FIRST IN FLIGHT:
LAUNCHING A NEW ERA
IN CANCER SURVEILLANCE

NORTH AMERICAN ASSOCIATION OF
CENTRAL CANCER REGISTRIES

2015 NAACCR ANNUAL CONFERENCE
JUNE 13-18, 2015 | WESTIN CHARLOTTE

NAACCR FINAL ABSTRACT PROGRAM
PLENARY, CONCURRENT & POSTER SESSIONS
NAACCR
2015 CONFERENCE
Final Abstract Program

NAACCR would like to thank the poster, plenary and concurrent session oral presenters for their contributions to the conference.

Electronic versions of the posters and oral presentations will be made available online at NAACCR.org after the conference.

Section | Page
--- | ---
Poster Listings | 3

**Plenary Presentations:**

**Tuesday, June 16**

Opening Ceremonies & Welcome:
8:00 am - 10:00 am | 5

Tuesday Plenary Session 1:
10:30 am - 12:30 pm | 6

**Wednesday, June 17**

Wednesday Plenary Session 2:
8:30 am - 9:45 am | 8

**Thursday, June 18**

Thursday Plenary Session 3:
10:00 am - 11:30 am | 9

Thursday PlenarySession 4:
3:00 pm - 4:00 pm | 10

**Concurrent Presentations:**

**Tuesday, June 16**

Tuesday Concurrent Session 1:
1:30 pm - 3:00 pm | 11

Tuesday Concurrent Session 2:
3:30 pm - 5:00 pm | 21

**Wednesday, June 17**

Wednesday Concurrent Session 3:
10:00 am - 11:30 am | 31

**Thursday, June 18**

Thursday Concurrent Session 4:
8:00 am - 9:30 am | 41

Thursday Concurrent Session 5:
1:00 pm - 2:30 pm | 51

Poster Sessions | 59

Author Index | 82

Program-at-a-Glance | 87
All delegates are encouraged to take the opportunity to visit the posters to become familiar with some of the latest advances and research in the field.

Posters will be available at Grand Ballroom C/D on Level 2 at the following times:

**Monday, June 15**
- 5:30 pm to 7:00 pm

**Tuesday, June 16**
- 7:00 am to 5:00 pm

**Wednesday, June 17**
- 7:00 am to 11:45 am

**Thursday, June 18**
- 7:00 am to 10:00 am

**P-01** Increasing Non-Hospital Cancer Reporting: The New Hampshire Experience  
*MC Celaya*

**P-02** Looking for Cases in All the Right Places  
*SMcFadden*

**P-03** Evolution of the Central Tracking Database: Opportunities for Enhanced Operations  
*WPadron*

**P-04** Partially Automating the Casefinding Audit Process  
*SRiddle*

**P-05** Enhanced Identification of Out of State Cases by Utilizing ‘Text--Place of Diagnosis’  
*XZhang*

**P-06** Implications of Misclassification of Melanoma Thickness Measurement (Breslow’s Depth) in Detroit SEER Data, 2004-2010  
*RShore*

**P-07** Enhancing the Carolina Mammography Registry (CMR) Through Linkage With the NC Central Cancer Registry (NCCCR)  
*MMarsh*

**P-08** Probabilistic Data linking Methodology for Record Linkage Using Cancer Registry Data and Private Insurance Clime Data  
*BJChoi*

**P-09** Evaluation of ‘Likely Deceased’ for Improving Follow-Up in Metropolitan Detroit SEER Data, 1973-1994  
*FVigneau*

**P-10** Construction of Korean Cancer Control Statistics Information System  
*HCho*

**P-11** Characteristics Associated With Delayed Reporting of Cancer Cases to the Ohio Cancer Incidence Surveillance System  
*RWeier*

**P-12** Using out of State Laboratory Data to Improve Case Ascertainment for Leukemias: The Puerto Rico Experience  
*CTorres*

**P-13** Collecting Comorbidities From Statewide Administrative Data  
*RMartinsen*

**P-14** Comparing Comorbidity Data Obtained From Hospital Discharge Files With Those Reported to Cancer Registries  
*RMartinsen*

**P-15** A Survey of Methods for Handling Missing Values in Population-Based Cancer Registries  
*KKoru-Sengul*

**P-16** Improving Cancer Reporting From Small and Rural Hospitals  
*TTrailer*

**P-17** Utilizing the NAACCR Geocoder to Improve the Quality of County at Diagnosis  
*JTPeorge*

**P-18** Evaluation of Pharmaceutical Transaction Information for Potential Augmentation of SEER Treatment Data  
*KCronin*

**P-19** KRAS Test Documentation in the Alaska Native Tumor Registry Among People With Late Stage Colorectal Cancer  
*TSchade*

**P-20** Tumour Size and Fuhrman Grade Further Enhance the Prognostic Impact of Perinephric Fat Invasion and Renal Vein Extension in T3a Staging of Renal Cell Carcinoma (RCC)  
*HHuang*

**P-21** Cancer Trends in North Dakota Before and After the Oil Boom  
*SOancea*
P-22  Invasive Cancer Incidence and Survival - United States, 2011  
S Singh

P-23  Thyroid Cancer Incidence in Algiers 2002-2012  
S Maraf

P-24  Treatment and Characteristics of Stage II Colon Cancer Patients in 8 States and 2 Metro Areas  
M O’Neil

P-25  Tobacco Use and its Impact on Cancer Cluster Investigations in Indiana  
A Raftery

P-26  Neighborhood Socioeconomic Status and Histologic-Specific Lung Cancer Incidence Rates by Race/Ethnicity  
S Gomez

P-27  Does Distance from a Radiation Facility Impact Patient Decision-Making Regarding Treatment for Prostate Cancer? A Study of the New Hampshire State Cancer Registry  
M Celaya

P-28  Female Breast Cancer Survival in North Carolina  
S Ali

P-29  Brain Tumor Survival: Results from the Current National Cancer Data Base  
T Dolecek

P-30  Big Data: The Future of Central Cancer Registries  
P Patel

P-31  Epidemiology of Human Papillomavirus (HPV) Associated Cancers in Florida: Analysis from a Population-Based Cancer Data Registry (1981-2009)  
F Miao

P-32  Prostate Cancer in Massachusetts: Declining Incidence and New Screening Guidelines  
S Gershman

P-33  A Comparison of Epidemiologic Patterns of Primary Liver and Intrahepatic Bile Duct Cancer in Massachusetts and Israel, 2002-2011  
R Knowlton

P-34  Ductal Carcinoma in Situ of the Breast: Trends in Incidence and Treatment  
C DeSantis

P-35  Excess Risk of Subsequent Primary Cancers Among Breast Cancer Patients, 1992-2011  
XR Li

C Pestak

P-37  New Use for an Established Big Data Set: Applying the NCDB Participant User File to a Local Population  
S White-Gilbertson

P-38  Survival Disparities in Skin Cancer for Pediatric and Young Adult Population in Florida: Analysis of Population-Based Cancer Data Registry (1981-2009)  
E Dunn

K Moore

P-40  Cancer Incidence in Ontario First Nations Across a 20-Year Period Using Linked Registry Data  
A Amartey

K Pawlish

P-42  Multigene Signature Methods and Results (SSF22 and 23) in Breast Cancer  
V Petkov

P-43  Data Analytics and Cancer Data: Meaningful Cancer Data Presentation  
I Zachary

P-44  Increase in Rectal Cancer Death Rates Among Young Adults in the United States  
K Miller

P-45  Merkel Cell Carcinoma in Florida: Analysis from a Population-Based Cancer Data Registry (1981-2009)  
K Moore
PS1
THE RIGHT TREATMENT FOR THE RIGHT PATIENT AT THE RIGHT TIME: A PERSPECTIVE ON PERSONALIZED CANCER MEDICINE
M Davidian
\(^1\)
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The goal of personalized treatment based on a patient’s genetic/genomic profile as well as clinical physiological, demographic, and other characteristics and past history is of ongoing interest. The most popular perspective on personalized medicine involves identifying biomarkers and associated subgroups of patients who are likely to benefit from a specific treatment or to whom a new treatment may be targeted. Most often, this focuses on treatment at a single point in the disease. In a chronic, progressing disease such as cancer, a series of treatment decisions must be made, and clinicians in practice seek to identify the “best” treatment option from those available at each decision based on all information on the patient to that point, including responses to previous treatments, so as to lead to the most beneficial long term outcome. This suggests an alternative perspective on personalized medicine as a sequential decision making process. We discuss recent advances along these lines, including methods for making this decision evidence-based using longitudinal data from observational databases and from the conduct of sequential, multiple assignment, randomized trials (SMART).

PS2
ENABLING RESEARCH: BIOSPECIMEN-BASED RESEARCH ON THE GENOMICS OF PROSTATE CANCER DISPARITIES
S Patierno
\(^1\)
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Cancer registries are crucial sources of biospecimens, demographic and molecular data for cancer research. We study why African Americans (AAs) exhibit higher incidence of and mortality from prostate cancer than Caucasian Americans (CAs). Although most disparities are caused by differences in access to care a significant portion of this disparity remains after controlling for social determinants of health, suggesting a potential biological contribution. In an expression-based comparison study we identified a set of differentially deregulated genes in localized AA versus CA prostate cancer that harbor distinct alternative splice variants and epigenetic alterations in key prostate cancer-associated gene networks. Preliminary analysis indicated that altered expression related to alternative splicing in these deregulated genes tracked with increased growth and more aggressive invasive characteristics of AA prostate cancer. Our current research is delineating the relationship between the genetic/epigenetic/post-transcriptional factors in AA prostate cancer and Gleason grade, manipulating splicing using novel splice-switching oligonucleotides and determining functional outcomes, and developing a collection of preclinical primary tumor explants and derivative cell lines from both AA and CA tumor specimens to assess biologic relevance of splicing alterations. Our research is focused on developing novel, specific approaches for prevention and treatment that help reduce prostate cancer disparities for AAs and improve outcomes for advanced stage prostate cancer in this patient population. Although race itself is not a biological construct we have been able to use race (ancestral genotyping) as a population-level construct to enrich for genetic and epigenetic differences that may have profound implications for the prevention, screening, diagnosis and management of prostate cancer for men of all races.
LAUNCHING A NEW ERA IN RESEARCH-APPLICATIONS FOR CANCER REGISTRIES

PS3

CANCER CARE DELIVERY RESEARCH AND THE NCI SEER PROGRAM: CHALLENGES AND OPPORTUNITIES
S Katz

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The NCI SEER program is uniquely positioned to leverage big data to inform oncology practice in the community. Indeed, no other big data initiative in oncology approaches the comprehensiveness and quality of data collection and generalizability of the results. But there are well known limitations to SEER data. First, the level of detail about tests and treatments is limited. Second, the quality and completeness of the clinical data that is collected may vary by cancer condition and across regions. Finally, information related to patient socioeconomic status is limited. A major challenge for SEER is to modernize the content of the data in a rapidly evolving landscape of cancer management. The first task is to leverage opportunities to obtain more granular information about rapidly emerging evaluative tests and treatments for cancer. Current data collection efforts largely depend on both passive and active reporting from pathology labs and hospitals. But more efficient data collection is on the horizon with advances in automated clinical data repositories and electronic medical records. Another emerging opportunity is SEER’s partnership with industry and academics. In particular, tumor genomic and genetic testing companies may well be interested in partnering with federal and state public health entities, such as SEER, to perform research that informs quality of care and the patient experience. Finally, there is need to augment clinical and treatment information in SEER with patient reported measures of communication, decision-making and health outcomes. Currently, there are a number of demonstration projects that will serve as useful models for rapid dissemination of findings from cancer care delivery research directly to providers. SEER will need to evolve in a rapidly changing landscape of cancer management, information technology, and partnerships to continue to remain a vital resource in population studies in oncology.

PS4

MAXIMIZING THE POTENTIAL OF POPULATION-BASED CANCER REGISTRIES TO INFORM CANCER RESEARCH
TC Tucker

1University of Kentucky, Lexington, KY, United States; 2Markey Cancer Center, Lexington, KY, United States; 3Kentucky Cancer Registry, Lexington, KY, United States

The ability of the central cancer registry to provide a population-based sample frame is what sets studies that use the central cancer registry apart from cancer research projects that use only samples of convenience. Findings from studies that use the central cancer registry can be generalized to the underlying population covered by the registry. Historically, population-based cancer registries have been criticized for being too slow to capture all of the cases needed to provide a current population-based sample frame. This has limited the value of the registry as a research resource. However, advances in informatics now make it possible to capture nearly all of the cancer cases occurring in a population very close to the time of diagnosis. The development of methods that use formalin fixed paraffin embedded tissue to perform full genome sequencing or stain for specific proteins have also made it possible for the central cancer registry to serve as a virtual population-based tissue repository. This presentation will review the ability of the central cancer registry to improve cancer research studies by providing a population-based sample frame that will lead to studies with strong external validity. The presentation will also describe how central cancer registries can use Natural Language Processing (NLP) to capture cancer cases at the time of diagnosis thereby making a population-based sample frame available more quickly. In addition, the presentation will describe how advances in laboratory science make it possible to view the central cancer registry as a virtual population-based tissue repository that can be used in cancer research studies. Finally, the presentation will describe how the central cancer registry can serve as an essential tool in the last phase of translational cancer research.
 Often, investigators conducting multi-state cohort or other studies or clinical trials obtain cancer diagnoses, outcomes, and mortality information by engaging individually with each population-based cancer registry, a process that takes many years to complete. This requires significant personnel and time effort on the part of both registry and investigator to obtain Institutional Review Board (IRB) review, data use agreements and perform and assess linkages, even when no matches are detected. In order to provide a one-stop resource for researchers seeking cancer outcome information on their study participants, a Virtual Pooled Registry (VPR) concept has been developed to streamline this process while assuring that registries maintain control of their data. These linkages could provide follow-up information, date of death, cause of death, and cancer diagnosis for a first or multiple primary cancers. A VPR has the potential to enhance completeness of ascertainment of diagnosis and other outcomes while simultaneously reducing costs and time associated with obtaining the relevant information. In addition to supporting research, this resource would be of value for cancer surveillance by permitting de-duplication of cases between registries using the same mechanism to look for the same case reported across multiple registries. An additional benefit of such a resource would be for post marketing surveillance to evaluate signals for drugs that may be associated with cancer. Currently these studies are costly and highly inefficient. A demonstration project with three state registries and a cohort study principal investigator has been conducted. Results to date and future plans will be presented.

The NAACCR data exchange standard represents a remarkable accomplishment that transformed and has sustained cancer surveillance data transmission activities since its introduction in the mid 1980s. Volume II ensures syntactic and semantic interoperability among all cancer registries from rural hospitals to population-based registries across North America. Ubiquitous adoption of the NAACCR standard has allowed the exchange of comparable cancer surveillance data among reporting facilities, registries, national agencies, public health agencies, and researchers for nearly two decades. No other chronic disease surveillance system enjoys the benefits of such a reliable and longstanding data exchange standard.

The landscape of cancer surveillance and cancer research is rapidly evolving. Cancer surveillance data are increasingly intertwined with electronic health records, biorepositories, molecular and genomic biomarkers, and other advances. New use cases are testing and often exceeding the limits of the NAACCR fixed-width data exchange standard. A fixed-width format limits flexibility, customizability, and adaptability to meet growing needs in the new era of research and surveillance. However, changes to the NAACCR standard must strike a delicate balance between accommodating new demands and impacting registries with limited resources. The NAACCR community itself is best equipped to chart its own course that embraces technological advancement, harmonizes with other evolving standards, and does so without undermining our cancer surveillance mission.

The Extensible Markup Language (XML) has emerged as a promising alternative to the ASCII fixed width record layout. Under the purview of the NAACCR Standards and Registry Development Steering Committee the XML Task Force was formed in 2014 to further develop and pilot test a NAACCR XML standard. Participants include registry software vendors, registries, federal agencies, national agencies, and other stakeholders.
PS7

UNLEASHING “BIG DATA” IN ONCOLOGY
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Healthcare organizations are increasingly attempting to leverage patient data to get a more complete view of care delivery. The adoption of electronic health record (EHR) systems, as incentivized by the federal government, has created new opportunities to use data to both improve care and lower costs. However, the availability of patient data must be met with the ability to interpret and use these data in a meaningful way. Only then can we further our ability to engage and improve care in the areas of personalized medicine, patient-centered care, health care delivery design and comparative effectiveness research. By rethinking how we consider the data and its analysis, all of these considerations can be addressed simultaneously. However, a key feature needed for success is the ability to capture high quality patient level data, both structured and unstructured, that we can then de-identify and reanalyze for multiple purposes.

This discussion will focus on the challenges in obtaining meaningful insights from available data, and the methods that Flatiron Health is implementing to address these challenges to obtain true, comprehensive insights to influence care.

PS8

BIG DATA INFRASTRUCTURE FOR CANCER OUTCOMES
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Big data has become ubiquitous in many realms of our lives including public health and medical research. For cancer research only big data on real world patients can capture true patient heterogeneity including comorbidity, racial and ethnic variation, disparities or access to care, and patient preferences. To address this, researchers have been linking disparate data sources to fill the gap between actual patient populations and those enrolled in clinical trials. Linked data sources allow researchers to observe large, retrospective, and heterogeneous cohorts of cancer patients from screening to end of life care through linkages between observational studies or datasets designed for purposes other than research. However, managing and leveraging big data for research is exceptionally challenging. And as linked data grow in complexity and scope, it has becoming increasingly complicated to understand the underlying populations each research dataset represents. The North Carolina Integrated Cancer Information and Surveillance System (ICISS) represents big data for population-based cancer research. This novel resource is supported through three central activities comprised of data, systems, and research methods. ICISS data include novel, longitudinal data linkages between metrics of cancer incidence, health services utilization, psycho-social risk factors, and mortality. Extensive information technology systems support the data resource and streamline research project management. Research is conducted within an interdisciplinary, team science approach in order to integrate diverse and novel methodologies for managing and using these complex data for research. Through these three distinct activities, ICISS demonstrates the successful development of an integrated research platform leveraging large, linked, multi-payer datasets for studying population health.
PS9
NCI SEER TRANSITION TOOLS – MOVING TO MORE MODERN TECHNOLOGIES
J Cyr

1Information Management Services, Inc., Calverton, MD, United States

The NCI SEER program has been developing tools to support the upcoming transition from the Collaborative Stage cancer staging system to the TNM 7th edition staging system. Tools need to be developed to facilitate the dissemination of information once decisions have been made about which data items cancer registrars need to collect for TNM, and how to stage incoming cancer data which will be submitted following the NAACCR standards. The tools under development to aid in this transition include a data storage mechanism for predictive and prognostic factors, permissible value lists for these factors as well as schema specific data items that are required for staging, an online editor for CS and TNM metadata, a REST API, an informational website, and a Java library for accessing the CS and TNM metadata offline. These tools can be used to provide broad support during the transition from CS to TNM, but can also be used in an agile way to support any future changes in cancer surveillance data collection. This presentation will outline how these various tools can be of use to software vendors, cancer registries, and anyone with an interest in the transition from CS to TNM data collection.

PS10
LAUNCHING A NEW ERA IN REGISTRY OPERATIONS: SURVIVORSHIP CARE PLANS
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Background: The number of cancer survivors in the U.S. is expected to reach 18 million by 2020. With cancer survivors living longer than ever, adherence to follow-up guidelines and participation in healthy behaviors is crucial for improved quality of life and prevention of second cancers. One mechanism for ensuring adherence to follow-up is the treatment summary and survivorship care plan (TS/SCP). While survivorship experts have recommended TS/SCPs for many years, implementation has been slow because creating TS/SCPs is time-consuming and currently is not a reimbursable activity. Nevertheless, in 2012, the American College of Surgeons’ Commission on Cancer issued new program standards requiring hospitals to provide TS/SCPs for all eligible patients. Many hospitals are concerned about how they will meet this standard.

Purpose: Cancer registries already collect data that represents nearly half of the recommended content of TS/SCPs. Cancer registries can play an important role in the TS/SCP effort by using registry data to lessen the burden for health care providers in creating TS/SCPs.

Methods: The Colorado Central Cancer Registry conducted a special project funded by the Centers for Disease Control and Prevention which successfully demonstrated that cancer registry data can be used to pre-populate TS/SCPs. A NAACCR file is uploaded to populate the treatment summary portion; providers can complete the care plan portion and deliver the TS/SCP to the patient. 

Results: Other TS/SCP software products (JourneyForward, On Q) followed suit and modified their tools to accept cancer registry data. Cancer registries – hospital based or central – will likely be enlisted to provide data for TS/SCPs. Registries can begin planning now as to what extent they will participate in this effort. 

Conclusions: Cancer registry data is increasingly being used for TS/SCPs. Registries can and should use the power of their data to improve care for the growing population of cancer survivors.

PS11
DATA ITEM CONSOLIDATION
F Ross

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The purpose of record consolidation is to combine data from different reporting sources for the same patient and tumor into a single best record for analysis in the central cancer registry. Each registry makes its own decisions about the applicability of the rules to their registry based on their operational approach, data uses, and available resources for that registry. Most registries already apply a mix of automated and manual methods to achieve a consolidated record. Automated methods are designed to identify and save the best data values from all submitted source records. Thus, source records are often prioritized, or weighted, in consolidation algorithms. The current challenge is to develop algorithms for AJCC staging data items.

PS12
THE NEW DEATH CLEARANCE MANUAL
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The Death Clearance Manual contains new minimum requirements, best practices, and guidelines for conducting the death clearance process, effective January 1, 2015, for deaths occurring in 2013. Consideration for all registries, with regard to varying levels of available resources, was a high priority in development of the minimum standards that everyone must follow. This presentation, on behalf of the NAACCR Death Clearance Workgroup, will highlight the contents of this comprehensive compilation of death clearance process instructions intended to provide all necessary information under one cover to successfully conduct death clearance.
Ps13
REPORTING DELAY ADJUSTMENT FOR NAACCR REGISTRIES
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Timely and accurate calculation of cancer incidence rates is hampered by reporting delay, the time elapsed before a diagnosed cancer case is reported to the cancer registries. While cases in NAACCR are first reported about two years after the end of a diagnosis year (e.g. 2012 cases were reported in the December 2014 submission), in subsequent submissions the data are updated as either new cases are found or new information is received about previously submitted cases. The idea behind modeling reporting delay is to adjust the current case count to account for anticipated future corrections (both additions and deletions) to the data. These adjusted counts are valuable in more precisely determining current cancer trends. While previously, delay adjustment was only available for the SEER 9 and SEER 13 registry groups, a coordinated effort by NCI, CDC and NAACCR has led to a unified approach to estimate and report delay-adjusted rates across all of US and Canada. This talk will describe how the modeling was conducted, why certain registries had to be excluded, and how to obtain delay adjusted rates in SEER*Stat. While eventually we hope to allow delay adjustment for regions of the country and even individual registries, this first year of release, delay adjusted rates will only be available for SEER 9, SEER 13, SEER 18, the U.S., and Canada.

Ps14
ELECTRONIC HEALTH RECORDS: THE INTERSECTION OF PUBLIC HEALTH SURVEILLANCE AND CLINICAL MEDICINE
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1CDC, Atlanta, GA, United States

Electronic health records hold the promise of revolutionizing electronic reporting with more accurate reporting for surveillance and other public health reporting purposes. The presenter will provide an update on the state of electronic health records as they relate to central cancer registries. In addition, the presenter will identify opportunities at the intersection of public health and clinical medicine to enhance these collaborations.
Finding the Needle in the Haystack — The Clinically Diagnosed Cases

M Potts\(^1\), J Haferson\(^2\)

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For a central registry, finding the histologically confirmed cases depends upon the registry’s receipt of pathology reports (electronic or hardcopy). Finding the clinically diagnosed cases depends upon the quality of ICD-9/ICD-10 coding within a hospital system and the central registry’s ability to process those records efficiently.

The Seattle Puget/Sound SEER registry has performed 100% independent casefinding from hospital disease index records since 1974 in addition to performing 100% independent casefinding of all pathology in our reporting region. Because we viewed the disease index casefinding as a quality control activity on the completeness of our pathology casefinding, we always ran all the ICD-9 codes through our system.

In the past two years, the majority of our hospitals have adopted EPIC as their electronic medical record (EMR) vendor. This change in vendor has resulted in the monthly disease index record volume increasing in volume from 10 times to 40 times the previous volume. For example, one mid-sized hospital went from submitting 400 records per month to 16,000 records per month. This increase in volume brought our casefinding program and processes to a slow crawl requiring greater FTE hours to process.

As part of our process improvement, we asked the question of whether we should limit the disease index casefinding to the primary sites most often diagnosed clinically rather than histologically to handle this workload. What would we gain? What would we lose?

Using NPI and ePath to Identify Clinics that Treat or Diagnose Cancer

C Klaus\(^1\)

\(^1\)North Carolina Central Cancer Registry, Raleigh NC, United States

What are cost effective options to identify clinics that treat or diagnose cancer and that are not reporting to a central registry, given provider data commonly available to central registries? To answer that question first requires attempting to identify the universe of treating and diagnosing clinics, so as to enable a process of elimination approach.

Each state or provincial central registry has its own universe of facilities that treat and diagnose cancer, whose annual cases meet a given threshold. The universe may change on a weekly or monthly basis. Central registries have an incentive to identify snapshot approximations of that universe, and generate a measure of confidence as to how well a snapshot captures the universe. Among provider data, the best data available to central registries to identify the universe may be ePath, NPI and annually updated lists of clinics with which hospitals have abstracting relationships. Both ePath and NPI have limitations on the comprehensiveness of their clinic capture; as a result, they may approximate but not necessarily capture the universe of clinics. There are also limits to the amount of time available to registry staff to use these databases to differentiate reporters, clinic turnover and clinics that are not reporting. This presentation evaluates the cost effectiveness of strategies (from a time standpoint) to merge these databases with each other and the central registry database of reporting facilities, to approximate the universe, and generate measure(s) of confidence in the process.
QUALITY CONTROL OF ALTERNATE DATA SOURCES IN THE ONTARIO CANCER REGISTRY
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In 2014, CCO’s Ontario Cancer Registry Information System (OCRIS) was decommissioned and replaced with the new Ontario Cancer Registry (OCR). This is the first revision of Ontario’s cancer registry rules and technology since the 1980s. OCRIS case counts were based on IARC multiple primary rules. OCR now conforms to the SEER MPH rules for counting multiple primaries.

Purpose: OCR relies almost entirely on administrative data sources. Ontario does not have a system of hospital cancer registries. It requires alternate sources of information for cancer registration as hospital registry case abstracts are not available. As Ontario moved from IARC-like rules to SEER rules, case counts naturally increased, and careful review of the characteristics of OCR data sources had to be undertaken to understand and control artificial inflation of case counts and address other quality issues.

Approach: Statistical review was undertaken of the effects of the four major OCR data sources – pathology reports, coded hospital discharges, cancer centre records, and death certificates – on incidence counts, and quality and completeness of case information. Characteristics of each source type were reviewed. Effect of differing source record combinations on counts and quality was examined. Cases were extensively manually reviewed to corroborate analytic findings and suggest solutions.

Results of the investigation will be presented with required remediation strategies - accounts of incoming data quality challenges and resulting external engagements, discovery of internal programming logic issues and remediation, and extent of manual case review required ongoing.

Conclusion: Administrative data can be used to accurately register cancer cases. However, this strategy must go hand in hand with the development of stringent quality assurance controls, including major investment in continuous analytic support, and frequent engagement with reporting sources.

WHAT CAN WE LEARN ABOUT CASE ASCERTAINMENT FROM REGISTRIES WITH HIGH INCIDENCE FOR EITHER BENIGN/BORDERLINE BRAIN OR IN SITU BREAST CANCERS?
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1NAACCR, Springfield, IL, United States; 2LSU School of Public Health, New Orleans, LA, United States; 3University of Kentucky, Lexington, KY, United States; 4CBTRUS, Hinsdale, IL, United States

Background: Our national cancer surveillance system tracks the burden of cancer to focus public health priorities and to inform public health programs. Registry data are integral for framing etiologic research investigations by comparing cancer risk among populations. Differences in case ascertainment may lead to biased conclusions.

Methods/Results Using CINA data, we calculated incidence rates by US registry for two cancer sites reporting high variability in rates: benign/borderline brain tumors and in situ breast cancers. Previous research indicated that variation in rates of benign/borderline brain tumors is likely due to variation in reporting completeness by registry. The root of variation for in situ breasts is less clear but likely driven by both underreporting and screening patterns. We ranked the registries by incidence rates. Correlations between incidence rates of benign/borderline brain tumors and in situ breast cancers were evaluated. Registries were then surveyed on case ascertainment practices (planned for January 2015). Survey results were evaluated for practices that may result in higher completeness for these sites. Data was reviewed in collaboration with Central Brain Tumor Registry of the United States.

Conclusion: In general, case completeness is tied to level of registry funding. But as cancer abstraction and case finding become ever more complex for all registries irrespective of funding level, it is important to determine specific methods that result in high levels of case ascertainment. To effectively inform both national and local public health practice and research, we need to define and promulgate effective methods that can be adopted by all registries.
INTRODUCTION TO XML– HOW IT WORKS AND WHAT IT OFFERS US

R Pinder¹
¹Los Angeles Cancer Surveillance Program, Los Angeles, CA, United States

XML has been around for years now, and most of us have heard something about the XML format. Belonging to a broad category of ‘markup’ type computer languages, for over a quarter century developers have realized the benefit of sending along both raw data plus information on how to USE that data in one package. XML is a structure based markup language characterized by the use of tags to encapsulate your data. It is designed to be both device and system independent, and with thoughtful design of the definitions included in those tags, can be application independent. In other words, integrating XML formatted data into disparate computer programs is possible because of the careful definition of the information in that data. That is the GOAL, at least!

This session will present the basics of the XML specification, give simple examples to show how the XML Markup language is structured, and explain the use of Schema and XSD files to define the data. The goal is to make the session highly interactive to ensure all attendees understand the syntax and structure of XML data.

CREATING, TRANSMITTING, AND WORKING WITH A NAACCR XML FILE

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An XML-based data exchange standard would provide many benefits over the current fixed-width file syntax of the NAACCR Volume II standard. However, it is difficult to produce an XML data exchange standard that strikes the right balance between backward compatibility, ease of implementation, and meaningful, forward-looking features. Compounding the problem, XML syntax is notorious for producing excessively large file sizes, long parsing times, and difficulty in working with relational databases or for general research use. This talk will discuss the strategies taken and conclusions reached by the NAACCR XML Task Force to define an XML data exchange standard that addresses the complex needs of the NAACCR community, provides a clear and graduated path to adoption, while performing well in practice.
XML TOOLS - EXAMPLES TO SLICE, DICE, LOAD, AND ANALYZE XML DATA
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Changing from a flat-file format to XML will provide many benefits, but also some technical challenges for the NAACCR community. To mitigate those technical challenges, the NAACCR XML Task Force is designing and implementing software libraries and tools specifically for files in the new format. The software libraries will be available for use in registry and vendor software. The NAACCR task force is developing libraries in multiple languages to accommodate the NAACCR community. The types of libraries will be reviewed and typical usage of the libraries will be demonstrated. A standalone application translating a NAACCR flat-file into its corresponding XML format (and vice versa) will be demonstrated. Other tools for analyzing and processing the XML data files will also be presented.

PREVIEW OF REGISTRY-SPECIFIC AND AGGREGATED RELATIVE SURVIVAL ESTIMATES IN CANCER IN NORTH AMERICA
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Background: Along with incidence and mortality data, information on population-based cancer survival is necessary to understand the burden of cancer.

Purpose: The NAACCR Survival Analysis Task Force (SATF) is charged to provide resources and guidance to NAACCR members on survival analysis-related activities. SATF is working towards routinely generating state and province-specific 5-year relative survival estimates by race, gender, and cancer site for inclusion in the Cancer in North America (CINA) annual report. For the December 2014 Call for Data, the publication of survival estimates in CINA was included as a Secondary Use of Data requiring active consent from registries. Through this mechanism, cancer survival estimates on a wider population than are currently available will be provided by NAACCR.

Methods: For a registry’s survival data to be eligible for inclusion in CINA, the data must meet Certification criteria and the registry must have performed active follow-up or linkage with their state/province and national death databases for all relevant years. Cases diagnosed with an invasive primary cancer between the ages of 15 and 99 years will be included in the analysis. Using state and province-specific life tables, relative survival estimates will be calculated using SEER*Stat software.

Results: Relative survival estimates will be presented by primary site, sex, stage, age group, race (US), country, and registry. The survival table shells to be published in CINA will be previewed.

Conclusions: The publication of survival estimates in CINA will be an important milestone for NAACCR and contribute towards the understanding of cancer burden in US and Canadian jurisdictions.
010

TO WHAT EXTENT DO NATIONAL WEALTH AND EXPENDITURE ON HEALTH EXPLAIN WORLD-WIDE VARIATION IN CANCER SURVIVAL?

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Background: The CONCORD-2 study revealed wide differences in 5-year survival between 67 countries for adults diagnosed 1995-2009 with cancer of the stomach, colon, rectum, liver, lung, breast (women), cervix, ovary or prostate, or leukaemia. Population-based survival reflects the overall effectiveness of health services. Health service effectiveness is likely to be influenced by national wealth and national investment in health.

Purpose: To evaluate the strength of any association between 5-year survival and annual variation in macro-economic indicators such as Gross Domestic Product (GDP), Total National Expenditure on Health (TNEH) and Direct Cancer Expenditure (DCE).

Data and methods: We will use CONCORD-2 results to analyse the association between 5-year survival and annual variation in macro-economic indicators such as Gross Domestic Product (GDP), Total National Expenditure on Health (TNEH) and Direct Cancer Expenditure (DCE).

