NAACCR 2011 CONFERENCE **final program**





Cancer Surveillance: Keeping Pace with Policy, Science, and Technology

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

Louisville, Kentucky June 18 - 24, 2011

Hyatt Regency Louisville and Kentucky International Convention Center





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Grant Information



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Exhibitor

WESTAT 1600 Research Boulevard, Room TB336, Rockville, MD 20850 United States Tel: 301-738-3557 Contact: Marsha Dunn Email: marshadunn@westat.com

Westat



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Welcome to NAACCR 2011





Welcome to Louisville!

On behalf of the NAACCR Board of Directors and the Scientific Program Committee, we welcome you to Louisville, Kentucky, the host city of the 2011 Annual Conference of the North American Association of Central Cancer Registries (NAACCR).

The Program Committee has set out to develop a highly informative, innovative, and inspirational agenda for this year's conference participants. The theme for the 2011 NAACCR Conference is "*Cancer Surveillance: Keeping Pace with Policy, Science, and Technology.*" The goals of this conference are to explore how public health policy, advances in medical science, and health information technology have an impact on cancer surveillance; and how cancer surveillance activities inform public policy and contribute to advances in the science of cancer care and cancer control.

The plenary sessions will commence with a health policy panel featuring three renowned international speakers discussing how cancer surveillance contributes to wellinformed public policy decisions. The first speaker is Dr. Howard Koh, Assistant Secretary for Health in the U.S. Department of Health and Human Services. He will outline how cancer surveillance activities fit with the recent health care reforms enacted in the United States. The second speaker is Michel Coleman, Professor of Epidemiology and Vital Statistics at the London School of Hygiene and Tropical Medicine. He will discuss the impact of the European survival studies on public health policy development regarding cancer care in Europe. Finally, Heather Logan of the Canadian Partnership Against Cancer will illustrate how cancer surveillance data are being used to shape public health policy in Canada.

Additional plenary sessions will feature examples of advances in medical science and health information technology, and how these advances are integrated into cancer surveillance activities. The final plenary session involves a conversation about current challenges in central cancer registry operations - defining the essential functions of population-based registries and exploring ways to advance their effectiveness in times of diminishing resources.

Oral and poster presentations will complement the overall conference theme through discussions of related topics in the following areas: Data Collection, Cancer Surveillance Informatics, Data Use and Research, and Using Registry Data for Change.

In addition to the scientific program, we encourage you to take advantage of the many other educational and recreational activities available during the 2011 Annual Conference. The Birds of a Feather will continue their early morning discussions, the GIS Committee will again sponsor a Run/Walk for Thursday morning, and two local area tours are available for Wednesday afternoon - one of historic Louisville and one of a nearby bourbon distillery. Louisville is a vibrant and growing city and we hope you enjoy its many attractions.

Frances Ross

Frances Ross, BA, CTR Chair, 2011 NAACCR Program Committee Director of Registry Operations Kentucky Cancer Registry

Thomas C. Inclaw

Thomas C. Tucker, PhD, MPH Director, Kentucky Cancer Registry Associate Director for Cancer Control Markey Cancer Control Program University of Kentucky

Dear Friends and Colleagues,

Welcome to the 2011 NAACCR Annual Conference, "Cancer Surveillance: Keeping Pace with Policy, Science, and Technology." The program contents emphasize the ways in which cancer surveillance affects and is affected by public health policy and by advances in medical science and heath information technology.

This year, the first plenary session features a health policy panel to discuss how present-day cancer surveillance data contribute to health policy development. The last plenary session focuses on some future challenges to populationbased central cancer registries and the need to evolve while remaining both efficient and effective. The other plenary and concurrent sessions consist of everything in-between—from data collection to data quality to data security, analysis, and use. They will inform us and aid our decision making.

This Conference would not be possible without the hardworking members of the Program Committee. I would

like to thank them, especially the chair Frances Ross and Thomas Tucker, for developing the well-integrated and informative plenary sessions and organizing the concurrent sessions. And, for our free afternoon, they have arranged tours of the beautiful city of Louisville with its huge urban forest, fabulous Victorian homes, race tracks, and myriad other sports venues—and another in which you can sample Louisville's world-renowned bourbon.

Please enjoy the Conference and enjoy Louisville—but not too much!

Maria J. Idymura

Maria J. Schymura, PhD President



Conference Objectives

The rapidly changing environment of cancer surveillance became intensely apparent in 2010, with the implementation of numerous developments in staging concepts, the use of electronic health records, and the re-classification scheme for hematopoietic and lymphoid neoplasms. This year's conference, "Cancer Surveillance: Keeping Pace with Policy, Science, and Technology," will explore how cancer surveillance both influences and is influenced by health policies, advances in science, and technology.

The objectives of the 2011 Annual Conference are to examine how cancer surveillance is essential to the development of sound health policy and advances in science, and to explore how innovations in technology can improve our cancer surveillance programs. The first plenary session will focus on how cancer

surveillance data are used to shape healthcare policies in the U.S., Europe, and Canada. This session will also explore how cancer surveillance data are used to measure the impact of health policies. In the second plenary session, examples will be given of both how changes in science have affected cancer surveillance and how cancer surveillance has contributed to science. The third plenary provides a discussion of the current health information infrastructure and gives examples of recent innovations in the use of health informatics for cancer surveillance. Finally, the last plenary session is a series of discussion questions related to central cancer registry operations - defining the essential functions of population-based registries and exploring ways to advance their operations in times of diminishing resources.

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Affiliation

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Thomas Tucker	Kentucky Cancer Registry
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Rosemary Dibble	Utah Cancer Registry
Mignon Dryden	Cancer Registries of Central and Northern California
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American Cancer Society American College of Surgeons American Joint Committee on Cancer

Conference Information

GENERAL INFORMATION

CONFERENCE REGISTRATION INFORMATION

The Conference Registration and Information Desk is located near the Cascade Ballroom (Streetside Lobby) and is open during the following days and times:

Monday, June 20thSTuesday, June 21stTWednesday, June 22ndTThursday, June 23rdT

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 11:30 am

Pre and Post Conference registration and check-in desks are located outside of the Conference Theatre room at the Hyatt Regency Louisville.

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/BREAKOUT SESSIONS

All Plenary Sessions and the Business Meeting will take place in Cascade Ballroom C of the Kentucky International Convention Center.

OPENING RECEPTION

Tuesday, June 21st, 2011

The welcome reception will be held in the Regency Ballroom (North) at the Hyatt Regency Louisville at 6:00 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 are able to conveniently download the 2011 NAACCR Annual Conference CE Hours Form from the NAACCR website at <u>www.naaccr.org</u>.

EXHIBITS AND POSTER INFORMATION

Exhibits and Posters will be located in Cascade Ballroom AB of the Kentucky International Convention Center.

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 will be available at these times:

Exhibit Hours

Tuesday, June 21	7:00 am to 5:00 pm
Wednesday, June 22	7:00 am to 12:00 pm
Thursday, June 23	7:30 am to 10:15 am

CYBER CAFÉ

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

ROOM LOCATION

Please note that activities for the NAACCR 2011 Conference will be held at both the Hyatt Regency Louisville (HRL) and the Kentucky International Convention Center (KICC). These designations will follow after each room location in the program schedule.

CONFERENCE EVALUATIONS

2011 conference evaluations will be 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 Plans

Hyatt Regency Louisville





Floor Plans

Kentucky International Convention Center



Level 2







Room locations are listed immediately after activity, ie. - CASCADE BALLROOM AB, KICC or 203, KICC etc.

SATURDAY, JUNE	18	PRE-CONFERENCE	8:30 am - 7:00 pm	COMMITTEE MEETINGS
8:30 am - 5:30 pm	Basic SEER*Stat Co	Durse	8:30 am - 10:00 am	Pathology Data Work Group CHURCHILL DOWNS, HRL
10:20 pm 5:00 pm	CONFERENCE THEATF	RE, HRL	8:30 am - 10:30 am	Registry Operations Committee REGENCY BALLROOM SOUTH A, HRL
12.30 pm - 3.00 pm	A Review Short Cou Herman Menck, Los	istnes. irse - DAY 1 s Angeles Cancer	8:30 am - 10:30 am	Data Use and Research Committee REGENCY BALLROOM SOUTH B, HRL
	Surveillance Program KEENELAND, HRL	m	9:00 am - 10:00 am	Race and Ethnicity Work Group KENTUCKY SUITE, HRL
SUNDAY, JUNE 19)	PRE-CONFERENCE	10:00 am - 11:00 am	Board / Sponsoring Member Organization Meeting PIMLICO AB, HRL
8:00 am - 4:15 pm	Central Cancer Reg A Review Short Cou Herman Menck, Los	istries: urse - DAY 2 s Angeles Cancer	11:00 am - 1:00 pm	Education Committee REGENCY BALLROOM SOUTH A, HRL
	Surveillance Program KEENELAND, HRL	m	11:00 am - 1:00 pm	Interoperability Ad Hoc Committee CHURCHILL DOWNS, HRL
8:00 am - 5:00 pm	Board of Directors N KENTUCKY SUITE, HR	Meeting L	1:30 pm - 3:30 pm	GIS Committee CHURCHILL DOWNS, HRL
8:30 am - 5:30 pm	Advanced SEER*St Carol Kosary, NCI CONFERENCE THEATF	at Course RE, HRL	1:30 pm - 3:30 pm	Data Evaluation and Certification Committee REGENCY BALLROOM SOUTH B, HRL
9:00 am - 4:00 pm	Applied Geocoding Recinda Sherman, Florida Cancer Data	for Cancer Registries System	2:30 pm - 3:30 pm	Cancer Registration Steering Committee Meeting (CRSC) PIMLICO AB, HRL
University of Sou PARK SUITE, HRL		tern California	2:30 pm - 3:30 pm	EDITS Work Group KENTUCKY SUITE, HRL
Monday, June 2	0	PRE-CONFERENCE	4:00 pm - 5:00 pm	CINA Editorial Subcommittee REGENCY BALLROOM SOUTH A, HRL
7:00 am - 8:30 am	Board of Directors N KENTUCKY SUITE, HR	Aeeting L	4:00 pm - 6:00 pm	Uniform Data Standards and Information Technology Committees Combined
8:00 am - 12:00 pm	SEER*Prep Training Carol Kosary, NCI	Course		Meeting KENTUCKY SUITE, HRL
0.00 cm 7.00 cm	CONFERENCE THEATF	RE, HRL	5:00 pm - 6:00 pm	Confidentiality Subcommittee REGENCY BALLROOM SOUTH B, HRL
9.00 am -7.00 pm	CASCADE BALLROOM (STREETSIDE LOBBY),	FOYER KICC	5:00 pm - 7:00 pm	Collaborative Stage Project Management Team PIMLICO AB HBI
1:00 pm - 5:00 pm	Poster Set-up CASCADE BALLROOM	AB, KICC	6:00 pm - 7:00 pm	Data Use and Research Committee's
1:00 pm - 5:00 pm	Exhibit Set-up CASCADE BALLROOM	AB, KICC		Survival Analysis Work Group REGENCY BALLROOM SOUTH A, HRL

TUESDAY, JUNE 2	1 CONFERENCE DAY 1	9:00 am - 9:30 am	The Impact of Cancer Survival Studies
6:30 am - 8:00 am	Breakfast CASCADE BALLROOM AB, KICC		on Health Policy Michel Coleman, BA, BM, BCh, MSc, FFPH Professor, London School of Hygiene
7:00 am - 8:00 am	Meet NAACCR If you are a new member or just want to learn more about NAACCR, join us for this informative session. You will learn more about NAACCR activities, how to participate in NAACCR committees, and the overall scope of the organization. You will also learn about the NAACCR website, navi- gational tips, and instructions on its use.	9:30 am - 10:00 am	Using Cancer Surveillance Data in Health Policy Development: Addressing Sustainability While Maximizing Outcomes Heather Logan, BSN, MS Executive Director of the Canadian Association of Provincial Cancer Agencies, Canadian Partnership Against Cancer
7:00 am - 5:00 pm	Registration CASCADE BALLROOM FOYER (STREETSIDE LOBBY), KICC	10:00 am - 10:15 am	Discussion Leader: Marcus Plescia, MD, MPH Director of the Cancer Prevention and Control Division, CDC
7:00 am - 5:00 pm	Visit Exhibits CASCADE BALLROOM AB, KICC	10:15 am - 10:45 am	Break CASCADE BALLROOM AB, KICC
7:00 am - 5:00 pm	Visit Posters CASCADE BALLROOM AB, KICC	Plenary Session #2	KICC
8:00 am - 8:30 am	Opening Ceremonies and Welcome Frances Ross, BA, CTR Thomas C. Tucker, PhD, MPH Kentucky Cancer Registry	10:45 am - 12:00 pm	Keeping Pace with Science Moderator: Brenda Edwards, PhD National Cancer Institute, Surveillance Research Program
Plenary Session #1: CASCADE BALLROOM C, 8:30 am - 10:15 am	KICC Keeping Pace with Policy	10:45 am - 11:15 am	Using Cancer Surveillance Data to Understand Genetic Differences in Colon Cancer Risk <i>Li Li, MD, PhD, MPH</i> <i>Department of Family Medicine,</i> <i>Case Western Reserve</i>
8:30 am - 9:00 am	University of Kentucky College of Public Health Cancer Surveillance and Health Care Reform in the U.S.	11:15 am - 11:45 am	The HER2neu Story and Its Impact on Cancer Surveillance Ed Romond, MD Hematology and Oncology, University of Kentucky Markey Cancer Center
	Howard Kon, MD, MPH Assistant Secretary for Health,	11:45 am - 12:00 pm	Discussion
		12:00 pm - 1:15 pm	United BioSource Luncheon (by invitation) <i>Peter Lieberman</i> OAKLAWN, HRL
		12:00 pm - 1:30 pm	COMMITTEE MEETING Clinical Data Workgroup 201-202, KICC
		12:00 pm - 1:30 pm	Lunch (on your own)

PROGRAM

Concurrent Session #1

1:30 pm - 3:00 pm

Section A: DATA QUALITY

207, KICC

Moderator: P Wilson

- 01 Casefinding Audits in Freestanding Radiation Therapy Centers; The California Experience *K Ziegler, California Cancer Registry*
- 02 The Canadian Partnership Against Cancer: National Collaborative Stage Audit Results J Shin, Canadian Partnership Against Cancer
- 03 Imputation of Race Using Surname and Residential Location FP Boscoe, New York State Cancer Registry
- 04 2010 Race Code 09 Recode *K Ziegler, California Cancer Registry*

Section B: INNOVATIVE APPROACHES TO DATA COLLECTION

208, KICC

Moderator: C Phillips

- 05 Integrating the SEER*RX Tool into Registry Systems AR Houser, C/NET Solutions
- 06 Mining the National Provider Index to Improve Case Ascertainment: Who's Not Yet on the Reporter Roster? *C Klaus, North Carolina Central Cancer Registry*
- 07 An Evaluation of Automated CS Data Collection: Unleashing the Power of the Electronic Health Record *G Lee, Cancer Care Ontario*
- 08 Improvements to a Web-Based Application for Physician Office Cancer Case Reporting AA Austin, New York State Cancer Registry, New York State Department of Health

Section C:

CAPTURING INFORMATION FROM ELECTRONIC REPORTING SOURCES

Moderator: N Aargaard

- 09 A Web-Based Software Application for Casefinding from ePath Reports *I Hands, Kentucky Cancer Registry*
- 10 Monitoring Electronic Report Flow Via a Restful Web Application *D Rust, Kentucky Cancer Registry*
- Automated Detection of Cancer in Diagnostic Imaging Reports
 G Cernile, Artificial Intelligence In Medicine Inc.

12 Efficiency and Accuracy Using the Cancer Pathology Reports Selection Algorithm (CPRSA): A Pilot Study V Rivera-López, Puerto Rico Central Cancer Registry / Puerto Rico Comprehensive Cancer Center

Section D: ANALYTIC EPIDEMIOLOGY

210, KICC

Moderator: D Deapen

- 13 Explaining the Geographic Distribution of Colorectal Cancer Survival: An Iowa Example
 K Matthews, University of Iowa
- 14 Assessing Factors That Influence Impact of Missouri's Breast and Cervical Cancer Control Program on Breast Cancer in the State *K Pena-Hernandez, Informatics Institute / Missouri Cancer Registry / University of Missouri*
- 15 Early-Stage Lung Cancer Survival in Kentucky: Exploring the Influence of Smoking Cessation and Mental Health Status *C Hopenhayn, University of Kentucky*
- 16 Using Race/Ethnic Comparisons to Explore Breast Carcinoma In Situ (CIS) Incidence and Breast Cancer Mortality Rate Trends in California, 1988-2007 J Morgan, School of Public Health, Loma Linda University / Region 5 of the California Cancer Registry

Section E: USING DATA TO ADVANCE SCIENCE 211, KICC

211, 100

Moderator: D Shipley

- 17 A Transdisciplinary Framework for Communicating Cancer Registry Data to the Public *G Gardiner, George Warren Brown School of Social Work and Public Health*
- 18 Technical Feasibility of Establishing a Proactive Cancer Cluster Surveillance System JJ Plascak, The Ohio State University Comprehensive Cancer Center - James Cancer Hospital and Solove Research Institute / The Ohio State University College of Public Health



- 19 Assessing the Non-Cancer Health Status of U.S. Cancer Patients H Cho, NCI
- 20 Nourishing a Healthy Appetite for Surveillance Statistics: A Cancer Registry Recipe for a Data-Hungry World D Turner, CancerCare Manitoba / University of Manitoba
- 3:00 pm 3:30 pm Break / Poster Viewing Stop and visit the scientific posters. Authors will stand near their posters to answer your questions. Get your passport stamped by five authors and you will qualify for a drawing of an iPod touch[™]. CASCADE BALLROOM AB, KICC

Note: Completed passports can be placed in the drop box near the NAACCR Exhibit Booth in the Exhibit Hall.

Concurrent Session #2

3:30 pm - 5:00 pm

Section A: EDUCATION AND TRAINING

207, KICC

Moderator: P Nicolin

- 21 Update on NCRA Informatics Efforts HR Menck, University of Southern California
- 22 Cyber Cancer Registry: Where We Are Where We Are Going *R Wilson, CDC / NPCR*
- 23 Results of the NCRA Hospital Workload Study HR Menck, University of Southern California

Section B: INNOVATIVE APPROACHES TO DATA COLLECTION

208, KICC

Moderator: G Levin

- 24 Economic Analysis of the National Program of Cancer Registries: Initial Findings F Tangka, CDC
- 25 Multidisciplinary Approach to Timely Reporting of Surveillance Statistics: Utility of SEER February Submission Files *BK Edwards, NCI*
- 26 SEER*ABS Abstracting Tool L Coyle, IMS, Inc.
- 27 Improving Ascertainment and Completeness: The Puerto Rico Central Cancer Registry Experience Y Román-Ruiz, Puerto Rico Central Cancer Registry / Puerto Rico Comprehensive Cancer Center

Section C: ANALYTIC EPIDEMIOLOGY

210, KICC

Moderator: D West

- 28 The Use of Cause-Specific Survival in SEER Population-Based Registries When Relative Survival Fails LAG Ries, NCI
- 29 Canadian Experience Creating Geographic Attributes Data in SEER Software *H Wang, Cancer Care Nova Scotia*
- 30 The Impact of the Pan-Canadian Cancer Surveillance and Epidemiology Networks *J Shin, Canadian Partnership Against Cancer*
- 31 Impact of Missing Data on Temporal Trends: An Application of Multiple Imputation (MI) in Breast Cancer Using Population-Based SEER Cancer Registry Data *N Howlader, NCI*

Section D: USING DATA TO ADVANCE SCIENCE

211, KICC

Moderator: A Stewart

- 32 Using Cancer Registry Data to Advance the Science of Drug Safety: Results from an Ongoing Post-Marketing Drug Safety Surveillance Study of Adult Osteosarcoma *K Midkiff, RTI Health Solutions*
- 33 Using Cancer Registry Data for Post-Marketing Surveillance of Rare Cancers
 H Weir, CDC
- 35 Selecting the Optimal Window Size for Spatial Scan Statistics *L Zhu, NCI*

Section E: COLLABORATIVE ENGAGEMENT

209, KICC

Moderator: C Wiggins

- 36 Surviving Survival Statistics: Users And Analysts Unite! The Canadian Cancer Survival and Prevalence Analytic Network (C-SPAN) Experience D Turner, CancerCare Manitoba / University of Manitoba
- Opportunities for Improving the Use of Cancer Registry Data in Drug Safety Studies: Factors Influencing Interview Response Rate D Harris, RTI Health Solutions
- 38 NCI SEER Edits Engine: An Interoperable Approach to Data Validation F Depry, IMS, Inc.

PROGRAM

- 39 A Collaborative Project to Enhance Capacity of Non-Registry Hospitals to Collect and Report Complete, Accurate, and Timely Case Data J Martin, Virginia Cancer Registry
- 5:00 pm 5:30 pm CONCORD-2 Study Open Discussion 211, KICC
- 5:00 pm 6:00 pm SPECIAL SHOWCASE: Meet and Greet Vendors / Exhibitors Stop by the vendors and have them stamp your passport. Hand in a passport with five stamps from exhibitors and you will qualify for an iPod touch[™] drawing! Cash bar available. CASCADE BALLROOM AB, KICC
- 6:00 pm Opening Reception REGENCY BALLROOM (NORTH), HRL

WEDNESDAY, JUNE 22 CONFERENCE DAY 2

- 6:30 am 8:00 am Breakfast CASCADE BALLROOM AB, KICC 7:00 am - 8:00 am Birds Of A Feather Electronic Health Record - Where is it? What Does it Mean to You? Rich Pinder Los Angeles Cancer Surveillance Program Susan Gershman Massachusetts Cancer Registry 212-217, KICC 7:00 am - 12:00 pm Exhibitor Showcase CASCADE BALLROOM AB, KICC 7:00 am - 12:30 pm Registration
 - CASCADE BALLROOM FOYER (STREETSIDE LOBBY), KICC

Concurrent Session #3

8:00 am - 9:30 am

Section A: DATA QUALITY

207, KICC

Moderator: K Davidson-Allen

40 Lessons Learned from SEER Reliability Coding Practice Studies Software Development *J Cyr, IMS, Inc.*

- 41 Growing Pains: Lessons Learned from the Implementation of the NAACCR v12 Record Layout *DK O'Brien, Alaska Cancer Registry*
- 42 Galloping into the Future: What's Next for the SEER Hematopoietic and Lymphoid Neoplasm Project *MB Adamo, NCI SEER*
- 43 What the GIST?! C Moody, California Cancer Registry

Section B: INITIATIVES IN INTEROPERABILITY

208, KICC

Moderator: G Yee

- 44 National Program of Cancer Registries -Advancing E-cancer Reporting and Registry Operations (NPCR-AERRO): Activities Overview
 S Jones, CDC
- 45 National Program of Cancer Registries Advancing E-cancer Reporting and Registry Operations (NPCR-AERRO): Clinic/Physician Office (CPO) Reporting to Registries Project W Blumenthal, CDC
- 46 NAACCR, Meaningful Use Criteria, Standards Development Organizations, and Interoperability *J Martin, Virginia Cancer Registry*
- 47 Highlights of Valuable CAP eCC Features for Cancer Registries
 A Pitkus, College of American Pathologists

Section C: DATA SECURITY

210, KICC

Moderator: L Stephenson

- 48 Central Cancer Registry: Documenting the Security of Your IT Infrastructure S Van Heest, CDC
- 49 Generating Accurate Statistical Models While Protecting Patient Privacy: Using Synthetic Data from the Central Cancer Registry TS Gal, Kentucky Cancer Registry / University of Kentucky / University of Maryland
- 50 Security Isn't Just a Central Cancer Registry (CCR) Issue: How One CCR Helped Reporting Facilities Improve Their Security N Cole, Missouri Cancer Registry / University of Missouri

51 ARRA HITECH: Challenges, Opportunities and Implications for Central Cancer Registries (CCRs) *I Zachary, Missouri Cancer Registry / University of Missouri Informatics Institute*

PROGRAM

Section D:

TRENDS IN INCIDENCE AND MORTALITY

209, KICC

Moderator: R Rycroft

- 52 Cancer Trends Among Persons of African Descent in Florida - A Florida Cancer Data System (FCDS) Publication *MN Hernandez, Florida Cancer Data System, University of Miami Miller School of Medicine, Sylvester Comprehensive Cancer Center*
- 53 Age-Period-Cohort Robust Bayesian Models for Projecting Cancer Incidence and Mortality in Puerto Rico *L Pericchi, University of Puerto Rico, Rio Piedras*
- 54 Differences in Non-Small Cell Lung Cancer Survival Between Appalachian and Non-Appalachian Areas of Kentucky *G Rinker, University of Kentucky*
- 55 Cancer Incidence Trends Among the Oldest-Old (85+) AM Stroup, Utah Cancer Registry, University of Utah

Section E: USING DATA TO ADVANCE SCIENCE

211, KICC

Moderator: D Christie

56 HPV Type Specific Prevalence in Six Cancers from Select U.S. Cancer Registries, 2000-2005 *M Saraiya, CDC*



- 57 Distribution of HPV Types Among a Population-Based Sample of U.S. Invasive Cervical Cancers Across Five U.S. States *C Hopenhayn, University of Kentucky*
- 58 CDC Human Papillomavirus Typing of Cancers Study with Seven Registries: Evaluating Representativeness *M Watson, CDC*
- 59 Distribution of HPV by Type in a Population-Based Sample of Invasive Oropharyngeal Cancers from Five U.S. Cancer Registries *E Peters, Louisiana Tumor Registry, Louisiana School of Public Health*
- 9:30 am 10:00 am Break CASCADE BALLROOM AB, KICC

Plenary Session #3

CASCADE BALLROOM C, KICC

10:00 am - 11:15 am	Keeping Pace with Technology Moderator: Ken Gerlach, MPH, CTR Centers for Disease Control and Prevention, National Program of Cancer Registries
10:00 am - 10:30 am	Electronic Cancer Data Sharing for Research: Opportunities and Challenges John Madden, MD, PhD Department of Pathology, Duke University School of Medicine
10:30 am - 11:00 am	Electronic Physician Reporting in the Emerging E-Health Environment Eric Durbin, MS Director of Cancer Informatics, Kentucky Cancer Registry
11:00 am - 11:15 am	Discussion
11:15 am - 12:00 pm	NAACCR Strategic Plan NAACCR's goals and objectives for the next five years will be presented. <i>Maria Schymura, PhD, NAACCR President</i> CASCADE BALLROOM C, KICC
12:30 pm - 2:00 pm	NAACCR Business Meeting Join us for the 2011 NAACCR Business Meeting. Beverages and a complimentary light lunch will be available for those who attend. NAACCR's fiscal status, committee progress, and registry certification will be presented. CASCADE BALLROOM C, KICC
2:00 pm - 5:00 pm	Free Afternoon

PROGRAM

THURSDAY, JUNE 23 CONFERENCE DAY 3

6:30 am - 8:00 am	Breakfast CASCADE BALLROOM AB, KICC
7:00 am - 8:00 am	NAACCR Run/Walk Sponsored by the NAACCR GIS Committee <i>Meet in Hotel Lobby</i>
7:00 am - 11:30 am	Registration CASCADE BALLROOM FOYER (STREETSIDE LOBBY), KICC
7:15 am - 8:00 am	COMMITTEE MEETING Cancer-Rates.Info Users Group CASCADE BALLROOM AB, KICC
7:30 am - 10:15 am	Exhibitor Showcase CASCADE BALLROOM AB, KICC

Concurrent Session #4

8:30 am - 10:00 am

Section A: DATA QUALITY

207. KICC

Moderator: M Celaya

- 60 Cancer Data Quality Control by Proportion of Unknown Stage - Data Assessment Workgroup #1 *Q Yu, LSU Health Sciences Center*
- Benign/Borderline Intracranial and Central Nervous System Tumors in the CINA Deluxe Data - Data Assessment Workgroup #2
 B Huang, University of Kentucky
- 62 Data Quality of Surgery and Radiation for Four Major Cancer Sites in CINA Deluxe - Data Assessment Workgroup #3 *B Wohler, Florida Cancer Data System*
- 63 Data Quality of Tumor Size and Depth for Breast Cancer and Melanoma in CINA Deluxe - Data Assessment Workgroup #4 *B Wohler, Florida Cancer Data System*

Section B: ISSUES IN DATA COLLECTION 208, KICC

Moderator: J Harris

64 Louisiana Tumor Registry's Experience with Implementing Routine Surveillance for Pre-Invasive Cervical Lesions LE Cole, Louisiana Tumor Registry / Louisiana State University Health Sciences Center, School of Public Health

- 65 Population-Based Surveillance for High-Grade Pre-Invasive Cervical Cancer in Kentucky, Louisiana, and Michigan, 2009 *EW Flagg, CDC*
- 66 Taming the Text: Incorporating eMaRC Plus into Florida Central Registry Pathology Laboratory Processing *J MacKinnon, University of Miami Miller School of Medicine*
- 67 High Grade Dysplasia and Carcinoma In Situ Are They SYNONYMOUS?
 G Noonan, CancerCare Manitoba / Data and Quality Management Committee

Section C: TRENDS IN INCIDENCE AND MORTALITY

209, KICC

Moderator: V Williams

- 68 Thyroid Cancer in the United States: Recent Increases *M Watson, CDC, Division of Cancer Prevention and Control*
- 69 Cancer Trends in the Oldest Old J Rees, Dartmouth Medical School
- 70 State Disparities in Colorectal Cancer Mortality Rate in the United States D Naishadham, American Cancer Society
- 71 Mapping Cancer Mortality-to-Incidence Ratios Can Help to Identify Racial and Gender Disparities in High-Risk Populations
 D Hurley, South Carolina Central Cancer Registry

Section D: ANALYTIC EPIDEMIOLOGY

210, KICC

Moderator: R Sherman

- 72 Proximity to Treatment and Likelihood of Mastectomy Among Early Stage Breast Cancer Patients *CJ Johnson, Cancer Data Registry of Idaho*
- 73 Travel Time to Diagnosing and Mammography Facilities and Breast Cancer Stage at Diagnosis *KA Henry, Cancer Institute of New Jersey (CINJ)*
- 74 Factors Associated with Mastectomy Among Asian Women Diagnosed with Early-Stage Breast Cancer in California: An Application of Recursive Partitioning to Identify High-Risk Groups

SL Gomez, Cancer Prevention Institute of California / Stanford University

75 Influence of Race, Socioeconomic Status, Insurance, and Hospital Type on Receipt of Guideline Adjuvant Systemic Therapy for Non-Metastatic Breast Cancer Patients *XC Wu, LSU Health Sciences Center / Louisiana Tumor Registry*

Section E: BEYOND CSV2

211, KICC

Moderator: M Adamo

- 76 When Policy Affects Data: The Effect of CoC's Shift in Staging Requirements JL Phillips, American College of Surgeons
- SEER Program for Continuous Evaluation of 2010 CSv2
 Implementation and Changes
 S Negoita, Westat
- 78 CS Parking Lot: What is it, What's in it, and Why Should I Care? J Seiffert, Northrop Grumman
- 79 Consolidation of Cancer Stage and Prognostic Factor Data Elements - Operational Issues in Collaborative Stage Data Collection System S Negoita, Westat
- 10:00 am 10:15 am Break / Exhibitor and Poster Viewing Be sure to visit Exhibitors and Posters to get your passport stamped. Drawing for iPod touch™ will take place at this time. CASCADE BALLROOM AB, KICC

Note: Completed passports can be placed in the drop box near the NAACCR Exhibit Booth in the Exhibit Hall.

10:15 am - 11:00 am Exhibit Break Down CASCADE BALLROOM AB, KICC

10:30 am All posters must be removed from boards.

