NAACCR 2013 CONFERENCE final program



THINKING BIG: The Future of Cancer Surveillance

Annual Conference and Workshops of the North American Association of Central Cancer Registries

Austin, Texas June 8 - 14, 2013 Hilton Austin





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NATIONAL CANCER INSTITUTE

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Statistics Statistique Canada Canada

Exhibitor

WESTAT

1600 Research Boulevard, Rockville, MD 20850 - 3129 United States Tel: 301-251-1500 Contact: Marsha Dunn Email: marshadunn@westat.com







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Welcome to NAACCR 2013





Welcome to NAACCR 2013

On behalf of the Board of Directors and the Program Committee, we welcome you to Austin, Texas, the host city of the 2013 Annual Conference of the North American Association of Central Cancer Registries (NAACCR). We hope you will enjoy participating in the Conference, as well as the pre- and post-conference courses.

The theme for the 2013 Conference is "*Thinking Big: The Future of Cancer Surveillance*," highlighting innovative and creative ideas for how science, technology, policy, and collaboration can shape the future of cancer surveillance. The plenary sessions will begin with a look back at past innovations and collaborations, how they have shaped our present, and opportunities for the future. Other plenary themes include information technology, the emergence of cancer care plans and the role of registries with survivorship, and comparative effectiveness consideration of screening and treatment outcomes. The speakers for each of these plenary sessions are recognized leaders in their areas of specialty.

The goals of this program are to not only hold a stellar scientific and thought provoking meeting, but to also recognize the leadership, critical work, and outstanding accomplishments that NAACCR, its membership, and partners continue to contribute to the greater cancer community. Oh, and let's not forget, it is absolutely required that while in Austin, you pull yourself up by the boots, and have a rockin' good time! In addition to the thought-provoking scientific agenda, we encourage you to take advantage of the many other educational and recreational activities available during the 2013 Annual Conference. The Birds of a Feather will continue their early morning discussions, and run/walk and biking events will once again be offered. You also won't want to miss the entertainment in the "Live Music Capital of the World." And if you feel like taking a walk on the wild side in the town whose motto is "Keep Austin Weird," then visit the largest urban bat colony in North America, scoot or cycle your boots around the beautiful Lady Bird Johnson Lake, or visit some of the over 100 restaurants and nightclubs along Sixth Street, the Warehouse District, and South Congress Avenue. All of this is within walking distance or a short pedicab ride from the Hilton Conference Hotel.

It is an honor to host the NAACCR 2013 Annual Conference and its attendees in Texas, and we hope ya'll thoroughly enjoy your time in Austin.

Melanie Williams

Melanie Williams, PhD Chair, NAACCR 2013 Annual Conference

Message from the President

NAACCR Members and Meeting Attendees

Welcome to Austin and the 2013 NAACCR Annual Conference. I look forward to 'Thinking Big' with fellow NAACCR members, staff and other partners who have journeyed to this beautiful city.

Today, working in the cancer surveillance field is definitely not for the faint of heart. The pressures impacting the work we do are many and varied, and they are being been felt to some degree in every central registry across North America. Examples include: the economic and political realities that continue to challenge our resource base; development of consensus on data standards that requires new partnerships with organizations outside the traditional surveillance community; and, electronic medical records that promise more timely and accessible data, but where implementation still remains largely out of reach.

With so much change affecting how we do business, an annual meeting becomes an important opportunity to exchange ideas and allow the tremendous creativity of NAACCR members to flourish. Solutions and new pathways for improving cancer surveillance will come from the professionals who know this work inside out. I challenge all meeting attendees to be part of the change that is needed to ensure cancer registration remains a vital component of future cancer control models. As you attend the plenary and concurrent sessions this week, be open to new ideas and consider how to apply what you learn when you return home. Once the meeting is over, think about how you can continue to stay connected to what is happening across the NAACCR organization and with its members.

Thank you to our hosts from the Texas Cancer Registry, the Program Committee and the Abstract Review Group for organizing an excellent agenda. The vibrant and energetic city of Austin is a perfect location for NAACCR members to meet and 'Think Big' about the future of cancer surveillance.

Mauren Reitz

Maureen MacIntyre, MHSA NAACCR Board President



Conference Objectives

GENERAL INFORMATION

This year's conference, "Thinking Big: The Future of Cancer Surveillance," will explore innovative and creative ideas for how science, technology, policy, and collaboration can shape the future of cancer surveillance. The focus of presentations will be on future directions, both realized and potential, from multiple perspectives on cancer surveillance in North America. Plenary sessions will offer national experts in the areas of cancer prevention and control, policy, health

information technology, survivorship, and comparative effectiveness research. Conference objectives also include showcasing a wide range of innovative data collection, registry operations, informatics projects, research, and collaborations through oral and poster presentations. Most importantly, attendees are encouraged to "think big," and have no limits as they vision with NAACCR about the future of cancer surveillance.

NAACCR Board 2012-2013

PRESIDENT



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2012-2014

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Program Committee

GENERAL INFORMATION

Member

Affiliation

Melanie Williams	Texas Cancer Registry (Chair)
Peggy Adamo	National Cancer Institute
Frances Babcock	Centers for Disease Control and Prevention
Charlie Blackburn	NAACCR
Tara Blando	United States Navy and Marine Public Health Center
Carol Burke	Pardee Hospital
Myles Cockburn	Los Angeles Cancer Surveillance Program
Mignon Dryden	Cancer Registries of Central and Northern California
Cynthia Dryer	State Health Registry of Iowa
Brenda Edwards	National Cancer Institute
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Jim Martin	Virginia Cancer Registry
Les Mery	Public Health Agency of Canada
Donna Morrell	Los Angeles Cancer Surveillance Program
Anne Pate	Oklahoma Central Cancer Registry
Susan Perez	Texas Cancer Registry
Edward Peters	Louisiana Tumor Registry
Rich Pinder	Los Angeles Cancer Surveillance Program



Chandrika Rao	North Carolina Central Cancer Registry
Karen Robbins	James H. Quillen VA Medical Center
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Recinda Sherman	Florida Cancer Data System
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Stacey Wan	Canadian Cancer Registry
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Conference Information

GENERAL INFORMATION

CONFERENCE REGISTRATION INFORMATION

The Conference Registration and Information Desk is located outside Salon H on the 6th Floor and is open during the following days and times:

Monday, June 10 Tuesday, June 11 Wednesday, June 12 Thursday, June 13 9:00 am to 7:00 pm 7:00 am to 5:00 pm 7:00 am to 12:30 pm 7:00 am to 10:30 am

Pre- and Post-Conference registration and check-in desks are located outside the Pre- and Post-Conference rooms.

Any inquiries about the conference, social functions, etc., may be answered by any of the staff at the registration desk. Registered participants will receive their conference documents and badges at the registration desk. Please note that entrance to the Reception and Awards Luncheon is by ticket only. Please be sure you wear your name badge to all social events, workshops, and sessions.

PLENARY SESSIONS / BUSINESS MEETING

All Plenary Sessions, Concurrent Sessions and the Business Meeting will take place on the 6th Floor. The Plenary Sessions and the Business Meeting will be held in Salon JK.

OPENING RECEPTION

Tuesday, June 11, 2013

The Opening Reception will be held in Salon JK on the 6th Floor at 6:30 pm. It serves as the perfect gathering place to enjoy networking, light refreshments, fabulous foods, and some unique entertainment.

CONTINUING EDUCATION CREDITS

Continuing Education credit is provided by the National Cancer Registrars Association (NCRA). You can conveniently download the 2013 NAACCR Annual Conference CE Hours Form from the NAACCR website at

www.naaccr.org/educationandtraining/annualconference.aspx.

EXHIBITS AND POSTER INFORMATION

Exhibits and Posters are located in Salon H on the 6th Floor.

All delegates are encouraged to take the opportunity to visit the exhibits and posters to become familiar with some of the latest advances and research in the field.

They are available at these times:

Exhibit Hours

Monday, June 10	5:30 pm to 7:00 pm
Tuesday, June 11	7:00 am to 5:00 pm
Wednesday, June 12	7:00 am to 12:30 pm
Thursday, June 13	7:00 am to 12:30 pm

CYBER CAFÉ

The Cyber Café is located within the Exhibit area and can be accessed during exhibition hours.

CONFERENCE EVALUATIONS

2013 conference evaluations are available in electronic format only.

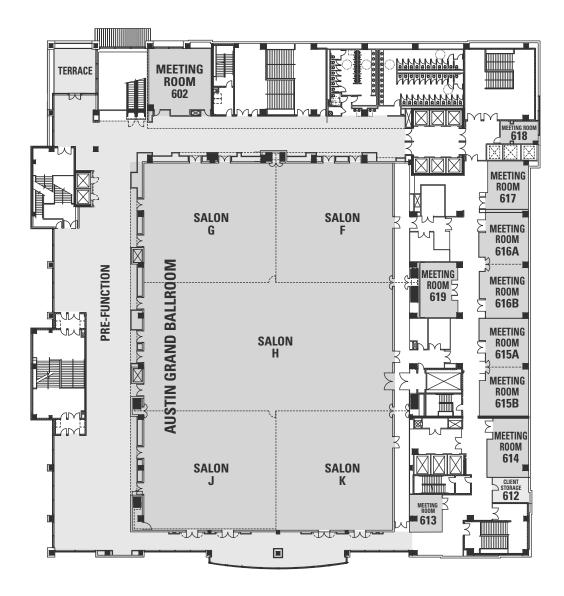
Please visit <u>www.naaccr.org/educationandtraining/annualconference.aspx</u> to complete your evaluation. All delegates will be emailed reminders and links to the evaluation forms after the conference.





Floor Plan Hilton Austin

SIXTH FLOOR







Program & Agenda

PROGRAM

SATURDAY, JUNE	8 PRE-CONFERENCE	MONDAY, JUNE 1	0 PRE-CONFERENCE
8:00 am - 5:00 pm	BioMedware Cryptography Meeting (Invitation only) MEETING ROOM 616B	7:00 am - 8:30 am	NAACCR Board Wrap Up Meeting (if required) MEETING ROOM 617
8:30 am - 5:30 pm	Basic SEER*Stat Software Training C. Kosary, National Cancer Institute MEETING ROOM 615A	8:00 am - 12:00 pm	SEER*Prep Software Training <i>C. Kosary, National Cancer Institute</i> MEETING ROOM 614
12:30 pm - 5:00 pm	Short Review Course: Central Cancer Registries (Day 1)	9:00 am - 7:00 pm	Registration PREFUNCTION SALON H
	H. Menck, FACE MEETING ROOM 615B	1:00 pm - 5:00 pm	Exhibit Set-up SALON H
SUNDAY, JUNE 9	PRE-CONFERENCE	1:00 pm - 5:00 pm	Poster Set-up SALON H
8:00 am - 12:00 pm	Using Geocoded Data in Cancer Registry Research and Practice <i>R. Sherman, Florida Cancer Data System</i> MEETING ROOM 616A	5:30 pm - 7:00 pm	Exhibit Showcase Poster Preview Be sure to connect with your colleagues at the Exhibitor Showcase and Poster Preview. Visit vendors, preview posters,
8:00 am - 4:15 pm	Short Review Course: Central Cancer Registries (Day 2) <i>H. Menck, FACE</i>		have a nibble, and enter a door prize give-away drawing. Cash bar available. SALON H
8:00 am - 5:00 pm	MEETING ROOM 615B BioMedware Cryptography Meeting	7:00 am - 7:00 pm	Steering Committee and Workgroup Meetings
	(Invitation only) MEETING ROOM 616B	10:00 am - 11:30 am	Professional Development and Recruitment Steering Committee
8:00 am - 5:00 pm	NAACCR Board Meeting MEETING ROOM 602	12:00 pm - 1:30 pm	SALON G Standardization and Registry
8:30 am - 5:30 pm	Advanced SEER*Stat Software Training C. Kosary, National Cancer Institute	12.00 pm 1.00 pm	Development Steering Committee SALON F
1:00 pm - 5:00 pm	MEETING ROOM 615A Using SaTScan for Cancer Surveillance F. Boscoe, New York State Cancer	3:00 pm - 4:30 pm	Research and Data Use Steering Committee MEETING ROOM 616AB
	Registry MEETING ROOM 616A	4:30 pm - 6:00 pm	Strategic Alliances Steering Committee MEETING ROOM 602
		5:00 pm - 6:00 pm	Communications Steering Committee



NAACCR 2013 CONFERENCE June 8 - 14, 2013 14



(Open to Priority Area Network)

MEETING ROOM 615AB

TUESDAY, JUNE 1	1 CONFERENCE DAY 1	(
6:30 am - 8:00 am	Breakfast SALON H	1
7:00 am - 5:00 pm	Registration PREFUNCTION SALON H	E
7:00 am - 5:00 pm	Exhibits and Posters Open SALON H	۸ (
8:00 am - 8:30 am	Opening Ceremonies and Welcome Melanie Williams, Ph.D., Texas Cancer Registry SALON JK	C
Plenary Session 1 SALON JK		(
8:30 am -10:00 am	Thinking Big: Vision and Future Directions Moderator: Tom Tucker, Ph.D., Kentucky Cancer Registry	
	How Will the Future Be Measured? Armin Weinberg, Ph.D., Chief Executive Officer, Life Beyond Cancer	۸ (
	Late Breaker Topic	
10:00 am -10:30 am	Break/Poster Viewing/Exhibits SALON H	C
Plenary Session 2 SALON JK		C
10:30 am - 12:00 pm	Doing the NAACCR Two-Step: Health and Information Technology Moderator: David Stinchcomb, Westat	C
	The ONC Vision for Health Information Technology and Public Health James Daniel, MPH, Public Health Coordinator, Office of the National Coordinator for Health IT	e A N
	IBM Watson: Transforming Cancer Data and Healthcare Rob High Jr., IBM Fellow, Vice President and Chief Technology Officer, Watson Solutions, IBM Software Group	0
12:00 pm -1:30 pm	Lunch (on your own)	C
12:30 pm	Cancer Survival in Appalachia MEETING ROOM 614	C

Concurrent Session 1

1:30 pm - 3:00 pm

Section A: DATA QUALITY CONTROL AND STANDARDS SALON G Moderator: J. Harris

- 001 Non Reportable HL7 Records: Are They REALLY Non Reportable? An MDCSS Perspective *N. Lozon, Wayne State University*
- 002 Are Benign and Borderline Brain Tumors Underreported? *X. Li, Louisiana Tumor Registry*
- 003 Treatment Capture from Follow Back to Oncology Offices F. Ross, Kentucky Cancer Registry
- 004 A Comparison of Collaborative Stage with UICC TNM D. Dale, Princess Margaret Cancer Centre

Section B: CAPTURING INFORMATION FROM ELECTRONIC REPORTING SOURCES SALON F

Moderator: L. Koch

- 005 Meaningful Use (MU) of Electronic Health Records (EHRs): Electronic Physician Reporting to Central Cancer Registries *W. Blumenthal, Centers for Disease Control and Prevention*
- 006 Meaningful Use Stage 2: Is This the Future of Cancer Surveillance in the United States?*E. Durbin, Kentucky Cancer Registry*
- 007 Dealing With Challenges in MU 2 Reporting I. Hands, Kentucky Cancer Registry
- 008 A Technical Approach to Interfacing with a Health Information Exchange for Electronic Physician Reporting *D. Rust, Kentucky Cancer Registry*

Section C: APPLICATIONS IN CANCER CONTROL MEETING ROOM 602

Moderator: M. MacIntyre

- 009 Targeting Lung Cancer Control Efforts Among African-American Menthol Smokers in Los Angeles County *L. Escobedo, University of Southern California*
- 010 Cancer Incidence in the Cherokee Nation of Oklahoma *C. Wiggins, New Mexico Tumor Registry*
- 011 Access to Pediatric Cancer Treatment Centers in Texas M. Austin, University of Texas MD Anderson Cancer Center
- 012 Colorectal Cancer Screening Rate and its Determinants in Rural Counties in Texas *G. Gong, Texas Tech University Health Sciences Center*

Section D:

GIS, INNOVATIVE SPATIAL ANALYSIS MEETING ROOM 615AB

Moderator: R. Pinder

- 013 NAACCR Geocoding Services First Year Reflections D. Goldberg, Texas A&M University
- 014 Investigation of Mesothelioma Incidence in Areas of Alaska with Naturally Occurring Asbestos *D. O'Brien, Alaska Cancer Registry*
- 015 The New York State Environmental Facilities and Cancer Mapping Project *F. Boscoe, New York State Cancer Registry*
- 016 The Role of Geography in Low Mammography Screening Rates and Late-Stage Breast Cancer Diagnosis in Utah *K. Henry, University of Utah*

Section E: ANALYTIC EPIDEMIOLOGY MEETING ROOM 616AB

Moderator: L. Liu

- 017 Productivity Loss Due to Premature Cancer Deaths in the United States, 2006-2010 – How Much Does Education Attainment Matter? *H. Weir, Centers for Disease Control and Prevention*
- 018 The Effects of Age, Income, and Place of Residence on the Stage of Disease at Diagnosis of Breast Cancer *B. Rettig, Nebraska Department of Health and Human Services*
- 019 Utah Baby Boomers, Early-Life Socioeconomic Status, and Cancer Risk: What we learned from Cancer Registry Linkage to State Birth Certificates *A. Stroup, Utah Cancer Registry*
- 020 Complete, Smoothed Life Tables and Life Expectancy in the Appalachian Population and Sub–Population by Region and Socioeconomic Status *B. Huang, University of Kentucky*
- 3:00 pm 3:30 pm Break/Poster Viewing/Exhibits SALON H



Concurrent Session 2

3:30 pm - 5:00 pm

Section A: NEW AND ALTERNATIVE DATA SOURCES SALON G

Moderator: C. Rao

021 Constructing a Process for Utilizing Insurance Claims Data: The Use of Medicaid Derived Treatment as a Launching Pad

C. Lefante, Louisiana Tumor Registry

- 022 Using Claims Data to Identify Patients Undergoing Active Surveillance for Prostate Cancer *M. Schymura, New York State Cancer Registry*
- 023 Working with NPI Numbers in Cancer Registries J. Phillips, American College of Surgeons
- 024 Standard Representation of Genomic Information Y. Heras, Lantana Consulting Group

Section B: RAPID REPORTING AND PATIENT CONTACT STUDIES MEETING ROOM 602

Moderator: S. Vann

- 025 Enhancing Cancer Registries for Early Case Capture of Pediatric and Young Adult Cancer Cases *C. Clerkin, Centers for Disease Control and Prevention*
- 026 Using the CER Core Activity Case Finding Process to Implement Rapid Case Finding *D. Rousseau, Hospital Association of Rhode Island*
- 027 Timely and Complete Capture of Pediatric and Young Adult Cancer Cases in Louisiana: A Comprehensive Approach *I. Landry, Louisiana State University Health Sciences Center*
- 028 The Goldilocks Quandary: How Much Patient Contact is Just Right? *C. Harrell, Utah Cancer Registry*



PROGRAM



Section C: CAPTURING INFORMATION FROM ELECTRONIC REPORTING SOURCES II SALON F

Moderator: J. MacKinnon

- 029 EHR Data Capture: Hopes, Fears, Dreams L. Alschuler, Lantana Consulting Group
- 030 Increased Cancer Incidence Reporting Through Use of Electronic Health Records (EHRs) *A. Headd, Missouri Cancer Registry*
- 031 National Program of Cancer Registries Advancing E-Cancer Reporting and Registry Operations Project (NPCR-AERRO): Update on Electronic Pathology Reporting Activities
 S. Jones, Centers for Disease Control and Prevention
- 032 Cancer Reporting from Molecular Laboratories a New Frontier of Electronic Reporting B. Schmidt, Louisiana State University

Section D: SURVIVAL ANALYSES

MEETING ROOM 615AB

Moderator: J. Jackson-Thompson

- 033 Global Surveillance of Cancer Survival (CONCORD) M. Coleman, London School of Hygiene and Tropical Medicine
- 034 Changes in Cancer Survival Trends H. Cho, National Cancer Institute
- 035 Impact of Incomplete Date Information on Survival Estimates *B. Qiao, New York State Cancer Registry*
- 036 The Use of Colorectal Cancer Mortality as an Endpoint for Survival and Screening Evaluation: Is Ontario's Data up to the Challenge?D. Nishri, Cancer Care Ontario



Section E: ANALYTIC EPIDEMIOLOGY II MEETING ROOM 616AB Moderator: P. Adamo

- 037 An Evaluation of Primary Payer Data Among Breast and Colorectal Cancer Cases in Massachusetts, 2005-2009 *R. Knowlton, Massachusetts Cancer Registry*
- 038 Insurance Status Association With Survival in Diffuse Large B-cell Lymphoma Patients *X. Han, American Cancer Society*
- 039 Immigration Factors and Prostate Cancer Survival Among Hispanic Men in California: Does Neighborhood Matter? *C. Schupp, Cancer Prevention Institute of California*
- 040 Hepatocellular Carcinoma in Texas A. Hakenewerth, Texas Cancer Registry

5:00 pm - 6:30 pm	Free
5:00 pm - 6:00 pm	CONCORD-2 Study MEETING ROOM 602
5:00 pm - 6:30 pm	National Coordinating Council for Cancer Surveillance MEETING ROOM 615AB
6:30 pm - 9:00 pm	Opening Reception SALON JK

WEDNESDAY, JUNE 12 CONFERENCE DAY 2

6:30 am - 9:00 am	Breakfast SALON H
7:00 am - 8:00 am	Walk/Run Sponsored by NAACCR G-SAD (Geography, Spatial Analysis and Demographics User Group) <i>Join us for a 5K walk/run along the river!</i> <i>No registration required and maps will be</i> <i>provided.</i> MEET IN HOTEL LOBBY

7:00 am - 12:30 pm Registration PREFUNCTION SALON H 7:00 am - 12:30 pm Exhibits and Posters Open SALON H NAACCR Now 8:00 am - 9:00 am Learn more about NAACCR's new committee structure, its link to the NAACCR strategic management plan, and the capabilities of Netlink in linking members to activities. SALON G Plenary Session 3 SALON JK Standing Tall After Cancer: 9:00 am -10:30 am Survivorship and Care Plans Moderator: Andy Miller, M.H.S.E., C.H.E.S., Executive Vice President of Operations, LIVESTRONG A Vision for Using Health IT to Meet Cancer Survivors' Needs Naveen Rao, Manager, Health Information Technology, LIVESTRONG Survivorship and Passport to Care Marc Horowitz, MD, Professor of Pediatrics, Baylor College of Medicine 10:30 am - 10:45 am Short Break/Poster Viewing/Exhibits SALON H

Concurrent Session 3

10:45 am - 12:15 pm

Section A: DATA QUALITY CONTROL AND STANDARDS II SALON G *Moderator: M. Williams*



- 041 2013 Revisions to the 2009 NAACCR Death Clearance Manual S. Bolick, South Carolina Cancer Registry
- 042 Death Clearance Multiple Primaries Overview B. Matt, Iowa SEER Registry
- 043 A Time- and Resource-Efficient Method for Annually Auditing All Reporting Hospitals in Your State: The Inpatient and Outpatient Hospital Discharge Files *M. Whiteside, Tennessee Department of Health*
- 044 Enhancing Data Quality and Process Improvement: The Cancer Registry of Greater California Experience *W. Roshala, Cancer Registry of Greater California*

Section B: INITIATIVES IN INTEROPERABILITY

SALON F

Moderator: N. Lozon

- 045 I Speak HL7. Do U? Introducing the NAACCR Volume V Supplement J. Harrison, New York State Cancer Registry
- 046 Making Submissions Easier: Innovative Software for Central Cancer Registries *L. Coyle, Information Management Services, Inc.*
- 047 Sharing SEER Program Data and Algorithms via Web Services – SEER API D. Annett, Information Management Services, Inc.
- 048 Using Web Services in a Registry Data Management System *F. Depry, Information Management Services, Inc.*

Section C: COMPARATIVE EFFECTIVENESS (OUTCOMES) RESEARCH MEETING ROOM 602

Moderator: M. MacIntyre

049 Impact of BMI on Breast Cancer Prognosis in Patient-Centered Research: A Florida Pilot Study *H. Xiao, Florida A&M University*



PROGRAM

050 Divergence in Chemotherapy Between Breast and Colorectal Cancers in Louisiana: A Preliminary Population-Based Result from the CDC CER Project Q. Nguyen, Louisiana Tumor Registry 051 Influence of Comorbidity Severity on Cumulative Mortality in Women with Locoregional Breast Cancer X. Wu, LSU Health Sciences Center 052 Are Sociodemographic Factors and Treatment Type Associated with Urine Leakage Among Localized Prostate Cancer Patients? X. Wu, Louisiana State University Section D: INNOVATIVE ANALYTIC METHODS AND STATISTICS MEETING ROOM 615AB Moderator: A. Hakenewerth 053 The Mathematical Biology of Pancreatic Cancer: Models of Carcinogenesis and Stages G. Jacquez, SUNY Buffalo 054 Method to Estimate Death Rates to Construct Complete Annual State Life Tables for the Participating States of NPCR X. Dong, ICF International 055 Using Multiple Imputation to Enhance Utility of SEER Summary Stage B. Huang, University of Kentucky 056 Weighting Method to Handle Missing Values in Estimating Tumor Stage Distributions in Population-Based Cancer Registration Q. Yu, Louisiana State University Section F: SALON JK ANALYTIC EPIDEMIOLOGY III MEETING ROOM 616AB 9:00 am -10:15 am Moderator: B. Gutierrez 057 Increasing Incidence of Non-Cardia Gastric Cancer Among Older Koreans in California A. Parikh-Patel, California Cancer Registry 058 Bouncing Balls: Investigating Drivers of Hospital Readmissions with Hospital and Cancer Registry Data M. Hernandez, Florida Cancer Data System presenting on behalf of J. Feldman 059 Traffic-Related Air Pollution and Childhood Cancer in Los Angeles County, California J. Ghosh, University of Southern California 060 Factors Associated with Invasive Cervical Cancer Diagnoses in Kentucky E. Durbin, Kentucky Cancer Registry 12:15 pm - 12:30 pm Short Break/Poster Viewing/Exhibits

SALON H

12:30 pm - 2:00 pm	Awards Luncheon SALON JK
2:00 pm - 3:30 pm	NAACCR Business Meeting The Annual Business Meeting will be held after a short 10 minute intermission following the Awards Luncheon SALON JK
4:00 pm - 7:00 pm	Bike Event The NAACCR Wednesday Fun Bike Ride. Come join us for a leisurely bike ride around Austin! Rent your bike and it will be available for pick up at a location very close to the conference hotel. Watch for more information through the NAACCR conference website or e'alerts sent out to attendees.

THURSDAY, JUNE 13 **CONFERENCE DAY 3**

6:30 am - 9:00 am	Breakfast SALON H
7:00 am - 10:30 am	Registration PREFUNCTION SALON H
7:00 am - 12:30 pm	Exhibits and Posters Open SALON H
8:00 am - 9:00 am	Birds of a Feather - The Future of Cancer Surveillanceor Not? SALON G

Plenary Session 4

Remember the Patient! Comparative Effectiveness and Outcomes Moderator: Donna Turner, Ph.D., CancerCare Manitoba

Comparative Effectiveness Research and Cancer Screening James Goodwin, M.D., George and Cynthia Mitchell Distinguished Chair Director, Sealy Center on Aging, The University of Texas Medical Branch Galveston

Comparative Effectiveness of Granulocyte Growth Factors Among Elderly Patients with Non-Hodgkin's Lymphoma Linda Elting, Dr.P.H., Professor, Department of Health Services Research, Division of OVP, Cancer Prevention and Population Sciences, The University of Texas, M.D. Anderson Cancer Center

10:15 am - 10:30 am Short Break/Poster Viewing/Exhibits SALON H

Concurrent Session 4

10:30 am - 12:00 pm

Section A: INNOVATIVE METHODS FOR DATA COLLECTION SALON G

Moderator: J. MacKinnon

- 061 Extraction of ICD-O-3 Topography from Path Reports Using Machine-Learning Techniques I. Hands, Kentucky Cancer Registry
- 062 Automated Consolidation of Collaborative Stage Data Items: The Pennsylvania Approach to Enhancing Automation and Implementing Consolidation in the Absence of National Standards M. Esterly, Pennsylvania Cancer Registry
- 063 Industry and Occupation Coding of Cancer Records The Good, the Bad and the Ugly N. Weiss, Weiss Consulting
- 064 Improving Data Quality and Completeness Using Claims in the PRCCR N. Vazquez, Puerto Rico Central Cancer Registry

Section B: INNOVATIONS IN CANCER SURVEILLANCE MEETING BOOM 615AB

Moderator: N. Lozon

065 Using the Colorado Central Cancer Registry to Pre-Populate Treatment Summaries and Care Plans: What We Learned C. Bledsoe, Colorado Central Cancer Registry





- 066 Standardizing Clinical Trial Data in EHRs: Successes and **Opportunities** B. Dolin, Lantana Consulting Group
- 067 Utilizing Modern Technologies for Improved Usability and Functionality in Web-Based Cancer Reporting C. Blu, Kentucky Cancer Registry
- 068 Seeing the Big Picture in Long-Term Surveillance for Rare **Events**

A. Gilsenan, RTI Health Solutions

Section C: COMPARATIVE EFFECTIVENESS RESEARCH **MEETING ROOM 602**

Moderator: V. Chen

- 069 Enhancing Infrastructure for Cancer Surveillance: Experience from the Centers for Disease Control and Prevention (CDC) Comparative Effectiveness Research (CER) Project
 - D. Butterworth, Centers for Disease Control and Prevention
- 070 Enhancing Cancer Registries for Comparative Effectiveness Research: Preliminary Results of Detailed Treatment Collection
 - C. Eheman, Centers for Disease Control and Prevention
- 071 Unlocking the Power of Qualitative Data Analysis for the Comparative Effectiveness Research Project in Florida M. Hernandez, Florida Cancer Data System
- 072 Collecting Detailed Chemotherapy and Other Adjunct Treatment Information for the CDC Comparative Effectiveness Research (CER) Project: Challenges and Lessons Learned V. Chen, Louisiana Tumor Registry

Section D: **RECORD LINKAGES** SALON F

Moderator: D. O'Brien

073 Assessment of Duplicate Cancer Cases in Utah and Idaho: Improving Interstate Cancer Surveillance C. Johnson, Cancer Data Registry of Idaho



- 074 Linkage of Central Cancer Registry Incidence and Hospital Discharge Data Provides a Valuable Resource to Study Breast Cancer Disparities in Illinois T. Dolecek, University of Illinois at Chicago
- 075 Analytic Challenges with National Survey Data Linked to a State-Level Cancer Registry E. Miller, Centers for Disease Control and Prevention
- 076 Florida Cancer Registry Enhancement to Examine Survival Disparities Among Non-Small Cell Lung Cancer Patients S. Tannenbaum, University of Miami

Section E: ANALYTIC EPIDEMIOLOGY IV MEETING ROOM 616AB

Moderator: S. Gershman

- 077 Does Beam Radiation of Prostate Cancer Increase Rectal Cancer Risk? J. Morgan, Loma Linda University
- 078 Disparities in the Use of Post-Mastectomy Breast Reconstruction in the Sacramento Area. California: A Pilot Study C. Morris, California Cancer Registry
- 079 The Effect of Primary Tumor Resection on Survival for Patients With Metastatic Colorectal Cancer: An Analysis of California Cancer Registry Data R. Cress, Cancer Registry of Greater California, Public Health Institute
- 080 Association of Treatment Type and Sociodemographic Factors with Changes in Urinary, Bowel and Sexual Symptoms Among Localized Prostate Cancer Patients J. Chotalia, Louisiana Tumor Registry
- 12:00 pm 1:00 pm Lunch (on your own)
- 12:00 pm 2:00 pm MTC Registry Luncheon (Sponsored Lunch Meeting -United BioSource, by invitation) **MEETING ROOM 416** All posters must be removed from 1:00 pm boards. SALON H Exhibit Break Down 1:00 pm - 2:00 pm SALON H

Plenary Session 5

SALON JK

1:00 pm - 1:30 pm		NAACCR Update on Steering Committees Moderator: Jill MacKinnon, PhD, Florida Cancer Data System	
		This informational session will provide you with the status of NAACCR's Steering Committees work and future initiatives.	
		Antoinette Stroup, BS, MS, PhD, Director, Utah Cancer Registry	
		Maureen MacIntyre, MHSA, NAACCR President	
1:30) pm - 1:45 pm	Short Break	
Con	current Session	5	
1:45 pm - 3:15 pm			
	tion A: VATIVE METHODS FOF DN G	R DATA COLLECTION II	
Моа	lerator: R. Pinder		
081	1 California's Comparative Effectiveness Research Study Tracking Database S. Riddle, Cancer Registry of Greater California		
082	2 Project HAN (Hospice, Adult Living and Nursing Homes) Progess-Year 2		

C. Rao, North Carolina Cancer Registry

- 083 Cancer Surveillance in the Era of Molecular Markers B. Riddle, Dartmouth College
- 084 Enhancing Lymphoma and Leukemia Reports in Puerto Rico, 2010 M. Traverso, Puerto Rico Central Cancer Registry

Section B: APPLICATIONS IN CANCER CONTROL II **MEETING ROOM 602**

Moderator: P. Adamo

- 085 Validation of SEER Treatment Data Using the SEER Patterns of Care Studies A. Noone, National Cancer Institute
- 086 Routes to Diagnosis, a New Measure for Awareness and Early Diagnosis Initiatives L. Elliss-Brookes, National Cancer Intelligence Network
- 087 Use of Stage Data in Pan-Canadian System Performance Reporting R. Rahal, Canadian Partnership Against Cancer

PROGRAM

088 Cancer Incidence, Stage Distribution and Treatment Patterns in Manitoba's First Nations: Using Cancer Registry Data in a Collaborative Environment to Improve Cancer Control

D. Turner, CancerCare Manitoba, University of Manitoba

Section C:

COLLABORATIVE RELATIONSHIPS AND COMMUNICATION STRATEGIES MEETING ROOM 615AB

Moderator: M. Williams

- 089 Payer and Registry Synergy: Collaboration and Data Sharing for Improved Understanding of Cancer Care *M. Perkins, United Healthcare*
- 090 Success Through Collaboration: Enhancing Surveillance Data with Insurance Claims*B. Wohler, Florida Cancer Data System*
- 091 Data Sharing Between Public Health and Clinical Care: A Possible Solution to Close the Gap to Completeness *J. Jackson-Thompson, Missouri Cancer Registry*
- 092 What Works? A Central Registry and a Community Hospital Collaborate J. Martin, Virginia Cancer Registry

J. Martin, Virginia Cancer negis

Section D: USING CANCER REGISTRY DATA TO ADVANCE SCIENCE SALON F

Moderator: A. Hakenewerth

- 093 Role of Cancer Registries in Surveying Climate Change Effects on Cancer Incidence: A North Carolina Case Study L. Carrasco, University of North Carolina - Lineberger Comprehensive Cancer Center
- 095 Is Melanoma Incidence Different in Children Than in Adults? L. Paddock, New Jersey State Cancer Registry
- 096 Cancer Incidence Trends Among Ethnic-Specific Asian and Pacific Islander Populations in the United States, 1990-2008 A. Noone, National Cancer Institute and L. Liu, Los Angeles Cancer Surveillance Program, Keck School of Medicine

