 1. Facility Adoption Rate, April–December 2022

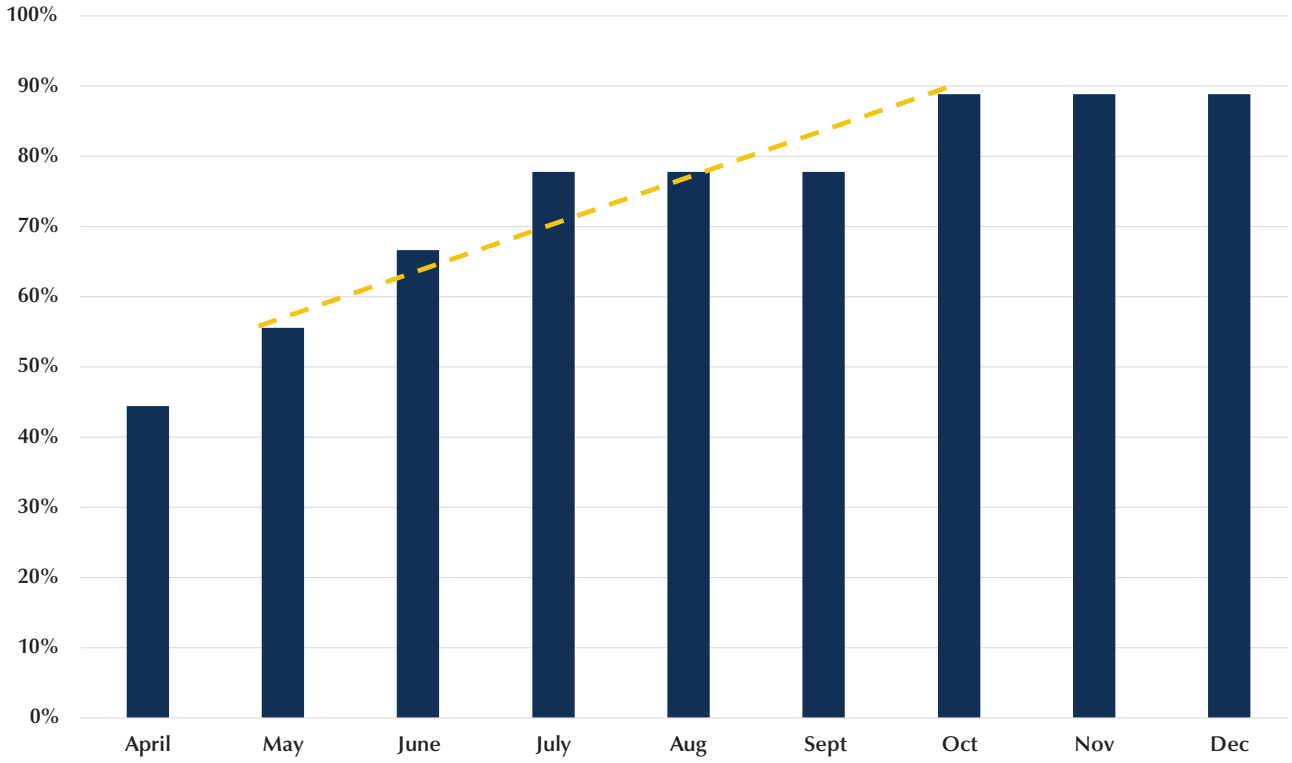
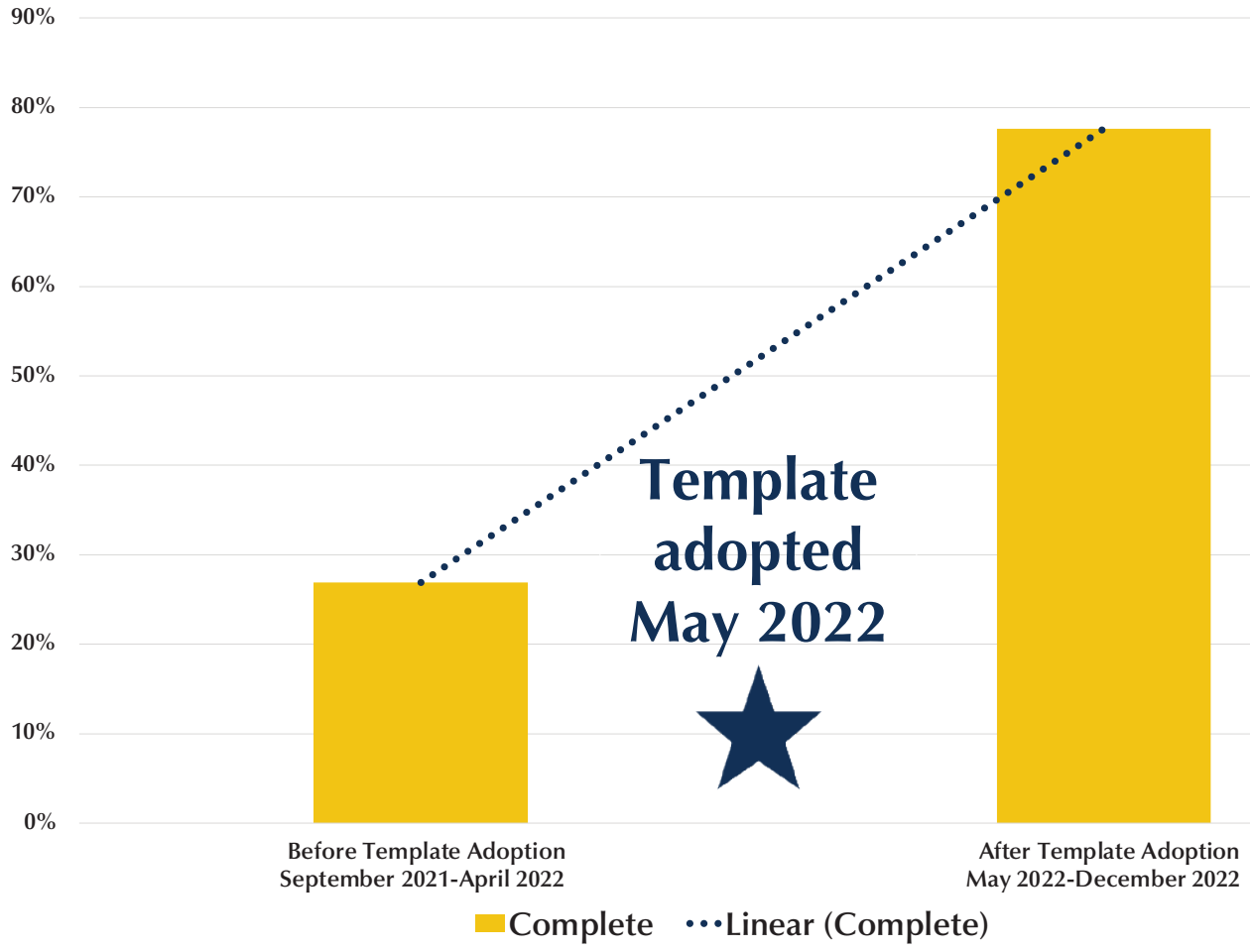