Concurrent Session #5

10:30 am - 12:00 pm

Section A: DATA QUALITY

207, KICC

Moderator: S McFadden

- 80 Using Technology to Increase Productivity and Data Quality *M Schlecht, California Cancer Registry*
- 81 Sex Misclassification in Central Cancer Registries RL Sherman, FCDS, University of Miami
- 82 Automating Business Rules as a Data Quality Tool *C Moody, California Cancer Registry*
- 83 The Effect of Administrative Boundaries and Geocoding Error on Cancer Rates DW Goldberg, University of Southern California

Section B: INITIATIVES IN INFORMATICS

208, KICC

Moderator: C Johnson

- 84 Predictions for Grid-Based Computing Systems at Central Cancer Registries: Modeling System Performance and Visualizing New Platform Technologies *ME Cryer, University of Utah*
- 85 A Paradigm Shift NAACCR Standards Volume V and The College of American Pathologists' (CAP) Electronic-Cancer Checklists IN Harrison, New York State Cancer Begistry

JN Harrison, New York State Cancer Registry

- 86 Automated Classification of Pathology Reports into SEER Histology/Site Recode Classes *G Cernile, Artificial Intelligence In Medicine Inc.*
- 87 Requirements Analysis and Recommendations for CAP eCC Reporting to Cancer Registries *K Gerlach, CDC-NPCR*

Section C: DATA USE AND RESEARCH 209, KICC

Moderator: J Martin

- 88 Exploring the Relationship Between Urinary Tract Cancer
 Incidence and Ingestion of Inorganic Arsenic
 A Pate, Oklahoma State Dept of Health
- 89 Urban-Rural Gradient in Medulloblastoma Incidence During 1995-2006
 FD Groves, University of Louisville
- 90 Predictors of Aggressive End-of-Life Care Among New York State Breast and Colorectal Cancer Patients DA Patel, New York State Cancer Registry / University at Albany School of Public Health
- 91 Age Disparity in the Dissemination of Imatinib for Treating Chronic Myeloid Leukemia *C Wiggins, New Mexico Tumor Registry / University of New Mexico Cancer Center*

Section D: ANALYTIC EPIDEMIOLOGY

210, KICC

Moderator: M Green

- 92 Exploring the Utility of CA125 as a Clinically Relevant Prognostic Factor in Patients with Ovarian Cancer *W Ross, Westat, Inc.*
- 93 Relevance of Gleason Score for the Initial Management of Prostate Adenocarcinoma: A Population-Based Perspective *S Negoita, Westat*

94	Prevalence of HPV Infection in Head and Neck Cancers by Anatomic Subsite <i>L Liu, University of Southern California</i>		
95	Influence of Socioeconomic Status and Hospital Type on Disparities of Lymph Node Evaluation in Colon Cancer Patients MC Hsieh, Louisiana Tumor Registry, School of Public Health, Louisiana State University Health Sciences Center		
Sec IN A	tion E: CLASS ALL THEIR (OWN	
211, <i>Moc</i>	KICC derator: R Pinder		
96	Annotating Biosp Collaboration bet Kentucky Cancer TS Gal, Kentucky University of Mar	ecimens with Cancer Registry Data - A ween the Markey Cancer Center and the Registry Cancer Registry / University of Kentucky / yland	
97	Maintenance of a Registry Data Management System: Collaborative Results Stemming from the SEER*DMS Change Control Board N Schussler, IMS, Inc.		
98	Towards Canadian National Population-Based Collaborative Stage Data <i>E Taylor, Canadian Partnership Against Cancer</i>		
99	The Feasibility of Microdata Sampl Uniqueness for F <i>M Yu, NCI</i>	Using U.S. Census 2000 Public Use e (PUMS) to Evaluate Population Population-Based Cancer Microdata	
12:(00 pm -1:30 pm	Awards Luncheon REGENCY BALLROOM (NORTH), HRL	FRIDA
2:00) pm - 3:00 pm	NAACCR Showcase Moderator: Maureen MacIntyre, BSN, MHSA, NAACCR President-Elect CASCADE BALLROOM C, KICC	
		Update on Cancer Surveillance Summit <i>B Edwards, National Cancer Institute</i>	
		Pooled Data Initiative D Deapen, Los Angeles Cancer Surveillance Program	
		Recruitment and Retention Workgroup J Ruhl, National Cancer Institute	
		CEO Cancer Gold Standard™ <i>B Kohler, NAACCR</i>	

ы Session #4:

E BALLROOM C, KICC

3:00 pm - 4:00 pm	The Finish Line Moderator: Dennis Deapen, DrPH Los Angeles Cancer Surveillance Program
	What is the Primary Purpose of Population-Based Cancer Registries? Donna Turner, PhD Epidemiologist, Manitoba Cancer Registry, CancerCare Manitoba
	How Do We Decide Which Data Variables to Collect? Edward Peters, DMD, SM, ScD Epidemiologist, Louisiana Tumor Registry, LSUHSC School of Public Health
	Do All Registries Have to Do All Things? Kevin Ward, PhD, MPH, CTR Director, Georgia Center for Cancer Statistics
4:00 pm - 4:30 pm	Invitation To 2012 NAACCR Conference Donald Shipley, MS Oregon State Cancer Registry CASCADE BALLROOM C, KICC
4:30 pm - 5:00 pm	Closing Remarks Frances Ross, BA, CTR Kentucky Cancer Registry CASCADE BALLROOM C, KICC

Y, JUNE 24

POST-CONFERENCE

n - 5:00 pm

Multilevel Modeling NAACCR GIS COMMITTEE CONFERENCE THEATRE, HRL







Poster Listing

- P-01 Visioning Timeliness, Improving Accuracy, and Enhancing Efficiency: Evaluation of Incident Data and Cancer Reporting to Central Registries *AM Stroup*
- P-02 California's Completeness, Timeliness, and Quality Report *S Riddle*
- P-03 Consistency Among Participants in a Breast Cancer Follow-Up Study *N Das*
- P-04 Memory vs. Modules: A Training Success Story N Rold
- P-05 3rd Edition of Cancer Registry Management: The Cancer Registry Textbook *HR Menck*
- P-06 Improving a Central Cancer Registry's (CCR's) Data Quality and Completeness: Preliminary Results from Two New Projects J Jackson-Thompson
- P-07 Non-Hospital Reporting Impact on Cancer Statistics in Maryland *M Mesnard*
- P-08 Status of WHO Grade as a Collaborative Stage Site Specific Factor for Brain Tumors *TA Dolecek*
- P-09 Improving Physician Reporting of Hematopoietic Malignancies to the New York State Cancer Registry (NYSCR)
 AA Austin
- P-10 All Together Now! Orchestrating the Electronic Transmission of Pathology Data into the Manitoba Cancer Registry: ePath Year 2 A Downey-Franchuk
- P-11 Linkage of Electronic Pathology Laboratory Reporting and Uniform Billing Data to Identify Cancer Cases for a Registry-Based Epidemiologic Study in New Jersey *KS Pawlish*
- P-12 Death Clearance: Design and Implementation of an Interface to Automate Vital Statistics Data Collection in a Population-Based Provincial Cancer Registry *SC Tamaro*

- P-13 Streamlining Multisite Ethics Reviews: Lessons
 Learned from the "Cancer in Young People in Canada"
 Surveillance Program
 D Mitra
- P-14 They Call Me Whello Yello: Revisiting the SEER Race and Nationality Descriptions *FP Boscoe*
- P-15 eHealth Initiatives and Cancer Surveillance: Putting the Puzzle Together *W Blumenthal*
- P-16 Type of Health Insurance Coverage (Government Health Plan vs. Non-Government Health Plan) Effect in the Survival of Colorectal Cancer Patients: The Experience in Puerto Rico, 2004 *KJ Ortiz-Ortiz*
- P-17 Histological Classification of Liver and Intrahepatic Bile Duct Cancers S Altekruse
- P-18 Cancer in the Appalachian Regions of North Carolina, Tennessee and Virginia, 2004-2006 *T Bounds*
- P-19 An Investigation of the Association Between Glioma and Socioeconomic Status: Effects of Controlling for Group-Level Spatial Autocorrelation JJ Plascak
- P-20 Risk of Cancer among Hispanics with AIDS Compared with the General Population in Puerto Rico: 1987-2003 J Pérez-Irizarry
- P-21 The Determinants of Colorectal Cancer Survival Disparities *LN Wassira*



Poster Listing continued

- P-22 Random Frequency-Matching of Controls to Cancer Cases in SEER-Medicare Data by Index Date to Radiation Therapy Date C Yee
- P-23 Incidence, Survival and Risk of Subsequent Primaries in Ocular Melanoma: Analysis of the Surveillance, Epidemiology and End Results (SEER) Data FD Vigneau
- P-24 Sub-Site Specific Colorectal Cancer Survival in Puerto Rican Hispanic Population *M Torres-Cintrón*
- P-25 Investigating a Possible Cancer Cluster in a Community with Saskatchewan Cancer Registry Information T Zhu
- P-26 Case-Control Study: Birth Weight and Risk of Childhood Acute Lymphoblastic Leukemia (ALL) *FD Groves*
- P-27 Collaboration with Multiple State Cancer Registries for a Data Linkage Drug Safety Surveillance Study – Yes You Can! A Gilsenan
- P-28 National Health Interview Survey (NHIS)-Florida Cancer Data System (FCDS) Data Linkage Project: Update LA Mcclure
- P-29 Six Degrees of Separation No More: Using Data Linkages to Improve the Quality of Cancer Registry and Study Data D Harris
- P-30 A Bayesian Hierarchical Spatial Approach for Constructing Cancer Risk Maps at a Finer Level than is Provided in Publicly Available Data
 F-C Hsieh



- P-31 Utility of Linking Medicaid and Medicare Claims Data to Death Certificate Only Records T Hinman
- P-32 Racial Differences in the Decline of Cervical Cancer Rates in North Carolina *G Knop*
- P-33 The Shifting Trends of Esophageal Cancer in U.S., 1975-2007 *M Tennapel*
- P-34 Space-Time Analysis of Racial Disparities in Advanced-Stage Prostate Cancer Incidence Across Florida
 P Goovaerts
- P-35 Incidence of Potentially Human Papillomavirus-Associated Cancers of the Oropharynx in the U.S., 2004-2007 JL Cleveland
- P-36 Cancer in the "Oldest Old" in Massachusetts, 1998-2008 *R Knowlton*
- P-37 Evaluating the Impact of Screening on Breast Cancer Incidence and Mortality Projections in Saskatchewan S Sarker
- P-38 Prostate Cancer Incidence, Stage at Diagnosis and Mortality in North Carolina S Ali
- P-39 Cancer Among Asians a nd Pacific Islanders in New Jersey 1990-2007 X Niu
- P-40 The Convergence of Oropharyngeal Cancer Rates Between Non-Hispanic Blacks and Whites in U.S. *C Desantis*
- P-42 Prevalence of Symptoms that Define Inflammatory Breast Cancer among Cases in a Population-Based Cancer Registry *F Martinez*
- P-43 Descriptive Epidemiology of Cervical Cancer in Massachusetts *B Backus*

Poster Listing continued

- P-44 Creating Tailored Local Cancer Control Plans: Are Cancer Surveillance Units at the Table? *AL Agustin*
- P-45 Multiple Primaries (MPs) in Survival Estimates: Should SEER Include or Exclude MPs? *N Howlader*
- P-46 Oregon's Experience with a Short-Term Media Campaign to Encourage Colorectal Cancer Screening D Towell
- P-47 Collaborative Study of Breast Reconstruction Following Mastectomy in the State of Maine: Geographic Disparity *D Nicolaides*
- P-48 Identifying Breast Cancer Screening Service Gaps: A Combined Geographic and Demographic Approach *AK Berzen*

- P-50 Linking Central Cancer Registries and Institutional Biorepositories to Facilitate Biospecimen-Based Research - A Pilot Study *R Cress*
- P-51 Prostate Cancer Screening and Incidence Among Men Under Age 50 J Li
- P-52 Moving Toward Survival Surveillance: Implementing and Evaluation Spatial Survival Scan Methods for Nebraska Cancer Registry *L Zhang*
- P-53 Male Breast Cancer Geographic Variation in the United States *M Kumar*
- P-54 Maximizing Data Changes Opportunities *W Roshala*





oral abstracts

concurrent session 1



CASEFINDING AUDITS IN FREESTANDING RADIATION THERAPY CENTERS; THE CALIFORNIA EXPERIENCE K Ziegler¹

¹California Cancer Registry, Sacramento, CA

Background: A casefinding audit of freestanding radiation therapy centers in California was performed to evaluate case completeness and data quality. An audit of this type had never been performed on freestanding radiation facilities; therefore the California Cancer Registry (CCR) determined that a casefinding audit was needed to determine if the CCR was in-fact receiving cases that were seen in these treatment centers.

Methodology: Prior to these audits, no protocol existed for conducting a casefinding audit in a freestanding radiation therapy center. Determining what information from which documents and in what format was needed. After careful consideration, facilities were requested to provide Consultation Reports with associated Treatment Summaries, and demographic information for each patient seen at their facility during a specified period of time. Access to the medical record was also requested. Each facility provided documentation depending on their ability. One facility provided a report which documented patients who accrued a new charge, while another facility provided a report that captured new patient encounters. One facility had the ability to provide electronic copies of Consultation Reports with the associated Treatment Summary.

Conclusions: Freestanding radiation therapy centers operate much like physician offices and the record keeping methods such as patient listings and treatment logs vary significantly between facilities. The lack of standardization presented unparalleled challenges at each facility audited. Several issues were identified by this audit. The issues range from access to the appropriate documents to the quality of the treatment information submitted versus the actual treatment given. Furthermore, a protocol was developed for future casefinding audits in these types of reporting facilities. This presentation will discuss issues identified and recommended corrections, as well as present the overall audit findings.

02

Notes

THE CANADIAN PARTNERSHIP AGAINST CANCER: NATIONAL COLLABORATIVE STAGE AUDIT RESULTS

<u>J Shin</u>¹, A Fritz¹, E Hamlyn⁵, D Dale², E Taylor¹, G Lockwood¹, A Cloth¹, J Brierley^{3,4}

¹Canadian Partnership Against Cancer, Toronto, Ontario; ²Princess Margaret Hospital, University Health Network, Toronto, Ontario; ³Department of Radiation Oncology, Princess Margaret Hospital, Toronto, Ontario; ⁴Department of Radiation Oncology, University of Toronto, Toronto, Ontario; ⁵Newfoundland & Labrador Centre for Health Information, St. John's, Newfoundland

BACKGROUND: In 2009 the Canadian Partnership Against Cancer and the Provincial and Territorial Cancer Registries (PTCRs) completed the first pan-Canadian cancer collaborative stage (CS) data quality audit. This audit was commissioned in response to an identified knowledge gap from the 2008 *Canadian Cancer Registry's Data Quality Framework project.* **PURPOSE:** To provide a preliminary assessment on the quality of the CS data collection system in Canada; to identify quality improvement opportunities in areas such as Collaborative Staging training and documentation. **METHODS:** The audit involved nine PTCRs and sampled cancer registry data representing over 78% of the Canadian population. Source documents were audited on thirty selected colorectal, breast, lung, and prostate cases with diagnoses in 2006 - 2008. Analysis was focused on the accuracy of the CS codes required to derive the AJCC TNM and Stage Group.

RESULTS: There was significant complexity involved in evaluating the CS data collection system on a pan-Canadian level. The overall major discrepancy (incorrect coding resulting in a change of TNM category) rate for all PTCRs was 2.8%. The major discrepancy rate for colorectal cancers was 1.7%; for breast, 1.6%; for lung, 5.6%; and for prostate 3.2%.

CONCLUSION: The overall rates for major discrepancies are low and indicate that CS data can be used with confidence by cancer researchers. In Canada there has been nationwide training for CS coding, its success is reflected in the low discrepancy rate. However further educational sessions will be considered to lower discrepancy rates for lung. Other areas identified for improvement of future audits include: developing a comprehensive methodological annex to enhance reliability and validity; planning a representational sampling method; standardizing methods for data collection; strengthening data quality infrastructure and capacity; and enhancing accessibility and usability of data.

IMPUTATION OF RACE USING SURNAME AND RESIDENTIAL LOCATION

LE Soloway¹, <u>FP Boscoe¹</u>, MJ Schymura¹ ¹New York State Cancer Registry, Albany, NY

The number of cancer reports with missing race has been increasing in recent years. In New York State the percentage of sources missing race has increased from 1.0% among cases diagnosed in 2004 to 2.5% among cases diagnosed in 2008. Increases in the volume of laboratory reporting are perceived to be a major contributor to this trend, but larger shares of missing race are seen across all source types. This trend can be partially offset through the use of a race imputation procedure which makes use of surname and residential location information. We identified surnames that were highly predictive of race (either white, black, American Indian/Alaska Native, Asian or Pacific Islander) using a list of 151,673 surnames occurring at least 100 times in the 2000 census. We also identified census tracts that were highly predictive of race based on 2000 census data. "Highly predictive" was variously defined as a positive predictive value (PPV) of 0.75, 0.85 or 0.95. These thresholds were applied to the 4,402 cases missing race in the NYSCR from 2004-2008. Accuracy of the method was tested by applying it to 502,759 cases from the same years for which the race was known. Using the 0.95 PPV threshold, 23 percent of the cases with unknown race could be assigned an imputed race. Using the 0.85 and 0.75 PPV thresholds, 48% and 59%, respectively, of the cases with unknown race could be assigned an imputed race. Most assignments were based on surname, rather than address (for example, 69.4% for name versus 21.5% for tract versus 8.8% for both name and tract for the 0.95 threshold). Applying this method to cases with known race, over 99 percent of the cases were correctly classified using the 95 percent threshold. Using the 85 and 75 percent thresholds, 97% and 95% of the known cases were correctly classified, respectively. This study demonstrates that the number of cases missing race can be substantially decreased with minimal misclassification.

04

2010 RACE CODE 09 RECODE

<u>K Ziegler</u>¹ ¹California Cancer Registry, Sacramento

Background

As part of the 2010 data changes, Race 09 (Asian Indian, Pakistani) became obsolete and was replaced with race codes 15(Asian Indian or Pakistani, NOS), 16 (Asian Indian), and 17 (Pakistani). The 2010 NAACCR Implementation Guidelines and Recommendation stated to at a minimum convert race 09 to race 15. The California Cancer Registry chose to evaluate each case coded to Race code 09 to ensure the correct new race code was applied.

Method

A SQL query was created to identify all cases coded to race code 09 in any of the Race 1 through Race 5 data fields. The Eureka data base is home to 3,912,421 patients and 5,570,128 admissions. Of those 3.9 million patients, 11,777 patients and 15,254 admissions were identified with race code 09 in one of the five race fields. Using the NAPIIA algorithm and SEER Race Code instructions as guidelines, each record was reviewed to determine the best race code to be applied to the record. This process was performed on each of the 15,254 admissions and separately on the 11,777 patients.

Results

The assumption would be that all race code 09 would be recoded to one of the three new race codes, however; only 84% of the cases were recoded to one of the new race codes, 15, 16, or 17. It was discovered that nearly 10% of the records should have never been coded to any Asian race code. An additional 10% of the records were recoded to Asian races other than those races captured in race codes 15, 16, or 17.

Notes	Notes

INTEGRATING THE SEER*RX TOOL INTO REGISTRY SYSTEMS

<u>AR Houser</u>¹, K Beaumont¹, B Gordon¹ ¹C/NET Solutions, Berkeley, CA

When the SEER*RX Tool was introduced, there was an immediate acceptance by the registry community. After the newness wore off, requests to integrate it more tightly into data collection systems began to trickle in. After working with the Collaborative Stage Data Collection System and using its API to automate many data entry processes, we began developing a plan to integrate the SEER*RX database along the same lines. We will report on the results of this effort, including providing interaction during data entry, validation (edits), and interaction with automated casefinding.

06

MINING THE NATIONAL PROVIDER INDEX TO IMPROVE CASE ASCERTAINMENT: WHO'S NOT YET ON THE REPORTER ROSTER?

<u>C Klaus</u>¹, L Stephenson²

¹North Carolina Central Cancer Registry, Raleigh NC; ²Wisconsin Cancer Reporting System, Madison, WI

This presentation summarizes the experience of the North Carolina and Wisconsin Cancer Registries with the National Provider Index for identifying non-hospital cancer care providers subject to State case reporting requirements.

Hospitals have been the traditional bedrock source for CCR case-finding. Yet for several years, an increasing proportion of cancer patients have been diagnosed and treated outside of that setting. Since non-hospital cancer care providers are often not licensed in a manner similar to hospitals or otherwise routinely tracked by public health agencies, they have been difficult to identify and monitor until recently. Monthly public releases of NPI files from CMS may be a source of significant empowerment to cancer incidence tracking.

A sequence of steps will be presented that other CCRs can study and implement. The presentation includes:

- 1. An overview of NPI data structure
- 2. Practical steps to use the data that include:
 - a. Pre-processing NPI data
 - b. Using taxonomy data to identify cancer care providers
 - c. Comparison with current CCR reporters list
 - d. Techniques used to contact, screen, and enlist off-roster providers

The benefits and costs of the pilot will be summarized.

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AN EVALUATION OF AUTOMATED CS DATA COLLECTION: UNLEASHING THE POWER OF THE ELECTRONIC HEALTH RECORD

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¹Cancer Care Ontario, Toronto, Ontario; ²University of Toronto, Toronto, Ontario; ³McMaster University, Hamilton, Ontario; ⁴University of Western Ontario, London, Ontario

Background: Ontario's model for population-based, cancer stage data collection centers on semi-automated data capture from synoptic (standardized) cancer pathology reports (SCPR), based on the College of American Pathologist electronic cancer checklists, submitted to the Ontario Cancer Registry in discrete data field format (DDF). An innovative software tool was developed to extract pathology-relevant stage data to be automatically pre-populated into Collaborative Stage (CS) data collection software, with manual review of clinical data in the electronic medical records by CS Analysts via remote access technologies.

Purpose: The purpose of the evaluation is to determine the impact of utilizing SCPR in DDF format on the completeness and timeliness of stage data collection.

Methods: The study will utilize a two phased, design including 1093 cancer cases (breast, colorectal, lung and prostate) across 44 hospitals, and eight analysts. Phase 1 will focus on a comparative analysis of the accuracy, and timeliness of manual versus prepopulated CS abstracts (CS V1), with Phase 2 comparing the timeliness and quality of CS abstracts using CS V2. T-tests and analysis of variance will be used to compare the impact of the methods on time required to complete the abstract and quality of information (e.g. need for overwrite). Focus groups will also be used to obtain analysts' experiences with the various methods. **Results:** The results presented will depict the completeness and timeliness of automatically pre-populated CS abstracts as compared to manual data collection, with comparisons by abstracting method and disease site. Thematic analysis of analyst's experiences will be shared.

Conclusions

Results of this study will be relevant to cancer registries and other traditionally, manually labor intensive patient data collection systems. The secondary data use of data in electronic clinical reports for cancer staging, and indicator development will also be explored.

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IMPROVEMENTS TO A WEB-BASED APPLICATION FOR PHYSICIAN OFFICE CANCER CASE REPORTING

<u>AA Austin</u>¹, AR Kahn¹, LA Bonanni¹, CG Sherman¹, JL Connell¹, JW Hoey¹, MJ Schymura¹ ¹New York State Cancer Registry, New York State Department of Health, Albany, NY

Based on the "best source" variable, about 2.3% of malignant cancer cases diagnosed 2006-2007 in New York State (NYS) were reported by physician offices, compared to 4.4% in the SEER 17 registries. Physician reports accounted for 5.1% of prostate cancers in NYS and 8.8% in SEER registries; for melanoma, physicians were the reporting source for 12.9% and 19.1% in NYS and SEER registries, respectively. Similar differences are noted for some hematopoietic malignancies.

To collect complete cancer information of non-hospitalized cases for which we had laboratory reports, the New York State Cancer Registry (NYSCR) implemented a laboratory followback program in 2005. As part of our followback program, we developed a secure Web-based reporting system for private practitioners and deployed it in 2009.

In 2010, we made substantial improvements to the electronic reporting system which included the following: a mechanism to submit new cases as well as followback requests; specific modules targeting cancers frequently diagnosed and treated in physician offices (melanoma, prostate cancer, hematopoietic malignancies); almost exclusive use of text drop down lists from which codes are mapped directly to the database; inclusion of more required fields; increased number of error edits that prompt users based on missing or inconsistent fields; and incorporation of hover tools to assist users.

We recognize the burden that public health laws place on physicians; however, we know that increasingly, patients are diagnosed and treated for cancer within the outpatient medical practice setting and we may not be informed about the case in a timely manner, if at all. This redesign focused on the premise that physicians themselves will not do the reporting and that the medical knowledge and experience among those designated to report will vary. This presentation will highlight the features of the application and lessons learned during the first six months of implementation.



A WEB-BASED SOFTWARE APPLICATION FOR CASEFINDING FROM EPATH REPORTS

<u>I Hands</u>¹, J Stewart¹ ¹Kentucky Cancer Registry, Lexington, KY

The KY Cancer Registry (KCR) receives nearly all cancer-related pathology reports of cancer diagnoses for the state's residents. Reports are transmitted to KCR as an electronic feed through various health information networks and are parsed into a database for retrieval and analysis. KCR has developed a webbased software application to filter, search, and view the more than 300,000 reports for casefinding at both the hospital and central registries. This web application is currently used to generate casefinding lists for the largest hospital group in KY and for central registry staff. It has proven invaluable for case finding audits, special studies, and overall improvement of case identification.

KCR used a combination of open source and commercial software tools to build a web application that accesses the epath database and generates casefinding lists in Excel, CSV file, or plain text formats. Individual epath reports can be viewed either directly in a web browser or as a PDF, including both a human readable rendering of the epath report and the original HL7 source. Epath casefinding lists can be generated based on multiple filter criteria such as facility, specimen date, epath message date, or KCR receipt date. Casefinding reports are highly customizable to show any subset of hundreds of data fields, final diagnosis summaries, and several coded values such as histology, topography, and diagnosis codes. The web application is built on top of a state of the art informatics framework and back-office infrastructure developed at KCR for use in many of our software projects.

A demo of the software will be shown with use cases for case finding and epath audits. The software tools, custom software framework, and systems infrastructure created to support the application will also be discussed.

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MONITORING ELECTRONIC REPORT FLOW VIA A RESTFUL WEB APPLICATION D Rust¹

¹Kentucky Cancer Registry, Lexington, Kentucky

The Kentucky Cancer Registry (KCR) began Epath reporting in November 2004. As of now, 39 of 48 pathology facilities report to the KCR and we receive about 91% of all cancer reports electronically. These facilities have accumulated over 300,000 reports with a flow rate of almost 2,000 per week.

Currently, two systems deliver Epath messages: AIM's (Aritifical Intelligence in Medicine Inc.) Transmed System and PHIN-MS (Pulic Health Information Network Messaging System). The sending feeds sometimes lose connection with KCR, and daily emails help analysts to determine the status of these connections. These emails contain a list of sending facilities paired with their respective accumulation of reports for the day. However, these repetitive emails can be an annoyance and are often cumbersome to read.

KCR is developing an application which plots the flow of Epath reports. This application uses two main analytic tools; an interactive chart and a grid that enables the KCR to view the status of incoming Epath reports in real time, without waiting for daily emails to be sent. This new monitoring system is a web application, and it is scalable in multiple dimesions (monitored facilities, covered time, etc.). It provides a unique and simple way to monitor electronic feeds.

In the presentation we will discuss the architecture of the application as well as the methods of data transaction. A thorough demo will show a very intricate approach in analyzing report flow.

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AUTOMATED DETECTION OF CANCER IN DIAGNOSTIC IMAGING REPORTS

<u>G Cernile</u>¹, S March² ¹Artificial Intelligence In Medicine Inc, Toronto, Ontario; ²QuantumMark LLC., Reno, Nevada

E-Path technology has proven adept at automatically detecting cases of cancer from histological diagnoses with a high level of sensitivity and specificity. However, not all cancers are histologically confirmed. Neoplasms of the central nervous system are often identified by diagnostic imaging, as are some lesions of the pancreas, biliary tract, and lung, with no subsequent histological confirmation. Finding these cancers by manual review is difficult since the prevalence of cancer diagnoses in imaging examinations is low. This may be one reason that CNS neoplasms are under reported or reported late.

A project to investigate the identification of CNS neoplasms by computer analysis of the text of imaging reports has been undertaken by QuantumMark LLC (Reno) and AIM Inc. (Toronto). In conjunction with the Small Business Innovation Research Program, this project is funded in part with Federal funds from the National Cancer Institute, National Institutes of Health, Department of Health and Human Services, under Contract No. HHSN261200900040C. The project team includes several radiology data providers, cancer registries, and a team of experts to evaluate test results.

Owing to the scope and breadth of diagnostic imaging examinations, raw data are first filtered by procedure codes to identify examinations of interest. Natural language processing analysis is then used to identify reportable cancers. Preliminary findings from a corpus of MRI studies of the brain and CT scans of the head show a sensitivity of 97% and a specificity of 98%. We expect the performance to improve with on-going tuning of the filters and natural language processing components. Ultimately, we envision a commercially viable E-Path compatible system that expands electronic cancer reporting beyond pathology, makes rapid case ascertainment of CNS and pancreatic neoplasms feasible, and perhaps differentiates between primary neoplasms and metastatic lesions. 12

EFFICIENCY AND ACCURACY USING THE CANCER PATHOLOGY REPORTS SELECTION ALGORITHM (CPRSA): A PILOT STUDY

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Background: Guidelines for electronic pathology (E-Path) reporting recommend that central cancer registries develop mechanisms for ascertaining cases from hospital and non-hospital sources to maintain a complete and accurate count of cases. The main challenge for the Puerto Rico Central Cancer Registry (PRCCR) was to establish an accurate and efficient selection mechanism for reportable neoplasms for use by the pathology laboratories. Objective: To develop a selection algorithm that identifies reportable cases to improve case ascertainment. Method: Pathology reports processed by a representative pathological laboratory in Puerto Rico (PR) were used to design and develop the CPRSA. To select the reportable neoplasms pathology reports, the CPRSA uses the NAACCR Search Terms List for Screening Pathology Reports and other supporting tables created by PRCCR. A CTR evaluated a random sample of the pathology reports previously classified as reportable or non reportable by the CPRSA setting a gold standard. Sensitivity, specificity, and positive and negative predictive values were calculated for both types of screening: using the NAACCR Search Terms List only, and using the CPRSA to assess accuracy. Results: We developed the CPRSA using iterative process to minimize the selection of false positive reports. After fine-tuning we reached an acceptable level of sensitivity and specificity. Selected reports using the NAACCR Search Terms List only vs. the reports selected by the CPRSA were compared: the sensitivity and specificity increased significantly when using the CPRSA. Implications: The pilot study shows that the CPRSA is an effective tool that improves case screening by increasing case ascertainment and, at the same time, reduces the resources needed to conduct this task. Our algorithm also allows the selection of pathology reports with negative findings from patients previously diagnosed with a reportable neoplasm to implement future passive follow-up mechanism.



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EXPLAINING THE GEOGRAPHIC DISTRIBUTION OF COLORECTAL CANCER SURVIVAL: AN IOWA EXAMPLE K Matthews¹

¹University of Iowa - Dept of Geography, Iowa City, IA

Like many epidemiological outcomes, quantity of life after diagnosis also varies by geographic location. I hypothesize that the geographic variability in the length of survival time is a function of the underlying population's access to health care, their socioeconomic conditions and related health behaviors. This research demonstrates a novel approach to adjust for known risk-factors associated with decreased colorectal cancer survival (age, race, gender and stage) and for modeling its geographic variability by within each Primary Care Service Area (PCSA) in Iowa. If geocodes are available, these methods can generalized to analyze the survival rate of any disease recorded in a cancer or reportable disease registry.

Data from the State Health Registry of Iowa, an NAACCR member registry and a SEER registry, identify the study population and their residential locations. The study population is all persons aged 50 and older newly diagnosed with colorectal cancer between 1997 and 2007. A survival analysis method called Cox Proportional Hazard modeling will be conducted within the Stata statistical software environment. Results from this model are then mapped at the PCSA level using ArcGIS 10, a geographic information analysis software.

Maps, charts and tables will depict the statistically significant relationships between the geographic distribution of colorectal cancer survival rates and its explanatory factors. My results show that the variance in colorectal survival rates per PCSA is statistically significant and that this geographic variance can be explained as a function of the PCSA's socioeconomic condition, demographic characteristics and access to health care.

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ASSESSING FACTORS THAT INFLUENCE IMPACT OF MISSOURI'S BREAST AND CERVICAL CANCER CONTROL PROGRAM ON BREAST CANCER IN THE STATE

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Background: The Missouri Cancer Registry (MCR) and Show Me Healthy Women (SMHW), Missouri's breast and cervical cancer control program, have conducted annual linkages for > 10 years but haven't made detailed studies or comparisons. A goal of the National Breast and Cervical Cancer Early Detection Program (NBCCEDP) is to address environmental factors to plan, manage and communicate priorities to achieve program efficiency and effectiveness. Our research efforts will address recent evidence of population declines in mammography rates and increases in the eligible population due to more uninsured women and an aging population. Purpose: 1) Develop a comparative framework for evaluation of the impact of SMHW; and 2) Identify factors that may contribute to diagnosis, treatment and outcome disparities in Missouri. Methods: Two new NBCCEDP variables, date of linkage and linkage status, allowed us to configure an extract file of SMHW patients from 2004-09. We evaluated SMHW breast cancer cases as a subset of all female breast cancer cases in the MCR database along with Missouri-specific SMHW program data, Behavioral Risk Factor Surveillance System (BRFSS) and Missouri county-level data. Health Profession Shortage areas (HPSAs), publicly available through HRSA (http://bhpr.hrsa.gov/shortage/), were also taken into account. Results: Sub-state analysis from this project will provide data and a framework to measure SMHW program quality and impact as well as identify sub-state areas where Missouri women are disproportionally at risk of excess late-stage diagnosis and mortality from breast cancer. Implications: Examining these factors to assess SMHW impact is as an innovative use of cancer registry data toward meeting NBCCEDP goals. Reports we create will demonstrate the use of cancer registries and cancer registry data for program planning and evaluation and provide a mechanism to make data-driven policy decisions to improve health outcomes among cancer patients.

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EARLY-STAGE LUNG CANCER SURVIVAL IN KENTUCKY: EXPLORING THE INFLUENCE OF SMOKING CESSATION AND MENTAL HEALTH STATUS

<u>C Hopenhayn</u>¹, W Christian¹, A Christian¹, J Nee¹, J Studts¹, T Mullett¹

¹University of Kentucky, Lexington, KY

BACKGROUND: About 70% of lung cancer cases are diagnosed at Stage III or IV, and the overall five-year survival rate is only 16%. Recent research suggests, however, that survival could improve with advances in early detection, and non-clinical factors could thus play a greater role in survival. For example, smoking cessation after diagnosis has been shown to influence survival. This study combines prospective data collection with cancer registry data to explore prognostic factors for early stage (Stages I and II) lung cancer.

METHODS: Patients are recruited in collaboration with the Kentucky Clinical Trials Network at seven sites in Kentucky. Three questionnaires are administered to participants after pathological confirmation and staging to gather data on smoking history, family and occupational history, potential exposure to carcinogens, and psychosocial indicators. Data are then linked to the Kentucky Cancer Registry to incorporate clinical and survival data, and facilitate follow-up.

RESULTS: At this time, the study has enrolled 106 subjects, with over 150 expected at the time of this presentation. Preliminary results indicate that 40% of study participants were former smokers at diagnosis, 37% quit after being diagnosed, and 23% continued smoking. Among those in the latter two groups, those who quit had a significantly (p<0.01) lower mean score on the Hospital Anxiety and Depression Scale than those who did not. Preliminary analysis of survival vis-à-vis smoking cessation and mental health should be possible by the time of this presentation.

CONCLUSION: Smoking cessation improves outcomes among those with early stage lung cancer, and is associated with lower levels of anxiety/depression. Effective smoking cessation programs that also address patients' mental health could improve survival. Future work will expand recruitment, refine data collection, address other potential prognostic indicators, and explore biomarkers in tumor samples.

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USING RACE/ETHNIC COMPARISONS TO EXPLORE BREAST CARCINOMA IN SITU (CIS) INCIDENCE AND BREAST CANCER MORTALITY RATE TRENDS IN CALIFORNIA. 1988-2007

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Background: Early detection has produced a record rise in breast CIS, while age-adjusted breast cancer mortality rates declined more moderately. **Objectives:** We used 1988-2007 California data to assess race/ethnic (R/E) trend differences in annual age-adjusted breast CIS incidence and mortality rates and correspondence between trends for R/E-specific CIS incidence and breast cancer mortality rates.

Methods: Age-adjusted CIS incidence rate trends among Asian/Other (A/O), Hispanic (Hisp), and non-Hisp black (NHB) women were compared for parallelism with the trend for non-Hisp whites (NHW). Similar tests were conducted for breast cancer mortality rate trends. Other comparisons assessed parallelism between R/E-specific incidence trends for CIS and mirror image mortality rate trends.

Results: Differences in trend slopes for CIS are seen for contrasts between NHW and A/O (percent difference in slopes and 95% CL is 5.44; 4.19, 6.65), NHB (3.14; 2.09, 4.14), and Hisp (5.37; 4.13, 6.61) women. Similar tests between NHW and each of the other R/E groups are seen for mortality rate slopes in A/O (1.29; 0.64, 2.01), NHB (0.84; 0.49, 1.21), and Hisp (0.05; 0.07, 0.95) women. Slope comparisons for each R/E group assessing parallelism between CIS incidence and mirror image mortality rates are: A/O (9.05; 7.84, 10.27), NHB (6.30; 5.44, 7.16), Hisp (8.19; 7.03, 9.33), and NHW (2.34; 1.65, 2.99) women.

Conclusions: Deviation between CIS incidence and mirror image mortality rate slopes is greatest for A/O and Hisp and least for NHW women. Upward slopes in age-adjusted breast CIS rate trends for NHW women differed from those for other R/E groups. Declines in breast cancer mortality rate trends were greatest and the rise in CIS was least for NHW compared to other R/E. These findings are consistent with earlier screening penetration, signified by higher initial CIS incidence, among NHW compared to other R/E groups and forecast continued declines in breast cancer mortality.



A TRANSDISCIPLINARY FRAMEWORK FOR COMMUNICATING CANCER REGISTRY DATA TO THE PUBLIC

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BACKGROUND: The general public is increasingly exposed to sophisticated visual displays of data. To keep pace, the cancer control community must develop clear and compelling ways to share new knowledge with the public and other audiences. **PURPOSE:** To help guide these efforts, we developed a transdisciplinary framework that integrates principles of information design, information processing and persuasive communication to understand how visual displays of cancer registry data are processed and understood by general audiences.

METHODS: A transdisciplinary team of communication scientists, cancer epidemiologists and information designers convened a series of meetings to determine best practices from each discipline[kk1].

RESULTS: Our transdisciplinary framework emphasizes the importance of information design principles (i.e., hierarchy, consistency and variation[Im2]) and describes how they may affect individuals' understanding and response to a visual display of data.

IMPLICATIONS: We assert that this transdisciplinary framework will help the cancer control community and cancer registries use data more purposefully and effectively.