Section E: ANALYTIC EPIDEMIOLOGY V MEETING ROOM 616AB

Moderator: C. Schmaltz

- 097 A Comparison of SEER and CINA Data for a Rare Cancer: Hodgkin Lymphoma, 1995-2008 *P. Jamison, National Cancer Institute SEER*
- 098 Recent Trends in Prostate Cancer Incidence by Age, Cancer Stage and Grade, the United States, 2001-2007 J. Li, Centers for Disease Control and Prevention

099 Does Cancer Incidence and Screening Utilization Vary Between Remote Northern Communities and the Rest of Saskatchewan? T. Zhu, Saskatchewan Cancer Agency, University of Saskatchewan 100 Analytical Software for Population-Based Cancer Statistics S. Scoppa, Information Management Services, Inc. 3:15 pm - 3:30 pm Short Break SALON JK NAACCR Showcase 3:30 pm - 4:30 pm Moderator: Betsy Kohler, NAACCR Executive Director SALON JK Virtual Pooled Data Project D. Deapen, Dr.PH, Los Angeles Cancer Surveillance Program Development and Demonstration of CI* Rank E. Feuer, PhD, National Cancer Institute 4:30 pm - 4:45 pm Invitation to 2014 Conference SALON JK 4:45 pm - 5:00 pm **Closing Remarks** Melanie Williams, Ph.D., Texas Cancer Registry SALON JK 5:00 pm Adjournment for the Day

FRIDAY, JUNE 14

POST-CONFERENCE

9:00 am - 4:00 pm The Use of Imputation Technique for Modeling Missing Information in Population-Based Cancer Registry Data *B. Das, Westat N. Howlader, National Cancer Institute* MEETING ROOM 615A
9:30 am - 3:30 pm Successful Communication: A ToolKit for Cancer Registries *D. Turner, CancerCare Manitoba R. Koscielny, CancerCare Manitoba*, *NAACCR Communications Steering Committee* MEETING ROOM 615B





Poster Listing

- P-01 Prostate Cancer Incidence Reported Among Department of Defense Military Treatment Facilities, 2005-2008 *T Blando*
- P-02 Spatial Analysis in Cancer Surveillance: Identifying Geographic Targets for Screening Interventions *RL Sherman*
- P-03 Addressing Colorectal Cancer Disparities in a Spatial Context *RL Sherman*
- P-04 No Racial Disparities in Stage at Diagnosis Is Nevada Doing Better for Cervical Cancer? *S El Ibrahimi*
- P-05 Overview of Brain Tumours in Alberta C Normandeau
- P-06 Return on Investment of Medicaid Linkages for NPCR's Enhancing Cancer Registry Data for Comparative Effectiveness Research (CER) Project: Idaho's Perspective *C Johnson*
- P-07 Establishing Data Linkage Policies for Administrative Records and Hospital Records – Lessons from Florida *J Feldman*
- P-08 Developing an Information-Sharing Portal for Comparative Effectiveness Research: An ICF Approach *Q He*

- P-09 Data Quality Improves: Canada Compares their Data Using SEER Validation List *G Noonan*
- P-10 Enriching the Florida Cancer Registry to Examine Survival Disparities in Female Breast Cancer Patients *SL Tannenbaum*
- P-11 Using the National Program of Cancer Registries Program Evaluation Instrument (NPCR-PEI 2009-2011) to Assess Data Completeness and Quality within the National Program of Cancer Registries Cancer Surveillance System (NPCR-CSS 2005-2010) *R Wilson*
- P-12 Routes to Diagnosis, a Novel English Methodology *LE Elliss-Brookes*
- P-13 Smoking and Mortality in Breast Cancer Patients *S Tannenbaum*
- P-14 Data Completeness Evaluation between SEER and NAACCR Methods in 8 SEER Registries *J Chang*
- P-15 Impact of Comorbidities on Treatment Choice for Colon Cancer Patients, Louisiana-CDC CER Project *MC Hsieh*
- P-16 Navigating the Registry-Specific Approval Process for a Long-Term Drug Safety Surveillance Study *D Harris*





Poster Listing continued

- P-18 Variations Among Cancer Registries in Accessing Patients for a Drug Safety Surveillance Study *K Midkiff*
- P-19 Use of Discharge Data to Supplement Comorbidity Information in Cancer Registries: The California Experience *J Rico*
- P-20 Disparities in Cervical Cancer Mortality Among Black, Non-Hispanic Women in Massachusetts *A MacMillan*
- P-21 The Epidemiology of Childhood Cancer in Massachusetts, 2000-2009 *R Knowlton*
- P-22 Thyroid Cancer Incidence Trend Among Asian and Pacific Islander Women in the U.S. *J Chang*
- P-23 Geographic Variations of Racial Disparities of Cervical Cancer Late-Stage Diagnosis in Texas Y Lin
- P-24 Childhood Cancer Rates, and Risk Factors: Spatial Point Process Approach *M Hossain*
- P-25 How Special Project #1 can Improve Hispanic Ethnicity Data in the Missouri Cancer Registry Database *CL Schmaltz*

- P-26 Evaluating and Addressing the Needs for Central Cancer Registry (CCR) Data Collection *I Zachary*
- P-27 Findings from the 2011-2012 NAACCR Death Clearance Evaluation Workgroup Issues Survey *M Williams*
- P-28 Improving the Quality of Cancer Incidence Data for Native Americans in Michigan Using Tribal Linkages *G Spivak*
- P-29 Breast Cancer Multiple Primary and Histology Data Quality and its Impact on Cancer Incidence and Survival *J Chang*
- P-30 "Where Are You From?": An Effort to Decrease the Percentage of County Unknown in Puerto Rico *C Torres*
- P-31 Demographic Disparities in Prostate Cancer: Diagnosis Context, Prognostic Factors, and the Propensity for Surgical Treatment *S Negoita*
- P-32 Cancer Incidence Rates in the Cherokee Nation *S Khan*
- P-33 Use of a GIS to Analyze Disparities in Cervical Cancer Incidence in New Jersey *LE Paddock*





Poster Listing continued

- P-34 Trends in Hepatocellular Carcinoma Incidence Among Non-Hispanic White, Hispanic and American Indian Residents of New Mexico, 1981-2009 *A Meisner*
- P-35 Usefulness of Collaborative Stage (CS) Site Specific Factors (SSF) 3, 4, 5 and 6 in Describing Short-Term Mortality Risk Disparities for Type II Endometrial Cancers in Metropolitan Detroit *FD Vigneau*
- P-37 Association Between Participation in a Population-Based Breast Cancer Study and Clinical and Socioeconomic Factors in the New Jersey State Cancer Registry *K Pawlish*
- P-38 Colonoscopy and Sigmoidoscopy in Medicare Population with Colorectal Cancer (CRC) – Screening or Diagnostic Use *SM Lai*
- P-39 Opioid Analgesic Use Among Nova Scotia (NS) Cancer Patients at the End of Life: Results from a Population-Based Study *G Walsh*

- P-40 Incidence of Brain Metastasis at Initial Presentation of Lung Cancer J Villano
- P-41 Capturing, Storing, Integrating and Using Electronic Health Record (EHR) Data at a Central Cancer Registry (CCR) *I Zachary*
- P-42 Collaboration in California: From Audits to Training -The Story of the Prostate Problem *K Ziegler*
- P-43 Invasive Cancer Incidence by State, Sex, and Site -United States, 2009 S Singh
- P-44 Improving Completeness of Adjuvant Therapy Data by a Linkage with an Electronic Prescription Data -Louisiana Tumor Registry's Experiences *X Li*
- P-45 Overview of National Program of Central Cancer Registries (NPCR) Data Linkages with Both Public and Private Data Sources for Improving Disease Control and Prevention *S Van Heest*







oral abstracts

concurrent session 1



NON REPORTABLE HL 7 RECORDS ARE THEY REALLY NON REPORTABLE? A MDCSS PERSPECTIVE

<u>N Lozon</u>,¹ L Coyle,¹ J Harris¹ ¹Wayne State University, Detroit, MI

Background: Complete case reporting is always on the minds of the Metropolitan Detroit Cancer Surveillance system staff. For the November 2012, submission to SEER and to NAACCR, the MDCSS decided to look at the Non Reportable 2010 HL7 records to see if they were really Non reportable.

Purpose: To present the methods and steps that were taken to re-screen 23,428 cases in the data base. The lessons learned and findings will be discussed.

Methods/Approach: Reviewed all Non reportable 2010 HL7 pathology reports that were not consolidated into patient data. Identified 23, 428 records as candidates for rescreening. Reviewed a list of the comments used by staff in the original screening process. Records that included definitive documentation were excluded from the rescreening, this eliminated thousands of records. The result was to look at cases that were documented as "benign" or "not a reportable case". 5915 pathology reports were rescreened.

Results: Results of the re-screening of 2010 diagnosed records will be presented as well as the re-screening of 2011 diagnosed records. Findings and lessons learned, and new procedures implemented by the registry will also be presented.

Conclusions: The presentation will provide an overview of the energy and work involved in having complete case reporting for each submission year.

002

ARE BENIGN AND BORDERLINE BRAIN TUMORS UNDERREPORTED?

<u>X Li</u>,¹ X Wu,¹ C Kruchko,² M Hsieh,¹ P Andrews,¹ B Huang,³ B Wohler,⁴ B Qiao,⁵ M Jamison⁶

¹Louisiana Tumor Registry, New Orleans, LA; ²Central Brain Tumor Registry of the United States, Hinsdale, IL; ³Kentucky Cancer Registry, Lexington, KY; ⁴Florida Cancer Data System, Miami, FL; ⁵New York State Cancer Registry, Albany, NY; ⁶NIH-National Cancer Institute, Bethesda, MD

Background: Benign brain tumors diagnosed in 2004 and after are reportable to population-based cancer registries in the US. Although there is a concern about underreporting, the magnitude of the issue and its variations by cancer registry are unclear. The objective of this study is to examine geographic variations in incidence of benign brain tumor by diagnostic confirmation, surgery, and type of reporting source compared with malignant brain tumors.

Methods: Data were obtained from the NAACCR CINA Deluxe 1995-2009 Analytic File including 45 state registries. DCO and autopsy cases were excluded.

Results: Rate ratios of benign versus malignant tumors varied by registry from 0.92 to 2.35. Benign tumors were more likely not to be microscopically confirmed (The majority of these cases were diagnosed through radiography without microscopic confirmation), and not to receive surgery compared with malignant tumors. Registries with a higher percentage of nonmicroscopically confirmed or non-surgery benign tumors were more likely to have higher incidence rates for benign tumors. Overall, incidence rates of benign tumors increased by 5.6% per year for non-microscopically confirmed cases and 5.5% per year for no-surgery cases from 2004 to 2009. In contrast, the rates of malignant tumors decreased in the same period. **Conclusions:** Incidence rates of benign brain tumors are higher

than malignant brain tumors. Percentage of non-microscopically confirmed or no-surgery cases are higher for benign than malignant brain tumors. Completeness of benign brain tumor reporting varies by registry, but benign brain tumor reporting is improving over time.

Notes	Notes

TREATMENT CAPTURE FROM FOLLOW BACK TO ONCOLOGY OFFICES

<u>F Ross</u>,¹ S Batts,¹ M Wooten¹ ¹Kentucky Cancer Registry, Lexington, KY

In Kentucky, hospitals are required to report **all** first course treatment given to patients, even if it was given elsewhere. Thus, patients with cancers who were reported to KCR by hospital and non-hospital facilities both are not followed back to the reporting NHF due to limited staff resources. As treatments are more frequently delivered in outpatient settings, it is suspected that treatment information is underreported in central cancer registries. The purpose of this study is to evaluate the amount of additional treatment information that could be obtained if KCR staff could follow back and review medical records from oncologists whose patients matched records already in the KCR.

KCR obtained lists of patients from 5 radiation oncology facilities, 6 medical oncology practices, and 3 multi-specialty clinics with both medical and radiation oncologists for the first 6 months of 2011. These were matched with the central registry; matched cases were reviewed to determine if treatment information was likely to be missing; and those patients were followed back to the physician's office records for chart review. Any missing treatments, or other cancer abstract information, were documented and compiled for analysis.

The results will summarize, for each facility, the number of matched cancer cases reviewed for possible missed therapies, the number of cases likely to be missing therapy and thus followed back, and the number of cases where missing treatments were found in the facility records.

In addition to the missing treatments, other relevant information discovered on these cancer patients will be analyzed. However, the addition of this information to central cancer registry records comes at a significant cost to hospital and central cancer registrars. An alternate method for capturing information electronically from oncology offices in Kentucky is currently being tested in a project funded by CDC for Comparative Effectiveness Research.

004

A COMPARISON OF COLLABORATIVE STAGE WITH UICC TNM

<u>D Dale</u>,¹ J Brierley,¹ M Jiang,¹ M Luettschwager² ¹Princess Margaret Cancer Centre, Toronto, Ontario; ²Cancer Care Ontario, Toronto, Ontario

Princess Margaret Cancer Centre (PM) in Toronto has a hospital based cancer registry that has been in operation since 1958. Staging has been an integral part of the registry since the 1970's with the responsibility of collecting the staging shifting between the registrar and the attending physician. The current staging information is collected mainly by the registrar using the UICC TNM 7th edition and is used extensively for research and administrative purposes.

Cancer Care Ontario (CCO) operates the Ontario Cancer Registry which has been in operation since 1964. Over the last few years a decision was made to incorporate into the registry; population based stage data. With targeted funding provided by the Canadian Partnership Against Cancer, CCO began reporting Collaborative Stage (CS) for the top four sites; breast, colo-rectal, prostate and lung for the diagnosis year 2010. Therefore we saw the opportunity to compare the derived stage group from CS with the TNM stage group from PM for the 2010 cases as a joint data quality exercise encompassing data collection processes and interpretation of staging rules.

For the top four sites the CCO CS derived stage group was made available. The PM stage group was appended to each case and a manual review was done by PM staff of the two variables. There were a total of 2075 cases in the initial file for comparison. Due to the PM data capture criteria for staging only analytic cases, 1705 cases were used in the comparison. Initially there was full agreement for 84.4% of the cases. The reasons for discrepancies were investigated.

The review of the colo-rectal and lung cases has begun. Thus far system issues at CCO and CS mapping errors have been identified for some of the differences. For colo-rectal, 10 cases are under review and 60 for lung.

The results of the detailed review for all four sites will be presented.



MEANINGFUL USE (MU) OF ELECTRONIC HEALTH RECORDS (EHRS): ELECTRONIC PHYSICIAN REPORTING TO CENTRAL CANCER REGISTRIES

<u>W Blumenthal</u>,¹ S Jones,¹ W Scharber,² L Havener,³ M Williams,⁴ S Baral,⁵ J Rogers¹

¹Centers for Disease Control and Prevention (CDC), Atlanta, GA; ²DB Consulting Group, Atlanta, GA; ³North American Association of Central Cancer Registries (NAACCR), Springfield, IL; ⁴Texas Cancer Registry, Austin, TX; ⁵Northrop Grumman, Atlanta, GA

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 (EHR). This final rule includes an optional objective for ambulatory providers to report cancer cases to central cancer registries (CCRs).

Purpose: To help central cancer registries prepare for MU. Methods: The Cancer Surveillance Branch (CSB) and NAACCR combined two workgroups (WG) as one new Physician Reporting WG under the NAACCR Interoperability Ad Hoc Committee. The purpose is to perform tasks for successful implementation of electronic physician reporting. The WG formed subgroups to address these objectives: identify existing software and/or develop software requirements and tools needed for CCRs to successfully implement physician reporting; develop guideline documents to assist CCRs; and develop education and communication tools for CCRs to address implementation of physician reporting. **Results:** The Software and Workflow Requirements subgroups developed use cases and requirements to help registries and inform software development for receiving and processing the electronic physician reports. The External Partner Interaction subgroup developed guidance documents to help registries work with various partners, including EHR vendors, physicians, Health Information Exchanges, and Regional Extension Centers. CSB also developed guidance documents to help states prepare for MU. The WG and two pilot states developed requirements and identified improvements for an alpha version of eMaRC Plus, which was enhanced to

receive and process physician reports. A beta release is expected in September 2013.

Conclusions: This presentation will: provide an overview of the tasks and products of each sub-group; review the steps CCRs should conduct in preparation for MU; and identify and summarize materials and tools developed by the WG and CSB to assist CCRs in preparing for MU.

006

MEANINGFUL USE STAGE 2: IS THIS THE FUTURE OF CANCER SURVEILLANCE IN THE UNITED STATES? <u>E Durbin</u>,¹ S Batts,¹ D Rust,¹ T Gal,¹ Y Dobyns¹

¹Kentucky Cancer Registry, Lexington, KY

Beginning in January 2014 the Meaningful Use (MU) Stage 2 final rule goes into effect for thousands of healthcare providers. The new rule supports the identification and reporting of cancer cases to state cancer registries by eligible healthcare providers. The Kentucky Cancer Registry (KCR) formed strategic partnerships with the CDC, KY Regional Extension Center (REC), KY Health Information Exchange (HIE) and healthcare providers in Kentucky to establish secure, standardized electronic reporting of cancer information from provider electronic health record (EHR) systems. KCR's experience to date offers a road map to assist other registries prepare for MU Stage 2.

The purpose of the project was to help develop the methods, policies, and standards necessary for direct electronic reporting of cancer cases and treatment information.

Publications and reports from the Office of the National Coordinator (ONC) have been used to understand MU initiatives. Strategic partnerships were established to recruit providers, develop and test standards and to develop software components necessary to integrate EHR data into registry operations. ONC reports indicate that MU initiatives are engaging providers at a rapid pace. Collaborative efforts by the KCR and the REC have resulted in commitments from 44 providers to establish electronic reporting to the KCR. On October 19, 2012 the KCR received the first real-time transmission of cancer reports from a dermatology practice in Paducah, Kentucky.

MU Stage 2 offers an opportunity for registries to obtain more complete, accurate and timely data for cancer patients seen in ambulatory settings. The REC has proven to be the most important partner for recruiting providers to participate. Challenges have included the time required for the HIE to develop the transport mechanism and the delays in vendor implementations of interfaces. All state cancer registries should be prepared to accept cancer reports from providers by 2014.

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DEALING WITH CHALLENGES IN MU 2 REPORTING

Y Dobyns,¹ S Batts,¹ D Rust,¹ <u>I Hands</u>,¹ E Durbin¹ ¹Kentucky Cancer Registry, Lexington, Kentucky

As part of the Meaningful Use Stage 2 objectives, ambulatory healthcare providers can elect to send electronic health information to cancer registries according to the standards specified in "Implementation Guide for Ambulatory Healthcare Provider Reporting to Central Cancer Registries" (IG) from August 2012. This specification is based on the Clinical Document Architecture (CDA), which in turn is a specialized application of Extensible Markup Language (XML). It mandates the inclusion of a great deal of information about the patient such as the patient's medical history, treating and referring physicians, medications administered, and other related health topics. This information is a rich source of data for cancer registries, potentially filling gaps in treatment collection and missed cases that have proven difficult for population-based registries. In order to realize these goals, implementers of the IG format must ensure that treatment information can be linked to specific cancer diagnoses, something the specification leaves as optional. Sending facilities must also take care to create CDA messages that not only pass a strict set of validation rules but also provide enough data in appropriate sections of the document to be useful to a cancer registry. And finally, registries must have the technical ability to validate and process incoming CDA messages, sometimes requiring the development of custom software tools. This presentation will outline the specific limitations and challenges of the IG format that have been discovered while the Kentucky Cancer Registry attempted to process CDA messages from an ambulatory healthcare provider. It will also include a demonstration of both custom and thirdparty software tools that have been useful in testing, validating, and processing CDA messages into our registry environment.

008

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A TECHNICAL APPROACH TO INTERFACING WITH A HEALTH INFORMATION EXCHANGE FOR ELECTRONIC PHYSICIAN REPORTING

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Background: In an effort to increase the quality of population based central cancer registry surveillance data, the Kentucky Cancer Registry (KCR) is implementing electronic cancer reporting for ambulatory healthcare settings. Over the past decade, cancer treatment has seen a shift from hospital settings to ambulatory settings. To facilitate complete, accurate, and timely cancer reporting from ambulatory settings, the KCR is collaborating with the Kentucky Health Information Exchange (KHIE), the Kentucky Regional Extension Center, the Centers for Disease Control and Prevention (CDC), healthcare providers, and multiple Electronic Healthcare Record (EHR) vendors to create an electronic system for Kentucky physicians to securely transmit cancer data to the cancer registry.

Purpose: To leverage the Kentucky HIE to establish direct electronic reporting of cancer cases and treatment information from Kentucky providers to the central cancer registry, and pilot a new Meaningful Use standard for electronic, structured treatment reports.

Methods: KCR has coordinated efforts by the CDC, KHIE, and EHR vendors to establish message structure, software components, and transport mechanisms necessary to interface with the central registry.

Results: Following 22 months of effort, the first implementation was validated on October 19, 2012 when the KCR received the first real-time transmission of data for cancer patients treated by Dr. Halden Ford from Paducah Dermatology PLLC, in Paducah, Kentucky.

Conclusions: Achieving this goal was not easy, and other central registries should prepare themselves to work with their respective HIEs in order to integrate electronic physician cancer reporting into their surveillance system. Although Kentucky's approach may not be applicable to all central registries, collaboration with EMR vendors and HIEs, as well as a strong cancer informatics program, are essential components of any successful ambulatory reporting initiative.

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TARGETING LUNG CANCER CONTROL EFFORTS AMONG AFRICAN-AMERICAN MENTHOL SMOKERS IN LOS ANGELES COUNTY

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This project uses geospatial methods to visualize the burden of cancer and promote delivery of cancer control interventions. In Los Angeles County, incidence rates of lung cancer are highest among African-Americans and linked to cigarette smoking. Studies show that African-American smokers prefer menthol cigarettes exposing them to more nicotine, the addictive substance in cigarettes.

We identified neighborhoods with the highest density of invasive lung cancer cases among African-Americans to promote a smoking cessation intervention. Patients diagnosed with invasive lung cancer from 2001-2010 were identified through the Cancer Surveillance Program, the population-based cancer registry for Los Angeles County. To calculate density values, patients' addresses at diagnosis were smoothed over a radius of a predetermined size. When stratified by race, high density of invasive lung cancer among African-Americans was observed in Health Service Planning Area 6.

Through the Patient Education and Community Outreach Center at the University of Southern California Norris Comprehensive Cancer Center, African-American menthol smokers were provided materials that linked them to evidence-based cessation services. These tailored materials dispel myths about menthol cigarettes, highlight reasons to quit, and promote the California Smokers' Helpline. Because menthol smokers tend to be socially interconnected, we also used social media and mobile-phone messaging. Messages were condensed into mobile-phone texts matching the information provided by participants to track reach. This effort is currently in progress and preliminary results will be reported.

This work applies geospatial methods to locate high-risk geographic areas and increase efficiency in delivering health education programs that, ultimately, will increase quit attempts among menthol smokers, a highly addicted segment of African-American smokers.

among menthol smokers, a highly addicted segment of Afric American smokers. Notes _____

010

CANCER INCIDENCE IN THE CHEROKEE NATION OF OKLAHOMA

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Background: The Cherokee Nation Cancer Registry (CNCR) area of coverage is concentrated in fourteen counties in Northeastern Oklahoma. CNCR surveillance data are a important component of cancer control efforts for the Cherokee Nation. **Purpose:** This study was designed to characterize cancer incidence rates in the Cherokee Nation of Oklahoma for the time period 1999-2008 and to compare these rates to those of non-Hispanic whites from the SEER Program.

Methods: The investigators utilized CNCR records to calculate cancer incidence rates for residents of the Cherokee Nation of Oklahoma. The study included incident cancer cases that were diagnosed among residents of the CNCR area of coverage from 1999-2008. Rates for non-Hispanic whites in nine core areas of the SEER Program during the same period served as comparison. Average annual age-adjusted incidence rates per 100,000 were calculated by the direct method using the United States 2000 standard population. Ninety-five percent confidence intervals (CI) for incidence rates were calculated using the Tiwari adjustment. Results: Overall incidence rates for Cherokee Nation (All cancers-combined; Rate=430.3 per 100,000; 95% CI=417.0-443.9) were lower than observed among non-Hispanic white residents in nine core areas of the SEER program (Rate=495.3; 95% CI=494.3-496.3). Breast cancer was the leading cancer among Cherokee women, followed by lung cancer and colorectal cancer. Prostate cancer was the leading cancer for Cherokee males, followed by lung cancer and colorectal cancer. Incidence rates for lung cancer were higher in the Cherokee Nation (Rate=81.0; 95% CI=75.2-87.0) than among SEER non-Hispanic whites (Rate=65.3; 95% CI=65.0-65.7).

Conclusions: Overall cancer incidence rates in the Cherokee nation were slightly lower than among SEER Program non-Hispanic whites. However, high lung cancer incidence rates indicate that tobacco control is an important priority in the Cherokee Nation.



ACCESS TO PEDIATRIC CANCER TREATMENT CENTERS IN TEXAS

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Introduction: Pediatric cancer patients often experience frequent and/or extended inpatient stays for their treatment. Distance has been shown to be a major barrier to the receipt of timely cancer care. Little is known, however, about the distance which pediatric cancer patients must travel for care.

Methods: Pediatric cancer patients aged <18 years were identified from the 1995-2009 Texas Cancer Registry (n =17,450). Hospitals were classified as pediatric cancer treatment centers if they were Children's Oncology Group (COG) members or had >= 100 discharges of pediatric patients with a cancer diagnosis in 2009 (n =13; determined using Texas Hospital Discharge Inpatient data). Straight-line distances between patients' home address and the closest pediatric cancer treatment center were calculated in ArcGIS, and descriptive statistics were performed.

Results: The median distance from a patient's home to the closest pediatric cancer treatment center was 15.44 miles (range =0.01-224.22). Of the 17,450 patients, 65% lived less than 25 miles to the nearest treatment center (25-49 miles =14%, 50-99 miles =11%, 100+ miles =10%). Over 20% of pediatric cancer patients, residing in 192 Texas counties, lived 50+ miles from a treatment center (median =96.5 miles). The majority of these counties (78%) were classified as non-core or micropolitan according to the U.S. Census.

Conclusions: Although a majority of pediatric cancer patients lived within a short distance to a treatment center, over 20% lived 50+ miles. The strain resulting from driving such long distances is significant financially and emotionally, particularly for families with a sick child in the hospital and well children at home. Studies are now underway to understand how this phenomenon impacts stage at diagnosis, the timeliness of treatment, and survival. **Acknowledgements**: Cancer Prevention and Research Institute of Texas (RP101207), NCI Cancer Prevention Training Program (CA57730), and NIH Core Grant (CA016672) 012

COLORECTAL CANCER SCREENING RATE AND ITS DETERMINANTS IN RURAL COUNTIES IN TEXAS

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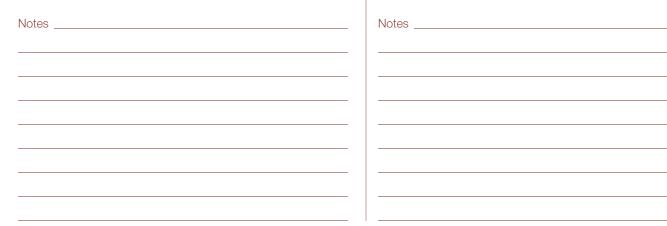
Background: Early detection by screening is the key to colorectal cancer control. However, colorectal cancer screening and its determinants in rural areas have not been adequately studied.

Purpose: This study was to investigate the screening rates and determinants of colonoscopy, sigmoidoscopy, and/or occult blood test (FOBT) in subjects of Project Frontier from rural counties of Cochran, Bailey and Parmer, Texas.

Methods/Approach: Subjects (*n*=820 with 435 Hispanics, 355 non-Hispanic whites, 26 African Americans, and 4 unknown ethnicity; 255 males, 565 females, aged from 40 to 92 years) were from Project FRONTIER. Stepwise logistic regression analysis was performed. Explanatory variables included ethnicity (Hispanic, white and African American), gender, health insurance, smoking status, household income, education (years), physical activity, overweight, other health screenings, personal physicians, family history (first-degree relatives) of cancers, and preferred language (English vs. Spanish) for interview.

Results: The screening rate for colonoscopy/sigmoidoscopy (51.8%) in this cohort aged 50 years or older is well below the rate of the nation (65.2%) and Texas (64.6%) while the rate for FOBT (29.2%) is higher than in the nation (17.2%) and Texas (14.9%). However, Hispanics had significantly lower rates than non-Hispanic whites for colonoscopy/sigmoidoscopy (37% vs. 66%) and FOBT (16.5% vs. 41.7), respectively. Stepwise logistic regression showed that predictors for colonoscopy/ sigmoidoscopy are health insurance (p<0.0001), having had screenings for other diseases (p<0.0001), older age (p<0.0001), having a personal physician (p=0.0171), and male gender (p=0.0517).

Conclusions: Screening rate for colonoscopy/sigmoidoscopy in this rural cohort is well below the national and Texas level mainly due to the lower rate in Hispanics vs. Non-Hispanic whites. Health insurance, having had a personal physician and older age are among the main predictors.



NAACCR GEOCODING SERVICES - FIRST YEAR REFLECTIONS D Goldberg¹

¹Texas A&M University, College Station, Texas

Last year, the National Cancer Institute, NAACCR, and Texas A&M University partnered to create, host, and support the Automated Geospatial Geocoding Interface Environment (AGGIE) System to provide free geocoding services for the Cancer Registry Community. This system went live in the summer/fall of 2012 and has been in production use by numerous Registries since this time. In this talk, we will provide an update on the status of the project, describe its current utilization, acknowledge challenges that have been identified and overcome, and outline a roadmap for the future of the project. We invite the NAACCR community to join this talk in an interactive manner to provide feedback and wishes, needs, and desires for the system as it moves forward. Through this exchange, we hope to determine the most pressing geocoding needs faced by the Cancer Registry Community so that the project team can focus research and development efforts to address the highest priority items that will have the most benefit to NAACCR members.

014

INVESTIGATION OF MESOTHELIOMA INCIDENCE IN AREAS OF ALASKA WITH NATURALLY OCCURRING ASBESTOS

<u>D O'Brien</u>¹ ¹Alaska Cancer Registry, Anchorage, AK

The Alaska Cancer Registry (ACR) has been working with the AK Section of Epidemiology's Environmental Public Health Program, the AK Division of Geological and Geophysical Surveys, and the US Geological Survey to investigate naturally occurring asbestos in Alaska and its associated risk to human health. The town of Ambler. located in northwestern Alaska above the Arctic Circle, was found to have naturally occurring asbestos in its local gravel pit. The gravel has been used for years in construction of the town's roads, airport runway, public utilities, and various local projects. The inhalation of asbestos fibers can cause mesothelioma, a rare form of lung cancer. There was a concern that people in Ambler and other communities in Alaska with naturally occurring asbestos in their construction gravel may have developed mesothelioma as a result of exposure. ACR examined its database for cases of mesothelioma diagnosed between 1996 and 2010. ACR identified 90 cases of mesothelioma located in 31 different towns in this 15-year time period. Only 15 towns have 2 or more case, and of those, only 7 towns have 3 or more cases. Multiple cases tend to be located in towns with relatively large populations. No cases were found in the town of Ambler. Occupations of 6 cases involved employment in shipyards or other asbestos-related work. Occupations of 15 cases involved plumbing or pipefitting, which may be related to asbestos exposure from pipe insulation. Geologists with the US Geological Survey and AK Division of Geological and Geophysical Surveys provided ACR with GIS maps of the locations of high concentrations of ultramafic and serpentine rocks. These are two rock types in which naturally occurring asbestos minerals are known to form. ACR then did a GIS analysis by overlaying the locations of mesothelioma cases with the geological data. There did not appear to be a correlation between the locations of mesothelioma cases and deposits of naturally occurring asbestos.

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THE NEW YORK STATE ENVIRONMENTAL FACILITIES AND CANCER MAPPING PROJECT

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In response to legislative requirements, in 2010 the New York State Department of Health (NYSDOH) developed a web site that provides cancer counts by census block group for 23 cancer sites, using the familiar Google Maps interface. It also includes the locations of 15 types of facilities regulated by the state Department of Environmental Conservation, from fuel tanks to wastewater discharge points. In 2012, clusters of high and low cancer incidence were added to the project. These were areas defined as significant excesses or deficits by the spatial scan statistic which also showed a difference between observed and expected counts of at least 50 percent. The underlying data are available through a separate portion of the NYSDOH website, allowing any interested parties to replicate our results or to use alternate criteria for identifying unusual patterns. This presentation will demonstrate the functions of the web site, how it has informed cancer surveillance in New York State, and the public and media response to the project to date. While complex and labor-intensive, the project has been effective at conveying the ubiquity of cancer in every village, town and neighborhood of New York State.

016

THE ROLE OF GEOGRAPHY IN LOW MAMMOGRAPHY SCREENING RATES AND LATE-STAGE BREAST CANCER DIAGNOSIS IN UTAH

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Purpose: Mammography screening rates in Utah have been lower than other states for nearly 20 years. We examine the role of geographic factors on mammography screening rates and latestage breast cancer diagnosis in Utah.

Methods: Mammography screening data from the 2008 and 2010 Utah Behavioral Risk Factor Surveillance System included Utah women aged 40-74 (weighted N=417,064). Utah Cancer Registry data included women 40+ years, who were diagnosed with breast cancer from 2004-2008 (N=6,500). Multilevel logistic regression was used to examine the association between measures of geographic access to mammography (travel time, geo access scores, rural/urban residence) and individual factors (age, race/ ethnicity, insurance) and the odds of (a) *not* having a mammogram within the last two years and (b) being diagnosed with late stage breast cancer.

Results: Overall 32.7% (95%Cl 31.1%-34.5%) of Utah women 40-74 reported *not* having a mammogram within the last 2 years and 31.3% of women aged 40+ were diagnosed with late-stage breast cancer. A disproportionate number 43.1% (95%Cl 39.9%-46.3%) of women 40-49 did not have a mammogram within the last 2 years compared to women 50-74 (26.8% 95%Cl 24.9%-28.7%). Geographic access measures were not associated with mammography screening and late-stage breast cancer diagnosis among women 40-74. Travel time was moderately significant for women living ≥20 minutes from a mammography facility compared to women living for age, race/ethnicity, and insurance . Women aged 50+ with low geo access scores had higher odds (**OR=1.20 95%Cl 1.04 1.37**) of late-stage breast cancer diagnosis compared to women with high geo access scores.

Conclusion: Geographic access may be a risk factor for late-stage breast cancer for specific segments of the population, who may benefit from targeted interventions to improve early detection. Future work should consider alternative geographic access measures.

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PRODUCTIVITY LOSS DUE TO PREMATURE CANCER DEATHS IN THE UNITED STATES, 2006-2010 - HOW MUCH DOES EDUCATION ATTAINMENT MATTER?