Results: We will select the best macro-economic indicator for each cancer. We will report correlations and trends in survival with trends in macro-economic indicators. We will monitor the BRICS countries (Brazil, Russia, India, China and South Africa), which have been in rapid economic development during 1995-2009.

Implications: Investments in health care are relevant in every country. In some countries, 5-year cancer survival is higher (or much higher) than in others of similar wealth. Higher survival may be related to greater investment in health systems or to better allocation of resources. If countries with higher survival show more effective cancer policies, then countries with lower survival may improve the overall effectiveness of their health systems by applying similar policies.

011

LOWER MORTALITY AMONG MARRIED CANCER PATIENTS: HOW MUCH OF THE EFFECT IS EXPLAINED BY SOCIOECONOMIC AND HEALTH INSURANCE STATUS?

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Background: Cancer patients who are married at diagnosis have lower mortality than the unmarried. Although this effect has been attributed to increased social support among married patients, whether economic resources influence this association remains unclear.

Purpose: We assessed whether overall mortality differences between married and unmarried cancer patients is modified by neighborhood socioeconomic status (nSES) and mediated by health insurance status.

Methods: We studied patients newly diagnosed (first invasive primary) with one of the 10 most common causes of cancer deaths from 2000 through 2009 in California. Information on patient nSES (block group-level Census data), insurance (primary and secondary payer source), demographic and tumor characteristics, and follow-up through 2012 were obtained from the California Cancer Registry. Using Cox proportional hazards regression, we estimated overall mortality [hazard ratio (HR)] associated with marital status among 377,932 males (194,216 deaths) and 378,447 females (175,414 deaths), stratified on stage and adjusting for age, race/ethnicity, cancer site, nSES, insurance status, and treatment.

Results: Prior to adjustment for insurance status, unmarried patients had higher overall mortality than married patients [HR (males)=1.28 (1.27-1.29), HR (females)=1.20 (1.19-1.21)]. This association was marginally stronger among patients from higher SES neighborhoods [HR (males)=1.30 (1.28-1.32), HR (females)=1.21 (1.20-1.23)] than from lower SES neighborhoods [HR (males)=1.27 (1.26-1.29), HR (females)=1.19 (1.18-1.21)] and only slightly lower after adjustment for insurance. The magnitude of the associations varied by race/ethnicity and cancer site, with the largest attenuation of HRs after adjustment for insurance seen among Blacks, regardless of nSES.

Conclusions: Neighborhood SES and insurance status had no considerable impact on the association between marital status and mortality after cancer diagnosis.
UNDERSTANDING INTERNATIONAL DISPARITIES IN CHILDHOOD LEUKAEMIA SURVIVAL: A WORLDWIDE ANALYSIS FROM THE CONCORD-2 STUDY

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Background: Childhood leukaemia, the most frequent malignancy occurring before the age of 15, includes morphologic subtypes with very different characteristics and prognosis. Prognosis also varies with the patient’s age, sex and other clinical features. The CONCORD-2 study has shown huge worldwide disparities in 5-year net survival in 75,000 children diagnosed with acute lymphoblastic leukaemia1. Very little information is available on international differences in survival for other types of childhood leukaemia.

Purpose: The CONCORD-2 study aims at exploring cancer survival patterns worldwide and starting global surveillance. In this analysis, we will examine international differences in survival from several subtypes of childhood leukaemia in relation to leukaemia patient characteristics.

Methods: Records of children (0-14 years) diagnosed with a haematological malignancy during 1995-2009, provided by population-based registries in more than 50 countries around the world, will undergo standardized and centralized quality control. For each type of leukaemia and in each country, we will estimate net survival up to 5 years after diagnosis. International differences in background mortality will be taken into account with appropriate life-tables.

Expected results: The results should identify international patterns and trends in childhood leukaemia survival by leukaemia subtype, sex and age at diagnosis.

Implications: Quantifying global differences and trends in survival from childhood leukaemia is the first step in understanding the determinants of inequality. This information will be key to informing policy-makers, as the basis for policies to reduce inequalities in survival.


USING CANCER REGISTRY DATA TO EVALUATE BREAST CANCER INCIDENCE BY SUBTYPE

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Background: Breast cancer is a heterogeneous disease comprised of subtypes with distinct epidemiologic and molecular profiles. To enable cancer surveillance research by molecular subtypes, all site specific factors (SSFs) necessary to identify the joint expression of hormonal receptors (ER/PR) and human epidermal growth factor-2 (HER2) became required data items in 2010.

Methods: This study evaluated the fitness for use of the SSFs that identify the HR/HER2 status of breast cancers for all US registries for diagnosis years 2010-2011. To align with commonly used molecular categories, four HR/HER2 categories were used (HR+/HER2-, HR+/HER2+, HR-/HER2+, and HR-/HER2- or “triple negative”). A case was considered incomplete if ER, PR or HER2 status was unknown or if HER2 was borderline (borderline HR cases were considered positive). Completeness was assessed by clinical and demographic variables commonly used in research, including derived area-based SES measures. A follow-up assessment will be conducted on the 2012 data.

Results: Completeness was too low for cases diagnosed in 2010 and in situ cases diagnosed in 2010-2011 to use in research. About 10% of female, invasive breast cancer cases had unknown HR/HER2 status nationally for 2011. Some otherwise high quality registries had >20% unknown and should be excluded from national-level analysis. Individual and SEER registries combined were compared and will be presented.

Conclusion: Understanding the epidemiologic and clinical differences among breast cancer subtypes is critical for guiding proper treatment and prevention approaches. With appropriate case selection, cancer registry data are suitable for national research on breast cancer subtypes.
Complete Completeness and Consistency of WHO Grade Assignment for Brain and Central Nervous System Tumors in the United States, 2004-2011

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Background: Central nervous system (CNS) tumors are categorized and graded for clinical and research purposes according to the World Health Organization (WHO) scheme which segregates tumors by histological type and predicted biological behavior. However, reporting of WHO grade in pathological reports is inconsistent despite its collection in cancer registration. We studied the completeness, consistency, and yearly trends in the collection of WHO grade for primary CNS tumors between 2004 and 2011.

Methods: Data from the Surveillance, Epidemiology and End Results (SEER) program were analyzed for the percentage of histologically diagnosed primary CNS tumor cases with concordantly documented WHO grades between 2004 and 2011. Yearly trends were calculated with annual percentage changes (APC) and 95% confidence intervals (95% CI).

Results: Completeness and consistency of the collection of WHO grade varied significantly by histological type and year. The percentage of cases with documented WHO grade increased significantly each year from 2004 to 2011: 39.0% of cases in 2004 had documented WHO grade, while 77.5% of cases had documented grade in 2011 (APC, 10.3; 95% CI: 9.0, 11.5). Among cases with documented WHO grade, the percentage graded concordantly increased significantly from 89.1% in 2004 to 93.7% in 2007 (APC, 1.8; 95% CI: 1.0, 2.6) and these values varied over time by histological type. One common trend among all histologies was a significant increase in the percentage of cases with documented WHO grade.

Conclusions: A sizeable proportion of reported CNS tumors collected by cancer registrars have undocumented WHO grade, while a much smaller proportion are graded discordantly. Data collection on grade has improved in completeness and consistency over time. Efforts to further improve collection of this variable are essential for clinical care and the epidemiological surveillance of CNS tumors.

The Impact of Reporting Practices on State and Local Lip Cancer Rates, Or: How Many Per Million Depends on the Vermilion

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Background and Purpose: Oral cancer prevention is a fundamental component of statewide comprehensive cancer control (CCC) programs, and incidence rates are widely used as benchmarks to measure progress within a state and compare states. These rates, however, are confounded by widely disparate rates in lip cancer arising from nonstandard reporting practices. Specifically, squamous cell carcinomas defined as “upper lip, NOS” and “lower lip, NOS” that do not mention the location of the cancer in relation to the vermilion border should be classified as skin and not reported. Although this is a longstanding issue, we are the first to our knowledge to attempt to quantify its impacts on cancer control efforts.

Methods: Using CINA data for the 2007-11 period, we compared rates of lip cancer, oral cancer, and oral and pharynx cancer between and within states. We additionally reviewed samples of text from case reports and interviewed registrars to better understand the mechanisms behind the reporting disparities.

Results: The rate of lip cancer among whites in the U.S. was 0.7 per 100,000, but state rates ranged from a high of 2.5 in Idaho to a low of 0.3 in Ohio, an eight-fold difference. Canada saw a wider range, from 3.0 in Manitoba to 0.3 in New Brunswick. The rates of oral and pharynx cancer excluding lip cancer in these states and provinces ranged from 8.7 to 10.1, meaning that lip cancer accounted for nearly all of the observed variation in rates. Within states, similar patterns were seen – in New York, county rates among whites ranged from 2.7 in a rural upstate county to 0.2 in Manhattan. These disparities were consistent with the anecdotal evidence gained from reviewing text and speaking with registrars.

Conclusion: There is a need for better education on how lip cancer should be abstracted and reported, especially so that CCC programs can best use surveillance data to target oral cancer prevention.
QUALITY ANALYSIS AND CODING RECOMMENDATIONS FOR PROSTATE CANCER SITE SPECIFIC FACTORS, 2004-2012

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Background: Changes in guidelines for PSA screening in 2012, and major coding changes to Gleason variables in 2010 led us to investigate inconsistencies in coding.

Methods: We reviewed PSA value (SSF1) and Path Extension (SSF3) for prostate cases diagnosed 2004-2012 and Gleason score from biopsy or TURP (SSF8) for prostate cases diagnosed 2010-2012. These SSF are needed for staging. We evaluated data coded as missing and reviewed concordance between each SSF and other available data.

Results and Recommendations:

PSA: 7% of cases (about 251 per year) were coded as missing PSA value (SSF1) while PSA level (SSF2) was present. 92% of these were coded 999 (unknown), rather than 997 (test ordered, result unknown). We randomly sampled 150 cases. Of cases with PSA value 999, 31% had a value in the consolidated abstract or available records. The remaining 69% had no PSA value, and SSF1 should have been coded 997. We recommend training on the importance of reviewing the text documentation and medical record when consolidating abstracts and reviewing SSF1 999 codes to see if they can be recoded to 997 when PSA level is known.

Path Extension: 67% of cases had Path Extension (SSF3) coded as missing, defined as 950 to 990. We reviewed reasons for missing codes in conjunction with the surgery code and reporting source. Only 6% had issues, mainly involving changing codes from 960 to 970 (no prostatectomy done). We recommend that surgery codes and reporting source be considered when coding, consolidating and quality checking SSF3.

Gleason Turp/Bx Score (SSF8): SSF8 was coded missing in 6% of cases; 42% of those required re-coding. Consolidation of SSF8 is complex, requiring accurate data in histology, diagnostic procedure, diagnostic confirmation and surgery of primary site. To evaluate effectively we recommend: 1) Limit to adenocarcinomas, 2) Evaluate cases confirmed by primary tissue and 3) Eliminate incidentally-diagnosed prostate cancers from cystoprostatectomy.

DETERMINING HOW TO MOVE FORWARD WITH COLLECTION OF PROGNOSTIC AND PREDICTIVE FACTORS KNOWN AS CS SSFS

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Background: Predictive and prognostic factors (PPF) are critical to understand cancer. Thus Csv2 introduced more than 1,000 of these as site specific factors (SSFs) under AJCC 7th Edition. More than 40% of the SSFs were designated as not required and were discontinued with CSV2-05 version. However, because of the importance of these factors in tumor characterization, an independent evaluation of PPFs by SEER was necessary to provide consistent information on which SSFs to continue to collect as well as to establish a process to decide when and whether to include new factors.

Objectives of the Evaluation: 1. Develop a systematic process for assessment of PPFs SSFs. 2. Review all SSFs including those never required. 3. Primary focus on predictive or prognostic biomarkers.

Results: The evaluation process included an assessment of the availability and quality of all SSFs in 2010-2012 SEER data and a review of SSFs in the light of national guideline recommendations, standard of care, or other evidence.

The evaluation captured the percentage of relevant cases a factor applies to, sources of where an PPF or SSFs might be found (availability to the registrar), timing (when in the disease course a factor should be assessed), methodologies used (FISH, RT-PCR, etc.) and whether automated collection is feasible.

A review of the oncology practice guidelines and evidence based literature also identified additional factors, now standard of care, which have significant prognostic or predictive value that should be considered for collection in the near future. Factors with emerging clinical importance that might play a role in the future were also noted for future consideration. The process included input from the registry community and subject matter experts.

Conclusion: The process provided an evidence-based and practical approach which can be effectively fused to make decisions about the collection of PPFs critical to understanding cancer and its outcomes.
AN IN-DEPTH STUDY OF KRAS BIOMARKER TESTING IN COLORECTAL CANCER PATIENTS

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Background: In 2008, the National Comprehensive Cancer Network updated its guidelines to recommend all stage IV colorectal cancer patients be tested for the KRAS gene mutation prior to treatment. However, population estimates on KRAS testing were scarce.

Purpose: The purpose of this study was to assess KRAS testing among stage IV colorectal cases using CDC’s Comparative Effectiveness Research data.

Methods: We evaluated KRAS testing among 3,589 stage IV colorectal cancer cases diagnosed in 2011. Chi-square tests were performed to examine patient characteristics and census-level variables associated with KRAS testing. A multivariate logistic regression was also performed to determine the predictors of KRAS testing after adjusting for the covariates.

Results: Of the 3,589 stage IV colorectal cancer cases, only 28% (n=995) had a documented KRAS test. Increased age at diagnosis (p<0.0001), race/ethnicity other than White (p=0.0162), public insurance (p=0.0019), and lower education by census tract (p=0.0011) were associated with less KRAS testing. There were also significant differences in KRAS testing by state of diagnosis (p<0.0001). After adjusting, age at diagnosis (p<0.0001) and state of diagnosis (p<0.0001) remained strong predictors of KRAS testing.

Conclusions: Despite the NCCN guideline recommendation, 72% of the stage IV colorectal cases diagnosed in 2011 had no documented KRAS test. Increased age was associated with less KRAS testing, and testing prevalence varied by state. The findings provide a population baseline measure of KRAS testing and suggest the need to not only expand the use of the test but to also assess future KRAS testing with cancer registry data. Additional analysis will be conducted on treatments given by KRAS testing status and KRAS gene mutation.

LINKING ONCOTYPE DX RESULTS TO SEER DATA AND PATIENT-REPORT TO ASSESS CHALLENGES IN INDIVIDUALIZING BREAST CANCER CARE

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Background: Oncotype DX is a multigene assay used to determine which early stage breast cancer patients will potentially benefit from chemotherapy. No population-based studies have examined whether patients who receive genomic testing meet guidelines or how test results influence treatment decisions.

Purpose: SEER records tumor genomic profiling variables from medical records, but the data have not been fully evaluated. To obtain complete data, a linkage protocol between two SEER registries, Genomic Health, and the University of Michigan has been developed. Newly diagnosed breast cancer patients included in the linkage have been surveyed about their receipt of genomic testing and its role in their chemotherapy decision. We will assess the role of genomic testing in this population-based sample of 5,200 women.

Methods: Genomic Health representatives will visit both SEER registries and together perform a probabilistic match of study patients in their databases, linking Oncotype DX test results to study participants. The SEER registries will send a de-identified encrypted dataset to the academic partner (U. of MI.) for analyses.

Results: Preliminary survey data from 801 patients shows that 42.4% reported receipt of genomic testing, 13.0% did not receive it, and 42.7% did not recall if their tumor was tested. The risk score was associated with the choice to receive chemotherapy and the majority found the genomic test useful in decision making.

Conclusions: The importance of genomic testing in treatment decisions confirms the need for novel partnerships to enhance registry data in order to assess the broader impact of genomic testing on patient decision making and survival. Additional analyses will be provided on the complete dataset and comparisons will be made between self-reported information, linkage with Oncotype DX results, and routinely abstracted SEER data. Our approach is a useful prototype for other linkage partnerships among registries, academia, and industry.
USE OF THE ONCOTYPE DX ASSAY AMONG CALIFORNIA BREAST CANCER PATIENTS – AN ANALYSIS OF LINKED DATABASES

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Background: The majority of breast cancer patients in the US are diagnosed at an early stage when treatment is generally associated with a good prognosis. Some of these patients are at high risk of recurrence, however, and will benefit from adjuvant chemotherapy. The Oncotype Dx (ODX), a tumor gene expression assay, can identify eligible early stage patients with a high risk of recurrence, and utilization of this assay is now considered the standard of care in HER and node negative, hormone receptor positive patients.

Purpose: This study sought to assess utilization of ODX among eligible breast cancer patients in California, identify predictors of receipt of the assay, and determine whether assay results influenced treatment.

Methods: ODX assay eligible patients diagnosed between 2008 and 2010 were identified through the California Cancer Registry. Patient identifiers were linked with Medi-Cal (California Medicaid) eligibility data from the California Department of Health Care Services, and with data provided by Genomic Health that included recurrence scores for patients receiving ODX.

Results: 23,789 eligible patients were diagnosed during the period and 26.7% received the assay. Patients who were enrolled in Medi-Cal, over age 65, black or Hispanic, and residing in low socioeconomic status (SES) neighborhoods were less likely to be tested. Age, SES, race, and tumor stage were predictors of ODX utilization. Patients with a score indicating a low benefit of chemotherapy were less likely to receive chemotherapy than patients having a score indicating a high benefit; however, half of Medi-Cal patients whose score suggested a high benefit of chemotherapy did not receive this treatment.

Conclusion: Linking cancer registry, Medicaid, and clinical data bases can identify opportunities for improving cancer care. The ODX assay was substantially underutilized in breast cancer patients in California during the study period, especially among women residing in low SES neighborhoods. When utilized, the results of the ODX assay appeared to inform treatment decisions.
FOCUSED AUDITS - A NOVEL APPROACH TO MONITORING DATA QUALITY IN THE CENTRAL REGISTRY
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Typically, central registry recoding audits are performed as the audit of choice for evaluating codes without reviewing source documents. The California Cancer Registry (CCR) decided to augment the recoding audit approach by also performing a different type of audit, a focused audit. This audit yields a more comprehensive glimpse into statewide data quality. Recoding audits traditionally target a primary site, randomly sample a select number of cases, and attempt to identify possible data quality issues within those selected cases. A focused audit, on the other hand, targets a known or suspected data quality issue for a particular data field or group of data fields across the entire central registry database.

The benefits to a focused audit are: Cases with a known or suspected issue are identified through data queries, analysis is performed, data is corrected retrospectively through data fixes, and corrective measures are implemented to prevent future occurrences. Focused audits are performed in a shorter period of time than traditional recoding audits. Every case in the database with the identified issue is corrected. In addition, summarizing results in a final report keeps upper management current on data quality issues and implemented solutions.

This presentation will outline California’s focused audit approach, illustrate findings of recent focused audits as well as implemented solutions and discuss the benefits to this approach. Audit results for focused audits currently in process are planned to include (but are not limited to): Race fields 1-5; Comorbidities and Complications: TNM Staging Consolidation Logic; unknown histologies and unknown sex. The template developed to report all focused audit findings will also be reviewed.

ASSESSING THE COMPLETENESS OF BIRTHPLACE INFORMATION COLLECTED BY THE CALIFORNIA CANCER REGISTRY
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Due to changes in lifestyle and acculturation, the risk of developing various cancers among immigrants appears to change as well. Depending on specific cancer types, the risk can be either increasing or decreasing, but deviates from those in the countries of origin towards the mainstream cancer patterns of the US. The degree and direction of these changes may also vary by immigrant groups. Monitoring cancer trends and patterns among immigrant populations can provide valuable information for cancer control and research. The information on birthplace uniformly collected by the population-based cancer registries in the US is critically important for classifying cancer patients by immigrant status and to investigate cancer incidence and mortality trends among immigrant subpopulations defined by country of origin. However, the completeness of data collection on birthplace remains a challenge across US registries. An earlier observation of California Cancer Registry (CCR) data showed that on average about 1/3 cancer patients in California had missing birthplace information. The proportion of unknown birthplace varied by regions and demonstrated an upward trend across all regions.

Using CCR’s current consolidated research-use data for 1988-2012, we will update the previous observations and perform detailed record analyses of the missing birthplace status by patient demographics, cancer type, and reporting facility characteristics to determine if missing birthplace data may affect certain population groups or cancer types more so than others. Multivariate regression analyses will be used to identify the independent variables that may contribute to the missing birthplace data. The findings will offer insights for improving the collection of birthplace data in the population-based cancer registry system, which will benefit the research use of registry data and enhance the cancer control efforts.
Background: Follow-up (FU) of cancer cases is an activity a registry uses to monitor the vital status of a patient. Through FU a patient’s contact information, vital status, date of last contact, treatment, and recurrence are updated to maintain accurate surveillance. Lost to FU refers to patients who at one point in time were diagnosed with cancer, but the registry has not been able to obtain vital status information for one year or longer. Patients lost to FU can bias results of survival and other studies. In addition, high rates of patient’s lost to follow-up lead to more expenditures as a result of extra resources needed in active FU efforts.

Objective: Increase the percent of adolescent registry cases receiving current FU.

Methods: One group of patients with high rates of lost to FU is high risk adolescents. Using data from the CRGC, we selected cases dx 1988–2011, not deceased, age at dx ≤ 25 years, who had not been followed for current vital status since 2011. We identified software, hired employees and conducted active FU to hospitals to obtain a more recent date of services, especially for cases currently under the age of 18.

Results: We identified 5,847 cases considered lost to FU. New information was identified for 4,210 (72.0%). The data items updated included SSN for 1,838 (31.4%), last Name for 948 (16.2%), first Name for 174 (0.03%), FU date for 3,555 (60.8%), and contact address for 2,603 (44.5%). The cases receiving a more recent FU date and diagnosed 2000-2011 for invasive cancers, age <20 and followed into 2012 increased 5.68%, those followed into 2013 increased 5.41%, and those followed into 2014 increased 5.81%.

Conclusion: This special project resulted in 60.8% of the eligible cases receiving a more recent FU date which was an increase of over 5% of cases currently followed. In addition, a new contact address, updates to SSN, last name, first name and date of birth will lead to an increase in future passive FU matches and a decrease in the active FU process.

Background: Incomplete follow-up information in cancer registries is more common among Hispanics and Asian/Pacific Islanders (API) than other racial/ethnic groups, biasing cancer survival estimates.

Purpose: To understand and develop approaches for addressing differential follow-up among Hispanic and API cases in the California Cancer Registry.

Methods: We conducted a survey of follow-up practices among regional registries; evaluated factors associated with cases “lost to follow-up;” conducted subject tracing; and tested analytical approaches for addressing differential follow-up.

Results: Among cases diagnosed from 2000-2009, 8.9% of Hispanics and 5.9% of APIs were lost to follow-up (alive and last follow-up date more than 2 years prior to December 31, 2012), compared to 1.9% of non-Hispanic Whites. Using recursive partitioning, Hispanics and APIs with missing Social Security Number (SSN) had the highest proportion of lost to follow-up, followed by earlier year of diagnosis and younger age (among Hispanics with missing SSN), and public health insurance and earlier year of diagnosis (among APIs with missing SSN). We used two online search tools to trace 1,740 Hispanics and 1,458 APIs lost to follow-up, and gained information for only 4.5% of Hispanics and 28.3% of APIs. Thus, we suggest a range of sensitivity analyses to quantify the potential impact of differential follow-up on survival differences among racial/ethnic groups.

Conclusions: Consistent with the practice among cancer registries of performing follow-up by data linkage with vital statistics and other databases, the most significant predictor of being lost to follow-up among cases was lack of SSN. Active follow-up by registries through calling facilities has become less feasible, and time-intensive tracing had minimal impact on survival statistics. This work emphasizes the value of patient SSNs in cancer registry data, and supports continued collection of SSN from reporting facilities.
025

USE OF ALTERNATE INFORMATION TO IMPROVE LINKAGE WITH THE NATIONAL DEATH INDEX (NDI)
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Background: The National Center for Health Statistics (NCHS) regularly conducts a linkage between NCHS surveys and the NDI using probabilistic linkage methods. Although probabilistic methods increase the likelihood of finding a true link with imperfect data, the process still misses links due to the negative impact of mismatched data items. In order to increase the likelihood of finding a correctly matching record, NCHS creates additional survey records for participants with alternate information available. Alternate records may include different Social Security Numbers (SSN) or dates of birth that have been identified through other linkages, formal names versus shorthand or nicknames, or use variations of name parts when complex (e.g. hyphenated) names are used.

Purpose: We are evaluating the effectiveness of using alternate records to identify correct linkages that would not have been identified otherwise.

Methods/Results: This will largely be a descriptive analysis assessing: how many links had an alternate record as the highest scoring record; how many deaths were identified with an alternate record that would have been missed otherwise; and which alternate information was most productive in identifying true links.

Implications: Demonstrating the effectiveness or ineffectiveness of this practice will help inform cancer registries if the use of alternate records is worth the effort.

026

LINKING CANCER REGISTRIES AND BIRTH DEFECTS REGISTRIES FOR CLUES ON GENETIC CANCER RISK
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Children born with birth defects have a significantly higher risk of cancer than children that are free of these conditions. This is well known among children with chromosomal anomalies, but in fact, is observed among children with a wide range of structural anomalies. As the methods for identifying complex genetic patterns improve and the cost of such studies declines, the feasibility of research to identify genetic markers associated with greater cancer risk also grows. Cancer registries can serve as a powerful tool, when linked with birth defects data and newborn screening biological material, to give focus to this type of research. The Michigan Cancer Surveillance Program data was linked to the Michigan live birth files and the Michigan Birth Defects Registry. The resulting information confirms the high rates of cancer in children with birth defects. These high relative rates vary by cancer type and by type of birth defect. The overall cancer risk ratio (RR) for children with birth defects was observed to be 2.7 compared to the general population for birth cohorts between 1992 and 2011. The relative risk is highest in very young children, with RRs >4.0 for children 3 years and under. The cancer types with the highest RRs were hepatic (6.10) and central nervous system tumors (3.28). Children with chromosomal anomalies were at greatest risk with a rate ratio of 7.70.

Mining registry data can provide considerable information that can help develop biologically sound and population-based approaches to genetic research and enable targeted case-finding to enhance recruitment efficiency. At the same time, the live birth files for a state provide a ready source for controls when needed.

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Background: To examine the health status of cancer survivors, we linked National Health Interview Survey (NHIS) of the National Center for Health Statistics with Florida Cancer Data System (FCDS).

Purpose: Compare age-group specific health status of Florida cancer survivors to those without a cancer history at the time of NHIS interview (pooled n=1,707,734).

Methods: Employing a probabilistic algorithm in LinkPlus v2, we conducted a linkage between 1997-2009 NHIS data and 1981-2010 FCDS data using Social Security Number, name, date of birth, address and sex. A cancer case was defined as any participant with a FCDS cancer record or reporting a cancer history in their NHIS interview (n=1,937). We evaluated health status using NHIS variables on self-rated health and functional limitations. Prevalence estimates accounted for the complex sample design.

Results: Age-group specific results indicated substantially worse health status in cancer survivors compared with no cancer history, with the largest differences seen in younger adult survivors. The proportion of 18-44 year old cancer survivors reporting fair/poor health was three times that of 18-44 year olds without cancer (% [95% confidence intervals]: 21.2% [13.9-30.9] vs. 6.7% [5.8-7.6]). Cancer survivors in this age group were nearly three times as likely to report two or more functional limitations relative to adults without a cancer history (19.5% [13.8-27.0] vs. 6.9% [6.2-7.6]). There was more than a two-fold difference in rates for middle-aged adults 45-64 years with vs. without cancer (36.2% [31.2-41.5] vs. 16.4% [15.3-17.5]).

Conclusions: Cancer survivors have a substantially lower self-reported health status relative to the general adult population living in Florida. Similar linkages conducted by other central cancer registries would represent an unparalleled data resource to evaluate the health status of patients and other outcomes such as mental health status, healthcare access, and utilization.
029

WHEN WILL CANCER BECOME THE LEADING CAUSE OF DEATH IN THE UNITED STATES?

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Background: Heart disease (HD) and cancer are the leading causes of death. Risk of death from both, as measured by age-standardized rates, has declined in recent years while observed HD deaths have declined and cancer deaths have increased.

Purpose: We analyzed mortality data to predict when cancer will overtake HD to become the leading cause of death.

Methods: Long term mortality data were used to project HD and cancer deaths to 2020, and apportion changes in deaths from population risk and changes in population growth and aging (demographics).

Results: Compared to 1969, the number of HD deaths in 2020 is predicted to decrease 28.3% among men [-75.3% risk, +47.0% demographics] and 20.8% among women [-75.1% risk, 54.3% demographics]. Cancer deaths are predicted to increase 92.3% among men [-31.0% risk, 123.3% demographics] and 99.5% among women [-22.8% risk, 122.3% demographics]. Cancer deaths are predicted to overtake HD deaths around 2012. Between 2010 and 2020, cancer deaths are predicted to increase 12.0% in men and 6.7% in women while HD deaths are predicted to decrease by 13.4% in women and begin to stabilize in men (decrease 1.6%).

Conclusions: The risk of HD death has declined more rapidly than for cancer and has offset the increase in HD deaths due to population growth and aging. Cancer will become the leading cause of death in the United States this decade. A greater emphasis on primary prevention to reduce incidence and improved survival to reduce deaths are needed to counter the effect of a growing and aging population.

030

2011 US BURDEN OF CANCER BY RACE AND ETHNICITY

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Death rate is the most commonly used measure to rank burdens of cancer sites and assess inequalities between 2 or more groups (e.g., race/ethnicity). However, it ignores differences in life-years lost due to premature deaths and associated disabilities between cancers and racial/ethnic groups. Herein, we provide for the 1st time disability-adjusted life years (DALY) lost by race/ethnicity (non-Hispanic Whites (NHW), non-Hispanic Blacks (NHB), non-Hispanic other races and Hispanics) and sex, for 24 cancers, in 2011, in the USA.

Incidence data were obtained from NAACCR, mortality data from the National Center for Health Statistics, population data from the Bureau of Census and treatment data from SEER. We used the 2000 US standard population and 2011 US life tables. Life-years lost (YLL) due to premature deaths were calculated by multiplying the number of deaths at each age group by the life expectancy, and life years lost due to disability (YLD) were obtained by multiplying the disability weight of the condition by its prevalence; these were summed to provide DALY.

Overall, about 9.6 million DALY (94% from YLL) were lost due to cancer. Lung, breast and colorectal cancers accounted for 40-45% of the total DALYs in all racial/ethnic groups except Hispanics (32%). NHB had the highest age-standardized DALY rates for all cancers combined and for 13 cancer sites, with prostate cancer rates 2.3 times higher in NHB than NHW. Although Hispanics had overall a lower burden of cancer, they showed higher burden for infection-related cancers.

Regardless of the race/ethnicity, YLL constituted the majority of the cancer burden, highlighting the need to direct efforts to prevent premature death, by developing primary prevention, early detection, screening, improving treatments and access to care. Public health programs, access to health care, and policy can address both disease management and risk factors to decrease the cancer burden that disproportionately affects minorities.
Changes in Most Common Cancers in Canada

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Background: Examining changes in cancer distribution can provide useful information for evaluating cancer control programs and also for future healthcare planning.

Purpose: This study characterized historical and projected distribution changes of different cancers from 1983 to 2032.

Methods: Age-period-cohort models with power-5 link function were used for projections based on national cancer data from 1983 to 2007.

Results: Prostate, colorectal, lung and bladder cancers figure among the top four most common cancers newly diagnosed in males in 1983–1987, 2003–2007 and 2028–2032. However, prostate cancer replaced lung cancer as the most frequent in 2003–2007, and colorectal cancer is projected to overtake lung cancer as the second most frequently diagnosed cancer in males by 2028–2032. For females, breast, lung, colorectal and uterine cancers are the leading incident cancers in these three periods, but colorectal cancer—the second most common type of cancer in 1983–1987—is ranked third as of 2003–2007. Thyroid cancer will replace NHL as the fifth most common cancer in females by 2028–2032.

Conclusions: Over the study period, declines in male lung cancer were observed. The reduction in smoking prevalence has been associated with declines in lung cancer incidence in males throughout the period. The changes in the cancer distribution reflect changes in risk factors, screening and early detection, coding and diagnostic practices, and preventive and treatment interventions.

Estimating the Impact of Childhood Cancer in the United States: Years of Life Lived with Disease and Years of Potential Life Lost, 2009

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Background: Cancer is one of the leading causes of death among children in the US, and central nervous system (CNS) tumors are the most common type of solid cancer in children <20 years. Incidence rates and overall survival are commonly reported cancer statistics, but they may fail to capture the full impact of childhood cancers. We describe the Years of Potential Life Lost (YPLL) and Years of Life Lived with Disease (YLLD) in children <20 years of age in the US to better understand the public health, economic and personal impact of childhood cancer.

Methods: We examined mortality data due to neoplasm in 2009 among children <20 years old in both the National Vital Statistics System (NVSS) and the Surveillance, Epidemiology, and End Results (SEER) datasets. Histology-specific YPLL and YLLD of CNS tumors, leukemias and lymphomas were measured using SEER data.

Results: There were 2,233 deaths and 153,390.4 YPLL due to neoplasm in 2009. CNS tumors were the largest cause of YPLL (31%). Among specific histologies examined, the greatest mean YPLL (myYPLL) was due to atypical teratoid/rhabdoid tumor (ATRT) (78 myYPLL) and high grade glioma (71 myYPLL). The histologies with the highest mean YLLD (myYLLD) were primitive neuroectodermal tumor (4.59 myYLLD), medulloblastoma (3.17 myYLLD) and acute lymphoblastic leukemia (3.09 myYLLD); ATRT had the lowest (0.63 myYLLD).