KEY WORDS:

Information design, visual design, information processing, health communication, cancer communication, visual displays, transdisciplinary model, data visualization, persuasion, public health

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TECHNICAL FEASIBILITY OF ESTABLISHING A PROACTIVE CANCER CLUSTER SURVEILLANCE SYSTEM

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Many government public health agencies routinely receive citizen requests to assess perceived elevated rates of cancer incidence. Not only are the frequency and nature of ensuing investigations time- and personnel-intensive, but their reactionary - as opposed to proactive characteristic creates situations which may violate traditional a priori statistical hypothesis testing. Lack of technical and statistical expertise, as well as standard national protocol, have also been identified by public health agencies as barriers to address community cancer concerns. The purpose of this study is to summarize the technical and statistical feasibility of conducting proactive cancer cluster surveillance. The spatial clustering software SaTScan will be used to demonstrate the feasibility of proactively surveilling a health department's cancer registry on a routine basis. SaTScan is freely available for download and use. A previously published SAS macro allows for quick and frequent runs of SaTScan, requiring only basic statistical and technical understanding. SaTScan results are easily interpretable in any text editing software. Further, mapping compatible files are automatically produced in every SaTScan run for the visualization of results within a Geographic Information System (GIS) or any cartographically capable software. A hypothetical dataset will be used to demonstrate the entire process from data setup, implementation of the SAS macro, and interpretation and visualization of results. This study will demonstrate the technical feasibility of initiating a proactive cancer cluster surveillance system. Many government institutions already possess the necessary physical resources to implement such a system. The routine personnel time investment required for such surveillance is likely to be offset by the resources consumed by the numerous community cancer requests that may be avoided (or, at least, more quickly addressed) with a proactive cancer cluster surveillance system.

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ASSESSING THE NON-CANCER HEALTH STATUS OF U.S. CANCER PATIENTS

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Background and Objective: Over the past 30 years, rapid scientific progress in oncology has lead to new tools for diagnosis and treatment of cancer. These advances translated into a higher proportion of cancer patients being cured and living longer. However, increased numbers of cancer survivors and treatment adverse events have made the competing mortality an increasingly relevant event in the study of cancer survivorship. The objective of this study is to provide an overall picture of survival for competing causes of death (non-cancer) for different cohorts of cancer patients. By comparing non-cancer survival with US life tables, we can assess overall health status of cancer patients exclusive of their cancer.

Methods: Data from the Surveillance, Epidemiology, and End Results (SEER) Program are used to estimate survival for competing non-cancer deaths. Left truncation survival methods are used to account for the fact that individuals come under observation after cancer diagnosis. Age, rather than the time since diagnosis, is used as the time parameter. Results are compared against sex, race, age and year of diagnosis matched US life tables.

Results: Individuals diagnosed with localized cancer have a better non-cancer survival than the general US population while individuals diagnosed with distant cancer have a lower non-cancer survival than the general US population. However, non-cancer survival for patients diagnosed with smoking related cancers (e.g., lung cancer) are lower than survival of the US population at all stages.

Conclusions: This paper quantifies the "Healthy Screener" effect for patients diagnosed with early stage cancer where screening plays a role. Conversely, it quantifies an "Unhealthy Nonscreener" effect of patients who do not seek screening or even ignore early symptoms. For cancers with common risk factors for the cancer and other cause mortality, the other cause survival is significantly worse than the general population. 20

NOURISHING A HEALTHY APPETITE FOR SURVEILLANCE STATISTICS: A CANCER REGISTRY RECIPE FOR A DATA-HUNGRY WORLD

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Objective: Centered on data in the Manitoba Cancer Registry, CancerCare Manitoba's comprehensive 2010 Community Health Assessment (CHA) measures the performance of the province's cancer system by examining over 20 health indicators, stratified by geography, type of cancer, and time period.

Methods: Indicators of cancer risk factor prevalence, screening participation, access to treatment, and outcomes have been carefully developed to reflect the most current, complete data available. The report was designed to appeal to a variety of users. Data are presented in several ways (tables, graphs and explanatory text in the form of questions and answers) to address various learning styles. We used extensive end-user engagement to ensure confidence in the results and ultimate uptake.

Results: Variation exists by service, geography and type of cancer, as well as over time. The CHA's 'omnibus' format, with indicators across the cancer control continuum presented in one place, has identified challenges not observed previously, e.g. high late-stage prostate cancer rates correlating with high prostate cancer mortality rates in the North (double the provincial average). Indeed, analysis showed consistent challenges in the northern (remote) areas of the province.

Conclusions: Measurement is an essential part of good cancer system management. By working with end-users and presenting data in an appealing format, we are reinforcing the need for population-based cancer data in health system planning in Manitoba. This approach has met with enthusiasm and has raised the profile of the Manitoba Cancer Registry, as evidenced by positive media and public officials' responses.

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Oral Abstracts

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oral abstracts

concurrent session 2



UPDATE ON NCRA INFORMATICS EFFORTS

<u>HR Menck</u>¹, EHR Policy Group Networking Subcommittee¹, Informatics Guidebook Subcommittee¹ ¹University of Southern California, Los Angeles, CA

Background: The agendas of NAACCR and NCRA both are concerned with the cancer data standards and interoperability. In this era of the electronic health record and electronic medical record (EHR/EMR) revolution, the role of Informatics has been underscored. Purpose: To present NCRA Informatics Committee activity to the NAACCR membership, for purposes of coordination. Methods: Two Subcommittees of the NCRA Informatics Committee were formed; including the Informatics Guidebook Subcommittee, and the EHR Policy Group Networking Subcommittee. **Results:** The purpose of the Informatics Guidebook Subcommittee is to develop, maintain and publicize a Guidebook for Informatics, and a document of Informatics Success Stories for registrars. The EHR Policy Group Networking Subcommittee was established with multiple purposes: to identify organizations engaged in the development and implementation of standards to monitor the integration of these standards and to assess the impact such standards may have on cancer registry activities; to comment on proposed national standards; to report on findings to the NCRA Board and membership; to partner with organizations such as the North American Association of Central Cancer Registries; and to suggest ways to meet challenges in adopting new practices. Some progress has been made in coordinating NCRA Informatics efforts with the IT and Interoperability Committees of NAACCR. Some members serve on both organization's Committees and some formal Liaisons have been appointed. Conclusions: The enormity of establishing Informatics training resources, understanding the different aspects and organizations important to the EHR/EMR revolution, being proactive in influencing these changes, and informing the membership in an era of large scale Collaborative Stage, and other changes, is not yet realized, nor even a clear pathway envisioned. The progress made to date may not be sufficient.

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CYBER CANCER REGISTRY: WHERE WE ARE - WHERE WE ARE GOING

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BACKGROUND: Access to practical training for cancer registry professionals is limited. Practical training is needed in diverse formats and methods of access.

OBJECTIVE: CDC's National Program of Cancer Registries (CDC/NPCR) Cyber Cancer Registry is a web-based interactive tool that allows users to log in and practice or test their skills in casefinding and abstracting. The application gives immediate feedback to users in practical exercises to assess the level of competency in cancer registry skills. METHODS: CDC/NPCR staff. NG contract staff. and NCRA (subcontractors) designed the Casefinding Module and Abstracting Modules. Modules have been created with real medical record data. The user determines whether they log in to practice or to test themselves. A certificate is provided for the training once completed. The software has online help, registry manual links, and reference materials. After one year of use, user statistics show >1100 users have logged into the Casefinding Module. This presentation displays the types of users, experience level, and accuracy from the use of the Casefinding Module. This presentation also previews the new Abstracting Module. This module allows the user to practice or test in abstracting skills. There is a "non-hospital" component that allows central registry staff to train physician office staff remotely for reporting cancer. Physician office staff can log in and practice any time and get immediate feedback. There are display types for Dermatology, Urology, Radiation Oncology, Medical Oncology/Hematology, and Free Standing Surgery Clinics. Central registry staff can log in and practice or test their ability to complete a physician's office abstract. NEXT STEPS: CDC/NPCR will complete an analysis of the 1st year's data from the Abstracting Module. Future phases of the application may include a Record Consolidation Module, Editing Module, and/or a Death Clearance Module.

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Oral Abstracts

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RESULTS OF THE NCRA HOSPITAL WORKLOAD STUDY

<u>HR Menck</u>¹, UCSF Center for the Health Professions¹, NCRA Workload Management Task Force¹ ¹USC, Los Angeles, CA

Background: Workload and staffing guidelines are critical to the advancement of the cancer registration profession. Having a cost-effective staffing model is important to produce high quality and timely data in the most efficient way. NCRA commissioned the UCSF Center for the Health Professions to study current practices. Additional support was received from the Commission on Cancer(CoC)and from the NPCR. Purpose: To better understand workload management patterns of hospital cancer registries. Methods: A web-based survey of hospital cancer registries was conducted by UCSF. The survey instrument was developed and tested by UCSF, and CoC, NCRA and NPCR advisors. The survey population included all CoC-accredited programs with annual caseloads of 200 or greater in 2004, 2005, or 2006. A total of 1240 programs were invited to participate. A total of 662 programs responded, for a response of 53%. **Results:** The average number of newly accessioned cases ranged from 101 to several thousand, with a mean of 1,301. The live cases under follow-up ranged from 223 to 70,000, with a mean of 8,003. The average number of FTEs reported ranged from 0.2 to 23, with an average of 2.8. Staff size was analyzed as a function of annual caseload in work categories of casefinding, abstracting, active and passive follow-up, quality assurance, and all other activities, and will be presented in detail. **Conclusions:** The data presented provides a rich source of staff benchmarking information. Registries can and should self-assess their staffing versus these current practice guidelines.

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ECONOMIC ANALYSIS OF THE NATIONAL PROGRAM OF CANCER REGISTRIES: INITIAL FINDINGS

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Background: In 2005, the Centers for Disease Control and Prevention (CDC) initiated an economic evaluation of the National Program of Cancer Registries (NPCR) to assess the cost associated with registry operations, identify factors that impact cost, perform cost-effectiveness analysis, and develop a resource allocation tool of central cancer registries' (CCR) operations. An assessment of the resources expended on CCR activities will provide critical information for improving efficiency of the NPCR. A web-based cost assessment tool (web-CAT) was pilot-tested and deployed to collect data from CCRs in 45 states, the District of Columbia, Puerto Rico, and the U.S. Pacific Island Jurisdictions. A multi-year evaluation is in progress, and findings from the first year of data are now available. Purpose: In this study, we examine the economic costs associated with operating a CCR particularly those costs related to performing core surveillance activities versus advanced surveillance activities. Methods: We developed a web-based cost assessment tool (web-CAT) to collect data from each NPCR-funded registry on all registry activities (including those funded by other sources). Data on actual expenditures were allocated to specific core and advanced activities. In-kind contributions were reported to assess the true economic cost of registry operations. **Results:** The cost per incident case reported will be presented overall and for each registry activity. Data will be presented by volume of cases reported, sources of other funding, registry structure, and for registries with and without major contractors. Conclusion: The findings from this study will allow CDC and the registries to better understand the resources required to operate a CCR.

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MULTIDISCIPLINARY APPROACH TO TIMELY REPORTING OF SURVEILLANCE STATISTICS: UTILITY OF SEER FEBRUARY SUBMISSION FILES

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Background: A priority area for the Surveillance Research Program (SRP) at the National Cancer Institute (NCI) is collecting quality data more efficiently and reporting cancer statistics more quickly. Purpose: To describe the quality and timeliness of SEER cancer incidence data using its February 2011 submission, and assess the feasibility of publishing preliminary 2009 incidence rates using these data. Methods: SEER registries submit data to NCI semiannually. For this study, data will include incidence cases diagnosed through 12/31/2009 and submitted in the NAACCR format as part of the February 2011 SEER submission. Completeness will be assessed based on trends and on area-specific population-based estimates. Record edits and data quality profile reports will be generated on a limited set of data elements. Data quality will be assessed by reporting source and region, and primary cancer site. Results: The February SEER submission represents a 14-month lag in reporting to SEER, which is 9 months earlier than the traditional full data submission in November. Aggregated tabular counts of 2008-2010 SEER February submission data has indicated high completeness rates (over 90%) with substantial variation across registries and cancer type. Quality of data elements (e.g., site, histology, behavior, age, gender, race, Spanish Origin) are also expected to vary across registries and by cancer type, but are anticipated to have high rates of completion (known values). Conclusion: The dissemination of cancer surveillance data is important for cancer prevention and control. Providing these data in a more timely fashion is possible although some limitations exist. NCI's SEER Program draws upon registry expertise, advanced informatics and technology, process improvement, multi-tier work flow, and applied statistical methodology to achieve significant improvements in obtaining more timely cancer surveillance data without sacrificing quality.

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SEER*ABS ABSTRACTING TOOL

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The NCI SEER Program developed the SEER*Abs abstracting tool, a fully configurable tool which is available at no charge to any registry. The screen layouts, search tools, export file formats, and integrated edits can be configured by registry staff. The synchronization component supports integration with any registry management system.

This presentation will highlight the flexibility and adaptability of the SEER*Abs software:

The declarative design model allowed registries to convert from NAACCR 11 to NAACCR 12 without modifications to database structures or software.

SEER*Abs can be customized for ad hoc data collection activities such as the CSv2 Data Availability Assessment.

SEER*Abs supports the SEER edits and other edit sets that are compatible with the SEER edits engine.

The integrated components include the CSv2 module, SEER*Rx database, and Hematopoietic Database.

Five central cancer registries configured SEER*Abs to support their specific abstracting needs.

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IMPROVING ASCERTAINMENT AND COMPLETENESS: THE PUERTO RICO CENTRAL CANCER REGISTRY EXPERIENCE

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Background: The Puerto Rico Central Cancer Registry (PRCCR) has been struggling with the completeness and timeliness standards for several years due to poor reporting of physicians. In our effort to complete the reports for the years 2005 through 2007, the PRCCR designed the Case Recovery Project (CRP) to collect these cases in the physicians' offices. **Objective**: To collect missed cases from patients with treatment plans exclusively at physicians' office, thus not requiring treatment from a hospital. Methods: Missing cases were identified through pathologic reports received from laboratories, which included the physicians' name who generated (referred) the pathologic report. Reports with positive findings and identified as missed cases were classified by physician specialty and ranked by number of cases owed to the PRCCR, which helped us prioritize the search of the missed cases. Eight persons were hired and provided with fast track training for two months. Once trained, the field registrars visited medical offices to abstract patient information on cases previously identified by the PRCCR as missed. Each registrar was equipped with a password secured laptop computer, a list of patients with a pre-filled abstract on Abstract Plus, and copies of the pathologic report, in PDF format. Results: Analysis of the pathology reports for the missing cases showed that the main debtors were Urologists, Hematologists and Dermatologists, accounting for 48.5% of the missed cases. An average of 500 newly identified cancer cases were collected each month. We expect to collect approximately 5000 new cases and share the learned lessons during the CRP. **Implications:** By the end of the CRP we anticipate that the data and case completeness corresponding to the years of 2005-2007 will reach at least 95% of expected cases.

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THE USE OF CAUSE-SPECIFIC SURVIVAL IN SEER POPULATION-BASED REGISTRIES WHEN RELATIVE SURVIVAL FAILS

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The strength of the relative survival rate is that information on cause of death is not needed. Expected rates for the general population are used in the denominator of the calculation. What if one wanted to calculate survival for Native Americans? Lifetables aren't readily available and calculation is difficult since mortality rates are understated for Native Americans. Cause-specific survival can be used to obviate this problem. Cause-specific (c-s) survival rates are calculated based on the underlying cause of death (COD) as coded on the death certificate. COD has become more available to SEER population-based registries and only a small percentage of cases lack this information.

This project developed tables of CODs to be considered as a death due to a specific cancer for several versions of ICD. Using only the site-specific cancer as the COD overestimates the c-s survival rates. Decisions were made on what should be considered a death due to cancer based on primary site and sequence number. The COD table is more extensive for cancers that are the only cancer for an individual compared to the first of more than one cancer. For those with one and only one cancer, any cancer was classified as a death due to the specific cancer under study. When looking at the first of multiple cancers, only that specific cancer site plus other related sites which represent common misclassifications were chosen. For example, for rectal cancer, many deaths are listed as colon cancer. The accuracy of the COD is also evaluated. In some instances, the COD may reflect the site to which the cancer metastasized rather than the primary site. Another potential problem is primary site/histology groups where the COD may be less specific than the original diagnosis. Survival rates by specific racial group are shown along with examples where the c-s survival rates perform similar to or better than relative survival rates.

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CANADIAN EXPERIENCE CREATING GEOGRAPHIC ATTRIBUTES DATA IN SEER SOFTWARE

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Background: Surveillance Epidemiology and End Results (SEER) software provide a convenient mechanism to analyze, manage, and disseminate cancer data. SEER software offer a facility called *county attributes* in U.S. SEER databases. The county attributes database is a geographic attributes link file which provides functionality for handling geographic variables within a uniform platform. The chief advantage of this structure is all geographic attributes are maintained separately from patient and population data. In the past year, Cancer Care NS has started to create SEER databases for its provincial cancer data and introducing a geographic attributes link facility is an important part of the work.

Purpose & Methods: The purpose of this study is to implement a geographic attributes facility in NS cancer data. Census Dissemination Area (DA) is the basic geographic unit in the Canadian Census. DA's are small areas with a population of 400 to 700 persons that can be aggregated into larger geographic unit, such as county or District Health Authority. Various information is collected on DA level, such as income, immigration, education, and labor force activity. DA was chosen as the geographic unit in this study and a unique geographic ID (GeoID) was assigned to each DA. A GeoID was then assigned in the patient data, according to residential postal code. Population data is also available for each DA. Geographic attribute variables for a DA were assembled in the geographic link data. Median household income and household income quintiles were selected for demonstration. Population, Patient, and geographic attributes databases were linked using the GeoID.

Conclusions: The geographic link facility provides an excellent mechanism to analyze cancer incidence and mortality utilizing underlying geographic attributes. Implementation of this facility in Canadian cancer data will expand and strengthen the utilization of SEER software in Canadian cancer research and surveillance.

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THE IMPACT OF THE PAN-CANADIAN CANCER SURVEILLANCE AND EPIDEMIOLOGY NETWORKS B Candas¹, J Shin¹

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BACKGROUND: In 2009, the Canadian Partnership Against Cancer (the Partnership) implemented four pan-Canadian Cancer Surveillance and Epidemiology Networks (CSENs) to meet the challenges of producing timely and quality surveillance products to monitor and inform cancer control initiatives throughout Canada. CSENs address: the entire continuum of colorectal cancer, survival and prevalence methodologies, projection methodologies, and palliative care.

PURPOSE: A CSEN evaluation will be performed: 1) a scientific evaluation of products generated by the networks and; 2) a program evaluation of the CSEN initiative from its inception whereby the performance of the program initiative measured against its objectives will be conducted.

METHODS: An International Scientific Advisory Committee has been set up to evaluate the scientific quality of the work plans, methods and products generated by CSENs. An Evaluation Working Group will assess the program design, implementation, and outcomes through a formative approach. An emphasis on the added value contributed by CSENs to stakeholders (cancer surveillance community, decision makers), will be central in this evaluation.

RESULTS: CSEN has demonstrated characteristics typical of successful networks. It has created pan-Canadian standards, increased analytic capacity within member cancer agencies and a produced high quality reports. Content expertise and resource capacity have been successfully leveraged through the networks to address gaps. Aligning formal project management methodologies and scientific approaches to meeting deliverables continues to be challenge.

CONCLUSION: The evaluation will inform approaches that will enhance the CSENs model in terms of its structure and the products generated by the networks. This information will help inform the Partnership on future network models within cancer surveillance as it plans for its next mandate.

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Oral Abstracts

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IMPACT OF MISSING DATA ON TEMPORAL TRENDS: AN APPLICATION OF MULTIPLE IMPUTATION (MI) IN BREAST CANCER USING POPULATION-BASED SEER CANCER REGISTRY DATA

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Background: Studies describing temporal incidence trends among women with estrogen receptor (ER) positive breast cancer using population-based cancer registry data continues to be a topic of interest. However, such biomarker data are often prone to missing observations and could bias the trend if proper adjustments are not made. Our objective is to impute missing ER status using MI and examine temporal incidence trends before and after imputation of unknown ER status. Methods: We analyzed breast cancer incidence data from 13 registries that are part of the Surveillance, Epidemiology, and End Results (SEER) database and represent approximately 14 percent of the US population. ER status was imputed for those with missing information using multivariate sequential regression method. Covariates used to impute ER status include age at diagnosis, SEER registry, year of diagnosis, race, ethnicity, progesterone receptor status, tumor size, grade, histology, lymph node status, and year 2000 county level poverty data. Results: Overall, 15% of the cases diagnosed with breast cancer had missing ER status in SEER-13 registries. The distribution of missingness varied over time and over age groups. For example, for age <50: unknown ER status ranged from 21% in 1992 to 6% in 2007; age 50-64 from 23% in 1992 to 6% in 2007; and age 65+ from 27% in 1992 to 9% in 2007. Blacks were more likely to have missing ER status compared to whites. Majority (75%) of the unknown ER tumors were allocated to ER positive tumors after imputation. Finally, age-adjusted incidence rates using imputed ER status were higher compared to observed ER status but the shape of the trend line remained unchanged. Conclusion: The changing distribution of unknown ER status over time influences ER positive and ER negative temporal trends. Imputed data set can be made available through SEER*STAT to facilitate analyses of breast cancer data that includes ER status.

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USING CANCER REGISTRY DATA TO ADVANCE THE SCIENCE OF DRUG SAFETY: RESULTS FROM AN ONGOING POST-MARKETING DRUG SAFETY SURVEILLANCE STUDY OF ADULT OSTEOSARCOMA K Midkiff¹, A Gilsenan¹, Y Wu¹, D Harris¹, D Masica², E Andrews¹ ¹RTI Health Solutions, RTP, NC; ²Eli Lilly & Co., Indianapolis, IN

Background: Adult osteosarcoma is very rare, and few population-based studies are reported in the literature. To monitor for a potential signal of a possible association between teriparatide treatment and osteosarcoma, a 15-year surveillance study was initiated in 2002. Objective: Characterize treatment and environmental exposures and the demographic profile in patients in a safety surveillance study. Methods: Incident cases of adult osteosarcoma diagnosed on or after January 1, 2003. are identified through cancer registries in the US. Currently, 15 US registries are participating (12 state registries, 1 regional registry, and 2 academic cancer centers). After consent, case information about demographics, prior treatment with medications, and exposure to possible risk factors is ascertained by telephone interview. Results: As of September 30, 2010, 1,236 patients diagnosed between January 1, 2003, and December 31, 2008, had been identified and 449 were interviewed. Characteristics were similar for interviewed and noninterviewed cases. Among cases interviewed, mean age was 60 years, 45% were female, and 83% were white. Osteosarcoma NOS (71%) and chondroblastic osteosarcoma (13%) were the most common morphologic types; leg bones (31%) and pelvis/sacrum (16%) were the most common anatomical tumor sites. Reported prevalence of possible risk factors was 26% for prior history of cancer, 20% for prior trauma or infection at site of cancer, 19% for history of radiation therapy, and 6% for history of Paget's disease. No cases reported use of teriparatide before development of osteosarcoma. Conclusions: Data from this 15year surveillance study advance the knowledge about the long-term safety of teriparatide. After 6 years of data collection, there is no signal of a causal association between teriparatide and osteosarcoma. Ongoing results expand on information from the literature and describe the distribution of possible risk factors among osteosarcoma patients.



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USING CANCER REGISTRY DATA FOR POST-MARKETING SURVEILLANCE OF RARE CANCERS

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Background: Diethylstilbestrol (DES) exposure and risk of clear cell adenocarcinma of the vagina and cervix (CCA) was first reported in 1971. Subsequent case reports and cohort studies suggest that CCA risk may persist with age and that DES may be associated with other cancers, including those in men. **Objective**: To show how cancer registry data can monitor the risk of CCA and other rare cancers. Methods: Data from the National Program of Cancer Registries (NPCR) and Surveillance, Epidemiology and End Results (SEER) Program were used to construct indirect standardized incidence ratios (SIR) comparing cancers diagnosed among patients born before, during and after 1947 through 1971 when DES was prescribed to pregnant women. Incidence rates among patients born before 1947 or after 1971 were applied to "exposed" person-years at risk in the SEER and NPCR/SEER datasets to calculate expected case counts and compare them to observed counts. Results: Among women between 15 - 29 yrs of age, CCA risk peaked in the 25-29 yr age group (SIR=6.1; 95% CI 3.9-9.4, SEER). Among women 40-54 yrs of age, CCA risk was greatest in the 40-44 yr age group (SIR=4.6; 95% CI 2.9-7.1, SEER/ SIR=3.9; 95% CI 3.2-4.8, NPCR/SEER). CCA risk remained elevated at older ages in the NPCR/SEER dataset. Risk was not elevated among women between 30-39 yrs of age in either dataset. Data for other cancers including among men will be presented. **Conclusion:** The DES cohort remains at increased CCA risk into older ages. This may be relevant for cancer screening decisions. The FDA maintains a post-marketing surveillance program to identify adverse events not apparent during the initial drug approval process and cancer registry data could be used to help monitor rare cancers.

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SELECTING THE OPTIMAL WINDOW SIZE FOR SPATIAL SCAN STATISTICS

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The scan statistics is widely used in spatial, temporal, and spatio-temporal disease surveillance to identify areas of elevated risk and to generate hypotheses about disease etiology. In such a statistics, the area of the scanning window is allowed to vary which may take any predefined shape. It is very useful when we lack a prior knowledge about the size of the area covered by the cluster. But varying window shapes and sizes may produce different clustering patterns for the same data. This talk proposes a cluster information criterion that takes into account of likelihood, number of parameters, and power and size to evaluate the choices of varying window sizes. Simulation studies and real cancer incidence and mortality data show that the proposed cluster information criterion can identify the optimal window sizes for the purpose of disease surveillance.



SURVIVING SURVIVAL STATISTICS: USERS AND ANALYSTS UNITE! THE CANADIAN CANCER SURVIVAL AND PREVALENCE ANALYTIC NETWORK (C-SPAN) EXPERIENCE

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Objective: To produce consistent survival statistics in a usable format, the Cancer Survival and Prevalence Analytic Network (C-SPAN) is engaging both analysts and end-users (decision makers, policy makers and patient advocates). Part of the Canadian Partnership Against Cancer's (CPAC) Cancer Surveillance and Epidemiology Networks initiative, C-SPAN integrates knowledge translation (KT) strategies in the creation of cancer surveillance products. Methods: Collaborative exploration and synthesis of methodological approaches occurs through C-SPAN's Methodology Working Group; important topics have included the use of all primaries (versus the first one), age-standardizing and suppression rules. Simultaneously, KT activities involve ongoing meetings/teleconferences with endusers. Surveys are being used to monitor the success of KT in terms of increased knowledge and data use. Results: A standard approach for relative survival calculations, from data extraction to calculation of relative survival, has been developed. User guides explain the steps and rationale behind major decision points. Programs are provided in three formats: SAS, STATA, and SEER*Stat. Un-adjusted, age-standardized and age-specific relative survival estimates are generated by cancer site and geographic region; different weights (the international and an "internal" Canadian standard) provide analysts with choices in terms of presentation, and the resulting differences will be articulated in this presentation. Survey results from the end-users show that the majority of participants had encountered some cancer survival concepts but not with the same level of understanding. **Conclusions:** The methods of engagement have proven successful with both key audiences - senior surveillance analysts and end-users. This approach, which requires ongoing commitment and energy, demonstrates the utility of integrated KT for cancer surveillance analysts and users alike.

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OPPORTUNITIES FOR IMPROVING THE USE OF CANCER REGISTRY DATA IN DRUG SAFETY STUDIES: FACTORS INFLUENCING INTERVIEW RESPONSE RATE

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Background: Privacy restrictions, delays in case reporting following diagnosis, and data quality have a measurable impact on the ability to efficiently conduct observational research involving patient contact. An ongoing 15-year postmarketing drug safety surveillance study, initiated in 2002, provides the opportunity to share insights with researchers who use state cancer registry data.

Objective: To assess the impact of various research challenges across participating state, SEER regional, and comprehensive cancer center registries; to evaluate factors that contribute to a successful patient interview; and to identify opportunities to improve efficiency and quality of observational research. **Methods:** Using experience derived from this study and input solicited from specific participating registries, we will describe the different challenges (e.g., data availability, study approval delays, different pathways to access patients) and their impact on interview completion rates.

Results: We will characterize identified challenges, and patient characteristics and their impact on interview completion rates for this study. We will focus specifically on the percentage of cases identified with contact information (and eligible for telephone interview) among total cases identified, as well as the time lag of reporting cases with necessary contact information to researchers. Additionally, we will assess patient characteristics that could impact telephone interview response rate. Specific registries will be depicted in a blinded manner. Suggestions elicited from participating registries will be described. Conclusions: Challenges to the efficient conduct of observational research lead to reduced participation rates and impede progress in monitoring drug safety. Experience with multiple cancer registries provides important insights into these effects. Lessons learned from this experience may help registries improve and expand use of their data for research purposes.

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NCI SEER EDITS ENGINE: AN INTEROPERABLE APPROACH TO DATA VALIDATION

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The NCI SEER program has developed the SEER edits engine to validate incidence data stored in any format. The edits engine is a software module that can be used by any Java-based program. The edits engine was initially utilized within the SEER Data Management System to edit data stored in a relational database, and is now being shared by two Windows applications: the SEER Abstracting Tool (SEER*Abs) and SEER*Edits. In the SEER Abstracting Tool, the edit engine validates data in the data entry forms. The SEER*Edits application validates data in the NAACCR file format. The SEER edits engine is distributed with the incidence data edits defined by the SEER Program and maintained by the NAACCR EDITS Committee. The edits engine has the flexibility to support any edit converted to the Groovy scripting language.

This presentation will focus on the design of the validation engine and its use by different applications. The presentation will also describe the process for converting other edit sets into a format compatible with the SEER edits engine. The following advantages of the edits engine will be highlighted:

Flexibility – the edits logic are written in Groovy, a flexible scripting language

Automated testing of edit logic – the edits engine executes "unit tests" to validate the edit logic

Interoperability - the edits engine is a standalone library that can be added to any Java project

Maintainability – All edits within the edits engine are declaratively defined in XML files

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A COLLABORATIVE PROJECT TO ENHANCE CAPACITY OF NON-REGISTRY HOSPITALS TO COLLECT AND REPORT COMPLETE, ACCURATE, AND TIMELY CASE DATA J Martin¹, C Sheffield²

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Difficulties smaller, non-registry hospitals have finding and reporting cases to central registries are well known. Or, are they? Non-registry hospitals may lack many resources CoCapproved registries have; dedicated CTRs, oncologists and other clinicians, registry software, and lower levels of IT support may all be absent. But, the absence of these resources is not the entire picture. To understand why smaller hospitals do not create registries, a working group in Virginia is collaborating 1) to investigate barriers keeping smaller hospitals from establishing registries and 2) to devise methods to establish or improve facility resources that will positively affect the quality and completeness of data such facilities submit. Partners in the project are the Virginia Comprehensive Cancer Control Program (VACCCP), the Virginia office of the American College of Surgeon's Commission on Cancer (CoC), the Virginia Cancer Registrars Association (VCRA), and the Virginia Cancer Registry (VCR). The project has three phases: 1) visit non-registry hospitals to assess needs and barriers; 2) analyze the needs and develop methods to address ones that can be addressed; and 3) implement the methods developed. This presentation outlines results from the needs assessment, summarizes potential methods to address needs, discusses steps to enhance non-registry hospital data guality and completeness, and outlines the leadership value of CTRs from VCRA and the importance of investing in continuing education for CTRs.. The project will benefit participating hospitals, will provide useful information for the Commission on Cancer, enhance the capacity of the VCRA to support nonregistry facilities, and increase the guality and completeness of data submitted to the Virginia Cancer Registry.

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oral abstracts

concurrent session 3



LESSONS LEARNED FROM SEER RELIABILITY CODING PRACTICE STUDIES SOFTWARE DEVELOPMENT

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The NCI SEER Program developed the SEER Reliability Coding Practice Studies web site as a mechanism to gather data on the coding skills of central and hospital registry personnel and on the consistency in the application of coding rules among abstractors. Three coding practice studies took place in 2010 for various cancer sites, as well as the implementation of a reliability study to test multiple primary coding practices. This presentation will highlight the following aspects of the SEER Reliability Coding software development:

Purpose: To collect data about the experience and training of those users performing cancer coding using the new CSv2 coding practice rules, as well to give users the opportunity to practice implementing the new rules via coding practice studies. **Approach:** A web based application to collect data in order to assess coding practice consistency and reliability. The system captures data about the users and their institution, and provides a mechanism for collecting the data items relevant to each study. **Results:** Based on our experiences, the web application was refined to enhance collection of the user's affiliation, to more actively engage the institute administrators in the user approval process, and to provide more efficient mechanisms for data entry when coding cases.

Future Plans: The web site will be adapted for the surveillancewide CSv2 field study planned for Fall 2011. In addition, the site will continue to be enhanced to provide more efficient mechanisms for data entry when cases involve multiple primary sites.

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GROWING PAINS: LESSONS LEARNED FROM THE IMPLEMENTATION OF THE NAACCR V12 RECORD LAYOUT DK O'Brien¹

¹Alaska Cancer Registry, Anchorage, AK

The implementation of the NAACCR v12 Record Layout has presented many challenges to the cancer registry community. The large number of new data items, the longer record length, and the new date format with associated date flags all had to be considered as registries changed the way they process data. The Alaska Cancer Registry (ACR) converted its database to the new v12 standards in mid-October 2010. Therefore, ACR had to modify its routines for data processing, as well as for data file preparation for the Call For Data, almost simultaneously. ACR had to add the 126 new data items to the registry database software's "record view" screen, and remove other data items that had been retired. ACR staff learned that dates and date flags had to be edited and consolidated as a single unit so that they didn't conflict. The new "Path Date Spec Collect" data items are 14-digit dates, but uploading cases with this field populated caused the upload to fail because an 8-digit date was expected. ACR developed an import/export text file specification for MS Access so that v12 data files could be imported for processing. Dozens of Access gueries that performed functions based on diagnosis year had to be modified to read the year from the left side of the date instead of the right side. ACR now uses Notepad++ and TextPad file editors to open raw data files since they accommodate the new longer record length of 22,824 characters without line truncation or wrapping. However, ACR discovered that Notepad++ has a limit of 11,893 records per file. ACR also discovered that the Link Plus software cannot process data files with more than 10,000 characters per line, so files used for Call For Data de-duplication had to be exported as Type C "confidential" records that are truncated at 5564 characters per line. Last year's Link Plus configuration files had to be modified for the new date format. This presentation will detail these and other findings related to the v12 standards implementation.

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GALLOPING INTO THE FUTURE: WHAT'S NEXT FOR THE SEER HEMATOPOIETIC AND LYMPHOID NEOPLASM PROJECT

MB Adamo¹ ¹NCI SEER, Bethesda, MD

Background: The SEER Hematopoietic and Lymphoid Neoplasm Project (Heme project) produced a comprehensive and easily-accessible repository of information and instructions for the cancer data collector. This up-to-date standard resource used by all data collectors ensures consistent interpretation of clinical data and consistent application of data collection rules. The Hematopoietic and Lymphoid Neoplasm Database (database) and the Hematopoietic and Lymphoid Neoplasm Manual (manual) were released on the SEER website in November 2009 effective for cases diagnosed January 1, 2010 and later.

Purpose & Methods: The next phase of the Heme project is to update and improve the database and the manual. In particular, plans are underway to develop software applications to increase the utility of the database. The software applications will automate certain features of the database that are of particular interest to central registries. For example, applications are planned for the determination of multiple primaries and identifying the more specific histology among several related histologies.

Results: The presentation will describe the planned updates and improvements, especially those pertinent to central registries. **Conclusion:** The Heme project database and manual are among the most innovative and unique resources available to cancer data collectors. These resources will be updated and improved to keep pace with the rapidly changing clinical science of hematopoietic and lymphoid neoplasms, to take advantage of the latest technology, and to fortify fundamental cancer registry vocabularies which underlie neoplasm classification. The Heme project established a model for data collection resources of the future.

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WHAT THE GIST?!