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¹Centers for Disease Control and Prevention, Atlanta, GA

Background: Socioeconomic status (e.g. education attainment) is inversely associated with cancer mortality in the general population. This study aims to estimate productivity loss due to premature cancer deaths (≤75 years old) in populations with lower education, controlling for race/ethnicity, age, and gender. Methods: The 2006-2010 mortality and population data will be used to estimate the gender- and age-specific number of cancer deaths for each racial group by applying the mortality rate of the population in higher-educated areas (≥85% residents with high school graduation) to the population in medium- and lower-educated areas. Excess deaths will be calculated as the difference between the observed and expected deaths. The life expectancy method will used to estimate the years of potential life lost (YPLL) associated with excess cancer deaths in lower SES groups and the human capital approach was used to estimate productivity loss due to YPLL.

Results: Preliminary results using 2004-2008 data found that there were on average 310,000 cancer deaths annually (78.0% whites and 13.7% blacks). If people in medium- and poor-educated areas had the same cancer mortality rates as those in higher-educated areas, the number of cancer deaths would decrease by 9.7% to 280,000. Decreased cancer deaths would result in \$57.2 billion in productivity gain in men and \$27.6 billion in women based on a 3% discount rate. Results will be updated once 2006-2010 mortality data become available.

Conclusion: Eliminating educational disparities could help decrease cancer deaths and associated productivity loss in the United States, particularly among whites and blacks.

018

THE EFFECTS OF AGE, INCOME, AND PLACE OF RESIDENCE ON THE STAGE OF DISEASE AT DIAGNOSIS OF BREAST CANCER

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Background: The issue of disparities in breast cancer morbidity and mortality has focused primarily on race as the key risk factor. Other factors have been less extensively studied. **Purpose:** The purpose of this study was to evaluate the associations between residence in high-poverty and rural areas and breast cancer diagnosis stage.

Methods: The study population comprised 6,190 Nebraska resident non-Hispanic white women aged ≥40 years who were diagnosed with invasive breast cancer during 2005-2009. Cases were geocoded to 2000 US Census Bureau census tracts according to address at the time of diagnosis, and were categorized into four poverty levels, based on the proportion of residents per census tract living below the federal poverty level (≥20%, 10-19.9%, 5-9.9%, <5%). Place of residence was defined as either urban (urban, suburban, or large rural town) or rural (small town), based on US Department of Agriculture Rural-Urban Commuting Area codes. We compared odds of late-stage diagnosis (stage ≥2) by census tract poverty level and urban/rural residence by using multiple logistic regression with a random effect for census tract.

Results: Among women aged ≥65 years, those living in census tracts with poverty levels of ≥20% and 10-19% had 1.7 (95% confidence interval [CI]: 1.1, 2.5) and 1.3 (95% CI: 1.1, 1.7) times the odds of late-stage diagnosis. Women aged 40-64 years residing in areas with these same poverty levels did not have higher odds of late-stage diagnosis. Rural residence did not increase the odds of late-stage diagnosis.

Conclusions: Increased risk of late-stage breast cancer diagnoses among women aged ≥65 years in low-income census tracts is difficult to explain and warrants future evaluation. The lack of association between rural residence and diagnosis stage suggests that the long distances to health care that are characteristic of rural areas do not hinder access to it.

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UTAH BABY BOOMERS, EARLY-LIFE SOCIOECONOMIC STATUS, AND CANCER RISK: WHAT WE LEARNED FROM CANCER REGISTRY LINKAGE TO STATE BIRTH CERTIFICATES

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Background: Our understanding of how SES affects cancer risk remains surprisingly underdeveloped as SES is often only measured at an area level.

Purpose: Capture individual SES through cancer registry linkage to state birth certificates and generate incidence rates by SES at birth. **Methods:** Birth certificates for a cohort of Utah Baby Boomers (born 1945-59) in Salt Lake and Weber counties were linked by the Utah Population Database to Utah Cancer Registry records. Individual SES was based on parental industry/occupation on birth certificates and transformed to Nam-Powers SES scores (Np-SES). Area SES was defined as average household income of census tract at birth (BiCT-SES) and at diagnosis (CaCT-SES) using 1960-2000 census data. Bivariate correlations between quartile SES measures were tested using Spearman's rank correlation (p). SES quartile incidence rates were estimated for all cancers, breast, prostate, colorectal, lung, cervical, pancreas, and melanoma, and incidence rate ratios (IRR) were generated comparing the lowest SES quartile (Q1) to the highest SES quartile (Q4).

Results: 94% of 126,335 births had Np-SES scores and 85% assigned a BiCT-SES. 8,989 births linked to cancer records and 90% assigned a CaCT-SES. Cases were disproportionately represented in the highest CaCT-SES quartile (Q4 31%) when compared to the cohort's BiCT-SES (Q4 13%). Bivariate SES correlations were modest but significant (p=0.09-0.20,p<.05). Compared to the highest SES quartile (Q4), lower SES (Q1) was significant and positively associated for all cancers combined (BiCT-SES IRR=1.06) and cervical cancer (BiCT-SES & Np-SES IRR=1.46). Lower SES (Q1) was inversely associated with melanoma (BiCT-SES IRR=0.72; Np-SES IRR=0.77), female breast (Np-SES IRR=0.84), and prostate (Np-SES IRR=0.76) cancers.

Conclusion: We found strong associations between cancer risk and SES at birth. Cancer registries must continue to look to other population-based sources for important individual SES data.

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020

COMPLETE, SMOOTHED LIFE TABLES AND LIFE EXPECTANCY IN THE APPALACHIAN POPULATION AND SUB-POPULATION BY REGION AND SOCIOECONOMIC STATUS

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Background: the Appalachian region has experienced higher rates of poverty and lower levels of education than the rest of the United States. The burden of cancer is higher for residents of Appalachia than for the United States as a whole. A CDCfunded project is attempting to examine relative survival in the Appalachian region and its sub-regions. The first part of the project is to develop complete, smoothed, life tables by region and socio-economic status.

Purpose: We will present the methodology to develop such specific life tables and the findings and implications of these life tables for Appalachia.

Methods: The inter-censal county-level populations and mortality data were acquired from the US National Center for Health Statistics for each of the calendar years 2000-2010. Appalachian region and its sub-regions are defined on the basis of the Appalachian Region Commission. County-level poverty and education data for years 2000-2005 and 2006-2010 were acquired from the US Census. Flexible Poisson regression models using splines were applied to smooth the raw mortality rates. Simulations were conducted to identify the best models by varying combinations of numbers and locations of knots. The complete, smoothed life tables will be based on a set of variables including state, race, Appalachian region, sub-region and socioeconomic status.

Results/Discussions: The specific life tables generated in this study are essential for estimating population-based cancer survival within the relative survival framework in Appalachia and in the individual states of the Appalachian region. For the first time, such life tables will also enable investigation of whether the wide regional variations in poverty and education in Appalachia have any impact on age-specific life expectancy of this particular population.



Oral Abstracts

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oral abstracts

concurrent session 2



CONSTRUCTING A PROCESS FOR UTILIZING INSURANCE CLAIMS DATA: THE USE OF MEDICAID DERIVED TREATMENT AS A LAUNCHING PAD

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Background: State Cancer Registries often look for innovative ways to enhance their data. Linkages with external datasets are both a cost effective and efficient option. The Louisiana Tumor Registry (LTR), in its effort to expand data resources, collaborated with the Louisiana Department of Health and Hospitals through a data sharing agreement to gain annual access to Louisiana Medicaid claims data.

Purpose: This project seeks to establish a repository of treatment information derived from Medicaid claims that will enhance LTR data as a whole.

Approach: The complex structure and volume of data collected by the state Medicaid office poses a challenge to the registry. To assess its full potential, LTR will construct an algorithm to extract pertinent information from Medicaid and link with the pre-existing cancer database. Sustainability and adaptability of the process are priorities. Medicaid records treatment information in the form of procedure codes which include CPT, HCPCS, and National Drug Codes. Every claim is coded and every surgical procedure or adjuvant therapy that is billed to Medicaid is represented. The codes are specific and can indicate the exact chemo agent administered, including dosage.

Results: Extracting treatment from Medicaid allows LTR to assess data completeness and serves as a template for future claims based linkages. It also aids in data collection within a unique population. The initial linkage showed 28% of LTR cases were Medicaid recipients. Review of a subsequent linkage revealed that, in 2010, 12% of breast cases alone were recipients at time of diagnosis. Utilizing the claims data that coincides with diagnosis date allows LTR to capture a complete account of cancer care.

Conclusion: The collection of treatment information can be a time consuming and difficult process for a registry to undertake. Utilizing pre-existing databases allows the registry to overcome some of cancer reporting's challenges and barriers.

022

USING CLAIMS DATA TO IDENTIFY PATIENTS UNDERGOING ACTIVE SURVEILLANCE FOR PROSTATE CANCER

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An increasing number of cancer cases are initially diagnosed in a private physician's office. Despite the best efforts of central cancer registries, such cases are less apt to be reported than cases diagnosed in a hospital setting. For tumors that demand near-term active treatment, this issue is not of great concern since the tumors are reported by the treating facilities. For prostate cancer, where treatment can consist of active surveillance ("watchful waiting"), there is greater concern that the tumor will never be reported, or will be reported only after a significant passage of time and with a questionable date of diagnosis. We reviewed medical claims dated prior to the reported date of diagnosis to see if such patients could be identified. Approximately 45,000 prostate cancer cases diagnosed in New York State between 2004 and 2006 were compared with Medicare claims dating back to 2002. About 3 percent of these were found to have a Medicare claim with a diagnosis of prostate cancer predating the registry date of diagnosis, including 1.5 percent by over three months and 0.5 percent by over one year. These findings were concentrated among the 18 percent of prostate cancer cases for which there is no analytic source in the New York State Cancer Registry. Although these percentages are low, inaccuracies in the date of diagnosis have a significant impact on survival estimates. For the presentation, we will expand our analytic cohort to include 2007 to 2009 diagnoses and our analysis to include prostate-cancer related procedures in addition to diagnostic codes. We will also include Medicaid claims.

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WORKING WITH NPI NUMBERS IN CANCER REGISTRIES

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Background: The use of National Provider Numbers (NPI) in cancer registries is tantalizing and, so far, elusive. Automated look-ups can select odd results, and manual look-ups can be frustrating. For example, automated hospital NPI look-ups may identify pharmacies named for the hospital's popular name (which can differ markedly from the legal name) or hospital departments rather than the hospital itself. Physician NPI lookups can identify practitioners with similar names but obviously unrelated fields of practice, such as an ophthalmologist whose NPI number was recorded as the colon surgeon.

Purpose: This presentation will provide guidelines for manual and automated searches for NPI numbers, recommendations for identifying incorrect numbers, and examples of administrative and research uses of NPI numbers.

Approach: The National Cancer Data Base (NCDB) requires Commission on Cancer accredited programs to submit NPIs for the facility and for the patients' primary surgeon, radiation oncologist and medical oncologist. Facility and physician NPI numbers were initially linked to the National Plan & Provider Enumeration System (NPPES) files to evaluate the quality of submitted numbers. Preliminary results indicate that the vast majority of NPI numbers "make sense". For example, among 54,556 reports for patients diagnosed with colon cancer in 2010 submitted to NCDB with surgeon NPI numbers recorded, 91% indicated practitioners whose specialty was surgical gastroenterology, surgical oncology, or colon or rectal surgery. Finally, several prototypical uses of NPI numbers were developed.

Implications: NPI numbers are near-universal identifiers for organizations and individuals in medical practice that can be used for record-linkages, evaluation of treatment experience and practice, and other promising applications. We will offer recommendations for improving the quality of NPI numbers in registries to bring those expectations closer to fulfillment.

024

STANDARD REPRESENTATION OF GENOMIC INFORMATION Y Heras¹

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Background: The use of genetic testing in clinical practice is rapidly expanding. Genetic testing is playing an increasingly important role in cancer prevention and prognosis, and leads to personalized cancer treatment. For genetic test results to be used in clinical setting and for clinical professionals to take full advantage of genomic advances in daily medical practice, genetic test results need to be put into useful and meaningful formats and be integrated into electronic health records (EHRs).

Today's EHRs, however, are not ready for genomic information. Lack of standards for data elements, terminology, structure, interoperability, and clinical decision support rules are some of the major barriers and challenges to the integration of genomic information with clinical data. The lack of structured and coded genetic test results will also be a barrier to cancer registries as they are looking to automate the extraction of data directly from EHRs. **Objective:** *Increase understanding and awareness of standards development efforts that are underway by the HL7 Clinical Genomics Work Group (CGWG).

*Stimulate interest of the NAACCR community to collaborate with the CGWG and to enhance standards to fit the needs of cancer registries.

Methods: This paper presents the standards that have been developed by the CGWG and their relevance to cancer registries. **Results**: *Assessment of genomic standards and their relevance to cancer registries

*Methods for enhancing these standards for use in cancer registries

Conclusions: *The essential infrastructure needs to be developed and to fit the rapid changing and evolving nature of the field of genetic testing for EHRs and cancer registries can handle the high volume of genomic information.

*Coded and structured standard representations of genomic information are critical to interoperability between EHRs and cancer registries.

*Active involvement of the NAACCAR community is critical.

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ENHANCING CANCER REGISTRIES FOR EARLY CASE CAPTURE OF PEDIATRIC AND YOUNG ADULT CANCER CASES

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Background: In 2008, the Caroline Pryce Walker Conquer Childhood Cancer Act was signed into law, authorizing CDC to award grants to establish a nationwide pediatric registry to capture cases within weeks of diagnosis. In response, CDC developed a funding opportunity for existing central cancer registries (CCRs) to implement activities to meet the mandate of the law. In September 2011 funding was awarded to seven CCRs.

Purpose: The purpose is to enhance CCR infrastructure for more rapid reporting of pediatric cases, termed Early Case Capture (ECC), and to increase availability of this data for researchers. Grantees will implement ECC reporting from facilities that diagnose and treat pediatric cases; develop methods for complete, timely, and accurate ECC; establish data access procedures for researchers; and submit data to CDC within 4 months.

Methods: CCRs have implemented various ECC approaches, including direct electronic reporting from out-of-state pediatric facilities; electronic reporting from state Health Information Exchanges (HIEs), Electronic Health Records (EHRs), and diagnostic imaging centers; and web-based follow back on cases identified using hospital discharge data.

Results: Innovative reporting relationships have been implemented. CCRs have expanded infrastructure to collect timely data and to report cases to CDC more rapidly. CDC has developed an ECC completeness estimate to evaluate the data submissions. Completeness, timeliness, and quality assessments will be shared during this presentation.

Conclusions: Pediatric ECC is possible; however, significant initial investment may be required. In the future, successful ECC initiatives may be expanded to other CCRs and to other types of cancer, laying the groundwork for more timely reporting of routine incident cases. More rapid receipt of data at the CCR will facilitate the ability for researchers to access pediatric cancer data in a timely manner.

026

USING THE CER CORE ACTIVITY CASE FINDING PROCESS TO IMPLEMENT RAPID CASE FINDING

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Historically, the Rhode Island Cancer Registry (RICR) has not conducted Rapid Case finding. The increasing needs of the Rhode Island Department of Health to perform surveillance activities on perceived areas of elevated cancer incidence, to conduct strategic planning and to provide researchers with current data requires reporting facilities submit data earlier that the current regulation of six months after diagnosis. As part of the Comparative Effectiveness Research (CER) Project supported by the Centers for Disease Control and Prevention, the RICR developed a process to identify and to begin abstracting eligible cases within a month of diagnosis. While this process involved only cancers included in the CER Core Activity Project, it will be expanded to include all reportable cancer cases. In addition, all Rhode Island hospitals must meet the increased clinical trial enrollment standard for the American College of Surgeon's Commission on Cancer accreditation process. This will enhance the relationship between the RICR and reporting hospitals. The RICR is heavily involved in the development of the Rhode Island Comprehensive Cancer Control Plan. With the goal of increasing the number of cancer patients enrolled in clinical trials, the statewide Rapid Case Finding process will be used to create a pool of patients who could benefit from treatment received as part of a clinical trial. Patients are not always advised of the availability of clinical trials and their potential benefits. This process will provide physicians with a method to identify and contact patients.

Generally the law of unforeseen consequences provides a negative outcome. In this instance the need to identify cases to be enrolled in the CER Core Activity project has provided a process to improve cancer incidence surveillance and strategic planning by the Rhode Island Department of Health and to create a pool of cancer patients who may benefit from the inclusion in clinical trials.

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TIMELY AND COMPLETE CAPTURE OF PEDIATRIC AND YOUNG ADULT CANCER CASES IN LOUISIANA: A COMPREHENSIVE APPROACH

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Background: Louisiana is one of the 7 states funded by the CDC for the Early Case Capture (ECC) of Pediatric and Young Adult (Age 0-19) Cancer Cases Project. To achieve rapid reporting of ECC cases (within 30 days of diagnosis) and increase availability of timely data, the Louisiana Tumor Registry (LTR) is striving to enhance its infrastructure and develop a comprehensive approach. Our objective is to share our experience in challenges and resolutions.

Methods: All potential reporting sources that diagnose and/or treat ECC cases were identified, including hospitals, pathology labs, radiology centers and large out-of-state children's hospitals. Our primary approach in capturing ECC cases in real time is via Epath reporting. We recruited major state facilities without Epath to report online via Webplus, and also worked with out-of-state children's hospitals in collaboration with CDC for timely reporting. Imaging centers were also targeted. Measures of ECC reporting timeliness will be calculated and compared between the two halves of 2012 to determine progress in reporting.

Results: We have expanded Epath to about 80% of cancer cases in the state. Children's Hospital in New Orleans (which treats about 50% of our cases) has begun the process of Epath implementation, along with other major medical centers. Progress has been made in both St Jude's and Texas Children's Hospitals, as well as imaging centers for capturing benign brain and pediatric cancers. In addition to sharing our experience in improving relationships with all facilities and enhancing infrastructure, we will also present timeliness of reporting of ECC cases between the first and second half of 2012 cases. **Conclusion/Implications:** Timely reporting of ECC cases is challenging but possible. Building infrastructure of Epath reporting and targeting larger in-state and out-of-state facilities while developing creative strategies to build sustainable relationships are the keys.

028

THE GOLDILOCKS QUANDARY: HOW MUCH PATIENT CONTACT IS JUST RIGHT?

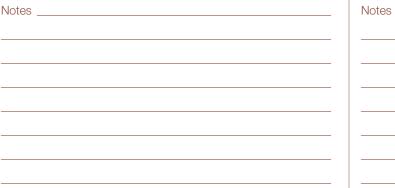
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Background: Population-based cancer registries are vital to epidemiological research, providing an unbiased source of cancer survivors for studies. However, recruiting research participants can be labor intensive and costly. The Utah Cancer Registry (UCR) utilizes an opt-in approach for researchers wishing to contact patients and obtains cancer survivors' permission to release their contact information to the researcher. **Purpose:** We analyzed the contact effort required to recruit cancer survivors for research studies to determine the optimal amount and type of contact effort needed to maximize recruitment.

Methods: A total of 42,880 contact attempts were made between 2008-2012 for 11,057 cancer survivors in 11 research studies. We excluded "lost" and ineligible patients. Bivariate analyses were conducted to examine the association between number of contact attempts and contact outcomes: patients who consented, patients who refused, and patients who never responded. Multinomial logistic regression models evaluating the association between contact outcome and potential predictive factors including sex, site, stage, diagnosis age, recruitment age, and time since diagnosis will be presented.

Results: 57% of patients consented, 24% refused, and 19% did not respond. An average of 2 contact attempts were made for consenting patients (range 1-23) and 75% responded within 4 attempts. An average of 4 contact attempts were made for refusing patients (range 1-16) and 75% responded within 5 attempts. Patients who did not respond received an average of 4 contact attempts (range 1-21).

Conclusion: Most patients responding to registry contact efforts responded within 4 attempts. Over 90% responded within 7 attempts. Multinomial logistic regression models will provide more information to inform best practices with regard to registry patient contact. Central registries should continue to evaluate patient contact to maximize research participation and minimize costs.



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EHR DATA CAPTURE: HOPES, FEARS, DREAMS

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Background:

Electronic health records (EHRs) are gaining traction and are viewed by the federal government as the key to efficient data capture and reuse. This paper looks at the potential of EHRs to ease data capture for cancer registries.

Purpose:

This paper addresses the following questions:

- * What is the program for Meaningful Use of certified EHRs?
- * How does Meaningful Use relate to registry data collection?
- * What is the CMS program for quality measure reporting?
- * How does quality reporting relate to registry data collection?
- * What other trends in electronic data encompass registry data?

Methods/approach:

This paper is based on our work designing and implementing standards for interoperability between clinical data systems and with registries for cancer data (NAACCR), quality (Child Health Corporation of America), public health (CDC's National Healthcare Safety Network) and research (CDISC).

Results:

* Assessment of Meaningful Use data against NAACCR data set * Further methods to automate data reporting based on

interoperability standards

Conclusions:

* Federal programs and incentives for EHRs lay a foundation and define a direction for data reuse

* Additional standards and applications can augment federal programs to dramatically raise the level of automation in registry reporting

030

INCREASED CANCER INCIDENCE REPORTING THROUGH **USE OF ELECTRONIC HEALTH RECORDS (EHRS)**

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Background:

Changes in medical practice and health care delivery have led to growing numbers of various cancer sites/types being diagnosed/ and Research Center (MCR-ARC) is one of two central cancer registries (CCRs) participating in CDC's National Program of Cancer Registries receiving American Recovery and Reinvestment Act (ARRA) funding to improve cancer reporting by streaming data directly from EHRs to the CCR (Special Project #3). **Purpose**: To increase case completeness by obtaining previously unreported cases and treatment information from EHRs. Methods: We recruited a large multi-specialty clinic with smaller satellite clinics. Using information provided by the Missouri Health Information Technology Assistance Center, we identified additional potential clinic/physician offices (C/POs) and critical access hospitals (CAHs); conducted site visits; and recruited project participants. We identified and collaborated with facilities' EHR vendors and CDC software developers to export files, develop interfaces and import, store and process data. We worked with other state and national organizations to identify and assess options for software that allows secure transfer of encrypted data via the Internet.

Results: We selected the University's secure messaging software MovelT and obtained test files and began to import electronic EHR data in 3/12. Some C/POs and CAHs are now routinely transmitting cancer data to the CCR. Work is ongoing; additional results (e.g., facilities reporting via an EHR, vendor software, interface and interoperability challenges, etc.) will be reported. Conclusions/ Discussion: Identifying cost-effective ways for CCRs and mandated non-hospital reporters to capture cases and report as mandated by law is challenging but rewarding. Obstacles remain to be overcome but use of EHRs presents a viable solution.



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NATIONAL PROGRAM OF CANCER REGISTRIES – ADVANCING E-CANCER REPORTING AND REGISTRY OPERATIONS PROJECT (NPCR-AERRO): UPDATE ON ELECTRONIC PATHOLOGY REPORTING ACTIVITIES

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Background: CDC's NPCR-AERRO project has successfully implemented electronic pathology (ePath) reporting from several national laboratories (labs) to over 30 central cancer registries (CCRs) using the NAACCR Volume V standard and the Public Health Information Network Messaging System (PHINMS). Reporting of molecular data is not as straightforward and standardized as reporting pathology reports, thus requiring more exploration. **Purpose:** The purpose of this project is to enhance the completeness, timeliness, and quality of cancer data through the automated capture of standardized data.

Methods: Through collaborations with labs and other experts, NPCR-AERRO continues to implement ePath reporting from additional labs to CCRs. CDC is also collaborating with the College of American Pathologists (CAP), the American Society of Clinical Oncologists (ASCO), the American College of Surgeons (ACoS), Cancer Care Ontario (CCO), cancer registry experts and genetics experts to identify a standard for reporting molecular data to CCRs. **Results:** Challenges have been identified with reporting standardized data for molecular tests. Several standards have been implemented through different pilot projects and lessons learned were captured which will be used to identify possible solutions for reporting these types of data. Work with CAP, ASCO, ACoS, CCO and other experts have resulted in the development of templates that describe standard information that labs should report to CCRs for molecular tests. The eMaRC Plus software has been expanded to receive and process synoptic reports and reporting of Collaborative Stage Site-Specific Factors from molecular reports.

Conclusion: We will present an update on NPCR-AERRO activities on expanding implementation of ePath reporting from national labs to CCRs, expanding eMaRC Plus functionality, exploring challenges with reporting molecular data, and identifying standard electronic formats as a solution for labs to report to CCRs.

032

CANCER REPORTING FROM MOLECULAR LABORATORIES – A NEW FRONTIER OF ELECTRONIC REPORTING

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Background and Purpose: Biomarkers and molecular data play an increasingly important role in cancer staging, treatment selection, response to therapy and prediction of recurrence. While molecular-genetic testing is still largely a cottage industry in the US, test volumes are increasing as more molecular assays become available, insurance coverage increases, and the technology becomes more automated. Molecular test results are needed by registries to complete many of the site-specific factor (SSF) data items used in Collaborative Staging. The challenge for the registry is to identify the sources of molecular test results, ensure systematic data collection, and incorporate this novel form of information into the registry database.

Methods: As a registry participating in the CDC's initiative to enhance cancer data for Comparative Effectiveness Research (CER), the Louisiana Tumor Registry (LTR) actively collects additional treatment and SSF data for all colorectal, breast and CML cases diagnosed in 2011. The LTR receives pathology reports for approximately 90% of all cases; about 65% are sent in HL7 format and 35% are faxed or sent to the registry as a PDF or in paper form. We evaluated the frequency that SSF data for CER cases were available from anatomical and molecular pathology records vs chart review. We further stratified pathology results on electronic vs paper reports.

Results: For regional and distant stage colorectal cancers, we will present tables of the frequency SSFs 1-10 are present in pathology reports vs only available through chart review; for CML, we will present tables of the frequency the BCR/ABL fusion gene is available. We will also discuss our experience with recruiting molecular labs to report electronically and with incorporating data from this new source into the registry database.

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GLOBAL SURVEILLANCE OF CANCER SURVIVAL (CONCORD)

<u>M Coleman</u>,¹ C Allemani,¹ H Weir,² T Tucker,³ CONCORD Working Group¹

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Background: Cancer survival varies widely around the world. Of 12.7 million cancer patients diagnosed annually around 2008, 56% occurred in low- and middle-income countries. Improvement of cancer survival in all countries is one of 11 goals for 2020 set out in the UICC World Cancer Declaration. UICC requires biennial evaluation of progress, but no mechanism exists for this.

Purpose: The CONCORD program is designed to initiate global surveillance of cancer survival. We will collect data from population-based cancer registries for 10 common adult malignancies and childhood leukaemia, using a standard protocol and standardised quality control checks. The data call has been issued, with a 31 March 2013 deadline. We aim to provide quantitative and directly comparable estimates of cancer survival, the population "cure" fraction, cancer prevalence and the number of avoidable premature deaths.

Methods: We expect to receive data from over 200 cancer registries in 60 countries on all 5 continents for patients diagnosed 1995-2009 or later with a cancer of the stomach, colon, rectum, liver, lung, breast, cervix, ovary or prostate, or leukaemia, including acute lymphocytic leukaemia in children. We will estimate relative and net survival, using life tables by age, sex, country, race and calendar year. We will use excess hazard models to examine the impact of stage and diagnostic investigations on survival differences.

Results/Discussion: Continuous, global surveillance of cancer survival will become a source of information for cancer patient groups and researchers, a stimulus for change in health policy and a key metric for cancer control.

Cancer survival disparities underpin national cancer control plans. CONCORD-2 will enable assessment of the contribution of health system characteristics to international differences in cancer survival.

We believe CONCORD is indeed "Thinking Big" to shape the future of cancer surveillance. We will report progress.

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034

CHANGES IN CANCER SURVIVAL TRENDS

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Background and Objectives: Medical advances may increase length of survival hence extend life of cancer patients. However, improved survival may reflect not only improved cancer treatment but also changes in diagnosis; increased early detection. To understand changes in cancer burden correctly, we analyze and interpret cancer survival trends in relation with trends in cancer incidence and mortality.

Methods: Using population-based cancer registry data from the Surveillance, Epidemiology, and End Results (SEER) Program and US mortality data, we analyzed trends in 5-year relative survival, incidence and mortality from 1975 to 2009. The trends are characterized as a function of the year of diagnosis, stratified by stage at diagnosis; join point models are used to evaluate and summarize the trends systemically. Cancers common in US population and those have increasing incidence rates in recent years are considered; Colon and Rectum, Breast, Lung and Bronchus, Prostate, Melanoma of Skin, Kidney and Renal Pelvis, Thyroid, Cervix and Hodgkin lymphoma.

Results: Patterns in incidence, mortality and survival can be explained in various scenarios: changes in true occurrence of disease (e.g. lung), increased early detection (e.g. breast, colon, melanoma, and cervix), and treatment being more effective (e.g. Hodgkin lymphoma).

Conclusion: Increased survival overtime is not necessarily reflecting decrease in burden of disease. To understand true progress against cancer, physician and policy maker should consider patterns in incidence, mortality and survival simultaneously - analyzing trends by stage at diagnosis may provide better insights.

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IMPACT OF INCOMPLETE DATE INFORMATION ON SURVIVAL ESTIMATES

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Background: It is not uncommon for population-based cancer registries to have incomplete or missing date components (i.e. day and/or month of diagnosis/last contact). Even when complete dates are reported, some registries have confidentiality/data use policies which only permit the release of month and year to researchers. How and to what extent survival estimates are affected by the use of incomplete date information has not been widely studied.

Objectives: 1) Evaluate how and to what extent incomplete date information affects survival estimates; 2) Evaluate how the algorithm utilized in SEER*Prep to recode the unknown month component of date fields affects survival estimates.

Methods: Cancer cases diagnosed from 2001 to 2009 among New York residents were used for this study. Observed survival rates were calculated for 23 major cancer groups using: 1) complete dates; and 2) only the month and year components of dates. The two sets of survival rates were compared and evaluated. For the second part of the analysis, we assumed that the diagnosis month was unknown and used the SEER*Prep built-in algorithm to recode unknown month. Observed survival rates were calculated and compared using: 1) the actual month and year; and 2) the recoded month and actual year.

Results: Survival rates tended to be overestimated if only month and year were used in the survival analysis, or if the month was unknown and the recoded value was used. Overestimation was more apparent for short term survival and for cancers with higher fatality rates. However, the 5-year survival rates were not affected.

Conclusions: If short term survival is the focus of interest, especially for cancers with a high fatality rate such as pancreatic cancer, complete date information should be used in the survival analysis.

036

THE USE OF COLORECTAL CANCER MORTALITY AS AN ENDPOINT FOR SURVIVAL AND SCREENING EVALUATION: IS ONTARIO'S DATA UP TO THE CHALLENGE? D Nishri¹

¹Cancer Care Ontario, Toronto, ON

Site-specific cancer mortality is an important end point for the evaluation of cancer screening programs. The use of site-specific mortality as an endpoint for survival estimation is also becoming more popular, especially when appropriate life tables are not available for the calculation of relative survival. However, if the coding of cause of death is inaccurate, the results of these analyses will be biased. In this talk, Ontario colorectal cancer cases will be used to explore the question posed by Welch & Black (2002): Are deaths within 1 month of cancer-directed surgery attributed to cancer on death certificates? For this analysis, 48,163 people with a single cancer case diagnosed 2002-2009 were identified from the Ontario Cancer Registry; 78.5% were found to have had an operation for colorectal cancer. By December 31, 2009, 30.6% of the surgical cases were deceased; of these, 61.2% had colorectal cancer as their cause of death, while another 16.8% were reported to have died from another cancer. If it is assumed that all deaths within one month of diagnosis and cancer-directed surgery should have cancer as the underlying cause, the potential underreporting of cancer-specific mortality can be estimated. The changing pattern of attribution of cause of death with elapsed time since surgery will be examined, as well as other factors that affect cause of death coding. This work will also investigate whether it is feasible to calculate site-specific survival for colon and rectum separately.

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AN EVALUATION OF PRIMARY PAYER DATA AMONG BREAST AND COLORECTAL CANCER CASES IN MASSACHUSETTS, 2005-2009

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Objectives: The purpose of this project is to examine primary payer data at diagnosis and at the beginning of each treatment modality for breast and colorectal cancer cases diagnosed in Massachusetts residents from 2005-2009. These years were selected in order to collect data before and after the 2006 passage of the Massachusetts Health Care Reform Law. **Methods:** 5000 breast and colorectal cancer cases were randomly selected for chart review, resulting in 7500 charts reviewed. Data fields which included primary payer at diagnosis and at each treatment modality, race/ethnicity, Hispanic identifier, and smoking were re-abstracted from every hospital in the state using Abstract Plus with a nearly 100% completion rate. In addition, hospital inpatient discharge data were matched to the cases to obtain payer data.

Results: The data have been cleaned, consolidated and sent to Westat for analysis. The hospital discharge match resulted in over 2000 matches or a 40% match rate. The first component of the analysis will compare the abstracted payer at diagnosis with the payer data in the MCR database to determine the reliability of the field and the extent to which this field reflects true primary payer at diagnosis as opposed to payer at the start of treatment. The second component will examine the treatment course of individual cancer patients and the changes in primary payer over the continuum of care. The final component will evaluate changes in primary payer before and after the passage of Massachusetts Health Care Reform. Hospital discharge data will be compared to the abstracted data to determine if discharge data are an adequate proxy for payer information.

Conclusions: The data collection phase of this project has resulted in excellent re-abstraction rates. Detailed analyses will be available in April 2013.

038

INSURANCE STATUS ASSOCIATION WITH SURVIVAL IN DIFFUSE LARGE B-CELL LYMPHOMA PATIENTS

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Background: Insurance status, an important factor determining access to care, has been shown to be associated with stage at diagnosis and receipt of treatment among patients of several cancer types, which both affect the prognosis and survival. We hypothesize that insurance status is associated with the overall survival among patients diagnosed with diffuse large B-cell lymphoma (DLBCL), the most common subtype of non-Hodgkin lymphoma.

Method: We examined this association using the data from National Cancer Database (NCDB), a nationwide, hospital-based cancer registry with a cohort of 9995 DLBCL patients aged 18-64, diagnosed in 2004-2005. Survival curves were drawn for patients with private insurance, Medicaid and no insurance. Cox proportional hazards model was fitted to estimate hazard ratios (HR) and the 95% confidence intervals (CI) for insurance types controlling for age, sex, race, area level education, disease stage, B-symptom presence, comorbidity score and initial treatment. Results: Compared to patients with private insurance, uninsured and Medicaid patients had a lower survival (5-year survival rates were 73% for private insurance, 59% for no insurance, and 54% for Medicaid, log-rank test P-value < 0.0001). After adjusting for potential confounding factors, uninsured (HR: 1.42, Cl 1.25-1.61) and Medicaid (HR=1.46, Cl=1.31-1.63) had a higher risk of death compared to patients with private insurance. Conclusions/Implications: Insurance status is associated with DLBCL survival. Further study is needed to determine the role of treatment delay, different treatment and/or other factors explaining these results.

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IMMIGRATION FACTORS AND PROSTATE CANCER SURVIVAL AMONG HISPANIC MEN IN CALIFORNIA: DOES NEIGHBORHOOD MATTER?