Conclusions: CNS tumors are the second most common malignancy in children but have the highest cost in YPLL. This study proposes a new measure of cancer impact, YLLD, which seeks to capture the amount of time children suffer with their disease before death. YPLL and YLLD complement the traditional indicators of mortality and help place CNS tumors in the context of other childhood malignancies.
SURVEY OF USERS OF STAGING DATA: WHAT DATA IS USED, WHAT DATA SHOULD BE COLLECTED?

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Introduction: As of December 2015 the Collaborative Staging Data Collection System (CS) will no longer be supported and transition will begin to a new TNM staging standard. In addition to “best stage,” CS allowed for collection of raw data such as tumour size and site specific factors (SSF). TNM in contrast allows only collection of composite data. Given the limited data available if only TNM variables are collected, a survey was conducted to assess needs of population based stage data users in Canada and to ascertain how much and how frequently data other than TNM was used in cancer surveillance and health care research.

Methods: Provincial/territorial cancer registries who collect and disseminate stage data and Canadian researchers known to have carried out research using population based stage data were sent an electronic survey asking what types of stage data had been provided and how it was used.

Results: 71 surveys were distributed, and 40 returned (54%). 38% of responders used stage data, 8% provided stage data for others and 46% did both. 83% used data both for cancer surveillance and outcome analysis, 63% for clinical research, 43% both for quality management and treatment guideline concordance and 29-34% for cross jurisdictional comparison, program planning, or screening program evaluation. Percentages using raw data and SSF for each use are given below.

<table>
<thead>
<tr>
<th>Use</th>
<th>Raw Data</th>
<th>SSF</th>
<th># Respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Surveillance</td>
<td>36%</td>
<td>52%</td>
<td>25</td>
</tr>
<tr>
<td>Treatment Guideline Concordance</td>
<td>50%</td>
<td>64%</td>
<td>14</td>
</tr>
<tr>
<td>Outcome Analysis</td>
<td>58%</td>
<td>27%</td>
<td>26</td>
</tr>
<tr>
<td>Quality Management</td>
<td>43%</td>
<td>50%</td>
<td>14</td>
</tr>
<tr>
<td>Program Planning</td>
<td>27%</td>
<td>36%</td>
<td>11</td>
</tr>
<tr>
<td>Screening Evaluation</td>
<td>44%</td>
<td>33%</td>
<td>9</td>
</tr>
<tr>
<td>Clinical Research</td>
<td>75%</td>
<td>75%</td>
<td>20</td>
</tr>
<tr>
<td>Cross Jurisdictional Comparisons</td>
<td>45%</td>
<td>38%</td>
<td>13</td>
</tr>
</tbody>
</table>

Conclusions: Although the survey is small, Canadian users of population based staging data want raw data as well as additional SSFs. Future collection of TNM data alone will be insufficient for the Canadian surveillance community. The Canadian Cancer Staging Working Group is preparing recommendations on the minimal data elements and SSFs for collection post CS.

SEER 2014 TRAINING ASSESSMENT FOR TNM STAGING

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Background: The Surveillance, Epidemiology and End Results Program conducted a training assessment for TNM staging. The aims of this assessment were to obtain information on training needs as we move to direct assignment of TNM, provide a baseline to evaluate effectiveness of training materials, and to collect data to evaluate the impact of TNM staging on incidence trends over time.

Methods: TNM and stage group have been collected on breast, prostate, colon, lung and ovarian cancer cases from multiple sources within medical records. TNM and stage group were also directly assigned by a series of reviewers and by study participants using the medical records with TNM information redacted. Estimates of how often physician-assigned TNM and stage group are available from the medical record will be shown and a summary of the variation when there are multiple occurrences of this information. Participant responses will be compared to preferred answers determined by a panel of reviewers. Analyses will be shown by cancer site and facility type. Generally, training needs identified by the study will be discussed.

Results: Pathologic T, N and M were more often available in the medical records compared to clinical values and varied by cancer site. Pathologic T and N were available about for about two-thirds of the cases but the clinical elements were only available for about 20% of cases. The percent agreement between participant responses and review panel also varied by data element and cancer site. Agreement was modest for most data elements and cancer sites, ranging from 67% for clinical N to 92% for clinical M for all cancer sites combined.
EVALUATION OF TNM STAGING DATA IN A LARGE VOLUME OF CANCER PATHOLOGY REPORTS USING AUTOMATED DATA EXTRACTION AND ANALYSIS

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In 2016, central cancer registries in the United States will transition from Collaborative Stage to directly assigned TNM stage. Hospital-based registries which report to the Commission on Cancer’s National Cancer Data Base (NCDB) have collected the individual components of clinical (c) and pathological (p) TNM, however, this is a new requirement for SEER and NPCR central registries. While the pathology report represents the prime source of information on pathological (p) TNM the completeness of these data elements in free text pathology reports is unknown and requires assessment to determine the utility of this data source.

This presentation describes the results of a study which utilized an adaptation of Artificial Intelligence in Medicine’s (AIM) Rapid Case Ascertainment (RCA) system to automatically assess the completeness of TNM reporting within the pathology report. Following a manual assessment of the RCA’s system’s ability to correctly identify and extract the p-TNM data elements and determine a baseline sensitivity and specificity measure for the tool, TNM data was automatically extracted and compiled from a large volume of pathology reports from several SEER registries for 5 types of cancer – breast, ovary, prostate, colorectal and lung. The ability of systems such as RCA to accurately identify these data items with a multitude of free-text pathology reports is a step towards the full automation and extraction of cancer registry data from free-text sources.

DISCORDANCE AND MISSING OF STAGING INFORMATION IN CANCER REGISTRY DATA: IMPLICATIONS FOR CER IN BLADDER CANCER

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Background: Cancer registry data often contains missing or discordance between TNM staging and AJCC staging variables. This staging information is often vital for cancer outcomes or comparative effectiveness research (CER). Identifying the most complete and appropriate staging information for different research is essential to avoid misclassification in registry based research.

Research Objectives: (1) to examine the missing and discordance between different staging variables (clinical staging, pathological staging and AJCC staging) in NCCCR. (2) Use T2 bladder cancer patients as an example to illustrate the possibility of misspecification of models by using different staging variables to select the sample for a CER study of treatment.

Methods: We used North Carolina Central Cancer Registry data to identify bladder cancer patients. Bivariate analysis between each staging variable in NCCCR were performed with Chi-square test. This population of bladder patients were then linked with administrative claims data (both private and public beneficiaries). Using different staging criteria to select the T2 stage bladder cancer patients, logistic models were used to estimate the probability of receiving a specific treatment.

Results: There are higher percentage of missing in clinical staging and pathological staging than the AJCC staging for bladder cancer patients. A large proportion of patients staging was changed from clinical to pathological and from clinical to AJCC. Failing to take into consideration variation of different staging variables can cause misspecifications in the models illustrated.

Conclusions: It is important to understand how and why discordance exists between staging variables in registry data. Which staging variable is appropriate for a CER depends on the types of research and cancer sites. Incorporating the most appropriate staging variable can reduce possible misspecification.
CHANGING INCIDENCE OF HODGKIN LYMPHOMA
HISTOLOGIC SUBTYPES: RISK FACTOR TRENDS OR EVOLVING DIAGNOSTIC PRACTICE?
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Histologic subtypes of Hodgkin lymphoma (classical (cHL)--e.g., nodular sclerosis (NS), mixed cellularity (MC), not otherwise specified (NOS); and nodular lymphocytepredominance (nLP)) are epidemiologically and prognostically distinctive. Rates have declined for MC and increased for NOS; whether these are true incidence changes is unclear. Therefore, we analyzed detailed HL histology-specific rate trends in 1992-2011 SEER data (21,372 incident HL cases) and reviewed 2007-11 NOS pathology reports from one SEER registry for insight into diagnostic practices. Overall cHL rates were stable until 2007, then dropped for whites (annual percent change (APC) and 95% confidence interval, -3.6 (-5.6, -1.5)). nLP rates increased steadily (1992-2011 APC 5.9 (5.1, 6.8)). NS rates were stable until 2007, then dropped (APC -0.9 (-2.9, -2.9)), decreasing for females in 1992-2011 (APC -0.8 (-1.4, -0.2)) and males since 2007 (APC -6.4 (-11.0, -1.5)), notably young adults. In 1992-2011, MC rates dropped (APC -0.4 (-4.7, -3.3)) and NOS rates rose (APC 5.3 (4.5, 6.2)) in almost every patient group and SEER registry, making NOS the second most common HL category by 1999. Misclassification of true MC as NOS over time was supported by similarities of 2007-11 NOS to 1992-96 NS rates, and by the minimal changes in combined MC/NOS rates (1992-2011 APC 0.9 (0.3, 1.5)). In 181 reviewed pathology reports, 11% justified the NOS diagnosis, 12% noted insufficient specimens, 8% suspected a more precise histologic subtype, 43% lacked further subtype information (more so for core/fine needle than excisional biopsies), and 19% were coded in error by registrars. Thus, cHL incidence rates are now declining, due to a true decrease in NS. Ongoing rate drops for MC and rises for NOS likely reflect diagnostic (e.g., inadequate tissue) and classification (e.g., overuse of NOS) practices--changes that are undermining accurate monitoring of true HL incidence and mortality patterns but should be remediable.

EVALUATION OF COMPLETENESS OF LYMPH NODE COUNT IN THE NORTH AMERICAN ASSOCIATION OF CENTRAL CANCER REGISTRIES FOR SELECTED CANCERS
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Background: Examining adequate number of regional lymph nodes is considered as a measure of quality of care for some cancers. The completeness of this information in population-based cancer registries is unknown.

Purpose: To evaluate the completeness of “regional nodes examined” information for female breast cancer, non-small cell lung cancer (NSCLC), and colon cancer in the North American Association of Central Cancer Registries (NAACCR).

Methods: Data on cases diagnosed in 2007-2011 with first primary invasive stage I-III cancer and received site-specific surgery were from 22 registries for female breast cancer and NSCLC, and 43 registries for colon cancer in the US. Registries with 100% unknown/blank information for “regional nodes examined” were excluded. We analyzed percentages of unknown/blank information for “regional nodes examined” by race, diagnosis year, registry, census tract level poverty, stage, and county level rural/urban.

Results: There were a total of 73,911 female breast cancer, 5,522 NSCLC, and 149,601 colon cancer cases. For all races combined, approximately 1.8% of female breast cancer, 8.3% of NSCLC, and 0.8% of colon cancer cases had unknown/blank information for “regional nodes examined”. These percentages did not substantially vary between 2007 and 2011, and stage at diagnosis for each of the three cancer types. The percentages of unknown/blank information were higher for cases residing in poor neighborhoods than in affluent neighborhoods (2.1% vs. 1.6% for breast cancer, 11.7% vs. 3.5% for NSCLC, and 1.1% vs. 0.3% for colon cancer). Cases reported from non-metropolitan areas had higher percentages of unknown/blank information (2.3% for breast cancer, 9.0% for NSCLC, and 1.4% for colon cancer).

Conclusion: Information on “regional nodes examined” for colon cancer cases was remarkably complete and better than NSCLC and female breast cancer cases in NAACCR, but varied by census tract level poverty and county level rural/urban status.
HAS IMPROVED IMAGING CONTRIBUTED TO REDUCED SIZE AT DIAGNOSIS FOR STAGE I LUNG ADENOCARCINOMAS?

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Background: Adoption of CT radiography purports to reveal smaller internal tumors and may have increased the proportion of stage I adenocarcinomas of the lung diagnosed at small size. The California Cancer Registry (CCR) is the state mandated cancer surveillance system for approximately 38 million residents. CCR data include anatomic site, histology, and stage and tumor size at diagnosis. CCR demographic information includes age, sex, race/ethnicity and a quintile socioeconomic status (SES) index. CCR data does not include radiology type used for diagnosis.

Objectives: We sought to determine whether there was a shift to smaller tumor size at diagnosis for stage I adenocarcinomas of the lung in California that corresponded with time-periods for adoption of CT imaging.

Methods: We identified all stage I adenocarcinomas of the lung diagnosed among California residents for 1990-2000 (early) vs. 2001-2011 (late) having data for tumor size, staging source and demographic characteristics. Tumor size was classified as 18-32 mm (large) vs. 1-17 mm (small) at diagnosis. Multiple-logistic regression was used to compute independent the odds ratio for large vs. small tumor size predicted by late vs. early time-period and for each of the other covariates.

Results: Reduced odds ratios for large versus small tumor size at diagnosis were evident for the late vs. early time-period (OR=0.74; 95%CI=0.70-0.77), with this effect independent of other covariates. Other predictors of small tumor size included younger age (Trend p<0.001), female gender and higher SES quintiles (Trend p<0.001), while Asian/others and Hispanics, relative to non-Hispanic whites, showed reverse effects.

Conclusions: Findings are consistent with a shift to smaller tumor size during the more contemporary time-period that coincides with adoption of CT imaging. Further analyses are ongoing to determine whether small vs large tumor size among stage I lung adenocarcinoma cases predicts survival differences.
A NEW ERA OF DATA QUALITY ASSURANCE AND PROCESS IMPROVEMENT
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Background: Assessing data quality was once a single dimensional process based in many instances on set activities, and often times using random selection criteria. Data quality has evolved into a multidisciplinary, comprehensive approach with automation influences, proactive implications and process improvement opportunities.

Purpose: This presentation provides an overview of the changes implemented in conducting cancer data assurance activities to improve overall cancer data quality while also identifying process improvements opportunities.

Methods/Approach: Enhanced methods of conducting audits and other quality control activities will be discussed, with an emphasis on identifying causes of data quality problems as well as tool enhancement opportunities.

Results: The results of various quality assurance activities and subsequent process improvements will be presented.

Conclusions/Implications: A robust data quality assurance plan involving a multidisciplinary approach can lead to improved overall data quality as well as operational process improvement efficiencies.

REMEDIY TO REDUCE DEATH CERTIFICATE ONLY CASES
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An audit of 2009 NC death certificates revealed that 33.5 percent of cancer-related deaths occurred in a hospice, assisted living or a nursing home facility.

Since the death clearance follow-back process is a two year delay, it is often impossible to obtain accurate information. A NC death certificate provides the place of death and the name of the signing physician. If the place of death is a residence, it is difficult to secure additional information. If the signing physician simply signed the certificate and did not treat the patient, he can provide little data.

The lack of complete information created the problem of 2,000+ DCO cases. A DCO case is a cancer case that has not been reported by a hospital, physician, pathology laboratory or treatment facility.

In order to reduce the number of DCOs the CCR explored the idea of capturing information on those cancer patients prior to their death.

Using a random sample, the CCR discovered the missed cases in a HAN, Hospice, Assisted Living or Nursing Home, facility ranged from 8.8 percent to 60.7 percent. In 2011, the HAN cancer collection program launched to capture the unreported cases before the death clearance process begins and to acquire more complete data.

The CCR’s priority is to collect complete, timely and accurate data on all cancer cases. As an update to the 2013 NAACCR Annual Conference presentation, the HAN remedy lowered death clearance cases, improved data quality, captured unreported cases and reduced manpower hours in the death clearance process.

A recent HAN report included 50+ patients. The quality report provided a diagnosis date, treatment details and other information for an accurate and complete abstract for all 50+ patients. The diagnosis date immediately changed the status of a DCO case to an MDO case. The DCO count dropped significantly.

If you are looking for a proven remedy to decrease the DCO count, visit the HAN project at www.schs.state.nc.us/schhs/CCR/HAN.
A REVIEW OF 2012 DIAGNOSIS YEAR CASES SUBMITTED FROM SEVEN PATHOLOGY LABORATORIES IN ILLINOIS

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Background: The Illinois State Cancer Registry (ISCR) receives pathology cases daily from seven laboratories via PHINMS. These cases are rarely processed due to workload constraints within the registry.

Purpose: A project was undertaken to evaluate the time required to process a year of pathology cases, determine the types of cancers not already reported to ISCR from other sources, and evaluate the information submitted.

Approach: A total of 2,768 path lab cases from diagnosis year 2012 were reviewed for reportability. All cases were partially abstracted in eMaRC Plus and then exported to Abstract Plus for completion. A linkage was then performed between the completed cases and the registry database using Link Plus software. Matched cases were manually reviewed to determine if information from the path case was more specific and should be added to the case already on the registry database. Unmatched cases were loaded onto the registry database as stand-alone cases.

Results: Of the 1,580 pathology cases determined to be reportable and exported from eMaRC Plus, 451 (29%) did not match a case already on the database. The top three primary sites identified were prostate (55%), hematopoietic and lymphoid (16%) and melanoma (8%). Of the 1,129 cases that did match to the registry database, 404 (36%) of them matched completely to cases already on the database with no different or additional information. The remaining 725 cases (64%) matched to an identical person and tumor on the registry database with some differences.

Conclusions: A total of 251 staff hours were used to process cases resulting in 0.2 FTE. However, the amount and type of data that could be improved by following this process each year for every pathology case is minimal so ISCR plans to only abstract cases that do not match a case already contained on the registry database. This will allow ISCR to capture all incident cases provided solely by pathology labs while limiting staff workload.

ENGAGING REGIONAL CANCER CENTRE HEALTHCARE PROFESSIONALS IN IDENTIFYING CANCER SURVEILLANCE INFORMATIONAL NEEDS

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Cancer Care Ontario (CCO) is a government agency that drives performance measurement and quality improvement for cancer care. Several Regional Cancer Centres (RCC) are moving towards adoption of ambulatory Electronic Medical Records (EMRs). CCO launched a project to provide a standards approach to the EMR process with the integrated patient cancer journey as central to the process. This approach included: 1) Information Standards; 2) Data Standards; 3) Functional Requirement Standards and 4) Interoperability Standards. A particular focus through end user engagement was to understand the cancer system surveillance informational needs. CCO sought to elicit concepts for both performance and quality measures including those assessing predisposition, risk factors (environmental and behavioral), screening and quality of care throughout the cancer continuum. 26 workshops (clinical and operational) were held with 13 RCCs and a modified Delphi process was deployed to merge like concepts to the vital few. Engaging multidisciplinary healthcare professionals (HCP) resulted in 135 participants at the clinical workshops, 106 in the operational and a further 194 who contributed to the online survey. The concepts were consolidated from an initial value of 1,598 to 118 during the Delphi process. This study revealed that of the 118 indicator concepts, 39 ideas (33%) were surveillance-based which were felt to be poorly captured at this point in time and could be facilitated through clinically-interoperable information technology systems like EMRs. Categories for surveillance-based indicators included; Prevention, 9; Screening, 2; Diagnosis 2; Treatment, 10; Survivorship, 5; throughout continuum, 10. Engagement with RCCs led to discoveries in surveillance informational needs that can be further developed into data standards across a clinically interoperable health system which can be used to improve the quality of care for patients throughout their cancer journey.
**045**

**EARLY ESTIMATES OF SEER CANCER INCIDENCE FOR 2012**

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**Background:** The most recent rates from registry data are typically three years removed from year of diagnosis.

**Purpose:** To examine the potential for earlier rates, early estimates of SEER17 incidence rates for the diagnosis year 2012 were recently issued.

**Methods:** All cancer sites, plus five cancer sites of colon and rectum, lung and bronchus, melanoma, female breast, and prostate cancer were included in the analysis. February (early submission) and November (full submission) incidence data for 2011, 2012, and 2013, plus the February 2014 submission were compared. Comparisons of case counts for the paired February and November submissions within a given year were used to assess completeness of the February submission. Reporting delay models are used to statistically adjust counts for recent diagnosis years for cases projected into the future, with February submissions requiring larger adjustments. Delay adjusted rates from the February submissions were compared to trends using the subsequent November submission using delay adjustment.

**Results:** Completeness for cancer sites assessed was above 91%. Most major cancer sites had a similar Annual Percent Change (APC) in trends for February and November 2013. However, there were slight changes in the number of joinpoints in the trends for certain cancer sites in view of the February 2014 submission data. In evaluating the trends, it is recommended to use the more conservative Average Annual Percent Change (AAPC).

**Conclusion:** It is possible to report cancer incidence rates based on the earlier February submission. We will continue to evaluate future data submissions to further review the feasibility of releasing early estimates of cancer incidence.

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**046**

**PROJECTING CANCER PREVALENCE: FINDING THE BEST METHODS FOR ONTARIO’S CANCER SYSTEM PLANNING**

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Prevalence, defined as the number of people alive on a specific date with a cancer diagnosed in the previous n years, is a measure of cancer burden that is becoming increasingly popular. Cancer system planners at Cancer Care Ontario are not only interested in estimates of current prevalence, but also in prevalence projections. In response to these requests, a project was undertaken to investigate methods currently in use and to select the method that would best meet CCO’s needs. Software obtained and tested included MIAMOD/PIAMOD and SEER’s ProjPrev. Statistical methodologies considered included a promising new procedure proposed by J. Maddams. The method selected was the simplest: fit linear models with either normal or Poisson errors, and linear, quadratic and cubic terms as necessary to produce reasonable extrapolated estimates up to 10 years in the future. Once this decision was made, a suite of SAS® programs were written to implement the method using Ontario Cancer Registry data. The code was used to generate prevalence projections for 2004-2010 and the estimates were then compared to observed prevalence for the same years. Based on these comparisons, guidelines were created for selecting the best projected prevalence estimates and projected prevalence was estimated for 2011-2019.

On January 1, 2011, there were 344,682 Ontarians living with a cancer diagnosis in the previous 10 years. The most prevalent cancers were prostate (73,485), breast (65,279), colon and rectum (42,156), thyroid (18,295) and melanoma (17,083). The best model for predicting breast prevalence was determined to be quadratic with normal errors, giving an estimate of 74,074 in 2019, an increase of 13%. In the presentation, the evaluation criteria used, and the pros and cons for different prevalence projection methods, will be discussed. More results will be given to illustrate how the models work with a variety of cancers showing different prevalence trends.
047

USE OF INCIDENCE-BASED MORTALITY (IBM) TOOL TO PARTITION TRENDS IN MORTALITY BY TUMOR SUBTYPES: APPLICATION TO NON-HODGKIN LYMPHOMA (NHL) CANCER

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Background: U.S. cancer mortality data derived from death certificates lack information pertaining to the onset of a cancer diagnosis (e.g., stage, tumor subtypes). Thus, death certificate mortality recorded in a particular year represents patients who were diagnosed during any year in the past, regardless of tumor characteristics, and these data cannot be used alone to assess mortality trends according to such characteristics. To overcome this limitation, the SEER Program has linked incidence data from the nine original SEER registries with mortality data from death certificates, providing researchers with a unique, Incidence-based Mortality (IBM) tool.

Objective: There are 2 main objectives: 1) Calculate the IBM rate and usual death certificate mortality rate in SEER to validate the use of IBM rates for NHL, 2) Calculate IBM rates for major NHL tumor subtypes under different scenarios (e.g., varying cause of death (COD) definitions) and discuss how assumptions under these different CODs might influence the IBM trends.

Methods: We will use IBM tool to partition mortality trends from 1975-2011 by tumor subtypes. Overall NHL mortality rates will be calculated from death certificate information. Trends will be compared and contrasted to evaluate how choice of COD might influence results. Joinpoint regression program will be used to assess changes in trends over time.

Preliminary Results: IBM rates appear to be underestimated when we use COD specified as due to NHL cancer death. However, IBM rates seem to mirror death certificate rates in 13 years when a broader definition of COD is used in addition to NHL. IBM trends by tumor subtypes will be calculated.

Discussion: IBM tool can be used to quantify population-level mortality trends by tumor subtypes, but caution is needed when interpreting the results, as many factors (e.g., under-ascertainment of hematologic malignancies, migration, COD misclassification) can influence or even bias these trends.

048

REDUCING CONFOUNDING BIAS IN REGISTRY-LINKED DATA THROUGH PROPENSITY SCORE METHODS

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Propensity scores (PS) methods are increasingly used to estimate valid treatment effects in observational studies of cancer outcomes. PS methods can minimize systematic differences in baseline characteristics between treatment groups and better control for measured confounders. Despite their popularity, not many studies provide a detailed description of how and why a specific PS approach was chosen and how they evaluated the performance of the PS.

While there are many ways to apply a PS, no one size fits all. Researchers need to consider several things when choosing the appropriate PS method including: the research questions of interest; available data; ensuring comparability of treatment groups; correct estimation of treatment effects; and how to check the validity of treatment effects on multiple outcomes.

This presentation will show how PS is applied and evaluated using an example from hepatocellular cancer patients reported in SEER. A total of 1,651 patients were included with 1,528 in TACE treatment group and 123 in Y90 treatment group, and the treatment effects on 3, 6, 12, and 24 month mortality were evaluated. As TACE is the standard therapy, we sought to answer “what would the effect of Y90 be among patients typically treated with TACE?” Specifically, we: 1) calculated a PS score for each patient from a multiple logistic regression, 2) dropped all patients with non-overlapping PS, 3) applied standardized mortality ratio weights using PS scores, 4) trimmed patients based on PS percentiles who received (or did not receive) the treatment contrary to indication, and 5) evaluated balance differences on all covariates. For each step, we will describe the approach, how it is operationalized, what the approach achieves, and why a specific method was chosen over the alternatives. We will also present how the treatment effects vary depending on the method applied.

When used correctly, PS methods are a powerful strategy to reduce a confounding bias in observational studies.
ASSESSING FITNESS FOR USE OF TWO INDICATORS OF THE RURAL-URBAN ENVIRONMENT IN THE NAACCR DATA FILES
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Studies have shown that residents of rural areas have lower screening rates, lower rates of follow up of abnormal screening tests, higher late stage diagnosis rates, and differences in cancer treatment patterns. Recognizing the importance of indicators of rural urban residence, NAACCR has historically made county-based urban/rural indicators, based on Beale codes, available in CINA for use by approved researchers. However, county-level area-based measures are imprecise and may mask important local variation in risk. Therefore, for the 2015 Call for Data, NAACCR began calculating two census tract-level urban/rural indicators. Including tract-level indicators of rural urban residence in the NAACCR CINA data will facilitate research in rural urban disparities at the national level and allow researchers to control for specific rural-urban differences in model based analysis of cancer risks and outcomes without releasing patient addresses or small-area location data.

The new indicators represent different and precise measures. Census Bureau’s Urban Rural Indicator Codes (URIC) codes measure the rural nature of a patient’s residence and can be an indicator of access to recreation, access to food stores, exposures to pollutants, crime levels, social cohesion, etc. USDA’s Rural Urban Commuting Area (RUCA) code is a measure of proximity to large urban centers and can be an indicator of access to oncology specialists and cancer treatment facilities. This presentation will provide an overview of how the new indicators (available for assessment in February 2015) are derived, assess their “fitness for use;” and provide basic descriptive statistical summaries of these newly available measures.

COUNTY MEASURES AND CANCER SURVIVAL FOR LUNG AND COLORECTAL CANCER IN APPALACHIAN KENTUCKY, OHIO AND WEST VIRGINIA
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Background: The Appalachian region in KY, OH and WV has higher rates of poverty, obesity, tobacco use, and lower levels of education and health care coverage than the non-Appalachian region. The population from this region also have had higher cancer incidence overall and significantly higher incidence for lung and colorectal cancers.

Aims: Examine the associations between cancer survival and county level measures, including rates for below poverty, education attainment, obesity, current smoker and health care coverage by Appalachian status.

Methods: Data on invasive lung and colorectal cancers for diagnosis years 2005-2009 from the KY, OH and WV cancer registries were acquired. The data were linked with the National Death Index to identify the vital status of all patients as of 31 December, 2010. Measures of below poverty and education attainment were derived from the American Community Survey data. Measures for obesity, current smoker and health care coverage were based on the BRFSS data. Five-year net survival by Appalachian status and county measures were estimated using appropriate regional-specific life tables.

Results/Discussion: Overall lung cancer survival was significantly worse for patients in Appalachian than in non-Appalachian regions of all three states. Lung and colorectal cancer survival was higher in Appalachian counties with higher education attainment and lower poverty, obesity and smoking. These associations were not found for patients with these cancers in non-Appalachian counties. No differences were found in lung or colorectal survival based on healthcare coverage.
MAPPING WITH CANCER, DEMOGRAPHIC, AND BEHAVIORAL RISK DATA

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Background: The capability of showing where the burden of cancer is high, and especially to put it into context with demographic, socioeconomic, and behavior risks can provide an important part of disseminating data to the public. The Missouri Cancer Registry and Research Center (MCR-ARC) has previously disseminated data to the public as tables via the Missouri Department of Health and Senior Services’ (DHSS) interactive MICA website and as interactive maps of selected cancers types (without additional contextual indicators). In 2014, a project was undertaken to provide additional indicators on demographic, socioeconomic, and behavior risk factors.

Purpose: To produce a better means of disseminating cancer data to the public, the interactive maps created in 2014 were improved.

Methods: Interactive county-level maps have been produced containing cancer incidence and survival from MCR-ARC, cancer mortality from NCHS, behavior risk factors from DHSS, demographics from the Census Bureau, and additional other sources. The cancer sites of interest had been selected based on having a high incidence and possible relationships to demographic, socioeconomic, and behavior risk factors. Input was solicited to improve usability and to tailor the selection of the contextual factors.

Results: The resulting maps provide an intuitive method of geographically visualizing the burden of cancer in relation to additional contextual factors. Using such maps may provide an intuitive interface for members of the public to utilize data from the cancer registry and to put the data into context of other related factors.

Discussion: A system capable of mapping the data interactively may provide a better means for members of the public to access cancer data since it allows them to see the data in a more intuitive means than a table. Additionally it allows the user to put the data in context in terms of geographic and other related factors such as behavior risks.

ARE DISTANCE BASED ON ADDRESSES BETTER THAN ZIP CODES FOR ASSESSING GEOGRAPHIC ACCESS TO CANCER TREATMENT?

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Background: Distance is used as a proxy measure for access to healthcare, but measures of distance vary among studies. Although research exists on the correlations between different distance metrics, the impact of different distance measures on healthcare access has not been directly examined.

Research Objective: We examined the differential effect of distance on receipt of radiation therapy (RT) after breast cancer surgery using multiple computational methods for distance (Euclidean and Network distance) and levels of measure granularity (address and ZIP code centroids).

Methods: We identified 1,938 women diagnosed with breast cancer in 2003-2005 in North Carolina and who were eligible for RT by linking registry data to Medicare insurance claims. Physicians providing RT were identified from the claims and their address was obtained from the Medicare Physician Identification and Eligibility Records. Patients’ addresses were obtained from the NC registry. Both the addresses and ZIP code centroids from patients and physicians were geocoded using ESRI ArcGIS. We computed nearest Euclidean distance using SAS and network distance using ArcGIS. The distance effects were compared using model predicted probability of RT receipt in logistic regression models, adjusting for patient demographics, tumor characteristics, and patient’s county as urban or rural.

Results: Mean Euclidean distances did not differ between addresses vs. ZIP codes; whereas network distances were longer from ZIP codes compared to addresses. Results from regression models suggested that the relationship between probability of receiving RT and distance was non-linear and differed by urban-rural areas.

Conclusions: Regardless computation method, impacts of distance with same level of granularity were similar. The effect of distance also differed by geographic areas. This study provides valuable information for researchers who are interested in using distances to evaluate geographic access to healthcare.
BUILDING CAPACITY FOR CANCER CONTROL ACTION: THE IARC REGIONAL HUB FOR CANCER REGISTRATION IN THE CARIBBEAN

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Cancer is the second leading cause of death in the Caribbean. While the region has faced a number of challenges that have compromised the availability, completeness and accuracy of surveillance data, health planners are now recognizing the value of and need for reliable cancer registry data in the region. With many islands now requesting technical assistance in planning and developing population-based cancer registries, a Caribbean Regional Hub for cancer registration has now been established as part of the Global Initiative for Cancer Registry Development (GICR), supported by the NCI and CDC in the U.S. The Regional Hubs, delivered through such international partnerships, combine provisions for technical support, training and advocacy to ensure cancer registry systems are developed across the world to inform national cancer control.

Initiation plans for the development of the Caribbean Hub began in 2014 and included a survey to collect updated activities on cancer registration throughout the Caribbean, and an in-person transnational meeting to discuss strategies. Meeting recommendations included a needs and infrastructure assessment to determine the current status, available infrastructure and resources requirements. The purpose of this presentation is to highlight progress and discuss future activities at the Caribbean Regional Hub as a means to provide reliable data to support cancer prevention and cancer control planning and evaluation in every country within the region.

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PROFILING CANCER WITHIN SELECT ONTARIO ABORIGINAL RESERVES

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Background: Several Aboriginal communities in Ontario have requested profiles of cancer among their populations to assist in priority setting and planning. Unfortunately, Aboriginal ethnicity is not routinely captured by the Ontario Cancer Registry (OCR). Additionally, there are often small numbers in these communities since cancer is a rare event.

Purpose: Identify and evaluate approaches for creating accurate and useful Aboriginal community cancer profiles from the OCR.

Approach: Postal code at diagnosis from the OCR can be used to allocate cancer cases to a particular Aboriginal community. Population estimates for Aboriginal reserves can be obtained from the Canadian census since each corresponds to a unique census subdivision. This approach is compatible for communities in rural areas of Ontario where postal codes are more likely to map directly to Aboriginal reserve boundaries. To increase sample size, diagnosis years can be combined, although results that can be released under small numbers guidelines may still be limited. Since many Aboriginal reserves are small and/or located in areas where reserve postal code(s) also cover substantial off-reserve areas, other or modified approaches are needed. Consultation with the community of interest is required to determine the approach that is most valuable.

Results: We will report on our evaluation of various methodological approaches unique to each community. For one Aboriginal reserve, we successfully prepared a cancer profile using a postal code that mapped with reasonable accuracy to the reserve. Overall cancer incidence was similar to the Ontario population, although there were significantly fewer prostate cancers and more lung cancers. Feedback from the reserve was extremely positive and our results were useful for their priority setting.