Figure 2. Key Data Item Completeness



Honorable Mention Winner

The Challenges of Collecting Long-Term Outcomes in Cancer Patients on the Population-Level: The Case of Metastatic Breast Cancer

Eileen Morgan[a]; Colette O'Neill[b]; Aude Bardot[a]; Paul Walsh[b]; Isabelle Soerjomataram[a]; Melina Arnold[a]; on behalf of all collaborators on the UNCOV-MBC project

Background

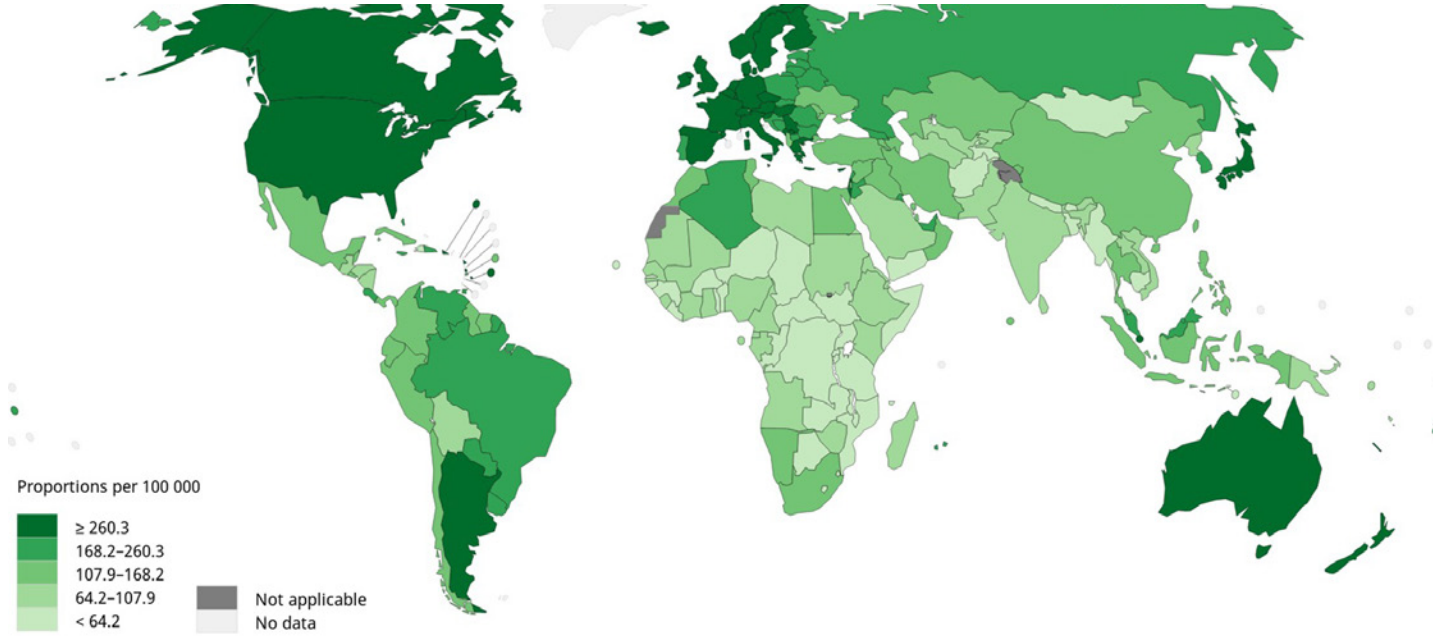
The number of breast cancer survivors is increasing, and more women are living with a previous diagnosis of this common cancer (Figure 1). Cancer recurrence is an important long-term outcome that is not often routinely collected or reported by population-based registries. In the case of breast cancer, one of the most important long-term outcomes is metastatic recurrence, which is responsible for the vast majority of breast cancer deaths. This review examines the landscape and (infra)structural needs of population-based studies investigating metastatic recurrence in women diagnosed with breast cancer to inform how this can be achieved in other settings.

Methods

We conducted a literature review of studies that used population-based registry data of women who had an initial diagnosis of nonmetastatic breast cancer and had reported outcomes on metastatic recurrence. This review is nested within a systematic review for which the search terms and criteria are described below (Figure 2).

Information on outcomes, methods of ascertainment, and definitions of recurrence were extracted. Registry infrastructure, sources, and funding were also reviewed.

Figure 1. Estimated Number of Prevalent Cases (5-Year) as a Proportion in 2020, Breast, All Ages



Data source: GLOBOCAN 2020. Graph production: IARC (https://gco.iarc.fr/today). World Health Organization. All rights reserved. The designations employed and the presentation of the material in this publication do not imply the expression of any opinion whatsoever on the part of the World Health Organization/International Agency for Research on Cancer concerning the legal status of any country, territory, city, or area or of its authorities, or concerning the delimitation of its frontiers or boundaries. Dotted and dashed lines on maps represent approximate borderlines for which there may not yet be full agreement.