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Background: Hispanics are more likely than non-Hispanics in the US to be diagnosed with later stage of prostate cancer, yet they experience better survival rates. We evaluated the impact of nativity (US- versus foreign-born), neighborhood socioeconomic status (SES), and Hispanic ethnic enclave (neighborhoods with high proportions of Hispanic residents and that tend to retain Hispanic sociocultural mores) on overall and prostate cancer specific survival among Hispanics.

Methods: We studied 35,427 Hispanic men diagnosed with invasive prostate cancer from 1995 through 2008 in the population-based California Cancer Registry, with vital status data through 2010. Nativity was based on registry data or, if missing, imputed from case Social Security Number. Block group-level neighborhood measures were developed from US Census data. We used stage-stratified Cox regression models to assess the effect of nativity and ethnic enclave on overall and prostate cancer specific survival.

Results: In models adjusted for neighborhood SES and other factors, foreign-born Hispanics had significantly lower risk of all-cause (adjusted hazard ratio (HR)=0.83; 95% confidence interval (CI)=0.80, 0.86) and prostate cancer-specific (HR=0.81; 95% CI=0.75, 0.87) mortality. Ethnic enclave appeared to modify this effect with the survival advantage more pronounced in the high ethnic enclave (HR=0.79; 95% CI=0.76, 0.84, for overall survival) compared to low ethnic enclave neighborhoods (HR=0.88, 95% CI=0.82, 0.94 for overall survival).

Conclusions: Despite lower SES, Hispanic immigrants have better survival after prostate cancer diagnosis than US-born Hispanics and this pattern was more striking among those living in ethnic enclaves. Identifying the modifiable individual and neighborhood-level factors that facilitate this survival advantage in Hispanic immigrants may help to inform specific interventions to improve survival not only in this growing population, but among all patients.

040

HEPATOCELLULAR CARCINOMA IN TEXAS

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Background: Incidence rates of hepatocellular carcinoma (HCC) have been increasing in both Texas and the United States. The literature suggests that rising prevalence of hepatitis B and C infections, obesity, and diabetes may explain the phenomenon. **Purpose**: This research describes HCC rates in Texas compared to the United States overall, from 1995-2010.

Methods: We plotted trend lines and computed annual percent change in HCC incidence from 1995-2010 in Texas and the United States overall (SEER) and stratified by sex, race/ethnicity, and geographic region.

Results: From 1995 to 2010, HCC incidence rates overall increased at a faster rate in Texas than in the United States as a whole. HCC incidence rates were highest in men and lowest for white non-Hispanics both nationally and in Texas. Nationally, Asian/Pacific Islanders experienced the highest incidence rates with blacks and Hispanics significantly lower, but by the end of the time period Texas rates for Asian/Pacific Islander, Hispanic, and black men were similar to each other and to the national Asian/Pacific Islander rate. Concomitant with HCC rate increases, age at diagnosis in Texas decreased, mirroring the national trend. In Texas, HCC rates were highest for men residing in the southern area of the state.

Conclusions/Implications: HCC is a rising public health issue in Texas. The epidemiology of the disease has changed dramatically since 1995, affecting a larger proportion of individuals at younger ages and disproportionately impacting Hispanics, Asian/Pacific Islanders, and blacks. Although alcoholism has historically been the most significant HCC risk factor in the United States, in recent years other important risk factors have been identified. Interventions designed to increase screening rates for hepatitis C, promote immunization for hepatitis B, and decrease obesity rates may be especially important for individuals of some race/ethnicities living in heavily burdened geographic areas.

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Oral Abstracts

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oral abstracts

concurrent session 3



2013 REVISIONS TO THE 2009 NAACCR DEATH CLEARANCE MANUAL

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Background/Purpose: The NAACCR Death Clearance Issues Workgroup was formed as part of the NAACCR Registry Operations Committee to identify areas in need of revision and clarification related to the Death Clearance Process. As a result, the "*July 2009 Death Clearance Manual*" was developed, and planned for going into effect for 2010 deaths, as part of the 2012 Call for Data.

Methods/Approach: After release of the new *July 2009 Death Clearance Manual*, additional areas were identified within the new Death Clearance Manual for further review and clarification. The Death Clearance Issues workgroup focused on the following areas:

- the ability for all states and provinces to equally access mortality data,
- the accuracy of mortality data,
- using underlying and multiple cause of death,
- non-reportable conditions,
- deciphering ambiguous terminology,
- determining multiple primaries,
- various follow-back sources,
- sufficient information to take a death certificate only (DCO) out of DCO status,
- estimating dates of diagnosis,
- how to handle DCOs when follow-back was not conducted, and
- assessing the cost-benefit for adding requirements to the DCO process.

Results: This presentation will provide an overview of the past two years of work by the NAACCR Death Clearance Issues Workgroup, and proposed changes to the *July 2009 Death Clearance Manual*.

Conclusions: Although death clearance often remains a challenge, the next version of the Death Clearance Manual should provide additional improvement, clarification, and consistency for conducting the Death Clearance Process.

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DEATH CLEARANCE MULTIPLE PRIMARIES OVERVIEW

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Background/Purpose: The NAACCR Death Clearance Issues Workgroup was formed as part of the NAACCR Registry Operations Committee to identify areas in need of revision and clarification related to the Death Clearance Process. As a result, the "*July 2009 Death Clearance Manual*" was developed, and planned for going into effect for 2010 deaths, as part of the 2012 Call for Data. In this Manual, basic guidance was provided for using multiple primary rules, based on ICD10. After release of the new *July 2009 Death Clearance Manual*, additional clarification was needed on creating multiple primaries during the death clearance process.

Methods/Approach: In order to create additional detail on determining multiple primaries, the Death Clearance Issues Workgroup created a sub-group to focus on this task. A more detailed guidance document was created for inclusion in the next Death Clearance Manual. Other Workgroup registries were solicited for input, and the rules were expanded.

Results: The following recommendations were made:

- Those where the Death certificate cause of death and a tumor matched on the registry's DB match at the first 3-characters

 called a Direct match and can be automatically linked together – no follow back. Some exceptions may apply.
- 2) The MI Rule for Solid Tumors For Death Clearance only MI can be applied and no follow-back (FB) needed
- Hematopoietic and Lymphoid Tumors Matching based on histology's was added – ranges for both Hematopoietic and lymphoid tumors
- 4) When tumor reviews are done taking into account the common metastatic sites when to FB and when not to.
 5) Unknown vs Known site when FB is done

Conclusions: Although creating multiple primaries through death clearance often remains a challenge, the next version of the Death Clearance Manual should provide additional improvement, clarification, and consistency for multiple primary rules in the Death Clearance Process.



Oral Abstracts

043

A TIME- AND RESOURCE-EFFICIENT METHOD FOR ANNUALLY AUDITING ALL REPORTING HOSPITALS IN YOUR STATE: THE INPATIENT AND OUTPATIENT HOSPITAL DISCHARGE FILES

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Tennessee (TN) participates in the Healthcare Cost & Utilization Project (HCUP) by providing inpatient hospital discharge (HD) data and, recently, outpatient HD data; however, only slightly more than half of all states currently provide outpatient data to HCUP. Reporting facility staff inevitably misses cases during casefinding operations; therefore, the ability of inpatient and outpatient HD data to identify potentially missed cases was examined. Patients with a cancer ICD-9 diagnosis code were identified in the HD files and linked using social security numbers to the main cancer database with Statistical Application Software to identify potentially missed cases for followback. Followback forms were prepared and sent to reporting facility main contacts for resolution. A total of 7626 inpatients and 11943 outpatients were followed back. During followback, 895 inpatients and 749 outpatients with reportable cancer diagnoses were identified as not reported. A total of 826 of the 895 inpatients were actually reported: 574 from Commission-on-Cancer (CoC)-approved facilities and 252 from non-CoC-approved facilities. A total of 707 of the 749 outpatients were actually reported: 493 from CoC-approved facilities and 214 from non-CoC-approved facilities. The 7 most common primary sites in descending order among inpatient HD cases actually reported were: lung, hematopoietic, brain, colorectal, unknown primary site, prostate and breast. The 7 most common primary sites in descending order among outpatient HD cases actually reported were: brain, lung, other endocrine glands (C75), hematopoietic, prostate, vulva and breast. A significantly larger fraction of outpatients had reportable in situ female breast and genitourinary cancers compared to inpatients. New cases actually reported during HD followback accounted for 4.62% of the TN Cancer Registry's annual submission of data. In conclusion, HD data proved to be a very valuable resource to identify missed cancer cases.

044

ENHANCING DATA QUALITY AND PROCESS IMPROVEMENT: THE CANCER REGISTRY OF GREATER CALIFORNIA EXPERIENCE

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Background: With the scarce supply of resources available to central registries, the approach to developing a comprehensive cancer data quality control program has changed dramatically. With this shift of extremely limited time and resources, the days of randomly conducting quality control activities, including audits, in the hopes of identifying significant findings have become a thing of the past. Targeted quality control activities must be conducted to maximize the best use of resources while improving overall data quality.

Purpose: Quality control activities must now focus on known problems, issues or data quality marker goals. Once the problem or issue is identified, the scope of the problem is assessed to develop the resolution. This may include a manual review and correction or a global fix.

Methods/Approach: While performing quality control activities, emphasis must also be placed on developing and/or improving tools and processes for increased efficiency. This dual approach maximizes quality control opportunities for improved and efficient operations. Although quality control efforts focus on improving data quality, these activities provide an excellent opportunity to also assess existing processes for improvement. Tools such as Data Miner, the Recoding Audit Module (RAM) in Eureka, Eureka reports and SQL queries are utilized to identify and monitor data quality control issues.

Results: This presentation will demonstrate some of the new approaches to develop and maintain a data quality control and auditing program for the Cancer Registry of Greater California (CRGC), along with a brief review of the results of these activities. **Conclusions:** A summation of the findings and conclusions will be discussed.

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I SPEAK HL7. DO U? INTRODUCING THE NAACCR VOLUME V SUPPLEMENT

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Background: Currently there are two recommended NAACCR standards for electronic reporting from pathology laboratories to central cancer registries: 1) Standards for Cancer Registries Volume V: Pathology Laboratory Electronic Reporting, Version 2.2 (Feb. 2009), based on Health Level Seven (HL7) Version 2.3.1; and 2) Volume V, Version 4.0 (Mar. 2011), based on HL7 version 2.5.1. The adoption of HL7 version 2.5.1 has not been as fast as anticipated in the U.S.; making the HL7 Version 2.3.1 the most widely supported standard among pathology laboratory information systems. This creates a dilemma for the potential user: which version of the NAACCR (and therefore HL7) electronic reporting standard to select?

Purpose: The NAACCR Pathology Data Work Group realized the need for a Volume V Supplement, a document which would provide an overview of the existing standard specifications at both the macro and micro levels in an easy to understand, 'compare and contrast', manner.

Approach: A sub group of the Pathology Data WG, the Supplement WG, created a list of known issues most often raised by the pathology laboratories and/or NPCR/ AERRO e-path project participants during an HL7 interface implementation. The list was reviewed, categorized and transformed into an outline which was then presented to (and approved by) the Pathology Data WG. Monthly conference calls and 'home-work assignments' moved the creation of the document forward.

Results: The Supplement, a work in progress, introduces the novice user to the main differences between the two HL7 standard communication protocols; for the intermediate/ advanced user, there is detailed and updated guidance regarding the differences between the two accepted NAACCR standards. **Conclusions:** The Supplement is a resource document expected to be used by central cancer registries and pathology laboratories during the many steps of the implementation process. Estimated posting on the NAACCR web site, late spring 2013.

046

MAKING SUBMISSIONS EASIER: INNOVATIVE SOFTWARE FOR CENTRAL CANCER REGISTRIES

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This presentation will focus on little software tools that are big time-savers. IMS programmers use a variety of PC tools to recode fields, compare files, and trouble-shoot data issues. These tools are freely available to central registries, but are under-used. These tools can be used to prepare data files for submission and to resolve common data issues.

The SEER Data Viewer can be used to view or modify large text files. It was primarily designed for managing cancer incidence data files. It is a convenient tool to use when performing a final review of a submission file. The NAACCR codebook is integrated into the tool; therefore, NAACCR data items can be selected by item number or field name. The user does not need to know the column locations. The data viewer can be used to view data in a tabular format; or it can be used to create a copy of the file with recoded or calculated values.

IMS staff use a PC tool specifically designed to compare two NAACCR data files. This tool can be used to review differences in the values of specific data items; or it can be used to identify records that are in one data file, but are not in another. This provides a simple solution to a common submission issue, no programming is required.

This presentation will also describe methods to apply algorithms for data items required for submissions, including NHIA, NAPPIA, Census Tract Poverty Code, Survival Time in Months, and algorithms for other derived data items.

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SHARING SEER PROGRAM DATA AND ALGORITHMS VIA WEB SERVICES – SEER API

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The SEER program has developed and maintains numerous data sets and algorithms to support central registry operations. It is inefficient to maintain multiple versions for different applications which may be written in different programming languages. The SEER Program developed the SEER API web services to address this issue. The goal of the SEER API is to provide a centralized repository of SEER tools that is available to all programming environments and operating systems. The SEER API is a free online resource for developers who wish to incorporate SEER data or algorithms into their own systems. This presentation will provide an overview of the APIs that have already been implemented, ones planned for the future, and how they may be used by your organization. Currently, APIs are available which allow access to data and functions related to Collaborative Staging, Hematopoietic and Lymphoid Neoplasm Database, SEER*Rx – Antineoplastic Drugs Database, NAACCR documentation, and SEER Incidence Site Recode.

048

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USING WEB SERVICES IN A REGISTRY DATA MANAGEMENT SYSTEM

<u>F Depry</u>,¹ L Coyle¹ ¹Information Management Services, Inc., Calverton, MD

Web services technology can provide a secure and costeffective method to exchange information between the cancer registry and its partners. The SEER Data Management System (SEER*DMS) now supports web services to provide API calls to the registries' data and resources. The SEER*DMS development team is collaborating with registry IT staff to use this technology in support of registry applications. For example, this technology will be used by registries to support Web-based systems that provide limited access to registry data for physicians and hospital staff.

This presentation will highlight the security and tracking features in the SEER*DMS implementation of web services. It will show the use of this technology to transfer data between a standalone PC tool and SEER*DMS. This technology is being used to support the casefinding workflow for some registries who use the SEER Abstracting tool and SEER*DMS.

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IMPACT OF BMI ON BREAST CANCER PROGNOSIS IN PATIENT-CENTERED RESEARCH: A FLORIDA PILOT STUDY

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Background: Breast cancer represents an increasing global burden as the health characteristics of the U.S. are changing with over one-third of adult women classified as obese. To explore the relationship between the prognostic and biologic effect of body weight and the development and course of breast cancer, the Florida Department of Health and the Florida Cancer Data System worked with a hospital system to analyze patient electronic medical records (EMR) linked to cancer registry data. Methodology: Hospital records with an ICD-9-CM diagnosis for breast cancer were used to identify electronic patients who were treated between 2007-2010. Sate cancer registry data were linked to the EMR for the patients. Survival was compared across BMI categories. BMI, biomarker test data, and comorbidities were analyzed. Results: Overall, 1,368 patients with the diagnosis of breast cancer were identified. Most patients were over 50 years old (74.34%), white (88.83%), and not Hispanic (92.51%). African American patients comprised 9.02%. Median follow-up time for those who died due to breast cancer was 709 days. Two-year survival was 94.7%. Overweight or obese patients were not significantly different from patients of normal weight in breast cancer survival. Breast cancer death rate for underweight patients was 2.1 times that of normal weight patients (p = 0.038). The proportion of underweight patients among those who died due to breast cancer was 13.21%, the highest compared to those in other groups. An increased hazard was associated with low BMI, triple negative biomarker status, distant stage, larger tumors, increased positive nodes, and Medicare users.

Conclusion: Low BMI (< 19) is associated with poorer prognosis in breast cancer patients. Neither overweight nor obese groups were associated with a significantly altered risk of breast cancer death following diagnosis. Mechanisms to understand the poorer prognosis for low BMI patients need to be defined.

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050

DIVERGENCE IN CHEMOTHERAPY BETWEEN BREAST AND COLORECTAL CANCERS IN LOUISIANA: A PRELIMINARY POPULATION-BASED RESULT FROM THE CDC CER PROJECT

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Background: The beneficial effect of chemotherapy for breast and colorectal cancers is well-known. However, there is no detailed evaluation of the first course of chemotherapy and its completion for breast and colorectal cancer patients at population level.

Objectives: To examine the divergence in chemotherapy between breast and colorectal cancers in Louisiana. **Methods:** Data on female breast cancer (N=2,316) and colorectal (N=1,538) cases diagnosed in 2011 were collected through the CDC-NPCR funded 10-state Comparative Effectiveness Research Study. All these cases were followed through 12 months of diagnosis. Chi-square and multivariable logistic regression were employed in analysis.

Results: Colorectal cancer patients, compared with breast cancer patients, displayed significantly older age (mean age 66.4 vs 61.9 years), higher proportion of late stage (stage III:19.1%) vs 8.7% and stage IV: 17.5% vs 5.4%) and lower proportion of stage 0 (8.4% vs 22.0%) (P < 0.0001). The most common chemotherapy regimens for colorectal cancers were 5-FU plus Oxaliplatin (FOLFOX), followed by Capecitabine alone, FOLFOX plus Bevacizumab, and Capecitabine plus Oxaliplatin (CAPOX) whereas the most common regimens for breast cancers were Docetaxel plus Cyclophosphamide, followed by Doxorubicin, Cyclophosphamide plus Paclitaxel; Doxorubicin, Cyclophosphamide plus Docetaxel; and Trastuzumab-based regimens. In a multivariate logistic model including age, race, sex, smoking, BMI, stage, and colony-stimulating factors (G-CSFs) (yes/no), patients with colorectal cancer, compared to those with breast cancer, were 2.1 times more likely to fail to complete chemotherapy (P < 0.0001). Further, older age and higher stage displayed odds ratios of 1.02 and 1.61, respectively (P < 0.05).

Conclusions: The fact that cancer site along with age and stage are predictors of premature termination of chemotherapy regimens has implications for clinical practice and health care policy in Louisiana.

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INFLUENCE OF COMORBIDITY SEVERITY ON CUMULATIVE MORTALITY IN WOMEN WITH LOCOREGIONAL BREAST CANCER

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Background: Prevalence of comorbidity at breast cancer diagnosis increases with age. The aim of this study was to examine the independent association of comorbidity on cumulative mortality by age and use of chemotherapy.

Methods: Data on 5,905 women diagnosed with locoregional breast cancer in 2004 were from the CDC-NPCR funded seven-state Patterns of Care Study. We collected comorbidities from medical records using the Adult Comorbidity Evaluation (ACE-27) and coded them into the severity levels of mild, moderate, and severe. Survival analysis employed the Kaplan-Meier method and Cox proportional hazards model.

Results: The proportion of women with any comorbidity at breast cancer diagnosis was higher among 70+-year olds than under-70-year olds (80% vs. 51%). Women with severe ACE-27 score who received chemotherapy had a significantly higher risk of breast cancer death compared with their counterparts who did not receive chemotherapy. Women with mild or moderate ACE-27 scores who received chemotherapy had the same risk of breast cancer death as those with no comorbidity. Only severe ACE-27 score significantly predicted the risk of breast cancer death (HR=2.06; 95% CI: 1.21-3.50) after controlling for age, tumor characteristics, and treatment. In contrast, all severity levels of comorbidity significantly predicted other causes of death after the adjustment.

Conclusion: Only sever ACE-27 score is an independent predictor of risk of breast cancer death whereas all severity levels of ACE-27 independently predict the risk of other causes of death. Women with severe ACE-27 score who received chemotherapy were at a higher risk of death from breast cancer. Providers should take into consideration the severity of comorbidities when determining treatment for breast cancer. 052

ARE SOCIODEMOGRAPHIC FACTORS AND TREATMENT TYPE ASSOCIATED WITH URINE LEAKAGE AMONG LOCALIZED PROSTATE CANCER PATIENTS?

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Background: Tremendous uncertainty remains regarding optimal treatment for localized prostate cancer. While watchful waiting, radiation, and prostatectomy are all viable options, none of them is considered the preferred treatment. There is a pressing need to collect and analyze information on patient-reported outcome to aid with treatment choice. The objective of this study was to examine the association of the change in urine leakage status before and after- prostate cancer treatment with sociodemographic factors and treatment type.

Methods: Data on 709 Louisiana men diagnosed with localized prostate cancer in 2011-2012 were from the baseline survey (within 4 months of diagnosis but before active treatment) and follow-up survey (6 months after the baseline survey) of the AHRQ-funded Comparative Effectiveness Analysis of Surgery and Radiation (CEASAR) Study. Chi-square and logistic regression were employed in the analysis.

Results: Overall 25% of the men had urine leakage at the baseline survey; black race, older age, low family income, low education, or public health insurance predicted pre-treatment urine leakage. At the 6-month follow-up survey, 53% of men had urine leakage, a significant increase over the baseline level, and the differences across sociodemographic groups no longer existed. About one third of the men developed urine leakage from baseline to the 6-month follow-up survey. Men receiving prostatectomy were significantly more likely to have urine leakage than those who did not receive any therapy or who received radiation without surgery even after adjusting for sociodemographic factors and other treatment.

Conclusion: The percentage of men with urine leakage increased significantly from the baseline survey to the 6-month survey. Differences in urine leakage status across sociodemographic groups diminished at the 6-month survey. Surgery significantly predicts a higher risk of urine leakage.



THE MATHEMATICAL BIOLOGY OF PANCREATIC CANCER: MODELS OF CARCINOGENESIS AND STAGES G Jacquez^{1,2}

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Pancreatic cancer has been called the "silent killer" because it is typically diagnosed at advanced stages and because the prognosis is so poor, with a mean survivorship of about one year. The last five years have seen an increased understanding of the genetic basis of pancreatic cancer, and the cascade of mutations and pathways that lead to carcinogenesis are beginning to be elucidated. However, these have yet to be incorporated into models that bridge scales from the cellular to the individual, to the population. We present two compartmental models of pancreatic cancer. The first models pathways and events at the molecular and cellular level that lead to pancreatic cancer, the second deals with cancer stage at diagnosis and may be estimated using cancer registry data. Residence times in these models corresponds to cancer latency, which has implications for cancer surveillance and medical geography.

054

METHOD TO ESTIMATE DEATH RATES TO CONSTRUCT COMPLETE ANNUAL STATE LIFE TABLES FOR THE PARTICIPATING STATES OF NPCR

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Background: CDC recognizes the substantial need to facilitate measuring relative survival at the state level. The critical component of the state level relative survival of a cohort is the state level expected survival rates which rely on state life tables. NCHS/CDC published the most current state life tables for Census 2000 in 2012. The lag of a decade of the state level life tables limits the effectiveness and timeliness of measuring relative survival for cancer patients at the state level.

Purpose: To explore modeling methodologies to estimate the annual state level death rates to the subpopulation level with only NCHS mortality data.

Methods: The basic methodologies were based on the NCHS published methods with the mortality data from NCHS and the populaton data from SEER*Stat. Beers ordinary minimized fifth difference formula was used to smooth the single-year population and mortality counts. Beers interpolation gave the first round of smoothing of the estimated death rates. Heligman-Pollard model and locally weighted scatter plot smoothing were tested to further smooth the estimated death rates.

Results: Five state level single-year death rates were estimated, state total, female, male, white and black for year 2000. The estimated state level mortality curves closely resembled the profiles of those published by NCHS. The example results will be demonstrated for each subpopulation.

Implications: With the estimated death rates, researchers may produce annual state level complete life tables. As a results, these tables may also help enhance the accuracy and timeliness of cancer related information for decision-makers at the state level to better benefit cancer patients as well as cancer research.

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USING MULTIPLE IMPUTATION TO ENHANCE UTILITY OF SEER SUMMARY STAGE

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Background: Missing data is a frequent problem in most large medical data sets. Staging of cancer is one of most important variables collected in the SEER data. Ignoring the issue of unknown stage may introduce biased estimates obtained from data analysis. Multiple Imputation(MI) has become an important and influential approach in the statistical analysis of missing data in recent years.

Purpose: Compare performance of several MI procedures and examine whether using MI will generate disparate results when compared to conventional methods.

Methods: A simulation study was conducted using breast and liver cancer cases from 2004-2008 SEER 17 registry data. DCO cases or cases less than 20 years old at time of cancer diagnosis were excluded. The simulation data were created in two steps: (a) creation of complete case data (where only cases without missing values were included). (b) examining and assessing patterns of missingness in the original data via logistic regression modeling, and then randomly imposing the missing patterns observed on the complete data to obtain simulated data with missing stage as well as other missing variables. Step (b) was necessary to properly mimic the characteristics for missingness observed in the original data. Several variations of MI were utilized via multiple statistical packages to impute the 2000 SEER Summary Stage for breast and liver cancer.

Results/Discussions: Performances of the various MI approaches varied under the scenarios considered. The results of this study will provide further insight into whether MI has utility (compared to standard approaches) when analyzing SEER data with unknown stage as well as whether the performances of MI procedures in several statistical packages are comparable in varying modeling scenarios.

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WEIGHTING METHOD TO HANDLE MISSING VALUES IN ESTIMATING TUMOR STAGE DISTRIBUTIONS IN POPULATION-BASED CANCER REGISTRATION

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Background: Accurate cancer stage at diagnosis is essential for monitoring trends in cancer stages and assessing effectiveness of early detection interventions. Because the missing of cancer stage is associated with many factors that may not be controllable by cancer registries, it is infeasible to completely eliminate unknown stage cases from registry database. To reduce the bias induced by unknown stage cases in stage statistics, it is necessary to adjust for that in data analysis. The objective of this study is to develop a new method that estimate the distribution of unknown stage cases using predictors of cancer stage and then weight known stage cases accordingly, so as to represent the stage distribution of the cancer patient population.

Methods: We use the 2004-2009 incidence data on invasive lung cancer from 38 population-based cancer registries that met NAACCR's high data quality criteria. Multiple additive regression trees are used to assess the association of unknown stage (outcome) with explanatory variables (including patient demographics, treatment, and tumor characteristics). The estimated probabilities of unknown stage cases are then used to weight known stage cases to estimate stage distributions at different years. Multiple artificial incomplete datasets from the complete dataset will be created with varying missing data mechanism and different proportions of missingness. The simulated data sets will be used to test the efficiency of the proposed method.

Results: In general, compared with estimation with only known stage cases, we estimated smaller proportions of localized and regional stages but larger proportion of distant stage in lung cancer over the years.

Conclusion: The proposed method will be compared with the traditional missing data analysis, e.g. multiple imputation method, using the artificial incomplete datasets. We expect to see the efficiency of the proposed method in terms of both calculation simplicity and estimation accuracy.

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INCREASING INCIDENCE OF NON-CARDIA GASTRIC CANCER AMONG OLDER KOREANS IN CALIFORNIA A Parikh-Patel,¹ S Kwong²

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The incidence of non-cardia gastric cancer in U.S. has been declining steadily over the past 20 years in most age and race/ethnic groups. Potential explanations for the observed declines include changes in dietary patterns, methods of food preservation, hygienic conditions, and treatment rates of H.pylori infection. Previous studies using national data have been limited to non-Hispanic whites and blacks. The objective of this analysis was to examine age-specific incidence of non-cardia gastric cancer by race/ethnicity, including by Asian subgroup. California Cancer Registry data were analyzed over the period 1990-2009. Four-year, age-adjusted rates were calculated for three age groups within each race/ethnic group: 25-29, 40-59, and 60+. Preliminary analyses indicated that non-cardia gastric cancer rates declined in within all age-groups and across all race/ethnicities, with the exception of Koreans 60+. In this group, incidence increased steadily, from 125.1 per 100,000 for the years 1990-1993 to 144 per 100,000 for the years 2006-2009, representing a 15% increase over the study period. Rates among 60+ Koreans were 2 to 5 times higher than their Chinese, Japanese, Filipino, Vietnamese and South Asian counterparts. Although gastric cancer rates tend to increase with increasing age, and are higher among immigrants, rates among all other comparable Asian subgroups were substantially lower than Korean rates in our analysis. Moreover, the rates among all 60+ Asian subgroups other than Koreans declined steadily over the study period, reflecting the expected effect of acculturation on cancer rates over time. This intriguing finding will be examined further and data stratified by sex, socioeconomic status and histology will be presented. Possible explanations for this contrary trend will be discussed. This finding highlights the need to disaggregate Asians into specific subgroups, as there are substantial variations in cultural factors that affect cancer risk.

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BOUNCING BALLS: INVESTIGATING DRIVERS OF HOSPITAL READMISSIONS WITH HOSPITAL AND CANCER REGISTRY DATA

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Background: Preventing hospital readmission has become a national quality of care priority for healthcare reform. Current cancer registry data include first course treatment information and does not capture unplanned readmissions during or following patients' therapy. By linking cancer registry data and electronic medical records (EMR), the Florida Cancer Data System (FCDS) and Florida Department of Health partnered with a Florida hospital system to analyze readmission trends and the effectiveness of treatments. Methods: EMR were transmitted for patients diagnosed with or treated for breast cancer between 2007 and 2011. Patients were identified by ICD-9CM cancer diagnosis codes. Patient EMR detail treatment data and include medications administered, discharge summaries, and clinicians' notes. Patient EMR transmitted to FCDS were matched with state registry data. We analyzed disease characteristics and patient health histories, comparing treatment modalities administered for readmitted and non-readmitted patients. Results: FCDS received and linked 12,804 unique registry tumor records for breast cancer patients. Patient treatments included surgery, radiation, hormonal therapy, and chemotherapy. Of 7,734 patients with multiple admissions, nearly half returned for inpatient care (51%). The majority returned for surgeries (59%), another group was treated in clinical observation units (22%), while others were admitted to the emergency room. Half of returning patients had at least 3 admissions. Exponential increases in charges were correlated to extended lengths of stay, observed by days hospitalized. Further analyses will compare patient demographics, comorbidities, tumor characteristics, and treatments between sub-groups. Implications for public health: Cancer registry data linked to detailed hospital EMR provide unique opportunities to investigate drivers of unplanned and avoidable readmissions, compare treatment effectiveness and patient centered outcomes.



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TRAFFIC-RELATED AIR POLLUTION AND CHILDHOOD CANCER IN LOS ANGELES COUNTY, CALIFORNIA

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Air pollution exposures have been linked to several childhood cancers, but few studies have examined the importance of in utero exposures, despite some genetic evidence of a prenatal origin of these diseases. In this study, we evaluate whether prenatal exposures to traffic-related air pollution increase cancer risk among children ages 0-5 years in Los Angeles County, California. We linked cancer registry data with birth certificates, and selected 20 controls for each case, frequency matched by birth year. Traffic-related air pollution exposures were based on a land use regression (LUR) model that captures small-area variations in air pollution. We estimated annual average exposure ("Unseasonalized LUR") to nitric oxide (NO), nitrogen dioxide (NO₂) and nitrogen oxides (NO₂) based on the birth certificate addresses, and further adjusted these exposures using air pollution monitoring station data to estimate exposures for each trimester and over the entire pregnancy ("Seasonalized LUR"). We used logistic regression models crude and adjusted for mother's race, education, parity, Census-based SES, prenatal insurance, baby's sex, and birth year. We observed increased odds of acute lymphoblastic leukemia (ALL) with each 25 ppb increase in LUR-estimated traffic pollution, particularly for first trimester (adjusted OR=1.03, 95%CI=0.99-1.08 for nitric oxide) and entire pregnancy (adjusted OR=1.09, 95%CI=1.01-1.18 for nitric oxide) averages. Odds of bilateral retinoblastoma increased approximately 6-18% per 25 ppb increase in LUR-estimated NO and NO_x exposures in the entire pregnancy, second and third trimesters. We did not observe associations with Unseasonalized (annual average) LUR-estimated exposures, nor with any other cancer outcomes evaluated. These data suggest that prenatal exposures to traffic-related air pollution may play an important role in some cancers among children ages 0-5.

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FACTORS ASSOCIATED WITH INVASIVE CERVICAL CANCER DIAGNOSES IN KENTUCKY

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Background: Cervical cancer remains the third most frequent malignancy and the fourth leading cause of cancer death in women worldwide. In the United States, Kentucky has the eighth highest incidence rate of invasive cervical cancer. Factors unique to each individual as well as contextual factors of the individual's underlying population have been shown to influence the risk of an invasive cancer diagnosis.

Purpose: This study was designed to assess the important individual and contextual factors associated with invasive cervical cancer diagnoses in Kentucky.

Methods: The Kentucky Cancer Registry resumed pre-invasive surveillance for 2009+ diagnoses through participation in a multi-state pilot project sponsored by the CDC. Bivariate and multivariate multilevel logistic regression methods were used to simultaneously assess individual factors and contextual socioeconomic factors associated with the probability of invasive diagnosis. The study also compared factors in sub-populations stratified by race, metropolitan residence and Appalachian residence.

Results: Increasing age, black race, histologic cell type of adenocarcinoma, residence in a metropolitan county, lower county education and higher county poverty were found to be independently associated with an increased odds of diagnosis with invasive cervical cancer while controlling for other factors. Adenocarcinoma emerged as the most significant factor associated with an increased odds of invasive diagnosis (OR 8.7, P-value <.0001). Residence in a metropolitan county was a significant risk factor while residence in Appalachia was not. **Conclusions**: Evidence from this study suggest that screening efforts should not ignore older women and should remain focused on black women in rural and Appalachian states such as Kentucky. The significantly increased odds of invasive diagnosis among women with adenocarcinomas raises concerns about the efficacy of current screening methods to detect adenocarcinoma in situ.

Notes	Notes

Oral Abstracts

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oral abstracts

concurrent session 4



EXTRACTION OF ICD-O-3 TOPOGRAPHY FROM PATH REPORTS USING MACHINE-LEARNING TECHNIQUES

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Cancer registries traditionally collect retrospective incidence data from a variety of clinical text sources to assist evidence-based public health interventions. A typical incidence record can require six months or longer to collect, which is often too long when the data is needed for clinical trials recruitment. As cancer registries are called upon to support more rapid uses of data, an efficient means of processing clinical text is needed. Our research attempts to speed up the collection of cancer incidence data by automatically extracting a single primary topography from pathology reports to serve as the basis for a cancer incidence record. Although similar attempts have been made with French language pathology reports, TNM staging, and multiple topographies[1,2], we are not aware of any published research where machine learning has been used to extract a single primary topography from English language path reports. We investigated three machine learning algorithms to classify path reports according to 58 generic and 139 subsite topographies from the ICD-O-3 standard using flat and hierarchical subsite techniques. Our best performing algorithm produced Micro and Macro F-scores of 0.908 and 0.748 respectively for generic site classification and 0.631 and 0.480 Micro and Macro F-scores respectively for the flat subsite technique. Hierarchical subsite classification yielded similar performance. These results show the potential of machine learning techniques to extract ICD-O-3 topography codes in near real-time.

