

NAACCR

2012 CONFERENCE
final program



Building Bridges for Cancer Surveillance: 25 Years of Progress



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

25th Anniversary Celebration

Portland, Oregon

June 1 - 8, 2012

Hilton Portland & Executive Tower





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Grant Information



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Happy 25th Anniversary NAACCR!

NAACCR

2012 CONFERENCE

final program and abstract book



On the occasion of our
25th Anniversary
we would like to express our sincere gratitude to our
VOLUNTEERS
for their generous support of our many initiatives
and for their countless hours of service to our mission of
reducing the burden of cancer in North America.
THANK YOU!
Board of Directors and Staff of NAACCR
"Working together to make every cancer case count!"



Exhibitors and Sponsors

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■ Exhibitor

AMERICAN CANCER SOCIETY

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■ Exhibitor

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Exhibitors and Sponsors *continued*

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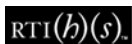
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■ Exhibitor

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Welcome to NAACCR 2012



Welcome to Portland!

On behalf of the NAACCR Board of Directors and the Annual Program Committee, we welcome you to Portland, Oregon, the host city of the 2012 Annual Conference of the North American Association of Central Cancer Registries (NAACCR).

The Program Committee has set out to develop an informative and exciting agenda for this year's conference participants. The theme for the 2012 NAACCR Conference is *"Building Bridges for Cancer Surveillance: 25 Years of Progress."* The goals of this conference are to explore how cancer surveillance has changed over the past 25 years, to examine NAACCR's role in guiding those changes, and to look ahead to see what the future holds for cancer data collection and use.

The plenary sessions will begin with a look back at the origins of NAACCR by the organization's first president, Dr. Donald Austin. He will provide a summary of population-based cancer surveillance activities that have brought the industry to where it is today. The second speaker, Dr. David Forman, Head of the Cancer Information Sections, International Agency for Research on Cancer, will provide a global perspective on cancer surveillance.

Additional plenary sessions will feature examples of advanced methods for using registry data to present incidence, mortality, and survival statistics. The final plenary sessions will focus on collaborative stage: anticipated changes, impact on registries, and uses in cancer research. Finally, participants will have an opportunity to discuss various issues concerning the collection and use of collaborative stage data.

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 Analysis and Use, 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 2012 Annual Conference. The Birds of a Feather will continue their early morning discussions and the GIS Committee will again sponsor a Run/Walk event. During the week of the conference, Portland will be celebrating the 2012 Rose Festival complete with parades, carnival rides, dragon boat races, and much, much more. We hope you enjoy your visit to Portland.



Donald Shipley, MS
Chair, 2012 NAACCR Program Committee
Cancer Control Programs Manager
Oregon Public Health Division

Message from the President

Dear Friends and Colleagues,

It is with a tremendous sense of pride and optimism that I welcome everyone to Portland for the NAACCR 2012 Annual Conference. This year's meeting theme, "Building Bridges for Cancer Surveillance – 25 Years of Progress" is clearly an excellent choice as we gather to celebrate the first quarter century of NAACCR achievements. During our time together we will have the opportunity to recognize the foresight and vision of NAACCR's founding members, who understood the need for a collaborative, standards-based organization to support cancer surveillance; a need that continues on today.

Under the guidance of our colleagues at the Oregon State Cancer Registry, attendees will experience a program that will challenge us and set us on the road for another 25 years of success. NAACCR is all about 'bridges' as it connects members with one another to solve problems and support our work. Over the course of 25 years, a knowledgeable community of practice

has emerged that is well positioned to address issues impacting cancer surveillance.

Over the next few days, please take the time to meet and greet your colleagues and friends and learn from one another. In addition, Portland is a dynamic and eclectic location for our sessions and there is sure to be something to suit everyone as you explore the city. Thank you for attending and contributing to making this is a memorable meeting!



Maureen MacIntyre, MHSA
NAACCR Board President



Conference Objectives

GENERAL INFORMATION

For the past 25 years, NAACCR has brought central cancer registries together to share successes and challenges. This year's conference, "Building Bridges for Cancer Surveillance: 25 Years of Progress," will explore how population-based cancer surveillance has changed over time and where the path ahead may lead.

The objectives of the 2012 Annual Conference are to examine how cancer surveillance practices in North America have changed over the 25 year history of NAACCR and how these practices influence current and future data collection and use. The first plenary session will focus on the history of NAACCR

and its relevance to global cancer surveillance efforts. In the second plenary session, examples will be given of newly developed approaches for presenting patient survival statistics and results of a study on the most effective ways of disseminating cancer statistics. The third plenary provides a discussion of Oregon's approach to meeting the requirements of health reform legislation in addition to a presentation from the Canadian Partnership Against Cancer on the National System Performance Reporting. The last two plenary sessions will give an overview of several ongoing efforts and a facilitated discussion among participants about the future of Collaborative Stage.