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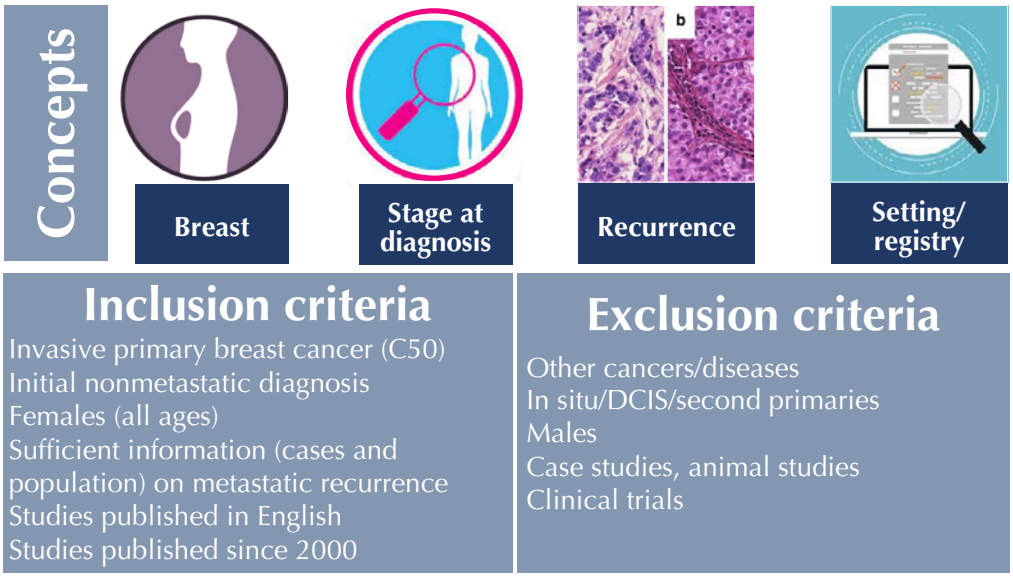
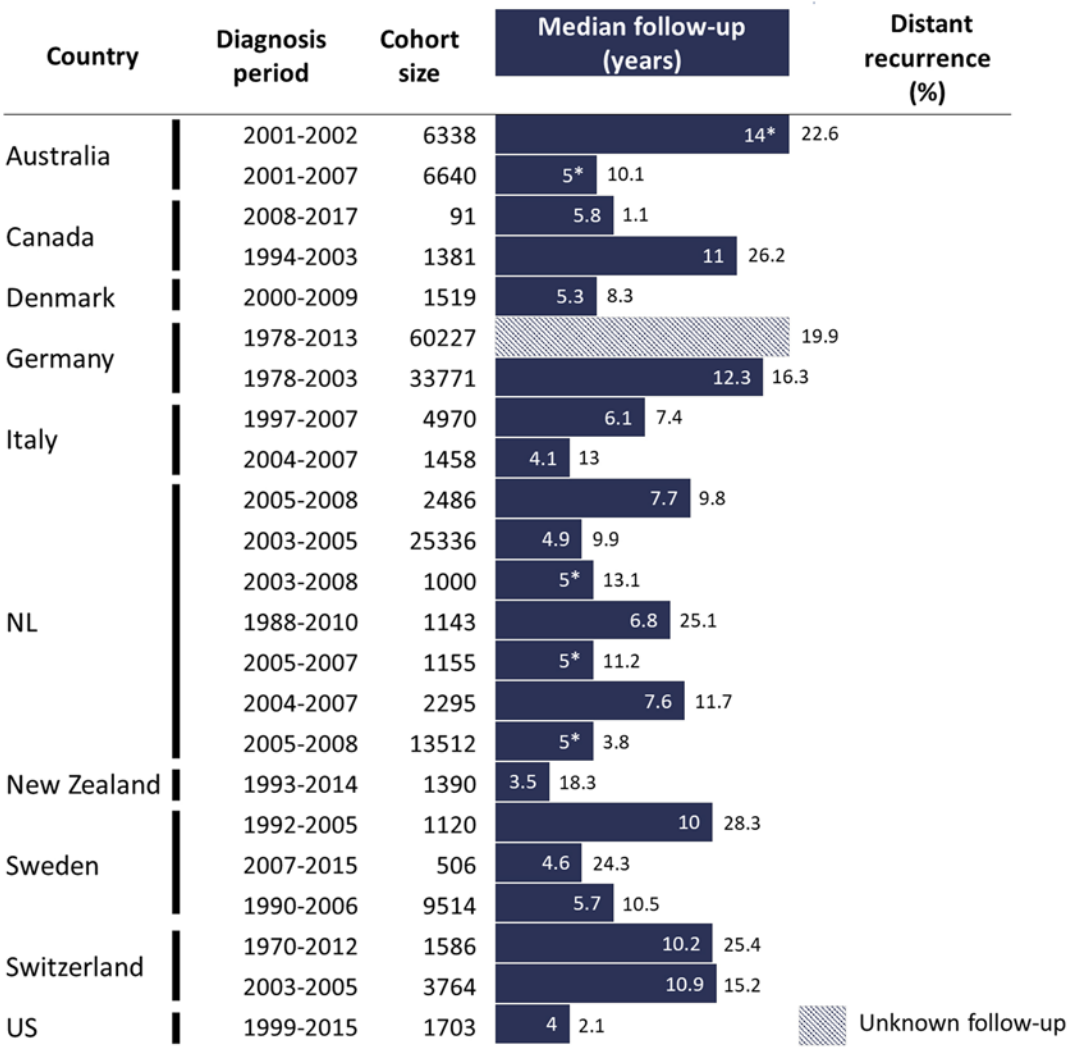
Figure 2. Search Strategy