[1] V. Jouhet, G. Defossez, A. Burgun, P. Le Beux, P. Levillain, P. Ingrand, V. Claveau, et al., Automated classification of free-text pathology reports for registration of incident cases of cancer, Meth of Inform in Med 51 (3) (2012) 242.

[2] A. Currie, T. Fricke, A. Gawne, R. Johnston, J. Liu, B. Stein, Automated extraction of free-text from pathology reports, in: AMIA Annual Symposium Proceedings, Vol. 2006, AMIA, 2006, p. 899.

062

AUTOMATED CONSOLIDATION OF COLLABORATIVE STAGE DATA ITEMS: THE PENNSYLVANIA APPROACH TO ENHANCING AUTOMATION AND IMPLEMENTING CONSOLIDATION IN THE ABSENCE OF NATIONAL STANDARDS

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Consolidation of Collaborative Stage (CS) data items submitted from multiple reporting sources is a large burden for central cancer registries, often requiring manual review by expert registrars. Standards for consolidation of CS, whether automated or manual, have not been established to date. We report on a strategy for automated consolidation of each CS data item based on a set of criteria starting with eliminating non-specific values. Our approach was to consolidate each CS data item separately based on all submitted values. This would allow for consolidation of quality data from multiple sources. Consolidation rules and logic for the Colon, Rectum, Lung, Breast, Prostate, and HemeRetic CS schemas were initially prepared to reduce manual review decisions for high-volume cancer sites. Rules were documented in English and a specialized language readable by CRS Plus—one of the Registry Plus software programs. The Registry Plus team included the programming logic into the CRS Plus software. The consolidation logic can be customized to meet the needs of the user. After review, the rules were embedded in a registry software system, tested, and evaluated. The final machine-readable rules have been deployed in a production environment since November, 15, 2012. The final rule set in both versions are publicly available free of charge at http://www.cdc.gov/cancer/npcr/.

We will present the English language version of the rules and discuss their integration in software. We will also present data assessing the effectiveness of our approach in reducing manual review needed to consolidate CS data items in the Pennsylvania Cancer Registry over several months.

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INDUSTRY AND OCCUPATION CODING OF CANCER RECORDS- THE GOOD, THE BAD AND THE UGLY

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Background: Usual industry and occupation information have been required reportable data items for cancer registries funded under CDC's National Program of Cancer Registries. However, this information has been collected in text form and few cancer registries have had the resources to code these data, limiting their usefulness for assessing occupational cancer risks. The availability of new coding software from the National Institute of Occupational Safety and Health (NIOSH), the NIOSH Industry and Occupation Computerized Coding System (NIOCCS)¹, may improve the registry's ability to code and provide these data for research.

Purpose: This project was undertaken to assess the use of NIOCCS to code occupation and industry information in cancer records reported to the Texas Cancer Registry (TCR) and to make recommendations for implementing this method of coding into ongoing operations.

Methods: A de-identified file of cancer cases containing a subset of data items (unique id, diagnosis year, age, usual occupation/ industry text, county at diagnosis and vital status) for diagnosis years 1995-2011 was input into the NIOCCS coding software. Manual coding was performed for case industry/occupation information not coded electronically. All records were coded to the 2000 US Census scheme. A sample of data quality checks was performed to assure appropriate and reliable coding, both by electronic and manual methods.

Results: A summary of findings including the quality of industry and occupation text available for coding, percentages of records autocoded, and agreement between records electronically and manually coded will be presented.

Implications: Lessons learned and recommendations for implementation of industry and occupation coding into ongoing registry operations will be discussed.

¹NIOSH Industry and Occupation Computerized Coding System. 01/11/2010. Available at: <u>http://www.cdc.gov/niosh/topics/</u> coding/pdfs/NIOCCS_Overview_110111.pdf

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IMPROVING DATA QUALITY AND COMPLETENESS USING CLAIMS IN THE PRCCR

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Background: The Puerto Rico Central Cancer Registry (PRCCR) has been improving the completeness and quality standards for the 2010 data. In our effort to enhance our data the PRCCR developed a program that uses claims of public insurance data to complement our case finding protocols and to recover unknown data fields.

Objective: To detect and recover missing cases and unknowns fields, otherwise not found.

Methods: The PRCCR identified a discrepancy on some of the primary sites of cancer such as multiple myeloma. lymphoma, liver, melanoma, leukemia, and lung and bronchus, among others. The PRCCR also identified essential unknown data fields for example demographic information, diagnosis dates, and treatment dates and procedures. To improve the methods of case finding and the recovery of unknown data the PRCCR established a collaborative agreement with ASES (the governmental health insurance company) to obtain claims data of approximately the 40% of the insured population of Puerto Rico. The claims database has 6.2 million records of the claims generated between 2007 and 2011. The claims database uses a probabilistic match to link the information with the cancer database. This procedure compares the first name, last name, social security number, birthday and sex between both databases in order to find a list of possible matches. The PRCCR tumor registrars verify the list of possible matches to determine if it is the same patient or not.

Results: Before using the claims database the PRCCR had a total of 11,458 incidence cases, 20 (.17%) of age unknown, 385 (3.36%) of race unknown, 1,137 (9.92%) of county unknown, and 706 (6.16%) of DCO's. By the end of the claims recovery project the PRCCR ended with 13,527 incidence cases (> 90% of expected cases), 8 (.06%) of age unknown, 86 (.64%) of race unknown, 372 (2.75%) county unknown, 649 (4.73%) of DCO's. The use of Claims is a novel program that will help the PRCCR to improve its case finding and data quality procedures.

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USING THE COLORADO CENTRAL CANCER REGISTRY TO PRE-POPULATE TREATMENT SUMMARIES AND CARE PLANS: WHAT WE LEARNED

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Background: A 2005 Institute of Medicine report highlighted the need for cancer patients to receive a Treatment Summary and Survivorship Care Plan (TS/SCP) at the end of cancer treatment. A TS/SCP document outlines the patient's diagnosis, treatments received, and plans for future care. The American College of Surgeons (ACoS) 2012 Program Standards now require accredited hospitals to start distributing TS/SCPs to cancer patients treated in their facilities by 2015.

Purpose: Development of TS/SCPs is a time-consuming and labor intensive process. To help oncology providers complete TS/SCPs and meet the ACoS Standards, the Colorado Central Cancer Registry (CCCR) piloted a program that pre-populated plans with data already collected by the registry.

Methods: Using the input of a multidisciplinary advisory board, the CCCR organized the development of a website which prepopulates TS/SCP templates. Oncology providers log in to a modified version of the Centers for Disease Control's (CDC) Web Plus system to complete the plans. The program was piloted in four hospitals in Colorado, and interviews were conducted with oncology providers, cancer survivors, and primary care providers to gather feedback.

Results: Overall feedback from both oncology providers and patients on the program and/or templates was favorable. Participants also provided recommendations for improvements to be incorporated before the program is finalized. A review of the pilot evaluation and a demonstration of the website will be included in this presentation.

Conclusions: This program may serve as a model for cancer surveillance programs to create partnerships with the oncology community in order to help complete TS/SCPs for patients. Once finalized, the program will be incorporated into the CDC's Web Plus program and available to any state that utilizes Web Plus.

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STANDARDIZING CLINICAL TRIAL DATA IN EHRS: SUCCESSES AND OPPORTUNITIES

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Background:

Studies have shown that it takes seven years or more for new research advances to be incorporated into clinical practice. Significant advances in health information technology connectivity are now bringing clinical trial data directly to physicians and speeding the process of moving medical advances from bench to bedside.

Purpose:

This paper demonstrates that clinical trial data can be packaged using certified electronic health record (EHR) standards which bring clinical trial data directly to the point of care and facilitate real-time data analysis.

Methods/approach:

This paper addresses the following questions:

- * How is clinical trial data incorporated into EHRs?
- * What new and existing standards support the interoperability of clinical trial data?

* How can the methods described under this paper be leveraged for standardizing other important clinical data?

Results:

- * Methods to automate information exchange based on interoperability standards
- * Improvements in physician access to clinical trial data **Conclusions:**

* Development and implementation of standards and applications can dramatically raise the level of automation in information exchange.

* The project demonstrated measureable successes that are being replicated in other clinical data standardization projects.

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UTILIZING MODERN TECHNOLOGIES FOR IMPROVED USABILITY AND FUNCTIONALITY IN WEB-BASED CANCER REPORTING

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Kentucky Cancer Registry is host to Cancer-Rates.info, a publicfacing web application that provides a rich source of cancer incidence and mortality data for just over a fifth of the nation's cancer registries. As modern web browser adoption rates climb and network connection speeds increase, the application is evolving to provide a better, faster, more interactive experience for the user.

There is a radical shift in the landscape of modern web development and Cancer-Rates.info is being updated to take advantage of some of the exciting new features that web browser vendors have implemented. This presentation will demonstrate how features like HTML5, CSS3, and modern JavaScript help to enhance, highlight, and speed up the great set of tools and data that the new application offers. The sharp increase in mobile adoption in recent years has caused us to rethink some strategies for disseminating the information that the service provides. The fresh, updated design is also responsive, meaning that the layout will adapt to any device or screen resolution it is being viewed on, all using the same single codebase.

Along with updating the design and enhancing existing features, the update introduces new functionality, including the ability to compare incidence or mortality maps and tabular data side by side. In addition, trend graphs have been updated to allow comparisons across multiple regions.

This presentation will include a live demonstration of the ongoing enhancements to Cancer-Rates.info and will provide a clear picture of future direction.

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SEEING THE BIG PICTURE IN LONG-TERM SURVEILLANCE FOR RARE EVENTS

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Background: Postmarketing safety studies aimed at identifying whether a medication is potentially associated with a rare cancer are challenging to implement, especially when there is no national cancer registry.

Objectives: To describe innovative efforts undertaken with state cancer registries to monitor for a possible association between teriparatide treatment and osteosarcoma in humans and provide an update on study progress.

Methods: Two studies are underway to address the objective: a retrospective 15-year case series surveillance study, initiated in 2003 after initial drug approval, and a prospective 12-year patient registry linkage study, initiated in 2009 after a new indication was approved. In the retrospective study, incident cases of adult osteosarcoma diagnosed January 1, 2003, or later are identified through US cancer registries, and exposure to possible risk factors is ascertained by telephone interview. In the prospective linkage study, patients enrolled in a voluntary Forteo Patient Registry are linked annually to adult cases of osteosarcoma diagnosed January 1, 2009, or later from participating cancer registry databases.

Results: As of September 30, 2012, for the retrospective study, 1,729 cases of adult osteosarcoma have been identified from 16 registries for diagnosis years 2003-2010; interviews were completed with patients or their proxy for 24% of cases. For the linkage study, over 29,000 patients have been registered, and the third annual linkage was completed with 38 participating cancer registries covering 86% of the US population aged 18 years and older. At this time, the studies do not support a causal association between teriparatide treatment and osteosarcoma in humans; however, both studies continue to progress. **Conclusions:** To monitor for a potential signal of a rare event, it is necessary to "think big" and apply innovative approaches to study design and operational implementation.

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ENHANCING INFRASTRUCTURE FOR CANCER SURVEILLANCE: EXPERIENCE FROM THE CENTERS FOR DISEASE CONTROL AND PREVENTION (CDC) COMPARATIVE EFFECTIVENESS RESEARCH (CER) PROJECT

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¹Centers for Disease Control and Prevention, Atlanta, GA; ²ICF International, Rockville, MD; ³DB Consulting, Potomac Falls, Virginia

Background: CDC selected 10 central cancer registries (CCRs) from the National Program of Cancer Registries (NPCR) as Specialized Registries to conduct various activities ranging from additional data collection to the expansion of electronic reporting. The goal was to develop sustainable methods to enhance cancer registry data in support of CER. In addition, six special projects were selected to explore innovative public health applications for CCRs that are of particular concern to CDC NPCR: 1) improve race/ethnicity data; 2) develop new uses of cancer registry data; and 3) implement electronic reporting from clinic and physician facilities.

Methods/Approach: A panel of presenters from CDC, ICF Macro (prime contractor) and state CCRs will share their respective experience and tools developed under the NPCR CER project

Implications: NPCR CER project aims to enhance CCRs at the national and state level in collecting cancer data for comparative effectiveness research. The tools and capacities that were developed from this project may be applied to other NPCR registries to further advance cancer surveillance goals.

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ENHANCING CANCER REGISTRIES FOR COMPARATIVE EFFECTIVENESS RESEARCH: PRELIMINARY RESULTS OF DETAILED TREATMENT COLLECTION

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Background: The Centers for Disease Control and Prevention (CDC) funded 10 central cancer registries (CCRs) from the National Program of Cancer Registries (NPCR) to serve as Specialized Registries for Comparative Effectiveness Research (CER). Funded through the American Recovery and Reinvestment Act, the project collected additional cancer treatment and other information for CER. A range of activities have been carried out by CDC, ICF Macro (as the prime contractor), and CCRs to support data collection, training, and methodology development.

Methods/Approach: Specialized Registries will be submitting detailed treatment information on female breast, colorectal, and chronic myeloid leukemia patients diagnosed in 2011 in their respective catchment areas. Basic data quality analysis will be conducted on preliminary data by reviewing CER-specific EDITS and NPCR data quality standards. Data quality by site and CCR will also be assessed.

Results: We will share an assessment of quality and completeness of preliminary treatment and other data from CDC's Specialized Registries. Issues and potential barriers to collection of data will be discussed and suggestions for best approaches for future data collection will be made.

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UNLOCKING THE POWER OF QUALITATIVE DATA ANALYSIS FOR THE COMPARATIVE EFFECTIVENESS RESEARCH PROJECT IN FLORIDA

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Background: The FCDS became an Enhanced Registry for Comparative Effectiveness Research in 2010, under NPCR/CDC. Collection of detailed first course of treatment for select cancers diagnosed in 2011 were captured across five Florida counties. These included planned and received treatments, NSC numbers, dosages, dates received, reasons for discontinued treatment, as well as biomarker status.

Methods: The FCDS recorded text documentation to contextualize treatment status. Notes were documented for cases specifically where available values did not capture treatment outcomes. We conducted an analysis of the contextual factors behind treatment decisions not already captured by codes. A qualitative assessment of the CTR's experience during data collection provided insight into the pattern of information available on patient charts, the trend in types of biomarkers tested, and differences between hospital-based and physicianbased treatment decisions.

Results: Treatment decisions were not always captured by available codes. Reason for refusing treatment, for example, was often due to lack of financial resources; drug shortages also affected planned treatments. Oncology practices had a higher rate of oncotyping than did hospitals. These oncotyping results drove breast cancer treatment decisions despite presence of nodes positive in patients. Additionally, many patients with low recurrence scores opted to forgo chemotherapy. Implications: Qualitative review of text patient data provides important contextual information by capturing a more comprehensive profile of treatments planned and received reasons for refusing treatment, and utilization of prognostic biomarkers for treatment decisions. Evaluation of experiencebased knowledge of registrars propels the CER project in Florida by adding value to the coded dataset and highlights emerging patterns that can be targeted in broader analyses.

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COLLECTING DETAILED CHEMOTHERAPY AND OTHER ADJUNCT TREATMENT INFORMATION FOR THE CDC COMPARATIVE EFFECTIVENESS RESEARCH (CER) PROJECT: CHALLENGES AND LESSONS LEARNED

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Introduction: Louisiana is one of 10 states participating in the CDC CER project. One of CER goals is to enhance cancer registry data by collecting detailed treatment on cancer cases (breast, colon, rectum, CML) diagnosed in 2011 from multiple sources. Educating abstractors to collect these non-NAACCR standard data items and maintaining good quality are LTR's priorities. The objective of this presentation is to share challenges and lessons learned in this process.

Methods: Several intense educational webinars with sampled cases were conducted by an oncology Clinical Nurse Specialist at the initial training before data collection; subsequently additional target sessions were added as needed. Detailed chemotherapy, hormonal therapy and biomarkers for these cancers were collected from hospitals, oncologists' offices, cancer or infusion centers, and radiation oncology records. Results: Numerous challenges were encountered, resulting in a very time-consuming process of chemotherapy data collection, including: patients treated at multiple facilities requiring many visits to complete one case; visitation restrictions by facilities and MD offices; non-universal EMR systems resulting challenging navigation; EMR containing no chemotherapy requiring additional paper charts review; and appropriate paper charts containing chemo data not available at visit. When information was available, chemo flow charts were not always available or some visit records were missing, making it difficult to calculate accurate chemo dose planned and total dose received.

Conclusion: Chemotherapy is complex. Time invested in the initial training and follow-up education as well as editing is vital to obtaining accurate data. The issues related to the time consuming process of collecting detailed chemotherapy will remain. Maintaining a good rapport with oncology clinics, organized planning and being flexible are vital. Electronic reporting of chemotherapy needs to be explored by central registry.



ASSESSMENT OF DUPLICATE CANCER CASES IN UTAH AND IDAHO: IMPROVING INTERSTATE CANCER SURVEILLANCE

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Cancer surveillance across the United States (US) occurs within state and territorial administrative boundaries. Central registry staff make decisions about residential status and reportability based on information submitted by health care providers and hospital tumor registrars. Because these data are de-identified and pooled for national statistics, it is not possible to consolidate information on the same case from multiple states and address issues related to case duplication. Furthermore, it is unknown what impact interstate consolidation and de-duplication might have on measures of the US cancer burden, such as incidence rates, or data quality indicators, such as percent of cases reported solely via death certificates. Utah and Idaho not only share a geographic border, but also population, commerce, and health care delivery systems. To ascertain the degree to which cancer cases are duplicated between the Utah Cancer Registry (UCR) and the Cancer Data Registry of Idaho (CDRI), the two surveillance systems will conduct a probabilistic linkage of 1970-2010 cases. Cancers that are determined to be duplicated cases will be flagged in a crosswalk file, and a process for adjudicating potential duplicates and/or multiple primaries will be developed. We will present results on the number of persons common to the two surveillance systems, the number of adjudicated duplicate/multiple primary cancer cases, and the impact of interstate duplication on cancer incidence statistics and for the counties that border the two states. To our knowledge, this is the first attempt to assess cancer case duplication across state boundaries.

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LINKAGE OF CENTRAL CANCER REGISTRY INCIDENCE AND HOSPITAL DISCHARGE DATA PROVIDES A VALUABLE RESOURCE TO STUDY BREAST CANCER DISPARITIES IN ILLINOIS

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Background: The Institute of Medicine and the National Cancer Institute have encouraged researchers to utilize health data set linkages to broaden research perspectives that might inform efforts to improve the quality of cancer care and reduce disparities. Purpose: The goal was to contribute scientific insights to better understand and direct research on breast cancer disparities in Illinois women through the linkage and enhancement of large data sets. Methods: A probabilistic linkage of the Illinois State Cancer Registry (ISCR) female breast cancer incidence data with Illinois hospital discharge data (IHDD) was conducted for years 2002-2005. Seven common variables were used for the matching algorithm (ISCR primary site/IHDD principal diagnosis, gender, reporting facility, ISCR diagnosis date/IHDD admission and discharge dates, date of birth, zipcode and county). This data set was then augmented with census data to impute SES and greater circle distance (GCD) measures of residence to FDA certified mammography centers in Illinois and surrounding states. The linkage was conducted using Automatch, Matchware Technologies. Inc. software.

Results: A total of 29,381 of 38,247 (76.8%) ISCR breast cancer records were matched to 44,696 IHDD records in a one-to-many relationship. Additional variables contributed by ISCR were race, Hispanic ethnicity, age, birthplace, residential geocodes, SEER general summary stage and morphology. IHDD provided additional variables on secondary diagnoses, procedures, charges, insurance status and visit type (outpatient or inpatient). Residential census tract poverty data and GCD measures to the 10 closest FDA mammography centers were appended to the data set. **Implications**: The linkage produced a data set of substantially greater value than either ISCR or IHDD alone with the potential to elucidate breast cancer disparities at the population level. Details on the linkage process and findings from selected analyses will be presented.

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ANALYTIC CHALLENGES WITH NATIONAL SURVEY DATA LINKED TO A STATE-LEVEL CANCER REGISTRY

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Background: Although data linkage provides an opportunity to conduct analyses that are not possible using the each contributing data source alone, it also produces additional analytic complexity. The CDC's National Center for Health Statistics (NCHS), in collaboration with the Florida Cancer Data System (FCDS) and University of Miami, conducted a pilot linkage between the 1986-2009 National Health Interview Survey (NHIS) and 1981-2010 FCDS data to examine risk factors and characteristics of Floridians who were diagnosed with cancer compared to those without cancer. Because the survey data are from a complex sample design and inferences are intended to be representative of the residents of Florida, analytic methods not commonly used with cancer registry data are needed.

encountered with the survey-registry linked data and describe methods that can be used to address them.

Methods: We describe methods used to account for survey design and to weight the data to make it generalizable to the Florida population. These methods include selection of the source population data, model weight adjustment, and poststratification.

Results: We will compare prevalence estimates and measures of association using smoking status and lung cancer as an example. The various methods used will be compared with each other and to unweighted results that do not account for the sample design.

Conclusions: Although these examples are specific to the NHIS-FCDS linkage, this linkage will provide insight into the complexities of analyzing survey and registry-linked data.

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FLORIDA CANCER REGISTRY ENHANCEMENT TO EXAMINE SURVIVAL DISPARITIES AMONG NON-SMALL CELL LUNG CANCER PATIENTS

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Introduction: Non-small cell lung cancer (NSCLC) is among the leading causes of cancer death in the U.S. However, evidence of disparities in mortality for NSCLC by race/ethnicity and socioeconomic status (SES) has not been completely studied. Purpose: To enrich the Florida Cancer Data System (FCDS) registry in order to investigate disparities in NSCLC survival. Methods: We linked 1996-2007 FCDS to Florida's Agency for Health Care Administration (AHCA) and the U.S. Census to form a large and markedly enriched NSCLC dataset (n=98,541). AHCA provided diagnoses and procedure codes for comorbidity information. Socioeconomic status categories from the U.S. Census were the percent of the population in the individual's neighborhood who were living in poverty: lowest (<5%), middlelow (≥5% and <10%), middle-high (≥10% and <20%), and highest (≥20%). Survival time was calculated as time from date of diagnosis to death or last contact. Race was categorized as: White, Black, Native American, Asian, Pacific Islander, Asian Indian or Pakistani, or Other. Ethnicity was defined as non-Hispanic or Hispanic. Cox regression models were fitted by incrementally introducing the following groups of variables: race/ ethnicity/SES, other demographics, clinical characteristics, and comorbidities.

Results: SES was a significant predictor of better survival, maintaining significance in a monotonic manner in all models even when FCDS was enriched with AHCA comorbidities. In the fully adjusted model compared to lowest SES, better survival was seen in middle-low (Hazard ratio [HR] .97; P<.024), middlehigh (HR .92; P<.001), and highest (HR .88; P<.001) SES. **Conclusion:** Even after adjusting for race, ethnicity, and all comorbidities, SES of the neighborhood in which cancer patients resided had a significant effect on survival. The linkage of FCDS with Census and AHCA data allowed us to verify that this finding was independent of patients' clinical characteristics and comorbidities.

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DOES BEAM RADIATION OF PROSTATE CANCER **INCREASE RECTAL CANCER RISK?**

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Background: Prostate cancer (PC) is the most common cancer among US men. Most PCs are localized at diagnosis and are candidates for beam radiation (RAD) or surgery (SURG). Research used California Cancer Registry (CCR) data for 1988-2010. The CCR is part of the SEER program. Since 1988, there has been mandatory reporting of data for invasive cancers to the CCR including stage, treatment, and demographic variables, with 99+% case reporting. Problem: We assessed whether RAD vs SURG treatment of PC was followed by increased rectal cancer hazards.

Methods: Record linkage was performed for PC and rectal (rectum and rectosigmoid jx) cancer in California (1988-2010) diagnosed 5+ years following treatment of organ-confined PC with RAD or SURG. Contrasting RAD vs SURG, the Cox proportional hazards ratio (HR) for rectal cancer was assessed for age (<50, 50-74, & 75+ years), race/ethnicity as Asian/Other (A-O), non-Hispanic black (NHB), Hispanic (Hisp) and NH white (NHW), and socioeconomic status (SES) quintiles (5 Highest).

Results: 5+ years post PC diagnosis there were 194 new rectal cancers among the 54,130 PC cases treated with RAD and 254 cases among 69,105 SURG patients. The rectal cancer HR with 95% CI for RAD vs. SURG was: HR_{RAD/SURG}=1.58, 95% CI=1.28-1.94. Following are HRs for age (HR_{Age}=1.02, 95% CI=1.00-1.34); race/ ethnicity (HR_{A-O/NHW}=0.99, 95% Čl=0.66-1.49; HR_{NHB/NHW}=1.09, 95% CI=0.75-1.57; HR_{Hisp/NHW}=1.07, 95% CI=0.78-1.47); SES (HR_{SES1/} sess=0.92, 95% CI=0.64-1.34; HR_{ses2/sess}=1.17, 95% CI=0.87-1.57; HR_{SES3/SES5}=1.20, 95% CI=0.92-1.57; HR_{SES3/SES5}=1.19, 95% CI=0.93-1.54); and PC diagnostic year HR $_{\rm Year}$ =0.94, 95%CI=0.92-0.97). Discussion: Increased rectal cancer hazards among PC cases treated with RAD vs. SURG was evident, independent of other covariates. Rectal cancer treatment is complicated among patients that already received pelvic RAD for PC. Further analyses that distinguish roles of different dose and delivery methods for RAD are ongoing.

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DISPARITIES IN THE USE OF POST-MASTECTOMY BREAST RECONSTRUCTION IN THE SACRAMENTO AREA, **CALIFORNIA: A PILOT STUDY**

C Morris,¹ S Martinez²

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Background: Previous studies show that breast reconstruction (BR) following a mastectomy is an indicator of patient outcomes, in that reconstruction involves a greater degree of medical care and follow-up. However, although health plans are required by law to cover BR as part of cancer treatment, the procedure is underutilized.

Purpose: The aim of this collaborative pilot study was to assess disparities in post-mastectomy BR in the 14 counties comprising the Sacramento area in California.

Methods: Breast cancer patients diagnosed between 2000-2009 and treated with mastectomy in the greater Sacramento area were identified through the California Cancer Registry. Logistic regression was used to assess the odds ratio (OR), or likelihood of receiving BR adjusting for demographic, geographic, and tumor-related factors.

Results: Of the 13,231 patients included in the study, 1,826 (13.8%) received BR. Younger age, stage at diagnosis, histology, and tumor receptor status were, as expected, significantly associated with receiving BR. However, even when all these characteristics were taken into account, patients living in a metropolitan area were almost twice more likely to receive BR than those in rural areas. Higher socioeconomic index (OR = 1.61) and treatment at an ACoS facility (OR = 2.80) were also associated with higher likelihood of BR, regardless of the number of plastic surgeons in the county. White women were significantly more likely to receive BR than African Americans (OR = 0.73), Latinas (OR = 0.75), and Asian/Pacific Islanders (OR = 0.55). **Conclusions:** Collaborative studies are an important step towards developing partnerships for wider dissemination of information and for increasing awareness of health disparities among the medical community and the affected populations.



THE EFFECT OF PRIMARY TUMOR RESECTION ON SURVIVAL FOR PATIENTS WITH METASTATIC COLORECTAL CANCER: AN ANALYSIS OF CALIFORNIA CANCER REGISTRY DATA

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Background As improvements in systemic therapy have increased survival, the value of resecting primary tumors for patients with metastatic colorectal cancer has been debated. **Purpose** The purpose of this study was to identify predictors of the use of primary resection for California patients with metastatic colorectal cancer, and to evaluate the effect of this surgery on survival.

Methods/Approach All patients diagnosed with metastatic colorectal cancer in California between 2003 and 2010 were identified using the California Cancer Registry. Primary resection was defined as partial, subtotal or total colectomy. Neighborhood socioeconomic status (SES) was categorized into quintiles based on Yost. RUCA scores were categorized into tertiles to evaluate rural versus urban residence. Cox proportional hazards models were used to conduct survival analyses. Results We identified 19,836 patients with Stage IV colorectal cancer, of whom 11,566 (58%) had their primary tumor resected as part of first course of treatment. Resection rates declined from 63% in 2003 to 53% in 2010. Predictors of resection included age (62% for age under 65 versus 51% for age 75+), SES (55% for patients of lowest SES versus 62% for those in the highest SES guintile) and residence (63% in rural versus 58% for urban areas). Median survival for all patients was 10 months. On multivariate analysis overall survival was better for patents treated with resection (HR: 0.467), patients under age 65 (HR: 1.385 for age 65-75, HR: 2.217 for greater than age 75), patients in the highest SES quintile (HR: 0.869), Hispanics (HR: 0.884), and Asian/Pacific Islanders (HR:0.892) but worse for blacks (HR:1.105).

Conclusion Receipt of primary resection by patients with metastatic colorectal cancer declined over the time period but was associated with better survival. We were unable to examine factors such as comorbid illness that would likely influence both treatment and survival.

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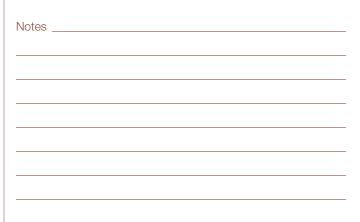
ASSOCIATION OF TREATMENT TYPE AND SOCIODEMOGRAPHIC FACTORS WITH CHANGES IN URINARY, BOWEL AND SEXUAL SYMPTOMS AMONG LOCALIZED PROSTATE CANCER PATIENTS

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Background: There is no consensus yet on optimal treatment for localized prostate cancer, though watchful waiting, radiation, and prostatectomy are all reasonable options. The objective of this study was to assess changes in patient reported urinary, bowel and sexual outcomes before and after prostate cancer treatment and the association of sociodemographic factors and treatment type.

Methods: Data from 942 Louisiana men diagnosed with localized prostate cancer in 2011-2012 were obtained by two patient surveys: the baseline (within 4 months of diagnosis) and follow-up (6 months of the baseline) administered through the AHRQ funded Comparative Effectiveness Analysis of Surgery and Radiation (CEASAR) study. The changes in the outcomes were based on the differences in patient reported symptoms in baseline and 6-month surveys. Chi-square and logistic regression were used in analysis.

Results: Overall 37% of men reported worsening of overall urinary function, 45% of men reported worsening of sexual symptoms and 12% of men reported worsening of bowel symptoms post-treatment. The most significant predictor of changes in the patient reported outcomes was the treatment type even after adjusting for sociodemographics and patient assertiveness. Worsening of urinary symptoms including leaking, bladder control, dripping, diaper use, and sexual symptoms including ability to achieve an erection, guality and frequency of erections and overall sexual function was significantly associated with prostatectomy. Bowel symptom changes were not associated with treatment type. Men who underwent radiation were significantly more likely to have pain and burning. No association was found for sociodemographics. Conclusion: Percentage of men with worsening symptoms increases significantly after treatment. Treatment type significantly predicts changes in many patient reported outcomes. Further research is needed to assess improvement in symptoms in long term.



Oral Abstracts

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oral abstracts

concurrent session 5



CALIFORNIA'S COMPARATIVE EFFECTIVENESS RESEARCH STUDY TRACKING DATABASE

S Riddle,¹ L Inferrera¹

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Region 3 of the Cancer Registry of Greater California (CRGC) faced an overwhelming task of tracking nearly 5,000 cases for the Comparative Effectiveness Research (CER) study. We needed to know which cases were sent with completed study information and which were not. Of those cases where we received incomplete information, we needed to be able to track which fields had deficient information, the source where we could find the information, and the ability to generate worksheets and various reports. This presentation will describe the initial design, modifications, and final product of our CER Study tracking system which was created in an Access database. We hope to show a quick demonstration of the tracker at the end of the presentation.

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PROJECT HAN (HOSPICE, ADULT LIVING AND NURSING HOMES) PROGESS-YEAR 2

<u>C Rao</u>,¹ C Britto¹ ¹North Carolina Central Cancer Registry, Raleigh, NC

The goal of Project HAN is to collect cancer diagnosis information from the HAN healthcare providers, thereby reducing the number of cases identified through Death Clearance only. **Year 2 Progress:**

We collected high numbers of cancer incidence for 2011 and 2012 from North Carolina HAN facilities. To date, 280 HAN facilities have reported a total of 7,163 cases for 2011 and 13,033 cases from 2012 diagnosis years respectively. Deduplication and linkage process with these cases will confirm the number of cases identified through HAN reporting. This will have a positive effect in reducing our death clearance cases and thus time spent on following back for the death clearance process. Accomplishments and learning outcomes are as follows: **Develop and maintain a contact list of** the HAN facilities

Work with state associations who serve and communicate with these facilities for better cooperation among HAN facilities. Learn the organizational structure: Identification of corporate entities who manage multiple sites enabled the project to move forward quickly and reduced the initial numbers of communications needed to implement the process.

Investigate various training modalities and solicit feedback: A Web site was utilized to house an on-line, on-demand training module as well as general information about the project, forms to be utilized for reporting, FAQs, and more. Feedback provided confirmed this was a helpful tool but still required training and guidance from the project coordinator to ensure the facilities/ organizations understood the report.

Take advantage of association meetings to improve communication and awareness of the reporting requirements, and manning of booths at association conferences to the list of helpful actions to take.

Through these efforts, awareness of reporting requirements and communication between the NCCCR and the HAN facilities has improved and is evidenced through increased reporting.

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CANCER SURVEILLANCE IN THE ERA OF MOLECULAR MARKERS

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Cancer has evolved into a disease described and treated by consideration of tumor molecular characteristics (biomarkers), rather than by anatomic site. Moreover, the FDA requires companion diagnostic markers as gatekeepers for some molecularly targeted chemotherapy drugs. Examples include Xalkori, which may be effective in only 5% of lung cancers with a particular chromosomal abnormality; Zelboraf for melanoma and Plessikon for leukemia. We explore opportunities and challenges the cancer surveillance community faces as biomarkers become diagnostic and prognostic tools for the evaluation and management of cancer. Registries are uniquely positioned to evaluate the effectiveness of biomarkers as they move from clinical trials into community treatment settings. Cancer registries face significant conceptual and informatics issues in the collection of biomarkers: (a) How should we select which biomarkers to collect?, (b) Should the registry collect just the end-result (e.g. "positive", "negative") or the continuous scale measures that would allow for re-analysis as standards change?, (c) How should biomarker data be stored?, (d) how should registries address issues of variability in biomarker measurements in different portions of a tumor, and in metastatic lesions?, (e) Should cancer incidence reports routinely include classifications based on biomarkers rather than anatomic site?. Using estrogen receptor (ER) and progesterone receptor (PR) data in breast cancer as an example, we will consider how changes in cut-off values over time affect registry data and discuss an approach to store the raw scores rather than dichotomous outcomes. We will discuss how capturing raw data in the registry might help answer questions such as: (a) what are the optimum prognostic thresholds, (b) are these biomarkers being properly used in a community setting, and (c) does ER/ PR status predict Tamoxifen and aromatase inhibitor treatment effectiveness in a community setting.