Conclusions: Our enhanced approaches to creating cancer profiles may provide accurate and useful information for community planning.

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SMOKING BEHAVIOR AMONG ADULT CHILDHOOD CANCER SURVIVORS: WHAT ARE WE MISSING?
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Background: Childhood cancer survivors (CCSs) are a growing population at increased risk for late health effects of cancer treatment that can be exacerbated by smoking.

Purpose: This study aims to compare smoking prevalence by age, age at smoking initiation, and time-trend of smoking prevalence from 1997 to 2010 between adult CCSs (diagnosed with cancer < 21 years) and non-cancer controls stratified by gender and by US region; and to identify risk factors of smoking among CCSs.

Methods: Data were pooled from the 1997-2010 National Health Interview Survey (CCSs: n=1,438; controls: n=383,805) and analyzed adjusting for sample weights and design effects. Smoking prevalence by age was calculated using weighted least square regression analysis. Age of initiation was expressed as mean ± standard deviation. Trend analysis using weighted linear regression of prevalence on year were used. Logistic regression analyses were performed to identify predictors of smoking among CCSs.

Results: Compared to the controls, CCSs were significantly younger, female, White, unemployed, have low income, weigh less, and were more likely to smoke (34.6% vs. 22.05%; P<0.0001). Smoking prevalence among CCSs peaked at age 20 and 35 years old (39% and 47%, respectively), while it peaked only at 25 years (27%) in the controls. Age at smoking initiation was earlier in CCS survivors than the controls. 1997-2010 smoking prevalence decreased slightly and consistently among the controls, but remained high and did not show a clear time-trend pattern among CCSs. CCSs who smoke were significantly more likely to be white, young, without health insurance, live below the poverty level, have a high school or less education, and report drinking alcohol relative to non-smoking CCSs.

Conclusion: Smoking prevalence in CCSs is persistently high, with prevalence differences noted across socioeconomic groups. Targeting CCSs with tailored smoking cessation and prevention interventions is highly needed.

USE OF PATIENT FOCUS GROUP DATA WITH CANCER REGISTRY DATA TO SUPPORT PERSON-CENTERED SYSTEM PERFORMANCE REPORTING
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Background: Measuring the performance of the cancer system should include information that reflects the experiences and perspectives of persons affected by cancer.

Methods: Qualitative data gathered from focus groups of men treated for prostate cancer were used to inform analysis on treatment patterns based on data from provincial cancer registries/agencies. Through 6 focus groups held across Canada with 42 men who had received treatment for prostate cancer, men were asked about their experiences during the treatment decision-making process. The quantitative analysis examined treatment patterns within one year of diagnosis by risk category for patients with localized prostate cancer in 2010.

Results: Many participants expressed a desire to be engaged and involved in the treatment decision-making process. While some patients were actively involved, others felt they were not given any options. Among patients with low- and intermediate-risk prostate cancer, the proportion receiving radical prostatectomy (RP) versus radiation therapy (RT) varied depending on the province. Among high-risk patients, RT was more common. However, a relatively large proportion of low- and high-risk patients did not have either within one year of diagnosis.

Conclusion: Embedding patient experiences in system-level reporting helps deepen our understanding of areas in cancer control. Patient choice, as well as clinical factors not captured in administrative data, play a role in influencing the type of treatment men with prostate cancer ultimately receive. While the findings here reflect the experiences of a small sample of men from across Canada who have been treated for prostate cancer, their experiences do provide important insights into underlying factors that help to partly understand some of the reported treatment patterns based on registry data. Further exploration and research is needed to definitively link patterns of care and the reasons for treatment modality chosen.
Invasive cervical cancer can be prevented through the follow-up of precursor lesions found by screening. Information on preinvasive cervical disease is an important intermediate endpoint to monitoring the outcomes of HPV vaccines; however, cervical cancer precursors are not required to be collected by U.S. central cancer registries. The Centers for Disease Control and Prevention funds four cancer registries in Louisiana, Kentucky, Michigan, and Los Angeles. The Centers for Disease Control and Prevention began collecting cases in 2010. Preliminary data analysis shows that cervical cancer precursor incidence rates varied widely by registry, ranging from 1.7% of all diagnoses in Louisiana to 8.0% of those in Los Angeles. The highest incidence rates were among white women in Kentucky and Louisiana, and were similar among white and black women in Los Angeles and Michigan. Adenocarcinoma in situ was rarely diagnosed, ranging from 1.7% of all diagnoses in Louisiana to 8.0% of those in Los Angeles. Variations between registries may be related to differences in disease, screening, pathology terminology, and data collection. Although treatment of precursor lesions generally yields good outcomes, the young age at diagnosis is cause for concern as treatment can cause reproductive health issues.

Data collection on cervical cancer precursors is feasible and can provide important information on public health efforts, including the outcome of HPV vaccines.

The Centers for Disease Control and Prevention funds four cancer registries in Louisiana, Kentucky, Michigan, and Los Angeles County to collect cervical cancer precursor incidence, which can provide information to help monitor effectiveness of HPV vaccination. Registries conducted audits to determine whether case collection was complete and accurate. The four registries reviewed 128,295 pathology reports from 33 facilities (28 hospital and 5 free-standing laboratories). Audit implementation varied across registries. Ninety-one percent of audited facilities used electronic reporting. Audits found 4% of cases were misclassified, including 13 missed cases and 40 false positives. Reasons for case misclassification included issues with the electronic case finding algorithm, misspellings or misclassification on pathology reports, or subsequent reports on the same person. Los Angeles and Kentucky registries also conducted audits to determine whether the terminology used to classify precancerous lesions is evolving towards newer recommendations. In 2012, the American Society for Colposcopy and Cervical Pathology (ASCCP) recommended moving from the 3-tiered cervical intraepithelial neoplasia (CIN1-3) classification to a 2-tiered low or high grade squamous intraepithelial lesion (LSIL or HSIL) classification system. For equivocal HSILs (formerly CIN2), ASCCP recommends p16 testing; p16 positive lesions should be considered to be HSIL. In Los Angeles, 83% of pathology reports included both HSIL and CIN terminology while 17% only used HSIL; in Kentucky, 21% of reports included both HSIL and CIN terminology while 51% only used HSIL. Among reports that only used HSIL terminology, 22% in Kentucky and 43% in Los Angeles included p16 results. Both regular audits to determine accuracy of case finding as well as surveillance of changes in terminology will be important to determining whether changes in reported preinvasive cervical disease can be attributed to HPV vaccination.
Background: The Kentucky Cancer Registry (KCR) has developed a population-based pre-invasive cervical cancer surveillance system. This system collects information on all pre-invasive cervical cancer cases defined CIN-3 or AIS. Since 2009, KCR has collected information on all pre-invasive cervical cancer cases meeting this definition. The pre-invasive cervical cancer data are being used to study variations in HPV genotypes among Kentucky women.

Research Questions:
1. Are the HPV genotypes different for non-Appalachian white women diagnosed with (CIN-3) compared to Appalachian white women?
2. Are the HPV genotypes different for non-Appalachian white women diagnosed with CIN-3 compared to non-Appalachian black women?
3. Are the HPV genotypes different for white women diagnosed with CIN-3 compared to white women diagnosed with AIS?

It is important to note that there were too few Kentucky African American women diagnosed with AIS and too few Appalachian women living in Appalachian Kentucky diagnosed with CIN-3 to make stable estimates.

Methods: To answer these questions, four population-based strata were formed: non-Appalachian white women, non-Appalachian black women, Appalachian white women diagnosed with CIN-3, and white women diagnosed with AIS. The KCR served as the honest broker for getting the tissue blocks and returning them. All of the tissue samples were collected from the clinical labs and processed in 5 months.

Results: Differences in HPV genotypes between each of the strata will be presented. Difference in HPV genotypes between Appalachian and non-Appalachian women or women diagnosed with CIN-3 compared to AIS have not previously been examined at a state population level.

Background: Electronic pathology (e-path) reporting is an essential data source for population-based cancer surveillance. Beginning in 2009, the Kentucky Cancer Registry (KCR) enhanced its e-path reporting system to capture pre-invasive cervical cancers. Population-based surveillance of both pre-invasive and invasive conditions has empowered the registry to answer important questions about the epidemiology of cervical cancer in Kentucky.

Purpose: This study was designed to assess the feasibility of electronic surveillance methods to capture population-based pre-invasive cervical cancers in Kentucky.

Methods: The KCR expanded and enhanced traditional e-path reporting infrastructures to report pre-invasive cervical cancers, defined as CIN-3 or AIS. Additional laboratories were targeted for new e-path reporting. Filtering algorithms in software applications were modified to include pre-invasive cervical cancers for transport to the registry using NAACCR HL7 standards. A specialized data management system was developed to abstract and maintain pre-invasive cases.

Results: The KCR successfully achieved population-based surveillance of pre-invasive cervical cancers. Approximately 1,400 new cases of pre-invasive cervical cancer and 200 new cases of invasive cervical cancer are reported annually in Kentucky. Data have shown that increasing age, black race, histologic cell type of adenocarcinoma, residence in a metropolitan county, lower county education and higher county poverty are independently associated with an increased odds of invasive diagnosis. Adenocarcinoma histology has emerged as the most significant factor. These findings have led to further exploration of the role of HPV genotypes in this phenomenon.

Conclusions: This study has shown that electronic reporting methods can be developed to achieve population-based surveillance of histologically confirmed lesions such as pre-invasive cervical cancers. We have shown that this informatics approach can empower registries to conduct epidemiological research that would not otherwise be feasible.
THE LAST FRONTIER: TRUE MODERNIZATION OF A CANCER REGISTRY’S ELECTRONIC COMMUNICATION

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Background: The Cancer Registry of Greater California (CRGC) distributes facility quality and completeness reports every other month. Each facility receives a Completeness, Timeliness, and Quality (CTQ) report and a Visual Editing report. The process the CRGC utilized required approximately 40 hours to distribute to all facilities and required the use of four separate programs. Over the period of one year, a total of 240 hours was expended distributing these reports. A true electronic solution was needed that would significantly reduce the amount of human interaction.

Methodology: The CRGC needed a solution that would be simple to use with minimal manual involvement. The CRGC examined several options and chose the software Go Anywhere. This system was programmed by CRGC IT staff to read the PDF files containing the reports and automatically create individual folders for each reporting facility and automatically place the PDF reports into the appropriate folder.

Result: This solution resulted in a savings of 239 hours a year and nearly $10,000. The process that once took approximately 40 hours every other month is now performed in less than five minutes. This program is now being expanded to handle incoming transmit files, transmit/upload logs, and other routine distributions.

Conclusion: Moving to an electronic platform is not enough if the electronic solution requires the same amount of human interaction as the paper solution. When moving a manual process to an all electronic solution the actual process must be evaluated and the only way to make the electronic solution worthwhile is to choose a solution where the resulting process utilizes little to no human intervention. The CRGC has benefitted greatly with the development of this system and while it was designed to resolve one problem, it has streamlined several monthly processes resulting in even more cost savings.
063

BETTER COMMUNICATION STARTS WITH TEAM WORK
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Background: Operations management strategies of central cancer registries must incorporate new operational efficiencies, while utilizing current technology, security, telecommuting and communication practices, to optimize production and quality. Historically, the Metropolitan Detroit SEER registry operated as a hierarchical collective of job-defined units: Abstracting, Editing, Follow-up, IT. Abstracting staff collected data at specific facilities, while editors worked on cases from every facility and any abstractor. Systemic coding errors across multiple abstractors/editors were often missed until scheduled quality audits.

Method: Due to the large volume and complexity of cases for one health system, we developed a team comprised of five cancer registrars and two editors assigned to only edit and consolidate the information from this specific hospital network. We discovered that there was more communication and feedback to the cancer registrars and editors because of the combined efforts between the two groups. We evaluated remaining staff, 15 abstractors and 10 editors to see if we could create teams to generate better communication, feedback, and training among the staff. The process of developing the teams, issues faced once teams were created, and the meeting schedule set for the teams to meet as a group will all be outlined in the session.

Results: Five teams were organized. The editors were assigned 50% of the cases which resulted in even distribution of work. Phone calls and emails between abstractors and editors have resulted in better communication between both groups, as well as a new electronic follow back procedures were implemented for quicker communication regarding questions that the editors have from the abstractors. Information is back to the editor in days, instead of months. One on one review of abstracted cases have resulted because the staff now work together to provide quality data.

064

BENEFITS AND CHALLENGES OF GOING PAPERLESS: IMPLEMENTATION OF A DOCUMENT MANAGEMENT AND WORKFLOW SYSTEM
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As cancer registry efforts to automate data collection from pathology labs, medical doctor’s offices, and other facilities continue, some communications with facilities are not yet automated, and fall to a paper-based system. The purposes of this study were: (1) to optimize common tasks with facilities that involve communicating via paper documents, and (2) to better facilitate remote employees working collaboratively with on-site employees, while performing tasks involving paper communications with facilities. A high-level description of the methods follows:

1. Document current workflow: Document the current system for requesting / transferring data between the cancer registry and facilities.
2. Measure current workflow: Observe and record the amount of time required to perform specific registry tasks using traditional methods.
3. Collect qualitative data: Survey employees’ satisfaction with current system, concerns about switching to a paperless system, and perceived benefits of each system.
4. Implement a paperless office system combined with a workflow system, including training of remote and on-site employees.
5. Measure costs of implementing the paperless office system combined with a workflow system, including time spent training employees, and reduced productivity as employees gain familiarity with the new system.
6. Measure revised workflow: Observe and record the amount of time required to perform specific registry tasks using the paperless office system with workflow processing.
7. Collect qualitative data: Survey employees’ satisfaction with paperless office system combined with the workflow system.
8. Analyze data collected.

Data presented will include an analysis of time savings due to the paperless system, with graphs of worker productivity before and after the paperless system implementation. Analyses of the paperless system cost and employee survey qualitative data will also be included.
MEANINGFUL USE OF ELECTRONIC HEALTH RECORDS: ELECTRONIC PHYSICIAN REPORTING TO STATE CANCER REGISTRIES

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Background: In August 2012, the Centers for Medicare and Medicaid Services (CMS) published its final rule for Stage 2 of Meaningful Use (MU) of Electronic Health Records (EHRs). This final rule included an optional objective for ambulatory providers to report cancer cases to central cancer registries. Physicians began reporting to cancer registries on January 1, 2014. The MU Stage 3 rules are currently in development.

Purpose: To help registries implement MU processes and use lessons learned to make improvements for Stage 3.

Methods: CDC and NAACCR have worked collaboratively with the cancer registry community, EHR vendors, CMS, and other partners to prepare for and support successful implementation of electronic physician reporting to cancer registries.

Results: The physician reporting workgroup (WG) develops: 1) guidance documents; 2) use cases and business requirements to inform development of software for processing electronic reports; and 3) communication tools to help cancer registries implement MU cancer reporting, including guidance on the MU processes of onboarding and testing. The recently formed CDC-NPCR Meaningful Use Collaboration WG brings together states and certified EHR vendors to provide MU support by addressing specific implementation issues identified. CDC has used the requirements and issues identified by these WGs to enhance the software application, eMaRC Plus, that cancer registries can use to receive and process physician reports. CDC also developed and enhanced CDA Validation Plus, a tool to be used by EHR vendors, providers, and cancer registries to validate files for improved interoperability.

Conclusions: This presentation will describe the activities of CDC and the cancer registry community to prepare for and implement MU reporting. It will also report on progress to date and lessons learned since implementation began in January 2014, including how lessons learned were used to improve the Stage 3 rules.

Notes

066

NORTH CAROLINA CENTRAL CANCER REGISTRY (NCCCR) AND MEANINGFUL USE STAGE 2 CANCER REPORTING

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Cancer reporting from ambulatory providers to state cancer registries is a new public health objective for Stage 2 Meaningful Use. In Fall of 2013, the North Carolina Cancer Registry initiated this project in preparation of implementing MU2 cancer reporting from eligible professionals using certified EHR system. This presentation outlines the methods used by NCCCR to identify, recruit eligible professionals, steps taken to educate physicians to facilitate MU2 reporting, registration portal for EPs attestation with PHA, testing and validation, transport mechanism options, success and challenges, plans to manage EHR data repository at the cancer registry, tracking and monitoring reporting from multiple physicians and the consolidation of EHR data for integration into the cancer registry database.

Notes
067

MEANINGFUL USE STAGE 3: POTENTIAL IMPACT ON CENTRAL CANCER REGISTRIES

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Background: Many rural clinics and physician offices under-report or do not report their cancer cases. The Meaningful Use (MU) incentive program opened the door to increase cancer reporting from these locations. The Missouri Cancer Registry and Research Center, Missouri’s central cancer registry (CCR), received funding to implement electronic health record (EHR) reporting directly from clinic/physician offices (C/POs) into the CCR. The expectation was that MU Stage 2 would lead to greatly increased reporting by C/POs. However, some vendors were slow to develop a cancer reporting module while others decided not to develop one. In addition, delays were experienced in on-boarding C/POs wanting to attest to MU. Changes in public health reporting proposed for MU Stage 3 may impact cancer reporting.

Purpose: Assess how MU Stage 3 could impact cancer Stage 2 reporting criteria as well as factors that may determine whether a C/PO will continue with MU past Stage 2.

Methods: We participated in national workgroups to determine the impact MU Stage 3 will have on cancer reporting. We worked with certified MU Stage 2 EHR vendors to analyze and assess changes to cancer reporting stemming from Stage 3 requirements. We assessed impact on the CCR of additional data storage needed for Stage 2 and Stage 3 EHR data and estimated staffing needs and storage costs.

Results: By the end of 2014 the FCDS had a total of 14 practices and 21 physicians in the testing and onboarding phase of the program. A majority of these practices were in the specialty of dermatology. There were an additional 21 practices and 71 physicians registered that were not in the targeted FCDS physician specialty groups. Many of these practices consisted of general practitioners and other specialty groups. A year end evaluation process led to modifications to the MU2 registration and tracking system, and identified partnerships for validation studies. Major challenges included the length of time in the onboarding and testing process, number of critical errors on test messages, communication lag time between vendors and providers, and the high number of non-specialty registrations as compared to targeted specialties. The FCDS partnered with select providers to initiate validation projects of EHR reported data.

Conclusions/Discussion: Final MU Stage 3 rules will not be completed until 2015. Under MU Stage 2, cancer reporting was an option that providers could choose. Additional proposed requirements for MU Stage 3 could enhance cancer data to the point where social and behavioral factors may be used to determine cancer risk assessments. It is hoped that MU Stage 3 will require elements optional in Stage 2, but it is feared that some C/POs will drop or not select cancer reporting.

068

PUTTING IT INTO PRACTICE: CHALLENGES IMPLEMENTING MU2 IN FLORIDA

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Background: The Florida Cancer Data System (FCDS) declared readiness for Meaningful Use (MU) Stage 2 Cancer Reporting in December of 2013 and went live with the MU2 registration system in January of 2014.

Purpose: The implementation and evaluation of the MU2 Cancer Reporting Program in Florida provides a detailed look at the challenges, lessons learned, and successes of the program.

Methods: The FCDS developed an MU2-specific registration system with a built-in tracking and automated email confirmation system. Communications and procedure guidelines were developed under the guidance of NAACCR’s Physician Reporting Work Group. Staffing positions were established for the coordination and quality control of MU2 activities.

Results: By the end of 2014 the FCDS had a total of 14 practices and 21 physicians in the testing and onboarding phase of the program. A majority of these practices were in the specialty of dermatology. There were an additional 21 practices and 71 physicians registered that were not in the targeted FCDS physician specialty groups. Many of these practices consisted of general practitioners and other specialty groups. A year end evaluation process led to modifications to the MU2 registration and tracking system, and identified partnerships for validation studies. Major challenges included the length of time in the onboarding and testing process, number of critical errors on test messages, communication lag time between vendors and providers, and the high number of non-specialty registrations as compared to targeted specialties. The FCDS partnered with select providers to initiate validation projects of EHR reported data.

Conclusions: The MU2 cancer reporting program in Florida encountered many challenges but offered opportunities for collaboration and future success of physician reporting.
THE IMPACT OF THE “PRESUMED ALIVE” FOLLOW-UP METHOD ON SURVIVAL RATES BY RACE/ETHNICITY AND NATIONAL ORIGIN IN NEW YORK
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Background: A recent study found that the “presumed alive” method results in generally higher cancer survival rates among Hispanics and Asians than among whites and blacks, regardless of cancer site or stage (Pinheiro et al, JNCI, 2014). This difference was attributed to absent or incorrect social security numbers (SSNs), inconsistent use of surnames, and deaths occurring outside the U.S.

Methods: Following Pinheiro et al., age-standardized observed survival rates were calculated for the 2000-2008 period by race/ethnicity for common cancer sites and those with poor prognoses. The analysis was then extended to all foreign-born persons, stratified by country. To better ascertain the influence of missing SSNs on these results, we also examined the proportion of missing SSNs by race, ethnicity, and birthplace. These proportions were substantially reduced in 2014 as a result of comprehensive linkage efforts, so we compared pre-2014 and 2014 values.

Results: Survival rates in New York were comparable to those for non-Hispanic whites, slightly higher for non-Hispanic blacks and substantially higher for Hispanics and Asians compared to rates in SEER18 based on “presumed alive.” The largest differences were observed for stomach cancer (Hispanics) and liver cancer (Asians). Generally, survival was higher among foreign born, independent of race. Improvement in SSN completeness may actually serve to magnify disparities, as missing SSNs among whites were reduced by half, from 2% to 1%, but by less than half among Hispanics (9% to 5%) and Asians (10% to 7%).

Conclusions: The Hispanic and Asian survival advantages appear conditional on having been born outside the U.S. Comparable survival advantages were seen for other immigrants. Improvements in data systems will reduce the absolute bias in survival but could increase the relative bias between groups. Caution must be exercised when applying the “presumed alive” method.

CONSTRUCTING LIFE TABLES FOR GLOBAL SURVEILLANCE OF CANCER SURVIVAL: EXPERIENCE FROM THE CONCORD-2 STUDY
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Background: Life tables are needed to adjust for background mortality when estimating population-based net survival from cancer. Official life tables are usually only available at national level. Background mortality can vary widely within countries1, so it is important to use region-specific life tables in net survival analyses.

Purpose: To construct registry-specific life tables for global surveillance of cancer survival.

Methods: Over 6,500 life tables were constructed for the CONCORD-2 study2. The methods varied by type of source data. A multivariable flexible modelling approach was used to construct life tables from raw death and population counts by age, sex, race (US), state/province and calendar year for 172 of 279 participating registries, including all 57 in North America.

Results: Life expectancy in the 279 registry populations varied widely. In North America it ranged from 68 to 79 years in males and 73 to 83 years in females in 2007. The impact on net survival estimates of using region-specific vs. national life tables will be presented in the context of the North American cancer registries.

Implications: The large range in background mortality, observed worldwide and within North America, emphasizes the relevance of using registry-specific life tables in geographic comparisons of net survival. The modelling approach performs well, even with scant data. Improvements to source data quality and accessibility are needed in low, middle and high income countries alike.

References
MULTIPLE MEDIATION ANALYSIS WITH SURVIVAL DATA: AN APPLICATION TO ANALYZE RACIAL DISPARITY IN STAGE III COLON CANCER SURVIVAL

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Background: Mediation analysis with continuous and discrete outcomes is well established and broadly used in many research fields. However, studies on mediation with survival data are limited; particularly in multiple mediator settings.

Objective: To develop and apply a statistical method for assessing the effects contributed by mediators on racial disparity in stage III colon cancer survival.

Methods: We used the semiparametric additive hazards model to estimate the risk of death for patients with stage III colon cancer. This methodology measures the total effect (TE) and direct effect (DE) of race, and indirect effects (IEs) from potential mediators as well as their corresponding relative effects (REs). The RE was defined as a ratio of IE to TE. Stage III colon cancer data diagnosed 1996-2008 were obtained from the Louisiana Tumor Registry. Patients were followed through December 31, 2012. The exposure variable is race (blacks, whites). Potential mediators included age, SES, marital status, insurance status, and colon subsite. Stage (IIIA, IIIB, IIIC), grade, status of multiple tumor (yes, no), type of surgery, adjuvant chemotherapy, number of lymph node (LN) examined, and number of LN positive are covariates.

Results: A total of 4,137 stage III colon cancer patients were included. Of those potential mediators, only SES, marital status and age had a significant mediation effect (indirect effect) on the racial disparity in survival (p<0.05) with REs = 44.6%, 21.5% and -38.6%, respectively. The direct effect from race became insignificant after controlling for mediators.

Conclusions: The majority of racial differences in colon cancer survival were explained by patient’s SES. Age at diagnosis appeared to be a suppression factor, because blacks were more likely to be diagnosed at younger age that had an average longer survival. Insignificant direct effect indicated that racial disparity in colon cancer survival can be explained by those mediators.
**073 USING ENHANCED REGISTRY DATA FOR CLINICAL MANAGEMENT AND CANCER CARE**

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**Background:** Historically, population-based cancer registry data were used to describe cancer burden, trends and survival. Despite increasing clinical data collected in recent years, their use by clinicians has been limited.

**Purpose:** We illustrate how enhanced cancer registry data can be used for NCCN guideline clinical management and care in 2 projects: Lynch Syndrome (LS) screening among young colorectal cancer (CRC) patients by microsatellite instability (MSI) and its impact on colon resection decision. Testing of biomarkers to classify breast cancer molecular subtypes and assess treatment.

**Methods:** Louisiana 2011 data from the CDC NPCR’s Comparative Effectiveness Research (CER) Project were used. CRC patients aged ≤50 were reviewed for MSI and IHC testing and timing of available results. Breast cancer patients with unknown subtype and treatment inconsistent with guideline recommendations were examined. Chi square test, univariate and multivariate analyses were employed.

**Results:** Among 274 CRC patients age ≤50, MSI and/or IHC testing was performed in only 23% of patients. Screening was associated significantly (p<.05) with CRC family history, urban location and cancer center care but low (p<.03) at public hospitals. Of those tested, abnormal MSI/IHC was seen in 22% with the majority (88%) showing abnormal patterns consistent with LS. Results were available preoperatively in only 17% of cases. Breast cancer molecular subtypes could not be determined in about 12% of 3,818 patients due to unknown ER/PR/HER2 status. Among patients with known receptors, 0.5% to 7% received therapies contradictory to receptor status and 10%-23% received no recommended systemic adjuvant treatment.

**Conclusion/Implication:** These findings were presented at professional conferences and published in a peer-reviewed clinical journal in 2014. They are informative, receptive to clinicians and have drawn clinical media attention. Registry data have great potential use in managing cancer care.

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**074 VARIATION IN STAGING AND TREATMENT OF RECTAL CANCER BY NATIONAL CANCER INSTITUTE (NCI) DESIGNATION AND MEDICAL SCHOOL AFFILIATION: ANALYSIS OF SURVEILLANCE, EPIDEMIOLOGY AND END RESULTS (SEER)-MEDICARE DATA**

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**Background:** Evidence suggests high-volume facilities achieve better rectal cancer outcomes compared to low-volume facilities. Better adherence to guideline-recommended staging and treatment may be a contributing factor. Our objective was to evaluate the impact of institutional characteristics on performance of guideline-recommended staging and neoadjuvant treatment of stage II/III rectal cancer.

**Methods:** Included were Medicare beneficiaries in SEER regions diagnosed with stage II/III rectal adenocarcinoma at age ≥66 years from 2005-09 and had Parts A/B Medicare coverage for >1 year pre- and post-diagnosis plus a claim for cancer-directed surgery. Institutions were classified according to National Cancer Institute (NCI)-designation, presence of a residency program, or medical school affiliation of the treating facility. Logistic regression was used to evaluate association of facility type with staging/treatment received after controlling for patient demographics, stage and comorbidities.

**Results:** 2,300 subjects (average age=75) met criteria. Compared to patients treated at facilities without NCI designations, greater proportions of those treated at NCI-designated facilities received recommended transrectal ultrasound (TRUS) or magnetic resonance imaging (MRI) of the pelvis (61% vs. 29%), neoadjuvant chemotherapy (65% vs. 41%), and radiation (72% vs. 46%) (all p<.0001). On multivariate analysis, odds ratios (95% confidence intervals) for receiving TRUS or MRI-pelvis, neoadjuvant chemotherapy, or neoadjuvant radiation among beneficiaries treated at NCI-designated facilities were 3.51 (CI: 2.60, 4.73), 2.32 (1.71, 3.16), and 2.66 (1.93, 3.67), respectively. Results by residency and medical school affiliation were similar.

**Conclusions:** Those treated at hospitals with an NCI-designation, residency program, or medical school affiliation received more guideline-concordant care. Initiatives involving provider education or virtual tumor boards may improve care.
075

PREVALENCE AND CHARACTERISTICS OF CANCER PATIENTS SEEKING CARE FROM MULTIPLE FACILITIES, SAN FRANCISCO BAY AREA OF CALIFORNIA, 2010-11
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Cancer patients may be seen at multiple hospitals for the same cancer to seek second opinions, receive different care, enhance geographic proximity, or accommodate changed insurance coverage. Little has been reported regarding the number of facilities where cancer patients receive cancer care. Therefore, in 9-county California population-based cancer registry data, we assessed the prevalence and characteristics of patients seen for their cancer by number of facilities in 1/1/2010-12/31/2012.

All registry reports for the same cancer patient within 365 days after the first were grouped into 4 mutually exclusive categories: 1) from a single membership-based institution or integrated health system known to share medical records (e.g., Kaiser Permanente, Veterans Affairs); 2) from membership-based and ≥ 1 non-membership-based facilities (e.g., private or public hospital or private physician office); 3) from a single, non-membership based institution and; 4) from ≥ 2 non-membership-based facilities.

Patients diagnosed by death certificate were excluded. We found that 31% of patients were ever reported by a membership-based facility; of these, 7% were reported by both a membership and non-membership based institution. Of patients never reported by any membership-based institution, 26% were reported by multiple facilities, with higher proportions for those with pancreas (35%) than prostate cancer (20%). Most patients reported by ≥ 2 facilities were diagnosed at one but treated at another; but some were treated at ≥ 2. After multivariable assessment, patients most likely to be seen at multiple facilities were younger and had later stage at diagnosis, with no clear associations with race/ethnicity, neighborhood socioeconomic status, or insurance type.

The prevalence of cancer patients seen at multiple hospitals is substantial, and future clinical studies of cancer care and outcomes should account for care received at all health care systems utilized.

076

QUALITY OF CARE AND OUTCOMES AMONG CANCER PATIENTS IN CALIFORNIA ACCORDING TO SOURCE OF HEALTH INSURANCE
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Background: Approximately $260 billion is spent annually in the U.S. diagnosing and treating cancer. Aging of the population, rising life expectancy, and increased population obesity, among other things, will substantially increase these costs in coming years. Despite generally improved cancer treatment, population disparities in the quality of cancer treatment and survival according to source of health insurance have been previously found.

Purpose: This study sought to evaluate differences in stage at diagnosis, quality of treatment and survival among cancer patients in California according to type of health insurance.

Methods: Persons with a diagnosis of breast, lung, colon, rectum, or prostate cancer during the period 2004-2012 were identified in the California Cancer Registry. Descriptive statistics on stage at diagnosis and 5-year relative survival by insurance coverage were generated. Cancer treatment across categories of insurance coverage was evaluated using the Commission on Cancer quality measures.

Results: Persons insured by Medicaid at the time of diagnosis were more likely to be diagnosed at later stages across all five cancer types. Approximately 25% of Medicaid members with breast cancer were diagnosed at late stage compared to 11% of patients having private insurance. Medicaid members also had poorer survival than patients with private insurance across all cancer types. Higher proportions of persons with breast, colon, and rectal cancer having VA insurance received recommended treatment compared to those with other types of insurance.

Conclusions: Significant differences exist in stage at diagnosis, treatment and survival among cancer patients in California according to their source of insurance coverage. The analysis was limited by the variable quality of payer source information in the CCR. These findings will be further examined through linkage with Medicaid enrollment files.
INCREASING TRENDS OF KIDNEY AND RENAL PELVIS CANCER IN CALIFORNIA
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Background: The incidence of kidney cancer (KC) in California has increased markedly over the past 2 decades, although mortality rates have largely remained stable. Primary risk factors for KC include smoking, obesity, hypertension, and long-term dialysis. Changes in the population prevalence of primary risk factors for KC and improved sensitivity or greater utilization of diagnostic tests could explain the increased incidence of the disease.

Purpose: This study sought to examine trends and possible reasons for the rising incidence of KC in California.

Methods: Joinpoint KC incidence trends from 1988-2011 were estimated by sex, race/ethnicity, and stage at diagnosis. Trends in the prevalence of tobacco use, obesity, and high blood pressure in California were obtained from CDC’s BRFSS data. Literature review was conducted to evaluate the use of imaging tests.

Results: KC incidence in California increased since 1988 in both sexes and among all racial/ethnic groups by 42% in the past decade only. Survey data show that while smoking has declined sharply in California since 1988, the prevalence of obesity increased from 15.1% to 24.7%, and hypertension from 22.1% to 25.7%, between 1995 and 2010. The increase in KC incidence has been limited largely to localized tumors, which increased significantly by 3.1% per year until 2000 and by 7.6% per year until 2008. Incidence of regional stage disease increased by 1.2% after 1995, and metastatic cases did not increase. Use of MRI, CT, and nuclear medicine diagnostic methods has increased by several fold since 1988.

Conclusion: While an increase in population obesity may account for some of the rising incidence of kidney cancer, the fact that the majority of the increase in reported cases is accounted for by early-stage disease suggests that the increased incidence of kidney cancer in California is largely attributable to greater utilization of advanced diagnostic imaging methods and earlier diagnosis of tumors.