DCIS, ductal carcinoma in situ. Four concepts were searched for key words, text, and medical subject headings using PubMed and Web of Science. Articles were screened based on predefined inclusion and exclusion criteria.

Figure 3. Characteristics and Reported Outcomes of Included Studies



NL, Netherlands; US, United States of America. *Only maximum follow-up provided.

Results

A total of 23 studies from 11 registries in 8 countries spanning Europe, North America, and Oceania were identified. Most studies were retrospective and collected recurrence data for ad-hoc studies rather than routine registry registration.

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 studies) to 3 months (n = 11) to 120 days (n = 1) to 6 months (n = 1) and was not stated in 6 studies.
- The start of follow-up differed between studies from initial diagnosis (n = 16) or treatment date (n = 7).

Conclusions

Including recurrence as an outcome is possible in population cancer surveillance and is key for survivorship research and clinical guidelines. International guidelines to routinely collect recurrence data are needed to allow comparable evaluation of metastatic recurrence to inform health-care providers and researchers of its impact on long-term outcomes of patients with breast cancer.

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Journal of Registry Management Continuing Education Quiz—WINTER 2023

THE BURDEN OF RARE CANCERS IN NORTH AMERICA

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

- Define rare cancers
- Describe demographic patterns of the burden of rare cancers

1. Rare cancers have poor outcomes due to which of the following?
   a) Lack of standard of care guidelines
   b) Limited treatment options
   c) Limited eligibility in clinical trials
   d) Timeliness of diagnosis
   e) All of the above
2. How did the Surveillance of Rare Cancers in Europe project define rare cancers operationally?
   a) Starting in an unusual place in the body
   b) Having a crude annual incidence rate <2 per 100,000 people per year
   c) Having a crude annual incidence rate <6 per 100,000 people per year
   d) Having a crude annual incidence rate <15 per 100,000 people per year
3. The Surveillance, Epidemiology and End Results (SEER) Program introduced a Rare Cancer Classification variable that includes cancer groups from tiers 1, 2, and 3 of the Joint Action on Rare Cancers list.
   a) True
   b) False
   c) Unknown if true or false
4. How many tier 2 rare cancer groups were rare in either the United States or Canada but not both?
   a) 3
   b) 1
   c) 2
5. Using Cancer in North America (CiNA) data, what was the approximate percentage of microscopically confirmed invasive cancers that were considered rare in Canada and the United States?
   a) 5%
   b) 10%
   c) 20%
   d) 45%
6. Children aged 0–14 years had the highest percentage of rare cancers.
   a) True
   b) False
   c) Unknown if true or false
7. Which geographic region had the lowest percentage of rare cancers among all invasive cancers?
   a) Puerto Rico
   b) Canada, Atlantic
   c) Canada, Ontario
   d) Canada, British Columbia
8. Which age group had the highest incidence rate of all rare cancers combined?
   a) 0–14 years
   b) ≥70 years
   c) 55–69 years
9. Which US racial/ethnic group had the highest percentage of rare cancers?
   a) Non-Hispanic American Indian/Alaskan native
   b) Non-Hispanic Asian/Pacific Islander
   c) Non-Hispanic Black
   d) Non-Hispanic White
   e) Hispanic (all races)
10. Which of the following best describes the burden of rare cancers in CiNA incidence data?
    a) Accurately reflected
    b) Likely underestimated
    c) Likely overestimated
    d) Unable to be assessed

Purchase Quiz to Earn CE:

1. Go to **http://www.cancerregistryeducation.org/jrm-quizzes**
2. Select quiz and "Add to Cart" (You may be prompted to login using your NCRA login).
3. Continue through the checkout process.
4. Once purchase is complete, the quiz will load automatically into "My Learning Activities" page.