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ENHANCING LYMPHOMA AND LEUKEMIA REPORTS IN PUERTO RICO, 2010

<u>M Traverso</u>,¹ N Perez,¹ C Torres,¹ N Vazquez,¹ G Ojeda,¹ I Veguilla,¹ Y Roman,¹ M Merced,¹ O Centeno,² K Ortiz¹ ¹Puerto Rico Central Cancer Registry, San Juan, PR; ²Infologica, Inc., San Juan, PR

Background: To achieve the completeness and optimize the data quality the Puerto Rico Central Cancer Registry (PRCCR) took on the task of evaluating the number of diagnosed cases of all the primary sites reported to the registry. With this effort, the PRCCR identified some primary sites, such as lymphomas and leukemias, with some missing cases in comparison with previous years. The PRCCR used all the conventional sources of case finding. Despite all the efforts, we noticed that cases from the hematologists-oncologists had being missed, because most of these specialists diagnose and treat their patients in their offices, being difficult to identify. However, with the availability of the newly acquired Claims database some of the possible missing cases could be identified.

Objective: To identify new cases of lymphomas and leukemias and the potential non-reporting physicians for the diagnosis year of 2010.

Methods: The Claims database was used to generate lists filtered by specialties for 2010. We will focus our study on the hematologist-oncologist specialty for being one with the most missing cases. Each case of these physicians was compared with PRCCR database to identify if the case was already in the database. If the case was in the database it was updated, if not, it was verified to evaluate if it was reportable. If reportable, the PRCCR registrars contacted the specialist and/or hospital where the patient was diagnosed or treated to acquire the information that was supposed to be reported.

Results/Conclusion: Counts were increased a 44% in approximately three months. Also, as part of this effort, we identified more than ten hematologists-oncologists from Puerto Rico which diagnosed and/or treated the most part of the cases in the Island. This effort might help us to make the follow up and perform pro-active case finding in order to achieve that these physicians report timely in the near future.

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VALIDATION OF SEER TREATMENT DATA USING THE SEER PATTERNS OF CARE STUDIES

<u>AM Noone</u>,¹ D Morrell,² K Cronin,¹ J Stevens,³ L Harlan¹ ¹National Cancer Institute, Bethesda, MD; ²University of Southern California, Los Angeles, CA; ³Information Management Services, Inc., Calverton, MD

Background: The National Cancer Institute's Surveillance, Epidemiology, and End Results (SEER) program is committed to providing high quality data for cancer research. As more patients receive cancer treatment in the outpatient setting, the collection of complete treatment data is becoming increasingly difficult. The SEER Patterns of Care (POC) studies provide an opportunity to validate the completeness of cancer treatment information collected by SEER using information collected from a detailed case review.

Purpose: This analysis evaluates the completeness and validity of chemotherapy, radiation and hormone therapy data for selected cancer sites collected by SEER using data collected by detailed review.

Methods: Treatment data for randomly selected individuals from SEER were compared to treatment data ascertained through medical record review and by physician query as part of the POC studies. All POC studies from 1996 to 2009 were analyzed which provided data for a variety of cancer sites. Sensitivity, specificity, positive predictive value and negative predictive value were calculated to quantify the concordance between SEER and POC using POC as the gold standard. Concordance will also be evaluated by patient characteristics such as age and stage at diagnosis. Data from the 2010 POC studies will be analyzed when available.

Results: A total of 23 cancer sites were evaluated and a majority of sites had data for two or more diagnosis years. The sensitivity of SEER data to capture radiation therapy was higher than for chemotherapy or hormone therapy. The sensitivity of SEER data varied by cancer site and year. In general, the PPV was high indicating that among those identified as having received treatment in SEER, a majority also had agents identified in POC. **Conclusion**: This analysis provided measures of completeness for SEER treatment data. In particular, the POC studies provide an opportunity to evaluate treatment data for individuals with cancer under age 65. 086

ROUTES TO DIAGNOSIS, A NEW MEASURE FOR AWARENESS AND EARLY DIAGNOSIS INITIATIVES L Elliss-Brookes¹

¹National Cancer Intelligence Network, London, UK

Background: Cancer survival in England is lower than the European average, which has been partly attributed to later stage at diagnosis. Understanding the impact of different routes to diagnosis on patient survival informs targeted implementation of awareness & early diagnosis initiatives and enables assessment of their success.

Purpose: This innovative study defines a methodology by which the route the patient follows to the point of diagnosis can be categorised to examine demographic, organisational, service & personal reasons for delayed diagnosis. Initial results have influenced the direction and focus of the national cancer agenda with the routine monitoring of Emergency Presentations (EPs) now a high priority.

Methods: Administrative hospital patient episodes data are combined with Cancer Waiting Times, cancer screening and cancer registration data. The method uses the diagnosis date as an end-point and then works backwards to identify the likely referral route. Every case of cancer diagnosed in England in 2006-2008 (740,000 cases) is categorised into one of 8 Routes to Diagnosis.

Results: Most cancers were diagnosed through one of EP (24%), Two Week Wait (26%) or GP Referral (21%) with the other five routes making up 29%. These proportions vary considerably with cancer type, with a high percentage of EPs in cancers of the brain & CNS (62%), pancreatic (50%) & lung cancer (39%), compared to skin (3%) & breast cancer (5%). The proportion of EPs also increases with increasing age. The substantially lower relative survival in the EP Route compared to other routes indicates that this distinction is of high clinical significance. **Conclusion**: Routes to Diagnosis can be used to explore possible reasons for delayed diagnosis and identify areas for further research. Understanding the reasons behind the difference in EP rates will help commissioners to raise awareness of early detection & treatment of cancer in high risk patent groups including the over 70s.

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USE OF STAGE DATA IN PAN-CANADIAN SYSTEM PERFORMANCE

J Klein-Geltink,¹ <u>R Rahal</u>,¹ T Forte,¹ C Sandoval,¹ G Lockwood,^{1,2} H Bryant,^{1,3} in collaboration with the System Performance Steering Committee and Technical Working Group ¹Canadian Partnership Against Cancer, Toronto, Ontario; ²Dalla Lana School of Public Health, University of Toronto, Toronto, Ontario; ³Departments of Community Health Sciences and Oncology, University of Calgary, Calgary, Alberta

The National Staging Initiative (NSI) was a collaboration of the Canadian Partnership Against Cancer (the Partnership), the provincial cancer agencies and programs (PCAs), and their associated cancer registries to collect standardized collaborative stage (CS) on a nationwide scale. The Partnership's System Performance Initiative, another national collaborative effort designed to develop and report on cancer control indicators, uses staging data to calculate key measures of the cancer system's performance, including diagnostic practices.

We used CS data elements to determine the uptake of guidelinerecommended diagnostic practices in breast cancer (ER/PR and HER2 testing) and colorectal cancer (the removal and examination of 12 or more lymph nodes). Because of the investment in CS in Canada, nine PCAs could provide data on the percentage of women newly diagnosed with invasive breast cancer in 2010 who were assessed for ER/PR and HER2 status, and eight PCAs provided data on the percentage of all colon resections with 12 or more lymph nodes removed and examined in 2007, 2008 and/or 2009. There was little variation by province in the percentage of women diagnosed with invasive breast cancer in 2010 who had diagnostic testing (92.2% to 98.1% for ER/PR testing and 87% to 96% for HER2 testing). However, there was substantial variation by province in the percentage of colon resections with 12 or more nodes removed and examined in 2009, from 59% to 89%, with little variation by sex but a difference of 9 percentage points between the youngest and oldest age groups. From 2007 to 2009, uptake increased in five of the seven provinces submitting more than one vear of data.

The use of population-based stage data is critical in improving our understanding of key care elements in the system. We expect that its impact will increase in Canada, as staging is now available through the cancer registries for over 90% of the four commonest cancers for 9 of 10 provinces since 2010.

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CANCER INCIDENCE, STAGE DISTRIBUTION AND TREATMENT PATTERNS IN MANITOBA'S FIRST NATIONS: USING CANCER REGISTRY DATA IN A COLLABORATIVE ENVIRONMENT TO IMPROVE CANCER CONTROL

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Background: Cancer has been thought to be less common in Canada's First Nations (FNs) than in non-FNs, but recent research shows this is changing. There are also concerns that malignancies are diagnosed later and treatment patterns differ for FNs compared to non-FNs. In Manitoba, FNs provincial and tribal organizations and government agencies collaborated to identify FNs in the Manitoba Cancer Registry and other health databases to explore cancer patterns as a basis for improving cancer services for FNs. **Objective**: Identify FNs in Manitoba's cancer registry, and describe recent cancer incidence, stage distribution and treatment in FNs and all other Manitobans (AOM).

Methods: We linked the Federal Indian Registry System database with the Manitoba Population Health Registry (1984-2008), and subsequently to the Manitoba Cancer Registry, which contains information on cancer stage and treatment as well as incidence. We used standard statistical tests to assess the differences in incidence. late-stage proportions, and treatment rates between FNs and AOM. Results: While cancer incidence has remained relatively stable for AOM in the past 25 years, rates in FNs have increased. Further, analysis of stage and treatment data have provided important insights; for example, while there are no significant differences in the rates of late-stage presentation for many cancers in FNs compared to AOM (e.g., breast and lung), there are non-significant trends to increased late-stage diagnosis for certain cancers (e.g., colorectal, prostate and liver) which might contribute to higher mortality rates. **Conclusions**: The findings from this collaborative project are central to quantifying cancer-related needs of Manitoba's FNs. These analyses provide the basis for further efforts, including early detection and prevention. Next steps include final analyses, knowledge translation, and working with all stakeholders to improve cancer service delivery for our province's FNs.

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PAYER AND REGISTRY SYNERGY: COLLABORATION AND DATA SHARING FOR IMPROVED UNDERSTANDING OF CANCER CARE

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A complete and accurate understanding of patients' healthcare is limited by the quality and extent of data. At UnitedHealthcare (UHC) claim level data is retained for a large population, but substantive cancer-specific clinical detail is absent. In 2007, UHC began a registry program to address this limitation that solicits clinical detail from providers. The registry now includes data from more than 6,500 providers on over 67,000 breast, colorectal and lung cancer patients.

UHC began collaborations with Florida Cancer Data System (FCDS) in 2011 to gain accurate cancer-specific clinical detail on UHC breast, colorectal and lung cancer members in Florida. FCDS sought claims data from UHC on the same cohort. The ultimate goal was to expand the analytic boundaries of this cohort for both entities.

After fulfilling legal and regulatory requirements, UHC provided a member file containing demographic, insurance coverage, and any clinical data available in the UHC Cancer Registry on members who had dates of service since July 1, 2007. The member level file contained 68,718 members. A claim-level file including dates of service, diagnostic and procedure codes, place of service, and provider detail was also provided and had over 8.3 million records. FCDS matched the member file and sent clinical detail to UHC for matched patients (15,199). Both organizations provided respective data dictionaries. In conclusion, a relatively easy exchange has created synergy in understanding a population's care. For example, UHC can produce provider specific reports detailing performance against evidence based care guidelines such as those from the National Comprehensive Care Network. UHC's Cancer Registry is now more complete for Florida membership and provides a large cancer population with an accurate longitudinal record and adequate data for case mix adjustment. Annual exchanges are planned with FCDS for all cancer types starting in 2013. UHC is seeking collaboration with other states.

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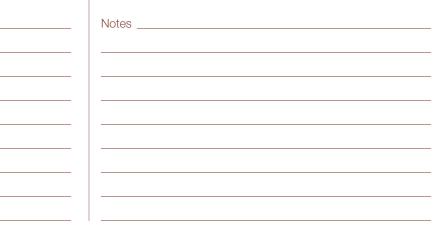
SUCCESS THROUGH COLLABORATION: ENHANCING SURVEILLANCE DATA WITH INSURANCE CLAIMS

<u>B Wohler</u>,¹ M Thiry,¹ L Voti,¹ G Levin,¹ M Rudloph,¹ J MacKinnon¹ ¹Florida Cancer Data System, University of Miami, Miller School of Medicine, Sylvester Comprehensive Cancer Center, Miami, FL

Background: Cancer surveillance at the registry level continues to expand into new and challenging areas. Additionally, as a result in the change in the diagnosis and management of some cancers, a growing number of cancer cases are not entering a hospital setting. The solution used in Florida is to capture data directly from the attending physician and Insurance companies. Beginning in 2011, FCDS began reaching out to physician offices and insurance companies as an information source. Insurance claims contain important information on treatment in the form of CPT, ICD9 and HCPC codes that can be crosswalked to NAACCR records

Methods: FCDS was able to forge a data exchange agreement with United Health Care in the spring of 2011. The claims data contains a wealth of information, up to 3 diagnostic codes, one procedure code, NPI information and indicators for HER2 status, KRAS status and a variable for anti-estrogen treatment indicator. **Results**: FCDS received 8,541,591 claims for 68,718 cancer patients; these records included both the insured and their dependents as well. These cancer patients and associated claims were from Florida residents only. Using Automatch 4.3, we were able to successfully match 32,631 of these patients. Linkage with Insurance companies presents a unique opportunity for registries to enhance data for cancer patients not covered by Medicare. These types of linkages also give the central cancer registry another tool for case finding.

This presentation will address some of the pitfalls associated with the match and the reasons for the low match rate. More importantly we will demonstrate opportunities for enhancement of data items; namely date of last contact, biomarkers and treatment variables. We feel that the United HealthCare linkage has the potential to enhance the Florida Cancer Data System and moves us further toward the purpose of public health including disease prevention and control.



DATA SHARING BETWEEN PUBLIC HEALTH AND CLINICAL CARE: A POSSIBLE SOLUTION TO CLOSE THE GAP TO COMPLETENESS

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Background: The Missouri Cancer Registry and Research Center (MCR-ARC) has received streamed pathology report data from national labs for several years; efficient processes to process and utilize that data are being improved and developed. Obtaining additional patient information from physicians to make cases complete has been labor intensive and expensive. Although challenging in terms of data processing/storage and human/financial resources, using electronic health records (EHRs) to obtain non-hospital cases offers a solution. MCR-ARC is one of two CCRs funded to pilot this option. CCRs must recognize and prepare for changes to standard operating procedures within the next few years. The majority of new cases will continue to be reported electronically but the number of cases reported directly from EHRs will continue to increase. Purpose: To assess CCR staffing and infrastructure needs for the next five years and adapt and/or develop the information technology infrastructure to support those needs.

Methods: MCR-ARC staff built on an existing strategic planning and training program to assess current strengths and weaknesses and identify current and future staffing and infrastructure needs. We identified existing and potential partners and funding sources and participated in exciting funded (e.g., Special Projects 1 & 3) and unfunded projects.

Discussion/Conclusions: Modeling the current information technology environment at the CCR, mandated reporting facilities and others involved in electronic data transfer and utilization is an important component in planning for the future. Identifying the resources to sustain and advance CCR staffing and upgrades of hardware/software is more difficult. Capture of additional cases and more complete treatment data will increase opportunities for new partners (research projects, clinical trials, etc.) and offers a potential source of revenue to support infrastructure needed to maintain high quality, complete and timely data.

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WHAT WORKS? A CENTRAL REGISTRY AND A COMMUNITY HOSPITAL COLLABORATE

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Background: Hospitals with ACoS-affiliated registries investigate patient characteristics, compliance with standards of care, and service delivery. Given the resources of an in-house registry, how could operations and patient care benefit from partnering with a central registry? What information might a central registry provide that is of value to the facility?

Purpose: Exploring such questions is the purpose of a collaboration between three partners: **1**) Community Memorial Healthcenter (CMH), in South Hill, Virginia, operates CMH Cancer and Specialty Care, an outpatient ambulatory clinic providing hematology and oncology services.**2**) The CMH clinic is affiliated with the Massey Cancer Center (MCC) at Virginia Commonwealth University in Richmond. **3**) The Virginia Cancer Registry (VCR) receives reports from the ACoS-accredited registry at CMH.

Methods: The methods employed do not go beyond core central registry competencies. VCR adopted them to assist CMH in understanding its patient population and assist it in improving patient care. 1) VCR provides standard statistical summaries (adjusted and crude rates, significance, rate ratios, counts, etc.) for an eight-county area the hospital serves; this baseline includes comparative state and national data and mortality data.2) The CMH registry works with VCR to validate the completeness and accuracy of case records each registry holds. 3) VCR educates CMH Cancer Committee members about registry resources. Committee members then will identify novel ways the central registry could contribute to their in-house resources. **Results:** Assessing the extent to which VCR products contribute to goals CMH and MCC staff establish to better understand and positively affect patient outcomes is the primary result. **Conclusion:** The partnership and its activities as outlined may provide information to induce stronger relationships between central registries, hospital cancer committees, and hospital registries.



ROLE OF CANCER REGISTRIES IN SURVEYING CLIMATE CHANGE EFFECTS ON CANCER INCIDENCE: A NORTH CAROLINA CASE STUDY

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Climate change is a global phenomenon with complex direct and indirect effects on the environment and human health. The potential effects of climate change on cancer incidence are being studied for different cancer types, in particular those that have a link with environmental factors such as prolonged sun exposure. Similarly, research is ongoing trying to determine other potential climate change and cancer incidence links. However, the capability of cancer registries to be able to identify and continuously monitor these incidences and detect potential human health-environment interactions has not been fully addressed. Data required for such research would entail inter-institutional collaboration to produce and acquire health and environmental spatial data of characteristics that could satisfy the requirements of epidemiological studies. This paper explores and discusses the role of spatial analysis in studying climate change and cancer interactions and its potential applications in central cancer registries. Incidence data from Central Cancer Registry of North Carolina will be used as a case study to identify connections between spatial distribution of skin cancer incidence and climate change. Recommendations will be given on characteristics of spatial data suitability for cross analysis of environment and cancer incidence.

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IS MELANOMA INCIDENCE DIFFERENT IN CHILDREN THAN IN ADULTS?

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Background: Since 1975 childhood melanoma rates have risen every year, accounting for 1-3 percent of melanoma cases. Because of the rarity of melanoma in children and the difficulty in differentiating tumor types, 40 to 60 percent of childhood melanoma cases are initially misdiagnosed. We examined differences between children/ adolescents and adults in demographic and clinical characteristics of melanoma.

Methods: Melanoma cases were identified from the North American Association of Central Cancer Registries (NAACCR) CINA Deluxe database for the years 1995-2008. Melanoma case distributions and average annual incidence rates by age, gender, stage, Breslow depth, etc. were calculated and compared using Chi square (x^2) statistics and rate ratios. Confidence intervals for age-adjusted rate ratios were calculated using the Tiwari method. Annual percent change (APC) was calculated using weighted least squares methods. Results: From 1995 to 2008, 4,845 melanomas were reported in individuals younger than age 20. Of these, 2.3% were infants, 2.8% were ages 1-4, 5,7% were 5-9, 16,4% were 10-14, and 72,8% were 15-19. Individuals in the youngest age group (ages 0-9) had more melanomas diagnosed in the late stages than did the two older (10-19, 20+) age groups (p<.0001). Additionally, the 0-19 and 80+ age groups had more melanomas with a Breslow depth greater than 4.0 mm, 19.9% and 21.3%, respectively (p<0.0001) compared to the middle-aged. Gender differences start at age 10 when female incidence begins to surpass that of males until ages 45-49 when there is a sharp upturn in male incidence rates. Rates were different by gender (p < 0.05) for every age group beginning at age 15. **Conclusion**: Melanoma incidence in children is significantly different than adults. While this study adds valuable epidemiologic information about melanoma for the youngest age groups, it is necessary to learn why these differences are occurring.

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CANCER INCIDENCE TRENDS AMONG ETHNIC-SPECIFIC ASIAN AND PACIFIC ISLANDER POPULATIONS IN THE UNITED STATES. 1990-2008

S Gomez,^{1, 2} <u>A Noone</u>,³ <u>L Liu</u>,⁴ D Lichtensztajn,¹ S Scoppa,⁵ J Gibson,⁵ C Morris,⁶ S Kwong,⁶ K Fish,⁷ L Wilkens,⁸ M Goodman,⁹ D Deapen,⁴ B Miller³

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Background: The lack of annual population estimates for Asians and Pacific Islanders (API) by ethnicity in the U.S. has precluded an examination of national cancer incidence trends among these fastgrowing but understudied populations.

Purpose: Through a collaborative effort between the NCI SEER Program and 13 SEER registries, we developed necessary subgroup-specific annual population estimates, in order to examine cancer incidence trends for 11 API ethnic populations from 1990-2008.

Methods: Cancer incidence data from 1990-2008 were obtained from 13 SEER registries. Age-adjusted annual incidence rates and trends by sex for five major cancers by time periods and average annual percentage change in incidence rates were computed using SEER*Stat and Joinpoint software. The API groups included are Asian Indians and Pakistanis (combined), Chinese, Filipinos, Japanese, Kampucheans, Koreans, Laotian, and Vietnamese, Native Hawaiians, Samoans, and Guamanians/Chamorros respectively. Rates for non-Hispanic Whites were included for comparison purposes.

Results: Among men, increasing trends were observed for prostate (Asian Indians and Pakistanis, Filipinos, and Koreans), colorectal (Koreans), and liver cancers (Filipinos, Koreans, and Vietnamese); while lung and stomach cancers generally remained stable or decreased. Among women, increases were observed for uterine cancer (Asian Indians, Chinese, Filipina, Japanese, and Samoans), colorectal cancer (Koreans, Laotians, and Samoans), lung cancer (Filipinas and Koreans), thyroid cancer (Filipinas), and breast cancer in most groups. Decreases were observed for stomach (Chinese, Japanese, and Samoans), colorectal (Laotians and Vietnamese).

Conclusions: Population-based cancer incidence rates for disaggregated API Americans fill a critical knowledge gap and help identify disparities in cancer burden and highlight where increased preventive and screening efforts are needed.

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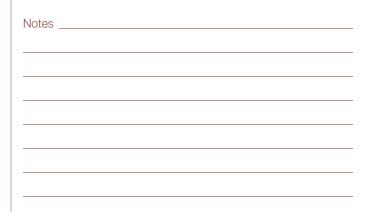
A COMPARISON OF SEER AND CINA DATA FOR A RARE CANCER: HODGKIN LYMPHOMA, 1995-2008 <u>P Jamison</u>,¹ D Lewis¹ ¹NCI/SEER. Bethesda, MD

Background: Hodgkin Lymphoma (HL) is a rare cancer with 9,060 estimated cases in the United States (U.S.) for 2012. Data from the Surveillance, Epidemiology, and End Results (SEER) program are frequently cited for incidence reports but are limited in population coverage. Cancer Incidence in North America (CINA) data are available from the North American Association of Cancer Registries (NAACCR) to provide high quality cancer data for the entire U.S.

Purpose: This analysis was conducted to determine if HL incidence based on CINA data follows established patterns observed in the SEER data and discussed in the current literature.

Methods: Age-adjusted incidence rates were calculated for 72,195 cases of HL from CINA covering 67% of the U.S. population and 14,878 cases from SEER covering 14% of the U.S. population for cases diagnosed from 1995-2008. Incidence by demographic characteristics was evaluated. Joinpoint regression was used to evaluate incidence rate changes. **Results**: Incidence rates by age, gender, race and ethnicity were stable for CINA and SEER populations. The classic bi-modal distribution of HL and male excess were observed in both datasets. Incidence rates of HL were 2.8 cases per 100,000 in CINA and 2.7 cases per 100,000 in SEER. Rates for Non-Hispanic (NH) whites, Hispanics, and NH blacks were similarly close. A rise in HL rates among NH blacks and NH other races was observed in both datasets. Geographic variation in HL rates was observed using the CINA data.

Conclusions: Results from both sources of data were very similar. The two datasets are not mutually exclusive however the geographic overlap is small. For a more complete examination of a rare cancer, CINA offers the potential to evaluate geographic variation, while SEER has more detailed race and ethnicity categories to assess changes in rates among smaller populations.



RECENT TRENDS IN PROSTATE CANCER INCIDENCE BY AGE, CANCER STAGE AND GRADE, THE UNITED STATES, 2001-2007

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Purpose: Widespread use of the prostate-specific antigen (PSA) testing has influenced prostate cancer stage, grade, and age at diagnosis. These factors are critical in determining treatment modality. The objective of this study was to examine trends of prostate cancer incidence by demographic and tumor factors and identify potential associations with cancer screening and treatment.

Methods: We described prostate cancer incidence rates and trends by demographics and cancer stage and grade using the 2001-2007 National Program of Cancer Registries (NPCR) and Surveillance, Epidemiology, and End Results (SEER) programs data (representing over 93% of U.S. population). We conducted descriptive and trend analyses using SEER*Stat.

Results: The overall prostate cancer incidence rate was stable from 2001-2007; however, rates significantly increased among men aged 40-49 years (APC=3.0%; 95% CI=0.6-5.5) and decreased among men aged 70 -79 years (APC=-2.3; 95% CI=-4.5--0.1), and 80 years or older (APC=-4.4; 95% CI=-5.8--3.0). About 56% of localized prostate cancers diagnosed from 2004-2007 had Gleason scores ≤ 6 . The incidence of poorly differentiated cancer significantly increased among localized (APC=8.0; 95% CI=2.0-14.3) and regional stage (APC= 6.1; 95% CI=0.6–11.8) prostate cancers during these years. **Conclusions**: The recent trends in prostate cancer incidence varied dramatically by age. Most of the localized prostate cancers were low-grade, suggesting active surveillance as a possible treatment option. Continued monitoring of prostate cancer incidence is needed to understand the increasing trend of poorly differentiated prostate cancers, especially with the recent updated US Preventive Service Task Force's recommendation against prostate cancer screening for men of all ages.

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DOES CANCER INCIDENCE AND SCREENING UTILIZATION VARY BETWEEN REMOTE NORTHERN COMMUNITIES AND THE REST OF SASKATCHEWAN?

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Background: Indigenous Canadians (ICs) are a fast growing segment of the population in the Canadian province of Saskatchewan (SK). In 2006, ICs made up 14.9% of the SK population, projected to 32.5% by 2045.

Healthcare is delivered to the SK population across 13 health authorities (HAs). In northern SK (NSK), there are 3 HAs, about 85% of the population self-identify as ICs. Few studies have examined the burden of cancer and screening utilization among ICs in Canada. The cancer burden and impact of screening on in situ and early stage cancers in a relatively remote, mostly IC population will be described..

Purpose: (1) Describe cancer incidence in NSK and; (2) compare incidence to the rest of the 10 HAs in SK; and (3) show how screening programs impact incidence rates of in situ and invasive cancers compared to the other 10 HAs.

Methods/Approach: Saskatchewan Cancer Registry (SCR) data (1990-2008) was used. The SCR (est. 1932) has excellent standards of quality control, completeness and follow-up. Cancer sites were grouped as: cervical, breast, colorectal, lung, prostate, and all others. Incidence rates were compared between NSK and the other 10 HAs by cancer site. Screening rates were identified from SK Cancer Agency databases of the Screening Program for Breast Cancer and the Prevention Program for Cervical Cancer. Incidence rates and 95% Cl for both in situ and invasive breast and cervix cancers among ICs and the other 10 HAs in SK were compared.

Results/Conclusions: Invasive cancer rates were higher in the NSK except prostate cancer. Lung cancer incidence rates were statistically significantly higher in NSK HAs. Smoking prevalence in the north among ICs is known to be high. In situ rates were lower in the north. Only cervix in situ was statistically significantly lower in NSK than the other HAs. By linking registry data and screening data, health behaviors and cancer burden can be tracked, allowing for targeted planning for special populations.

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ANALYTICAL SOFTWARE FOR POPULATION-BASED CANCER STATISTICS

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The NCI has developed numerous statistical methods and associated software tools for the analysis and reporting of cancer statistics. These freely available software tools enable cancer researchers to calculate incidence, mortality, survival, prevalence, spatial statistics, health disparities, and other related statistics. This presentation will provide the audience with an overview of capabilities of these tools.

The SEER*Stat software provides a convenient, intuitive mechanism for the analysis of SEER and other cancer-related databases. SEER*Stat can be used to view individual cancer records and to produce statistics for studying the impact of cancer on a population. SEER*Stat can calculate frequencies, crude and age-adjusted incidence, mortality, and prevalence rates, survival probabilities, and Multiple Primary Standardized Incidence Ratios.

The Joinpoint regression program is statistical software for the analysis of trends using joinpoint models, that is, models where several different lines are connected together at the "joinpoints". The software takes trend data (e.g. cancer rates) and fits the simplest joinpoint model that the data allow. This enables the user to test whether an apparent change in trend is statistically significant.

The Health Disparities Calculator (HD*Calc) is statistical software to generate multiple summary measures to evaluate and monitor health disparities. HD*Calc allows the user to import SEER data or other population-based health data and calculate any of eleven disparity measurements. HD*Calc supports the use of a range of health disparities measures, allowing researchers to select and apply different measures to their data. Cross-sectional and trend data (e.g., cancer rates, survival, stage at diagnosis) categorized by disparity groups (e.g., area-socioeconomic status, race/ethnicity, geographic areas) can be imported into HD*Calc to generate four absolute and seven relative summary measures of disparity.

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Oral Abstracts

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PROSTATE CANCER INCIDENCE REPORTED AMONG DEPARTMENT OF DEFENSE MILITARY TREATMENT FACILITIES, 2005-2008

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The Navy and Marine Corps Public Health Center's Health Analysis Department conducted an analysis on prostate cancer, providing age-adjusted prostate cancer incidence rates that assess trends among race and location using Department of Defense Central Cancer Registry (DoDCCR) data from 2005 to 2008. The DoDCCR maintains consolidated tumor data derived from Automated Central Tumor Registry (ACTUR) records on TRICARE beneficiaries, including active duty, retirees, and family members. The DoDCCR follows SEER guidelines and standard practices in determining multiple cancers for an individual. The DoDCCR utilizes the North American Association of Central Cancer Registries (NAACCR) developed standards for data coding and Centers for Disease Control and Prevention (CDC) National Program of Cancer Registries (NPCR) Registry Plus (CRS Plus) software as a standard to consolidate records. This poster highlights analyses on prostate cancer incidence as reported by tri-service DoD Medical Treatment Facilities between the years 2005-2008. Four metrics assess the prostate cancer burden in the DoD population: (1) counts stratified by race and year of diagnosis, (2) counts stratified by age group and year of diagnosis, (3) age-adjusted incidence rates stratified by state and year of diagnosis, and (4) age-adjusted incidence rates stratified by year of diagnosis."The views expressed in this presentation are those of the author and do not necessarily reflect the official policy or position of the Department of the Navy, Department of Defense, or the U.S. Government."

P-02

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SPATIAL ANALYSIS IN CANCER SURVEILLANCE: IDENTIFYING GEOGRAPHIC TARGETS FOR SCREENING INTERVENTIONS

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Public Health Context: Colorectal cancer (CRC) is a common cancer in industrialized countries. It is the third most commonly diagnosed invasive cancer, and the third leading cause of cancer-related death in the United States. Because prognosis and quality of life is critically dependent upon the stage of cancer at diagnosis, routine screening can reduce mortality due to CRC through early detection. Because effective screening by colonoscopy can lead to the identification and removal of precancerous lesions, CRC is potentially eradicable through secondary prevention. Therefore, a diagnosis of CRC, particularly a late stage diagnosis, can be viewed as a preventable, adverse health outcome.

Only about 50% of the general population receives CRC screening, so, while all groups would benefit from increased CRC screening, high risk communities may potentially benefit the most. Because public health resources are limited, geographically targeting high risk populations for enhanced screening efforts is pragmatic public health policy.

Methods/Results: This paper describes an analysis of spatial clustering of CRC in Florida. The objective was to identify geographically based targets for CRC screening interventions. The initial Bernoulli cluster detection analysis identified areas with high risk of late stage CRC; however, none of the results were statistically significant. Despite the lack of statistically significant results, we still needed to answer the question of where to market a screening intervention. Innovative post-hoc analysis, including combining separate models of cluster detection, changing scale and scan method, were conducted to identify target areas.

Significance: The selected geographic areas must have real potential for attenuating excess CRC burden through increased screening efforts. Reliance on SaTScan parameter defaults, pre-determined cut-points, or cookie cutter analysis is not appropriate.

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ADDRESSING COLORECTAL CANCER DISPARITIES IN A SPATIAL CONTEXT

<u>R Sherman</u>,¹ K Henry,² L McClure,¹ A D'Andrea,¹ D Lee¹ ¹University of Miami, Department of Epidemiology, Miami, FL; ²University of Utah, Department of Geography, Salt Lake City, UT

Public Health Context: Colorectal cancer (CRC) is 3rd most commonly diagnosed invasive cancer and 3rd leading cause of cancer-related death in US. Routine screening can not only reduce mortality through early detection, but screening with colonoscopy has to potential to reduce incidence of CRC. This makes a late-stage diagnosis of CRC a preventable disease. Despite strong evidence that CRC screening saves lives, screening rates remain low. Recent screening rates have been improving, but minorities consistently have lower screening rates compared to non-Hispanic Whites. This translates to an increased burden of CRC diagnosed at a late stage for these groups.

A multi-disciplinary team addressing colorectal cancer disparities has been working to identify geographic areas in Florida with higher burdens of CRC diagnosed at a late stage. Identifying the location of these populations is required to determine the physical location for screening intervention programs, and the characterization of the demographics of these populations at risk is important to inform what type of intervention is appropriate for each community.

Methods/Results: CRC cases diagnosed in 2005-2009 were analyzed using SaTScan spatial scan software to identify clusters of CRC in Florida. Numerous SaTScan runs were conducted with varying methods and parameters to determine the most appropriate geographic area. Once the high risk areas were selected, logistic and hierarchical regression was performed (and compared) to identify demographic risk factors (individual from registry data; area-based from census) associated with increased risk of a late stage CRC diagnosis. This poster focuses chiefly on detailing the demographic risk factors associated with late stage CRC diagnosis.

Significance: argeting high risk communities for screening efforts should be public health policy. Successful interventions will be tailored based on the characteristics and specific risks of the population.

P-04

NO RACIAL DISPARITIES IN STAGE AT DIAGNOSIS – IS NEVADA DOING BETTER FOR CERVICAL CANCER?

<u>S El Ibrahimi</u>,¹ K Morgan,² S Moonie,¹ M Chino,¹ P Pinheiro^{1,2} ¹University of Nevada, Las Vegas School of Community Health Sciences, Department of Epidemiology and Biostatistics, Las Vegas, NV; ²Nevada Central Cancer Registry, Las Vegas, NV

Background: Stage at diagnosis is a significant predictor of cervical cancer (CC) prognosis. Disparities relating to CC in Nevada have not been studied. The purpose of this study is to determine if differences exist in CC stage at diagnosis in relation to race/ethnicity and insurance status.

Methods: The study population consisted of 1,434 women diagnosed in 1995-2008, identified through the Nevada Central Cancer Registry (NCCR). Multiple logistic regression modeling was used to calculate the odds of being diagnosed with CC at a regional or distant stage in relation to localized stage.

Results: Adjusted for age, SES, marital status, insurance, histology, and diagnosis period; the estimates for CC stage at diagnosis for Blacks [aOR=0.8, 95% CI: 0.53-1.38], Hispanics [aOR=0.9, 95% CI: 0.63-1.21], and Asian/Pacific Islanders [aOR=1.5, 95% CI: 0.97-2.32] were not significantly different compared to White women. Women who were uninsured [aOR =1.9, 95% CI: 1.30-2.80] or insured under Medicaid [aOR=2.8, 95% CI: 1.80-4.59] were more likely to be diagnosed at non-localized stage than privately insured women.