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Background: Based on our current reporting standard, Gastrointestinal Stromal Tumors (GIST) are reportable only if they are *stated* to be malignant by a pathologist or clinician. Information such as depth or extent of invasion, tumor size, mitotic rate, or results of immunohistochemical tests such as CD117 are not factors considered for reportability. The rigidity of this coding standard was explored by conducting a GIST recoding audit in California.

Method: There are a total of 2,908 GIST cases in the California Cancer Registry (CCR) data base. A recoding audit was conducted by sampling 40 cases from each region for a total of 320 cases. The sample was created by listing all GIST cases by region and date case loaded on a spreadsheet, and then selecting the last 40 cases that were reported. A primary auditor reviewed each case to determine whether or not the case was reportable per reporting standards. A secondary auditor independently analyzed the same cases. The results of both the primary and secondary auditor were compared. The Audit Project Manager reconciled any differences between the two auditor's recoding results.

Results: One hundred nine (109) cases were identified in the database that did not meet these strict coding requirements and may be considered non-reportable. These 109 cases represent over 29% of the cases reviewed. This finding suggests that as many as 30% of the cases in the CCR data base may be non-reportable based on the current reporting standard, indicating an over-reporting of GIST cases. Internet research coupled with discussions with clinicians provided information on our medical community's broader interpretation of when GIST cases are malignant as opposed to benign and/or borderline. This presentation will provide the results of the recoding audit as well as recommendations for next steps.

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NATIONAL PROGRAM OF CANCER REGISTRIES -ADVANCING E-CANCER REPORTING AND REGISTRY OPERATIONS (NPCR-AERRO): ACTIVITIES OVERVIEW

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Background: The National Program of Cancer Registries-Advancing E-cancer Reporting and Registry Operations (NPCR-AERRO) is a collaborative effort to take advantage of electronic medical records (EMR) and advance automation of cancer registration by developing a set of cancer surveillance models, requirements, and products. Purpose: The goal of NPCR-AERRO is to enhance the completeness, timeliness, and quality of cancer data through automated capture of standardized electronically available data. Methods" CDC's NPCR-AERRO has engaged stakeholders from across the U.S. and Canada to collaborate on development of consistent data exchange standards and tools that benefit both data providers and cancer surveillance community. The stakeholders have explored and provided consensus based recommendations for the use of EMRs and data standards. Results: NPCR-AERRO has initiated activities to: support development and adoption of standardized reporting of cancer data from varied health care institutions including implementation of NAACCR Volume V; develop recommendations for reporting discharge data; develop a standard format for physician office reporting; implement standardized physician EMR systems reporting to central registry systems; and develop a tool for receiving both standardized pathology and physician office data. Conclusions: The NPCR-AERRO activities explored data exchange standards that currently exist at the local, state and national levels; tested implementation of existing standards; and developed standards where none exist. This presentation will provide an overview of the cancer surveillance model for data exchange and identify where standards exist, where they are being developed, and where they still may be needed. An update will be provided on electronic pathology reporting, and development and evaluation of the eMaRC Plus tool for states to receive and process both pathology and physician office data.

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NATIONAL PROGRAM OF CANCER REGISTRIES -ADVANCING E-CANCER REPORTING AND REGISTRY OPERATIONS (NPCR-AERRO): CLINIC/PHYSICIAN OFFICE (CPO) REPORTING TO REGISTRIES PROJECT

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Background: Until recently, complete and high quality cancer data reporting has been achieved primarily from hospital cancer registries. However, the need for data from outpatient settings has increased as advances in medicine now allow patients to obtain care outside the hospital setting. Data collection from outpatient settings, such as physician offices, is often less complete which leads to underreporting of certain types of cancers and treatments.

Purpose: To develop standards, methods, and tools, and test the implementation of, electronic clinician reporting from CPO Electronic Medical Records (EMRs) to cancer registries. Methods: CPO Workgroup was formed and has engaged in activities that include defining criteria for reporting and developing a list of data items to include in a physician report. NPCR-AERRO has worked with Integrating the Healthcare Enterprise (IHE), which brings together software vendors and the healthcare community. Results: Within IHE, and based on input from the workgroup and cancer community, NPCR-AERRO has developed a standard format for cancer reporting, and is working with several EMR vendors to develop and test implementation of this standard. NPCR is also funding Comparative Effectiveness Research (CER) special projects with two registries to pilot test implementation of electronic reporting from physician offices to registries through their EMRs. Electronic Mapping, Reporting, and Coding (eMaRC) Plus software is being enhanced to enable registries to receive and process these reports. **Conclusions:**This presentation will describe the accomplishments and lessons learned from testing/ demonstrating at IHE Connectathon and Healthcare Information and Management Systems Society (HIMSS) Showcase and CER projects. It will include either a live or mock demonstration of an EMR vendor transmitting a cancer case to a registry and will demonstrate eMaRC Plus' ability to receive and process the physician office report from the EMR.



NAACCR, MEANINGFUL USE CRITERIA, STANDARDS DEVELOPMENT ORGANIZATIONS, AND INTEROPERABILITY

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NAACCR recognizes that interoperable data standards are necessary if cancer surveillance is to benefit from developing electronic medical records standards. Purposes of this discussion are to describe the changing context within which NAACCR interoperability groups function and to focus on opportunities and issues. The discussion is situated in the context of the achievements and continuing work that NAACCR interoperability work groups perform. Issues broad and narrow occur. Of increasing importance, for example, is meaningful use criteria the Federal Department of Health and Human Services is developing. Such criteria, and the guidelines and rules that come from them, will have important effects on how surveillance programs access and exchange cancer data. Because data may reside in different locations - hospital records, centralized warehouses, etc. - developing products that meet meaningful use criteria is important. Structured and synoptic reporting have qualities that make them amenable to automatic data processing. The College of American Pathologists synoptic reports have demonstrated their value, for example, but the concept of synoptic or structured reports is not completely specified. Cancer records may contain large text blocks, which are less easily processed automatically; this circumstance is an invitation to develop new methods for extracting meaningful data from text. The cancer surveillance community as a whole is developing interoperable standards for both structured (quantitative and qualitative) and non-structured data, so the community is in a position to influence emerging national standards. During this period, the need to monitor the work of and work with standards development organizations (SDO) such as HL7 is apparent; here, HL7 is a proxy for the array of organizations developing standards with which cancer surveillance will need to comply.

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HIGHLIGHTS OF VALUABLE CAP ECC FEATURES FOR CANCER REGISTRIES

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Background: The transformation of the CAP Cancer Protocols into electronic format highlighted several valuable CAP eCC features necessary for promoting the interoperability of cancer reporting and aiding cancer surveillance activities.

Purpose: With the frequency of CAP eCC releases and updates, it was evident a versioning and errata process was needed for the CAP eCC components providing much value to registries and end users. Some end users needed enhancements to aid their implementations and provide interoperability of cancer data. An assessment of other cancer registry needs is described in the "Requirements Analysis and Recommendations for CAP eCC Reporting to Cancer Registries report."

Methods: A versioning and errata process was subsequently developed, reflecting not only CAP Cancer Protocol updates, but also content or technical changes to the CAP eCC contained in the release documentation. As maps to the various component encodings were developed and included in the CAP eCC versions were needed not only for the component encodings, but also for the maps. These encodings include SNOMED CT, CS v 2.0 and the NAACCR data elements. Additional metadata has been included in CAP eCC releases providing guidance to end users, aiding the collection and transmission of cancer registry data, such as with multiple primary tumors. **Results:** Integration of component versioning has occurred with the 2011 CAP eCC releases. Technical enhancements and metadata released has aided vendors in better implementing the CAP eCC content and providing end user guidance in collecting data utilized by cancer registries.

Conclusions: Integration of CAP eCC features such as versioning has aided cancer surveillance activities with the communication of CAP eCC component versions and maps submitted to registries. Other features in the CAP eCC have provided for the collection of data better suited to cancer registry needs.

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CENTRAL CANCER REGISTRY: DOCUMENTING THE SECURITY OF YOUR IT INFRASTRUCTURE

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Background: Obtaining data sharing agreements has become increasingly more complicated. These agreements provide a level of assurance that sensitive data are secure and available only to those with a legitimate purpose. It is the data owner's responsibility to protect data, even if it is distributed outside their IT Infrastructure. Sharing of cancer registry data often requires documentation that the requesting organization has addressed National Institute of Standards and Technology (NIST)-required minimum security protections be submitted prior to data sharing. Central cancer registries are often requested to process and sign Memorandum of Understanding (MOU) and Authority to Operate (AtO) agreements, which summarize the security risks in their IT Infrastructure.

The CDC requires Certification and Accreditation (C&A) on all systems deployed within CDC, but does not provide C&A on systems developed for its funded programs. CDC does provide assurance that all registry products created by CDC have passed the CDC C&A processes, and provides a detailed checklist in a spreadsheet of how the products meet NIST requirements. This checklist details how CDC or the administrator addresses the NIST requirements during development, installation operations and maintenance of the registry tool. We feel that this model can be used by software developers for central cancer registries to meet the data sharing requirements in MOUs and AtOs. **Purpose:** Assist central cancer registries in general understanding of data security and how to address MOUs and AtOs to obtain cancer registry data sharing agreements.

Methods: Provide examples of approaches to address current MOUs and ATOs to obtain cancer registry data.

Results: The CDC C&A processes and the detailed checklist of NIST requirements provides central cancer registries the most current information on addressing security inquiries when pursuing data sharing agreements with other organizations.

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GENERATING ACCURATE STATISTICAL MODELS WHILE PROTECTING PATIENT PRIVACY: USING SYNTHETIC DATA FROM THE CENTRAL CANCER REGISTRY

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Cancer Registries collect privacy sensitive data on cancer patients. These data need to be used in population-based cancer research to fulfill the goals of the central cancer registry.

Data sharing can be done in multiple ways: Through IRB approved protocols, when the data recipient proves that his/her research is valuable and cannot be done without the knowledge of Protected Health Information (PHI). In this case the data recipient gives assurances that the data will not be used for any other purpose and will be destroyed when the results are obtained.

In an anonymized format, where PHI is removed or changed making it impossible to re-identify individual patients in the data set.

Although there is a rich collection of literature on privacy preserving data mining and publishing techniques [1, 2], whether common models for analyzing patient data (e.g., regression analysis and proportional hazard models) will generate similar results using anonymized data compared to the original data has not been investigated. As a result medical researchers are skeptical about using these techniques and in turn, they seek to obtain raw data which exposes them to greater privacy risks. The authors of this abstract are proposing techniques that generate random synthetic data based on the distribution of the original dataset and the characteristics of the targeted statistical model. Our experiments show that using these techniques we are able to create de-identified datasets that give similar results compared to the original datasets when the targeted statistical model is used.

References: Aggarwal, C.C., Yu, P.S.: Privacy-Preserving Data Mining: Models and Algorithms: Springer Publishing Company, Incorporated. pp. 514 (2008)

Wong, R.C.-W., Fu, A.W.-C.: Privacy-Preserving Data Publishing: An Overview: Morgan and Claypool Publishers (2010)

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SECURITY ISN'T JUST A CENTRAL CANCER REGISTRY (CCR) ISSUE: HOW ONE CCR HELPED REPORTING FACILITIES IMPROVE THEIR SECURITY

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Background: The Missouri Cancer Registry (MCR) has been working diligently to improve internal security for the last 3 years. New security measures have been implemented and an MCR security team is in place to continue oversight. However, at the 2010 Missouri Tumor Association's annual meeting, it became apparent that many hospital cancer registrars are not aware of, and are not implementing, security best practices within their environments. Moreover, information from reports such as the Ponemon Institute's November 2010 "Benchmark Study on Patient Privacy and Data Security" indicate "protecting patient data is not a priority" for hospitals and that the "HITECH Act has not resulted in significant change to the industry's approach to data protection."

Purpose: Educate internal and external partners and facilities about compliance with the new regulations and how to achieve data security and meet confidentiality and privacy requirements for patient health information.

Methods: MCR is creating an education/awareness program for Missouri cancer reporters to increase security of patient health information. MCR's security team and education coordinator are providing various mechanisms to teach hospital registrars about safeguarding their data. This includes articles in newsletters, special newsletter supplements, a security checklist for hospital cancer registries and an area on the MCR website devoted to data security and other security-related issues.

Results: An overview of MCR's education/awareness program will be presented along with sample materials. Changes made by reporting facilities and barriers to changes will be discussed. **Conclusions:** By transmitting what we have learned, we help bring Missouri cancer reporters into compliance, not only with HIPAA but with the additional HITECH act requirements.

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ARRA HITECH: CHALLENGES, OPPORTUNITIES AND IMPLICATIONS FOR CENTRAL CANCER REGISTRIES (CCRS)

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Background: The American Recovery and Reinvestment Act of 2009 (ARRA) was signed in February 2009. The Health Information Technology for Economic and Clinical Health Act (HITECH) provisions of ARRA in Title XIII include changes in privacy (subtitle D) that CCRs need to take into account, particularly those that apply to HIPAA and non-HIPAA entities regarding breach and safe harbor. The HITECH privacy provisions extend the HIPAA Security rule. With the deadlines for the interim and the final rule having passed, CCRs need to be in compliance and meet data security standards for cancer registries. **Purpose:** To ensure Missouri Cancer Registry (MCR) compliance with new and existing security regulations and standards.

Methods: We reviewed the literature and related publications that address the new regulations and the HITECH ACT. We also reviewed existing regulations; HIPPA; NPCR security standards; and internal policies and procedures (P&Ps) as well as best practices and standards on the state and national level. We analyzed the impact of the new regulations on MCR; developed and implemented an action plan; and identified changes that needed to be made internally to meet security standards. **Results:** We revised existing P&Ps and implemented new P&Ps; developed an action plan; and conducted trainings for staff. MCR security rules were expanded. Examples will be presented. Conclusions: The new rules and regulations have many challenges but they also offer opportunities for CCRs to: 1) achieve greater internal and external data security; 2) meet confidentiality and privacy requirements for patient health information; and 3) increase security awareness and compliance among external reporting partners through training (see separate abstract on helping reporting facilities improve security).



CANCER TRENDS AMONG PERSONS OF AFRICAN DESCENT IN FLORIDA - A FLORIDA CANCER DATA SYSTEM (FCDS) PUBLICATION

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Background: In the US, persons of African Descent account for 13.5% of the population. In 2008, there were 3.1 million (16%) persons of African Descent among Florida's rapidly growing population. FCDS has created a Monograph focusing on the cancer experience of Persons of African Descent in Florida. **Methods:** The data included all cancer cases diagnosed among Florida residents between 1988-2007. Primary cancer site and histology data were categorized according to SEER site groups. The top 11 cancers among all Florida residents for 2007 were selected. Cancer incidence trends between 1988-2007 were conducted using joinpoint regression model.

Results: Cancer rankings among Whites and persons of African Descent were similar for the top four cancers. Proportionally, males of African Descent had lower urinary bladder rates, and higher proportions of prostate, stomach and liver cancers. Females of African Descent had higher proportions of cancer of the breast, and lower proportions of lung cancer than their White counterparts. Although Whites and persons of African Descent had decreasing trends since the early 1990s in overall cancer rates, the decrease was greatest for males of African Descent. While racial disparities in distant stage incidence persisted to the end of the study, with higher rates among persons of African Descent for cancers of the breast, colon and rectum, bladder, liver, stomach and cervix, these gaps reduced significantly, with some disparities disappearing altogether.

Implications: Cancer disparities between persons of African Descent and Whites in Florida remain an issue. In particular, persons of African Descent continue to have higher proportions of prostate, breast, and cervical cancers. However, declining trends in advanced stage cancers are tightening the racial gap. 53

AGE-PERIOD-COHORT ROBUST BAYESIAN MODELS FOR PROJECTING CANCER INCIDENCE AND MORTALITY IN PUERTO RICO

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Background: Race is not available in Puerto Rican data so the Worksheet for Completeness of Case Ascertainment can't estimate completeness. Cancer data is subject to unavoidable delays. Projections of cancer incidence and mortality provide a valuable indication of the current and future burden. They better inform planning and decision making, and assist in the efficient allocation of resources to meet the future needs for the prevention, detection, and treatment of cancer. **Objective:** To estimate the present and predict the future (2014) of incidence and mortality for top cancer in Puerto Rico (PR), by gender, age group and primary cancer site to design public policy; and to give an indication of the degree of cancer registry completeness. Methods: Incidence and mortality data from Puerto Rico Central Cancer Registry, were obtained for the years 1985 to 2004. A robust Age-period-cohort (APC) model with autoregressive errors were fitted using Bayesian methods. Results: Predictions of overall cancer counts and rates increased for incidence, but mortality rates are slightly decreasing in PR. Age specific trends of overall cancer incidence rates predicts an increased in aged between 40-74, and reveal a deceleration or decline at old ages (75+). Continuum of the previously increase incidence and mortality trend for colorectal and female breast cancer were predicted. A decreased trend for lung cancer cases in males are predicted, while female cancer is stable. An annual version of the model is a powerful aid to estimate the completeness of the measured cases at the Registry. Conclusion: The APC model enables us to accurately predict the cancer incidence and mortality in Puerto Rico. Given that PR is a Hispanic population with different cancer rates behavior as compared to US race/ethnicity groups, the estimate of completeness based in APC model lead us to use as a tool of estimate overall completeness of cancer cases in PR, by comparing current data with predictions.

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DIFFERENCES IN NON-SMALL CELL LUNG CANCER SURVIVAL BETWEEN APPALACHIAN AND NON-APPALACHIAN AREAS OF KENTUCKY

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Kentucky leads the nation in lung cancer incidence and mortality, with even greater lung cancer disparities in the Appalachian area of Kentucky. Lung cancer within Appalachia has been associated with socioeconomic, lifestyle, and environmental factors, leading to increased incidence and mortality in central Appalachia (of which Kentucky is part), as compared to other Appalachian areas. There is a lack of published data regarding lung cancer survival in Central Appalachia and Kentucky. The purpose of this study was to examine differences in non-small cell lung cancer survival between residents of Appalachian and non-Appalachian areas of Kentucky, controlling for cell type, stage at diagnosis, treatment modality, socioeconomic indicators, rurality, smoking status, insurance status, age, gender, and race. This population-based survival analysis included cases of non-small cell lung cancer reported to the Kentucky Cancer Registry between 2002 and 2006 (N = 16,848) and utilized Kaplan-Meier survival curves and Cox regression analysis. Appalachian status was associated with poorer survival in both localized (hazard ratio [HR] = 1.22; 95% confidence interval [CI] = 1.09 - 1.37) and regional (HR = 1.10; 95% CI = 1.01 – 1.20) non-small cell lung cancer. Other factors associated with decreased survival included lack of recommended treatment, history of smoking, older age, and male gender. Results of this study will be useful for planning public health interventions to improve lung cancer surveillance and public health policy, and to decrease Kentucky's public health burden related to lung cancer.

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CANCER INCIDENCE TRENDS AMONG THE OLDEST-OLD (85+)

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Background: Persons \geq 85 years are one of the largest growing segments of the US population [1]. However, little is known about incidence trends for cancer in this population as concerns about small sample sizes and misreporting of age among individuals at advanced ages have lead to the customary practice of aggregating rates by grouping persons aged 85+ years. Purpose: Characterize trends in cancer incidence among persons aged 85 years and older. Methods: Numerator data were obtained from the California and Utah SEER registries and included incident cases aged \geq 85 years. Denominator (population) data by single year of age, sex, and region were calculated using the cohort-component estimation method, which utilizes decennial US Census population counts and mortality data from the National Center for Health Statistics. Age- and sex-specific rates and trends are described and compared to rates derived by traditional aggregation methods. Results: Utah and California rates were generated for cases diagnosed from 1973-2003 and 1988-2003, respectively. Rates for individuals 85-89 years were higher than the traditional rates for 85+ years combined; and, rates for 90-94 years and 95-99 years were similar to the 85+ years combined group. Trends in traditional rates were most similar among the youngest age group (85-89 years), but larger variation and divergence from traditional rates were found among older age groups. Conclusion: Findings from this study are similar to age-specific cancer mortality trend previously reported in the literature [2], and provides important insight into cancer incidence trends among a growing aged population. [1] He W, Sengupta S, Velkoff VA , DeBarros KA. U.S. Census Bureau, Current Population Reports, P23-209, 65+ in the United States: 2005, U.S. Government Printing Office, Washington, DC, 2005. [2] Boscoe FB (2008). Subdividing the age group of 85 years and older to improve US disease reporting. Am J Public Health, Jul;98(7):1167-70.

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HPV TYPE SPECIFIC PREVALENCE IN SIX CANCERS FROM SELECT U.S. CANCER REGISTRIES, 2000-2005

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OBJECTIVE: To determine the baseline prevalence of HPV types in cancers commonly associated with HPV using population-based cancer registry tissue samples from regions of the United States: Hawaii, Louisiana, Michigan, Florida, and Kentucky. METHODS: Central cancer registries identified all cases of invasive cancer from eligible primary sites [cervix, vagina, vulva, penis, anus, tongue, tonsil, oropharynx, other head and neck] diagnosed in 2000-2005. Archived tissue was retrieved from a representative sample of eligible cases, and one diagnostic block per case was serially sectioned for DNA extraction with confirmation of histology in sections immediately preceding and following. Histology review, extraction and testing were performed at CDC. All samples were tested using the Linear Array HPV Genotyping Test (Roche Diagnostics), and those negative for HPV or failing to amplify endogenous control were re-tested with INNO-LiPA HPV Genotyping Assay (Innogenetics). Samples failing to amplify control sequences in both assays were considered inadequate and excluded from analysis.RESULTS: To date, HPV testing has been performed on 1846 cancers; 1808 (97.9%) yielded adequate results on eligible samples. HPV was detected in 80.7% of adequate samples; HPV 16 or 18 in 60%. HPV detection stratified by anatomic site: Cervix (n=531) 91% [67% % 16/18]; Anus (n= 94) 89% [80% 16/18]; Vulva (n=137) 72% [53% 16/18]; Tongue/tonsil/oropharynx (n=422) 72% [61% 16/18]; Vagina (n=55) 73% [55% 16/18]; Other head and neck (n=132) 33% [22% 16/18]; Penis (n= 64) 64% [47% 16/18]. Results will be updated to include 2 additional cancer registries (Los Angeles and Iowa). CONCLUSION: If vaccine coverage were high and reached those at highest risk, an efficacious HPV16/18 vaccine could prevent the occurrence of a large proportion of HPV-associated cancers in the United States. Periodic measurement of HPV distribution will be an important monitoring activity.

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DISTRIBUTION OF HPV TYPES AMONG A POPULATION-BASED SAMPLE OF U.S. INVASIVE CERVICAL CANCERS ACROSS FIVE U.S. STATES

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OBJECTIVES: To analyze the distribution of HPV types in tumor samples from invasive cervical cancer (ICC) cases, by demographic and clinical variables, from a population-, cancer registry-based study in 5 U.S. states: FL,HI, KY, KA & MI. METHODS: A population sample of primary, ICC cases was identified across the 5 registries. Paraffin-embedded tissue samples were retrieved for DNA extraction and HPV-typing. The results were linked to registry data, following a standard protocol for variable selection and linkage. Statistical analyses were performed to describe the distribution of HPV types by age, race, state, rural/urban county of residence, tumor histology, stage and grade. For this analysis we included all 531 ICC samples that were eligible for HPV testing. RESULTS: 511 (91%) of the ICC samples were HPV-positive, distributed as follows: 50% HPV-16, 17% HPV-18, 21% other carcinogenic and 3% non-carcinogenic. Although HPV-16, and to a lesser extent HPV-18, predominated across age groups, the percentage of other carcinogenic types rose with age. The proportion of other types was higher for Asian and Hispanics than for Whites, while a greater contribution from HPV-18 was observed for Blacks. HPV-16 and HPV-18 represented 61.3% and 21.8%, respectively, of squamous cell tumors compared to 38.2% and 30.4% of adenocarcinoma/adenosquamous cell tumors. A detailed distribution by demographic and clinical covariates will be presented at the conference, and results will be updated to include 2 additional cancer registries (Los Angeles & IA). CONCLUSION: This US population-based study confirms results from previous studies regarding the higher prevalence of HPV-16 and 18 among ICC cases, and the preventive potential of current HPV vaccines. The analysis also shows variability in the distribution of HPV types across demographic and clinical subroups, which may represent high risk groups that may require different screening strategies after full vaccine implementation.

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CDC HUMAN PAPILLOMAVIRUS TYPING OF CANCERS STUDY WITH SEVEN REGISTRIES: EVALUATING REPRESENTATIVENESS

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Most studies evaluating human papillomavirus (HPV) genotypes in cancers have been based on convenience samples and were not population-based. The CDC HPV Typing of Cancers Project is a collaborative project including cancer registry investigators in Louisiana, Kentucky, Florida, Hawaii, Michigan, Los Angeles and Iowa. For the period 2000-2005, the registries identified approximately 500 cancers from 6 HPV-associated cancer sites (cervix, vagina, vulva, anus, penis, and some oropharyngeal cancers) using random sampling. Three registries had existing tissue banks from which cases were drawn, while four registries worked with local pathology labs to select a representative block from each case for testing at the CDC HPV lab. Registries found that tissue samples were more readily available from some pathology labs and some areas of the states than others. In addition, some blocks were ineligible for testing because histology review of sections before and after those to be extracted failed to demonstrate the lesion, or failed to yield amplifiable HPV DNA. Typed cancers were compared with NPCR/SEER registry data and evaluated for representativeness (compared to cancers diagnosed in participating registries) based on the following: sex (for anal and oropharyngeal cancers), age (20-39, 40-59, 60-79, 80+), race, Hispanic ethnicity, and histology. Despite the limitations encountered, preliminary results show that typed cancers were generally representative of cancers diagnosed in the population from included registries, with a few exceptions. Preliminary analysis showed that the proportion of typed anal cancers among females (67%) was slightly higher than among reported cancers in the population (60%). The proportion of typed vaginal cancers among black women (6%) was lower than the proportion of cases of vaginal cancer among black women in the registry data (18%). Final results will use updated, complete data and will include statistical testing to determine significance.

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DISTRIBUTION OF HPV BY TYPE IN A POPULATION-BASED SAMPLE OF INVASIVE OROPHARYNGEAL CANCERS FROM FIVE U.S. CANCER REGISTRIES

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OBJECTIVES: To estimate the prevalence and type distribution of HPV in a population-based sample of archived oropharyngeal (OP) tissue by demographic and clinical variables from cancer registries that participated in the CDC HPV Cancers Typing Project.

METHODS: A representative population-derived sample of OP cancer cases was identified from each of the cancer registries prior to 2006. Upon case identification, paraffin-embedded tissue samples were retrieved for HPV DNA extraction and typing by the CDC lab using the Linear Array HPV Genotyping Test and those negative for HPV or failing to amplify controls were re-tested with INNO-LiPA HPV Genotyping Assay. HPV results were linked to demographic and clinical data from the cancer registries. Statistical analyses were performed to describe the presence and distribution of HPV types by sex, age, race, tumor site and stage. For this analysis we included all OP cancer samples eligible for HPV testing, (N=422). RESULTS: HPV was detected in 73% of the 422 OP cancers genotyped; overall, 59% were positive for HPV 16, 2% were positive for HPV 18, and 9% were positive for other carcinogenic HPV types. HPV positivity was inversely associated with age: among those <50 years, 81% were HPV positive compared to 71% positive for those 50 and older. Of 312 OP cancers diagnosed in males, 63% were HPV16 positive compared to 47% of the 112 females. HPV prevalence was similar among Whites (75%), Hispanics (77%), and Asians (74%) and lowest among Blacks (46%). Additional and more detailed HPV typing distribution will be presented at the conference. CONCLUSION: HPV detection was high among oropharyngeal cancers and greatest among younger cancer patients. Interestingly Blacks had a substantially lower prevalence of HPV positivity compared to Whites. Further studies are needed to evaluate preventive strategies and to determine the effect of HPV positivity in this population on relative survival by age, sex, and race/ethnicity.



Oral Abstracts

Notes	



oral abstracts

concurrent session 4



CANCER DATA QUALITY CONTROL BY PROPORTION OF UNKNOWN STAGE - DATA ASSESSMENT WORKGROUP #1

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Background: Accurate information on cancer stage at diagnosis is critical to cancer control. The proportion of unknown stage cases may relate to not only the quality of abstraction but also the availability of stage information in medical records. The purpose of this study was to identify factors that were associated with variations in the proportion of unknown stage. **Methods:** The 2004-2007 incidence data on invasive female breast, prostate, colorectum, lung and cervix cancers were from 45 population-based cancer registries that met NAACCR's high data quality criteria. Multiple linear regression was used to assess the association of unknown stage (outcome) with explanatory variables (i.e., race, gender, age, diagnostic confirmation, type of reporting source, metro/nonmetro, and diagnostic year). The outcome and explanatory variables were analyzed at registry level. Results: Registries with a higher proportion of non-microscopically confirmed or non-hospital cases were more likely (p<0.05) to have a higher proportion of unknown stage for every studied cancers after adjustment. For female breast and cervical cancer, higher proportion of black cases was also significantly associated with a higher proportion of unknown stage in the model. For lung cancer, the year of diagnosis was also a significant predictor of unknown stage, as later diagnosis years had a lower proportion of unknown stage than earlier years. 45% variances in the proportion of unknown stage were explained by the explanatory variables for colorectal and cervical cancers, 46% for female breast cancer, and 54% for lung cancer. **Conclusions:** Proportion of non-microscopically confirmed cases, non-hospital reporting source, black race (breast and cervical only), and/or earlier diagnosis year (lung only) are positively related to the proportion of unknown stage. After adjusting for these factors, the proportion of cases with unknown stage may be a good indicator for assessing the quality of abstraction.

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BENIGN/BORDERLINE INTRACRANIAL AND CENTRAL NERVOUS SYSTEM TUMORS IN THE CINA DELUXE DATA. DATA ASSESSMENT WORKGROUP #2

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Background: Since 2004, US registries have been required to collect benign/borderline intracranial and CNS brain tumors (benign/ borderline brain tumors). However, data completeness has not been examined. Because benign/borderline brain tumors often did not receive therapy and were likely collected from non-hospital settings, it is a challenging task to collect complete cases. The goal of this study was to describe characteristics of benign/borderline brain tumors and identify factors that may serve as an indicator of completeness of reporting. Methods: Data were extracted from the 2004-2007 CINA Deluxe Data for the 48 US cancer registries. Age-adjusted rates for benign/borderline brain tumor cases were calculated by race, gender, year at diagnosis, anatomic subsite, metro status and registry. Rate ratios of benign/borderline vs malignant brain tumors were also calculated. Multivariate linear regression models were used. Results: Overall age-adjusted incidence rate was 12.3/per 100,000. Female had higher rate than male (14.7 versus 9.5/per100,000). Incidence rates varied considerably by registry (6.6-18.1/per 100,000). Surgery for benign/borderline brain tumors also varied by registry (39.9-84.4%). Controlling for the variables mentioned above, surgery was the only factor significantly associating with the rate of benign/borderline brain tumor in the multivariate model (coefficient=-0.13, p<0.0001). Surgery was also significantly associated with the ratio of benign/borderline vs. malignant brain tumor in the model (coefficient=-0.017, p=0.0005). Discussion: Because non-surgical cases were likely reported from non-hospital settings which may not report benign tumors, the negative association of % of surgery cases with incidence rate indicates that % of surgery cases may be an indicator of completeness reporting for benign/borderline brain tumors. The rate ratio of benign/borderline vs. malignant brain tumors and % of surgery cases also supports the hypothesis.



DATA QUALITY OF SURGERY AND RADIATION FOR FOUR MAJOR CANCER SITES IN CINA DELUXE - DATA ASSESSMENT WORKGROUP #3

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Background: The NAACCR Data Assessment Work Group was created in 2010 to assess the quality and completeness of specific variables contained in CINA Deluxe and to provide recommendations to researchers on how the data can be used. This presentation will examine the quality of surgery and radiation data for four major cancer sites - female breast, prostate, lung and colorectal. Methods: Data were extracted from the 1995-2007 CINA Deluxe Data set. First, the availability of surgery and radiation data by registry and diagnosis year was examined. Then, more specific analyses were conducted using data from 2004 to 2007. Percentages of unknown surgery and radiation were used as indicators of data quality, and were examined by registry, age, gender, race, stage, laterality, reporting source, diagnostic confirmation, rural-urban, and diagnosis year. Data quality based on SEER 17 was analyzed for comparison purposes. Results: The availability of surgery and radiation data in the CINA Deluxe dataset varied by diagnosis year and registry. In general, surgery data showed better quality than radiation data. Data quality varied considerably among registries, and was also affected by type of reporting source, diagnostic confirmation, and rural-urban. There were no major changes in data quality between 2004 and 2007. Percentages of unknown surgery and radiation in CINA were higher than in SEER17 data. Further analyses will focus on specificity of treatment information. Discussion: The percent of unknowns is higher in CINA compared to SEER. Data quality varied widely by registry, and was also affected by other factors. Researchers must take these factors into account when they use the surgery and radiation data.

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DATA QUALITY OF TUMOR SIZE AND DEPTH FOR BREAST CANCER AND MELANOMA IN CINA DELUXE – DATA ASSESSMENT WORKGROUP #4

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Background: The NAACCR Data Assessment Work Group was created in 2010 to assess the quality and completeness of specific variables contained in CINA Deluxe and to provide recommendations to researchers as to how the data can be used. This presentation will focus on data quality regarding tumor size for breast cancer and tumor depth for melanoma. Methods: Data were extracted from the 1995-2007 CINA Deluxe Data with analysis restricted to 2004 -2007. Tumor size and depth were stratified by age, race, reporting source, diagnostic confirmation, positive lymph nodes, morphology type, rural-urban residence, and diagnosis year. Melanoma tumor depth is collected in CS Site-Specific Factor 1, which is not a NAACCR required variable for the study years; some registries do submit it and this variable was analyzed as available. Results: Distribution of breast cancer size varied widely across the registries: 13% - 26% for tumors measuring 0 – 1 cm; 27% – 37% for 2 - 3 cm tumors; 17% - 23% for 4 - 5 cm tumors and 16 - 26% for tumors > 5 cm. The widest range was for unknown tumor size, 2 - 17% across registries. The majority of melanoma cancer (43% - 66% across registries) was reported with depths between 0 and 1 mm; 1 -2 mm depths ranged from 10% to 15% across registries; 2-4mm depths, 5% - 10%; and > 4 mm, 2 - 7%. The percent of unknown depth varied substantially by registry (7% - 32%). Discussion: Tumor size is important for assessing the adequacy of adjuvant chemotherapy for breast cancer patients. Large variations in tumor size distribution may indicate data quality issues. Tumor depth is an important prognostic factor for early-stage melanoma. Variations were smaller than those of breast tumor size, indicating that registries may have better quality of data on melanoma depth. NAACCR should consider requesting all site specific factors for all schemas as available.

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LOUISIANA TUMOR REGISTRY'S EXPERIENCE WITH IMPLEMENTING ROUTINE SURVEILLANCE FOR PRE-INVASIVE CERVICAL LESIONS

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Background: Since 2008, the Louisiana Tumor Registry (LTR) has been collecting precancerous cervical lesions as part of the CDC's multi-state NPCR Cervical Intraepithelial Neoplasia (CIN) Surveillance Project. Initial efforts were to develop the requisite infrastructure and to evaluate the feasibility of routine surveillance using the existing registry. Subsequent efforts were implemented to assure sustainability of data collection as part of routine registry activities. Objective: To evaluate past data collection procedures, to report the results from one complete year (2009) of data collection, and to discuss future directions of the LTR to enhance CIN data collection. Methods: The LTR collected diagnoses of cervical adenocarcinoma in situ, carcinoma in situ, CIN grade III, and severe dysplasia from hospital tumor registries and pathology laboratories by three mechanisms: 1) electronic reporting (e-path), 2) Web Plus, and 3) direct reporting of central registrars. Findings: In 2009, the LTR collected 1,255 CIN cases, which was 94% of the expected case count for Louisiana in one year. Only 2% of CIN cases were missing required data variables, compared to greater than 10% among other participating state registries. The majority of Louisiana CIN cases were reported through e-path; however e-path is not utilized in all Louisiana pathology labs and hospital registries, and e-path requires extensive manual review to determine eligibility and to obtain demographic variables. In order to enhance efficiency and feasibility, the LTR is developing a rapid case ascertainment core for special studies that will augment the CIN project and hopefully become a more effective mechanism for reporting CIN cases.