TRENDS IN EARLY STAGE HEPATOCellular CARCINOMA, CALIFORNIA 1988-2011
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Background: California Cancer Registry (CCR) data are being used to explore the impact of hepatocellular carcinoma (HCC) surveillance on patient outcomes. HCC is the second leading cause of cancer-related mortality worldwide and rates are increasing in the United States. The incidence has tripled since the 1980s and prognosis is generally dismal with a 5-year survival of 12% or less. The purpose of this analysis was to determine the trend in diagnosis of early stage HCC in California from 1988-2011.

Methods: Patients 20+ years old, diagnosed with stage I or II HCC during 1988-2011 in California were included. Four race/ethnic groups were created; non-Hispanic White, Hispanic, non-Hispanic Black, non-Hispanic Asian/Pacific Islander (Asian/PI). An additional analysis included Asian subgroups. Stratified proportions of early HCC were evaluated to estimate any trends and significant disparities.

Results: A total of 15,529 patients were diagnosed with early HCC. The proportion of patients diagnosed at an early stage increased from 19.1% to 52.1% between 1988 and 2011, at an average rate per year of 5.7% from 1988-2001 and then 2.5% from 2001-2011. The increase was most pronounced among Asian/PIs where proportion rose from 15.8% in 1988 to 55.1% in 2011. Early HCC was highest among patients 65+ years old increasing from 7% per year during 1988 and 1995 and then 3.4% per year during 1995 and 2011. The proportion increased in both males and females from 1988-2011, but at slightly less dramatic increase in more recent years.

Conclusions: The proportion of patients diagnosed with early HCC disease has increased steadily since 1988. However, the rate of increase has slowed in the past few years. It is not entirely clear whether better diagnostic imaging or better surveillance has led to these findings and whether earlier diagnosis has led to improved patient survival.
079

BREAST CANCER AMONG THE U.S. MALE POPULATION
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Background: Most studies of breast cancer focus on the female population, with very few focusing on the male population. The incidence of male breast cancer (MBC) continues to increase with a 13% change and a 0.17% per year change in the age-adjusted incidence rate from 1998-2011. However, because of its rarity, MBC remains an understudied disease. Most previous studies were based on limited data, and their results may not be generalizable to the US.

Purpose: To analyze the more than 27,000 cases of breast cancer among the US male population for 1998-2012, which will be the most current data available.

Methods: MBC demographic characteristics (including US Census region and economic status), stage at diagnosis, histologic type, biomarkers, treatment, and survival will be evaluated and presented using the most recent data at the national level. All proposed characteristics will be compared with those found among the female population.

Results: Preliminary results show that 54% of MBC are diagnosed at an early stage compared to 68% of female breast cancer (FBC) cases. Mastectomies were performed in 66% of MBC compared to 37% FBC. Survival rates are similar, though MBC has a lower rate compared to FBC; 85% and 89%, respectively.

Conclusions: Preliminary results show differences in cancer characteristics for MBC compared to FBC. The preliminary results of this analysis show that a detailed analysis of cancer characteristics in MBC is possible using this dataset. Additional analyses will be completed to further explore MBC and its differences with FBC.

080

STOMACH CANCER IN NORTH AMERICA: GEOGRAPHIC VARIATION IN NET SURVIVAL BY AGE AND SEX
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Background: CONCORD-2 study results showed that five-year age-standardized net survival for stomach cancer patients diagnosed during 2005-09 was 25% in Canada and 29% in the US (pooled data for 44 states). Survival varies widely with age at diagnosis, so reliable estimates of survival by age and sex are valuable for both patients and clinicians. Geographic variation of survival by age and sex should provide insights into differential patterns of care.

Purpose: To describe the geographic distribution of age- and sex-specific net survival in Canada and the US for stomach cancer patients diagnosed during 2005-09.

Data and Methods: Data on 101,924 adults (15-99 years) diagnosed with stomach cancer during 2005-09 were submitted by 12 Canadian provinces and territories and by 44 US states. Standardized quality-control procedures were applied to all data sets. We estimated age- and sex- specific five-year net survival using the non-parametric Pohar-Perme estimator. Single-year-of-age life tables by sex, state/province, calendar year and race (in the US) were used to correct for background mortality.

Results: We will present comparative data on major quality control indicators, such as the proportion of patients registered solely on the basis of a death certificate, for each state in the US and province in Canada. We will present the variation in five-year net survival by sex and age group (15-44; 45-54; 55-64; 65-74; 75-99 years) in the 56 participating jurisdictions in Canada and the US.

Implications: Inequalities in sex- and age-specific net survival offer the potential to improve survival by targeting specific groups of the cancer population.
081

PLANS FOR MULTI-RACE REPORTING OF DEATH DATA
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Since 2000, the Census Bureau has reported population data using multiple race categories. The NCHS developed a method to “bridge” Census Bureau data with multiple race groups into the traditional five single race categories to use for disease incidence and mortality reporting. Since 2003, the U.S. standard death certificate has allowed for the recording of multiple race categories. Over the last ten years, U.S. vital statistics offices have implemented the 2003 death certificate standard and have been reporting multiple race categories. This presentation will share data on the degree of multiple race reporting in the mortality file and will describe NCHS plans to begin reporting mortality data using multiple race categories in our 2015 reports. NCHS plans to continue to do race bridging for at least a few years beyond 2015 so as to be able to assess the effects of the change. The bridged data will be used for analysis purposes, but will not be included in our official publications. Once the multi-race reporting has been established, NCHS plans to stop providing bridge race population data.

082

FEASIBILITY OF MULTI-RACE REPORTING FOR CANCER INCIDENCE
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The NCHS has provided bridged race group populations since the Census began reporting data using multiple race categories in 2000. These bridged populations are used as the denominator for cancer rate reporting. NCHS is planning to begin reporting data using multiple race categories in 2015 and to discontinue generation of bridged populations. This presentation looks at the feasibility of converting to multiple race reporting for cancer incidence data. The NAACCR reporting standard includes fields for up to five different races for each record. We first provide a summary of the use of these fields in current SEER incidence data, including the variation in multi-race reporting by year, registry, age group, vital status, and reporting source. We then discuss the availability of multiple race information in medical records and EHR systems. Finally, we describe possible implications for cancer rate and trend reporting.
SECTION A: ISSUES OF RACE

083

STATISTICAL ISSUES OF BRIDGING SINGLE-RACE AND MULTIPLE-RACE REPORTS IN THE POPULATION DATA

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In compliance with the revised federal policies on collecting race data, the US 2000 census, which provides denominators used in calculating vital and disease incidence rates, allowed multiple-race responses. Despite the recent compliance efforts, the quality of multiple-race numerator data, for example, in vital statistics and cancer surveillance systems, has yet to be improved to be used in calculating rates. This presentation looks at the statistical challenges and solutions to bridging the denominators to single-race categories and its implications on cancer health disparities research. We first reviews the statistical methods used by the National Center for Health Statistics (NCHS) to bridge county level population estimates. We then introduce and evaluate a race bridging approach that the National Cancer Institute (NCI) has developed to bridge the census tract level population estimates. The bridged census tract data are calibrated to the NCHS county level estimates, so that the aggregated rates are consistent to those as if the NCHS estimates were used. We finally demonstrate the gain in accuracy in estimating cancer health disparities using census tract socioeconomic attributes compared to that using their county counterparts.

084

CLARIFYING RACE REPORTING IN NEW JERSEY

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Background: Although there are inconsistencies in reporting, race remains an essential component of central cancer registry data collection and cancer surveillance reporting. The NAACCR Race and Ethnicity Identifier Assessment Project confirmed the importance of publishing cancer rates by race and ethnicity.1 The amount of tumors reported with an unknown race is increasing. Not only does a high percentage of unknown race impact race-specific estimates, it directly effects studies that are being conducted by race, especially those using rapid case ascertainment (RCA).

Purpose: The aim of this analysis was to characterize the cases that are being reported and the facilities reporting to the New Jersey State Cancer Registry (NJSCR) with unknown race.

Methods: We identified incident cancer tumors (CTCs) diagnosed in 2012 that were reported initially with Race=99/unknown. Univariate analyses were conducted for patient, tumor, and reporting characteristics.

Results: The records with unknown race were 57.4% male and spread evenly throughout NJ with the highest proportion in the metropolitan region (25.5%). Records submitted for prostate (22.9%), melanoma (22.9%), and breast (10.4%) tumors had the highest frequency of unknown race. Most CTCs (89.1%) were first instances of cancer (seq=00). After normal case processing, race could not be updated on 25.2%. Of facilities submitting records with unknown race, approximately 29.1% were New Jersey based hospitals and 25.7% from out-of-state facilities.

Conclusions: Researchers using prostate, melanoma, or breast tumors should consider the high proportion of unknown race data. Clearly, all reporting facilities should be educated on the importance of identifying race when reporting cancer. Classifying race promotes optimal health outcomes, and permits accurate race-specific counts that can assist in prioritizing resources.

AUTOMATING THE MULTIPLE PRIMARY RULES

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Background: It is critically important to population based cancer registries to accurately count the number of reportable diagnoses in the resident patient population. The Surveillance, Epidemiology and End Results (SEER) Program of the National Cancer Institute established the SEER Multiple Primary Rules for solid tumors and the SEER Hematopoietic and Lymphoid Neoplasm Database for accurately identifying and consistently counting cancer cases. The Kentucky Cancer Registry (KCR) was interested using these tools for refining its automated tumor linkage routines.

Purpose: Automating the SEER multiple primary rules was undertaken to more accurately and efficiently link reports being merged into the central registry database.

Methods: KCR software developers examined and developed ways to automate the SEER MP rules for both solid and hematopoietic malignancies. New routines were tested using the KCR central registry consolidated records, as well as source records from reporting facilities. Tests were conducted to identify overcounting (two primaries entered when only one should have been) as well as undercounting (multiple source reports were consolidated into one primary when they should have been two).

Results: Results from the tests to identify overcounting include the total records reviewed with the automated MP rules, the number of potential duplicate primaries identified, and number of actual duplicates found by an experienced CTR performing manual review. The tests for undercounting have been harder to develop and assess but continuing efforts are underway to produce quantifiable results.

Conclusions: KCR successfully identified and eliminated duplicates using the new routines. More testing will allow measurement of time savings gained by using the new routines for record processing. It is expected that implementation of these processes will streamline tumor linkage and make it more consistent with SEER coding instructions.

REAL TIME DISCRETE DATA ELEMENTS FROM SYNOPTIC RADILOGY REPORTS TO ENHANCE CANCER REGISTRY OPERATIONS

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Background: Ontario Cancer registry (OCR) data currently includes hospital source only cases. OCR performed an audit in late 1990s which identified that there is over-registration of cancer cases as opposed to under-registration of cases. Over registration negatively impacts system level cost estimates and population based studies, and this could be avoided by having other data sources in the registry to confirm the diagnosis.

Purpose: We have identified key benefits for clinician accessible pathologic and radiologic data from synoptic reports. Right time, right place accessibility to this data will increase the quality of cancer registry data, as the case will be ascertained by more than one source. A common structured data format will enhance usability and data integrity for cancer registry research and surveillance. The purpose of the project is to identify the key benefits that radiology reports will have on cancer registry data collection.

Approach: The CCO Synoptic Radiology Reporting Project has road mapped the deployment of synoptic reporting for cancer imaging in Ontario. CCO is deploying a three phased, five work stream approach to this project:
1. Clinical Content Standardization
2. Development of Technical Standards for Clinical Interoperability
3. Change Management
4. Infrastructure
5. Data-enabled Quality Initiatives

Results: We will present benefits of adding radiology as a source of cancer registry operations and the impact it will have on patient care. This will be a collaborative effort including stakeholders like College of American Pathologists and Radiologic Society of North America, Ontario radiologists and others.

Implications: Ensuring there are two or more source records to confirm cases in the OCR has a direct impact on how the cancer care system uses cancer registry data, including surveillance and research.
COMPARING A STANDARD (NAACCR VOLUME V) WITH A DRAFT STANDARD (HL7 VERSION 2.5.1 IMPLEMENTATION GUIDE: ELR REPORTING TO PUBLIC HEALTH, RELEASE 2)

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Background: In May 2014 the HL7 organization published a “Draft Standard for Trial Use” (DSTU) implementation guide (IG) that may influence how cancer registries receive and process pathology laboratory data. Here referred to as ‘the Draft Standard.’ The HL7 Version 2.5.1 IG for Electronic Laboratory Reporting (ELR) to Public Health, DSTU, Release 2 (US Realm), “merges constraints and elements necessary for laboratory reporting to public health” with an already established laboratory HL7 IG. The intent of a DSTU is to gather comments from the field to be used towards a future and final standard.

Purpose: Central cancer registries tend to rely on the infrastructure that comes with the Public Health Information Network (PHIN) supported systems, and they leverage ELR implementations of many laboratory systems. Changes proposed in the Draft Standard may have implications for the NAACCR community, IGs that require stakeholders to implement different messaging interfaces could be costly and negatively impact standardization of cancer reporting. Therefore, a gap analysis was needed.

Approach: A task force (TF) was formed representing various organizations: central cancer registries (U.S. and Canada); vendors; Centers for Disease Control and Prevention, National Program of Cancer Registries; the Surveillance, Epidemiology, and End Results Program, and including an independent HL7 expert. The TF compared NAACCR’s current standard for electronic pathology laboratory reporting with the Draft Standard.

Results: The comparison document, a work in progress, lists differences between the current standard and the Draft Standard (e.g., data types, formats, and values), and provides suggestions to resolve the differences.

Conclusions: This analysis will be of use to all central registries utilizing the current standard, and especially to cancer registries operating within PHIN supported systems. Expected completion date for the document is late spring 2015.

USE OF INTEGRATING THE HEALTHCARE ENTERPRISE (IHE) STANDARDIZED DATA CAPTURE (SDC) CONTENT PROFILE TO EXCHANGE STANDARDIZED DATA BETWEEN CLINICAL CARE AND CANCER REGISTRIES.

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Background: As adoption of Electronic Health Record (EHR) systems increases in the United States, healthcare organizations and providers are collecting more information at varying levels of detail. Over the past year, the Office of the National Coordinator (ONC) Standards & Interoperability Framework Structured Data Capture (SDC) initiative developed use cases, identified national standards for the structure of common data elements and form model definition, developed guidance to assist in implementation, and conducted pilots for evaluation of SDC. This work was used to develop the Integrating the Healthcare Enterprise (IHE) SDC Profile to enable an EHR system or other application to retrieve a data collection form from a form repository and submit data to entities based on the completed form.

Purpose: The purpose of this project was to test use of SDC Profile for standard data exchange from clinical care to cancer registries, as defined in the College of American Pathologists (CAP) Cancer Protocols, the CAP Biomarker Reporting Templates, and the Meaningful Use Stage 2 Physician Reporting to Cancer Registries Implementation Guide.

Methods: Staff from Centers for Disease Control and Prevention (CDC), CAP, ONC, Agency for Healthcare Research and Quality (AHRQ), National Cancer Institute (NCI), California Cancer Registry, and several EHR vendors collaborated to test use of SDC specification to exchange health data. Testing partners developed functionality in their systems.

Results: Each partner system was tested against the SDC Profile criteria at IHE Connectathon. Implementation benefits and challenges were documented and recommendations for improvement were made to ONC. Testing at IHE provided an opportunity to observe how the SDC profile could be implemented for cancer registries. The CDC eMaRC Plus and California Cancer Registry systems were further developed with prototype modules to receive standardized data using the SDC Profile.

Conclusion: This presentation will provide details about SDC Profile, describe how SDC Profile could assist cancer registries with capturing cancer data, and will provide results from IHE testing and Healthcare Information and Management Systems Society demonstration.
Lung Cancer Incidence in a Rural Montana County Undergoing Asbestos Screening, 2000-2008

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Background: In response to asbestos exposures from a vermiculite mine in Libby, Montana, the federal government funded screening for asbestos-related abnormalities in select portions of Lincoln County since 2000.

Purpose: To determine whether such screening is associated with diagnosis of lung cancer at earlier staging. A priori, we hypothesized that as a consequence of asbestos screening, lung cancer would be detected earlier among screening participants compared to Lincoln Co. residents who were not screened and residents of other Montana counties.

Methods: Screening program participants (n=8,043) from the period 2000-2008 were linked to data from the Montana Central Tumor Registry. Participants with lung cancer were compared with other Lincoln county lung cancer cases and with cases from other Montana counties by stage, age, and sex.

Results: The proportion of lung cancer cases diagnosed at local stage was greater among screening participants compared to those of both other Lincoln Co. residents and other Montana counties (31.6% [n=6] vs. 15.5% [n=22] and 16.7% [n=1,088], respectively). Conversely, the proportion with unknown stage at diagnosis was zero among screening participants and 14.8% (n=21) and 12.0% (n=781) among other Lincoln Co. cases and other Montana counties, respectively. Differences in stage at diagnosis were statistically significant comparing screening participants to other Lincoln Co. cases (p=0.02) and to other Montana counties (p=0.03). Differences in age and sex were not statistically significant.

Conclusion: These results suggest one impact of the screening conducted in Libby is the detection of lung cancer at earlier stage. By extension, residents of rural Montana counties with an elevated risk of lung cancer may benefit from access to similar screening chest radiography.

Investigation of a Possible Link Between Pollution from WWII Military Facilities and Cancer in Yakutat, Alaska

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The Alaska Cancer Registry (ACR) periodically conducts cancer studies for communities that have concerns about their cancer rates. In June 2014, ACR was contacted by CDC’s Agency for Toxic Substances and Disease Registry (ATSDR) on behalf of the Yakutat Tlingit Tribe to perform a cancer study of the community of Yakutat.

Yakutat is an isolated community located on the northern part of the Alaska panhandle with a population that is about 43% Alaska Native. The nearby Ankau Saltchucks is a peninsula estuary that has been traditionally used as a source of subsistence food for the Yakutat community. It was also used as a U.S. military site in the 1940s during WWII and by several federal government agencies through the 1970s. The community has expressed concerns about apparent elevated rates of illnesses, including cancer, and that they may be caused by wastes left behind from the former military installations. The area has undergone environmental investigations since about 2003.

The community established a Culture Camp on the peninsula at an old military garrison site in 1985 to teach children about traditional Tlingit lifestyles. It operated during the summers until 2003 when the community closed it due to healthcare concerns.

ACR generated three reports as a result of this study. The first report used the Standard Incidence Ratio (SIR) to evaluate the number of observed cancer incidence cases and the number of expected cases over the time period 1996-2011. The second report was similar to the first but used the Standard Mortality Ratio (SMR) to evaluate cancer deaths. The third report evaluated the annual number and types of cancers in the community for incidence and mortality. The study concluded that there were no increases in cancer for the community. As a result of the study, the Yakutat Tlingit Tribe leaders decided to shift their focus from trying to find causes of their community’s cancers to screening and early detection of cancer in the community.
CONFIDENCE INTERVALS FOR RATE RATIOS BETWEEN GEOGRAPHIC UNITS
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Ratios of age-adjusted rates between a set of geographic units and the overall area are of interest to the general public and to policy stakeholders. These ratios are correlated due to two reasons – the first being that each region is a component of the overall area and hence there is an overlap between them; and the second in that there is spatial autocorrelation between the regions. Existing methods in calculating the confidence intervals of rate ratios take into account the first source of correlation. This paper addresses spatial autocorrelation, along with the correlation due to area overlap, in the rate ratio variance and confidence interval calculations. The proposed method divides the rate ratio variances into three components, representing no correlation, overlap correlation, and spatial autocorrelation, representatively. Results with simulated and real cancer mortality and incidence data show that with increasing strength and scales in spatial autocorrelation, the proposed method leads to substantial improvements over existing methods. If the data do not show spatial autocorrelation, the proposed method performs as well as existing methods. The calculations are relatively easy to implement, and we recommend using this new method to calculate rate ratio confidence intervals in all cases.

MODEL-BASED SMALL AREA ESTIMATION FOR CANCER SCREENING AND SMOKING RELATED BEHAVIORS
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Background: National health surveys, such as the National Health Interview Survey (NHIS), the Behavioral Risk Factor Surveillance System (BRFSS), and the Tobacco Use Supplement to the Current Population Survey (TUS-CPS), have been used to collect data on cancer screening and smoking related measures in the U.S. noninstitutionalized population. These surveys are designed to produce reliable estimates for the national and/or state level. However, policy makers, cancer control planners and researchers often need county level data for cancer surveillance and related research. In such case, model-based small area estimation (SAE) techniques have to be used to provide estimates with adequate precision.

Purpose of the Study: This study introduces the SAE concept and reviews several SAE research projects conducted at the National Cancer Institute (NCI).

Methods/Approach: In all projects, Bayesian methods are developed to combine information from one or two national surveys and the relevant sources such as census, administrative records, or related census and generate estimates with increased precision.

Results: State and county level estimates for a number of outcomes (current and ever smoking prevalence, mammography and pap smear screening rates, rates of workplace and home smoking bans, etc) at different time periods are produced.

Conclusions: The model-based SAE techniques represent an effective means of generating estimates where there is small (or zero) state or county sample. The SAE results, which are released and disseminated at several NCI’s websites including the state cancer profiles website and the Surveillance, Epidemiology, and End Results (SEER) data base, provide a useful resource for the broad cancer surveillance society to fulfill multiple needs.
NONCLINICAL FACTORS ASSOCIATED WITH PREMATURE TERMINATION OF ADJUVANT CHEMOTHERAPY FOR STAGE I-III BREAST CANCER

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Background: Premature termination of adjuvant chemotherapy may lead to an adverse impact on prognosis of breast cancer patients. Population-based patterns of care studies have not examined factors associated with its occurrence due to difficulties in collecting such data.

**Purpose:** The objective of this study is to examine the association of nonclinical factors with premature termination of adjuvant chemotherapy among stage I-III breast cancer patients.

**Methods:** Data on women diagnosed with stage I-III breast cancer in 2011 were obtained from a CDCs Comparative Effectiveness Research (CER) project including seven U.S. state cancer registries. Chemotherapy completion status was collected with information available through 12 months after diagnosis. Univariate analysis and multivariate logistic regression were employed in data analysis.

**Results:** Of 6,607 patients who received adjuvant chemotherapy, 23% terminated chemotherapy prematurely. Older age, Medicare only (or other public insurance only)/Medicaid insurance, and residence in a low education area were significantly associated with higher proportion of premature termination of chemotherapy without adjustment. After including all nonclinical factors (i.e., age, race/ethnicity, insurance, and poverty and education at census tract level) and clinical factors (i.e., comorbidity, lymph nodes, tumor size, and grade) in the model, significant predictors of premature termination of chemotherapy included Medicare only (odd ratio [OR], 1.37; 95% CI, 1.13 to 1.65), Medicaid (OR, 1.48, 95% CI, 1.23 to 1.78), or no insurance (OR, 1.44, 95% CI, 1.09 to 1.91).

**Conclusion:** Medicare only, Medicaid, and no insurance are significantly associated with higher proportion of premature termination of chemotherapy even after controlling for clinical and nonclinical factors. More research is warrant to identify underlying cause of this association.

THE EFFECT OF COMORBIDITY ON THE USE OF ADJUVANT CHEMOTHERAPY AND TYPE OF REGIMEN FOR RESECTED STAGE III COLON CANCER PATIENTS

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Background: Post-surgical chemotherapy is guideline-recommended therapy for colon cancer patients with stage III disease. Factors associated with patients not receiving adjuvant chemotherapy were identified in numerous studies; comorbidity is recognized as an important factor besides patient’s age.

**Objectives:** To assess the association between comorbidity and the use of adjuvant chemotherapy and type of chemotherapy regimen.

**Methods:** Stage III colon cancer patients who underwent surgical resection were obtained from ten CDC-NPCR Specialized Registries which were participants of a Comparative Effectiveness Research (CER) project. Type of comorbidity included no comorbidity documented, Charlson and non-Charlson comorbidities. The impact of comorbidity on adjuvant chemotherapy use was assessed by multivariate logistic regression and association with type of chemotherapy agent by Pearson chi-square test.

**Results:** Of 3,275 patients with resected stage III colon cancer, 62% received adjuvant chemotherapy. Patients with any Charlson comorbidity were less likely to receive chemotherapy than those with non-Charlson comorbidity; however, after adjusting for other predictors only patients who had two or more or had moderate to severe Charlson comorbidities were significantly less likely to have chemotherapy (ORs 0.66 [95% CI, 0.49-0.88] and 0.59 [95% CI, 0.40-0.87], respectively). No significant association was found between Charlson comorbidity and no comorbidity documented. A significant positive association was noted between severity of comorbidity and single agent use (p<0.0001). Capecitabine and FOLFOX were the most common single and multi-agent regimen used among all types of comorbidity.

**Conclusion:** Type of comorbidity was significantly associated with receipt of guideline recommended chemotherapy and type of agent in stage III resected colon cancer patients. Personalized medicine to provide better care based on individual patient’s condition ought to be recognized.
“FIRST IN FLIGHT” OR “WHEN PIGS FLY” – CAN CANCER REGISTRIES PLAY A CRITICAL ROLE AT THE NATIONAL LEVEL IN STUDYING CANCER AS AN ADVERSE OUTCOME FROM DRUG TREATMENTS?
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Background: Patients, clinicians, the Food and Drug Administration, researchers and pharmaceutical manufacturers have a stake in knowing if specific treatments impact cancer development. Clinical trials have known limitations for studying cancer as an adverse outcome. Postapproval safety studies frequently provide the best opportunity to characterize the risk of cancer from treatments but can be limited due to challenges in case identification, exposure assessment and data sources. Lack of access to high-quality, national cancer outcome data that can be linked with treated populations is an unmet need for rare cancers.

Objective: Provide current examples of cancer signals under study in the postapproval setting at the national level, identify limitations and discuss how cancer registries may play a role.

Methods: We review public information, including FDA postmarketing commitments to study rare cancer outcomes in nononcological drugs to describe the nature of the medication exposure (e.g., by age, prevalence) and the outcome ascertainment method used (e.g., medical claim, cancer registry) to estimate the current gap to be filled through access to a national, linkable cancer registry, if one existed.

Results: We describe current examples of cancer signals under study, including the treatment indication, origin of the signal (preclinical, clinical, or postapproval), approved approach to identify cancer outcome, and strengths and limitations of the design.

Conclusions: Postmarketing drug safety studies require the ability to properly identify and classify cancer outcomes. These studies also rely on proper treatment exposure classification and risk window assessment due to uncertain periods of cancer induction and latency. Cancer registries could play a vital role at the national level through linkages with treated cohorts from postapproval registries and database studies to efficiently and accurately quantify cancer risk for existing and emerging drug treatments.

LONG-TERM CANCER SURVEILLANCE: FIVE-YEAR UPDATE FOR THE FORTEO PATIENT REGISTRY DATA LINKAGE STUDY
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Background: The Forteo Patient Registry is a voluntary prospective cohort study designed to estimate the incidence of osteosarcoma in patients taking teriparatide (Forteo). Adult patients residing in the United States (US) who provide consent and personal information through a simple, one-time enrollment process during a 10-year enrollment period will be linked with participating state cancer registries for 15 years to ascertain osteosarcoma cases diagnosed after patients started treatment. Due to the rarity of adult osteosarcoma (2.7 cases per million population), this study requires a large number of teriparatide users from across the US and participation by a large number of state cancer registries.

Objective: To provide a study update after 5+ years of patient enrollment and completion of 5 annual data linkages.

Methods: The Forteo Patient Registry was launched on July 23, 2009 and the first annual linkage occurred in August 2010. State cancer registries were enrolled into the study on an ongoing basis from 2009-2013. Patient enrollment will continue through September 2019 and cumulative annual linkages are planned through 2024.

Results: In 2009, cancer registries in all 50 states plus the District of Columbia were invited to participate. Cancer registry enrollment was completed in 2013 and a total of 41 state cancer registries, covering 92% of the US population aged 18 years and older, participated in the 5th annual linkage, completed in October 2014. As of September 30, 2014, 44,635 patients had enrolled in the Forteo Patient Registry. No matches were found during the first 5 annual linkages.

Conclusions: The registries did not find any incident cases of osteosarcoma among patients in the Forteo Patient Registry during the first 5 years of the linkage; however, our ability to draw conclusions about the incidence of osteosarcoma among teriparatide users is restricted due to the limited amount of follow-up time currently available.
INCREASING NON-HOSPITAL CANCER REPORTING: THE NEW HAMPSHIRE EXPERIENCE

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Background: Diagnosis and management of cancer is occurring more frequently in outpatient settings. This fact coupled with a national awareness that there may be inconsistent reporting by non-hospital (outpatient) entities prompted the NHSCR to formulate an outreach plan to focus on capturing the underreported cases. CDC-NPCR requires states to increase physician reporting by 10% each year for physician specialties, including Dermatology, Urology, Gastroenterology, Medical Oncology, as well as Surgery Centers, Nursing Homes and Hospice facilities.

Purpose: The intent of the project was to increase overall cancer reporting by non-hospital sources and meet NPCR’s standard of ten percent or more per year.

Methods: A letter detailing the importance of reporting cancer cases to the NH State Cancer Registry was sent to specialty practices in New Hampshire. During the initial phase, contact information was gathered and updated, as well as reporting methods, pathology reference labs, hospital affiliations and EHR utilization. Through discussions with each practice, we identified the preferred mode of reporting, and subsequently ensured cancer reporting was implemented by tracking physician reporting and performing on-site audits, beginning with the largest practices serving the state.

Results: Results have been positive, and everyone has been cooperative and willing to comply with cancer reporting, although detailed documentation of the legal requirements was occasionally required.

Discussion: We have experienced infrequent pushback and noncompliance. Perseverance, communication and education have proven helpful in these cases. We have continued with outreach including the dissemination of quarterly newsletters, educational talks to physician practice group meetings, and site visits for audit and educational purposes.

LOOKING FOR CASES IN ALL THE RIGHT PLACES

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Background: Researchers, public health planners, and physicians rely on the completeness and validity of registry data. NCI’s SEER program provides Data Quality Profile (DQP) markers each SEER registry is contractually obligated to meet. In early 2014, it became apparent that, for the first time in over 40 years, Utah Cancer Registry (UCR) was not going to meet the Completeness Estimate (CE) portion of the DQP for 2012 cases.

Purpose: UCR assessed ways to enhance case completeness and determined which sites affected the shortfall.

Methods: A nine step plan was developed. The steps included surveying dermatology and urology clinics to identify pathology labs that they worked with, sending abstractors to review pathology from non-registry hospitals, and reviewing thousands of accession numbers from hospitals.

Results: Through contact with clinics, we learned of 11 labs used by Utah providers that had not been reporting to UCR. 74 new 2012 cases were identified from these labs. An additional 134 new 2012 cases were identified through additional case ascertainment strategies. After these case-finding efforts, prostate remained the cancer site with the lowest CE, 72%. Only 11% of found cases were prostate.

Conclusion: Surveying dermatology and urology clinics resulted in the bulk of newly identified cases with the greatest long-term reward. This step was effective and will become part of UCR’s surveillance procedures. Reviewing pathology for non-registry hospitals resulted in the lowest return on investment as the labor costs were high with few new cases found, and is not recommended. Even with the additional case-finding efforts, UCR was unable to meet the CE goal. We believe future calculations of CE should consider changes in screening recommendations and practice patterns, especially for prostate cancer.
**P-03**

**EVOLUTION OF THE CENTRAL TRACKING DATABASE: OPPORTUNITIES FOR ENHANCED OPERATIONS**

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**Background:** Like many central cancer registries (CCRs), the Missouri Cancer Registry and Research Center (MCR-ARC) receives data from hundreds of facilities. In the past, monitoring these bundles of data moving through the QA process was the primary purpose of maintaining a tracking database (TDB). Currently, the TDB is used to monitor timeliness of bundle processing and to manually create MCR-ARC performance reports. Although set up to track hospital submissions, the TDB now contains data from multiple reporting sources. Redesigned from an Excel spreadsheet tracking notebook in 2010, the database includes many more functions but currently lacks the ability to add or alter facility contact information. This is a critical function needed to unlock several other capabilities.

**Purpose:** To review the current capabilities and shortfalls of the MCR-ARC tracking database and assess the CCR’s future needs, identifying the functions necessary to support those needs.

**Methods:** We conducted a review of the MCR-ARC database needs and how the current system was developed. We carried out interviews with staff to assess current-state capabilities and identify future functions.

**Results:** Several potential uses were identified. The central MCR-ARC TDB should ideally maintain its current functions and offer additional capabilities, e.g., the ability for facilities to update their data through forms on the MCR-ARC website, non-hospital tracking, yearly hospital update reports, automatically-generated delinquency letters, QA quality and QA staff-specific reports, low-volume facility reports, annual in-kind letters, audit tracking, and a user manual for complex tasks.

**Conclusions:** The existing TBD is helpful for many tasks but has limitations. As the types and amounts of data increase, it will be necessary to update the TBD to provide reports and information MCR-ARC needs to better carry out its mission.

**P-04**

**PARTIALLY AUTOMATING THE CASEFINDING AUDIT PROCESS**

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The Cancer Registry of Greater California (CRGC) has a 5 year goal to audit every facility. The current Casefinding Audit process is performed manually and is one of the most time intensive audits to complete. The CRGC set out to see if any automation could be incorporated into the Casefinding Audit process in order to reduce the turnaround time.
**P-05**

**ENHANCED IDENTIFICATION OF OUT OF STATE CASES BY UTILIZING ‘TEXT--PLACE OF DIAGNOSIS’**

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**Background:** The New York State Cancer Registry (NYSCR) previously conducted a study identifying non-New York residents by searching for the names of other countries and other states in the field ‘TEXT--PLACE OF DIAGNOSIS’. This is an extended study that adds state abbreviations, and names of major cities in the US and the world to the search criteria.