Conclusions: No significant differences in stage at diagnosis were found between minority groups and Whites. The 2012 report "Cancer in Nevada" found that White women in Nevada were unfavorably afflicted by cancer in general, with low survival and later stage at diagnosis compared to the US. Screening levels for the state are also below the US average. While survival analysis on cervical cancer is not feasible until NCCR completes follow-up for all cases, this unique pattern of disparity (the absence of one), particularly between Whites and Blacks deserves further study. It would be of interest to know if the lack of racial disparities reflects progress in public health or an unfavorable pattern of early detection among Whites. These findings will contribute to a more informed public health debate on the state of cancer prevention and early detection in Nevada.

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Poster Sessions

P-05

OVERVIEW OF BRAIN TUMOURS IN ALBERTA

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While age-standardized incidence/mortality rates for brain cancer have remained stable in Alberta since 1990, they are still a hot topic due to the recent increase in cellphone usage and the long latency periods associated with cancer. Brain metastases are a common complication of lung cancer patients. As the Alberta Cancer Registry (ACR) only codes metastases found at the time of diagnosis, many brain metastases go unreported. The lack of brain tumour coding standardization across registries also makes it difficult to compare results.

The purpose of this study is to: 1) Evaluate the differences between brain tumour coding definitions 2) Compare Alberta brain tumour data to other areas 3) Propose methods to estimate brain cancer metastases.

ACR data was used to evaluate the differences in brain tumour coding definitions. Brain tumour sites were broken down by sex. A summary of brain metastases was produced and compared to data from the Kentucky Cancer Registry.

Over 70% of brain metastases originated from lung cancer. The patient profile (age and sex) of those in Alberta whose lung cancer metastasized to the brain is very similar to those in Kentucky. Brain metastases were found at the time of diagnosis in 10% of lung cancer cases in Alberta, similar to other research.

A method must be developed that can accurately estimate the number of brain metastases that occur after initial diagnosis. There are three main data sources that may assist in order to estimate brain metastases - patient chart reviews, cancer treatment/billing data and death certificates.

P-06

RETURN ON INVESTMENT OF MEDICAID LINKAGES FOR NPCR'S ENHANCING CANCER REGISTRY DATA FOR COMPARATIVE EFFECTIVENESS RESEARCH (CER) PROJECT: IDAHO'S PERSPECTIVE

<u>C Johnson</u>,¹ E McKeeth¹ ¹Cancer Data Registry of Idaho, Boise, ID

Many central cancer registries have demonstrated improvements in treatment information gained via linkages with hospital discharge datasets and claims data. In 2010, Idaho was selected to participate in the National Program of Cancer Registries Enhancing Cancer Registry Data for Comparative Effectiveness Research (CER) Project. This project was funded as part of American Recovery and Reinvestment Act (ARRA) Comparative Effectiveness Research activities through the Centers for Disease Control and Prevention. As part of Idaho's CER activities, we conducted, for the first time, linkages with Idaho Medicaid claims data. The linkages were used for casefinding by identifying cancer-related claims that did not link to a record in the Cancer Data Registry of Idaho (CDRI) database; to gather information on comorbidities; and to collect treatment information. We carefully documented staff time invested in conducting probabilistic linkages between our CDRI database and the Medicaid claims data, apportioning claims as cancer-related or not, translating procedure codes to NAACCR treatment variable values, and updating our database with information on comorbidities and treatment gained through the linkages. We will present results on person-hours of staff time invested versus information gained. We will discuss our perspective on the utility of claims linkages as a casefinding source in a state lacking a hospital discharge data system, and as a sustainable approach for collecting treatment and comorbidity information.

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ESTABLISHING DATA LINKAGE POLICIES FOR ADMINISTRATIVE RECORDS AND HOSPITAL RECORDS – LESSONS FROM FLORIDA

<u>J Feldman</u>,¹ Y Huang,¹ M Hernandez,⁴ J Mackinnon,⁴ F Tan,³ D Lee,² T Hylton,¹ A Adams-Thames¹

¹Florida Department of Health, Tallahassee, FL; ²Sylvester Comprehensive Cancer Center, University of Miami Miller School of Medicine, Miami, FL; ³Indiana University-Purdue University Indianapolis, Indianapolis, IN; ⁴Florida Cancer Data System, Sylvester Comprehensive Cancer Center, University of Miami Miller School of Medicine, Miami, FL

Background: The Florida Department of Health (DOH) and Florida Cancer Data System (FCDS) linked registry data with breast cancer patients' hospital electronic medical records (EMRs). EMR linked to cancer registry data enables research on effectiveness of treatment and other patient-centered outcomes. However, technical barriers must be resolved to perform EMR linkages.

Methods: The Florida DOH worked with a Florida hospital to link their EMR for patients diagnosed with and/or treated for breast cancer between 2007 and 2011. Medical ICD-9-CM codes were used to identify patients from EMR data. The hospital system assigned staff to identify data for patients' treatment profiles, medication orders, discharge reports, and clinicians' notes for patient health history from various hospital computer systems. Patient EMR were transmitted through FCDS' Secure File Transfer Protocol and matched with registry data. Pathology and treatment data were processed to remove protected health information.

Results: Hospital EMR transferred 12,804 tumor records to FCDS for a match with 11,504 breast cancer patients. Hospital staff identified EMR fromwithin its network of providers, inpatient and outpatient care units, billing departments, and external pharmacies. These data were processed in a flat file format that the registry could receive and interpret.

Implications for public health: Incorporating cancer data from EMR is feasible if hospital leadership makes it a priority and dedicates staff with data linkage expertise. Data linkage policies and procedures are needed to address patient confidentiality concerns. Data linkage policies and procedures should: (1) address how to protect patient confidentiality and define the legal obligation for reporting data; (2) define the ownership of data; (3) establish compatibility of data systems within the network of hospitals and the state cancer registry; and (4) ensure secure means of data transmission through data sharing agreements.

P-08

DEVELOPING AN INFORMATION-SHARING PORTAL FOR COMPARATIVE EFFECTIVENESS RESEARCH: AN ICF APPROACH

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Background: CDC's Comparative Effectiveness Research (CER) project aims to develop new sustainable methods for rapid data collection and the expansion of data items collected through linkages and electronic reporting, to develop new capacity for innovative public health applications of cancer registries, and to develop datasets for researchers to address CER-related research questions. Ten registries were selected to participate in the CER data collection (Core projects). As the project involves not only in technical support but also communication, collaboration and numerous administrative tasks, a decision was made to develop a web-based information-sharing portal under the NPCR-CER project. The information-sharing portal purports to facilitate technical communications with all parties involved in the project, the prompt delivery of general guidelines and training materials, and collaboration among participating registries, CDC and ICF Macro.

Methods/Approach: Through presentation and demonstration, we will showcase how the information-sharing portal was developed under the NPCR-CER project and how this tool has been used for project management, multi-sites coordination, technical assistance, and information-sharing.

Implications: The CER information sharing portal enables rapid and secure data and document exchange with features such as automatic email notification, online technical assistance request submission, processing, and tracking, event announcements and FAQs, project tasks management and tracking, among others. These features and functions on the portal can be easily customized and expanded so that the portal can be quickly adapted and used for many other projects.

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DATA QUALITY IMPROVES: CANADA COMPARES THEIR DATA USING SEER VALIDATION LIST

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Background: The Canadian Cancer Registry (CCR) is a national dynamic administrative survey established in 1992, which contains person-oriented information on cancer incidence, mortality and stage from the thirteen provincial/territorial cancer registries (PTCRs). In order to ensure comparability and accuracy, the Resolutions Issues Group (RIG), a subcommittee of the Data Quality Management Committee (DQMC) conducted data verification of site/histology combinations within the CCRutilizing the 2009 SEER Validation List.

Purpose: To utilize the SEER Validation List as an inclusion list to determine which site/histology combinations are applicable to the CCR and to produce reports on records falling outside of the inclusion list.

Method: The Resolution Issues Group began by analyzing the site/histology combinations contained within the SEER Validation List and adding those combinations that were specific to the CCR scope (including /1 behaviors). Queries were run to check frequencies of questionable combinations in the data at the CCR. Those combinations falling outside acceptable site/ histology groups were discussed amongst the committee and returned to registries for review and correction.

Results: A data clean up of records with unlikely combinations were returned to the CCR after review and corrections were made. Some errors were identified and assigned to different workgroups for further examination. A customized Canadian version of the SEER Validation list will be used to do future data verifications with the ability to return cases with improbable combinations back to the registries for correction.

Conclusions: This initiative resulted in improved data quality, accuracy and comparability across Canada with future plans to implement aCCR edits package (including this topography/ histology comparison) for PTCRs to run their data through prior to submission to CCR. More to follow next year.....

P-10

ENRICHING THE FLORIDA CANCER REGISTRY TO EXAMINE SURVIVAL DISPARITIES IN FEMALE BREAST CANCER PATIENTS

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Introduction: Breast cancer is one of the leading causes of cancer death in all U.S. women. However, disparities in mortality by race, ethnicity, and socioeconomic status (SES) may still exist. **Purpose:** To fully investigate race/ethnicity/SES disparities in breast cancer survival using an enhanced Florida Cancer Data System (FCDS) registry.

Methods: Data were obtained from linkage of 1996-2007 FCDS to U.S. Census and Florida's Agency for Health Care Administration (AHCA) (n=127,754). AHCA contains diagnosis and procedure codes for all patient encounters at hospitals and free-standing surgical and radiological treatment centers. Our primary clinical endpoint was survival time that was calculated as the elapsed time from the dates of diagnosis to death or last contact. Race was categorized as: White, Black, Native American, Asian, Pacific Islander, Asian Indian or Pakistani (AIP), or Other. Ethnicity was defined as non-Hispanic or Hispanic. Categories of SES were based on percent of the census block living in poverty: lowest (<5%), middle-low (\geq 5% and <10%), middle-high (\geq 10% and <20%), and highest (\geq 20%). Univariate and multivariate Cox regression models were fitted with demographic and clinical characteristics and comorbidities. Results: Independent predictor of worse survival in the unadjusted model was Black (hazard ratio [HR] 1.44; P<.001) and for better survival were Asian (HR .71; P<.001), AIP (HR .65; P=.013), and Hispanic (HR .92; P<.001). Utilizing the enriched linked dataset and adjusting for all covariates, Black (HR 1.28; P<.001) and Hispanic (HR .90; P=.001) remained significant, but Asian (HR .84; P=.10) and AIP (HR .87; P=.38) did not. For SES, there was a monotonic improvement in survival for each higher SES category in unadjusted and adjusted models (P<.001). **Conclusion:** Using an enhanced FCDS registry for female breast cancer patients provided the strengthened ability to identify racial, ethnic, and SES disparities in survival outcome.

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USING THE NATIONAL PROGRAM OF CANCER REGISTRIES PROGRAM EVALUATION INSTRUMENT (NPCR-PEI 2009-2011) TO ASSESS DATA COMPLETENESS AND QUALITY WITHIN THE NATIONAL PROGRAM OF CANCER REGISTRIES CANCER SURVEILLANCE SYSTEM (NPCR-CSS 2005-2010)

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Background: The NPCR-PEI is a web-based survey designed to evaluate the operational attributes of NPCR-funded registries & their progress toward meeting program standards. The NPCR-CSS receives, processes, & disseminates cancer incidence data submitted to CDC by NPCR-funded grantees. This study provides more recent information about data quality/assurance, its association with registry workload, & the CCRs' ability to maintain high quality NPCR-CSS data.

Methods: NPCR-PEI data were linked to the NPCR-CSS data to perform frequency analyses for data elements relevant to administration, registry workload, reporting completeness, data exchange, data content/format, data guality/assurance & data linkages. The completeness rates for 7 NPCR-CSS data elements (vital status, cause of death, type of reporting source, follow-up source, primary site, date of diagnosis, & date of last contact) were calculated. Statistical differences in trend analyses by calendar year & NPCR registry were calculated. Correlation analyses by calendar year & NPCR registry were performed showing the association between incidence rates for 5 cancer sites & registry attributes for data quality/assurance & workload. Results: Cumulative mean percent data completeness for the NPCR-CSS data elements is 91.3% with a 0.6% increase from 2005 to 2009. The NPCR-PEI data showed a 10% increase in the use of electronic reporting systems; a 3% increase in the use of registry-specific edits; & about 8% increase in the use of Registry Plus software from 2005 to 2009. Results from correlation testing & other analyses will be presented. **Conclusion:** There have been improvements in the use of electronic reporting systems & data quality assurance procedures by CCRs as well as slight increases in NPCR-CSS data completeness between 2005 & 2009.

Impact: This study provides more recent information about data quality & assurance. These results will inform CDC where technical assistance may be needed to assist the CCRs.

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P-12

ROUTES TO DIAGNOSIS, A NOVEL ENGLISH METHODOLOGY

<u>L Elliss-Brookes</u>,¹ S McPhail,¹ A Ives,² M Greenslade,² J Shelton,¹ S Hiom,³ M Richards⁴

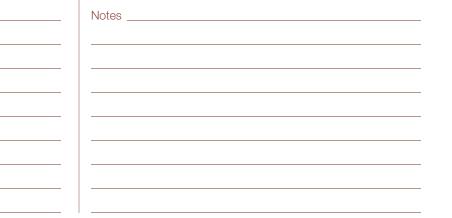
¹National Cancer Intelligence Network, London, UK; ²South West Public Health Observatory, Bristol, UK; ³Cancer Research UK, London, UK; ⁴National Cancer Action Team, London, UK

Background: Cancer survival in England is lower than the European average, which has been partly attributed to later stage at diagnosis when there are fewer options for effective treatment. Understanding the routes taken by patients to their cancer diagnoses and the impact of different routes on patient survival will inform targeted implementation of awareness and early diagnosis initiatives and enable assessment of their success.

Purpose: This innovative study defines a methodology by which the route the patient follows to the point of diagnosis can be categorised to examine demographic, organisational, service and personal reasons for delayed diagnosis.

Methods: Routes to Diagnosis uses routinely collected data sources to work backwards through patient pathways to examine the sequence of events that led to a cancer diagnosis. Administrative hospital patient episodes data are combined with Cancer Waiting Times data, data from the cancer screening programmes and cancer registration data. The method uses the cancer registration diagnosis date as an end-point and then works backwards to identify the likely referral route. Every case of cancer registered in England diagnosed in 2006-2008 (740,000 cases) is categorised into one of eight 'Routes to Diagnosis'. **Results:** The results are fascinating. Different cancer types show substantial differences between the proportions of cases that present by each Route to Diagnosis. Patients presenting via Emergency Routes have significantly lower one-year relative survival. Results show differences in Routes to Diagnosis for tumour type, age, sex, deprivation, geography, ethnicity and year. Relative survival estimates are presented for 1, 3, 6, 9 and 12 month periods.

Conclusion: Linked cancer registration and administrative data can be used to robustly categorise the route to a cancer diagnosis for all patients. These categories can be used to enhance understanding of and explore possible reasons for delayed diagnosis



Poster Sessions

P-13

SMOKING AND MORTALITY IN BREAST CANCER PATIENTS

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Background: The relation between smoking and breast cancer is complex. There is no conclusive evidence of causality but smoking may be associated with mortality in breast cancer patients; smokers have more co-morbidities and worse health related behaviors. This possible association may also differ by race.

Purpose: To enhance the Florida Cancer Data System (FCDS) with the Florida Agency for Health Care Administration (ACHA) data to clarify this possible association, by allowing adjustment for sociodemographic, clinical-pathological variables, and comorbidities.

Methods: Data were obtained by linking the 1996-2007 FCDS, ACHA, and the U.S. Census via unique identifiers. Inclusion criteria were female ≥18 years, diagnosed with breast cancer and residing in the state of Florida (n=127,754). Smoking status was assessed by self report. To analyze the association between smoking and all-cause mortality in breast cancer patients, we performed sequential multivariate logistic regression models with progressive adjustment for main confounders.

Results: After adjusting for all covariates including comorbidities, compared to those who never smoked, current and former smokers had worse survival (hazard ratio [HR] 1.07; P<.001 and 1.05; P=.011). Compared to those who never smoked, those who smoked 1-2 and >2 packs/day had worse survival (HR 1.10; P<.001 and 1.40; P<.001). Current White smokers had worse survival compared with never smokers (HR 1.39; P<.001). Compared with Black never smokers, Black current smokers have a non-significant worse survival (HR 1.10; P=.089). **Conclusions:** Smoking is associated with an increase in all-cause mortality in female breast cancer patients after adjustment for main confounders including health behaviors and comorbidities. This could be due to the fact that smokers have been shown to be less screening adherent to mammography recommendations. This association has been shown to be significant for Whites and non-Hispanics.

P-14

DATA COMPLETENESS EVALUATION BETWEEN SEER AND NAACCR METHODS IN 8 SEER REGISTRIES

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Background: Data completeness (DC) is a key element in evaluating cancer data quality. There are two methods of evaluating completeness done by the Surveillance, Epidemiology, and End Results (SEER) and North American Association of Central Cancer Registries (NAACCR) programs. Currently, the differences of measuring completeness in central cancer registries have not been well-addressed.

Methods: Eight SEER registries DC between 2005-2009 for NAACCR method was obtained from the annual Cancer in North America publication and DC for SEER method was calculated from up to past 10 year incidence. Delayed-reporting was estimated for cases diagnosed in 2008 of current submission with previous submission year. Difference of DC of two methods was analyzed by *Pearson* correlation and *Mann-Whitney U* test. **Results:** The overall average DC for SEER method was 99.7% \pm 1.6% and for NAACCR method was 105.5% \pm 6.8%. Delayed-reporting of these registries in the same period by the SEER and NAACCR methods were 1.1% and 4.1%, respectively. Data show that the two methods are uncorrelated (y= 0.17) but significantly different (p< 0.001).

Conclusions: A significant difference between SEER and NAACCR methods indicates an underlying difference in their algorisms, assumption, purpose of utilization and application. One should be cautious while interpreting DC utilizing two different methods, and the difference hints a new method needed for measure a cancer registry's data quality.

Notes	Notes

IMPACT OF COMORBIDITIES ON TREATMENT CHOICE FOR COLON CANCER PATIENTS, LOUISIANA-CDC CER PROJECT

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Background: Planning treatment for cancer patients depends on tumor stage and grade, patient's age, life expectancy, health condition, and preference. Stage III colon cancer patients with comorbidities are less likely to receive adjuvant chemotherapy than those without comorbidity.

Purpose: To examine the relationship between treatment choice and comorbid condition(s) for stage I-III colon cancer. **Methods:** Stage I-III colon cancer cases, diagnosed in 2011, were obtained from the Louisiana Tumor Registry, one of the CDC Comparative Effectiveness Research (CER) Project participating registries. CER registries were required to collect detailed and timely treatment for breast, colorectal and CML cases diagnosed in 2011 and complete comorbidities for all cancer sites. The comorbidities selected in this study were diseases used in the Charlson comorbidity index (CCI) and were grouped to: no comorbidity, mild (CCI = 1), moderate to severe (CCI=2, 3, or 6), and two or more comorbidities. Treatment included surgery, radiation, and chemotherapy.

Results: 35% of eligible colon cancer patients had comorbid condition(s). Diabetes is the most common comorbidity (51%) followed by chronic obstructive pulmonary disease (24%) and congestive heart failure (15%). Over 97% of all patients received surgery and 99% of stage II/III patients received colon resection. Stage III patients received adjuvant chemotherapy were three-fold higher than stage II patients (67% vs. 21%); and only 1.5% of stage II/III patients received adjuvant radiation. Stage II or III patients with comorbidities, particularly with moderate to severe disease, were less likely to receive adjuvant chemotherapy than patients without comorbidities.

Conclusion: Primary site surgery is not affected by the patient's comorbid conditions and remains the main treatment choice for colon cancer patients. However, comorbidity does affect the decision for additional adjuvant chemotherapy for stage II/III colon cancer patients.

P-16

NAVIGATING THE REGISTRY-SPECIFIC APPROVAL PROCESS FOR A LONG-TERM DRUG SAFETY SURVEILLANCE STUDY

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Background: The Forteo Patient Registry Study was initiated in 2009. In this ongoing study, data from patients taking teriparatide who voluntarily enroll in the Registry are linked with data from participating state cancer registries annually to determine the incidence of osteosarcoma.

Objective: To describe the variation of state cancer registry approvals required for participation in this linkage study. Methods: Cancer registries in all 50 states and the District of Columbia were invited in May 2009 to participate in the study. Registries interested in participating provided information regarding necessary approval requirements (e.g., Institutional Review Board [IRB], Data Privacy Board, Registry, and Data Use Committee). RTI-HS collaborated with interested registries to submit all necessary applications for study approval. Results: In total, 41 state cancer registries expressed an interest in participating. For the first annual linkage in 2010, 27 registries had obtained all approvals and participated in the linkage. In 2011, 37 registries participated, and in 2012, 38 state cancer registries, covering 86% of the US population aged 18 years and older, participated. Applications are under review for the 3 registries not currently participating. We will describe the variation in the approval process (whether local IRB review is required, and if so whether it was expedited or full review, and what type of additional reviews were required), among the participating registries in this multiyear linkage study.

Conclusion: Cancer registry participation in postmarketing safety studies is critical for surveillance studies examining cancer outcomes. Understanding the process for engaging multiple cancer registries in these types of studies will be important for future researchers and cancer registries to maximize collaboration and timely conduct of studies.

Notes	Notes

VARIATIONS AMONG CANCER REGISTRIES IN ACCESSING PATIENTS FOR A DRUG SAFETY SURVEILLANCE STUDY

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Background: The Osteosarcoma Surveillance Study, a 15year surveillance study monitoring for a potential safety signal of a possible association between teriparatide (an osteoporosis treatment) and osteosarcoma in humans, was initiated in 2003. Multiple state, SEER regional, and comprehensive cancer registries are actively participating in this study.

Objectives: To describe the variety of patient access pathways, i.e., permissions required before a researcher can contact a potential study participant identified by the participating cancer registries, and the impact of each pathway on study interview completion rates.

Methods: In this study, incident cases of adult osteosarcoma diagnosed January 1, 2003, or later are identified through US cancer registries. Prior to contacting an eligible patient or his or her proxy regarding participation in the study, RTI-HS adheres to the required patient access pathway applicable to each cancer registry. Patient access pathways include a mix of initial contact by the cancer registry or RTI-HS and active permission versus passive notification of physicians and/or patients.

Results: We will describe the various patient access pathways required by the participating cancer registries. We will also provide results regarding the percentage of cases identified with contact information (and therefore eligible for telephone interview) among total cases identified and the interview completion rate for each patient access pathway and registry.

Conclusions: Postmarketing drug safety surveillance for a rare outcome such as osteosarcoma requires the participation of multiple cancer registries to be effective. However, the heterogeneity in requirements to gain access to patients for studies requiring patient contact presents unique challenges to the success of these collaborations.

P-19

USE OF DISCHARGE DATA TO SUPPLEMENT COMORBIDITY INFORMATION IN CANCER REGISTRIES: THE CALIFORNIA EXPERIENCE

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Background: Comorbid/complication fields are required to be abstracted from the medical record by ACoS approved facilities, but are not required to be transmitted to NAACCR. As a result, the California Cancer Registry has never consolidated nor evaluated these data items. However, one of the objectives of the NPCR Comparative Effectiveness Research (CER) project allowed California to evaluate the usefulness of enhancing comorbidity information with California's Office of Statewide Planning and Development (OSHPD) discharge data. **Objective**: To evaluate the usefulness of discharge data to supplement abstracted ICD-9 comorbid conditions from a patient's medical record.

Methods: California Cancer Registry cases were linked to California's OSHPD data files (Hospital, Ambulatory Surgery and Emergency Department) which each contained 25 ICD-9 diagnostic fields per patient admission/encounter. Based on the presumption of quality of data, codes were selected in priority order by the discharge file from which they originated: hospital discharge, ambulatory surgery, and emergency department records.

Results: Approximately 81% of all cancer sites linked to a discharge record on one of the three OSHPD files. The aggregation of all cancer sites had the highest match yield when linked to the hospital discharge dataset, 71%. The largest problem identified were the number of admissions/encounters that linked to a single patient; inpatient discharge (1-69), ambulatory surgery (1-83) and emergency encounters (1-238). *Updated results from the 2011 linkage, including the total yield of tumor records for which comorbidity information was added, will be presented.

Conclusion: Discharge data has proven to be an incredibly useful source to complement comorbidity data in central cancer registries. However, states would benefit from a national standard when attempting to consolidate these data.



DISPARITIES IN CERVICAL CANCER MORTALITY AMONG BLACK, NON-HISPANIC WOMEN IN MASSACHUSETTS

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Massachusetts; ²JSI Research and Training Institute, Inc., Boston, Massachusetts

Background: In Massachusetts, despite high rates of screening, Black non-Hispanic women are more likely to be diagnosed late for cervical cancer, and have the highest cervical cancer mortality rates compared with women of other racial or ethnic groups (2.5 per 100,000 for Black non-Hispanic women vs. 1.4 per 100,000 for White non-Hispanic women).

Purpose: To learn why the cervical cancer mortality rate for Black, non-Hispanic women is twice that of White non-Hispanic women, and why Black non-Hispanic women are diagnosed at later stages.

Methods: The MCR, BRFSS, Women's Health Network, and the Comprehensive Cancer Control program collaborated to prepare presentations on incidence, mortality and screening to illustrate cervical cancer disparities in Massachusetts. MDPH contracted with JSI Research and Training Institute to conduct a series of focus groups with consumers, providers and community leaders to explore and identify factors contributing to a late stage at cervical cancer diagnosis.

Results: Summaries of each focus group were written and analyzed from its unique perspective – consumer, community leader, and provider. The top three key findings included: 1) follow-up of medical care after an abnormal Pap test result is a significant challenge; 2) inadequate or no insurance coverage is a barrier to screening and follow-up; 3) constant changing of both treatment and screening guidelines cause confusion among patients and providers. The top final overall recommendations included 1) developing and implementing a cervical cancer education and awareness campaign 2) reexamining and assessing cervical cancer screening guidelines 3) improving patient-provider relationships.

Conclusion: Focus groups provided insight and identified barriers contributing to racial disparities in cervical cancer mortality rates among Black non-Hispanic women in Massachusetts. Results will inform cancer control efforts to reduce this disparity.

P-21

THE EPIDEMIOLOGY OF CHILDHOOD CANCER IN MASSACHUSETTS, 2000-2009

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Objectives: The purpose of this project is to present the epidemiology of cancer among Massachusetts children and adolescents (birth to 19 years old) from 2000-2009. **Methods:** Preliminary data were run on the ICD-O3 types of childhood cancer (leukemia, lymphoma, CNS tumors, sympathetic nervous system tumors, retinoblastomas, renal tumors, hepatic tumors, malignant bone tumors, soft tissue sarcomas, germ cell tumors, epithelial tumors, and other cancers)

Results: Leukemia, lymphoma, and CNS tumors represented a much higher percentage of childhood cancer cases compared with adult cancer cases. The highest percentages of leukemia, retinoblastomas, renal, and hepatic tumors were found in the 0-4 age group while the highest percentages of lymphoma, soft tissue sarcomas, germ cell, and epithelial tumors were found in the 15-19 age group. The number of diagnosed cases of childhood cancer types did not change much by year from 2000-2009. During this time period, white, non-Hispanics had a disproportionate percentage of CNS, sympathetic nervous system, and renal tumors compared to their percentage of the general 0-19 Massachusetts. Additionally, black, non-Hispanics had a higher percentage of renal tumors and Hispanics had a higher percentage of hepatic tumors.

Conclusions: Preliminary analyses indicated differences in age groups and race/ethnicity. Rates by year of diagnosis, race/ethnicity, sex, and age group will be compared. In addition, further analyses will be done comparing the histologies of the childhood cancers, such as lymphoid leukemia, myeloid leukemia, Hodgkin's lymphoma, non-Hodgkin's lymphoma, and the various types of brain tumors (ependymoma, astrocytoma, and glioma). Massachusetts data will be compared with national data as well.

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THYROID CANCER INCIDENCE TREND AMONG ASIAN AND PACIFIC ISLANDER WOMEN IN THE U.S.

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Background: Thyroid cancer incidence has been steadily increasing in the United States over the past 40 years. High incidence rates among Non-Hispanic White and Asian and Pacific Islander (API) women have been observed, however, within the API ethnic group, the trends in thyroid cancer incidence have not been well-addressed.

Objectives: To quantify national thyroid cancer burden among API ethnic group with new SEER API dataset and to investigate trends of thyroid cancer among API females.

Methods: We used the data from National Cancer Institute's Surveillance, Epidemiology, and End Results (SEER) program to obtain information on cases diagnosed during 1990-2008. Trends in thyroid cancer incidence for each Asian American (AA) group (Chinese, Filipino, Korean, Japanese and Vietnamese) were estimated by SEER registry, age, tumor stage, and size were estimated compared to Non-Hispanic White women. **Results:** Age-adjusted incidence rates of thyroid cancer were highest among Filipino (17.6 per 100,000) and lowest among Japanese (7.5 per 100,000) women from 1990-2008. The ethnic-specific rates varied across registries. Thyroid cancer rate peak around age 55-59 years among Vietnamese women and around age 65-69 years among Chinese women; Thyroid cancer rates increased sharply among women with localized stage disease compared to those with later stage across all ethnic groups.

Conclusions: The variation in thyroid cancer incidence and across AA groups and by tumor stage and size was intriguing. The geographical variation of thyroid cancer incidence might suggest socioeconomic variation across AA group; future studies on investigating differential socioeconomic influence among AA group should be explored.

P-23

GEOGRAPHIC VARIATIONS OF RACIAL DISPARITIES OF CERVICAL CANCER LATE-STAGE DIAGNOSIS IN TEXAS Y Lin¹

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Cervical cancer is the third most common cancer among women in the United States. Texas ranks the second in the estimated number of new cases of cervical cancer, accounting for 1080 new cases in 2012. There has been striking progress in the decrease of cervical cancer late-stage diagnosis rates. However, disparities still exist among different population groups. Few studies have examined how racial disparities in cervical cancer late-stage diagnosis vary spatially. This study investigated geographic patterns of racial disparities in cervical cancer latestage diagnosis in Texas based on data collected from the Texas Cancer Registry from 1995 to 2008. In addition, we considered the impact of socioeconomic status (SES), socio-demographic factors (immigration and language), socio-environmental factors, and spatial access to cervical cancer preventive services. We first used the population-weighted rate difference and rate ratio to measure racial disparities at the census-tract level, and then utilized logistic regression to analyze the associations between racial disparities and the factors mentioned above. Results suggest that there are significant geographic variations in the racial disparities of cervical cancer late-stage diagnosis. Females from census tracts with the lowest SES experienced higher cervical cancer late-stage diagnosis rate, with odds ratios of 2.89 (CI: 2.16-3.87) for African Americans and 2.34 (CI:1.78-3.06) for Hispanics. Furthermore, we observed significant associations between racial disparities and socio-demographic factors. Other factors, including socio-environmental factors and spatial access to preventive services, did not explain the racial disparities in late-stage diagnosis in this study. This study may help administrators develop more informed strategies to address cervical cancer disparities in Texas.

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CHILDHOOD CANCER RATES, AND RISK FACTORS: SPATIAL POINT PROCESS APPROACH

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In previous research, childhood cancer incidence rates have been positively linked to county-level crop intensity after controlling for the effects of other socio-demographic factors, e.g., population density or median household income. Although the findings are intriguing, the data analysis has important methodological limitations, including: a) the cancer incidence rates were aggregated by relatively large geographic units, e.g., within a county or census tract, and b) the analysis was conducted at one level, e.g., either at county or census tract level. Since these studies are ecologic in nature, ecologic bias cannot be ruled out, no definitive causal pathways can be established and risk estimates at the aggregate level may not reflect risk estimates at the individual level. We propose to adopt an integrated approach to overcome these pitfalls. The method is based on a spatial point process modeling approach and importantly, this spatial point process modeling method has the potential to generate causal hypothesis on an individual-level. The estimates obtained from this method can also be adjusted for the effects for multilevel and cross-classified covariates.

We applied the spatial point process models to Ohio childhood cancer incidences, and compared the findings with the area level analysis where separate areal models are fitted to the data aggregated at census tract level and county level. The results will be presented for each model and will discuss how the levels of aggregation impacted the estimates, which is commonly known as the modifiable areal unit problem (MAUP) in GIS, and how to overcome it.

Address data naturally form point processes in space and the modeling of such data is often either prohibited due to confidentiality restrictions on health records or because the models are less familiar to the practitioners. Whenever data permits, validating the results from ecological models for various levels of aggregation are recommended.

P-25

HOW SPECIAL PROJECT #1 CAN IMPROVE HISPANIC ETHNICITY DATA IN THE MISSOURI CANCER REGISTRY DATABASE

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Background: Although Missouri's Hispanic population remains relatively small (3.7% in 2010), it grew by a staggering 92% from 1990 to 2000 and has continued to increase. It also varies dramatically by region, being as high as 18.6% in Sullivan Co. Imputation of ethnicity for Missouri cancer cases is very sensitive to variations in the NAACCR Hispanic Identification Algorithm (NHIA) and casts a large degree of doubt on cancer incidence rates calculated for Hispanic Missourians. This is due to: 1) a high percentage of cases -- ranging from 14% to 27% by year -- in the Missouri Cancer Registry and Research Center (MCR-ARC) database with unknown ethnicity; and 2) the possible miscoding of a sizable proportion of cases as non-Hispanic rather than unknown. To conduct surveillance on this demographic, improvements are needed in the completeness and accuracy of Hispanic data in the database.

Purpose: To identify ways to improve quality of data on ethnicity in the MCR-ARC database.

Methods: Abstracts submitted to MCR-ARC are being analyzed to determine the facilities to focus on to improve Hispanic data. Additionally, a survey of facilities was conducted to determine the methods admission staff use to collect and report race and ethnicity.

Results: Initial analysis of facility abstracts shows that a fairly small number of facilities have a large number of excess abstracts missing ethnicity and are contributing a very large percentage of the cases in the MCR-ARC database with this field missing. Final results will be presented at the conference. Moreover, the survey indicates that many admission departments are collecting ethnicity based on observation rather than patients' self-identification.

Conclusions: Initial analysis of the facility abstracts indicates that MCR-ARC may be able to focus its resources efficiently with reabstractions audits at specific facilities and by providing training to facility admission staff on the collection of these data.



Poster Sessions

P-26

EVALUATING AND ADDRESSING THE NEEDS FOR CENTRAL CANCER REGISTRY (CCR) DATA COLLECTION

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Introduction: In recent years, many changes/elements have been introduced to the CCR data collection process. Changes and complexity have led to missing/incomplete data elements; delays in responding to research requests; and a decrease in quality. CCR data collection includes, at a minimum, data on demographics, tumor characteristics and treatment from diverse sources. A common, identified and standardized set of data elements is needed to make data available quickly and efficiently for public health, surveillance and research.

Purpose: Develop and administer a questionnaire for CCRs to identify data needs and barriers.