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POPULATION BASED SURVEILLANCE FOR HIGH-GRADE PRE-INVASIVE CERVICAL CANCER IN KENTUCKY, LOUISIANA, AND MICHIGAN, 2009

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Population based data are needed to assess the impact of human papillomavirus (HPV) vaccine since its first US licensure in 2006; HPV vaccination is routinely recommended for females 11 or 12 years of age, with catch-up vaccination through age 26 years. Cancer registry data on cervical cancer will provide long-term evidence of impact, but surveillance strategies should include endpoints that are more proximal in time to HPV infection. Cervical intraepithelial neoplasia grade 3 (CIN3) and adenocarcinoma in situ (AIS) are abnormal lesions detected during routine cervical cancer screening; these earlier manifestations of oncogenic HPV infection afford an opportunity to measure outcomes which occur 5-10 years after HPV infection. CIN3 and AIS are the most appropriate surveillance endpoints, because these lesions are the immediate precursors of invasive cervical cancer and show the most consistent inter-pathologist agreement in histopathology interpretation. The Centers for Disease Control conducted a multi-site project in the Kentucky. Louisiana, and Michigan central cancer registries to assess the feasibility of collecting data on CIN3/AIS lesions using existing registry infrastructure, a standardized case definition, and well-defined coding rules. Each central registry employed different methods to collect data, ensure quality and completeness, and engage local registries. Age-adjusted incidence of CIN3/AIS in 2009, using the 2000 US Standard Population, ranged from 76.1 (Kentucky) to 54.2 (Louisiana) per 100,000 women. Highest rates were observed in those aged 20 to 29; rates among these women were 269.8 in Kentucky, 194.5 in Louisiana, and 187.3 in Michigan. This project demonstrates that routine collection of CIN3/AIS lesions by cancer registries is feasible, and could provide an earlier endpoint than cervical cancer with which to evaluate the impact of HPV vaccination in the US.

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TAMING THE TEXT: INCORPORATING EMARC PLUS INTO FLORIDA CENTRAL REGISTRY PATHOLOGY LABORATORY PROCESSING

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Background: Florida has been successful in receiving electronic pathology reports (over 1 million electronic pathology records from approximately 600 laboratories annually) but not as successful in operationalizing the 'unmatched' cases. After matching the incoming records against Florida's cancer incident master file, approximately 45% do not match and contained a 'cancer keyword'. Visual review of over 450,000 pathology records is not operationally feasible, therefore, Florida would follow-back on a small sample.

Methods: In August 2010, FCDS began working with CDC's eMaRC Plus software in conjunction with the FCDS pathology software. After overcoming several technical issues, all 2008 pathology records were processed through eMaRC Plus for reportability status and coding.

Results: After consolidating the pathology reports at the patient level, eMaRC Plus coded the FCDS pathology records as follows: 31,000 unmatched 'reportable' cases; 5,700 unmatched 'non-reportable' cases; and 600 unmatched cases that did not contain a cancer term.

Visual review of these cases found there was 100% concordance with eMaRC's coding of no cancer terms; 97% concordance with eMaRC's coding of non-reportable and 70% concordance with eMaRC's coding of reportable cases (with 44% concordance of autocoded primary sites). The site distribution of the unmatched, reportable cases was 50% prostate, 30% reportable skin, 3% bladder, 2.5% cervix and 1.5% breast. **Conclusions:** While not perfect, integrating eMaRC Plus software into the FCDS routine operations should enhance Florida's ability to more fully operationalize pathology reports. There are still several technical issues to overcome. Additionally, the personnel necessary to follow back on approximately 30,000 records is not inconsequential.

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HIGH GRADE DYSPLASIA AND CARCINOMA IN SITU - ARE THEY SYNONYMOUS?

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Background: With the implementation of AJCC 7th Edition Staging Manual for cancer cases diagnosed from January 1, 2010 forward, an issue was identified and brought forward to the Data and Quality Management Committee (DQMC) for resolution and/or guidance. The issue was generated based on a statement written within the digestive system chapter, specifically the esophageal site. It states in this chapter that "high grade dysplasia includes all noninvasive neoplastic epithelia that was formerly called carcinoma in situ, a diagnosis that is no longer used for columnar mucosae anywhere in the gastrointestinal tract". The Canadian Cancer Registries asked for clarification from the DQMC, is high grade dysplasia synonymous with carcinoma in situ and thus eligible for capture? Purpose: To provide national guidance to determine if high grade dysplasia should be reportable and collected by the provincial/territorial cancer registries. Method: The National Pathology Standards Committee composed of pathologists from across Canada were consulted for advice and direction on reporting requirements to assist the Registry Community. In addition, DQMC's consultant pathologist, various provincial pathologists and clinicians were also approached for their opinion. **Results:** The DQMC has received a variety of opinions and direction with no consensus. It was then decided to pursue this issue further at the National level with NAACCR's Cancer Registration Steering Committee for further advice and direction.

Conclusions: Further discussions regarding the impact of this change to cancer reporting statistics will be followed up by the Canadian Council of Cancer Registries (CCCR) and the appropriate research bodies. The objective is to clarify the high grade dysplasia issue, provide guidance to the Canadian Cancer Registries and to understand the potential broader application to the rest of the Gl tract and other disease sites.

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THYROID CANCER IN THE UNITED STATES: RECENT INCREASES

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Rates of thyroid cancer have continued to increase in the U.S. since the 1980's; while not understood, this increase is unlikely to be due solely to improved diagnosis. Data from CDC's NPCR and NCI's SEER Program, covering 89.4% of the U.S. population, the largest source of cancer incidence data in the country to date, will be used to examine invasive thyroid cancer from 1999-2007. Incidence and trends will be examined by 5year age group, U.S. Census region, race, Hispanic ethnicity, and sex. Preliminary data from 1999-2006 showed that thyroid cancer increased nearly 7% per year (annual percent change [APC] 6.95), from 6.7 to 10.9 per 100,000. Rates increased more quickly for females (APC 7.25) than males (APC 6.13). Females also had higher incidence of thyroid cancer (13.0 per 100,000) than males (4.5 per 100,000). Thyroid cancer incidence occurred at a relatively young age, with a median age of 48 for females and 53 for males. For females, rates peaked at age 45-49, while the peak among males was during age 65-69. Rates increased most steeply among those age 65-69 years, for both males (APC 8.0) and females (APC 10.76). Rates were highest in the Northeast for both females (16.3 per 100,000) and males (5.5 per 100,000) of all ages. Although mortality rates are low, the treatment and management of thyroid cancer is far from trivial and can have a long-term impact on the health and quality of life of survivors. After treatment, patients require life-long thyroid hormone replacement therapy, and survivors are at increased risk for future cancers, particularly when diagnosed at a young age. The more detailed analyses made possible by the large population coverage of the combined NPCR/SEER data may help identify possible reasons for recent increases so that research can focus on specific etiologic hypotheses and ultimately trends in incidence may be reversed. Final analysis for this presentation will include data up to 2007.

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CANCER TRENDS IN THE OLDEST OLD

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Background: Individuals aged 80 years and older comprise an increasing proportion of cancer patients in developed countries. Compared with the younger population, they differ substantially in how they present with cancer, the stage at diagnosis, the treatment they are given, and survival.

Purpose: This international collaborative study aims to summarize and compare trends in cancer-related measures among the oldest old in New Hampshire and Norway. Norway is a small northern European country which resembles New Hampshire in its predominantly Caucasian population and cold winter climate. However, Norway provides all of its citizens with free medical care, including screening mammography but not screening colonoscopy.

Methods: We will summarize cancer incidence data from New Hampshire for the period 1995 through 2006 to show cancer incidence, stage at diagnosis, frequency of multiple cancers, and 1- and 3-year survival for each major cancer site. Changes in these measures over time will be evaluated. We will also assess specific issues affecting cancer reporting in this age group, such as the frequency of "death certificate only" reports, and the frequency of missing key variables, including histological verification.

Implications: This is a hypothesis-generating study to identify issues affecting the oldest old cancer patients, to evaluate trends over time in this elderly population with cancer, and to compare these factors in New Hampshire and Norway.

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STATE DISPARITIES IN COLORECTAL CANCER MORTALITY RATE IN THE UNITED STATES

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Background: Colorectal Cancer (CRC) mortality rate has been decreasing for many decades in the United States, with the decrease accelerated in the most recent time period. The extent to which this decrease varies across states and how this might have influenced the geographic pattern is unknown. This paper examines the temporal and geographic patterns of CRC mortality rates by state. Methods: Trends in colorectal cancer death rates from 1990 through 2007, by state, were analyzed using joinpoint analysis; we also calculated the total percent change in state-specific CRC mortality rates between 1990-94 and 2003-07. Maps of state level mortality rates for these two time intervals were created using ArcGIS to examine changes in geographic patterns. Correlation between CRC screening rates and changes in mortality rates, by state, were examined. **Results:** CRC mortality rates decreased in all states except in Mississippi, from 1990 to 2007. Northeastern states showed the largest decrease in mortality rates while Southern and Appalachian states showed the smallest decrease. Consequently, the highest CRC mortality rates shifted from the Northeastern states to the Southern and Appalachian states. The decrease in CRC mortality rates, by state, strongly correlated with uptake of screening (r = -0.65, p < 0.0001). **Conclusions:** Progress in CRC mortality significantly varies across states, with states in the North showing the most progress and the Southern and the Appalachian states showing the least progress; the burden of CRC mortality shifted from the Northeast to the South and Appalachian states. Improving access to and utilization of screening in the Southern and Appalachian states may accelerate the decrease in CRC cancer death rates.

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MAPPING CANCER MORTALITY-TO-INCIDENCE RATIOS CAN HELP TO IDENTIFY RACIAL AND GENDER DISPARITIES IN HIGH-RISK POPULATIONS

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Background: Comparisons of incidence and mortality rates are the metrics most commonly used to define cancer-related racial disparities. In the United States (US), and particularly in South Carolina (SC), these largely disfavor African Americans (AAs). Though very rarely used, the mortality-to-incidence rate ratio (MIR): 1. "adjusts" the estimate of cancer mortality for cancer incidence; 2. provides a population-based indicator of survival; 3. can be computed from readily available cancer registry sources; and 4. may be used to pinpoint areas of greatest public health interest and future research need. Methods: SC Central Cancer Registry incidence and Vital Registry death data were utilized to construct MIRs. ArcGIS 9.2 was used to map cancer MIRs by gender and race for eight Health Regions within SC for all cancers combined, and for breast, cervical, colorectal, lung, oral, and prostate cancers. **Results:** For all cancers combined, EA females had the best survival (MIR: 0.37);AA males (MIR: 0.50) had the worst. The MIR differences between race groups for both breast and cervical cancer in females, for oral cancer in both genders, and for prostate cancer in males, are striking; i.e., 55%, 50%, 85% and 58% higher, respectively, in AAs than EAs. Conclusion: Comparing and mapping race- and gender-specific cancer MIRs provides a powerful way to visualize the scope of the cancer problem. Using these methods, AAs were found to have much higher cancer MIRs compared to EAs for most cancer sites in nearly all regions of SC. Future work must be directed at explaining and addressing the underlying differences in cancer outcomes by region and race. MIR mapping allows for pinpointing areas where future research has the greatest likelihood of identifying the causes of large, persistent cancerrelated disparities. Other regions with access to high-quality data may find it useful to compare MIRs and conduct MIR mapping.

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PROXIMITY TO TREATMENT AND LIKELIHOOD OF MASTECTOMY AMONG EARLY STAGE BREAST CANCER PATIENTS

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It is well-established that women with early stage breast cancer who live far from a radiation therapy facility in the U.S. are more likely to opt for mastectomy over breast-conserving surgery (BCS), in large part because of the barrier presented by the need for dozens of radiation appointments. In an effort to reassess and refine this relationship, we analyzed over 100,000 breast cancer patients in 10 states diagnosed between 2004 and 2006 who received either mastectomy or BCS. The NAACCR Shortest Path tool, developed as part of this project, was used to calculate the shortest travel distance to the location of surgery and to the nearest radiation treatment center. The likelihood of receipt of mastectomy was modeled as a function of these distance measures and other demographic variables using multilevel logistic regression. Consistent with previous findings, the likelihood of mastectomy increased with distance: women traveling over 75 km for treatment are about 1.4 times more likely to receive a mastectomy than those traveling under 15 km. Age under 50, Asian or Pacific Islander race, whether the tumor was the second or subsequent tumor, and state of residence were also strongly associated with mastectomy. Unlike previous studies, we were able to distinguish between patients without a radiation facility nearby and those who bypassed a local facility to receive treatment at a more distant location. We found that the increased likelihood of mastectomy was about the same in both groups, but that far more women fell into the latter category. Thus, while the existence of geographic barriers to breast cancer treatment remains a valid concern, the number of bypassing patients hints that this concern may have been overstated.

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TRAVEL TIME TO DIAGNOSING AND MAMMOGRAPHY FACILITIES AND BREAST CANCER STAGE AT DIAGNOSIS

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Background Until recently, there was some consensus that reduced access to healthcare and screening services due to geographic barriers was associated with higher risk of late stage breast cancer at diagnosis. But several current studies suggest this may no longer be the case. Using a multistate dataset we reexamine this issue by investigating whether travel time to a patient's diagnosing facility or nearest mammography facility impacts breast cancer stage at diagnosis. Methods We included women 40 years and older diagnosed with first primary breast cancer from 10 states from 2004-2006. For 161.619 women we calculated travel time to their diagnosing facility and nearest mammography facility. Logistic multilevel mixed models of late versus early stage were fitted, and odds ratios were calculated for travel times controlling for age, race/ethnicity, census tractbased poverty, rural/urban residence, health insurance, and state random effects. **Results** Seventy-six percent of all women in the study lived less than 20 minutes from their diagnosing facility and 93% lived less than 20 minutes from the nearest mammography facility. Late stage at diagnosis was not associated with increasing travel time to diagnosing facility or nearest mammography facility. Age under 50, Hispanic of any race, Non-Hispanic Black race/ethnicity, high census tract poverty, and no health insurance were all significantly associated with late stage at diagnosis. Conclusion Travel time to diagnosing provider or nearest mammography facility was not a determinant of late stage of breast cancer at diagnosis and greater geographic proximity did not assure better outcomes. Further research simultaneously examining geographic accessibility and screening capacity will help public officials target communities with inadequate resources. Other factors that can affect geographic access should also be considered such as reliable transportation, insurance acceptance, public transportation, and travel costs.



FACTORS ASSOCIATED WITH MASTECTOMY AMONG ASIAN WOMEN DIAGNOSED WITH EARLY-STAGE BREAST CANCER IN CALIFORNIA: AN APPLICATION OF RECURSIVE PARTITIONING TO IDENTIFY HIGH-RISK GROUPS

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In the early 1990's, evidence-based guidelines recommended breast conserving surgery (BCS) as a viable alternative to mastectomy for early-stage breast cancer. Yet, Asian women are more than two-times more likely than other groups to have mastectomy, given the same tumor characteristics. The reasons for this remain unclear, but may relate to biological factors such as large tumor-to-breast ratios, patient-provider communications, language barriers, cultural factors, and transportation difficulties. Recursive partitioning (RP) is a nonparametric method for detecting interactions among multiple factors, and thus may provide additional insights into the subgroups, jointly classified by sociodemographic and clinical characteristics, that are most likely to have mastectomy. We applied RP to Asian women diagnosed with stage I-II breast cancer between 1990-2007, in the California Cancer Registry. Excluding tumors that are contraindicated for BCS, 49.4% of 21,120 women had mastectomy. RP revealed 18 mutually-exclusive subgroups, with mastectomy rates ranging from 25.4% to 72.2%. The subgroups with the highest proportion of mastectomy were women who had tumors larger than 3 cm (% mastectomy = 72.2); those with tumors between 2-3 cm and diagnosed before 1996 (% mastectomy = 71.2); and those age 64 or older, with tumors between 2-3 cm, diagnosed on or after 1996, and in a hospital with few patients of high SES (% mastectomy = 65.7). We will also present results from polytomous logistic regression analyzing factors associated with mastectomy, BCS with radiation, and BCS without radiation, focusing in particular on Asian ethnicity and nativity, neighborhood socioeconomic status, ethnic enclave, and network distance to nearest radiation facilities. RP, used in conjunction with traditional methods like logistic regression, applied to cancer registry data can be a powerful tool for identifying the subgroups most likely to have mastectomy following early-stage breast cancer.

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INFLUENCE OF RACE, SOCIOECONOMIC STATUS, INSURANCE, AND HOSPITAL TYPE ON RECEIPT OF GUIDELINE ADJUVANT SYSTEMIC THERAPY FOR NON-METASTATIC BREAST CANCER PATIENTS

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Background: Information on how sociodemographic and hospital factors influence receipt of guideline adjuvant systemic therapy for breast cancer patients is scarce. We assessed the association of these nonclinical factors with receipt of guideline adjuvant systemic therapy for nonmetastatic breast cancer patients. Methods: Data on 6,822 breast cancer cases diagnosed in 2004 were collected for the CDC NPCR-funded Patterns of Care Study. Guideline chemotherapy or hormonal therapy was defined as receiving/not receiving the therapy consistent with the Guidelines. Nonclinical factors included race/ethnicity (white, black, AI/AN, API, Hispanic), insurance (none, private, Medicaid, Medicare/other public, unknown), census tract-level poverty (<20%, >20% in poverty) and education (<25%, >25% no high school), and hospital Commission on Cancer (CoC) status. Clinical factors included tumor size, histology, grade, lymph node, receptor status, and comorbidity. Multiple logistic regression was used. Results: There were 57% women receiving guideline chemotherapy. Medicaid beneficiaries, residents of high poverty area, and women treated at nonCoC hospitals were less likely (p<0.05) than privately insured, residents of low poverty area, and those treated at CoC hospitals to receive guideline chemotherapy after adjustment. The majority of women receiving adjuvant chemotherapy had guideline regimens (87%). Uninsured women and those treated at nonCoC hospitals were less likely (p<0.05) to receive guideline regimens after adjustment. About 79% of women received guideline hormonal therapy. Blacks, APIs, Hispanics, Medicaid beneficiaries, residents of high poverty and low education area, and women from nonCoC hospitals were less likely to receive guideline hormonal therapy after adjustment. Conclusions: Sociodemographic and hospital factors influence receipt of adjuvant systemic care for nonmetastatic breast cancer patients. To reduce disparities in care, target interventions are needed.



WHEN POLICY AFFECTS DATA: THE EFFECT OF COC'S SHIFT IN STAGING REQUIREMENTS JL Phillips¹

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Beginning in 2008, the Commission on Cancer (CoC) of the American College of Surgeons (ACoS) implemented a major policy change in its staging requirements. Prior to that date, managing physicians were required to record stage (clinical, pathologic or both as appropriate) for 90% of the records reviewed by the surveyor. Registrars were required to copy that information into the abstract, with the unanticipated consequence that registrars often became "staging police" with respect to the program's physicians. The modified policy requires cancer programs to assure that applicable staging is used in treatment planning. Registrars are required to report clinical staging information in the traditional AJCC fields whether it was supplied by the physician or not, and to complete Collaborative Staging (CS) which was seen by the CoC as an equivalent measure of "final stage". A 2004 CoC comparison of physician AJCC and registrar CS stage assignments, controlling for clinical or pathologic measurements, found substantial agreement between the physician AJCC and registrar CS staging.

The purpose of the current study was to determine the effect of the change in CoC policy on staging data for cancers diagnosed in 2008 using 2006-2008 diagnoses of stageable cancers reported to the National Cancer Data Base. Prior to 2008, most physicians recorded only one of clinical or pathologic staging, generally assigning pathologic stage using the elements available on the pathology report. The shift in CoC policy raised the possibility of a sharp drop in reported pathologic stage, and a potential shift away from physician to registrar clinical staging. However, our findings indicate a decrease in unknown clinical stage without loss of pathologic staging. Both analytic and clinical implications of these and other findings will be discussed, including implications for possibly collecting pre-treatment CS data.

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SEER PROGRAM FOR CONTINUOUS EVALUATION OF 2010 CSV2 IMPLEMENTATION AND CHANGES

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In late 2009, SEER formed a multi-disciplinary team to evaluate the data collection and coding of new CSv2 variables. The process transitioned from traditional large, resource-intensive, cross-sectional studies to smaller studies, less resource-intensive that provided continuous and timely feedback. Four studies were planned, implemented, analyzed, and released within a year. We propose a break-out session devoted to program methodology and study results to highlight the paradigm shift in the conduct of data quality assessments and to describe data availability and quality of the CSv2 data elements. These studies form a baseline to assess data quality improvement. In this session, the presenters will: discuss the results of the following completed studies: (1) site-specific factor (SSF) data availability and SSF data location within the medical record for breast, colon, prostate, lung, and melanoma; (2-4) SSFs and extent of disease coding consistency for the same five sites among all SEER regional programs, including preferred answers define. We will include sufficient time for discussion of both the new approach and the data results.

These studies revealed that SSF information was available in source documents and also identified where the information was found. Coding consistency of the SSF data items, and even several stagingvariables, was poor. The CSv2 mapping teams reviewed results and concluded that incomplete documentation in coding manuals contributed to low consistency. The results were used to revise the CSv2 coding manuals, made available in time for coding 2011 cases. In conclusion, the new paradigm in quality assessment enabled rapid planning, implementation, and analysis of data based on sound scientific principles, further leading to timely recommendations that were able to be implemented immediately. The entire process took less than one year and is being repeated in 2011.

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CS PARKING LOT: WHAT IS IT, WHAT'S IN IT, AND WHY SHOULD I CARE?

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Background: After the first release of Collaborative Stage (CS) version 2, a thorough data validation process was undertaken in 2010. Standard templates were applied to enhance consistency; questions from users and trainers were addressed; mapping to derived stages was verified; ambiguities were clarified; and schemas were proofread. Results were incorporated as version 020302. For a variety of reasons, including time and resource constraints, and the complexity of some issues, numerous known issues were set aside into a "Parking Lot." **Purpose:** To evaluate known unresolved issues with Collaborative Stage v020302 and proposed solutions with regard to, e.g., who will need to be involved to craft a solution; the impact of proposed solutions on code structures; the possible necessity for additional data elements; and overall impact on cancer registries. Methods: Gathered Parking Lot issues from committee documents, assessed each to determine its complexity; which individuals, CS teams, or agencies can propose and approve resolution; resources required; possible timelines for implementation; and impact on registries. **Results:** Analysis has identified some issues that will require clarification from the American Joint Committee on Cancer about the meaning and intent of their Cancer Staging Manual, 7th ed. In at least one case, in-depth review of staging parameters with AJCC physicians will be needed. To resolve other issues, Standard Setters will need to achieve a consensus. Some issues can be addressed by the CS Mapping Team through existing mechanisms. Resolution of others may require modifications of code structures to increase consistency in collecting types of data such as genetic tests and laboratory test values. Collection of additional CS data items may be required in a few cases. Conclusions: The analysis of Parking Lot issues will be presented with emphasis on the issues with the greatest future implications for cancer registries.

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CONSOLIDATION OF CANCER STAGE AND PROGNOSTIC FACTOR DATA ELEMENTS – OPERATIONAL ISSUES IN COLLABORATIVE STAGE DATA COLLECTION SYSTEM

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Background: Collaborative Stage Data Collection System (CS) has been developed in an effort to standardize the collection of anatomic stage and other prognostic factors. While detailed rules have been developed to ensure accurate abstraction and coding of CS data elements, no guidance has been provided for consolidation of CS data elements in population-based registries. **Purpose:** This project aims to review operational issues related to the consolidation of CS data elements in central cancer registries that might result in inconsistent assignment of cancer stage and, therefore, prognosis across populations. This project will compare final consolidated stage in CS v2 when data are initially consolidated by CS v1 rules and then converted to CS v2 codes versus when abstract data are converted to CS v2 followed by consolidation. Approach: We plan to review tumors with multiple source abstracts available in the Maryland Cancer Registry. The analysis will include tumors diagnosed between years 2004 and 2009 and abstracts provided by all types of reporting sources with the exception of vital statistics. A random sample of tumors initially consolidated by CS v1 rules will be reconsolidated using abstracts first converted to CS v2. **Results**: Results will describe the distribution of CS data elements from multiple-source tumors by CS Schema and CS version. In addition, the results might show discrepancies between converted CS v2 values versus CS values obtained from reconsolidation. Furthermore, the results may present abstract source-level CS value data patterns that result in unique consolidated values, and therefore are feasible for automation. Implications: This project will assess whether a misclassification bias has been introduced by converting consolidated CS data elements from CS v1 to CS v2. In addition, the project will evaluate whether best value selection algorithms are a feasible option to automate CS data elements consolidation.

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Oral Abstracts

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oral abstracts

concurrent session 5



USING TECHNOLOGY TO INCREASE PRODUCTIVITY AND DATA QUALITY

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Background: The California Cancer Registry (CCR) has established a goal of abstract to research-ready processing with as limited human intervention as possible. The overall objective is to process a high percentage of cases, particularly those that are straight-forward and routine without manual review. Achieving this objective would reallocate staff time into more complex issues such as data analysis, problem resolution, automation, and/or problem identification.

Method: To achieve this objective multiple automation approaches have been deployed to our state-wide data base. Eureka Data Management System (EDMS). Automation tools have been used for Quarterly Submissions for regional registries, Annual Extract for Data Submissions, Geocoding processing, Probablistic Linkage, Passive Follow-up through consolidation, Electronic Death Record images replacing DC images, Auto Complete DCO cases to name a few. Certified Tumor Registrar's are applying their numerous years of experience creating Automation Rules through the use of Business Rules Management Solutions (BRMS) to achieve data quality. Time spent to manually perform tasks as originally designed was compared to the streamlined automation processes. **Results:** Presentation will highlight the automation approaches implemented by CCR to-date in the Eureka Lean Six-Sigma Automation Report and demonstrate the accumulated reallocation since inception in hours and FTE's. Since inception of EDMS we have been able to reallocate numerous staff to other projects. This report is looking at; Average Time to complete 1 unit of work, Submissions, Geo-coding, Quantity of Work Automated, Workload Reallocation to name a few. Presentation will also discuss ideas for future process improvements utilizing automation tools.

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SEX MISCLASSIFICATION IN CENTRAL CANCER REGISTRIES

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Site-sex edits are a standard tool to improve quality of the sex code in cancer registries. But the percentage of sex-specific cancers is low (20% of invasive cases). Visual review and follow-back to improve the quality of the sex coding is labor intensive and typically only performed as a special project on subsets of data.

The New York State Cancer Registry (NYSCR) created an edit for identifying potential sex misclassification for cancer registries. The edit uses the most popular male and female first names based on decade of birth to flag potentially miscoded cases. This edit was tested by the Florida Cancer Registry (FCDS).

Breast (100x more female than male cases), thyroid (3x more female than male cases), liver (more minorities), and colorectal cases diagnosed in Florida from 1981-2008 were evaluated using the NYSCR edit. Most, 68%, of the 953,074 cases agreed with the edit's probable sex, 31% could not be evaluated, and 0.5% disagreed. Additionally, 145 cases were unknown in the registry but the edit identified a probable sex. Results varied by site: 21% of the male breast cases were flagged by the edit as probably female; and 1.3% of the male thyroid cases. Results varied by year and race/ethnicity. The NYSCR edit may be appropriate for automated correction of sex in specific instances. Results for FCDS breast cases were compared to a 2003 FL QC project. Male breast cancer cases were reviewed visually by first name and 904 were identified as probably female. Hospitals were asked to verify male sex. All but 3 cases were subsequently changed to female. The NYSCR edit identified 729 (81%) of the cases correctly as females and 1 case correctly as male. For the 2 other male cases (and the remaining cases), the NYSCR edit was unable to assign a probable sex. Sex misclassification is likely artificially inflating male breast cancer rates in FL. For male breast cancers, it may be appropriate to change to female cases the NYSCR edit flags as female.

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AUTOMATING BUSINESS RULES AS A DATA QUALITY TOOL

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Background: California Cancer Registry (CCR) reduced visual editing of incoming Admissions from 100% to 40%. This decision necessitated a new approach to verifying the quality of the data in our database. A management decision was made to create a business model for writing, programming and implementing automated business rules as a quality control tool. Methods: Core project team members were assembled consisting of a Project Manager, experienced CTR's and software Programmer. Through collaborative efforts between the Core Team members, a module for developing automated business rules was created. Initial efforts were directed at verifying Admission level information as analytic or non-analytic. The data field "Class of Case" was used as the key data field for this determination. CTRs developed rule sets to evaluate the Class of Case assignment for each Admission. By collaborating with programmers, programmed code was developed that would auto-correct Class of Case or related fields when specified conditions existed. Short term project goal was to implement Class of Case rule sets. Long term project goal is to eventually automate the manual consolidation process.

Results: Presentation will provide attendees with updates to the BRMS rule writing project in California. Currently, project has implemented 2010 data changes for class of case to existing rule sets. Class of case for Class 38 (autopsy only), Class 49 (DCO) have been implemented with significant progress underway on Class 43 (Path Only). Additionally, auto-change rules are in progress for over 44 edits. BRMS team members are analyzing CS site specific factors to determine the feasibility of implementing auto-change rules for site specific schemas.

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THE EFFECT OF ADMINISTRATIVE BOUNDARIES AND GEOCODING ERROR ON CANCER RATES

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Geocoding is the process of translating address data into a geographic representation, such as latitude and longitude coordinates or a census tract value. The process of geocoding 'an address at time of diagnosis' occurs routinely for cancer research, surveillance, and prevention. Unfortunately, for many reasons, a geocoding algorithm can fail to match an address at a street level. When this occurs the geocoder must use another piece of address data, such a ZIP code, city or county, to 'locate' the address and assign it attributes such as census tract value. block group value and latitude/longitude coordinates. . When this occurs, the geocoded attributes (census tract value, block group value, etc.) are less accurate than if they were based on a street level match. For example, if a geocoding algorithm cannot match an 'address at time of diagnosis' at the street level, it may place the address at the centroid of the geography associated with the address' ZIP code. The geocoding algorithm will output the county, census tract, block group and latitude/longitude values that correspond to the ZIP centroid location. In this study, we present an examination of how frequently this scenario occurs based on a review of geocodes from the California Cancer Registry (CCR). Specifically, we look at the prevalence of incorrect county assignments that are due to a street address being geocoded to the centroid of a ZIP code boundary. This is important to know because routinely assigning cancer cases to incorrect counties can skew county-level cancer incidence rates and lead to mis-directed cancer prevention services that are based on county-level data. Our results indicate that ZIP code boundaries with jagged edges that cross or are proximate to county boundaries account for many of these incorrect county assignments.

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PREDICTIONS FOR GRID-BASED COMPUTING SYSTEMS AT CENTRAL CANCER REGISTRIES: MODELING SYSTEM PERFORMANCE AND VISUALIZING NEW PLATFORM TECHNOLOGIES

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Background: Cancer registries face tough choices when considering future computing platform technologies. Data sharing among cancer registries and clinical providers is key to the evolution of personalized medicine especially in the area of biospecimen data banking. However, adopting any large-scale distributed information technology system, without knowing its strengths and limitations, can impact the operational capabilities of a cancer registry. **Purpose:** Develop and test a novel hybrid agent-based modeling system to assess the performance impact of a complex, Grid-based computing system that may be applied at the Utah Cancer Registry. Methods: The modeling engine was calibrated and configured using performance monitoring data from interoperable virtual machines set up for the cancer Biomedical Informatics Grid caTISSUE Suite, which was then used to predict the performance of future system configurations. Performance measures between the existing legacy system were compared to proposed Grid-based systems for both dependent and independent workflows. Results: We found improved performance of distributed workflows running on multiple Grid nodes over that provided by legacy systems. The implemented systems demonstrate the ability of the hybrid agent-based model to calibrate between real world system performance and predictions made by the models. Conclusions: These models can assist registries in understanding the benefits of using Grid computing technology and overcome barriers to its adoption. Without requiring the construction of actual systems to test and measure performance, our models provide predictions of the performance degradation resulting from increased workflow load. Enabling cancer registries to visualize new platform technologies such as interoperable virtual biospecimen data banking systems and how to integrate data from them into their operations can ultimately assist the registries in determining the best technologies to adopt.

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A PARADIGM SHIFT – NAACCR *STANDARDS VOLUME V* AND THE COLLEGE OF AMERICAN PATHOLOGISTS' (CAP) ELECTRONIC-CANCER CHECKLISTS

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The need to address transmission of clinical data in a synoptic or 'structured and coded' format to cancer registries was recognized years ago by the CDC-NPCR through the Reporting Pathology Protocol (RPP) pilot projects. The purpose of RPP1 (2001) was to explore sending pathology reports for colon and rectum cancers in a structured format. This format is characterized by question and answer style pairs, where, for example, "Tumor Border Configuration" is the question and "Infiltrating" the answer. In RPP1 the question part was sent using LOINC and the answer part using SNOMED CT codes. The RPP2 (2004) evaluated the use of CAP cancer checklists for three additional sites (breast, prostate and malig. melanomas of the skin). The checklists were SNOMED CT encoded, which evolved during the project into the CAP electronic Cancer Checklists (eCC). The eCCs are electronic encoded representations of cancer checklists which allow clinical information to be transmitted as discrete data elements versus the traditional (narrative) free text. Results of the RPP projects were included (as a short section) in several versions of The NAACCR Standards for Cancer Registries Volume V- Version 2.1, Version 2.2 and Version 3. These guidelines needed an update to reflect the progress of the eCCs. Therefore, the most recent Volume V, a work in progress, includes guidance on transmission of Health Level Seven (HL7) version 2.5.1 messages containing (traditional) text-based pathology reports, as well as an expanded section with examples of message structure and format of synoptic cancer pathology reports, including samples of fully encoded eCCs. The Work Group accomplished this challenging task in collaboration with numerous professionals from CDC-NPCR, Canadian Partnership Against Cancer, CAP, consultants, federal agencies, laboratory and registry information system vendors, and the Canadian Provincial/Territorial Registries who provided synoptic cancer pathology implementation expertise.

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AUTOMATED CLASSIFICATION OF PATHOLOGY REPORTS INTO SEER HISTOLOGY/SITE RECODE CLASSES

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Artificial intelligence techniques play an increasingly important role in cancer reporting. Key word searches, used for case identification, were supplanted by natural language processing a decade ago. Refinement of this technology and the development of the knowledge base resulted in accurate case finding and computer assisted coding. A more recent, parallel effort to further enhanced the technology to extract key data elements to render reports machine readable continues.

Work, undertaken in conjunction with the Kentucky Cancer Registry over the past two years, has combined these systems and supplemented it with a third layer that is able to draw inferences based on a set of rules, to assign cancer cases to SEER Histology /Site Recode Classes.

The initial identification of cases as cancer is based on ICD-O-3. Assigning cases to the Recode Classes is based on: morphology, behavior, grade and laterality. The use of a layered approach, where each layer of software carries out a specific set of functions, permits improvement in functionality in a controlled manner and extension to other types of data.