**Methods:** The place of diagnosis field was searched for any occurrence of thousands of possible string combinations using the INDEX function in SAS. Combinations that overlapped names of places or medical facilities in New York State (e.g., Rome, Athens) or commonly used medical abbreviations (e.g., TX) were excluded – although TX following a comma was included as it more likely referred to the state abbreviation than to treatment. Cases flagged as possible residents of other states were sent to LexisNexis for verification; those not verified by LexisNexis underwent clerical review. Cases flagged as possible residents of other countries only underwent clerical review.

**Results:** The project is still in progress; to date, approximately 16,000 cases have been flagged as potential non-NY residents, about ¾ of these from other states and ¼ from other countries. Results thus far show that a substantial proportion of these are not NY residents. A highly disproportionate share of these were sent by other states rather than by hospitals.

**Conclusions:** Many out of state cases can be identified utilizing the field ‘TEXT--PLACE OF DIAGNOSIS’. Closer attention to this field can also reduce the number of cases sent erroneously via interstate data exchange.

**P-06**

**IMPLICATIONS OF MISCLASSIFICATION OF MELANOMA THICKNESS MEASUREMENT (BRESLOW’S DEPTH) IN DETROIT SEER DATA, 2004-2010**

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**Background:** Research by Gimotty et al (J Clin Oncol 32, 2014 (suppl; abstr e20044)) suggested some primary melanomas in SEER data were misclassified as ultra-thin.

**Methods:** We did a quality review of Breslow thickness recorded on all 3799 melanomas in the Detroit SEER registry data from 2004-2010. We categorized tumors as “ultra-thin” (<=0.25 mm, n=447, 11.8%) and “non-ultra-thin” (>=.26mm, n=3,352, 88.2%). To measure the effect of misclassification on hazard ratios (HR) for overall survival, we used Cox regression categorizing thickness into 4 levels (<=0.25 mm, 0.26-0.50 mm, 0.51-1.0 mm, >=1.1 mm) controlling for sex and age.

**Results:** Our reviewers coded 76 lesions (2.0%) as missing or unavailable. Of the remaining 3723 where pathological records were available, we found 306 (8.2%) measurements required correction. Errors were more common among lesions initially coded ultra-thin (26.2%), compared with those coded as non-ultra-thin (5.7%). Of the 306 subsequently corrected measurements, 144 (47.1%) were 10- or 100-fold thicker than originally recorded. This suggests unfamiliarity with metric units. Only 345 (9.1% of those verifiable) melanomas were ultimately classified ultra-thin, compared with 447 (11.8%) originally. Both crude and age- and sex-adjusted HRs were lower for all thickness categories, when using original measurements compared to corrected measurements. With <=0.25 mm as a reference group the adjusted HRs were 1.4, 1.8, and 3.9 for 0.26-0.50 mm, 0.51-1.0 mm, and >=1.1mm, respectively, using original measurements, and 2.0, 2.7, and 6.5 using corrected measurements. The adjusted HR for the 2nd thinnest (0.26-0.40 mm) category, however, was not significantly greater than 1.0 using original thickness measurements, but greater than 1.0 using corrected measurements.

**Conclusion:** Misclassification of thicker melanomas as ultra-thin is a common but addressable error that has important implications for melanoma researchers using the SEER registry.
ENHANCING THE CAROLINA MAMMOGRAPHY REGISTRY (CMR) THROUGH LINKAGE WITH THE NC CENTRAL CANCER REGISTRY (NCCCR)

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Background: Since its inception in 1994, the Carolina Mammography Registry (CMR) has served as a population based mammography registry with participating breast imaging facilities spanning 34% of NC counties. To ensure complete breast related follow-up and outcome information on participating women, CMR data is linked with pathology data from the NC Central Cancer Registry (NCCCR).

Purpose: To describe how the CMR and NCCCR linkage enhances the CMR data collection, quality, and monitoring for breast cancer screening and outcomes in NC.

Methods: Probabilistic data matching is used to link women with a breast imaging examination in CMR with breast cancer cases in the NCCCR. In this form of matching, records must contain two or more common identifiers such as first and last name, last four digits of social security number, date of birth, address, city, or zip code. Each set of candidate matched records is assigned a numeric match score that indicates the degree of agreement between the records. These match scores are used to determine which records create a match, a possible match, or a non-match.

Results: The final CMR and NCCCR linked dataset is used to determine cancer detection rates and to examine how these cancer detection rates vary across NC facilities, across years and by screening and diagnostic indication of the breast imaging examination. In addition, we are able to evaluate in-situ and invasive cancer diagnoses by socio-demographic characteristics, breast cancer risk factors (family history of breast cancer and breast density), imaging modalities (mammography, ultrasound, breast magnetic resonance imaging) and mammographic findings.

Conclusions: Through linkage of the CMR and NCCCR data, breast cancer trends may be evaluated by year, histology, mode of detection, and breast cancer risk factors to ensure continued data quality and complete information for women participating in CMR.

PROBABILISTIC DATA LINKING METHODOLOGY FOR RECORD LINKAGE USING CANCER REGISTRY DATA AND PRIVATE INSURANCE CLIME DATA

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Background: Most clinical research data contain patient identifiers such as names, birthdates, address, SSN, etc. Linking datasets using the identifying information has become increasing common in order to create more powerful and compete research data.

Research Objective: Linkages from the UNC Integrated Cancer Information and Surveillance System can be used to demonstrate several ways to optimize data linkages and improve data quality. Different data linkage algorithms are applied depending on the specifications of each research project. We will compare linkage algorithms, and demonstrate a new method to maximize the matching probability.

Methods: We build on the field of probabilistic linkage methodologies and from the work of Fellegi and Sunter1 as well as Winkler and Thibaudeau2. We employed clustering and MCMC algorithm to find the best combination of matching probability for each identifier to maximized sensitivity and positive predictive value in probabilistic linking. We then use M-probability and U-probability to calculate the linkage weight which is the measure that conveys the discriminating power of a variable.

Results: We identify the optimized matching probabilities for each individual identifier. This method enables us to calculate the matching weights for each patient, and it helps to determine the optimized sensitivity and positive predictive value for each data linkage.

Conclusions: This method of probabilistic linking can help identify the relationships and correlations between identifiers in two different data sets. This method can guide researchers who want to link data with imperfect identifiers and help them evaluate their data.

P-09
EVALUATION OF ‘LIKELY DECEASED’ FOR IMPROVING FOLLOW-UP IN METROPOLITAN DETROIT SEER DATA, 1973-1994
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Background: SEER evaluates registries on follow-up via the SEER Data Quality Profile (DQP) for cases diagnosed 1995-2008. Meeting DQP follow-up requirements is fairly routine, but maintaining 95% follow-up for cases diagnosed 1973-1994 is challenging. We investigated whether intensive active follow-up of ‘Likely Deceased’ cases for this earlier timeframe was cost effective.

Methods: Cases diagnosed 1973-1994 in Metropolitan Detroit that did not have a follow-up date of 2013 or later were evaluated by age, race, cancer site and stage, to determine categories of ‘likely deceased’ individuals, where more intensive follow-up methods might find vital status. Intensive follow-up included reviewing the central cancer registry database (DB) for death certificates, researching cases on Lexis-Nexis© and calling patients’ last known phone number. We tracked staff time to measure cost effectiveness.

Results: Of 396,187 total cases, 85% were deceased and 15% alive. 27% of living cases had no follow-up after 2012. 212 (1.4%) cases were age 100 or older (Elderly) and 163 were distant stage (Distant) for selected cancer sites. One staffer worked 48.5 hours to investigate Elderly and 49.0 hours for Distant cases. After intensive follow-up, results were: Death Certificate found on database (Elderly: 12%, Distant: 1%), Death found in Lexis-Nexis© (Elderly: 22%, Distant: 10%), Alive found in Lexis(Elderly: 13%, Distant: 0%), Lost to Follow Up (Elderly: 29%, Distant: 15%), Patient found Alive via phone call (Elderly: 4%, Distant: 67%), and case needs further research after more intensive follow-up methods, therefore perhaps not time effective (Questionables) (Elderly: 21%, Distant: 6%).

Conclusions: Performing more intensive follow-up in pre-1995 diagnosed cases improved follow-up in Elderly and in Distant Stage cases. These more focused methods for selected cases appear to be cost effective.

Notes

P-10
CONSTRUCTION OF KOREAN CANCER CONTROL STATISTICS INFORMATION SYSTEM
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A cancer control program is based on reliable and accurate statistics and evidence. As a part of a cancer big data management and utilization effort, we conducted a pilot project aimed at creating an integrated cancer control database (DB) by combining the cancer management project DBs from four business departments within the National Cancer Control Institute (NCCI), and to establish new index service using the combined DB. Fifteen indices were selected for a new service through the use of an integrated DB obtained from the results of four projects. Because standardization of the raw data was essential for data integration, data structures and variable definitions were examined. Then, comprehensive data cleaning was conducted. The actual integrated DB was created by an IT company, and ECminer program was used for the processes. Through analysis of the current computing environment, a new server was introduced that considered the DB capacity of integrating data from four sources. For this, a method that does not violate the Personal Data Protection Act was used. For DB standardization, a standard term dictionary, domain dictionary, code dictionary, and conversion mapping specification were prepared. Data was downloaded as txt file format from the four business departments DBs and uploaded through the ETL (Extraction, Transformation, Loading) process to the standardized integrated DB to create the new indices: age-standardized cancer incidence rates based on income level; false-positive rates, cancer detection rates, positive predictive values, screening rate; the percentage of people eligible for cancer policy support who are actually receiving support and; the length of illness from cancer diagnosis to death for individuals who used palliative hospice medical facilities. These indices are available through the Korean Cancer Control Statistics Information System (KCCSIS) website. The KCCSIS will contribute to the advanced national cancer control program through integration and utilization of scattered cancer management information.

Notes
P-11

CHARACTERISTICS ASSOCIATED WITH DELAYED REPORTING OF CANCER CASES TO THE OHIO CANCER INCIDENCE SURVEILLANCE SYSTEM

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Background: In accordance with Ohio law, each incident case of cancer must be reported to the Ohio Cancer Incidence Surveillance System (OCISS) at the Ohio Department of Health within six months of the date of diagnosis and/or first contact with a treatment facility. Despite this reporting requirement, NAACCR estimates of data completeness show that OCISS data do not typically meet the 95% completeness standard at 24 months after year of diagnosis. Preliminary review suggests this is partly related to delayed reporting of cases. Incomplete data hampers the utility of OCISS data for public health surveillance and cancer research purposes, especially for data requests sooner than 24 months after year of diagnosis.

Purpose: Identify characteristics associated with delayed reporting of cancer cases to OCISS.

Methods: We will examine data received from reporting sources with a cancer diagnosis date from 1/1/2008-12/31/2012. For each of several time periods (≤6 months, 7-12 months, 12-24 months, >24 months), logistic regression will be used to identify factors associated with delayed reporting. Factors of interest include demographics (e.g., age, sex, race, primary insurance), tumor characteristics (e.g., anatomic site/type, stage at diagnosis), first course of treatment, geographic characteristics (e.g., urban/rural residence, socioeconomic measures) and type of reporting source. Death certificate only cases will be excluded from analysis, as will those from pathology labs, other states, the Veteran’s Administration and Department of Defense.

Implications: Characteristics identified as being associated with delayed reporting will be used to inform efforts to improve timely reporting. Results will also inform researchers of potential data quality issues. The methodology developed for this project may be beneficial to other cancer registries that want to explore delayed reporting or characteristics of cancer cases reported across different time periods.

P-12

USING OUT OF STATE LABORATORY DATA TO IMPROVE CASE ASCERTAINMENT FOR LEUKEMIAS: THE PUERTO RICO EXPERIENCE

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Background: An important issue of reliable cancer registry data is the completeness of case ascertainment (CCA), generally defined as the percentage of all incident tumors in a registry population that is captured in the registry’s database (DB). Historically, in the Puerto Rico Central Cancer Registry (PRCCR) we have the concern of a possible underestimation of our CCA in some cancer types, like leukemia due to poor physician’s reporting. Since most leukemia patients are diagnosed and treated in oncologists/hematologists (OH) private offices, these cases are mostly identified from pathology. Another barrier is that most of the OH in Puerto Rico (PR) send blood samples to out of state laboratories (OSL). One important goal in order to meet the NAACCR Gold Certification is to find these OSL sources that would allow us to improve the CCA for leukemia in particular.

Objective: To improve the CCA of leukemia using OSL data.

Methods: A US mainland specialized OSL, where most of the OH send their blood samples, was approached and agreed to share information of PR cases, establishing an important accomplishment for the PRCCR. The OSL file was received in HL7 format and added to the PRCCR system in order to perform follow up of potential missing cases. The first step was to establish direct communication with OH to explain the importance of reporting to the PRCCR as required by law. Next, an exclusive list of cases was generated for each OH, whose cancer information was missing or incomplete. These lists and the requested information were exchanged using WebPlus as a secure transport method in order to update our cancer DB.

Results/Conclusion: The CCA for leukemia has increased significantly. Collaboration with OSL has been established for the long term, as well as with the OH in order to achieve acceptable level of CCA and optimize the overall PRCCR’s data flow for years to come.
**P-13**

**COLLECTING COMORBIDITIES FROM STATEWIDE ADMINISTRATIVE DATA**

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**Background:** Comorbidities at the time of cancer diagnosis affect outcomes in a variety of ways and are of interest in numerous research settings. Cancer registry data, however, often contains missing or incomplete information on comorbidities. We aimed to supplement cancer registry comorbidity data with data from California’s Office of Statewide Health Planning and Development (OSHPD). OSHPD data contains information on all admissions to hospitals, emergency departments, and ambulatory surgery centers in California.

**Methods:** We used a probabilistic linkage method to locate all admissions for patients diagnosed with cancer between February 1st, 2011 and June 30th, 2011 and used these records to find ICD-9 codes for non-cancer diagnoses. We grouped these ICD-9 codes into categories which included the conditions that comprise two commonly used comorbidity indexes, Charlson and Elixhauser. We calculated the proportion of cases for which we obtained OSHPD comorbidities for several cancer sites.

**Results and Conclusions:** Overall, we obtained comorbidities for 74% of cancer cases. This ranged from a low of 45% for melanoma to a high of 87% for pancreatic cancer. Hospital admission data can be used effectively to capture comorbidities although the effectiveness varies by cancer site. Augmenting discharge data with data from ambulatory surgery centers increases the effectiveness of this method.

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**P-14**

**COMPARING COMORBIDITY DATA OBTAINED FROM HOSPITAL DISCHARGE FILES WITH THOSE REPORTED TO CANCER REGISTRIES**

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**Background:** The NAACCR standard record layout includes ten fields for the collection of comorbidities/complications. These items are required for any hospital with a CoC-accredited cancer program and are reported when available by all other facilities. Despite these requirements, no nationally recognized guidelines exist on how to select meaningful codes. The objective of this study was to examine and compare comorbidity data from two different sources: (a) cancer registry records submitted from hospitals and (b) data gathered from California’s Office of Statewide Health Planning and Development (OSHPD) hospital discharge files.

**Methods:** We compared comorbidity data collected from hospitals to those gathered from OSHPD records between 30 days before diagnosis and 180 days after diagnosis. We grouped these ICD-9 codes into categories which included the conditions that comprise two commonly used comorbidity indexes, Charlson and Elixhauser. We created contingency tables for several comorbidity categories and cancer sites.

**Results and Conclusions:** There was little agreement between OSHPD and hospital-submitted comorbidities, with kappa statistics under .10 for all sites. OSHPD records contained far more comorbidities than hospital-submitted records and most OSHPD comorbidities were not reported to the registry by hospitals, even when comorbidities were reported. On the other hand, most of the comorbidities submitted by hospitals were also recorded in OSHPD files. Further studies involving a gold-standard set of comorbidity data are needed to ensure that comorbidities are collected consistently across cancer registries.
P-15

A SURVEY OF METHODS FOR HANDLING MISSING VALUES IN POPULATION-BASED CANCER REGISTRIES
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Advanced statistical methods for handling missing values are available and have been used in several population-based surveys but uptake in these methods in cancer registries has been limited and is in need of improvement. Inferences from population-based cancer registries are used for studying cancer epidemiology, patterns of diagnosis, treatment and clinical outcomes. These registries provide valuable sources of data for health services research. However, often registries have missing patient information on important demographics, clinical and clinicopathological characteristics. Ignoring missing information or mishandling might lead to inaccurate inferences resulting in under or over estimating the real effect. Therefore, proper handling of missing values in the cancer registries during data capturing, analysis and reporting need further investigation to improve the quality of results. Depending on the missingness mechanism several ad-hoc methods (simple and hot-deck imputation) and advanced statistical model-based approaches (regression and multiple imputation) for handling and accounting for missing values in cancer registries can be introduced. When these methods are applied to handle the missing information on demographics, clinical and clinicopathological characteristics of cancer patients, inferences can be more accurate. This study will facilitate broader use of all of these methods by describing their properties, comparing with each other, illustrating their use with a large population-based cancer registry data and showing how they can be implemented using standard statistical software. Application of these methodologies can be a model for many cancer registries.

Notes

P-16

IMPROVING CANCER REPORTING FROM SMALL AND RURAL HOSPITALS
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The vitality of cancer analytics relies on the data collected from all healthcare facilities and providers. There are about 50 small and/or rural hospitals (SRH) in Alabama. Due to the small number of cases and high staff turnover rate in these hospitals, it was challenging for the ASCR to repeatedly train SRH staff to complete cancer abstraction. Before 2008, two ASCR case-finding auditors (CFA) performed cancer reporting on site for these hospitals. When Web Plus became available in 2007, the ASCR quickly adapted the system and modified processes to reduce each CFA’s travel and workload. Each CFA was assigned a set of SRH documents to review for reportable cases. SRH staff entered cases in Web Plus with a display type containing minimum coding fields but all the text fields. The CFA then completed the abstracts. Starting in 2013, the ASCR further improved this process. One CFA reviews all the SRH documents to identify reportable cases. One certified tumor registrar (CTR) operating as the small hospital reporting coordinator (SHRC) completes the abstracts. While the major tasks remain the same, the new process allows the CFA to focus on obtaining audit documents and performing audits in a more timely fashion. As a CTR, the SHRC can complete abstracts more efficiently and accurately. The tracking database was also modified significantly to allow both the CFA and SHRC to track facility status in both the auditing and abstraction processes. With electronic health record system becoming widely implemented, SRHs are also moving towards eliminating paper in the reporting process-some even allowing the ASCR to remotely access their patient records. The ASCR will continue to improve processes to take advantage of opportunities provided by electronic health records. The collaborative efforts between the ASCR and these hospitals have fostered a stronger partnership due to dual accountability, efficient systems integration, and effective education and training.

Notes
P-17

UTILIZING THE NAACCR GEOCODER TO IMPROVE THE QUALITY OF COUNTY AT DIAGNOSIS

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The quality of data is crucial for any data analysis, and misclassification of variables can easily lead to erroneous conclusions. In the state of Alabama, there exist a few zip codes that extend across the borders of multiple counties, and there are a few municipalities that extend across county borders. As such, misclassification of the county at diagnosis variable can occur. When this occurs, certain counties will appear to have incidence rates that are artificially higher or lower than what the true rates should be.

The NAACCR Geocoder (NG) is a powerful tool that can be used to supply cancer registries with many geographical variables for each case such as latitude, longitude, GIS coordinate quality, census tract, census block, census block, census tract certainty, geocoded county, etc. By comparing the geocoded county result from the NG to the reported county at diagnosis in the ASCR, I am able to identify cases with potentially misclassified county at diagnosis and update the county at diagnosis field.

From 2002 through 2011, approximately 5% of ASCR cases had an incorrect county at diagnosis value based on the NG. Every county in Alabama had at least one miscoded case. However, once adjustments were made and incidence rates recalculated, 47 of the 67 counties saw no significant change to their incidence rates. Ten counties had a new incidence rate that was outside of the 95% confidence interval of the original rate, but was not significantly different as the new 95% confidence interval overlapped the original 95% confidence interval. Ten Alabama counties had new incidence rates that were either significantly higher or significantly lower than the original incidence rates. The majority of counties with significantly different rates were clustered around Jefferson County which contains Birmingham, the largest city in Alabama.

The ASCR will continue to utilize the NG to obtain geographic information and to improve the quality of our data.

P-18

EVALUATION OF PHARMACEUTICAL TRANSACTION INFORMATION FOR POTENTIAL AUGMENTATION OF SEER TREATMENT DATA

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Background: A pilot is being performed to evaluate the completeness and representativeness of information on orally administered antineoplastic treatments available from the IMS Health pharmaceutical transactions database for cancer cases captured in the SEER Registries. The pilot includes 10 specific drugs used for treating breast cancer, colon cancer, CML and Myeloma.

Methods: An initial comparison between IMS Health Data and cases identified in SEER for the State of Louisiana will be made to determine the completeness and representativeness of patients included in the IMS Health transaction data base. A second comparison will be made to identify patients that received specific drugs included in the pilot compared to other potential data sources including SEER-MEDICARE part B and D, SEER patterns of care studies, and comparative effectiveness treatment information collected by CDC. This comparison will assess the completeness of the pharmacy information captured by IMS Health as well as the accuracy and completeness of the other data sources mentioned.

Analysis: Linkages of all data sets required for the pilot comparisons will be completed in the beginning of January for Louisiana. Initial estimates from the pilot will be available for the NAACCR conference.
KRAS TEST DOCUMENTATION IN THE ALASKA NATIVE TUMOR REGISTRY AMONG PEOPLE WITH LATE STAGE COLORECTAL CANCER

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Background: Prior to full clinical implementation of KRAS gene status determination of late stage colorectal cancers (CRC) in 2013, KRAS testing was done as a part of diagnostic workup at some medical facilities. Detection of the KRAS biomarker is now routine for this subset of CRCs. We wanted to determine the extent of KRAS documentation in tumor registry abstracts for a period prior to the implementation of the FDA-approved KRAS test.

Purpose of Study: The activity is to serve as a quality assurance activity of the Alaska Native Tumor Registry. The goal is to identify the proportion of late stage CRC patients who had KRAS testing documented in the tumor registry.

Methods/Approach: Data are from the Surveillance, Epidemiology and End Results (SEER) Alaska Native Tumor Registry, a population-based registry which includes Alaska Native people living in Alaska at the time of diagnosis. We identified 359 CRCs diagnosed during years 2009-2013 and treated at a single facility. Of 359 CRCs, 100 were found coded for late stage disease at the time of diagnosis as defined by two variables, SEER summary stage 2000 for distant disease and/or Collaborative Stage code for metastatic disease. We reviewed medical records, including pathology reports and physician dictations for evidence of KRAS testing and compared findings with the tumor registry abstract.

Results: Of the 100 late stage CRCs, 57% had a KRAS test performed. Approximately half of the CRC tumors tested were shown to have the KRAS wild type gene. Nearly 20% of KRAS test results (11 of 57) were not coded or noted in the tumor registry record but found through re-review of medical records. Seventy patients received chemotherapy, but most often this was noted to be for palliative care. We found reasons for not testing KRAS gene status and/or not administering chemotherapy for 16 people who either refused, died prior to treatment, or for whom chemotherapy was contraindicated. KRAS testing increased to 76% in 2013.

Conclusions: These results suggest that more than half of late stage colorectal cancers were KRAS tested during years 2009-2013. Nearly 20% of KRAS results were not documented or coded in the tumor registry abstract. KRAS testing increased for late stage CRC 2013 but testing is performed at laboratories outside of the hospital. We found the results are not always included in the original path report. Tumor registry abstractors should note that KRAS testing is performed for most late stage CRCs, and to look for evidence of KRAS testing and results. Medical record documentation is needed for all patients who refuse chemotherapy, for whom chemotherapy is contraindicated or for patients who have died prior to treatment to improve our documentation of this subclass of CRC treatment.

TUMOUR SIZE AND FUHRMAN GRADE FURTHER ENHANCE THE PROGNOSTIC IMPACT OF PERINEPHRIC FAT INVASION AND RENAL VEIN EXTENSION IN T3A STAGING OF RENAL CELL CARCINOMA (RCC)

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Introduction: The 7th Edition of AJCC TNM stages T3a RCC as those with perinephric fat invasion - confined within Gerota fascia, and renal vein tumour extension - where there is a risk of tumour embolisation. The objective of this study was to evaluate the prognostic values of these two T3a categories, as stand alone factors and in combination with tumour size and Fuhrman grade.

Materials And Methods: We analyzed 143 consecutive radical nephrectomy cases (group A: perinephric fat n=101, group B: renal vein involvement n=42) with pT3a RCC treated in Singapore General Hospital from 2002 to 2012. Median follow-up was 47.5 months. Kaplan-Meier and Cox Regression analyses were used.

Results: There were no statistical differences between the two groups in age, gender, ECOG status, Charlson Cormorbidity score, Fuhrman grade and histology subtypes. However, patients with renal vein invasion had larger tumours and tended to be more symptomatic (p=0.001). 29 patients (28.7%) in A and 17 patients (40.5%) in B had recurrence of RCC respectively (p=0.176). Patients in A appeared to have better prognosis in term of disease-free survival compared to B, however the difference did not reach statistical significance (p=0.103). Employing tumour size and Fuhrman grade significantly enhanced the prognostication of patients with perinephric fat invasion. For RCC ≤ 4 cm, the presence of perinephric fat invasion did not signify worse prognosis. However, for RCC ≥ 4 cm, perinephric fat invasion results in significantly worse outcome compared to similar size-band groups in lower stages (p=0.035).

Conclusions: This study shows that patients with RCC invading into perinephric fat appears to have better prognosis than RCC extending into the renal vein. T3a category is a diverse group. Stratification of these patients into tumour size and Fuhrman grade further enhances the prognostic value of these two T3a sub-categories.
P-21

CANCER TRENDS IN NORTH DAKOTA BEFORE AND AFTER THE OIL BOOM

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Based on the census estimates1, the population of North Dakota (ND) has increased between 2002 to 2006 by about 11,000 individuals, while between 2007 and 2011 it has increased by about 33,000 individuals. This rapid increase in population is continuing as of 2014 and the source of it is the discovery of the Parshall Oil Field in 20062 and the subsequent job “boom” which lead ND to have the lowest unemployment rate in the US. With this population increase also comes the need for a better understanding of the increase in medical care needs in ND, including oncology treatment facilities and personnel. As a first step in this direction one needs to understand the cancer incidence trends in ND before and after the oil boom. To this end the North Dakota Statewide Cancer Registry (NDSCR) data is used, and age-adjusted incidence trends between 2002-2011 for 4 major cancer sites (prostate cancer – males only, breast cancer – females only, lung and bronchus, colon and rectum) are examined. Joinpoint regression models3 and annual percentage change (APC) statistics are used to determine the direction and magnitude of trends. In addition to the statistical analysis results, trend graphs and cancer intensity maps of ND will be presented.

References:

P-22

INVASIVE CANCER INCIDENCE AND SURVIVAL - UNITED STATES, 2011

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Due to earlier detection of cancers, effective and improved cancer treatments, and better general medical care, the percent of individuals living after a cancer diagnosis has increased over the past decades. Surveillance of cancer incidence and survival are essential in monitoring and understanding CDC’s efforts to support the needs of cancer survivors, estimated to be 13.7 million in 2012.

Methods: We analyzed data from U.S. Cancer Statistics (USCS) for 2011. USCS includes incidence and survival data from CDC’s National Program of Cancer Registries and NCI’s Surveillance, Epidemiology, and End Results (SEER) program and mortality data from the National Vital Statistics system. The 5-year relative survival was calculated for cases diagnosed during 2003-2010 and followed through 2010.

Results: In 2011 a total of 1,532,066 invasive cancers were reported to cancer registries in the United States (excluding Nevada), an annual incidence rate of 451 per 100,000 persons. Cancer incidence rates were higher among men (508) than women (410), highest among blacks (458), and ranged by state from 374 to 509 per 100,000 persons. The 5-year relative survival was 65% and was similar for men and women, but higher for white persons than black persons (60%). The 5-year relative survival was highest among those diagnosed with cancer before age 45 years (81%) and decreased with increasing age. Among the most common cancer sites, 5-year relative survival was highest for prostate cancer (97%) and breast cancer (88%), intermediate for colorectal cancer (63%), and lowest for lung cancer (18%).

Conclusion: Differences in cancer survival may be due to differences in stage at diagnosis, timeliness in follow-up after diagnosis, appropriate treatment after diagnosis, as well as multiple chronic conditions. Personalized cancer survivorship plans with information about diagnosis, treatment received and their potential effects, recommended follow-up and ongoing care, and other resources can be useful tools for cancer survivors and their health care providers.
P-23

THYROID CANCER INCIDENCE IN ALGIERS 2002-2012
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Background: Algiers Cancer Registry covers population of 4,736,392 in three areas: Algiers population estimated at 3,241,670 with 1,627,074 women and 1,614,596 men, Boumerdes area with a general population of 866,567: 421,944 women and 444,623 men. The third, Tipaza population, 628,155 with 311,287 women and 316,868 men. Thyroid cancer incidence is increasing in the female population in Algiers, classified in third position after breast cancer and colon rectum cancer, this cancer has seen a clear association sex-impact. We therefore examine this association to address future public health needs.

Methods: Patients were selected from the Algiers Cancer Registry and categorized with type histological and age. Coding was done using the International Classification of Diseases for Oncology (ICDO-3) and the data abstracted were analyzed using the Epi6info computer software and CanReg5 computer software.

Results: 35 cases were unregistered in Algiers’ female population year 2000, 33 cases were unregistered in Algiers’ male population in the same year, in year 2012 the number is 254 in Algiers female population, only 44 in Algiers male population, 625.7% is the percentage increasing.

Conclusion: Thyroid cancer incidence is markedly increasing in the female population; Comprehensive cancer control programs are much needed. The cancer plan for 2015-2019 requested by the President of the Republic will be an important step to solve the most common cancers in Algeria.

P-24

TREATMENT AND CHARACTERISTICS OF STAGE II COLON CANCER PATIENTS IN 8 STATES AND 2 METRO AREAS
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Background: Some practice guidelines recommend adjuvant chemotherapy after surgery for high-risk stage II colon cancer patients; however, the criteria of high-risk are ill-defined and the long-term benefits are debated.

Purpose: To document a baseline of current patterns of care by assessing selected patient and tumor characteristics using a population-based cohort of stage II colon cancer patients diagnosed in 2011.

Methods: We used data from 10 central cancer registries participating in the National Program for Cancer Registries’ (NPCR) Enhancing Cancer Registry Data for Comparative Effectiveness Research (CER) project to identify the demographic and clinical determinants of stage II colon cancer patients receiving adjuvant chemotherapy. We evaluated factors associated with adjuvant chemotherapy through logistic regression.

Results: Preliminary analyses of the 3,999 stage II colon cancer patients show that 14.0% were treated with surgery and adjuvant chemotherapy compared to 83.6% by surgery alone. The patients treated with surgery and adjuvant chemotherapy were white (82.3%), non-Hispanic (83.4%), female (50.5%), and lived in urban areas (51.7%). The median age was 61 years and most were insured by Medicare alone (no private supplement) (28.2%) or private insurance (45.9%). Approximately one-third (34.5%) had a T4 depth of invasion and 13.4% has less than 12 lymph nodes examined. Compared to surgery alone, the two characteristics associated with adjuvant therapy were younger age (median 61 years vs. 71 years; adjusted odds ratio [aOR]: 0.94, P<.01) and T4 invasion (aOR: 4.16, P<.01).

Conclusions: In this population-based cohort, younger stage II colon cancer patients with T4 depth of invasion were more likely to receive adjuvant chemotherapy in addition to surgery. Ongoing data collection on outcomes, especially recurrence, will help clarify whether or not adjuvant treatments in high-risk colon stage II patients are effective.
P-25

TOBACCO USE AND ITS IMPACT ON CANCER CLUSTER INVESTIGATIONS IN INDIANA
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Background: The public often expects a cancer cluster investigation to yield a causal agent related to contaminants in water, air or soil. However, it is well known that tobacco use is tied to various cancers - one of every three cancer deaths in the U.S. is linked to smoking. Thus, identifying a true cancer cluster proves to be a difficult process. A comprehensive approach designed to seriously consider tobacco use of reported cases should be implemented.

Purpose: An investigation into a suspected cancer cluster includes an approach that weighs public concerns, provides statistical analysis, and includes assessment of tobacco use. Tobacco use information is readily available from the Indiana State Cancer Registry (ISCR). In 2012, Indiana had the sixth highest prevalence of adult smokers. Therefore, it was of interest to determine the impact tobacco use had among reported cases.

Methods: Indiana’s protocol for cancer cluster investigations is a four-tiered process. Level one being the most basic level to determine an excess of cancers with levels 2-4 involving more complex analyses. In Indiana, from June 2011 to November 2014, 12 of the 25 inquiries developed into a level one investigation; none proceeded to levels 2-4. Verification of cases and tobacco use occurred via the ISCR or through medical record ascertainment.

Results: Verification of reported cases led to the discovery of tobacco use (current or previous) among 49% of the 84 cases with documented status leaving 51% who reportedly did not use tobacco.

Conclusion: Tobacco use among cases reported in cancer clusters needs to be considered when weighing the impact of exposures. Exploration into the tobacco use of cases may diminish or eliminate fears regarding chemical or environmental exposures and offers an opportunity for education on the risks of tobacco use. Limitations include the lack of information in records about personal tobacco use.