Methods: We conducted a systematic review of the literature; looked at long-term and new required data elements; and developed a questionnaire for CCRs. The instrument contained eight topic areas: research; data collection; database; use of data; additional data items; data requests; new data fields; and CCR data set.

Results: 43 of 51 CCRs (84%) responded. CCR data are used for public health surveillance (100%) and research (96%). Data are available online in interactive tables for over 50% of CCRs; 87% have more than 10 years of data available. CCRs report that treatment data are not complete but are of high interest to data requestors. Over 70% report there are too many required data elements.

Discussion/Conclusion: Cancer registration is a rapidly changing field. Basic questions remain: What data elements are needed for what purpose and what are the common elements? By constantly adding data elements, are we getting too specific versus complete? Can treatment data be of value if the fields are incomplete? Data that are collected by CCRs are most beneficial for data analysis and research, public health, and surveillance when data are accurate, timely and complete. Cancer registries have data available for use but need to review what data are needed/used and build collaborations/partnerships to connect common interests and increase accessibility.

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P-27

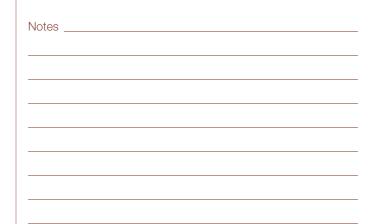
FINDINGS FROM THE 2011-2012 NAACCR DEATH CLEARANCE EVALUATION WORKGROUP ISSUES SURVEY

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Background: In June 2009 the Death Clearance Issues Workgroup, as part of the NAACCR Registry Operations Committee was charged by the NAACCR Board to assess the impact of the changes resulting from a soon-to-be released "July 2009 Death Clearance Manual." The Board requested that implementation of the minimum requirements document would occur for 2010 deaths, as part of the 2012 Call for Data, and that an assessment would assist in addressing concerns expressed by some of the membership over the additional requirements. Purpose: Subsequently, the Death Clearance Evaluation sub-group formed, to 1) identify which of the changes in the death clearance minimum requirements were in most need of evaluation, and 2) determine the methods used to evaluate them. The Death Clearance Issues Workgroup provided an initial table of questions and concerns for consideration gathered from comments by workgroup and other NAACCR membership, both anecdotally, as well as through a March 2010 "Q&A Session for Death Clearance Webinar."

Methods/Approach: After receiving additional feedback from the NAACCR Registry Operations Committee, NAACCR Board, and the North Carolina Registry who completed the evaluation as a pilot, the request to complete the NAACCR Death Clearance Evaluation was sent March 2011, with a due date of no later than the end of September 2011. Due to a lack of response, the evaluation deadline was extended to December 2011, and eventually April 2012.

Results: This presentation will provide an overview of survey responses from 18 NAACCR population-based cancer registries. The participating registries included Alaska, Detroit, Florida, Greater Atlanta, Greater Bay, Idaho, Kentucky, Louisiana, Massachusetts, Montana, North Carolina, New Hampshire, New Mexico, New York, Pennsylvania, Utah, and Texas. **Conclusions**: The 18 NAACCR registry responses provided helpful insight into current challenges, progress, and future direction for the Death Clearance Process.



IMPROVING THE QUALITY OF CANCER INCIDENCE DATA FOR NATIVE AMERICANS IN MICHIGAN USING TRIBAL LINKAGES

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National studies have shown cancer incidence and mortality for Native Americans to be underestimated due to racial misclassification in medical charts. The Michigan Cancer Surveillance Program links with data from two sources to address this problem. Cases in the state registry are linked annually to Indian Health Service (IHS) records. In addition, the Michigan registry has been linked to rosters of five Michigan tribes, and the IHS, increasing the number of known Native American cases in the statewide registry. The IHS link contributes 2/3 of these cases with the tribal roster links uniquely contributing the remaining 1/3 of the misclassified cases. Analyses of the linked data identify patterns in the Native American incidence rates that might otherwise go undetected. Of particular concern, although Native American women had a much lower incidence rate for early stage breast cancer (in situ + localized) as compared to white females, the rates for late stage (regional + distant) were similar. Native American cases for this cancer peaked at ages 50-54, while white cases showed a peak at ages 70-74. Additionally, the percentage of pre-menopausal cases varied, from 22.2% for white to 36.5% for Native Americans. For both breast and colorectal cancer, Native Americans were diagnosed at younger ages than the age that recommended screening should begin. This raises concerns about access to care, and the need for improved treatment and prevention programs focusing on the at-risk population. Presenting data on the linked data set and working towards a goal of linking to more rosters for Michigan's 12 federally recognized tribes, will provide further clarity on disparities in cancer incidence and mortality among Michigan's Native Americans.

P-29

BREAST CANCER MULTIPLE PRIMARY AND HISTOLOGY DATA QUALITY AND ITS IMPACT ON CANCER INCIDENCE AND SURVIVAL

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Background: SEER MPH manual became effective in 2007. There is a need to review the MPH data quality before and after the effective date to show the usage of variables affecting correct MPH case reporting, establish a method for identifying potential incorrect MPH records, and explain correct use of MPH records in survival statistics.

Methods: A total of 400,644 patients with breast cancer diagnosed between 2004-2009 were retrieved from the SEER18. Cases were stratified by sequence number, number of breast cancer, number of other cancers and year of diagnosis. All patients with three or more breast cancer records were identified and evaluated based on variables using T and M stages (AJCC 6th edition), treatments, and MPH timing rules. *Kaplan–Meier* analysis was conducted to compare the breast cancer survivals among the four groups: single primary, single and first primary combined single, first and second primary, and combined all breast cancer records.

Results: The overall MPH rate is 109.4%, and the breast cancer-specific MPH rate is 104.3%. Comparing the 3-year period, before (2004-2006) and after (2007-2009), MPH manual effective date, the rate of single primary, first primary and second primary breast cancer changed 111.1%, 68.7%, 124.9% and 151.8%, respectively. 32.8% cases with 3 or more breast cancer primaries, and 521 records (58.8%) seemed problematic based on the timing rule, histology, T and M stages, and treatments. The 5-year overall survivals between the above four groups were significantly different.

Conclusions: The breast cancer MPH reporting rates changed in the 2007 manual. Greater than 50% of cases with 3 or more breast cancer primaries are problematic and should be verified. In addition to the MPH manual, variables indicating advanced staging and treatment should be used for correct MPH reporting. The finding from this study also indicates a need of a MPH data use guideline for researchers to correct use MPH cases in cancer survival analysis.



"WHERE ARE YOU FROM?": AN EFFORT TO DECREASE THE PERCENTAGE OF COUNTY UNKNOWN IN PUERTO RICO

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Background: As a Registry supported by CDC's **National Program of Cancer Registries (NPCR)** we must meet certain standards and generate the Call for Data (CD) report. NPCR evaluates the quality of various data items submitted including the percentage of County Unknown (CU). Historically, in the Puerto Rico Central Cancer Registry (PRCCR) we have long been aware of the high proportion of our cases with CU. Although Puerto Rico (PR) is a small island, it has 78 counties. For 2008, 2009 and 2010 the percentage of CU was 4.65, 8.95 and 9.92 respectively. One important goal in order to meet the NAACCR Silver Certification is to find a source that allows us to decrease the percentage of CU in the future. **Objective:** To recover cancer patients' county information from different sources in order to decrease the percentage of CU for the 2010 CD.

Methods: Public and private Insurance Companies (IC) were approached to share their databases with PRCCR's. Some IC accepted to collaborate with us, establishing an unprecedented event in the PRCCR. The cancer data was linked with insurers' administrative databases using the probabilistic match procedure of the CDC's Link Plus software. This effort was complemented when direct communication with hospitals and physicians was established to explain them the PRCCR's Law and the importance of timely data. Also we generated exclusive lists to them which contained the patients whose county information was missing. The lists were distributed via fax and/or via encrypted email. The information was acquired through the source of preference of an authorized contacted person. Results/Conclusion: The percentage of CU for 2010 was decreased from 9.92 to 2.75 in two months. Future collaborations will be kept with PR's public and some private IC as well as with the hospitals and physicians in order to achieve acceptable level of this important parameter and optimize the overall PRCCR's data flow for the years to come.

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DEMOGRAPHIC DISPARITIES IN PROSTATE CANCER: DIAGNOSIS CONTEXT, PROGNOSTIC FACTORS, AND THE PROPENSITY FOR SURGICAL TREATMENT

<u>S Negoita</u>,¹ M Dunn¹ ¹Westat, Rockville, MD

Background and Purpose: Age and race disparities have been described for Prostate Cancer (PCa), with higher incidence and mortality reported for African Americans (AA). Early disease detection by PSA screening has been encouraged before year 2011 by most health organizations. Most cases are diagnosed because of symptoms. However, a sizable proportion of cases have been diagnosed after screening or incidental to prostate resections for benign disease. Treatment recommendations are guided primarily by recurrence risk and expected survival. There is no clear advantage of surgical treatment over other modalities and proportionally fewer AA receive surgery. Since radical prostatectomy is not an option for patients with incidental diagnosis, and surgery is not recommended for certain recurrence risk categories, in PCa the propensity for surgical treatment might be affected by factors other than the classical disease stage and comorbidity. This study will investigate to what extent demographic disparities in PCa surgical treatment can be explained by demographic patterns in the distribution of diagnosis context and of recurrence risk.

Approach and results: To measure the propensity for surgical treatment, investigators will develop clinical case scenarios using Collaborative Staging data, one scenario for each valid combination of diagnosis context (screening, incidental, symptomatic) and recurrence risk. Each PCa patient in the SEER Public Use data set diagnosed between 2004 and 2009 (except cases with unknown surgical treatment) will be assigned to the corresponding clinical case category. Not all clinical scenarios have recommendation for surgery. The total number of cases with recommendation for surgery will be calculated and contrasted with the observed number, by race and other demographic categories.

Implications: Propensity for surgical treatment might vary across certain demographic groups, and should be adjusted for when measuring treatment disparities.

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CANCER INCIDENCE RATES IN THE CHEROKEE NATION

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Background: The Cherokee Nation Cancer Registry (CNCR) has participated in the National Cancer Institute's Surveillance, Epidemiology, and End Results (SEER) Program since 1997. Methods: The investigators utilized existing records in the population-based CNCR to characterize cancer incidence rates for residents of the Cherokee Nation of Oklahoma. The study included incident cases of malignant neoplasms that were diagnosed among residents of the CNCR area of coverage during the time period 1999-2008. Rates of non-Hispanic white residents of nine core areas of the SEER Program during the same calendar time period were calculated for comparison purposes. Average annual age-adjusted incidence rates per 100,000 were calculated by the direct method using the United States 2000 standard population. Ninety-five (95) percent confidence intervals for incidence rates were calculated using the Tiwari adjustment.

Results: Overall incidence rates for Cherokee Nation (All cancers-combined; Rate=430.3 per 100,000; 95% Confidence Interval (CI)=417.0-443.9) were lower than observed among non-Hispanic white residents in nine core areas of the SEER program (Rate=495.3; 95% CI=494.3-496.3). Breast cancer was the leading cancer among Cherokee women, followed by lung cancer and colorectal cancer. Prostate cancer was the leading cancer for Cherokee males, followed by lung cancer and colorectal cancer. Incidence rates for lung cancer were higher in the Cherokee Nation (Rate=81.0; 95% CI=75.2-87.0) than among SEER non-Hispanic whites (Rate=65.3; 95% CI=65.0-65.7).

Conclusions: Overall cancer incidence rates in the Cherokee nation were slightly lower than among SEER Program non-Hispanic whites. However, high lung cancer incidence rates indicate that tobacco control is an important priority in the Cherokee Nation.

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USE OF A GIS TO ANALYZE DISPARITIES IN CERVICAL CANCER INCIDENCE IN NEW JERSEY

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Background: Although cervical cancer incidence and mortality declined in New Jersey (NJ) during the past three decades, over 400 women were diagnosed with and 120 women died of cervical cancer annually during 2005-2009. Nearly all invasive cervical cancer can be prevented by HPV vaccination and PAP screening. We used a GIS to ascertain geographic and socioeconomic patterns in cervical cancer incidence and stage. **Methods:** Spatial clusters of cervical cancer incidence rates and percent late stage at diagnosis in 2005-2009 among NJ women age 20 and older (N=2105) were ascertained using the Poisson model in SATScan software. U.S. Census American Community Survey 2005-2009 population estimates were used for the incidence rates and to characterize the geographic areas of significant clusters. Incidence rates were age-adjusted using three age groups (20-44, 45-64, 65+).

Results: Two significant incidence clusters were found, one each in northeastern (n=302, RR=1.6, p<0.0001) and northern (n=63, RR=1.91, p=0.042) NJ. No significant clusters of late stage cervical cancer were found. Higher percentages of cervical cancer patients in the two clusters were black, Hispanic, unmarried and uninsured compared with the rest of New Jersey. Also, the percent of cases diagnosed in the late stage (regional and distant stages) was higher in the northeastern cluster. **Discussion:** The results will assist the statewide cancer prevention and control program to identify high risk areas and populations as well as help community and other groups working on cervical cancer prevention in the two cluster areas.

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TRENDS IN HEPATOCELLULAR CARCINOMA INCIDENCE AMONG NON-HISPANIC WHITE, HISPANIC AND AMERICAN INDIAN RESIDENTS OF NEW MEXICO, 1981-2009

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Background: In New Mexico (NM), hepatocellular carcinoma (HCC) is a leading cause of cancer incidence and mortality, particularly among Hispanics and American Indians. HCC is closely associated with chronic hepatitis B and C infection. **Purpose**: This investigation was designed to characterize time trends in HCC incidence rates among NM's three largest racial/ ethnic groups: American Indians (AI); Hispanics (H); and non-Hispanic whites (NHW).

Methods: Eligible subjects were identified from existing records in the population-based NM Tumor Registry, a founding member of the National Cancer Institute's Surveillance, Epidemiology, and End Results Program. The study included incident cases of HCC (International Classification of Diseases for Oncology-Third Edition anatomic site code C20.0 and histology code 8170/3) diagnosed among NM residents from 1981 to 2009. Ageadjusted incidence rates were calculated by the direct method using the United States 2000 standard population. Ninety-five percent confidence intervals for incidence rates were calculated using the Tiwari adjustment. Temporal trends in incidence rates were assessed with joinpoint regression techniques.

Results: The average annual age-adjusted incidence of HCC in NM varies by race/ethnicity (AI=6.2, H=6.2, NHW=2.3 per 100,000). HCC rates increased during the study period in all 3 groups. The greatest annual percent change (APC) was observed among H (APC=5.1, p=0.00) and NHW (APC=4.7, p=0.00). Modest increases in HCC incidence rates among AI were not statistically significant (APC=1.4, p=0.32).

Conclusions: HCC rates remained high among Al during the study period, but their rate of increase was not as great as H and NHW. H are now poised to surpass Al with the highest HCC rates in NM. Culturally-sensitive programs have been effective in reducing the burden of hepatitis in NM. The result of these programs should show a corresponding reduction in HCC incidence in the future.

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USEFULNESS OF COLLABORATIVE STAGE (CS) SITE SPECIFIC FACTORS (SSF) 3, 4, 5 AND 6 IN DESCRIBING SHORT-TERM MORTALITY RISK DISPARITIES FOR TYPE II ENDOMETRIAL CANCERS IN METROPOLITAN DETROIT F Vigneau,^{1,2} M Cote^{1,2}

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Background: SEER began collecting Site Specific Factors (SSF) 3-6: # of positive pelvic nodes (PNP), # of pelvic nodes examined (PNE), # of positive para-aortic nodes (PANP) and # of paraaortic nodes examined (PANE) in 2010. Two years incidence data were collected by the Detroit SEER Program. SEER also collects # regional lymph nodes examined (RLNE) and # positive (RLNP). Type II endometrial cancers have poor short-term prognosis and occur at greater proportions in African Mercian women (AA). **Purpose:** To examine the presence of complete data collection for SSF 3-6 and evaluate racial mortality risk disparities to determine usefulness of these variables.

Methods: Incident Type II endometrial cancers in Caucasian (C) and AA women in Metropolitan Detroit diagnosed 2010-2011 with Primary Site=C54.1 and Histology Type: 8310, 8441, 8460, 8461, 8050, 8070, 8071, 8072, 8560, 8041 and 8323 were included, for n=225 cases, n=161 (72%) C and n=64 (28%) AA. Frequencies for each SSF, RLNE and RLNP were performed to examine whether each variable had a defined value. Two Cox proportional hazards modeling risk of death were generated, adjusted by Race, Age, SEER Summary Stage, Surgery (Yes/No), Radiation (Yes/No), Chemotherapy (Yes/No), RLNE (Yes/No) and RLNP (Yes/No), with the second model also adjusted by PNE, PNP, PANE and PANP.

Results: Unknown values were: PNE (4%) and PANE (5%) compared to RLNE (2%); PNP (33%) and PANP (52%), compared to RLNP (33%). PNE were done for local (66% C, 74% AA), regional (78% C, 74% AA) and distant (42% C, 46% AA) stage and PANE for local (37% C, 63% AA), regional (70% C, 65% AA) and distant (12% C, 15% AA) stage. Small #s for SSF 3-6 made assessment of racial mortality risk disparities difficult (Final Model HR: 1.54, 95%CI: 0.75-3.13).

Conclusion: Large proportions of PNP and PANP were unknown, making significance testing and interpretation difficult, but where present PNE and PANE are done as frequently for AA as Ca, by stage.



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ASSOCIATION BETWEEN PARTICIPATION IN A POPULATION-BASED BREAST CANCER STUDY AND CLINICAL AND SOCIOECONOMIC FACTORS IN THE NEW JERSEY STATE CANCER REGISTRY

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The Women's Circle of Health Study-1 (WCHS) is a populationbased case-control study in New Jersey and New York City designed to evaluate risk factors for early/aggressive breast cancer. As part of the study. African American (AA) and white women diagnosed with breast cancer during 2005-2011 and residing in seven NJ counties were identified through rapid case ascertainment by NJ State Cancer Registry (NJSCR) staff. Data collection involved in-person interviews and collection of saliva samples. To evaluate whether the study participants differed from the general eligible case population, 1093 NJ breast cancer patients who participated in the study were compared to all NJSCR breast cases meeting eligibility criteria from the same area. Univariate statistics were used to compare demographic and clinical characteristics between the groups, stratifying by race. The study participants were significantly younger than the total case population among both AA and white patients (p<0.0001). Among white women, census tract poverty level (CTPL) was significantly different between the participants and the case population, with a higher proportion of participants residing in the wealthiest census tracts (71% vs. 61%). CTPL was not significantly different between AA participants and the AA case population. The distribution of stage at diagnosis differed significantly between AA participants and all AA cases, with a higher proportion of local stage (47% vs. 39%) and lower proportion of distant stage cancers (3% vs. 9%) in the participants. A similar association among white patients was observed, but was of borderline significance. In terms of other clinical factors, the WCHS participants had a significantly higher proportion of estrogen receptor positive and progesterone receptor positive tumors than the eligible case population. These findings may help in the interpretation of results from WCHS analyses, as well as help formulate better recruitment strategies in future studies.

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COLONOSCOPY AND SIGMOIDOSCOPY IN MEDICARE POPULATION WITH COLORECTAL CANCER (CRC) – SCREENING OR DIAGNOSTIC USE

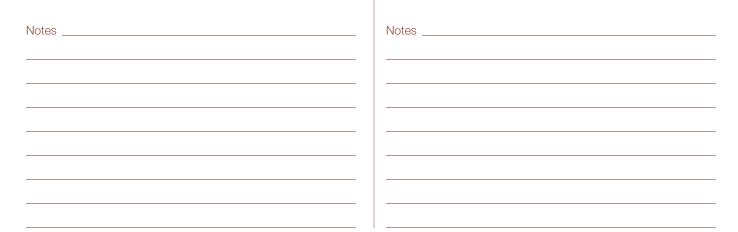
SM Lai,¹ J Jungk,¹ S Garimella¹ ¹University of Kansas Medical Center, Kansas City, KS

Relatively few data are available on the use of FOBT, colonoscopy, and sigmoidoscopy among individuals who have been diagnosed with CRC at state level. We examined use of these tests in KS Medicare beneficiaries with CRC in 2008. Indications on use of these tests within one year prior to the CRC diagnosis were also examined. Urban and rural differences were also described.

CRC cases were identified from the Kansas Cancer Registry while use of FOBT, colonoscopy, and sigmoidoscopy was obtained from linked Medicare MEDPAR, Outpatient and Carrier claims files. For this study, we included CRC cases diagnosed in 2008 that were continuously enrolled in Medicare fee-for-service Part A and B for at least one year prior to diagnosis. Appropriate CPT, HCPCS and ICD-9-CM codes were used to identify use of FOBT, colonoscopy, sigmoidoscopy and CRC-related symptoms.

Preliminary analysis showed 571 of the total 1,428 invasive CRC diagnosed in 2008 were linked with the Medicare data and met the enrollment criteria for the study. This cohort included 55% female, 4.2% non-white, 2% Hispanics, and 12% being lowincome. The median age was 77. In this cohort, 409 patients (72%) had at least one endoscopy or FOBT claim prior to or at diagnosis. Of these, 82 patients had a benign CRC diagnosis documented in the year prior to invasive CRC diagnoses and 346 had CRC-related symptoms documented at diagnosis or in the 90 days prior. Only 47 patients had neither a non-invasive diagnosis nor CRC-related symptoms. Patients ages 85+ years and patients living in metro counties were less likely to have colonoscopy/sigmoidoscopy/FOBT documented in the year prior to or at diagnosis. Patients with endoscopy/FOBT in the year prior to or at diagnosis had an earlier stage at diagnosis than those without. Stage at diagnosis was similar across urban/rural settina.

Colonoscopy, sigmoidoscopy, and FOBT were commonly used, but a high percentage of them may potentially be diagnostic rather than screening.



OPIOID ANALGESIC USE AMONG NOVA SCOTIA (NS) CANCER PATIENTS AT THE END OF LIFE: RESULTS FROM A POPULATION-BASED STUDY

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Background: Pain is common among persons with cancer. Opioid analgesics are the mainstay of pharmacological therapy for moderate to severe pain because they are cheap, effective and easy to administer. The systematic analysis of population-level data on opioid use by cancer patients is limited in North America, however, NS has datasets that can support such analysis.

Study Objective: The study population includes all NS residents diagnosed with cancer from 1991 onward and living in NS during the period 2005 – 2010 who died between July 1, 2006 and December 31, 2010. The objective is to describe the prescription of opioid analgesics to these cancer patients at the end of life (EOL) period in the disease trajectory.

Methods: Opioid use by NS cancer patients was studied by linking data from two provincial health datasets: the NS Cancer Registry (NSCR); and the NS Prescription Monitoring Program (NSPMP) database. Univariate and multivariate analyses were used to describe drug use patterns at EOL, including number of prescriptions, morphine-equivalents/day, and time from chronic opiate use to death. Covariates included age group, sex, urban or rural residence, cancer type, and survival prognosis.

Results: Among the EOL subgroup (n=5,698), 80% of prescriptions were for strong opioids, 18% for weak opioids, and 2% for other opioids. Variations in opioid use were observed both in terms of morphine-equivalents/day and duration of chronic treatment among younger patients and those with poorer prognosis cancer types. No differences were apparent by sex or place of residence.

Conclusions: This study is the first of its kind in NS and provides a baseline understanding of the use of opioid analgesics among the NS cancer population at the EOL. This information can be used by CCNS and its stakeholders to identify focus areas for improving cancer pain management and allow exploration of areas that may benefit from ongoing monitoring.

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INCIDENCE OF BRAIN METASTASIS AT INITIAL PRESENTATION OF LUNG CANCER

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Background: No reliable estimates are available on the incidence of brain metastasis (BM) in cancer patients. This is of value in planning for patient care and in working toward measures to prevent or decrease the likelihood of metastatic disease.

Purpose: To analyze the first mandatory population-based reports on incidence of BM at diagnosis.

Methods: The Kentucky Cancer Registry (KCR) is an NCI SEER and CDC NPCR registry and in 2010 the Collaborative Stage Work Group (CSWG) of the American Joint Committee on Cancer required implementation of the Collaborative Stage Data Collection System version 02.03.02 (CSV2). This was also used in Alberta Cancer Registry (ACR). This required detailing sites of metastases at diagnosis, including brain. Lung cancer cases were broken down using the AJCC 6 staging system.

Results: In 2010 KCR recorded 529 total cases of BM with lung 463 (87.5% of cases) and in ACR of the top five cancers having BM 89% was lung primary. Mandatory recording has increased the number of cases at diagnosis by greater than 70% and over 5-fold from the previous year. ACR did not have an increase. Stage IV was the most common stage at presentation for both registries, 45-50% of cases. The percentage of cases having brain involvement (21-26% of stage IV lung) as well as bone (34-38%) and liver (25-29%) were similar in both registries.

Conclusion: Mandatory recording of BM for newly diagnosed cancer significantly increased the incidence in the KCR, but not for ACR. BM from lung cancer dominates the incidence at initial diagnosis for both registries. Informal analysis demonstrates data from Kentucky and Alberta for BM from lung cancer were similar, with complete data collection for 2010 and near-complete for 2011. Ten percent of all lung cancer presented with BM or slightly above 20% of stage IV. More research is needed for epidemiological studies in BM and offers the potential to impact clinical care.

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CAPTURING, STORING, INTEGRATING AND USING ELECTRONIC HEALTH RECORD (EHR) DATA AT A CENTRAL CANCER REGISTRY (CCR)

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Background: Healthcare entities that participate in Healthcare Information Exchanges (HIEs) need to prepare for expanded security and information environments. With the American Recovery and Reinvestment Act of 2009 (ARRA), HITECH (Information Technology for Economic and Clinical Health) requires more than the mandated transition to the EHR; standardization, interoperability and data exchange must move from abstract concepts and become reality. The EHR allows for real-time data sharing but presents challenges: interoperability of data elements and formats, need for data storage; data quality assurance; and record consolidation issues.

Purpose: Describe steps taken by the Missouri Cancer Registry and Research Center (MCR-ARC) to receive, process and incorporate EHR data while maintaining the quality and security of all CCR data.

Methods: We reviewed MCR-ARC's existing data processes/ data storage to identify potential problems and plan for large amounts of EHR data to be received, processed and stored. Questions that were asked and answered included where the large amount of incoming data could be stored securely; the cost to store and back up the increased volume of data; software to be utilized to import and process the incoming records so that multiple entries for an individual are combined into a single record; when and how an ERH record will be imported into the main CCR database for editing and possible consolidation; and what will be done with records deemed incomplete by CCR and national standards.

Results: How incoming data are being received, processed, stored and imported into the main CCR database will be presented.

Discussion/Conclusions: Receiving, processing and storing large amounts of data being streamed from a variety of EHRs has presented many challenges but has led to capture of previously unreported cancer cases. We will describe solutions and discuss issues yet to be resolved.

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COLLABORATION IN CALIFORNIA: FROM AUDITS TO TRAINING - THE STORY OF THE PROSTATE PROBLEM K Ziegler¹

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The California Cancer Registry (CCR) conducted a recoding audit of prostate cases. The results of the audit were concerning and education was warranted. In order to ensure the audit finding were not an anomaly, a plan was developed to conduct a mini-reliability study that utilized Survey Monkey to test how registrars would code the cases in real time. The mini reliability study was conducted with assistance of the California Cancer Registrars Association (CCRA). The results of the mini-reliability study were analyzed and demonstrated the same problems that were identified in the prostate audit. The results were published on the CCR and CCRA websites. The CCR along with the regional registries in California developed training modules that were presented at regional registry hosted QC meetings and CCRA meetings around the state. The ability to utilize the state cancer registrar association when developing and conducting this training was demonstrates the usefulness in pooling together resources to develop statewide training.

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The United States Cancer Statistics: 2009 Incidence and Mortality report (USCS) combines data from all states and the District of Columbia on cancer incidence (newly diagnosed cases) from the CDC's National Program of Cancer Registries (NPCR) and the NCI's SEER and cancer dealths from CDC's NCHS to produce official federal statistics on cancer incidence and mortality. The current year report provides statespecific and regional data for cancer cases diagnosed in 2009, the most recent year for which incidence data are available. Methods: Data on new cases of invasive cancer diagnosed during 2009 were obtained from population-based cancer registries affiliated with the NPCR and SEER programs, and submitted to CDC or NCI by November 2011. This report covers 98% of the US population. Statistics are reported for 68 primary cancer sites and subsites for men, and 72 primary cancer sites and subsites for women. The childhood cancer ection includes incidence among children aged 19 years or younger.

Results: For 2009, 1,476,504 cancer cases were diagnosed (757,545 in males and 718,959 in females). The age-adjusted incidence rate was 459 prer 100,000 (524 in males and 414 in females). Overall cancer incidence rates were highest among black males and white females.

Prostate cancer is the most common cancer among all men. Lung cancer is the second among all groups except Hispanic men, where it is third. Colorectal cancer is third among all groups except Hispanic men, where it is second.

Breast cancer is the most common cancer among all women. Lung cancer is second among Asian/Pacific Islander and Hispanic women and third among all other groups.

Conclusion/Implications: Pooled cancer incidence data at the national, regional, and state levels help federal and state public health officials monitor trends and respond to reports of suspected increases in occurrence, develop reseach hypotheses, allocate health resources, and plan and evaluate the impact of cancer control programs.

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IMPROVING COMPLETENESS OF ADJUVANT THERAPY DATA BY A LINKAGE WITH AN ELECTRONIC PRESCRIPTION DATA - LOUISIANA TUMOR REGISTRY'S EXPERIENCES

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¹Louisiana Tumor Registry, New Orleans, LA; ²Health Policy & Systems Management Program, LSUHSC, New Orleans, LA

Background: Population-based cancer registries do not have complete data on adjuvant therapy due to inadequate resources. Thus seeking more cost-effective way to capture such information is always the goal of Louisiana Tumor Registry (LTR). The objective of this study was to link registry data with an electronic prescription data to capture information on adjuvant therapy and assess the effectiveness of this linkage by comparing information capture with a pattern of care study. **Methods:** We linked LTR data with the electronic prescription (E-prescription) data from the Healthcare Services Division (a public hospital system) for breast and colorectal cancers diagnosed in 2010 and 2011. Identification of chemo and hormonal therapies were based on a list of chemo and hormonal drug from website http://www.chemocare.com/, sponsored by the Scott Hamilton CARES. Information on adjuvant treatment for 2010 cases was from registry routine abstraction whereas information for 2011 cases was obtained from the CDC-NPCR funded CER project.

Results: We found that 22% of 2010 breast and colorectal cancer cases without chemo/hormonal information in registry database actually received chemo and/or hormonal therapy based on E-prescription data. In contrast, only 1.4% of 2011 breast and colorectal cancer cases without chemo/hormonal therapy in CER project database received these therapies based on E-prescription data.

Conclusions: Linkage of registry data with e-prescription data is a cost effective way to capture complete information on adjuvant therapy.

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OVERVIEW OF NATIONAL PROGRAM OF CENTRAL CANCER REGISTRIES (NPCR) DATA LINKAGES WITH BOTH PUBLIC AND PRIVATE DATA SOURCES FOR IMPROVING DISEASE CONTROL AND PREVENTION

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Background: NPCR Central Cancer Registries (CCRs) commonly conduct linkages with a wide range of private and publicly available databases. NPCR-funded registries are required to perform certain linkages. These linkages assist in identifying missing cancer cases; supplement the registry with missing data such as race and ethnicity; and allow for the study of comorbidities, survival, and disparate issues among special populations. Utilizing multiple sources of information on the same event may permit cross-validation to improve data accuracy. Data linkage is a funding requirement for all of the NPCR-funded programs and it provides an opportunity to enhance NPCR registries' relationships with outside programs.

Purpose: To facilitate data linkages to improve the quality and richness of CCR data. Linked data from multiple databases are a valuable resource in cancer surveillance and in the evaluation of factors influencing cancer trends and quality of care.

Methods: Provide an overview to approach data linkages that will take advantage of existing publically available publications. Linked data from multiple databases are a valuable resource in cancer surveillance and in the evaluation of factors influencing cancer trends and quality of care. These linkages greatly expand the availability and richness of cancer registry data on a variety of health-related issues that can be examined. Investigators may link databases to examine changes in patterns of carcer, the use of cancer tests and procedures, and the costs of cancer treatment, as well as to enhance case finding and follow-up for persons with cancer.

Results: NPCR CCRs are encouraged to use data linkages with a wide range of private and publicly available databases to decrease the cost of data collection and increase timeliness of reporting.

Conclusions: Investigators should be encouraged to link databases to examine changes in patterns, especially those that enhance case finding and follow-up for persons with cancer.

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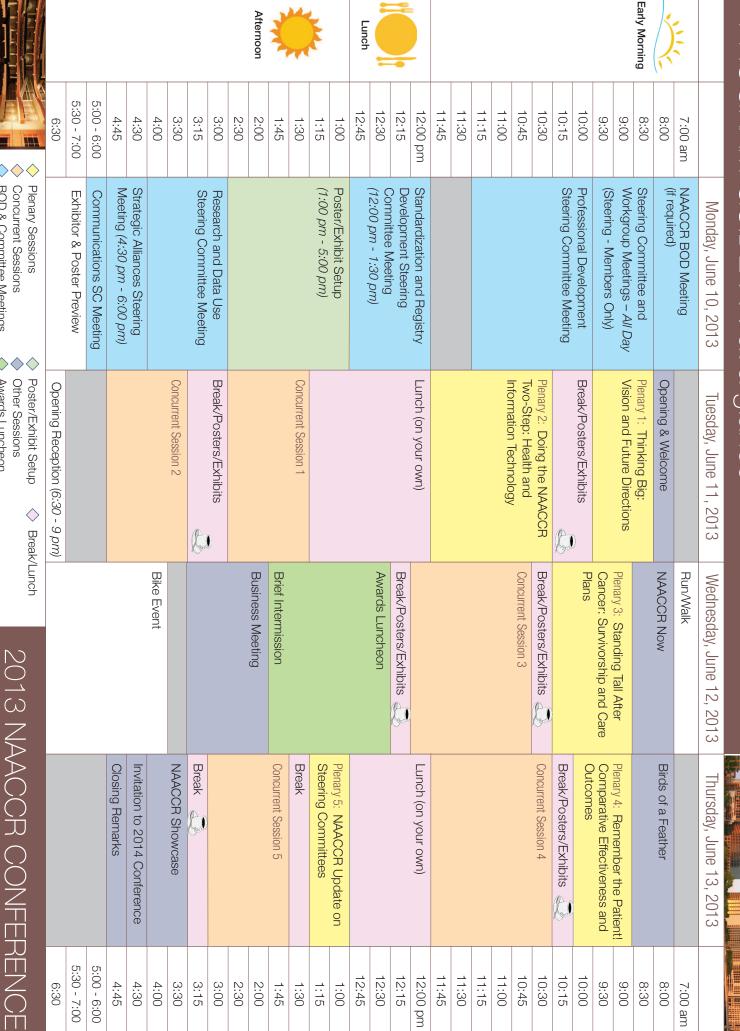
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