Rules used by the inference engine were heuristically derived and based on feedback from registrars as they reviewed reports. Identifying the factors on which coding decisions are based proved to be challenging. In instances where relevant information was not explicitly mentioned in the pathology report it was possible, to a limited extent, for the AI system to infer codes from the pathology narrative. Conversely, Spurious morphology or topography terms appearing in the text require identification as such so they could be removed during processing. Metrics were established for performance assessment and the results of system tests will be presented and discussed.

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REQUIREMENTS ANALYSIS AND RECOMMENDATIONS FOR CAP ECC REPORTING TO CANCER REGISTRIES

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Background: The creation, implementation, and maintenance of the College of American Pathologists (CAP) electronic Cancer Checklists (eCC) for cancer pathology reports are complex and challenging. Specifically, cancer registries have the challenge of receiving and processing the checklist reports. Purpose: A multidisciplinary workgroup (WG) of experts and stakeholders was assembled to discuss and document issues, requirements, and recommendations for reporting eCC cancer pathology data to cancer registries. Methods: The WG conducted 10 sessions using web-based teleconferences. Facilitation and business modeling techniques were used to support analysis and requirements gathering. A partitioning approach was used to reduce complexity, to focus analysis, and to facilitate brainstorming. Results: Requirements and recommendations were formulated for five categories: eCC advancement, data collection and validation, report transmitting/messaging, reporting process, and implementation. 16 operational requirements and 51 recommendations to stakeholders were formulated. Examples of areas addressed include HL7 conformance testing and conversion of the eCC pathology data to NAACCR data items. Developed requirements do not encompass a comprehensive specification, but rather reflect most problematic issues. A summary report was distributed to the NAACCR Pathology Data WG and vetted to that WG and CAP staff. Conclusions: The WG provided a forum for collaboration among stakeholders and experts to analyze existing practices and develop consensus-based recommendations. Presentation of the main WG product-a summary report of selected requirements and recommendations – to various groups within pathology and cancer registration communities proved its usefulness as an instrument to inform the targeted audience and stimulate discussions. Implementation of developed recommendations by process stakeholders would positively impact the eCC reporting process to cancer registries.

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EXPLORING THE RELATIONSHIP BETWEEN URINARY TRACT CANCER INCIDENCE AND INGESTION OF INORGANIC ARSENIC

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Background: Inorganic arsenic (As) is well established as a human carcinogen. Health effects from ingestion of water contaminated with high concentrations of As have been extensively studied; however, health effects from exposure to the lower concentrations that are typical in the continental US are not as well defined. The Garber-Wellington aquifer, which is a source of drinking water for central Oklahoma, has elevated concentrations of naturally occurring arsenic. While concentrations of arsenic can be no higher than 10 ppb in public water systems, there is no protection for people who obtain their drinking water from wells. Due to potential exposure to elevated As concentrations, and the known evidence that this exposure may result in cancer, there is sufficient need to determine if there is a measurable effect on this population in central Oklahoma. **Study Purpose:** The purpose of this project was to ascertain if there is a relationship between urinary tract cancer incidence and concentrations of As in well water in central OK. This geographic area is unique because of the elevated arsenic concentrations in the aquifer which is a source of drinking water for the study area. Many of the studies that have been conducted on this topic use a health outcome of death, however this study used health outcomes at diagnosis, providing more power to identify a relationship between exposure and health outcome. Methods: Data from the cancer registry was used to identify individuals diagnosed with urinary tract cancers. Arsenic concentrations were obtained from a dataset compiled by the Oklahoma Water Resources Board. Results: This analysis of this study is not completed however it will be finished prior to May 2011. **Implications:** If a relationship between arsenic exposure via well water and cancer incidence can be determined, it will provide public health officials another avenue of public education with which to assist in reducing the cancer burden.

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URBAN-RURAL GRADIENT IN MEDULLOBLASTOMA INCIDENCE DURING 1995-2006

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Background: Previously-reported regional and seasonal patterns of medulloblastoma incidence in agricultural states have implicated pesticide exposure as a risk factor. Objectives: To test the hypothesis that medulloblastoma incidence is higher among residents of non-metropolitan counties. Methods: Data on medulloblastoma (site=C716, with histology = 9470, 9472, 9472, or 9474) for 1995-2006 were obtained from the Cancer Incidence in North America ("CINA Deluxe") online database of the North American Association of Central Cancer Registries (NAACCR). Incidence rates and 95% confidence intervals were calculated and stratified by sex, race, year of diagnosis, and degree of urbanization Incidence rates (per million person-years at-risk, age-adjusted to the United States 2000 standard population) for white, black, and Asian males and females in both metropolitan and non-metropolitan counties, and rate ratios (non-metropolitan versus metropolitan) were calculated using SEER*Stat. Results: There were 3282 medulloblastoma cases during 1995-2006, including 2802 among whites (1746 males and 1056 females), 311 among blacks (177 males and 134 females), and 100 among Asians and Pacific Islanders (64 males [rate per million =1.0] and 36 females [rate per million =0.7]). Rates for white males in non-metropolitan (1.5) and metropolitan (1.6) counties were almost identical, yielding a rate ratio of 0.9 (95% CI=0.8-1.1). Rates were lower among white females in non-metropolitan (0.9) and metro (1.0) counties, among black males in non-metropolitan (0.8) and metropolitan (0.9) counties, and among black females in nonmetropolitan (0.9) and metropolitan (0.7) counties, yielding rate ratios of 0.9 (95% confidence interval: 0.7-1.0), 0.9 (95% confidence interval: 0.5-1.5) and 1.4 (95% confidence interval: 0.8-2.4), respectively. Implications: These findings do not confirm that medulloblastoma incidence is higher among residents of non-metropolitan counties.

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PREDICTORS OF AGGRESSIVE END-OF-LIFE CARE AMONG NEW YORK STATE BREAST AND COLORECTAL CANCER PATIENTS

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Resources are often inappropriately managed at the end of life, with much of the expense coming from multiple, potentially avoidable hospitalizations in the last month of life. This aggressive care neither sufficiently prolongs nor improves the quality of a patient's life. Focusing on palliative care, rather than life-prolonging care, may be a better alternative for these patients, reducing cost and distress for patients and their families. As part of a linkage between the New York State Cancer Registry database and Medicare, Medicaid, and the Statewide Planning and Research Cooperative System (SPARCS), we evaluated the quality of end-of-life care among New York breast and colorectal cancer patients. All adult cases of breast and colorectal cancer that were diagnosed from 2004 to 2006 were included in this study and linked to SPARCS hospital discharge data dating from 2002 through 2007. We used logistic regression analysis to determine predictors of ICU stays, multiple hospitalizations, and multiple ER visits in the last month of life, as proxy measures of aggressive end-of-life care. Preliminary results show that female patients with private insurance may be significantly more likely than those with Medicare to obtain aggressive end-of-life care. Older age, advanced tumor stages, and longer survival time from diagnosis may be negatively associated with aggressive hospital care, while racial minorities may be more likely to obtain life-prolonging care. Our study findings will be shared with the New York State Department of Health, the NCI SEER-Medicare program, other central cancer registries, state Medicaid programs, universities, and the greater research community. We hope that our results will pave the way towards improving the quality of end-of-life cancer care in New York State.

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AGE DISPARITY IN THE DISSEMINATION OF IMATINIB FOR TREATING CHRONIC MYELOID LEUKEMIA

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BACKGROUND: Imatinib is a highly effective treatment for Chronic Myeloid Leukemia (CML). It was approved by the Food and Drug Administration in 2001 and thereafter rapidly became front-line therapy. **PURPOSE:** This study characterized the impact of imatinib on CML survival and mortality rates in the general population. METHODS: Investigators utilized data from the National Cancer Institute's Patterns of Care study. Abstractors reviewed medical records and queried physicians regarding therapy for 423 patients diagnosed with CML in 2003 who were randomly selected from registries in the Surveillance, Epidemiology, and End Results (SEER) Program. Characteristics associated with the receipt of imatinib were documented, as were survival differences between those who received imatinib and those who did not. Data from populationbased cancer registries and vital records were used to assess CML survival and mortality rates in the general population during time periods before and after the introduction of imatinib.

RESULTS: Imatinib was administered to 76% of patients in the Patterns of Care study. Imatinib use was inversely associated with age: 90%, 75%, and 46% for patients ages 20 to 59 years, 60 to 79 years, and 80 or more years, respectively. After adjusting for age, imatinib use did not vary significantly by race/ethnicity, socioeconomic status, urban/rural residence, presence of comorbid conditions, or insurance status. In the general population, CML survival improved and CML mortality rates declined during the period when imatinib became widely available; these improvements diminished with increasing age.

CONCLUSIONS/IMPLICATIONS: Widespread dissemination of imatinib resulted in dramatic improvements in CML survival and decreased CML mortality rates in the general population of the United States. Use of imatinib was inversely associated with age and, consequently, imatinib-derived benefits were diminished among the eldest segments of the population.



EXPLORING THE UTILITY OF CA125 AS A CLINICALLY RELEVANT PROGNOSTIC FACTOR IN PATIENTS WITH OVARIAN CANCER

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Background: Ovarian cancer is the leading cause of mortality from gynecologic cancers in the United States. Carbohydrate antigen 125 (CA125) is the best-established tumor marker for ovarian cancer. Information on CA125 is collected by participating registries in the Surveillance Epidemiology and End Results (SEER) Program. CA125 levels correlate with patient's response to surgical resection or chemotherapy and therefore, predict survival in these patients. However, elevated levels are typically found in about 90% of advanced stage patients and about 50% of Stage I ovarian cancer patients. Levels of this antigen are also elevated in endometrial, pancreatic, lung, breast, and colon cancers and in menstruation, pregnancy, endometriosis, cirrhosis, and other gynecologic and nongynecologic conditions. **Purpose**: To investigate the utility of CA125 as a predictor for survival in patients with ovarian cancer. Methods: A secondary analysis was conducted on 16,635 women who were diagnosed with ovarian cancer between 2004 and 2007 and were residents of areas covered by the population-based SEER Program. Cases siting ovarian cancer as a 1st or only malignancy were included. Regression, trends, and survival statistics were conducted. Results: Overall 3-year survival was 48% with an average survival of 17 months. At diagnosis, CA125 was elevated in 65% of participants, 45% were elevated at stage I and 74% were elevated at stage IV. Indepth analyses for different strata and models, (i.e., stage, race, CA125 levels, histology, etc.) will be presented. Correlation between CA125 levels and disease stage at diagnosis and how it predicts prognosis for survival will be discussed. **Conclusion**: Clinical trials have rendered mixed reviews on CA125 as a monitoring factor for patients with ovarian cancer. This analysis provides some additional supporting evidence from a populationbased perspective for the use of preoperative CA 125 as a clinically significant prognostic factor.

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RELEVANCE OF GLEASON SCORE FOR THE INITIAL MANAGEMENT OF PROSTATE ADENOCARCINOMA: A POPULATION-BASED PERSPECTIVE

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Background: The Gleason score (GS) is recommended for use in the staging workup of all prostate adenocarcinomas (PA). In addition, the GS is employed by various predictive models to determine recurrence risk. Recommendations for the initial therapy of PA are based on the anatomic extent of disease, PSA level, life expectancy, as well as GS.

Purpose: This investigation explores the completeness and accuracy of GS data collected with the Collaborative Stage Data Collection System (CS), measures the relevance of GS for recurrence risk assessment, and tests whether initial therapy is associated with the GS values.

Methods: SEER 17 Database was used to select PAs diagnosed between 2004 and 2007. Tumors missing histologic confirmation, special variants of adenocarcinoma, and patients with metastatic disease were excluded. Comparisons of GS data with certain standard cancer registration elements, such as histologic grade, Gleason primary and secondary patterns, were conducted to assess data quality. Recurrence risk was stratified according to the National Comprehensive Cancer Network practice guidelines in oncology. Initial therapy was categorized as surgery, radiation, or active surveillance.

Results: GS data were available for over 96% of PAs, although frequently the data did not reflect the patterns of a TRUS-guided biopsy. Approximately one third of the PAs have been assigned an intermediate, high, or very high recurrence risk because of a GS higher than 6. There was no strong association between the GS and the initial therapy.

Conclusion: GS data are easily available and, most likely, highly accurate. GS is a relevant factor for stage distribution and recurrence risk assessment. GS does not appear to be a strong determinant of the initial therapy.

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PREVALENCE OF HPV INFECTION IN HEAD AND NECK CANCERS BY ANATOMIC SUBSITE

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Background: In recent decades, molecular and epidemiologic data have linked Human papilloma virus (HPV) with head and neck squamous cell carcinoma (HNSCC). The reported prevalence of HPV in HNSCC varied between 0-100%. This broad variation in HPV detection rates is attributable to tumor site, HPV detection method, specimen source and collection method, use of HPV type specific vs. universal primer, and sample size and composition. Inability to classify cases by anatomic subsite and to differentiate primary, recurrent, and metastatic tumors may also have contributed to the inconsistencies. Purpose: To eliminate the confounding factors in the assessment of the HPV prevalence by using tissues from primary HNSCC cases linked with population-based cancer registry records by anatomic subsite. Methods: 195 formalin fixed paraffin embedded (FFPE) tissue blocks from the Los Angeles Residual Tissue Repository (RTR) were tested for HPV DNA by polymerase chain reaction (PCR) and genotyped. Associations between HPV infection and patient demographics, tumor characteristics, and survival status were examined. **Results:** Overall, the HPV prevalence rate is 31.8% in all HNSCC cases tested. HPV16 was found in 98% of all HPV infected cases. The highest HPV prevalence rate of 52.1% was found in oropharynx, followed by 32.2% in larynx, 25.0% in nasopharynx, 22.6% in hypopharynx, and 18.4% in oral cavity. HPV infection is significantly more common in men than in women (37.1% vs. 17.3%). Despite the reported better radiocurability of HPV+ tumors, the HPV+ patients had similar distribution of treatment modalities as the HPV- patients. No survival difference was observed between HPV+ and HPV- patients.

Conclusions: Given about 1/3 of the HNSCC patients had HPV infection, testing for HPV in HNSCC patients may be warranted for better treatment decisions and prognosis. Impact on HNSCC from HPV vaccination to prevent cervical cancer should be monitored.

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INFLUENCE OF SOCIOECONOMIC STATUS AND HOSPITAL TYPE ON DISPARITIES OF LYMPH NODE EVALUATION IN COLON CANCER PATIENTS

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Background: An adequate number of lymph nodes (LNs) dissected is necessary for proper staging of colon cancer. The National Comprehensive Cancer Network (NCCN) has recommended a minimum of 12 dissected LNs for colon cancer patients. This study assessed the compliance with the NCCN recommendation and examined the association of socioeconomic status (SES) and hospital type with adequate number of LNs dissected for colon cancer patients. Methods: Stage I-III colon cancer incident cases (10,460) diagnosed in 1996-2007 were obtained from the Louisiana Tumor Registry. A composite census tract-level SES was created serving as a surrogate for individual-level SES. Hospitals where patients received colon resections were categorized into five groups according to the classification of Commission on Cancer (CoC) Accreditation Program. Multiple logistic regression analyses were used. Results: Of 10,460 colon cancer cases, 43.9% had ≥12 LNs dissected. Residents of areas scoring in the lower SES quintiles were less likely to receive a dissection of \geq 12 nodes than those of the highest SES quintile (the most affluent areas). After adjusting for race, sex, age, stage, grade, anatomic subsite, diagnosis year, and hospital type, SES was no longer significant. In contrast, hospital type was still significantly associated with the number of LNs dissected. Patients receiving colon resections at a teaching hospital with cancer program were more likely than those treated at a public hospital or a community hospital with cancer program to have an adequate node dissection after adjustment. Patients diagnosed in 2002-2007 were more likely (OR=1.99, 95% Cl, 1.84-2.17) than those diagnosed in 1996-2001 to have ≥ 12 LNs dissected after adjustment. Conclusion: The hospital type is an important determinant of adequate LN evaluation for colon cancer. Training and education are required to eliminate this disparity in the facilities with lower proportion of adequacy of LN dissections.

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ANNOTATING BIOSPECIMENS WITH CANCER REGISTRY DATA – A COLLABORATION BETWEEN THE MARKEY CANCER CENTER AND THE KENTUCKY CANCER REGISTRY

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Biorepositories are important resources in cancer research, playing a critical role in biomarker discovery and validation as well as in genetic research and other research areas. It is important to annotate the collected biospecimens with meaningful data in order to maximize the research driven potential of repositories. Central cancer registries maintain rich, well defined, and high quality diagnostic, clinical, and outcome data. Data routinely collected at central cancer registries can greatly enhance the research potential of cancer biospecimens. However, to exploit this potential we must first carefully consider the implications regarding patient confidentiality, patient consent, and honest brokerage between the data and researchers.

We present a case study of the collaboration between the Markey Cancer Center's Biospecimen Core Program (BCP) and the Kentucky Cancer Registry (KCR). The BCP currently maintains seven specimen collection protocols with more than forty thousand samples (fresh frozen tissue, serum, plasma, urine, etc.). KCR provides IT services to the Markey Cancer Center which includes the management of the BCP's biorepository information system, caTissue. After a formal approval process (overview of the protocol's IRB documents), consented patients from three collection protocols at the BCP have been linked with KCR data. A small set of NAACCR defined variables are directly stored in the caTissue software as annotations. A more complete registry dataset are also maintained in a linked data warehouse to allow honest brokers to provide extended de-identified datasets to investigators as needed.

In the presentation we will highlight KCR's policy decisions, achievements and the technical and organizational challenges that we encountered during this work.

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MAINTENANCE OF A REGISTRY DATA MANAGEMENT SYSTEM: COLLABORATIVE RESULTS STEMMING FROM THE SEER*DMS CHANGE CONTROL BOARD

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The NCI SEER Program developed the SEER*DMS data management system that is centrally designed, yet customized for each registry. Since 2005, SEER*DMS has been deployed at nine central registries and three others are in the process of transition. The use of a single data management system by nine to twelve registries requires a structured approach to system enhancements. It also provides opportunities for collaboration among registry staff and centralized responses to changes in the cancer reporting world.

The Change Control Board (CCB) is the SEER*DMS steering committee for change management. Membership includes key members of the SEER registries, the IMS development team, and NCI surveillance systems staff. The CCB evaluates plans and proposals for all significant changes and enhancements to SEER*DMS, including the development of new features and changes to algorithms, database structure, and hardware infrastructure.

A member of the SEER*DMS development team will describe methods used by the SEER*DMS community to facilitate interregistry communication and to apply a disciplined approach to system changes. This presentation will highlight the impact that a centralized support structure has had on the SEER*DMS registries, including changes related NAACCR 12 and CSv2, and the increasing number of reports and scripts which meet community-wide needs.

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TOWARDS CANADIAN NATIONAL POPULATION BASED COLLABORATIVE STAGE DATA

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Background: In 1992, the Canadian Cancer Registry began collecting cancer data from provincial/territorial cancer registries (PTCRs). A 2005 report on PTCR's found cancer registration in Canada was undergoing a change. Six PTCR's were collecting Collaborative Stage (CS), while the remaining PTCR's were collecting TNM. The report advised that Canada should standardize the collection of CS data and support the adoption and implementation of electronic efficiencies. Purpose: The Canadian Partnership Against Cancer (the Partnership) created The National Staging Initiative (NSI) in 2008 to assist PTCRs achieve a CS data capture rate of 90% for all Breast, Colorectal, Lung and Prostate cancer cases diagnosed on or after January 1st 2010. Methods/Approach: NSI Key components: Registry Upgrades/implementations to support CSv2; use of existing IT infrastructure; adoption and implementation of the College of American Pathologist's (CAP) Cancer checklists; access to ehealth records; integration of e-health data where possible; formal project management practices; sustainability. The Partnership provided a portion of the funding and has been instrumental in assisting the PTCR's strengthen their relationships, and leveraging shared successes. **Results:** CSv2 upgrades will be completed by eight PTCR's by March 31st 2011. Nine PTCR's will implement e-workflow enhancements by March 31st 2012. Nine PTCR's will have access to e- health records. CAP cancer checklists have been endorsed as the pan-Canadian content standard for cancer pathology and implemented in an electronic format in three provinces. Conclusions: National population-based staging data set will be available for Breast, Colorectal, Lung and Prostate cancer cases for the 2010 coding year in the spring of 2012; adoption of structured pathology reporting in Canada will enable better patient care, improved data quality and create efficiencies in PTCR's; eworkflow improvements will streamline staging processes.

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THE FEASIBILITY OF USING U.S. CENSUS 2000 PUBLIC USE MICRODATA SAMPLE (PUMS) TO EVALUATE POPULATION UNIQUENESS FOR POPULATION-BASED CANCER MICRODATA

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The National Cancer Institute's Surveillance, Epidemiology, and End Results Program routinely collects and publishes data on cancer patient demographics, tumor characteristics, and treatment information from population-based cancer registries. It has been the most authoritative source of data for describing cancer incidences and survivals. The release of high quality and confidential cancer registry data for research and health care planning is central to the agency's mission. Although SEER data are protected under a data user agreement, it is still crucially important to develop a plan to quantify the potential disclosure risks. While the internal disclosure threat presented by record uniqueness has been well addressed, little consideration has been given to the external threat in which a data intruder seeks to find out whether a known person in the population has cancer by matching his characteristics with those from registries records. In this presentation, we develop a non-parametric approach to estimate the proportion of record unique patients who are also unique in the population given specifications of SEER data files. We match categorical "key" variables between the SEER county-level data with the Census 2000 PUMS. We multiply impute county codes for PUMS. The methods can be conveniently applied to future assessments in which yearly updated PUMS from the American Community Survey are used after 2010. The results show that PUMS files have great potential to be used in routine disclosure risk assessments. The risk estimates tend to be conservative compared with those calculated from the 100% Census 2000 summary data that are treated as the gold standard. The upward bias is in the neighborhood of 2 to 3 times. The statistical evidences produced from this research will serve as the basis for planning SEER data dissemination, especially on how to disseminate geographic data and apply statistical disclosure limitation methods to protect data confidentiality.

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posters 01 - 54



P-01

VISIONING TIMELINESS, IMPROVING ACCURACY, AND ENHANCING EFFICIENCY: EVALUATION OF INCIDENT DATA AND CANCER REPORTING TO CENTRAL REGISTRIES

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Background: In 2008 SEER investigators met to discuss the future and vision of cancer surveillance, including: challenges in obtaining complete, timely, and accurate population-based surveillance data in an era of reduced funding; and, sustaining the relevance of central registries as approaches to cancer prevention, control, and research undergo dramatic paradigm shifts. A two-tiered reporting system was recommended, wherein a limited set of data are made available within 6 months of diagnosis. Questions of whether central registries receive these data in that time period, and the extent to which the initial data are complete and accurate remain unanswered. Methods: This was a retrospective cohort study of incident records submitted to the Utah Cancer Registry (UCR). Completeness of incident data and lag time between diagnosis and submission to UCR was evaluated using all electronic pathology, paper path, and abstract-only records received in 2009. Data quality was evaluated using a systematic, random sample of 1,000 incident cases diagnosed in 2008 and 2009. Results: UCR received incident records via e-path, paper path, and hospital abstracts on average of 6, 24, and 147 days after diagnosis, respectively. The completeness of incident data varied by reporting source with electronic pathology records having the largest rates of incomplete data. About half of the sampled records required edits with nearly 30% due to coding errors in primary site, histology, laterality, and diagnosis date. Error rates varied by cancer site, but none of these edits resulted in changes to SEER Site Recode. Conclusion: SEER registries are known for high quality data, but the issue of timeliness is still a concern. Registries must continue to improve the completeness and quality of incident data transmitted electronically; work closely with reporting facilities to improve timeliness of abstract submissions; and, begin considering efficiencies in the visual editing process.

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P-02

CALIFORNIA'S COMPLETENESS, TIMELINESS, AND QUALITY REPORT

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The California Cancer Registry (CCR) has created a report that summarizes Completeness, Timeliness, and Quality for reporting facilities.

This report us used by central registry staff, hospital abstractors, and reporting facility administrators to monitor compliance with California's reporting standards and was created to to provide its audience with a concise summary of a reporting facility's statistics over the course of the current year and past 2 years.

This poster will outline how the *Completeness, Timeliness, and Quality Report* helps the CCR and reporting facilities understand where the reporting facility stands with regards to California's reporting standards and how the summarized information is a representation of more detailed monthly reports.

P-03

CONSISTENCY AMONG PARTICIPANTS IN A BREAST CANCER FOLLOW-UP STUDY

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The New Mexico Women's Health Study: Long-term Quality of Life is a follow-up of women who previously participated in a population-based, case-control breast cancer study of Hispanic and non-Hispanic white women conducted between 1992 and 1996. Cases were obtained from the New Mexico Tumor Registry (1992-1994). Controls were residents of New Mexico and matched on ethnicity, age-group and health planning district. A total of 100 women who completed the follow-up questionnaire were randomly selected from 430 subjects and asked to respond to selected questions one year later. Only one subject reported a different date of birth and there were no differences for height at age 65. However, 36% of women reported a different height at age 18, and 17% reported differently about their use of hormone replacement therapy. Only a small fraction of women reported a different answer when asked about their diagnosis of diabetes (3%), mother's diagnosis of breast cancer (2%), and colon cancer (4%), family history of cancer other than breast cancer (5%) and smoking (5%). However, on average, a higher percentage of women reported differently when asked about their sister's (breast: 30%, colon: 27%) and daughter's (breast: 33%, colon: 32%) cancer diagnoses. When stratified, greater inconsistency was observed among controls (64%) than cases (36%) and among non-Hispanic white (70%) women than among Hispanic (30%) women. When results of QC and LTQOL were compared to NMWHS data, 1% and 9% women were inconsistent in reporting their ethnicity and smoking history respectively. These preliminary results suggest that overall women were consistent in their answers except when asked to recall events from the remote past. To further investigate these preliminary findings, reliability tests will be conducted.

P-04

MEMORY VS. MODULES: A TRAINING SUCCESS STORY

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Background: Cancer registry data collection rules have been changing at a seemingly ever-increasing rate in recent years. As a result, keeping up to date with training has become both more important and more difficult. The rules have become very complex and cannot all be contained in one manual, let alone retained in one's memory. Cancer registrars may leave a training session thinking "we've got it now", but audits show that there is a learning curve as registrars let go of old ways, adapt and apply new codes.

Purpose: To share a unique training method Missouri Cancer Registry used to illustrate to hospital registrars the importance of consulting manuals

Method: At the 2010 annual meeting of the Missouri State Tumor Registrars Association, MCR presented a program entitled "Piece of Pie: Use of Memory over Modules." Registrars were given a quiz to take on the first day in which they were asked to answer data coding questions without benefit of manuals. Multiple choice questions had been formulated by Quality Assurance staff to illustrate common errors in coding. Aggregate results of the quiz were tabulated and worked into a PowerPoint presentation of the answers to the quiz questions on the last day. The presentation had two purposes: 1) to illustrate with pie charts the proportion of answers that were wrong when registrars relied solely on memory, and 2) to teach the correct coding of the scenarios presented.

Results/Conclusions: Requiring active participation in the quiz stimulated interest in the presentation of the answers. There was a mood of eager anticipation for the presentation which we had not experienced when doing traditional "Common Pitfalls in Coding" talks in the past. Results for many questions showed that the majority of participants did not know the correct answer in this situation. Several commented that they had thought they were right, but now knew better. The take home message was to use the manuals!

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P-05

3RD EDITION OF CANCER REGISTRY MANAGEMENT: THE CANCER REGISTRY TEXTBOOK

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Background: Over the last several decades, NCRA has developed and maintained several generations of both a comprehensive textbook for central registries and another for hospital registries. The 2nd Editions of both are now several years old. After surveying the market, NCRA desired to merge the 3rd Editions of both the central registry and the hospital textbooks. The economics of cancer registry textbooks does not allow stipends for authors or editors. Their volunteer effort requires a multi-year time-intensive unpaid commitment. Purpose: To develop a comprehensive textbook for management and use of central and hospital registries, suitable for CTR Exam preparation, and other uses. Methods: NCRA Planned for a textbook with six major sections. An editor-in-chief and the NCRA executive director conducted an initial survey, and then recruited six editors and 65 authors. A publishing contract with Kendall Hunt was executed. A CD with study questions, and separate answers, for each chapter was to be enclosed. **Results:** The six subject matter sections are: Planning and Design of Registries, Informatics, Operations, Uses of Registry Data, Standard Setters and Professional Organizations, and Central and Other Registries, and these collectively include 42 chapters. The textbook has been printed, and is available for purchase. A Short Course, somewhat paralleling the content of the textbook, and taught by many of the authors, has been offered as a workshop before NCRA and NAACCR Annual Meetings for 20 plus years, and is still available. The Textbook and Short Course together underscore the science and methodology of cancer registration as a science and profession. **Conclusions:** The textbook appears suitable as comprehensive source material for, and in preparation for, the CTR exam, and for other interested parties wanting to learn about cancer registration.

P-06

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IMPROVING A CENTRAL CANCER REGISTRY'S (CCR'S) DATA QUALITY AND COMPLETENESS: PRELIMINARY RESULTS FROM TWO NEW PROJECTS

J Jackson-Thompson^{1,2,3,4}

¹Missouri Cancer Registry, Columbia, MO; ²Dept of Health Management & Informatics, Columbia, MO; ³MU Informatics Institute, Columbia, MO; ⁴University of Missouri, Columbia, MO

Background: The Centers for Disease Control and Prevention National Program of Cancer Registries (CDC-NPCR), having received funding through the American Recovery and Reinvestment Act of 2009, contracted with Macro International to establish subcontracts with a subset of NPCR CCRs. The purpose of these subcontracts is to enhance data collection and facilitate comparative effectiveness research. The Missouri Cancer Registry (MCR) received funding for special projects to enhance race and ethnicity data and improve reporting through use of electronic health records (EHRs). Purpose: To provide an overview of how a CCR is improving: 1) quality of race and ethnicity data; and 2) case completeness. Methods: We entered into subcontracts with Macro that outlined major activities to be accomplished and time frames. We also entered into collaboration with the University's newly-funded Health Information Technology Assistance Center (HIT-AC), a comprehensive regional center to support primary care providers in adopting EHRs and utilizing health information technology effectively to improve health care in Missouri. This collaboration enabled MCR to piggyback onto HIT-AC pilot projects. Monthly conference calls and reports allowed all parties to keep in close contact. **Results:** Pilot sites were selected, training materials developed and both projects launched. Progress in the first six months will be reported, with an emphasis on barriers encountered and overcome; lessons learned; and next steps. **Conclusions**: Collaboration between HIT-AC and MCR has been a positive experience for both groups. HIT-AC took the lead in identifying HER vendors, establishing contracts and selecting pilot sites. They included sites that were important to MCR. MCR's experience working with physicians and critical access hospitals as well as their experience training reporting facility staff benefitted HIT-AC.

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P-07

NON-HOSPITAL REPORTING IMPACT ON CANCER STATISTICS IN MARYLAND

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Background: The Maryland Cancer Registry has undertaken various tasks to enhance reporting by non-hospital reporters, including, physician offices, ambulatory surgery centers, laboratories, and radiation therapy centers. With limited resources, the Maryland Cancer Registry has implemented processes which appear to have improved the completeness and quality of reporting.

Purpose of the project: This project aims to show the impact on abstracts, tumors, treatment and staging information received by the Maryland Cancer Registry. The analysis will include a review the various tasks implemented to enhance reporting by non-hospital reporters.

Approach: We plan to review tumors diagnosed between 2000 and 2009 and compare trends over time by type of reporting source by source (abstracts) and tumors. Analysis on treatment and staging information completeness will be conducted on 2004 – 2009 data.

Results: A comparative analysis will be presented by source and cancer type. Trending data will show the effect on tumors and specific sites impacted by the various, newly developed, activities of the Maryland Cancer Registry. Results will highlight the impact on workload for the staff in the Maryland Cancer Registry as well as the positive impact on tumor reporting by the various non-hospital reporting types.

Implications: This communication will present the MCR registry operations positive experience and lessons learned through various activities that aimed to improve non-hospital reporting.

P-08

STATUS OF WHO GRADE AS A COLLABORATIVE STAGE SITE SPECIFIC FACTOR FOR BRAIN TUMORS

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The World Health Organization has developed a grading system for primary brain tumors in the WHO Classification of Tumours of the Central Nervous System.¹ Clinicians use this grading system to guide treatment options, as well as to estimate outcomes. As a result, clinicians and researchers are very interested in the classification of population-based brain tumor data according to the WHO grading system. In 2004, WHO Grade was added to formal data collection procedures as Collaborative Staging Site Specific Factor 1 for brain tumors. The study objective is to document the initial quality of this variable for future data research purposes. Using the SEER 17 registries research data set for the years 2004-2007, 58,611 primary brain and CNS tumors (ICD-O-3 site codes C70.0-C72.9, C75.1-C75.3) were reported. We then restricted our analyses to only those histologies with WHO grade assignments (n=44,784). The percent of unknown/missing WHO grade ranged from 17% to more than 99% depending on the histology. Of those coded with WHO grade, the percent miscoded ranged from a low of 0% for craniopharyngioma to a high of 44% for diffuse astrocytoma. For the latter, the appropriate WHO grade is 2, but only 45% of all reported diffuse astrocytomas were coded to WHO grade 2, while 2%, 22%, and 12% were coded to 1, 3, and 4, respectively, and 18% were unknown. Similarly, the correct WHO grade assignment for glioblastoma (GBM), the most common glioma, is 4. However, of 9,538 GBM, only 4,817 (50%) were reported with WHO grade 4, while 0.2%, 0.2%, and 2% were reported 1, 2 and 3, respectively and 47% were coded as unknown WHO grade. The reasons for these inaccuracies require further investigation to improve data quality. The usefulness of this data element will require more precise coding and a focus on assuring greater completeness (i.e. fewer unknown). ¹Louis DN, Ohgaki H, Wiestler OD, Cavenee WK (eds): WHO Classification of Tumours of the Central Nervous System. IARC: Lyon, 2007.

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IMPROVING PHYSICIAN REPORTING OF HEMATOPOIETIC MALIGNANCIES TO THE NEW YORK STATE CANCER REGISTRY (NYSCR)

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Background: Increasing proportions of patients are diagnosed and treated for cancer within the confines of physicians' offices. Frequently, patients with hematopoietic conditions are not hospitalized. Based on the "best source" variable, 7.5% of myeloproliferative and myelodysplastic malignancies diagnosed in 2006-2007 were reported by physicians in SEER 17 registries, compared to only 3.3% in New York.

Purpose: The NYSCR was selected for the "Improving the Reporting of Hematopoietic Diseases by the NPCR-Funded Central Cancer Registries" project. The overall objective of this project was to improve and enhance the reporting of polycythemia vera and other reportable hematopoietic diseases diagnosed in physician offices.

Methods: We have identified hematologists and their private practices; developed a database to record all contacts; administered a survey at initial contact; developed training tools for casefinding, reportability requirements and reporting of cases; performed quality review of data collected; and provided continual support to the practices.

Results: In the study area (about 25% of New York's population), we have identified 104 physicians in 43 practices that are not reporting with a radiation treatment center. The survey revealed that only 8 practices have electronic medical records, but most have internet access to use our Web-based system. We will present an evaluation of our ability to encourage reporting, the adequacy of training tools, resources used in terms of time and effort, and potential barriers to implementation of physician reporting.

Conclusions: We are challenged to maintain completeness of data reporting and rely on physicians to report non-hospitalized cases. Our experiences will guide our future project plans for outreach to other private practitioners across New York State.

P-10

ALL TOGETHER NOW! – ORCHESTRATING THE ELECTRONIC TRANSMISSION OF PATHOLOGY DATA INTO THE MANITOBA CANCER REGISTRY: EPATH YEAR 2

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Background: The Manitoba Cancer Registry (MCR) is leading the Manitoba Cancer Stage Information Initiative (MCSII) with National Staging Initiative (NSI) funding from the Canadian Partnership Against Cancer (2008-2012). A key objective is to improve the timeliness of data transfer through electronic transmission of pathology data (ePath).