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Multiple Author Index—Vol. 50 (2023)

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Liu B, Lee FF. Utilizing Residential History to Examine Heterogeneous Exposure Trajectories: A Latent Class Mixed Modeling Approach Applied to Mesothelioma Patients. Winter;50(4):144-154.

Levie, Katherine

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Matt, Bobbi

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Ramos, Tonatiuh Suárez

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Saraiya, Mona

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Stair, Erin

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Tortolero-Luna, Guillermo

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Treend, Katie

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Unger, Elizabeth R.

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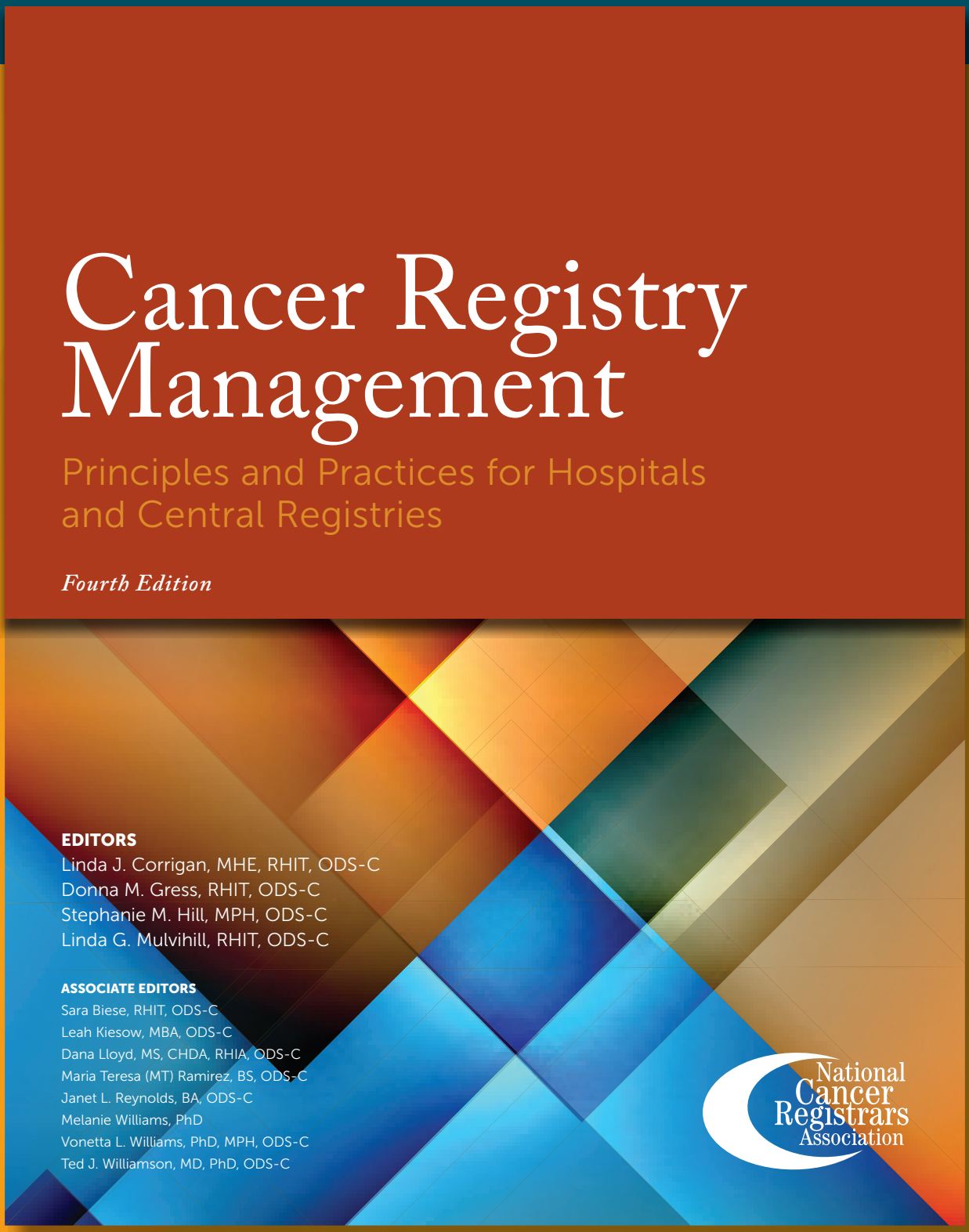

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