P-26

NEIGHBORHOOD SOCIOECONOMIC STATUS AND HISTOLOGIC-SPECIFIC LUNG CANCER INCIDENCE RATES BY RACE/ETHNICITY
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Background: Lower socioeconomic status (SES) has been associated with higher incidence rates of overall lung cancer across racial/ethnic groups, yet the relationship between SES and the incidence of histology-specific lung cancer is not well understood.

Purpose: To examine the association between SES and histologic-specific incidence rates of lung cancer among Asians/Pacific Islanders (API), Blacks, Hispanics, and non-Hispanic Whites (NHW), we conducted a large population-based cross-sectional study of 68,481 incident lung cancer cases diagnosed in California from 2008-2011.

Methods: Each lung cancer case from the California Cancer Registry was assigned a previously validated, multidimensional neighborhood-SES index using the 2007-2011 American Community Survey data. SES quartile-specific lung cancer incidence rates and rate ratios by histologic-specific cell type and gender were estimated using SEER*Stat for each race/ethnicity.

Results: For males, lower SES was associated with higher incidence rates of small cell lung cancer (SCLC) in API and NHW; higher incidence rates of adenocarcinoma, squamous cell carcinoma (SCC), large cell and other specified carcinoma (LC+OC), and unspecified lung cancer (unspecified) among API, Blacks, and NHW. Interestingly, SES was not associated with the incidence of any histologic-specific cell types of lung cancer in Hispanic males. For females, lower SES was associated with higher incidence rates of SCLC in API and NHW; lower incidence rates of adenocarcinoma in Hispanics and NHW; higher incidence rates of SCC, LC+OC, and unspecified lung cancer among API, Blacks, and NHW, and lower incidence rates of LC+OC and unspecified lung cancer in Hispanics.

Conclusions: Our findings demonstrate the associations between SES and the incidence rates of histologic cell types of lung cancer differ by race/ethnicity and gender.
DOES DISTANCE FROM A RADIATION FACILITY IMPACT PATIENT DECISION-MAKING REGARDING TREATMENT FOR PROSTATE CANCER? A STUDY OF THE NEW HAMPSHIRE STATE CANCER REGISTRY

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Introduction: Decision-making regarding treatment for prostate cancer is complex and often involves subjective patient concerns. We have anecdotally observed that distance from a radiation facility may deter patients from seeking this therapy; this relationship was previously shown for early stage breast cancer patients in New Hampshire. We sought to determine whether a similar relationship is present for prostate cancer patients in the state.

Methods: Patients with clinically localized prostate cancer diagnosed 2004-2011 were identified from the NHSCR, and categorized by age, D’Amico risk category, year of treatment, marital status, and estimated time to the nearest radiation facility, both in-state and out-of-state. A multivariable logistic regression model was created to determine the relationship between distance to a facility and choice of initial treatment.

Results: Univariate analysis revealed that age >65, diagnosis prior to 2007, and travel time >30 minutes were associated with initial radiation therapy (p<0.05). Multivariate analysis revealed that the following factors were independently, positively associated with initial radiation: intermediate or high risk disease, age >65 years, diagnosis prior to 2007, and estimated travel time >30 minutes from a radiation facility (OR 1.41; 95% CI 1.21-1.65; p<0.05). Among patients who selected radiation versus surgery, travel time >30 minutes was again positively and significantly associated with use of radiation (OR 1.57; 95% CI 1.30-1.89, p<0.05).

Conclusion: Greater travel time from a radiation facility was associated with increased use of radiation. These data are encouraging that, in a rural state, distance to a facility is not ostensibly deterring patients from seeking radiation treatment should that be their preference.

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FEMALE BREAST CANCER SURVIVAL IN NORTH CAROLINA

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Background: Female breast cancer is the most commonly diagnosed cancer in North Carolina. It also accounts for the largest number of cancer-related deaths among women. It is anticipated that 9,610 females in North Carolina will be diagnosed with and 1,398 females will die of cancer of the breast in 2014\textsuperscript{1}. The survival of all patients diagnosed with cancer in a given population is one of the most important measures of the overall effectiveness of the health-care system in the treatment and management of cancer\textsuperscript{2}.

Specific Objectives of the Study:
1) To conduct five year breast cancer relative survival analyses among African-American and White women by stage categories.
2) To examine survival differences among African-American and White women.
3) To examine recent breast cancer survival disparity by race and payer at diagnosis.

Data and Methods: This study is intended to conduct female breast cancer relative survival analysis using SEER\textsuperscript{3}Stat, which follows the Ederer II method (Ederer and Heise 1959)\textsuperscript{3}. Presumed alive survival months will be used to calculate relative survival rates.

Analysis Plan:
A.
   i) Cancer Stages: localized, regional, distant and unknown at the time of diagnosis will be used for survival analysis and unknown stage will be set to missing.
   ii) Flowing Tables / information will be provided for the study

B. Declared or reported race or ethnicity of women will be grouped into two categories: white and African-American.

References:
1. http://www.schs.state.nc.us/data/cancer.cfm
BRAIN TUMOR SURVIVAL: RESULTS FROM THE CURRENT NATIONAL CANCER DATA BASE

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The American College of Surgeons’, National Cancer Data Base (NCDB), established in 1989, is a comprehensive clinical surveillance resource oncology data set that annually captures approximately 70% of all newly diagnosed malignancies in the United States. We evaluated the current NCDB to describe recent hospital-based epidemiologic survival patterns for brain and central nervous system (CNS) tumors. The study sample consisted of patients diagnosed with malignant brain and CNS tumors defined as International Classification of Diseases for Oncology Version 3 (ICD-O-3) primary site codes, C70.0-C72.9, C75.1-C75.3 for diagnosis years 1998-2006 (n=120,793). Histology subtypes were selected according to the World Health Organization Classification of Tumours of the Central Nervous System. Survival estimates using the Kaplan-Meier method were generated using SAS version 9.3. The study follow-up cutoff date was December 2011. Observed 5-year survival estimates were as follows: Anaplastic Ependymoma 56.8% (52.69%, 60.69%), Astrocytic and Oligoastrocytic Tumors 38.8% (38.15%, 39.39%), Embryonal Tumors 63.2% (61.81%, 64.63%), Glioblastoma 4.0% (3.84%, 4.16%), Primary Malignant CNS Lymphoma 29.4% (28.40%, 30.30%), Malignant Meningioma 61.2% (59.09%, 63.32%), Nerve Sheath Tumors 67.7% (61.68%, 72.96%), Oligodendrogial Tumors 68.4% (67.39%, 69.33%), and Pilocytic Astrocytoma 91.9% (91.05%, 92.59%). Histology, age at diagnosis, and primary site of tumor location were important factors influencing survival outcomes. Brain tumor survival estimates from the population-based Surveillance, Epidemiology, and End Results (SEER) Program research database indicate that the malignant brain tumors are well represented in NCDB as evidenced by comparable survival estimates between the two cancer data sources. The NCDB provides valuable information on brain and CNS tumor survival patterns available from a large, high quality cancer surveillance database.

BIG DATA: THE FUTURE OF CENTRAL CANCER REGISTRIES

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Introduction: Advances in IT have brought a significant progression in the area of data computing. Most CDC/NPCR funded central cancer registries (CCRs) currently are incidence-only registries, relying primarily on abstracts which contain data from diagnosis through first course of treatment. Expanding data collection, such as capturing electronic health record (EHR) data and conducting additional linkages needed for survival analysis will enrich the data collection and expand the efficacy of the data. All these factors will lead to huge data. Managing massive data will be a concern for CCRs.

Purpose: Address issues related to collecting and managing large amounts of information to continually provide high quality data.

Method: A systematic review of the current data collection was performed and long-term and new required data information was assessed. We also performed research on how data-driven companies perform efficiently. The strategy contained three points of action: 1) potential agreements to link with administrative datasets to improve information about patients; 2) follow-up data for survival patients; and 3) approximate amount of new data that will be collected.

Results: Managing exponential amount of data is challenging and careful planning is needed. Having a strategy for future crisis can increase the odds of effective outcome.

Discussion: Cancer registration is a rapidly changing with new technology advancing. The concerns are: 1) how much data will be collected with increasing linkages and sources; 2) how will integrated health IT changes in healthcare affect CCRs; and 3) how will sensitive patient information be managed with growing data?

Conclusion: Detailed, precise and apt data collection by CCRs is a high priority to aid public health research and surveillance to address cancer issues effectively. Data security and management are vital concerns for cancer registries when they initiate alliances with other entities for data collection.
EPIDEMIOLOGY OF HUMAN PAPILLOMAVIRUS (HPV) ASSOCIATED CANCERS IN FLORIDA: ANALYSIS FROM A POPULATION-BASED CANCER DATA REGISTRY (1981-2009)

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Background: Human papillomavirus (HPV) has been associated with several types of cancer: cervical, vulvar, vaginal, penile, anal, oropharyngeal, bladder. High-risk HPV infection accounts for approximately 5% of all cancers worldwide.

Purpose: We report HPV-associated cancer incidence from 1981-2009 in Florida adults to inquire about the burden of cancers that are highly likely to be caused by high-risk HPV infection.

Methods: We analyzed data from the Florida Cancer Data System where we included adult (≥18 yrs) Florida residents at the time of diagnosis. For patients with multiple HPV-associated cancers, the earliest reported cancer was set as the primary site. Incidence per 100,000 for each gender was age-adjusted by using the 2000 US population.

Results: There were more male (n=111,554) than female (n=99,923) patients diagnosed with HPV-associated cancers. HPV-associated cancers in men included bladder (80.7%), tongue (8.9%), tonsil (5.3%), anal (2.9%), penile (2.2%), while cancers of the cervix (45.5%), bladder (29.3%), vulva (11.3%), anus (4.9%), tongue (4.5%), vagina (2.6%), tonsil (2.1%) were reported in women. There were no significant changes in incidence for male penile cancer or for female tongue, tonsil and vaginal cancers from 1981-2009. In contrast, the incidence of female vulvar and anal cancers and male tongue, tonsil, anal cancers increased significantly from 1981-2009. In 2000, bladder cancer incidence began to decline significantly for men and women: incidence in 2009 was 2/3 of the rate in 2000. For women, cervical cancer incidence remained at 2/3 of the rate in 2000. However, by 2009 the incidence decreased to 12.

Conclusions: HPV prevention efforts may be associated with the overall decline in incidence beginning in 1996. Elucidating patterns of incidence can lead to implementation of gender-targeted medical and public health interventions as well as assessment of past HPV-associated cancer screening and prevention efforts.

PROSTATE CANCER IN MASSACHUSETTS: DECLINING INCIDENCE AND NEW SCREENING GUIDELINES

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Background: Prostate-specific antigen (PSA) screening practices are reflected in prostate cancer incidence trends. However, population-based screening for prostate cancer has led to screening-related overdiagnosis and overtreatment. Screening guidelines have been evolving as the balance between benefit and harm becomes more established.

Purpose: To describe the declining prostate cancer incidence and new screening guidelines in Massachusetts.

Methods: Prostate cancer incidence data from the Massachusetts Cancer Registry (MCR) for 2007-2011 were evaluated. A Massachusetts Prostate Cancer Screening Guideline Panel comprised of various stakeholders in collaboration with the Massachusetts Health Quality Partners (MHQP) was convened to develop the Massachusetts prostate cancer screening guidelines.

Results: Prostate cancer was the most common type of cancer diagnosed in Massachusetts men from 2007 through 2011. Black, non-Hispanic men had the highest age-adjusted prostate cancer incidence rate (244.8 per 100,000), 1.8 times that of white, non-Hispanic men (138.8 per 100,000), 1.5 times that of Hispanic men (162.9 per 100,000) and 3.4 times that of Asian, non-Hispanic men (72.7 per 100,000). Among Massachusetts men, the incidence rate of prostate cancer decreased by 5.6% per year from 2007 through 2011, a statistically significant decrease. The new Massachusetts guidelines advise against routine screening for average risk men ages 50-69 and high risk men (black men or men with a family history of prostate cancer). Instead, they recommend patient education and individualized shared decision making based on specific benefit and harms, and patient’s values and preferences.

Implications: The Prostate Cancer Workgroup has been charged with increasing the education of men and providers about shared decision making in prostate cancer screening. The MCR will monitor prostate cancer incidence and mortality trends to assess impacts of the new screening guidelines.
A COMPARISON OF EPIDEMIOLOGIC PATTERNS OF PRIMARY LIVER AND INTRAHEPATIC BILE DUCT CANCER IN MASSACHUSETTS AND ISRAEL, 2002-2011
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Objectives: While geographically distant, Israel (IS) and Massachusetts (MA) are similar in size and population. MA has the 3rd highest Jewish population in the United States (4.2%) and, like IS, a growing immigrant population. The MCR in collaboration with the ICR will examine patterns of liver and intrahepatic cancer in both places from 2002-2011 as well as patterns of risk factors, such as hepatitis B and C infection.

Methods: This study evaluated primary liver and intrahepatic bile duct cancer incidence data from the MCR and the ICR on cases diagnosed from 2002 to 2011. Additionally, data on hepatitis B and C infection and injection drug use were examined from MA and IS.

Results: While incidence trends for liver cancer from 2002 to 2011 have increased significantly for both males and females in MA, no trends were detected in IS. During this period, there were 2,036 cases of liver cancer reported in IS compared to 5,049 reported in MA. In Massachusetts racial/ethnic disparities exist for liver cancer with black, non-Hispanics (NH), Asian, NH, and Hispanics having significantly elevated incidence rates compared to white, NH. In Israel, the incidence rates for 2011 varied by gender and population group with both Jewish and Arab males having higher incidence rates than females. In the Jewish population, incidence was highest in the subgroup born in Africa and lowest in those born in Asia.

Conclusions: In MA the incidence rate of liver cancer has significantly increased in the decade from 2002-2011. This increase may in part be due to hepatitis B and C infection rates. In IS, the trends have remained steady. In both places, the rates among males were higher than females. Further analyses will involve hepatitis B and C and injection drug use patterns in both places. This collaborative effort is an example of international comparisons aiding in understanding cancer epidemiology.

DUCTAL CARCINOMA IN SITU OF THE BREAST: TRENDS IN INCIDENCE AND TREATMENT
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Background: Incidence rates for ductal carcinoma in situ (DCIS) increased rapidly following the introduction of mammography as a population screening tool in the US. Questions remain about the optimal management of this condition. The purpose of this study is to examine recent trends in DCIS incidence and treatment.

Methods: Using data from 13 Surveillance, Epidemiology, and End Results registries, we examined trends in incidence (1992-2011) and treatment (1998-2011) for DCIS for women in 3 age groups (40-49, 50-69, 70+). We also present current treatment patterns (2007-2011) for DCIS patients from 48 states and the District of Columbia.

Results: Incidence rates for DCIS increased rapidly through the late 1990s for all three age groups, followed by a slower rate of increase for women ages 40-49 (2.0% per year) and 70-79 (1.1% per year) and stable rates for women ages 50-69. During 2007-2011, 69% of DCIS patients underwent breast-conserving surgery and 27% underwent mastectomy. Although the proportion of patients undergoing mastectomy for DCIS has remained relatively stable (23%-27%) over the last two decades, the use of bilateral mastectomy has increased from 2% in 1998 to 8% in 2011. However, treatment patterns varied substantially by age. Fifty-three percent of patients under age 40 underwent mastectomy, opting for bilateral mastectomy (28%) slightly more often than unilateral mastectomy (25%). In contrast, 70% of DCIS patients aged 40 and older underwent breast-conserving surgery. Overall, 68% of patients who had breast-conserving surgery received radiation therapy, with lower rates in patients aged 70 and older.

Conclusions: Breast-conserving surgery plus radiation therapy remains the most common treatment for DCIS, but an increasing proportion of women, particularly younger women, elect bilateral mastectomy.
P-35

EXCESS RISK OF SUBSEQUENT PRIMARY CANCERS AMONG BREAST CANCER PATIENTS, 1992-2011
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Background: Excess risk of subsequent cancers has been found among breast cancer patients. Previous population-based studies focused primarily on invasive cancer. The purpose of this study is to evaluate excess risk of subsequent cancers among both in situ and invasive breast cancer patients by age at diagnosis.

Methods: We included first primary female breast cancers diagnosed in 1992-2011 from SEER13. Observed/expected (O/E) and excess absolute risk (EAR) were calculated to assess the risk.

Results: A total of 22,364 breast cancer and 33,215 other cancers were observed among 507,015 women who had survived 2 months or more after a primary breast cancer (416,874 invasive, 90,141 in situ) during 1992-2011. The risk of subsequent breast cancer and other cancers increased by 77% (O/E = 1.77, EAR=26 per 100,000 person-years) and 8% (O/E = 1.08, EAR=7) respectively. Overall, the risk of subsequent breast cancer was higher for in situ (O/E = 2.57, EAR=52) than invasive breast cancers (O/E = 1.59, EAR=20). However a reversed pattern was noted for the risk of other subsequent cancers with in situ having a lower risk (O/E = 1.01, EAR=3) than invasive breast cancer (O/E = 1.10, EAR=8).

The risk of subsequent breast cancer decreased with advancing age for both in situ and invasive breast cancers. However, the excess absolute risk of subsequent corpus and uterus cancer increased with advancing age for both in situ and invasive breast cancers. The excess absolute risk of subsequent breast cancer among in situ patients increased over time (year <1, 1-4, 5-9, and 10+, EAR = 48, 49, 54, 58 respectively), while the risk of subsequent other cancers decreased over time. Invasive breast cancer survivors had the lowest risk of developing any subsequent cancers 1-4 years post-diagnosis.

Conclusions: Excess risk of subsequent cancers varies by type of breast cancer (in situ/invasive), times from the diagnosis of the first cancer, age, and type of subsequent cancer.

Notes

P-36

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Background: Ovarian cancer is of public health concern as it is the 5th most common cancer among women in the United States (US), estimated to account for 21,980 incident cases and 14,270 deaths in 2014. Nationwide, the incidence and mortality rates have been decreasing since the mid-1980s. Data on ovarian cancer in Hispanics is limited so we used data from the New Mexico Tumor Registry (NMTR), the state-wide, population-based central cancer registry, where nearly half of the population is Hispanic (47.3%).

Purpose: To describe trends in ovarian cancer incidence and mortality in Hispanic white (HW) women compared to non-Hispanic white (NHW) women in NM.

Methods: Using data from NMTR, age-adjusted incidence rates were estimated for invasive, epithelial ovarian cancer from 1981 to 2011. Mortality rates were estimated using data from National Center for Health Statistics for all deaths attributed to ovarian cancer from 1992 to 2011 (most of which are due to epithelial ovarian cancer as this represents ~90% of all ovarian cancer). Rates were calculated by the direct method using the 2000 standard US population. Temporal trends and annual percent change (APC) in both rates were determined using SEER*Stat and Joinpoint software.

Results: Between 1981 and 2011 there was a significant reduction in the age-adjusted epithelial ovarian cancer incidence among NHW women in NM (from 13.4 to 10.5 per 100,000, APC=-1.4, p<0.05), and a more modest but significant reduction in HW women (from 8.4 to 7.7 per 100,000, APC=-1.0, p<0.05). A non-statistically significant decrease in the age-adjusted ovarian cancer mortality rates were seen among NHW (APC=-0.7, p=0.1) and HW women (APC=-0.1, p=0.9).

Conclusion: We found that HWs are experiencing a decrease in the incidence of epithelial ovarian cancer, although not as strong as that seen in NHWs. For unknown reasons, this is not accompanied by an analogous decrease in mortality, and should be investigated further.

Notes
NEW USE FOR AN ESTABLISHED BIG DATA SET: APPLYING THE NCDB PARTICIPANT USER FILE TO A LOCAL POPULATION

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Background: The online National Cancer Database (NCDB) tool for survival analysis was used to evaluate the performance of our facility compared to national survival trends for patients diagnosed from 1998-2006. We found that survival rates for our stage IV head and neck cancer patients increased over time more sharply than the national rates for this group during the same time period.

Purpose: We were able to describe multiple factors which changed over time at the local level by querying our cancer registry, but could not determine which reflected national trends and which were specific to our facility. Broadly, literature review indicated that oropharyngeal squamous cell cancer became more common nationally during this time, as it did in our patient population. However, we needed a way to compare cancer characteristics, demographic shifts, and treatment patterns between our facility and the nation to isolate and describe clinically important local trends.

Methods/Approach: The NCDB Participant User File (PUF) has recently been made available via a periodic application process. We obtained nation-wide records for head and neck patients during the studied timeframe. The file includes our variables of interest as well as survival data.

Results: The NCDB PUF provides sufficient data to build a meaningful picture of national trends, against which local performance can be evaluated to identify facility-specific successes.

Conclusion: Our registry plans to present this application of the NCDB PUF to campus clinicians and researchers to encourage use of this available big data set.

SURVIVAL DISPARITIES IN SKIN CANCER FOR PEDIATRIC AND YOUNG ADULT POPULATION IN FLORIDA: ANALYSIS OF POPULATION-BASED CANCER DATA REGISTRY (1981-2009)

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Background: Age and stage at presentation play important roles in skin cancer (SC) prognosis. If diagnosed at an early stage, melanoma can be treatable, with 5-yr survival >90%.

Purpose: We elucidated survival disparities in SC in Floridian pediatric/young adults (0-24 yrs) across sociodemographics like race/ethnicity, socioeconomic status (SES), children (C) (<9yrs), adolescents (A) (9-19), young adults (YA) (20-24). SC included malignant melanoma (MM), UV exposure related (UVR), and Other subtypes.

Methods: Florida Cancer Data System (1981-2009) was linked with US census to explore median survival and 1-, 3-, 5-yr survival rates by sociodemographics. Cox regression models were used to obtain hazard ratio (HR) and 95% confidence interval (95%CI).

Results: There are 1,303 patients who had SC where 63% MM, 18% UVR; 64% YA, 32% A, 4% C; 58% girls; 60% middle-high/highest SES. Overall median survival was 5.8 yrs (95%CI: 4.3-7.3) including MM (7), UVR (4); YA (5.4), A (7.7), C (2.4); Hispanic (7.5), non-Hispanic (5.8); White (5.8), Black (17.2); highest SES (8.3). Overall 1-, 3-, 5-yr survival was 91%, 69%, 55%, respectively. Whites (W) had higher survival than Blacks (B) at 1-yr (W: 91.5%; B: 77.9%) and 5-yr (W: 55%; B: 52%) but similar at 3-yr (B: 69.3%; W: 68.8%). Non-Hispanic survival was comparable to White. 1-yr survival was similar across SES. 5-yr survival was 71% for highest SES but 48-56% for all other SES. At 1-, 3-, 5-yr, children had greatest survival but YA had lowest. 5-yr survival was higher in MM (61%) than UVR (34%). Compared to MM, Other SC subtypes (HR=[1.52]; 1.05-2.21) had significantly worse survival but UVR ([1.33]; 0.73-2.43) did not. Compared to YA, significantly better survival was seen in A (HR=[0.68]; 0.49-0.94) but not C ([2.11]; 0.66-6.75).

Conclusions: It is important to elucidate determinants associated with survival outcomes as SC is on the rise in the pediatric/YA population. Disparities in survival should be addressed to effectively target at-risk populations.
BURDEN OF ADULT SKIN CANCERS IN FLORIDA: ANALYSIS OF POPULATION-BASED CANCER DATA REGISTRY (1981-2009)

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Background: Skin cancer (SC) is the most common cancer in the US; 1-in-5 develops it in their lifetime. SC incidence has increased over the past few decades worldwide - this is a public health threat and warrants study to determine which groups carry the most burden.

Purpose: We report the demographics and survival trends of SC from 1981 to 2009 in the Florida adult population (>18 yrs) to study disparities between certain ethnic, racial, gender, and socioeconomic (SES) groups and SC mortality.

Methods: The Florida Cancer Data System (1981-2009) was linked with US census data to explore median survival and 5-year survival rates by sociodemographics for all SC. Survival was compared by type, gender, race, ethnicity, SES and modeled with Cox regression to calculate hazard ratio (HR) and 95% confidence interval (95% CI).

Results: There were 80,924 patients with SC where 67% had malignant melanoma (MM), 19% UV-related, and 14% other types of skin cancer including 2.4% Merkel Cell Carcinoma (MCC). Majority were male (59.3%), White (99%), middle-high/highest SES (75%), living in urban area (95%) and had localized SC (53%). Overall median survival was 4.5 yrs (95%CI: 4.5-4.6) including MM (4.8), UV related (5.5). Higher median survival time was seen in White (4.5) than Black (3.4), female (5.4) vs male (4.1) and non-Hispanic (4.5) vs Hispanic (3.9). The 5-yr survival rates were higher in UV-related SC (54.3%) than MM (48.7%). Compared to MM, MCC (2.11; 2.01-2.26) and other skin cancer subtypes (1.39; 1.34-1.43) had significantly worse survival, but UV-related SC (0.88, 0.94) had better survival. Significantly worse survival was seen in Black vs White (HR=1.33; 1.19-1.48), Hispanics vs non-Hispanic (1.08; 1.01-1.15) but not female vs male (0.78; 0.76-0.80).

Conclusions: There are survival disparities in skin cancer across types, ethnicities, races, genders, and SES. This study identifies groups with the highest mortality burden in addition to high-risk types of SC.

CANCER INCIDENCE IN ONTARIO FIRST NATIONS ACROSS A 20-YEAR PERIOD USING LINKED REGISTRY DATA

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Background: Information on cancer burden among Ontario’s Aboriginal population is limited, due to lack of race/ethnicity data in Ontario’s health databases. An earlier study used linkage between the Ontario Cancer Registry and the Indian Registry System, which includes identifiers on all First Nations people legally recognized by the federal government, to produce estimates of cancer incidence and survival in Ontario First Nations, between 1968 and 1991. It found that incidence was lower than in the general population but increasing faster, and that survival following a cancer diagnosis was worse. Given that Aboriginal people have high rates of smoking, obesity and alcohol consumption, all important predictors of cancer risk, and suffer from higher rates of comorbidity, it is imperative to continue generating information about cancer to support the need for action.

Purpose: The objective of this study is to estimate cancer burden in Ontario’s First Nations population from 1991 to 2010.

Methods: The Indian Registry System (IRS) has been linked to the Registered Persons Database (RPDB), which includes information on all persons with Ontario health insurance coverage, and the Ontario Cancer Registry using deterministic and probabilistic methods. Incidence, mortality, survival and prevalence rates will be estimated and compared with those for non-Aboriginal Ontarians.

Results: Linkage of the IRS with the RPDB yielded a cohort of about 176,000 First Nations living in Ontario; linkage between the cohort and the Ontario Cancer Registry has yielded 7,400 cancer cases diagnosed between 1991 and 2010. Incidence rates for major cancers, including trends over time, will be presented for Ontario First Nations and the general population.

Conclusions: Findings from this study will help focus efforts towards actions and interventions that can reduce the cancer burden within this population.
RACIAL/ETHNIC DIFFERENCES IN RISK OF SUBSEQUENT INVASIVE BREAST CANCER AMONG WOMEN DIAGNOSED WITH INVASIVE BREAST CANCER AND DUCTAL AND LOBULAR BREAST CARCINOMA IN SITU IN NEW JERSEY, 1992-2012

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Women diagnosed with breast cancer and breast carcinoma in situ are at increased risk for subsequent primary breast cancer, and this risk may vary by race and ethnicity. The risk of developing subsequent invasive breast cancer by race and ethnicity, age group, and histologic subtype was examined in a cohort of 136,561 New Jersey women diagnosed with invasive breast cancer and breast carcinoma in situ from 1992 to 2012, using data from the NJ State Cancer Registry. Standardized incidence ratios (SIR) for invasive breast cancer and 95% confidence intervals (CI) were calculated using the MP-SIR session of SEER*Stat. Compared to the NJ female population, risk of subsequent breast cancer was significantly elevated in the four racial/ethnic groups included in the analysis [whites: SIR=1.41, 95% CI 1.37-1.46; African Americans (AA): SIR=2.50, 95% CI 2.29-2.71; Asian/Pacific Islanders (API): SIR=2.32, 95% CI 1.90-2.80; Hispanics: SIR=2.11, 95% CI 1.86-2.38]. The risk for subsequent breast cancer was significantly elevated during the first 5 years, 5-10 years, and 10+ years after diagnosis of the index cancer. The risk for subsequent breast cancer was highest among the youngest women diagnosed with the initial cancer before age 40, in particular among younger AA and Hispanic women (SIR= 9.19, 95% CI=7.25-11.48; SIR=6.60, 95% CI=4.69-9.02, respectively). The risk for subsequent invasive breast cancer was significantly higher among women initially diagnosed with lobular carcinoma in situ (LCIS) (SIRs 3.01, 4.82, 4.65, 4.68 in whites, AA, API and Hispanics, respectively). Risk for contralateral breast cancer was higher than that for ipsilateral breast cancer. Our findings support the importance of continued surveillance of breast cancer patients, especially AA women, women diagnosed at younger ages, and LCIS patients. The risk of subsequent breast cancer continued to be elevated more than ten years after diagnosis.

Notes

MULTIGENE SIGNATURE METHODS AND RESULTS (SSF22 AND 23) IN BREAST CANCER

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Background: Multigene signature methods and results (SSFs 22 and 23) for breast cancer (BCa) have been required for collection by SEER since 2010. Oncotype DX is the most widely used multigene signature assay in the United States and is included in oncology clinical practice guidelines for early stage [node negative, hormone receptor positive (HR+), HER2 negative, tumor size > 0.5cm] BCasince 2008. Oncotype DX has been validated for risk stratification of distant recurrence and to predict the benefit of chemotherapy in node negative, HR+ disease in 2004. The test was validated for node positive HR+ BCa in 2008 and for ductal carcinoma in situ (DCIS) in 2011.

Purpose: The objective of this study is to assess availability, quality of manual data collection and disparities in who receives Oncotype Dx testing among BCa patients.

Methods: We analyzed cases diagnosed with female BCa in 2010-2012 from SEER 18, for the November 2013 submission. SSF22 was available for 11.9% of selected cases. Among cases that met the guidelines criteria, 27% had the testing. The majority of the tests were Oncotype DX (93.5%), 2.8% had MammaPrint, 2.6% were other tests and in 1.1% with a test performed no specific test was reported. Out of 25,484 tested cases, 81.5% had localized disease (per guidelines), 2.0% had DCIS, 16.1% had lymph node involvement, and 0.4% had distant disease. Concerning BC subtypes, 89.8% were HR+/HER2- (as guidelines recommend), 3.2% were HR+/HER2+, 1.7% were triple negative, 0.4% were HER2+/HR- and in 4.9% the subtype was unknown. In 4,945 cases with Oncotype Dx testing that did not meet the guideline criteria, half had localized disease but the tumor size was < 0.5cm, or were HR-, HER2+ or had unknown HR/HER2 status.

Conclusion: The majority of BCa Oncotype Dx testing met the criteria for testing set in clinical guidelines but there are significant uses of the testing outside the guidelines.

Notes
DATA ANALYTICS AND CANCER DATA: MEANINGFUL CANCER DATA PRESENTATION
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Background: State cancer registries enable public health professionals to study, understand and address the burden of cancer in a state. Registry data are critical for cancer program activities, cancer control, prevention and treatment. Registries have a lot of data available that can be very useful to many stakeholders.

Purpose: Present different ways of making cancer data meaningful, interesting and accessible to stakeholders through visual tools.

Methods: Explore methods of benchmarking and dashboards for cancer registry data. Review and compare tools available to present cancer data in useful ways.

Discussions: Disease registries hold large amounts of data that also needs to be presented in a meaningful way to become useful for various stakeholders.

Conclusions: Disease registries have the ability to make data available in a meaningful way by using tools such as dashboards and score cards and quality reporting. Key components to display are disease registry data reported but also to provide data to reporters.

INCREASE IN RECTAL CANCER DEATH RATES AMONG YOUNG ADULTS IN THE UNITED STATES
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Introduction: Colorectal cancer mortality rates have been decreasing in the United States for several decades, largely as a result of screening in adults 50 and older. Previous studies have reported increasing colorectal cancer incidence rates in adults <50 years, in whom screening is not recommended for those at average risk, but mortality trends for this age group have not been analyzed.

Objective: To assess the temporal trends in colon and rectal cancer mortality rates among adults 20-49 years by sex, race, and 10-year age group.

Methods: Colorectal cancer mortality data for the years 1970-2011 were obtained from the National Center for Health Statistics. Mortality rates for adults 20-49 years were calculated using SEER*Stat software and trends were analyzed using Joinpoint regression. In addition, delay-adjusted incidence trends in the Surveillance, Epidemiology, and End Results (SEER) Program 9 areas were calculated for comparison.

Results: From 1970-2011, 97,057 colon and 24,068 rectal cancer deaths occurred among adults 20-49 years. Colon cancer rates per 100,000 began increasing in 2004 in white males only (1.4% per year). Rectal cancer mortality rates have significantly increased since the mid-1980s in both men and women and in each racial group (2.6% per year in white women; 2.1% in white men; 1.5% in black women; 1.1% in black men). Rectal cancer mortality rates have also significantly increased in each 10-year age group (20-29, 30-39, and 40-49), with the largest percent increase occurring among adults 30-39 (2.6% per year).

Conclusion: In contrast to overall trends, rectal cancer death rates have been increasing in young adults for the past three decades. Further studies are needed to examine the potential causes of this trend.
Merkel Cell Carcinoma in Florida: Analysis from a Population-Based Cancer Data Registry (1981-2009)

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Background: Merkel cell carcinoma (MCC) is an uncommon yet highly aggressive neuroendocrine neoplasm of the skin. The majority of MCC cases are associated with Merkel cell polyomavirus infection. Incidence of MCC has increased over the past few decades.

Purpose: We report sociodemographics and survival of MCC in adult (>18 yrs) Floridians to identify the disparities between gender, racial, ethnic, and socioeconomic (SES) groups and mortality.