Methods/Approach: The electronic transmission of pathology results in Manitoba currently involves transmitting narrative reports converted into HL7 2.3.x over secure data links to CancerCare Manitoba (CCMB). The reports are routed through case-ascertainment software, flagged reportable or nonreportable, and sorted into the MCR's intake stream. The reportable queue is monitored by staff and reports are validated with existing or new patient records before advancing to the abstracting queue for coding and staging. Results In Year 2, CCMB moved away from a prototype environment and signed data-sharing agreements with Manitoba's two public and four private labs. This action governed the transmission of electronic pathology results and secured permission from the private labs to share pathology results with CCMB clinicians. Within a short period of time, all the labs were on-board and CCMB worked hard to establish an HL7 specification to ensure that these results would be reported as similarly as possible across all labs. The extensive review and QA of test data from each implementation has proven a valuable exercise for both the MCR and its lab partners, as well as served to refine the sensitivity and accuracy of CCMB's case-finding software (ex. 3 false-negatives in 1557 test reports from DSM-Brandon).

Conclusions: While testing and monitoring will continue well into the project's final year and eventually transform into an operational requirement, results to date indicate a high level of confidence in the completeness, accuracy and timely delivery of reportable neoplasm reports from Manitoba's labs to the MCR.



P-11

LINKAGE OF ELECTRONIC PATHOLOGY LABORATORY REPORTING AND UNIFORM BILLING DATA TO IDENTIFY CANCER CASES FOR A REGISTRY-BASED EPIDEMIOLOGIC STUDY IN NEW JERSEY

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Implementation of electronic pathology laboratory reporting (Epath) from several hospital-based and national laboratories has improved the timeliness and completeness of cancer reporting in the New Jersey State Cancer Registry (NJSCR) and is a resource for rapid case ascertainment in epidemiologic studies. One limitation is the lack of information on race in E-path for identifying cases for studies that are enrolling cases from specific racial groups. The NJ Department of Health and Senior Services Uniform Billing (UB) hospital discharge data are a potential resource for obtaining information on patients, and the data are generally available five days after the end of the month for all patients billed the previous month. We recently utilized this resource to identify African-American breast cancer patients for an on-going study (the Women's Circle of Health Study). We identified 1702 women diagnosed with breast cancer reported to E-path during January through July 2010, all with unknown race. We used LinkPlus to match the E-path records with the NJ UB file by name, date of birth, social security number and address and found 1088 matches (64% of the total). We identified 144 potentially eligible cases for the study, and there were only 19 patients with unknown race (1.7% of the total matches). Possible reasons for cases reported by E-path who did not match to the UB file include delays in patients receiving treatment, delays in hospitals sending billing information and delays in processing of the UB data. Our preliminary results suggest that the linkage of the UB data with E-path is a useful method to ascertain missing patient information for epidemiologic studies that would not have otherwise been obtained until the hospitals submitted cases six months after diagnosis. Our presentation will discuss activities related to this project, plans for future testing, and the potential for this linkage becoming part of the NJSCR standard operations workflow.

P-12

DEATH CLEARANCE: DESIGN AND IMPLEMENTATION OF AN INTERFACE TO AUTOMATE VITAL STATISTICS DATA COLLECTION IN A POPULATION-BASED PROVINCIAL CANCER REGISTRY

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Background: Death clearance is a critical component of cancer registration, allowing for linkage of vital statistics data, ascertainment of new cases from death certificates and more accurate survival analyses. Until Sept. 2010, death clearance at the British Columbia Cancer Registry was carried out using a series of complex manual processes. Receipt of funding from the Canadian Partnership Against Cancer to enhance the registry's technical capability permitted the design and construction of an automated vital statistics interface. **Purpose:** To integrate a series of manual operations undertaken by two separate departments and build an interface to allow for the automated upload and validation of a monthly VS death listing. Methods: BC Vital Statistics Agency places a monthly encrypted flat file on a secure FTP server accessible to the surveillance analyst team. Using prior procedures, a monthly death listing was generated and transferred to the registry analyst team, who then manually compared the VS data to the registry data to generate death clearance reports.A detailed current state business analysis was undertaken, including workflows, dataflows, volumes, frequencies, outcomes and challenges. A technical strategy to automate the process was developed, culminating in the design and implementation of an integration broker type interface. Results: Based on business logic defined by the current state analysis, parsing and processing logic was developed to inform the integration broker interface. User acceptance testing confirmed that development efforts were consistent with business requirements. In initial processing of one year of VS data, 94.3% of records were automatically processed and 5.7% of records generated exception reports for manual processing. Conclusion: Automation of death clearance is expected to result in increased efficiency and data quality. Detailed assessment of process improvement metrics are being conducted.



STREAMLINING MULTISITE ETHICS REVIEWS: LESSONS LEARNED FROM THE "CANCER IN YOUNG PEOPLE IN CANADA" SURVEILLANCE PROGRAM

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BACKGROUND: The role of research ethics boards (REBs) in the creation of surveillance systems is paramount. On one hand, REBs must protect research subjects from the harms of unethical research. On the other hand, they have an obligation to encourage research that will benefit society. These roles can simultaneously complement and conflict with each other. We provide a descriptive analysis of the ethics approval process for a multisite, hospital-based childhood cancer surveillance system in Canada, the Cancer in Young People in Canada (CYP-C) program.

METHODS: The CYP-C program was launched to contribute to cancer control in children, and includes diagnostic, treatment, and outcome data from seventeen pediatric oncology centers across Canada, the C¹⁷ Council. The research protocol disseminated to the REBs of the C¹⁷ hospitals (N=12) was non-interventional, did not alter the standard of care, and met the *Tri-Council Policy Statement* criteria for a consent waiver. Local REBs receiving the ethics applications were the unit of analysis. The type of change requested and the time to study approval were prospectively recorded. Data on the governance of REBs were collected for sub-group analysis.

RESULTS: The time to obtain full approval varied greatly, from 13 to 364 days (mean/median: 77/ 53 days). Six out of twelve REBs requested changes to the protocol. Requests pertained mainly to non-local issues, such as the legislative authority to conduct surveillance (N=1), recruitment methods (N=1), information leaflets (N=3), and patient confidentiality (N=2). Local changes requested involved the release of full postal code data (N=1), the inclusion of vulnerable subjects (N=1) and the clarification of a local complaint policy (N=1).

CONCLUSION: We underscore the need for a multicentred ethics framework in Canada. This effort will ameliorate the administrative burden of ethics reviews, yield timely research, and improve consistency in decision making among REBs.

P-14

THEY CALL ME WHELLO YELLO: REVISITING THE SEER RACE AND NATIONALITY DESCRIPTIONS

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The Division of Vital Statistics of the National Center for Health Statistics and the Census Bureau each maintain a list of race recodes for write-in responses to the race question. For example, if "Italian" is written in, this is recoded as white. An (approximate) union of these two lists is provided as Appendix D of the SEER Program Coding and Staging Manual and offered as guidance for assigning race when it is not directly coded.

Here, we assess the validity of this information by crosstabulating race and birthplace in the New York State Cancer Registry (NYSCR). Some anomalies are evident, mainly in Central America and the Caribbean. For example, "Panamanian" recodes to white, but most of the cases born in Panama are coded as black in the NYSCR.

The list also embeds a number of obsolete and obscure terms such as Whello, Yello, Brava, Ebian, and Hamitic. In a 2002 paper Laws and Heckscher raised questions about the existence of such terms and their propensity to be widely reproduced in public health data systems. While they may be harmless since they never actually appear in public health records (beyond their presumed original appearance which placed them on the list), this is still no reason to maintain them indefinitely. Conversely, the list omits some obvious designations such as Danish and New Zealander. It is time for the cancer registration community to scrutinize this list for continued validity and applicability.

Notes	Notes

EHEALTH INITIATIVES AND CANCER SURVEILLANCE: PUTTING THE PUZZLE TOGETHER

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Background: The National Program of Cancer Registries-Advancing E-cancer Reporting and Registry Operations (NPCR-AERRO) is a collaborative effort between public and private sector organizations committed to automating cancer registry operations and implementing electronic reporting from critical data sources to cancer registries for the purpose of increasing timeliness, quality, and completeness of data used to quantify the national cancer burden accurately. **Purpose:** NPCR-AERRO participates in eHealth activities to represent the cancer surveillance community's interests and provide information to the cancer community stakeholders. Methods: NPCR-AERRO is participating in national and international activities related to the development of standardized, interoperable systems to facilitate the development of an Electronic Health Record (EHR). These activities support development of content and format data standards, functional system requirements, and testing criteria, and work at the policy level to establish the cancer standards within federal Health IT initiatives. Results: Activities: 1) develop new international standards ("profiles") in Integrating the Healthcare Enterprise (IHE) for anatomic pathology and physician office electronic reporting to central cancer registries; 2) collaborate with HL7 to develop two functional profiles that describe the recommended capabilities for EHR systems to meet the needs of the cancer registries and cancer surveillance; 3) monitor and participate in various Meaningful Use workgroups to effect policy change; 4) support Comparative Effectiveness Research projects to implement pathology and physician office electronic reporting; 5) Develop public health reporting functional profile. **Conclusions** This presentation will provide an overview of various eHealth activities in which NPCR-AERRO participates and will describe how they move the cancer community toward greater interoperability to improve cancer surveillance.

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P-16

TYPE OF HEALTH INSURANCE COVERAGE (GOVERNMENT HEALTH PLAN VS. NON-GOVERNMENT HEALTH PLAN) EFFECT IN THE SURVIVAL OF COLORECTAL CANCER PATIENTS: THE EXPERIENCE IN PUERTO RICO, 2004

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Background: Access to health insurance and quality of medical care may influence the survival of cancer patients. During the 1990's, the government of Puerto Rico (PR) implemented a Health Care Reform (HCR) to ensure access to health services and to eliminate disparities in medical care services. The HCR developed a Government Health Plan (GHP) to allow access to health services among medically indigent citizens and to provide a special coverage of service and treatment for high-risk conditions such as cancer. Purpose: To compare the 3-year relative survival among CRC patients by type of health insurance coverage (GHP vs. Non-GHP). Methods: Patients with a diagnosis of CRC reported in the PR Central Cancer Registry database in 2004 were linked with health insurance claims data from GHP to identify GHP patients (GH, 37.9%) and those with health insurance other than GHP (Non-GHP, 62.1%). The maximum relative survival ratio was compared by health insurance groups. A Poisson regression model was used to assess relative excess risks of death, after adjusting for confounders. **Results**: Three year relative survival was 66.0% for GHP patients and 77.3% for Non-GHP patients. In the crude model, GHP patients had a 1.5 (p<0.05) increased risk of death than Non-GHP patients. In stratified analyses by stage at diagnosis, a significant increased risk of death in early stage was observed among GHP patients (2.6; p<0.05). A tendency towards a reduced risk of death was observed in late stages among GHP patients, although differences were not significant (p>0.05). In multivariate analysis; after adjustment by age, treatment and stage, the aforementioned risk of death among GHP patients was no longer sustained (1.1; p>0.05). Conclusion: Although overall relative survival among CRC patients with GHP was significantly lower than patients with Non-GHP in PR; when other factors such as age, treatment and stage are considered, the risk of death was no longer influenced by health coverage.



P-17

HISTOLOGICAL CLASSIFICATION OF LIVER AND INTRAHEPATIC BILE DUCT CANCERS S Altekruse¹

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Clear definitions of histological groups are essential for studies of liver and intrahepatic bile duct cancers. We developed a histological classification based on review of liver and intrahepatic bile duct cancers diagnosed within Surveillance, Epidemiology, and End Results (SEER) registries from 1973-2007. Among 64,131 primary liver and intrahepatic bile duct cancers diagnosed within SEER 17 registries, 108 unique ICD-O histology codes were identified. In the five recent years of diagnosis, 2003-2007, the leading histological groups were hepatocellular carcinoma (75%) and cholangiocarcinoma (12%). Remaining microscopically confirmed carcinomas were other specified (3%) and poorly specified carcinomas (3%). Hepatoblastomas (1%) were grouped separately. Sarcomas (1%) included rare histologies, as did other specified malignancies. Poorly specified malignancies accounted for 5% of cancers. Overall, only 68% of diagnoses were microscopically confirmed. Similarly, in SEER 13 registries from 1992-2007, 71% of cases were microscopically confirmed. The incidence rate of hepatocellular carcinomas with no microscopic confirmation increased more than twice as rapidly as the rate of microscopically confirmed hepatocellular carcinomas (annual percent changes: 7.7% versus 3.2%, respectively; both statistically significant, P≤0.05). Factors contributing to incomplete histological classification may include reluctance to obtain biospecimens from late stage cases and administration of therapy in lieu of histological confirmation after positive diagnostic imaging. Conclusion: The proposed histological classification described in this report, based on ICD-O-3, is subject to revision. It is provided to facilitate more complete classification of liver and intrahepatic cancers. Our findings raise concerns about the effects of incomplete histological characterization of these cancers on measures including prognosis, incidence, trends, and disparities.

P-18

CANCER IN THE APPALACHIAN REGIONS OF NORTH CAROLINA, TENNESSEE AND VIRGINIA, 2004-2006

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Background: Cancer incidence and mortality in Appalachia is higher than in the rest of the US. North Carolina, Tennessee and Virginia contain Appalachian areas with similar cancerrelated issues. To assess these issues, these states are collaboratively analyzing central registry data. Purpose: The purpose is to analyze differences in cancer incidence and mortality for the Appalachian and non-Appalachian regions of each state and the tri-state Appalachian and non-Appalachian area for 2004-2006. The sites selected are lung, colorectal, female breast, cervical, and prostate cancers. The analysis will include an assessment of CINA data quality. Methods: SEER*Stat was used to analyze records in the NAACCR CINA Deluxe data file. Age-adjusted incidence rates and 95% confidence intervals were calculated for comparisons between the states and Appalachian and non-Appalachian regions. Each participant provided age-adjusted mortality rates and 95% confidence intervals for comparisons.

Results: Statistics describing the five cancers in the Appalachian and non-Appalachian regions of each state, and the tri-states area combined, will be presented. Major comparative categories will be: race, gender, stage, treatment, geographic, and poverty levels. Data quality issues also will be presented.

Conclusions/Implications: Relative homogeneity of rates in the tri-state area will imply that similar factors affect each state. Relative heterogeneity will imply that factors affecting one state may not operate similarly in the other(s). Important lessons that may influence improving cancer surveillance in the Appalachian areas of the three states, and that will inform public health prevention and control, may result from this project.

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P-19

AN INVESTIGATION OF THE ASSOCIATION BETWEEN GLIOMA AND SOCIOECONOMIC STATUS: EFFECTS OF CONTROLLING FOR GROUP-LEVEL SPATIAL AUTOCORRELATION

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The etiology of glioma is largely unknown with ionizing radiation and family history being the only recognized risk factors. Glioma rates vary by demographic factors (race, sex) and geo-political boundaries and this variation suggests higher glioma rates in groups with higher socioeconomic status (SES). The primary goal of this analysis is to investigate the glioma-SES relationship within a hierarchical framework using Surveillance Epidemiology and End Results (SEER) data. Cases were defined as individuals 25+ years diagnosed with glioma between 2000 and 2006 and residing within the SEER 17 catchment area. County-, sex-, race-, age-specific sub-groupings were created in order to investigate individual-level associations. Principal component analysis was utilized to create two distinct county-level socioeconomic variables. A Bayesian hierarchical Poisson spatial conditionally autoregressive (CAR) model was utilized to simultaneously estimate individual- and county-level effects while controlling for county spatial dependence. Those residing in counties of the 4th, 3rd, and 2nd quartiles of SES have glioma incidence rates that are 1.10 (95% CI: 1.02-1.18), 1.12 (95% CI: 1.02-1.19), 1.15 (95% CI: 1.07-1.23) times that of the 1st guartile, respectively. The assumption of error spatial independence was questionable for both random intercept (RI)-only and RI + SES covariates models (Moran's I and p: 0.0676 and 0.001; 0.0366 and 0.06, respectively). A RI + SES + CAR model properly controlled for the spatial dependence (Moran I=0.0258, p = 0.166) yielding less biased estimates. Absence of data on individual SES precludes any conclusions which may attribute the increased glioma rates to individual SES as opposed to possible contextual affects due to county SES. Subsequent studies should strive to collect analogous SES data at each level to fully address the glioma-SES relationship. Proper consideration of model assumptions is critical for yielding unbiased estimates.

P-20

RISK OF CANCER AMONG HISPANICS WITH AIDS COMPARED WITH THE GENERAL POPULATION IN PUERTO RICO: 1987-2003

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Background: The risk of cancer among Hispanics with Acquired Immune Deficiency Syndrome (AIDS) in the United States and Puerto Rico (PR) has not been well described. The purpose of this study was to determine the risk of AIDS related and non-AIDS related cancers among Hispanics with AIDS in PR. Methods: A probabilistic record linkage of the PR AIDS Surveillance Program and PR Central Cancer Registry databases was conducted. AIDS cases were grouped according to year of AIDS onset and antiretroviral therapy availability: 1987-1989 (limited availability), 1990-1995 (mono and dual therapy), and 1996-2003 (highly active antiretroviral therapy: HAART). Cancer risk was described using the standardized incidence ratios (SIR). Results: A total of 612 cancers were identified after 3 months of AIDS diagnosis: 409 (66.7%) AIDS related and 203 (33.1%) non-AIDS related. Although a decreasing trend in the risk of AIDS and non-AIDS related cancers was observed, the risk for both remained higher in the AIDS group compared to the general population in PR. Non-AIDS related cancers with higher risk during the HAART availability were: oropharyngeal, anal, liver, larynx, eye and orbit, Hodgkin lymphoma, and vaginal. Conclusion: Hispanics with AIDS in PR consistently showed a greater risk of AIDS and non-AIDS related cancers compared to the general population in PR and that has not changed over time.

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THE DETERMINANTS OF COLORECTAL CANCER SURVIVAL DISPARITIES

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BACKGROUND: Despite overall decreasing incidence and mortality rates for Colorectal Cancer (CRC) in the US population, substantial disparities in CRC survival are observed between racial/ethnic groups. This is in part due to lower CRC screening among ethnic minorities. PURPOSE OF THE STUDY: To ascertain the determinants of CRC racial/ethnic survival disparities in Nevada. METHODS: A cohort of 11,459 men and women diagnosed with CRC in 1995 - 2006 and registered in the Nevada Cancer Registry was examined. Life-table method and Cox proportional hazard regression were used to assess cause-specific survival rates and prognostic factors for survival. The 5-year age-adjusted survival rates were compared for each racial/ethnic group for the diagnosis periods 1995 – 1998 and 1999 – 2001. RESULTS: Blacks were more often diagnosed with distant stage disease, 21.6% compared to 17.5% in Whites. Blacks also had a high proportion of proximal colon tumors (49.8%), which is associated with lower survival. Univariate analyses yielded a 20.6% higher risk of CRC death for Blacks compared to Whites [HR = 1.21, C.I_{95%} = 1.05 - 1.39]. When diagnosis stage, gender, age, health insurance type, diagnosis period, and tumor sub-location were added to the model, stage of diagnosis was the most important prognostic factor [distant vs. localized stage HR = 11.0 (C.I_{95%} = 9.7 - 12.5). Blacks (again) and Hispanics showed an overall increased risk of death in relation to Whites, HR=1.24 (C.I $_{95\%}$ = 1.07 – 1.43) and 1.16 (C.I_{95%} = 1.00 – 1.34) respectively. CONCLUSION: Raceethnicity is a persistent determinant of survival disparities in Nevada even after adjusting for common demographic and tumor factors. Further determinants of survival disparities, such as course of treatment, should be investigated. Additionally, more public health intervention programs should tailor CRC screening awareness towards minorities as well as ensuring equal access to healthcare and quality treatment.

P-22

RANDOM FREQUENCY-MATCHING OF CONTROLS TO CANCER CASES IN SEER-MEDICARE DATA BY INDEX DATE TO RADIATION THERAPY DATE

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Background: For a case-control study describing post-radiation therapy (RT) urinary and/or bowel complications in prostate cancer patients, we randomly matched controls to cases, not by demographic characteristics, but by index dates in controls to the RT dates of cancer cases. We were unable to find a detailed method for this type of matching in the literature. **Purpose:** To demonstrate our method of control-matching to

cancer cases using SEER-Medicare data.

Methods: Using the 5% non-cancer random sample of Medicare data, we included only those who have both Medicare Parts A and B, and no HMO coverage, for no less than the minimum number of desired study follow-up months (FUM), plus 12, counting from 12 months before the earliest diagnosis month (EDM) in our study. We need this minimum coverage time to calculate comorbidities 12 months pre-, and complications postindex date. We randomly selected an index month between the period 12 months after the initial coverage (or EDM, whichever is later) and the minimum FUM before the end of coverage. Based on the frequency counts of cases' RT months by year, we randomly chose the desired number of controls to frequency match RT months (4:1). In the subsequent frequency table of controls by index months, if some specific months have a smaller frequency than required, we again performed the random selection of index months for those not selected in the first iteration. We added these to the original sample of controls, and repeated as necessary.

Result & Conclusion: This is one method to produce a sample of randomly matched controls by index dates to RT dates of cancer cases.

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INCIDENCE, SURVIVAL AND RISK OF SUBSEQUENT PRIMARIES IN OCULAR MELANOMA: ANALYSIS OF THE SURVEILLANCE, EPIDEMIOLOGY AND END RESULTS (SEER) DATA

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Background: Ocular melanomas (OM) are rare but comprise the greatest number of melanomas (4%) after skin melanomas (94.7%). Methods: Using SEER*STAT© software, we analyzed age-adjusted incidence (IR) rates of malignant OM from 1973-2007 by sex, race (European American-EA, African American-AA, Other) and year of diagnosis group (1973-1984, 1985-1996, 1997-2007), SAS© was used to perform log-rank tests comparing survival differences by sex and race of 1st primary OMs. Standardized Incidence Ratios (SIR) were generated in SEER*STAT© of 1st primary OMs to evaluate risk of developing a subsequent cancer (SubCa). Results: There were 4,837 OMs with IR=6.3 per million. Males (IR: 7.2, CI: 6.9-7.5; 52%) had significantly greater incidence than females (IR: 5.5, CI: 5.3-5.7; 48%). EAs (IR: 7.3, CI: 7.1-7.5, 97%) and Other race (IR: 1.5, CI: 1.2-1.8, 2%) had significantly greater incidence than AAs (IR: 0.5, CI: 0.3-0.7, 1%). The rate ratio of OM to skin melanoma for AA compared to EA was similar, but was significantly less for Other races compared to EA. IR significantly decreased over time (1973-1984: 6.9, Cl: 6.5-7.2; 1985-1996 & 1997-2007: 6.0, Cl: 5.7-6.3). Males and females had similar survival (p=0.1225) for 1st primary OM (N=4,296), as did EAs and AAs (p=0.8998) but Other race had significantly better survival than EAs (p=0.0052). 5-year survival was similar across year of diagnosis groups (p=0.2250). Risk of SubCa was significantly higher in OM patients (SIR: 1.17, CI: 1.08, 1.27) than the general population, with greatest risk in females (SIR: 1.23, CI: 1.08, 1.39) and no increased risk in children (ages <20). Of 584 cases with a SubCa, 5 and 1 were AA and Other race, respectively. The top 5 SubCa sites in EA were prostate (19%), lung (12%), female breast (10%), skin melanoma (9%) and bladder (6%). Conclusions: Incidence rates of OM are highest in Males and EAs but survival is similar by sex and for EAs and AAs. Females have greatest risk of SubCas.

P-24

SUB-SITE SPECIFIC COLORECTAL CANCER SURVIVAL IN PUERTO RICAN HISPANIC POPULATION

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Background: Colorectal cancer (CRC) is the second most common type of cancer in Puerto Rico. Both incidence and mortality of CRC are increasing among Puerto Ricans. Colorectal cancer survival varies by stage at diagnosis, however, studies on the prognostic value of anatomic sub-site have generated variable results. Purpose: To examined the survival of CRC by sub-site location using data from the Puerto Rico Central Cancer Registry. Methods: An analysis of CRC cases (greater than 50 vears of age at diagnosis) from 2001-2003 was conducted by sub-site (proximal, distal, rectum, and other). Five-year maximum relative survival ratio by CRC sub-site was calculated and a Poisson regression model used to calculate the relative excess risk of death. Results: The sub-site distribution of the 2,945 CRC cases analyzed was as follows: proximal (35.04%), distal (26.89%), rectum (30.19%), and other (7.88%). A larger proportion of proximal cancers presented in regional stage (42.02%) or distant stage (36.72%). In addition, proximal cancers had the greater proportion of mucinous adenocarcinoma histology (48.73%). The five-year relative survival was 59% for proximal cancer, 63% for distal and 53% for rectum. Before adjustment for confounder variables (stage, histology, and treatment) the excess risk of death for distal cancer was significantly lower (0.80; CI 95%: 0.67-0.95) compared with proximal tumors. However, after adjustment, the excess of risk of death for distal cancer continued being lower, although marginally significant (0.85; CI 95%: 0.71-1.02) compared with proximal tumors. Conclusions: In this analysis, distal colon cancers presented in an earlier stage, and had a lower excess of risk death compared with proximal tumors. These differences could be associated to several factors among which are genetic factors, current early detection strategies, or treatment methods.

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INVESTIGATING A POSSIBLE CANCER CLUSTER IN A COMMUNITY WITH SASKATCHEWAN CANCER REGISTRY INFORMATION

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Background: Recently the Saskatchewan Cancer Agency (SCA) was contacted regarding a possible cancer cluster occurring among residents in a small area of one of the province's major cities. The SCA's Epidemiology department is responsible for investigating possible cancer clusters in the province. Between 1930 and 1979, there was an operational Oil Refinery located in this neighborhood. In 1980, after the refinery was removed from the land, the area surrounding it became commercial and residential property owned by the city.

Purpose: Using SCR information and CDC methodology, investigate the possibility of a cancer cluster in this residential area of the city.

Methods: The Saskatchewan Cancer Registry (SCR) was established in 1932 and is the oldest cancer registry in Canada and has comprehensive follow up (less than 2% loss to followup). The SCR has electronic data records of all cancer sites dating back to 1969. Standardized cancer incidence ratios with 95% confidence intervals were calculated using data from the SCR and Saskatchewan Health Covered Population.

Results: Between 1995 and 2006 135 invasive cancer cases were diagnosed among residents of this area. The expected site specific cancer cases in this area were calculated using the age and site specific rates for the whole province. 95% Cl and p-values show there was no statistically significant difference in cancer incidence between the expected cancer cases and observed cancer cases for thirteen oil refinery risk related cancer sites in this area.

Conclusion/Implications: The results of the statistical analysis concluded that the cases identified in this specific population did not constitute a cancer cluster. An investigation such as this can only be conducted with Registry data that has comprehensive follow-up and a long existence. These are two of the major strengths of the SCR.

P-26

CASE-CONTROL STUDY: BIRTH WEIGHT AND RISK OF CHILDHOOD ACUTE LYMPHOBLASTIC LEUKEMIA (ALL)

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Background: Previous studies have found an elevated risk of ALL among children with higher birth weight. Methods: Cases of ALL occurring among children under five years of age were abstracted from the Arizona, Illinois, and Kentucky cancer registries. The birth certificate for each case was matched with the birth certificates of four control children of the same sex, race, and ethnicity, who were born in the same county on or near the same date. Odds ratios for ALL among children of low (<2.5 kg) or high (>4 kg) birth weight were calculated by conditional logistic regression. Results: Compared with children of normal birth weight (2.5-4.kg), those with higher birth weight had an elevated risk of ALL in the first five years of life [OR=1.314; 95% CI=(1.041-1.650)]. The excess risk was confined to non-Hispanic whites [OR=1.831; 95% CI=(1.106-2.568)], whether male [OR=1.623; 95% CI=(1.039-2.535)] or female [OR=2.179; 95% CI=(1.299-3.656)]. No such excess risk was observed among Hispanics [OR=1.101; 95% CI=(0.684-1.772)], African-Americans [OR=1.030; 95% CI=(0.553-1.918)], or others [OR=0.810; 95% CI=(0.426-1.504)]. Low birth weight was associated with a non-significantly reduced risk of ALL among children of all races [OR=0.778; 95% CI=(0.541-1.119)], and among non-Hispanic whites [OR=0.943; 95% CI=(0.569-1.562)], Hispanics [OR=0.906; 95% CI=(0.452-1.815)], African-Americans [OR=0.831; 95% CI=(0.177-1.534)], and others [OR=0.381; 95% CI=(0.115-1.306)]. Low birth weight was statistically significantly associated with reduced risk among girls [OR=0.545; 95% CI=(0.305-0.965)], but not among boys [OR=1.0403; 95% CI=(0.651-1.670)] of all races. Discussion: This study confirms the association between high birth weight (>4000 grams) and ALL previously reported by other studies in children of European ancestry. The few studies that did not find such an association were conducted in more diverse populations, and did not adequately control for race.



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COLLABORATION WITH MULTIPLE STATE CANCER REGISTRIES FOR A DATA LINKAGE DRUG SAFETY SURVEILLANCE STUDY – YES YOU CAN!

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Background: The Forteo Patient Registry is a voluntary prospective cohort study designed to estimate the incidence of osteosarcoma in patients taking teriparatide. Adult patients residing in the United States who provide consent will be enrolled over 5 years. Data are linked with participating state cancer registries for 12 years to ascertain cases diagnosed after patients started treatment.

Objective: To describe the recruitment of state cancer registries into this safety surveillance study and the progress with the first annual data linkage.

Methods: Cancer registries in all 50 states and the District of Columbia were invited in May 2009 to participate in the first annual linkage. A database was developed to track the recruitment process. All necessary applications and agreements for study approval were submitted to cancer registries. Registries that completed all local approval requirements and attended training on a standard linkage algorithm were included in the first annual linkage in September 2010.

Results: In total, 42 cancer registries, having 78 unique reviews (IRB or other), expressed an interest in participating and 27 (covering 70% of the adult US population) participated in the first annual data linkage. Of those 42 registries, 28 required local IRB review and 14 accepted the RTI IRB review. At least one additional approval was required at 36 of the 42 registries. For the 27 states participating in the first linkage, the average time from submission of the first application to the date a registry was linkage-ready was 94 days (range: 10 days to 195 days). The remaining 15 registries are still in the process of obtaining future approval.

Conclusions: Although there are substantial challenges to conducting a linkage study involving many state cancer registries, the results of the first linkage indicate that it is feasible for a large number of states to perform a data linkage concurrently using a standard data-linkage algorithm.

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NATIONAL HEALTH INTERVIEW SURVEY (NHIS)-FLORIDA CANCER DATA SYSTEM (FCDS) DATA LINKAGE PROJECT: UPDATE

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Background: This Pilot Project was designed to evaluate the feasibility of performing a record linkage between the National Health Interview Survey (NHIS) of the National Center for Health Statistics (NCHS) and the Florida Cancer Data System (FCDS) databases. The NHIS provides a wealth of cancer-related information (e.g., screening behaviors, cancer risk factors, healthcare access/utilization) and has also been linked to the National Death Index, Social Security, EPA, Medicare, and Medicaid data, further enriching the cancer linkage. **Purpose:** The Pilot will provide the opportunity to assess the feasibility and logistics of linking NCHS national population-based survey data with individual state cancer registries; ultimately, this linkage will provide highly enriched data for incident cancer cases who have participated in the NHIS.

Methods: We completed the initial linkage of the 1987 NHIS dataset with the entire FCDS database employing a probabilistic algorithm through Automatch® using name, social security number, date of birth, and sex. **Results:** There were 126,612 NHIS records linked with 2,421,032 FCDS records, resulting in 863 matches (and 955 primary tumors). These matches represent NHIS participants diagnosed with cancer in Florida prior to or subsequent to their NHIS interview. These de-indentified linked data will be deposited in the secure Research Data Center (RDC) of the NCHS and can be analyzed by approved researchers through the RDC.

Conclusions: In addition to the RDC analyses of this initial linkage, we are currently expanding the FCDS data linkage to all NHIS years and are compiling detailed linkage documentation. The ultimate goal of this Pilot is to develop a model for conducting linkages between NCHS population-based surveys and the CDC National Program of Cancer Registries and SEER Cancer Registries.



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SIX DEGREES OF SEPARATION NO MORE: USING DATA LINKAGES TO IMPROVE THE QUALITY OF CANCER REGISTRY AND STUDY DATA

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Background: A data linkage is a process commonly used to determine if persons in one database also reside in a second database. There are two general types of linkages: deterministic (rules-based) and probabilistic (statistical). Specialized linkage software programs such as AutoMatch and Link Plus are used to perform the linkages. For those cancer registries unable to afford a data linkage program, the Centers for Disease Control and Prevention (CDC) offers Link Plus for free on its Web site. **Objective:** To explore the variety of reasons to link a database with cancer registry files. The presentation will also illustrate the value of data linkages in increasing the quality of cancer registry and study data.

Methods: The stated objectives will be achieved by offering realworld examples of the value of linking population-based cancer registry databases with other sources. Potential examples include linking a study cohort to a cancer registry database to determine cancer diagnoses and burden among the cohort; using the linkage process to update the vital status and date of last contact for patients in the cancer registry database; evaluating the effectiveness of cancer control and prevention programs; and using linkages for drug safety surveillance studies.

Results: The presentation will include results from data linkages between cancer registry files and other files, including linkages with public use files to update vital status, with cancer control data to evaluate program effectiveness, and with other databases to determine cancer burden in specific populations. **Conclusions:** If used properly, data linkages can be effective in increasing the quality of a cancer registry's data, allow researchers to have a better understanding of cancer burden in their cohorts, help to determine if cancer screening efforts are effective, and allow cancer registry data to be used in novel ways.

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A BAYESIAN HIERARCHICAL SPATIAL APPROACH FOR CONSTRUCTING CANCER RISK MAPS AT A FINER LEVEL THAN IS PROVIDED IN PUBLICLY AVAILABLE DATA

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A Bayesian hierarchical spatial model is developed to construct disease risk maps using covariates available at a finer areal scale when the outcome variable is available at a larger administrative areal level. A Poisson log-linear model with a conditionally autoregressive random effect is employed. The method is illustrated using data on the number of breast cancer incidence in Connecticut towns in 2000, and the covariates are socioeconomic factors at the census block group level from the US Census and an indicator of the existence of a mammography facility within 8 km of the centroid of each census block group. This model provides estimates of the standardized morbidity ratio (SMR) for breast cancer at the census block group level, using incident cases reported at the town level. Moreover measurement errors associated with covariates assessment are considered. For model selection, we use DIC to compare different models. The results show that high school completion and availability of mammography facilities within 8 km of the census block group centroid have a significant positive association with breast cancer, but this may be partially explained by other socioeconomic factors, such as per capita income.



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UTILITY OF LINKING MEDICAID AND MEDICARE CLAIMS DATA TO DEATH CERTIFICATE ONLY RECORDS T Hinman¹

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¹New York State Cancer Registry, Albany, NY

Background: Death Certificate Only (DCO) cases represent approximately 2.7% of all annual cancer cases for New York State (NYS) before follow back is conducted. Subsequent routine follow back procedures result in approximately 0.8% of cases still lacking diagnosis and treatment information. Matching to claims data was investigated to reduce the DCO rate further and improve the completeness of information in the cancer registry overall.

Purpose: To determine if linking NYS DCO records with Medicaid and Medicare claims data will yield useful information to identify contacts for further follow up.

Methods: DCO cases for 2002-2006(n=4,781) were matched to Medicaid and Medicare claims data. Data were restricted to only those records identified in either Medicaid or Medicare. Only claims with a cancer diagnosis (ICD-9 140-208, 230-239) were analyzed. Procedure codes relating to cancer

diagnosis, staging and treatment were identified with the *Current Procedural Terminology*, Fourth Edition. Claims were also linked to obtain provider name and address.