Methods: The Florida Cancer Data System (1981-2009) was linked with US census data to explore median survival and 1-, 3-, 5-year survival rates by sociodemographics. Survival was compared by gender, race, ethnicity, SES. Survival was modeled with Cox regression to calculate hazard ratio (HR) and 95% confidence interval (95%CI).

Results: There were 1,951 patients diagnosed with MCC. Majority was male (66.8%), white (99%), never smoked (40%), middle-high/highest SES (66%), living in urban (96%) and had Medicare (60.1%). Overall median survival time was 2.1 yrs (95%CI: 1.9-2.3) where blacks had better survival (4.6; 0.2-10.3) than whites (2.1;1.9-2.3). Overall 5-year survival rate was 21% (18-23) but the rates were higher for blacks (36%; 6-69) than whites (20%;18-23), and non-Hispanics (21%;18-23) than Hispanics (8.3%;2-23). However, 5-year rates were almost comparable between male (19%;17-22) and female (23%;19-28) and across lowest (19%), middle-low (20%), middle-high (21%), highest (22%) SES. Although not statistically significant, black vs. white (HR=0.85; 0.43-1.71) and female vs. male (0.92; 0.81-1.05) showed better survival as opposed to Hispanic vs. non-Hispanics (1.29;0.90-1.83). Compared to the lowest level, patients in the highest SES had significantly better survival (0.78;0.60-0.96).

Conclusion: In Florida, it is evident that there are clear MCC survival disparities across genders, ethnicities, races, and SES. By identifying which groups carry the largest MCC burden, we can establish group-specific screening efforts.
### AUTHOR INDEX

All numbers identify Abstracts and Posters, NOT page numbers

* Indicates Author is Presenter

<table>
<thead>
<tr>
<th>Author</th>
<th>Abstract/Poster Numbers</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>A</strong></td>
<td></td>
</tr>
<tr>
<td>Ackerman, S.</td>
<td>P-03</td>
</tr>
<tr>
<td>Adamo, M.</td>
<td>034</td>
</tr>
<tr>
<td>Ali, S.</td>
<td>P-28*</td>
</tr>
<tr>
<td>Allemari, C.</td>
<td>010*, 012, 070, 080</td>
</tr>
<tr>
<td>Alversen, G.</td>
<td>058</td>
</tr>
<tr>
<td>Amartey, A.</td>
<td>054, P-40*</td>
</tr>
<tr>
<td>Andall-Brereton, G.</td>
<td>053</td>
</tr>
<tr>
<td>Anderson, R.</td>
<td>081</td>
</tr>
<tr>
<td>Andrews, E.</td>
<td>095, 096</td>
</tr>
<tr>
<td>Andrews, P A.</td>
<td>073, 093</td>
</tr>
<tr>
<td>Angel, E</td>
<td>077</td>
</tr>
<tr>
<td>Antao, V.</td>
<td>089</td>
</tr>
<tr>
<td>Aheart, K.</td>
<td>055</td>
</tr>
<tr>
<td>Arias, E.</td>
<td>081*</td>
</tr>
<tr>
<td>Asfar, T.</td>
<td>055*</td>
</tr>
<tr>
<td>Austin, A D.</td>
<td>036</td>
</tr>
<tr>
<td>Ayres, C A</td>
<td>P-01</td>
</tr>
<tr>
<td><strong>B</strong></td>
<td></td>
</tr>
<tr>
<td>Babcock, F.</td>
<td>040, P-24</td>
</tr>
<tr>
<td>Bajracharya, S.</td>
<td>088</td>
</tr>
<tr>
<td>Bannon, F.</td>
<td>010, 012, 070, 080</td>
</tr>
<tr>
<td>Barnholtz-Sloan, J S.</td>
<td>014*, 032*</td>
</tr>
<tr>
<td>Bateman, C.</td>
<td>0-P-02</td>
</tr>
<tr>
<td>Benefield, T.</td>
<td>P-07</td>
</tr>
<tr>
<td>Bittoni, M.</td>
<td>P-11</td>
</tr>
<tr>
<td>Blumenthal, W.</td>
<td>065*, 088</td>
</tr>
<tr>
<td>Bolick, S.</td>
<td>PS12</td>
</tr>
<tr>
<td>Bonaventure, A.</td>
<td>010, 012*, 080</td>
</tr>
<tr>
<td>Bonner, J.</td>
<td>068</td>
</tr>
<tr>
<td>Boscoe, F P.</td>
<td>015*, 069, P-05</td>
</tr>
<tr>
<td>Brat, D J.</td>
<td>014</td>
</tr>
<tr>
<td>Bray, F.</td>
<td>053</td>
</tr>
<tr>
<td>Brierley, J.</td>
<td>033*</td>
</tr>
<tr>
<td>Brittain, J.</td>
<td>025</td>
</tr>
<tr>
<td>Bryant, H.</td>
<td>056</td>
</tr>
<tr>
<td>Butterworth, D.</td>
<td>040</td>
</tr>
<tr>
<td>Byrne, M J.</td>
<td>058, 059, 060</td>
</tr>
<tr>
<td><strong>C</strong></td>
<td></td>
</tr>
<tr>
<td>Canadian Cancer Staging Working Group</td>
<td>033</td>
</tr>
<tr>
<td>Canchola, A.</td>
<td>011</td>
</tr>
<tr>
<td>Carreira, H.</td>
<td>010, 012, 080*</td>
</tr>
<tr>
<td>Celaya, M</td>
<td>P-01*, P-27*</td>
</tr>
<tr>
<td>Centeno, O</td>
<td>P-12</td>
</tr>
<tr>
<td>Cernile, G</td>
<td>035</td>
</tr>
<tr>
<td>Chang, E</td>
<td>037</td>
</tr>
<tr>
<td>Chang, Y K.</td>
<td>036, 048*, P-08</td>
</tr>
<tr>
<td>Charlton, M E.</td>
<td>074*</td>
</tr>
<tr>
<td>Chen, K</td>
<td>P-20</td>
</tr>
<tr>
<td>Chen, HS</td>
<td>PS13, 045</td>
</tr>
<tr>
<td>Chen, V W.</td>
<td>018, 057, 058, 071, 073*, 093, 094, P-24, P-35</td>
</tr>
<tr>
<td>Chen, Y S.</td>
<td>020</td>
</tr>
<tr>
<td>Cheng, I</td>
<td>011, P-26</td>
</tr>
<tr>
<td>Chew, H K</td>
<td>020</td>
</tr>
<tr>
<td>Cho, H</td>
<td>P-10*</td>
</tr>
<tr>
<td>Choi, B J.</td>
<td>036, P-08*</td>
</tr>
<tr>
<td>Choudhury, R</td>
<td>084</td>
</tr>
<tr>
<td>Chrisman, A</td>
<td>039</td>
</tr>
<tr>
<td>Christie, A</td>
<td>P-32</td>
</tr>
<tr>
<td>Clarke, C A.</td>
<td>011, 037, 075</td>
</tr>
<tr>
<td>Coebergh, J W.</td>
<td>030</td>
</tr>
<tr>
<td>Cole, L</td>
<td>058</td>
</tr>
<tr>
<td>Coleman, M P.</td>
<td>010, 012, 070, 080</td>
</tr>
<tr>
<td>CONCORD Working Group.</td>
<td>010, 012, 070, 080</td>
</tr>
<tr>
<td>Cook, L S.</td>
<td>P-36</td>
</tr>
<tr>
<td>Cope, L</td>
<td>P-37</td>
</tr>
<tr>
<td>Copeland, G.</td>
<td>026*, 057, 058</td>
</tr>
<tr>
<td>Couse, M</td>
<td>014</td>
</tr>
<tr>
<td>Cress, R D.</td>
<td>020*, 078</td>
</tr>
<tr>
<td>Cromwell, J W.</td>
<td>074</td>
</tr>
<tr>
<td>Cronin, K.</td>
<td>034, 045, 083, P-18*, P-42</td>
</tr>
<tr>
<td>Cyr, J</td>
<td>PS9, 034</td>
</tr>
<tr>
<td><strong>D</strong></td>
<td></td>
</tr>
<tr>
<td>Dale, D</td>
<td>033</td>
</tr>
<tr>
<td>Davidian, M</td>
<td>PS1</td>
</tr>
<tr>
<td>Day, T</td>
<td>P-37</td>
</tr>
<tr>
<td>de Blank, P M.</td>
<td>032</td>
</tr>
<tr>
<td>Deapen, D.</td>
<td>PS5, PS15, 019, 022, 057, 058</td>
</tr>
<tr>
<td>DeCaria, K.</td>
<td>056</td>
</tr>
<tr>
<td>DeGuire, B.</td>
<td>096</td>
</tr>
<tr>
<td>Depry, F.</td>
<td>007*</td>
</tr>
<tr>
<td>DeSantis, C.</td>
<td>P-34*</td>
</tr>
<tr>
<td>Dibble, R</td>
<td>P-02</td>
</tr>
<tr>
<td>Dietz, N A.</td>
<td>055</td>
</tr>
<tr>
<td>Dolecek, T A.</td>
<td>P-29*</td>
</tr>
<tr>
<td>Dong, X</td>
<td>072</td>
</tr>
<tr>
<td>Dressler, E V.</td>
<td>P-29</td>
</tr>
<tr>
<td>Dunn, E</td>
<td>P-31, P-38*, P-39, P-45</td>
</tr>
<tr>
<td>Durbin, E</td>
<td>PS6, 059, 060*</td>
</tr>
</tbody>
</table>
## AUTHOR INDEX

<table>
<thead>
<tr>
<th>Name</th>
<th>Pages</th>
</tr>
</thead>
<tbody>
<tr>
<td>E</td>
<td></td>
</tr>
<tr>
<td>Eheman, C R</td>
<td>079, P-24</td>
</tr>
<tr>
<td>Engels, E</td>
<td>047</td>
</tr>
<tr>
<td>Ewing, D</td>
<td>078*</td>
</tr>
<tr>
<td>F</td>
<td></td>
</tr>
<tr>
<td>Feuer, E J</td>
<td>PS13, 045, 047, 092</td>
</tr>
<tr>
<td>Fisher, J</td>
<td>P-11</td>
</tr>
<tr>
<td>Flagg, E</td>
<td>057, 058</td>
</tr>
<tr>
<td>Freeman, T</td>
<td>P-16*</td>
</tr>
<tr>
<td>Friese, C</td>
<td>019</td>
</tr>
<tr>
<td>Frizzelle, B</td>
<td>052</td>
</tr>
<tr>
<td>Fung, S</td>
<td>056</td>
</tr>
<tr>
<td>G</td>
<td></td>
</tr>
<tr>
<td>Gail, K</td>
<td>P-26</td>
</tr>
<tr>
<td>Garrett, E</td>
<td>057, 058</td>
</tr>
<tr>
<td>Garrett, A</td>
<td>P-11</td>
</tr>
<tr>
<td>Gene, C</td>
<td>P-32</td>
</tr>
<tr>
<td>George, J A</td>
<td>016, P-06, P-09</td>
</tr>
<tr>
<td>George, J T</td>
<td>P-16, P-17*</td>
</tr>
<tr>
<td>Gersman, S</td>
<td>P-32*, P-33</td>
</tr>
<tr>
<td>Gibson, J T</td>
<td>082, 083</td>
</tr>
<tr>
<td>Giddings, B</td>
<td>P-13, P-14</td>
</tr>
<tr>
<td>Gilijahn, L</td>
<td>050, P-11</td>
</tr>
<tr>
<td>Gillesen, A</td>
<td>095, 096</td>
</tr>
<tr>
<td>Gimotty, P</td>
<td>P-06</td>
</tr>
<tr>
<td>Glaser, S</td>
<td>011, 037*, 075*</td>
</tr>
<tr>
<td>Golden, C</td>
<td>025</td>
</tr>
<tr>
<td>Gomez, S L</td>
<td>011*, 024*, 075, P-26*</td>
</tr>
<tr>
<td>Green, R</td>
<td>P-07</td>
</tr>
<tr>
<td>Greenwood-Hickman, M A</td>
<td>P-07</td>
</tr>
<tr>
<td>Gress, D</td>
<td>034</td>
</tr>
<tr>
<td>Groves, C</td>
<td>034</td>
</tr>
<tr>
<td>Guerry, D</td>
<td>P-06</td>
</tr>
<tr>
<td>Guo, J</td>
<td>050</td>
</tr>
<tr>
<td>H</td>
<td></td>
</tr>
<tr>
<td>Hafterson, J</td>
<td>001, 062</td>
</tr>
<tr>
<td>Haile, R W</td>
<td>P-26</td>
</tr>
<tr>
<td>Halvorson, G</td>
<td>023*</td>
</tr>
<tr>
<td>Hamilton, A</td>
<td>019*</td>
</tr>
<tr>
<td>Hamma, C</td>
<td>061, 064*</td>
</tr>
<tr>
<td>Hands, I</td>
<td>006*</td>
</tr>
<tr>
<td>Hansen, D</td>
<td>P-13, P-14</td>
</tr>
<tr>
<td>Harding, A</td>
<td>096</td>
</tr>
<tr>
<td>Harewood, R</td>
<td>010, 012, 080</td>
</tr>
<tr>
<td>Harrell, J</td>
<td>P-02</td>
</tr>
<tr>
<td>Harris, D</td>
<td>095, 096*</td>
</tr>
<tr>
<td>Harrison, J N</td>
<td>087*</td>
</tr>
<tr>
<td>Hebert, L</td>
<td>043</td>
</tr>
<tr>
<td>Helgerson, S</td>
<td>089</td>
</tr>
<tr>
<td>Henderson, L M</td>
<td>P-07</td>
</tr>
<tr>
<td>Henley, J</td>
<td>P-22</td>
</tr>
<tr>
<td>Herly, K A</td>
<td>049*</td>
</tr>
<tr>
<td>Herget, K</td>
<td>P-02</td>
</tr>
<tr>
<td>Hernandez, J</td>
<td>056</td>
</tr>
<tr>
<td>Hernandez, M</td>
<td>068*</td>
</tr>
<tr>
<td>Hoots, T</td>
<td>P-07</td>
</tr>
<tr>
<td>Howlader, N</td>
<td>013, 047*, P-42</td>
</tr>
<tr>
<td>Hrabe, J E</td>
<td>074</td>
</tr>
<tr>
<td>Hsieh, M C</td>
<td>018, 038, 071*, 073, 093, 094*</td>
</tr>
<tr>
<td>Hu, L</td>
<td>P-26</td>
</tr>
<tr>
<td>Huang, B</td>
<td>004, 013, 038, 050*, 060</td>
</tr>
<tr>
<td>Huang, HH</td>
<td>P-20*</td>
</tr>
<tr>
<td>Hudson, A</td>
<td>050</td>
</tr>
<tr>
<td>Hurley, D</td>
<td>009</td>
</tr>
<tr>
<td>Hurley, S</td>
<td>011</td>
</tr>
<tr>
<td>Hyams, E S</td>
<td>P-27</td>
</tr>
<tr>
<td>I</td>
<td></td>
</tr>
<tr>
<td>Induni, M</td>
<td>061</td>
</tr>
<tr>
<td>Ingimarsson, J P</td>
<td>P-27</td>
</tr>
<tr>
<td>Inudi, M</td>
<td>023</td>
</tr>
<tr>
<td>Ivey, M</td>
<td>053</td>
</tr>
<tr>
<td>J</td>
<td></td>
</tr>
<tr>
<td>Jackson-Thompson, J</td>
<td>051, 067*, P-03, P-30, P-43</td>
</tr>
<tr>
<td>Jain, P</td>
<td>086</td>
</tr>
<tr>
<td>Jemal, A</td>
<td>030, 038, P-34, P-44</td>
</tr>
<tr>
<td>Ji, L</td>
<td>039</td>
</tr>
<tr>
<td>Johnson, C J</td>
<td>009*, 015</td>
</tr>
<tr>
<td>Jones, C</td>
<td>P-40</td>
</tr>
<tr>
<td>Jones, S</td>
<td>065, 088*</td>
</tr>
<tr>
<td>Judson, D</td>
<td>025</td>
</tr>
<tr>
<td>Juhasz, R</td>
<td>019</td>
</tr>
<tr>
<td>Jung, K-W</td>
<td>P-10</td>
</tr>
<tr>
<td>K</td>
<td></td>
</tr>
<tr>
<td>Karlitz, J J</td>
<td>018, 073</td>
</tr>
<tr>
<td>Katz, S</td>
<td>PS3, 019</td>
</tr>
</tbody>
</table>
AUTHOR INDEX

Ke, M ........................................... 048, P-08
Keegan, T H M ............................... 011, 024, 037, 075
Kelly, J J ........................................ P-19
Khan, S .......................................... P-40
Kim, B-W ........................................ P-10
King, M J ......................................... 003*
King, J ............................................ 079, P-22
Kizer, K W ....................................... 020, 076, 077
Klaus, C ......................................... 002*
Knop, G .......................................... P-07
Knowlton, R ................................. P-33
Koch, L .......................................... 043*
Kollman, J ....................................... P-11
Kong, H-J ........................................ P-10
Koru-Sengul, T ......................... P-15*, P-31, P-38, P-39, P-45
Kosary, C ................................. 034, 035*
Krakoff, M ................................. PS13, 045
Kruckko, C ................................. 004, 013, 014, 032
Kukreti, V ........................................ 044
Kuo, T-M ................................. .036, 052*, P-08
Kurian, A ........................................ 019
Kwan, D ........................................... 086

L

Lake, A ........................................ PS13
Lambe, M ........................................ 027
Langlo, C ........................................ 026
Larson, T ........................................ 089
Laura, G .......................................... P-08
Laviolette, M .................................. P-27
Leadbetter, S ................................... 029
LeBlanc, W G .................................. 028
Lee, D J ......................................... .028*, 055
Lee, B L .......................................... P-20
Lee, G .......................................... 086*
Lefante, J ....................................... 071
Lefante, C ....................................... 071
Leung, G ........................................ P-28
Lewis, D R ................................. 045*
Li, X-R ......................................... 038, 073, P-35*
Lichtensztajn, D .......... P-13, P-14
Lin, C ............................................. 074
Lin, CC ........................................... 030
Liu, B ........................................... 034, 092*
Liu, J ............................................. 056
Liu, L ............................................. 022*
Liu, M ........................................... P-29
Loch, M M ...................................... 073, 093
Lockwood, G ......................... 033, 056
Lortet-Tieulent, J ...................... 030*
Louis, D N ...................................... 014
Louzado, C ..................................... 056
Lozon, N L ................................. .063*, P-06, P-09
Lupo, P ........................................... 026
Lym, R L .......................................... 014
Lynn, M .......................................... P-11

M

MacMillan, A ................................... P-32
Magan, C ....................................... 039
Manzon, A ...................................... 044
Maraf, S ........................................ P-23*
Mariotto, A B ................................. 009
Marret, L D ................................. 054, P-40
Marsh, M ........................................ P-07*
Martin, D ........................................ 053*
Martinez, M .................................... 011
Martinsen, R ................................. P-13*, P-14*
McClure, L A ................................. 028
McDowell, B D ................................ 074
McFadden, S ................................... P-02*
McIntyre, M ................................... 033
McKinley, M .................................... P-26
McLaughlin, R ................................ 024
Meisner, A ....................................... P-36
Meng, K ........................................... 036*
Merriam, G ..................................... P-32
Mery, L ........................................... 031, 053
Meyer, A-M ................................. 036, 048, 052, P-08
Meyer, A ........................................ PS8, 052, P-08
Miao, F ......................................... P-31*, P-38, P-39, P-45
Midkiff, K ....................................... 095*
Midthune, D .................................. PS13, 045
Miller, D ........................................ PS13
Miller, E A ....................................... 025*, 028
Miller, K D ....................................... P-44*
Moldwin, R ..................................... 088
Moller, B ........................................ 029
Moody, C ........................................ 021*
Moore, K ....................................... P-31, P-38, P-39*, P-45*
Moravan, V .................................... 046
Morgan, J W .................................... 039*
Morris, C R ......................... 020, 076, 077*, 094, P-13, P-14, P-24
<table>
<thead>
<tr>
<th>Name</th>
<th>Page Refs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nagaraj, S</td>
<td>066</td>
</tr>
<tr>
<td>Negoiita, S</td>
<td>034</td>
</tr>
<tr>
<td>Nicolin, P</td>
<td>063</td>
</tr>
<tr>
<td>Nielsen, M</td>
<td>036</td>
</tr>
<tr>
<td>Nishri, E D</td>
<td>.003, 046*, 054, 070, P-40</td>
</tr>
<tr>
<td>Niu, X</td>
<td>P-41</td>
</tr>
<tr>
<td>Noone, A-M</td>
<td>.034*, 035</td>
</tr>
<tr>
<td>Nyambose, J</td>
<td>P-32</td>
</tr>
<tr>
<td>O'Flarity, M B</td>
<td>073, 094</td>
</tr>
<tr>
<td>O'Neil, M E</td>
<td>079, P-22, P-24*</td>
</tr>
<tr>
<td>Oancea, S C</td>
<td>P-21*</td>
</tr>
<tr>
<td>O'Brien, D K</td>
<td>090*</td>
</tr>
<tr>
<td>Oh, C-M</td>
<td>P-10</td>
</tr>
<tr>
<td>Olowokure, B</td>
<td>053</td>
</tr>
<tr>
<td>Ostrom, Q T</td>
<td>014, 032</td>
</tr>
<tr>
<td>Paddock, L</td>
<td>084*</td>
</tr>
<tr>
<td>Padron, W</td>
<td>P-03*</td>
</tr>
<tr>
<td>Parekh, V</td>
<td>088</td>
</tr>
<tr>
<td>Parikh-Patel, A</td>
<td>.076*, 077</td>
</tr>
<tr>
<td>Parrish, P</td>
<td>043</td>
</tr>
<tr>
<td>Paskett, E</td>
<td>P-11</td>
</tr>
<tr>
<td>Patel, M</td>
<td>P-26</td>
</tr>
<tr>
<td>Patel, P</td>
<td>P-30*</td>
</tr>
<tr>
<td>Patierno, S</td>
<td>PS2</td>
</tr>
<tr>
<td>Pawlish, K S</td>
<td>P-41*</td>
</tr>
<tr>
<td>Pearson, J</td>
<td>091</td>
</tr>
<tr>
<td>Penberthy, L</td>
<td>.034, P-18, P-42</td>
</tr>
<tr>
<td>Pestak, C</td>
<td>P-36*</td>
</tr>
<tr>
<td>Peterson, M</td>
<td>052</td>
</tr>
<tr>
<td>Petkov, V</td>
<td>.017*, P-42*</td>
</tr>
<tr>
<td>Pickle, L</td>
<td>091</td>
</tr>
<tr>
<td>Pinder, R</td>
<td>005*</td>
</tr>
<tr>
<td>Pinheiro, P</td>
<td>024</td>
</tr>
<tr>
<td>Potts, M</td>
<td>.001*, 062*</td>
</tr>
<tr>
<td>Prummel, M V</td>
<td>054*</td>
</tr>
<tr>
<td>Qiao, B</td>
<td>038, 069</td>
</tr>
<tr>
<td>Quesnai-Crooks, S</td>
<td>053</td>
</tr>
<tr>
<td>Rachet, B</td>
<td>070</td>
</tr>
<tr>
<td>Radhakrishnan, S</td>
<td>P-25*</td>
</tr>
<tr>
<td>Raftery, A</td>
<td>P-25*</td>
</tr>
<tr>
<td>Rahal, R</td>
<td>056</td>
</tr>
<tr>
<td>Ransdell, P</td>
<td>085*</td>
</tr>
<tr>
<td>Rao, C</td>
<td>042</td>
</tr>
<tr>
<td>Rees, J R</td>
<td>P-01, P-27</td>
</tr>
<tr>
<td>Ren, Y</td>
<td>072</td>
</tr>
<tr>
<td>Richardson, L</td>
<td>PS14</td>
</tr>
<tr>
<td>Rico, A</td>
<td>.018*</td>
</tr>
<tr>
<td>Riddle, S</td>
<td>.061, 064, P-04*</td>
</tr>
<tr>
<td>Rogers, J</td>
<td>065, 088</td>
</tr>
<tr>
<td>Rold, N</td>
<td>P-03</td>
</tr>
<tr>
<td>Román, Y</td>
<td>P-12</td>
</tr>
<tr>
<td>Roschala, W</td>
<td>.041*, P-04</td>
</tr>
<tr>
<td>Ross, F</td>
<td>PS11, 085</td>
</tr>
<tr>
<td>Rouse, C</td>
<td>032</td>
</tr>
<tr>
<td>Ruppert, L</td>
<td>P-25</td>
</tr>
<tr>
<td>Rush-George, P</td>
<td>P-09</td>
</tr>
<tr>
<td>Ryan, L</td>
<td>065</td>
</tr>
<tr>
<td>Rycroft, R</td>
<td>PS10</td>
</tr>
<tr>
<td>Ryerson, B</td>
<td>P-22</td>
</tr>
<tr>
<td>Salahuddin, N</td>
<td>066*</td>
</tr>
<tr>
<td>Salcido, J</td>
<td>032</td>
</tr>
<tr>
<td>Sandin, F</td>
<td>027</td>
</tr>
<tr>
<td>Sandoval, C</td>
<td>056</td>
</tr>
<tr>
<td>Sanoff, H</td>
<td>048</td>
</tr>
<tr>
<td>Saraiya, M</td>
<td>053</td>
</tr>
<tr>
<td>Schade, T L</td>
<td>P-19*</td>
</tr>
<tr>
<td>Scharber, W</td>
<td>065, 088</td>
</tr>
<tr>
<td>Scheuer, M</td>
<td>026</td>
</tr>
<tr>
<td>Schlichting, J A</td>
<td>.074</td>
</tr>
<tr>
<td>Schmaltz, C</td>
<td>.051*, P-30</td>
</tr>
<tr>
<td>Schmidt, B</td>
<td>058</td>
</tr>
<tr>
<td>Schussler, N</td>
<td>034</td>
</tr>
<tr>
<td>Schymura, M J</td>
<td>069*</td>
</tr>
<tr>
<td>Scoppa, S</td>
<td>PS13, 082</td>
</tr>
<tr>
<td>Secord, S</td>
<td>056</td>
</tr>
<tr>
<td>Semenciw, R</td>
<td>031</td>
</tr>
<tr>
<td>Sens, M A</td>
<td>P-21</td>
</tr>
<tr>
<td>Shelton, B</td>
<td>059</td>
</tr>
<tr>
<td>Shen, X</td>
<td>P-16</td>
</tr>
<tr>
<td>Sherman, R L</td>
<td>.004*, 013*, 038, 049</td>
</tr>
<tr>
<td>Shore, R</td>
<td>.016, P-06*, P-09</td>
</tr>
<tr>
<td>Siegel, R L</td>
<td>P-44</td>
</tr>
</tbody>
</table>

**AUTHOR INDEX**
AUTHOR INDEX

Silverman, B ................................................. P-33
Simoes, E .................................................. P-43
Sineshaw, H M .............................................. 038*
Singh, N .................................................... P-04
Singh, S ..................................................... P-22*
Smith, A ..................................................... 036
Sobotka, H .................................................. P-11
Soerjomataram, I ........................................ 030
Solimani, N .................................................. 044*
Soman, A ..................................................... 029
Spika, D ...................................................... 010, 012, 070*, 080
States, L ..................................................... 039
Stattin, P ..................................................... 027*
“System Performance” Steering Committee
and Technical Working Group .......................... 056
Stephens, J .................................................. P-11
Stern, M C ................................................... 022
Stinchcomb, D G ............................................ 049, 082*
Stoyanoff, S .................................................. 058
Group ...................................................... 084, P-41
Styles, T S ................................................... 040*, 093, 094, P-24
Sullivan, R ................................................... 010
Sun, L ......................................................... 034
Sweeney, C .................................................. P-02

T
Tannenbaum, S L .......................................... 028
Theis, B ...................................................... 046
Thompson, T .............................................. 018, 029, 093, 094
Torode, J ..................................................... 053
Torres, C R ................................................... P-12*
Torruellas, C ............................................... 078
Trailer, T ..................................................... P-16
Tran, K ....................................................... 056*
Tucker, T C .................................................. PS4, 010, 050, 057, 058, 059*, 060
Turner, D .................................................... 009

V
Vázquez, N ................................................... P-12
Vigneau, F ................................................... 016, 063, P-06, P-09*
Villano, J L ................................................... 024

W
Wakelee, H A .................................................. P-26
Ward, E ....................................................... P-34
Ward, K ....................................................... 019, 034
Warren, J .................................................... P-18
Warther, B ................................................... P-11
Watson, M ................................................... .057*, 058*
Weatherby, B ............................................. 065
Weier, R ..................................................... P-11*
Weir, H K ................................................... 009, 012, 029*
West, D ...................................................... 018, 023, 040, 077
Wheeler, S .................................................. 052
White-Gilbertson, S .................................... P-37*
Whitlock, J ................................................... .016*, P-06, P-09
Wiggins, C ................................................... P-36
Williamson, L ............................................. 089*
Wilson, R J .................................................. 009, 040, 072, 079*, P-22
Wohler-Torres, B ........................................ 038
Wolf, N ....................................................... 044
Wolinsky, Y .................................................. 032
Won, Y-J ..................................................... P-10
Woods, L M .................................................. 070
Wright, K B .................................................. 074
Wu, M ......................................................... 013, 038, 040
Wu, X C ..................................................... 004, 013, 018, 038, 073, 093*, 094, P-35

X
Xie, L .......................................................... 031*

Y
Yang, J ......................................................... 024
Yemane, S ................................................... P-03, P-30
Young, M .................................................... 043
Young, S .................................................... 054
Yu, M ......................................................... 082, 083*
Yu, Q ......................................................... 038, 071
Yuen, J S P ................................................... P-20

Z
Zachary, I ................................................... 051, P-43*
Zavala, D ................................................... P-12
Zephyr, D ................................................... 050
Zhang, J ..................................................... 022
Zhang, K ..................................................... 072*
Zhang, L ..................................................... 073
Zhang, X ..................................................... .069, P-05*
Zheng, Y ..................................................... P-21
Zhou, L ...................................................... 036, 048, P-08
Zhou, M ..................................................... 093
Zhou, X ..................................................... P-21
Zhu, L ......................................................... 091*
Ziegler, K ................................................... .061*, 064
Zou, Z ......................................................... PS13
### PROGRAM-AT-A-GLANCE

<table>
<thead>
<tr>
<th>TIME</th>
<th>MONDAY, JUNE 15</th>
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<td>8:00</td>
<td>COMMUNICATIONS STEERING COMMITTEE MEETING</td>
<td>NAACCR ROUNDTABLE (Grand Ballroom A, Level 2; 7:00 am - 8:00 am)</td>
<td>BIRDS OF A FEATHER ROUNDTABLE (Grand Ballroom A, Level 2; 7:00 am - 8:00 am)</td>
<td>NAACCR 2015 5K RUN/WALK (Meet in Hotel Lobby; 6:30 am)</td>
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<td>Communications Priority Area Network Meeting (Tryon Room, Level 2; 8:15 am - 10:15)</td>
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<td>PROFESSIONAL DEVELOPMENT STEERING COMMITTEE</td>
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<td>12:00 pm</td>
<td>BOARD/CHAIR TRAINING (Independence Room, Level 2; 12:00 pm - 2:00 pm)</td>
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**Plenary Sessions**

- **Keynote Address**: (Providence Ballroom, Lobby Level; 8:30 am - 10:00 am)
- **Plenary Session 2**: Big Data! (Providence Ballroom, Lobby Level; 8:30 am - 9:45 am)
- **Plenary Session 3**: (Various Rooms; 10:00 am - 11:30 am)
- **Plenary Session 4**: (Various Rooms; 8:00 am - 9:30 am)
- **Plenary Session 5**: (Various Rooms; 1:00 pm - 2:30 pm)
- **Plenary Session 6**: (Various Rooms; 9:00 am - 10:30 am)

**Concurrent Sessions**

- **Concurrent Session 1**: (Various Rooms; 1:30 pm - 3:00 pm)
- **Concurrent Session 2**: (Various Rooms; 3:30 pm - 5:00 pm)
- **Concurrent Session 3**: (Various Rooms; 10:00 am - 11:30 am)
- **Concurrent Session 4**: (Various Rooms; 8:00 am - 9:30 am)
- **Concurrent Session 5**: (Various Rooms; 1:00 pm - 2:30 pm)
- **Concurrent Session 6**: (Various Rooms; 9:00 am - 10:30 am)

**Committee Meetings**

- **Professional Development Steering Committee**: (Independence Room, Level 2; 8:45 am - 10:45 am)
- **Research & Data Use Steering Committee**: (Sharon Room, Level 2; 10:30 am - 12:00 pm)
- **Research & Data Priority Area Network Meeting**: (Harris Room, Level 2; 10:00 am - 11:00 am)
- **Research & Data Use Steering Committee**: (Harris Room, Level 2; 10:00 am - 11:00 am)

**Other Sessions**

- **NEXUS TABLET DRAWING**: (Grand Ballroom C/D, Level 2; 10:00 am - 11:00 am)
- **NEXUS TABLET DRAWING**: (Grand Ballroom C/D, Level 2; 10:00 am - 11:00 am)

**Break/Lunch**

- **Break (Grand Ballroom C/D, Level 2; 9:30 am - 10:00 am)**
- **Break (Grand Ballroom C/D, Level 2; 9:30 am - 10:00 am)**

**Awards Luncheon**

- **Exhibitor Showcase and Poster Pre-Viewing**: (Grand Ballroom C/D, Level 2; 5:30 pm - 7:00 pm)
- **Exhibitor Showcase and Poster Pre-Viewing**: (Grand Ballroom C/D, Level 2; 5:30 pm - 7:00 pm)