Results: Preliminary findings resulted in 4,033 Medicaid claims matching to164 DCO cases. Diagnosis and/or treatment related procedural codes were noted on 35% (n=58) of the records. From Medicare, 2,177 claims matching to 417 DCOs were identified. Of these, 40% (n=167) had corresponding procedures relating to diagnosis and/or treatment. Records containing a diagnosis and/or treatment procedure code had corresponding provider name and addresses to contact for follow up. Of the total number of records, 62% had out-of-state providers. **Conclusions:** Linking to Medicaid and Medicare has the potential to provide additional information regarding diagnosis and treatment of DCO cases. Provider name and address is available for follow up.

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RACIAL DIFFERENCES IN THE DECLINE OF CERVICAL CANCER RATES IN NORTH CAROLINA

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Objective: To analyze the declining trend in cervical cancer incidence and mortality during 1996-2001 and 2002-2007 between whites and African Americans in North Carolina. **Method:** Data collected from the North Carolina Central Cancer Registry (CCR) will be used to calculate both age-adjusted and age-specific incidence and mortality rates for cervical cancer by race. All rates calculated will be expressed per 100,000 population.

Results: There was a decline in the cervical cancer mortality rate for African Americans in North Carolina from 1996-2001 (5.7) to 2002-2007 (3.9). The mortality rates dropped by more than 30% for African Americans in age groups (30-39, 50-59, 60-69, 70-79, 80+) whereas the decline in cervical cancer rates for whites was not as noticeable among the white population.

Conclusion: This study will analyze the change in rates in the two time periods between the two racial groups.

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THE SHIFTING TRENDS OF ESOPHAGEAL CANCER IN U.S., 1975-2007

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Background: Esophageal cancer is an aggressive disease with a dismal outcome. Over the past 30 years there has been a dramatic shift in trends of esophageal cancer.

Purpose: Examination of trends through descriptive epidemiology can aid in hypothesis generation to discover the reasons for these dramatic changes. Methods: The SEER*Stat 6.6.2 was accessed to identify trends in esophageal cancer from 1975-2007 in the original 9 SEER registries. Chi-square tests were preformed on rate ratios for 11 year increments. A refers to the comparison between 1975-1985 and 1986-1996; *B* between 1986-1996 and 1997-2007. Results: An increase in the incidence of esophageal adenocarcinoma (EA) for white males and females occurred in A and B (all p<0.01). No increase in black males for A (p=0.06), but an increase did occur in B (p<0.01). No increase occured for black females. A decrease in incidence of esophageal squamous cell carcinoma (ESCC) for white and black males occurred in A and B (all p<0.01). No decrease occurred in white or black females for A(p=0.21; p=.69); there was a decrease in B (p<0.01; p<0.01). An increase was seen in lower EA for white males and females for A and B (all p < 0.01). This rise within the white population corresponds to increased ambulatory care visits and hospital discharge rates for gastrointestinal esophageal reflux disease (GERD). For esophageal cancer mortality, an increase occurred in white males and females for A and B (all p < 0.01) while a decrease in black males occurred (p<0.01; p<0.01). No decrease occured for black females in A (p=0.09) but there was in *B* (p<0.01). **Conclusion:** Rates of EA are increasing while rates of ESCC are decreasing. Rates of GERD are similar while rates of Barrett's esophagus and EA are markedly different. Further investigation and clinical studies of these differences will help to better understand esophageal cancer, identify risk factors, and provide opportunities to decrease mortality.

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SPACE-TIME ANALYSIS OF RACIAL DISPARITIES IN ADVANCED-STAGE PROSTATE CANCER INCIDENCE ACROSS FLORIDA

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Striking racial/ethnic differences in incidence and mortality of prostate cancer still persist in the United States and Florida. Eliminating such disparities requires a better understanding of factors responsible for the geographic and ethnic differences in prostate cancer late-stage incidence and mortality over time. The objectives of the present study were: 1) to visualize how the county-level percentage of late-stage diagnosis changed from 1981 to 2007 across Florida, 2) to explore the impact of ethnicity on these geographical and temporal trends, and 3) to group counties with similar temporal trends.

Number of prostate cancer cases and associated stage at diagnosis recorded yearly from 1981 through 2007 for each county and 3 ethnic subgroups (White, Black, and Hispanic) were downloaded from the Florida Cancer Data System website. All three ethnic groups experienced a 50% decline in the stateaverage percentage of late-stage diagnosis. This drop, which started in the early 1990s when PSA became widely available, was the most pronounced for Hispanics whose rates are now similar to Whites; Blacks still have a 25% larger rate compared to the two other ethnic groups. These temporal trends are however not uniform across Florida; cluster and boundary analysis revealed geographical disparities that were substantial for all ethnic groups before the mid 1990s. The gap among Florida counties is narrowing with time as the rate of late-stage diagnosis decreases. One outlier is the Big Bend region of Florida where the decline in late-stage diagnosis has been the slowest in all Florida for both Whites and Blacks. This approach can be easily generalized to other states and cancer sites, with clear applications in (a) monitoring and surveillance of cancer incidence and mortality, (b) the generation of hypotheses for in depth individual studies of risk factors that are causal, or impact survival; and (c) establishing the rationale for targeted cancer control interventions.

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INCIDENCE OF POTENTIALLY HUMAN PAPILLOMAVIRUS-ASSOCIATED CANCERS OF THE OROPHARYNX IN THE U.S., 2004-2007

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BACKGROUND: Human papillomavirus (HPV) is associated with some oropharyngeal cancers (OPCs), specifically of the tonsils and base of tongue. The effectiveness of the vaccine in preventing these cancers is unknown. Baseline incidence rates of OPCs potentially associated with HPV, 1998-2003, were previously published. The purpose of this study is to update these incidence rates using data from 2004-2007. **METHODS**: Data from CDC's NPCR and NCI's SEER Program, covering 99.2% of the U.S. population, was used to examine invasive cancers in oropharyngeal sites known to be associated with HPV and diagnosed during 2004-2007. Incidence and trends were examined by site, race, Hispanic ethnicity, and sex. **RESULTS:** In all, 44,966 cases of potentially HPV-associated OPCs were identified, including 20,310 (45.2%) tonsillar, 18,144 (40.4%) base of tongue (including lingual tonsil), and 6,512 (14.5%) other oropharyngeal sites. Incidence rates were higher among whites than other racial groups; higher among non-Hispanics than Hispanics; and highest for tonsils (1.62 per 100,000 persons) vs. base of tongue (1.45) and other oropharynx (0.52). Rates were higher among males than females for tonsil (2.72 vs. 0.60), base of tongue (2.48 vs. 0.53) and other oropharynx (0.83 vs. 0.25). The annual incidence rate of potentially HPV-associated cancers of the tonsil continued to increase significantly from 2004 (1.57) through 2007 (1.65) (annual percentage change, 1.71 P<.05). Changes in annual incidence rates for base of tongue and other oropharynx were not statistically significant.

CONCLUSIONS: Although incidence rates of potentially HPVassociated cancers of the tonsil continued to increase, base of tongue and other oropharyngeal rates remained relatively stable. It likely will be decades before the impact of HPV vaccines in preventing these cancers can be evaluated. Periodic surveillance of these cancers is important as evidence continues to emerge on their association with HPV.

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CANCER IN THE "OLDEST OLD" IN MASSACHUSETTS, 1998-2008

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Objectives: This study examined the distribution and characteristics of cancer diagnoses in Massachusetts (MA) elders aged 85 and older ('oldest old'), including trends in incidence. From 1997 to 2005, the percentage of the oldest old in MA grew from 1.8% to 2.2%, an increase which is likely to continue. As the population ages and life spans increase, better knowledge of cancer within this group will become increasingly relevant. Methods: MCR data were used to calculate age specific cancer incidence rates for the oldest old cases in order to compare them with the younger age groups. Comparisons of reporting sources were also examined along with stage at diagnosis and treatment data. Results: From 1998 to 2007, the oldest old represented approximately 2% of the MA population, but approximately 8% of cancer cases, a disproportionate level of cancer burden though not as disproportionate as the 65-74 group (7% versus 25%) or the 75-84 group (5% versus 24%). Compared to younger age groups, the incidences of unknown primary, leukemia, and stomach cancer were all proportionately higher among the oldest old. Preliminary analyses of stage at diagnosis patterns for lung, prostate, and female breast cancers revealed that the oldest old are significantly more likely to be diagnosed at a later stage of diagnosis than the younger groups. Conclusions: Preliminary analyses indicate a variation in the epidemiology of cancer in the oldest old. The larger percentage of unknown primary sites in the oldest old suggests metastatic cancer detected though scanning with no further follow up. Further analyses will examine the epidemiology of cancer in this group, initial treatment information, and reporting trends.

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EVALUATING THE IMPACT OF SCREENING ON BREAST CANCER INCIDENCE AND MORTALITY PROJECTIONS IN SASKATCHEWAN

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Background: Breast cancer is the most commonly diagnosed cancer among females in Saskatchewan (SK). Approximately 630 women are diagnosed with and 150 women die of breast cancer each year. The Saskatchewan Cancer Agency's Screening Program for Breast Cancer (SPBC) was started in 1990 for women between 50-69 years. From 2000 to 2007, 290 cancers were diagnosed per year on average in the screening target population. Of the diagnosed cases about 148 cancers on average were found annually through screening. **Purpose:** To predict trends in breast cancer incidence and mortality in Saskatchewan within the next decade and to speculate on the scope of influence of screening on those trends. Methods: Rates will be projected with the power method used in the Canadian Partnership Against Cancer's (CPAC) Projections network. In order to do the projection, the prediction package 'Nordpred' written in R will be used. Our projections will be based on actual SK incidence figures from 1983-2007 sourced from the SK Cancer Registry (SCR). Age-standardized incidence rates will be calculated for two five year periods from 2008 taking into account age, period and birth-cohort effects. The impact of the screening program on incidence and mortality rates will be assessed in three periods: initial effects upon introduction, effects during the subsequent period, and post-screening effects up to

five years beyond the last screening episode. Implications: Predicting breast cancer incidence and mortality trends can serve as an aid for the planning and evaluation of cancer services. Further, the impact of screening in reducing

cancer burden can be assessed by comparing the number of cases in its absence with those that have actually occurred. An investigation such as this can only be conducted with Registry data that has comprehensive follow-up (less than 2% loss to follow-up) and a long existence. These are two of the major strengths of the SCR.

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PROSTATE CANCER INCIDENCE, STAGE AT DIAGNOSIS AND MORTALITY IN NORTH CAROLINA

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Introduction: Prostate cancer is the most common cancer in American men. The American Cancer Society estimates that for the year 2010 in the United States about 217,730 new cases of prostate cancer will be diagnosed and 32,050 men will die of prostate cancer. Prostate cancer is the 2nd most frequently occurring and 5th leading cause of cancer deaths for men in North Carolina.

The specific objective of this study is to examine recent prostate cancer incidence, mortality and stage at diagnosis, in North Carolina.

Methods and Data: All data on prostate cancer incidence will be obtained through the North Carolina Central Cancer Registry (CCR). Data on prostate cancer deaths will be obtained from the Vital Statistics unit of the State Center for Health Statistics (SCHS). Population data from the National Center for Health Statistics (NCHS) will be used in the denominators of the rates, which are expressed per 100,000 populations. Five-year (2003–2007) incidence and mortality rates will be calculated. Rates for the 13 year period 1995–2007 will be used to examine trends in prostate cancer incidence and mortality.

Outline of the paper: This paper will be divided into six sections: (i) Abstract (ii) Introduction (iii) Methods (iv) Results (v) Conclusion and (vi) Discussion. Figures, tables, and graphs will be included. **Conclusion:** This study will help us to determine the quality and completeness of the data that NC CCR collects. This study will help the NC CCR in terms of training and data collection procedures from the hospitals, as well as its core mission to evaluate the cancer control programs, conduct research, and monitor prostate cancer trends. Further this study will provides program outcomes to the researchers and public health practitioners another tool for evaluating the progress of cancer control programs in North Carolina.

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CANCER AMONG ASIANS AND PACIFIC ISLANDERS IN NEW JERSEY 1990-2007

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The Asian and Pacific Islander (API) populations are rapidly growing in the United States. The need for API cancer data is increasing. The cancer incidence and survival statistics are based on data from the New Jersey State Cancer Registry, and include all invasive cancers and bladder in situ cancers diagnosed during 1990-2007. Age-adjusted rates and five-year relative survival rates were tabulated using SEER*Stat. API cancer cases (N=15.512) accounted for about 2% of the total cancer cases diagnosed among NJ residents in 1990-2007. Compared to the total NJ population, NJ APIs had lower incidence rates for all cancers combined and for the commonly diagnosed cancers (prostate, breast, lung, and colorectal). APIs had higher stomach and liver cancer incidence rates. NJ APIs had lower incidence rates than U.S. APIs for all cancers combined and the commonly diagnosed cancers with the exception that the incidence rates for stomach, bladder, and thyroid cancer and non-Hodgkin lymphoma were higher for NJ API males and uterine and thyroid cancer incidence rates were higher for NJ API females. From 1990 to 2007, the cancer incidence and mortality rates for APIs followed similar trends as in the NJ population for most cancers except for increasing female breast cancer mortality rates. The five-year relative survival rate for all cancers combined in API males diagnosed in 1990-2002 was lower than NJ males due to of the larger proportion of liver and stomach cancer. API females had higher all cancer and breast cancer survival than NJ females. Although APIs had lower incidence rates for many types of cancer compared to the population in both NJ and the U.S., stomach and liver cancer incidence rates were higher for APIs. Prevention from chronic infection with the bacterium Helicobacter pylori and infections with hepatitis B and C viruses are essential to reduce these cancer burdens in the API population.

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THE CONVERGENCE OF OROPHARYNGEAL CANCER RATES BETWEEN NON-HISPANIC BLACKS AND WHITES IN US

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Background: Previous studies reported on the narrowing of black-white disparities in death rates for lung cancer and for a combination of other tobacco-related cancers, especially in men. In this paper, we examine temporal changes in black-white disparities in incidence and death rates for cancers of the oral cavity and pharynx and whether mortality patterns vary by educational attainment. Methods: We calculated agestandardized death rates for cancers of the oral cavity and pharynx by level of education among 25-64 year old non-Hispanic black and non-Hispanic white men and women for 1993-2007 using data from NCHS. Education levels were recorded on death certificates and categorized into three groups (less than high school graduate, high school graduate and some college). We also examined incidence rates for blacks and whites for all ages combined and for ages 25-64 years. Joinpoint regression models and black-white rate ratios (RR) were used to assess trends. Results: From 1993-2007, overall incidence and death rates decreased in black and white men and women, although decreases were larger for blacks than whites. The black-to-white incidence RR (95% confidence interval) among men decreased from 1.3 (1.1-1.5) to 1.0 (0.9-1.1) for all ages and from 1.9 (1.6-2.2) to 1.0 (0.9-1.2) for ages 25-64. Similarly, the mortality RR for men ages 25-64 decreased overall (from 3.3 [3.0-3.7] to 1.7 [1.5-1.9]) and in each level of educational attainment. However, significant declines in death rates were limited to those with at least a high school diploma for black men and to those with some college for white men. **Conclusions:** The black-white disparity in oropharyngeal cancer rates among men aged 25-64 is eliminated for incidence and is

rates among men aged 25-64 is eliminated for incidence and is converging for mortality, which in part reflects faster declines in tobacco use among blacks than whites. The lack of decrease in death rates in the less educated group underscores the need for strengthening current smoking cessation efforts.

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PREVALENCE OF SYMPTOMS THAT DEFINE INFLAMMATORY BREAST CANCER AMONG CASES IN A POPULATION-BASED CANCER REGISTRY

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BACKGROUND: Inflammatory breast cancer (IBC) is an aggressive form of neoplasia that accounts for approximately 1-2 percent of incident breast cancer cases. The clinical presentation of IBC mocks an inflammatory immune response, but is actually caused by tumor cells that block the lymphatic system of the breast, especially in the skin of the breast. The clinical diagnosis of IBC is based on the presence of symptoms that include short duration of clinical symptoms, skin involvement, peau d'orange, discoloration (including redness or black/dark patches), dermal lymphatic involvement (tumor emboli in the lymphatics), ulceration, palpable mass, nipple inversion, increased breast density, skin thickening, pain, tenderness, warmth, and edema, as well as characteristics that describe the tumor as a non-inflammatory process.

PURPOSE: The purpose of this review is to document the prevalence the above-listed symptoms that lead to the diagnosis of this disease.

METHODS: Investigators from the University of New Mexico are systematically reviewing medical records for IBC cases that were diagnosed in a population-based sample of New Mexico residents during the period 1988-2003. The presence or absence of the described symptoms is being documented, as is the duration of the symptoms, as applicable and available. **RESULTS:** This presentation will summarize results from our review of medical records.

CONCLUSIONS/IMPLICATIONS: Results from this investigation will be relevant to the identification of IBC cases in central cancer registries.

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DESCRIPTIVE EPIDEMIOLOGY OF CERVICAL CANCER IN MASSACHUSETTS

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Purpose: The descriptive epidemiology of cervical cancer in Massachusetts will provide information for the Massachusetts Department of Public Health's cancer control program to target cervical cancer screening programs. Methods: Counts and incidence rates were used for histology, staging, and race/ethnicity tables using diagnosis years 2003-2007. Incidence and mortality rates were plotted and annual percent change was calculated for 1982-2007 and probabilities were calculated for 1998-2007. Results: Age-adjusted incidence and mortality trends (APCs) decreased 0.5% and 2.0% respectively per year until around 1996 then decreased 4.4% and 9.2% respectively per year until 2007. Age-specific incidence rates fluctuated between 10.1 and 13.9 per 100,000 between ages 40-84. Hispanics had the highest incidence rates; however, black, non-Hispanics had the highest mortality rates among race/ethnic groups. The probability of developing and dying from cervical cancer over the lifespan (0-85 years) was 0.6% and 0.2%. Discussion: Papanicolaou (Pap) smear screening, which is used to detect treatable cervical cancer precursors, is responsible for the decreased incidence and mortality of invasive cervical cancer. The use of HPV vaccines could potentially reduce rates even further. Advocacy for cervical cancer screening needs to continue as a component of cancer control efforts.

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Poster Sessions

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CREATING TAILORED LOCAL CANCER CONTROL PLANS: ARE CANCER SURVEILLANCE UNITS AT THE TABLE?

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Despite the availability of reliable screening methods and statewide programs providing free breast cancer screening, invasive breast cancer incidence rates remain highest among all invasive cancer rates in Los Angeles County (LAC). Community-based cancer control coalitions can target areas by using population-based cancer registry data presented in a way that finds and identifies high-risk population subgroups that would most benefit from targeted screening. A new movement in LA to introduce such evidence-based (EB)/informed cancer control has helped integrate cancer surveillance data into mainstream cancer control efforts.

In this study, we describe the use of cancer control data tools and processes to aid community outreach efforts targeting high-risk areas and populations. Previous analyses using kernel density estimation found spatial variations in the distribution of invasive cancer by Service Planning Area in LAC. SPA4 is one of the areas with densest concentration of invasive breast cancer among non-Spanish-surnamed white (NSSW), among Spanish-surnamed white (SSW), and among NSSW, black and SSW combined.

USC Norris Patient Education and Outreach Center's (PEOC) coordinated efforts have helped translate scientific advances to surrounding communities through capacity building of cancer coalitions. The PEOC has integrated registry data into a SPA4 coalition to identify and target high-risk areas. PEOC and Cancer Surveillance Program's (CSP) involvement in community coalitions have shown to contribute in focusing the coalition's efforts towards EB cancer control.

The SPA4 task force will develop a tailored cancer control plan with expert help from USC PEOC and CSP. We will report on the challenges/successes, and evaluate the effectiveness of the resulting programs. PEOC and CSP plans to replicate this process in other areas with high rates of invasive breast cancer, and provide a model of translational cancer control effort for other registries to follow.

P-45

MULTIPLE PRIMARIES (MPS) IN SURVIVAL ESTIMATES: SHOULD SEER INCLUDE OR EXCLUDE MPS?

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Background: Population-based cancer registries typically exclude multiple primaries (second or later tumors) from survival estimates. Rosso et al. [Eur J Cancer 2009;45:1080-1094]and Ellison [Cancer Epidemiol. 2010 Oct;34(5):550-5] recently showed that relative survival estimates decreased when multiple primaries were included. In this poster we evaluate the impact of including multiple primaries using SEER data and compare our results with those from Europe and Canada. Methods: All malignant primary tumors diagnosed between 2000 and 2006 were included from the 17 registries of the SEER Program. Follow-up was through Dec 31, 2007. Life table method was used with monthly intervals. Relative survival estimates for all tumors were compared to those including first tumors only (sequence number 00 and 01). Results: The overall proportion of multiple primaries in SEER data was 16.5% (range: 13.1%-18.7%) with slightly higher proportion among women. Registries starting before 1975 reported an average of 17.1% of MPs compared with 16.1% in registries starting in 1992 or later. Overall differences in survival estimates after including multiple primaries were small, ranging from (-0.6 to -2.6). Conclusion: Even though empirical estimates changed very little, current evidence does not warrant SEER to change their policy of excluding second or later multiples in relative survival analyses unless appropriate expected rate tables could be developed for these primaries . Expected rates for cancer patients with 2 or more tumors are likely to be too high using general life table because it does not account for fact that these patients had prior cancers. Without further adjustment to the current expected rates the SEER Program will not include MPs in survival calculation.

 Notes

OREGON'S EXPERIENCE WITH A SHORT-TERM MEDIA CAMPAIGN TO ENCOURAGE COLORECTAL CANCER SCREENING

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Screening gap: Colorectal screening in Oregon is at about 60% for Oregonians age 50-75. Oregon's Colorectal Screening program aims to use a multiple front campaign to move the screening rate to 80%. Intervention strategy: The core strategy of this campaign is mobilizing people who have been screened to encourage others to be screened. This approach is unique for a CRC prevention campaign, since most other campaigns directly address the unscreened individual.

Methods: A pilot media campaign in one county will serve as a foundation for a statewide comprehensive five-year marketing campaign to increase colorectal cancer screening rates. This campaign will take place in February 2011 with preliminary results expected in April 2011. The campaign will combine targeted provider engagement with a small-scale media campaign focused on mobilizing people who have been screened. Providers will be equipped to handle screening requests and will encourage their patients to be screened; motivated will encourage patients who have been sc reened to share their stories; persons who have been screened will be encouraged to share their story with their social networks. Screening rates will increase through education and outreach and by increasing availability of screening and treatment . Evaluation: Evaluation will measure the effectiveness of this campaign and provide insight for the five-year statewide campaign. Measured outputs will include number of ad placements, number of messages contained in media stories, number of collateral pieces distributed, provider participation in luncheon presentations. Measured outcomes will include awareness of the campaign message, behavioral intention to be screened, whether materials were used, and number of referrals for screening. Evaluation will include pre-and post-tests and luncheon conferences for physicians, and surveys of screened individuals, unscreened individuals, and community partners.

P-47

COLLABORATIVE STUDY OF BREAST RECONSTRUCTION FOLLOWING MASTECTOMY IN THE STATE OF MAINE: GEOGRAPHIC DISPARITY

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Background: The TWG is a collaboration of the Maine Cancer Registry (MCR), hospital cancer registrars, and the Maine Chair of the Cancer Liaison Physicians. Data from the MCR database is used to evaluate staging & treatment for various cancers. Results are compared with national standards. Strategies to improve care throughout the state are developed; dissemination of results is emphasized. In 2010, a concern was voiced that women in Maine seemed less likely to have breast reconstruction than elsewhere.

The purpose of the study was to determine the validity of this concern and to investigate contributing factors. Maine has a small population (1,317,253 in 2004) in a relatively large-sized rural state. The population is the "oldest" in the US. Thus, age & geography were hypothesized to play a role.

Methods: We designed a simple retrospective study for years of diagnosis 2004-06. We analyzed cases coded as having had any mastectomy with or without reconstruction. We compared for age, hospital location, county and Public Health District. We learned that some women had later reconstruction and were incorrectly coded. We then requested follow-back at a selected sample of hospitals with small, medium or large case loads and in varied geographic areas. The registrars performed chart reviews to document subsequent reconstruction. This data was collected centrally for additional analysis & to update the central database.

Results: The % of Maine women who have reconstruction is small compared to US estimate. Age proved to be an important factor: older women were less likely to have undergone reconstruction. Geography was also important & correlated with location of plastic surgery practices.

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IDENTIFYING BREAST CANCER SCREENING SERVICE GAPS: A COMBINED GEOGRAPHIC AND DEMOGRAPHIC APPROACH

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Background: For breast cancer, early detection is the key to favorable survival outcomes, and proximity to a mammography facility can be a driving factor in whether a woman will be screened. The Georgia Breast and Cervical Cancer Program (BCCP) exists to provide breast cancer screening to women 40 to 64 years of age who are uninsured and/or underinsured and at or below 200% poverty level. Purpose: Certain areas of Georgia have higher proportions of women who qualify for BCCP services but reside in counties that have no mammography facilities. We looked into whether women residing in low access/high need counties experienced higher proportions of late stage breast cancer diagnoses (regional or distant). Methods: Using Geographic Information Systems (GIS) and data from the Georgia Comprehensive Cancer Registry (GCCR), all breast cancer cases reported to GCCR from 2003-2007 were geocoded based on patient address, and then subset based on age at diagnosis and stage of cancer. Results: Among women diagnosed between ages 40-64 there was no difference in the overall percentage of late stage diagnoses in the low access/high need counties, as a group, from that of the remaining counties. Areas with low access to mammography facilities do not seem to correspond to areas with high late stage breast cancer incidence. Only six of 159 total counties in Georgia that were classified as low access/high need had proportions of late stage breast cancers in the highest quartile, and six more counties had proportions of late stage breast cancer in the second quartile. However, ten counties containing mammography facilities and low BCCP eligibility had high proportions of late stage breast cancer. Implications: Use of U.S. Census county demographic profile data regarding sex, age, poverty, and educational attainment can explain some of these findings. Additionally, data from the GCCR may assist in directing services to areas and populations with true need.

P-50

LINKING CENTRAL CANCER REGISTRIES AND INSTITUTIONAL BIOREPOSITORIES TO FACILITATE BIOSPECIMEN-BASED RESEARCH – A PILOT STUDY ME McCusker¹, M Allen², I Feldman³, A Fernandez-Ami², KP

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Background: Central cancer registries can serve as hubs to support population-based biospecimen research. Linkages between institutional biorepositories and cancer registries can identify patients with rare tumors or from specific population sub-groups, and registries can provide follow-up information and comparison groups of patients without biospecimens. Purpose: To determine if University of California, Davis Cancer Center Biorepository (UCD) biospecimen records could be linked with California Cancer Registry (CCR) patient records. Methods: We performed a probabilistic data linkage between 3,092 UCD records and 3.3 million CCR records. Each UCD record included first name, middle initial, last name, gender, date of birth, race/ethnicity, medical record number, tissue site, tumor behavior, pathology specimen date, and pathology report number. UCD race/ethnicity, tissue site and tumor behavior variables were re-coded to align with CCR codes. The linkage comprised six sequential comparisons to account for coding differences, such as typographical errors or variations in coding from the medical record. Results: For 2005-2009, 1,040 UCD records with a unique medical record number, tissue site, and pathology date were linked to 3.3 million CCR records. Of these, 844 (81.2%) matched between both databases. Overall, matches were highest for cancers of the cervix (100%) and testis/other male genital system (100%). Matches were lowest for cancers of the skin (20%) and bones/joints (33.3%). For common cancers, matches were highest for lung and respiratory system (93%), breast (91.7%), and colon and rectum (89.5%) and lower for prostate cancers (72.9%). **Conclusions:**Records can be successfully matched between cancer registries and institutional biorepositories to identify cases for population-based biospecimen research. Such linkages can foster productive collaborations between cancer registries and biorepositories, and provide a foundation for virtual biorepository networks.

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PROSTATE CANCER SCREENING AND INCIDENCE AMONG MEN UNDER AGE 50

<u>J Li</u>¹, R German¹, J King¹, D Joseph¹, X Wu², E Tai¹, U Ajani¹ ¹CDC, Atlanta, GA; ²Louisiana State University, New Orleans, Louisiana

Background: Since the introduction of prostate-specific antigen (PSA) screening test in 1986, prostate cancer incidence rate has increased steadily and dramatically in men under age 50. This study aims to better understand socio-demographic variations in cancer screening and incidence, and clinical characteristics of prostate cancers in men under age 50.

Methods: We examined prostate cancer testing data from the Behavioral Risk Factor Surveillance System (2002, 2004, 2006, and 2008) and cancer incidence data from the CDC's National Program of Cancer Registries and the NPC's Surveillance, Epidemiology, and End Results programs (2001-2006). We estimated the weighted percentage of self-reported cancer testing using SUDAAN and age-adjusted cancer incidence rates and trends using SEER-STAT.

Results: A total of 29,176 prostate cancer cases were identified from 2001-2006 among men under age 50. Of these, 551 (1.9%) were among men under age 40. Incidence rates remained stable from 2001-2006: however the incidence of well-differentiated tumors decreased significantly (APC=-24.7) during this time period. About 44% of men aged 40-49 years old reported having a prostate cancer test in the past two years. Prostate cancer testing and incidence rates were highest among men who were black, non-Hispanic, or lived in the northeast. Black men had more than a 2-fold increase in cancer incidence than white men. Conclusions: The magnitude of prostate cancer testing and incidence in men under age 50 reveals significant health/public health problems in this younger population. This study demonstrates substantial regional differences in prostate cancer testing and incidence. It also confirms that cancer testing and incidence vary according to race and ethnicity. We observed a large health disparity in cancer incidence between blacks and whites. The incidence rate remained stable over time; the dramatic change in well-differentiated cancer may be due to "Grade inflation".

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P-52

MOVING TOWARD SURVIVAL SURVEILLANCE: IMPLEMENTING AND EVALUATION SPATIAL SURVIVAL SCAN METHODS FOR NEBRASKA CANCER REGISTRY L Zhang¹, M Qu¹, G Lin^{1,2}

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Survival rate is the most important indicator in comparative effectiveness analysis. Spatial and temporal surveillance on survival rates is one way to move the cancer data reporting toward this area. Nebraska cancer registry conducted a feasibility study of spatial temporal surveillance on cancer survivals last year. Based on recently developed spatial survival scan and other methods, spatial survival surveillance was conducted at the ZIP CODE and county level. First, the registry updated recent 5 leading cancer deaths (Lung, colorectal, pancreatic, breast, prostate) by using two updating strategies: the National Death Index and the Social Security Administration (SSA) benefit verification system. It was found that the SSA system providing slight more death records in same year coverage, but with the exception of pancreatic cancer, one year lag in registry data were likely cover over 90% deaths with an annual NDI update and the real time state vital statistic update. Second, while conducting regular temporal surveillance of survival curves by race, age group, staging and tumor type, it is unrealistic disaggregated surveillance for a segment of population. As some counties are so small, there were very few incidences accompanied by very few survival cases, suggesting spatially varied impact of censoring by demographic and staging variables. Third, even though computational is an issue for infectious disease surveillance, it is not an issue, as the registry only needs to do annual surveillance. However, as cancer competing with other state surveillance activities, computational time could be a potential concern. It is concluded that cancer registrars may have to work with medical staff to determining meaningful use of spatial surveillance so that data items such as treatments and procedures can also be incorporated into future surveillance. The latter effort may require data integration from electronic health records (EHR) due to limited resources.



Notes

MALE BREAST CANCER – GEOGRAPHIC VARIATION IN THE UNITED STATES

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Background: Incidence of male breast cancer (MBC) continues to increase ever year but due to its rarity compared to women, there is little attention paid to understanding the disease. Furthermore while there have been some previous descriptive analyses on MBC, most of the findings have been based on limited data sets that may not be generalizable to all populations in the United States.

Purpose: To describe the geographical distribution of MBC in the United States and to assess demographic risk factors and histological distribution of MBC.

Methods: For our analysis of geographical variation and other risk factors for MBC, we used combined NPCR and SEER from 2004-2006 representing 100% of the US population and for our analysis on histology of MBC, we used combined data from 1999-2006 representing 90% of the US population.

Results: Incidence and mortality rates of MBC increased significantly with each 10 year age group. When compared to whites, incidence and mortality rates of MBC were significantly higher among blacks and significantly lower among Asian/Pacific Islanders. Fewer whites were diagnosed at a late stage (pvalue 0.00), but the same was not true for blacks (pvalue 1.00) or Asian/Pacific Islanders (pvalue 0.21). Our study found a difference in incidence rates among the four geographical regions with incidence rates being the highest in the South, in black men and men over the age of 80 years.

Conclusion: Our paper presents an in-depth analysis of the demographic and geographic variation of male breast cancer incidence. Additional research should address geographical variability related to differences in treatment and mortality. Furthermore, other possible causes for variation in stage at diagnosis among racial groups should be investigated. Variations in stage, diagnosis and mortality support the need for increased awareness of breast cancer among men.

P-54

MAXIMIZING DATA CHANGES OPPORTUNITIES W Roshala¹

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Background: The 2010 data changes process presented a multitude of challenges for central registries. Close examination of internal and external processes and open communication were key for optimal implementation. **Purpose:** To examine our current data changes processes and assess the impact of the 2010 data changes.

Methods: Assess all facets of our data changes process for improvement opportunities.

Results: Although the 2010 data changes process was externely labor intensive, many process improvements resulted from these efforts. This presentation will discuss the opportunities for process improvement as a result of the 2010 data changes process.

Conclusions: Forced changes can lead to better long-term solutions.

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Poster Sessions

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Louisville, Kentucky June 18 - 24, 2011

Hyatt Regency Louisville and Kentucky International Convention Center

	Afternoon							Lunch																Early Morning				All session	PRO
	6:00-9:00 pm	5:00	4:30	4:00	3:30	3:00	2:30	2:00	1:30	1:00	12:45	12:30	12:00 pm	11:45	11:30	11:15	11:00	10:45	10:30	10:15	10:00	9:30	9:00	8:30	8:00	7:00 am		ns/events are at t	GRAM
Plenary Sessions Concurrent Sessions			Poster/Exhibit Setup											Committee Meetings All Day (HYATT)					(HYATT)	NAACCR BOD Meeting	Monday, June 20, 2011	he Kentucky International Conver	GUIDE at						
2011 NAACCR CONFERE	Opening Reception (HYATT)	Meet and Greet Vendors/Exhibitors		The Quarter Pole	Concurrent Session 2:	Break (poster viewing)		ine first lurn	Concurrent Session 1:				Lunch (on your own)				Keeping Pace with Science	Plenary 2:	Ł	Break S			Keeping Pace with Policy	Plenary 1:	Opening & Welcome	Meet NAACCR	Tuesday, June 21, 2011	ntion Center (KICC) unless otherw	a dance
							Free Afternoon	Adjourn		NAACCR Business Meeting				NAACCR Strategic Plan						Break				Concurrent Session 3: The Backstretch		Birds of a Feather	Wednesday, June 22, 2011	vise specified	
	Adjourn	Plenary 4: The Finish Line Invitation to 2012 Closing Remarks						Break				(HYATT)		Concurrent Session 5: The Home Stretch							Break (poster viewing/drawing)			Concurrent Session 4: The Final Turn		Run / Walk	Thursday, June 23, 2011		
	6:00-9:00 pm	5:00	4:30	4:00	3:30	3:00	2:30	2:00	1:30	1:00	12:45	12:30	12:00 pm	11:45	11:30	11:15	11:00	10:45	10:30	10:15	10:00	9:30	9:00	8:30	8:00	7:00 am			