NAACCR Board 2011-2012



2010 - 2014

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2011 - 2013

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Program Committee

Member	Affiliation
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Margaret Adamo	National Cancer Institute
Charlie Blackburn	NAACCR
Rosemary Dibble	Utah Cancer Registry
Mignon Dryden	Cancer Registries of Central and Northern California
Brenda Edwards	National Cancer Institute
Susan Gershman	Massachusetts Cancer Registry
Betsy Kohler	NAACCR
Nancy Lozon	Metropolitan Detroit Cancer Surveillance System
Maureen MacIntyre	Cancer Care Nova Scotia
Les Mery	Public Health Agency of Canada
Fran Michaud	National Program of Cancer Registries (CDC)
Donna Morrell	Los Angeles Cancer Surveillance Program
Lilia O'Connor	Public Health Institute
Edward Peters	Louisiana Tumor Registry
Rich Pinder	Los Angeles Cancer Surveillance Program
Joan Pliska	Oregon State Cancer Registry
Frances Ross	Kentucky Cancer Registry
Recinda Sherman	Florida Cancer Data System



GENERAL INFORMATION

Andrew Stewart	Commission on Cancer
Monica Thornton	NAACCR
Deborah Towell	Oregon State Cancer Registry
Thomas C. Tucker	Kentucky Cancer Registry
Donna Turner	CancerCare Manitoba
Shannon Vann	NAACCR
Kevin Ward	Metro Atlanta SEER Registry
Melanie Williams	Texas Cancer Registry

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National Cancer Institute
National Cancer Registrars Association
Public Health Agency of Canada

Sponsors with Distinction

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 outside the Grand Ballroom and is open during the following days and times:

Monday, June 4	9:00 am to 7:00 pm
Tuesday, June 5	7:00 am to 5:00 pm
Wednesday, June 6	7:00 am to 12:30 pm
Thursday, June 7	7:00 am to 10:30 am

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

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

PLENARY SESSIONS / BUSINESS MEETING

All Plenary Sessions and the Business Meeting will take place in the Pavilion Ballroom on the Plaza Level.

OPENING RECEPTION

Tuesday, June 5, 2012

The welcome reception will be held in the Pavilion Ballroom 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 will be able to conveniently download the 2012 NAACCR Annual Conference CE Hours Form from the NAACCR website at www.naaccr.org.

EXHIBITS AND POSTER INFORMATION

Exhibits and Posters will be located in the Grand Ballroom.

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

Monday, June 4	5:00 pm to 6:30 pm
Tuesday, June 5	7:00 am to 5:00 pm
Wednesday, June 6	7:00 am to 12:30 pm
Thursday, June 7	7:30 am to 12:30 pm

CYBER CAFÉ

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

CONFERENCE EVALUATIONS

2012 conference evaluations will be available in electronic format only.

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

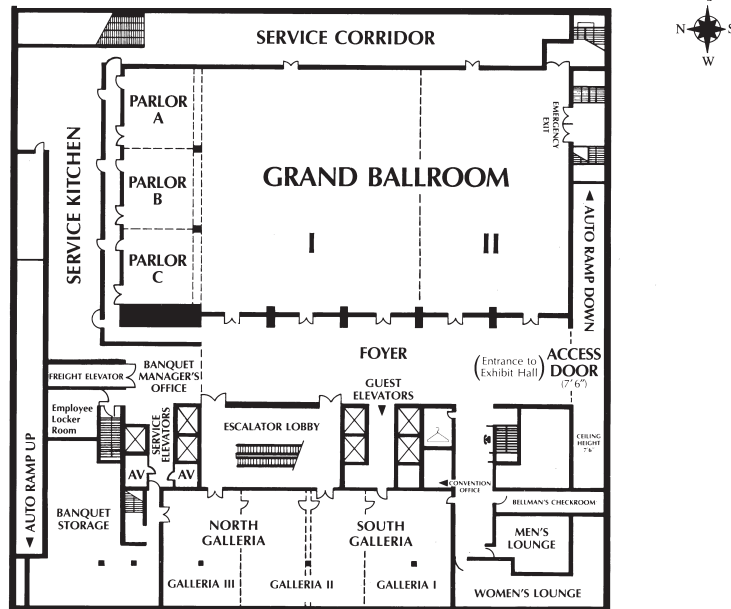


Floor Plans

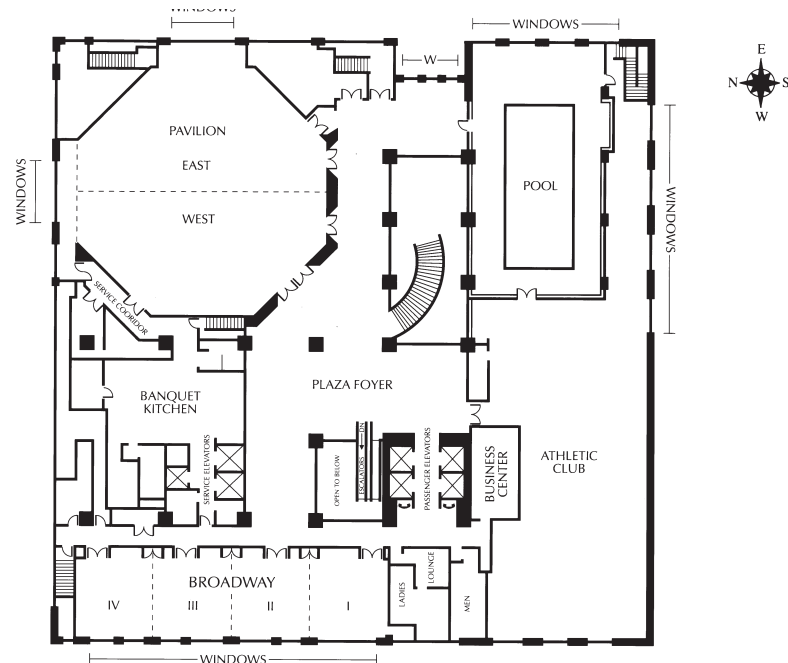
GENERAL INFORMATION

Hilton Portland & Executive Tower

BALLROOM LEVEL



PLAZA LEVEL

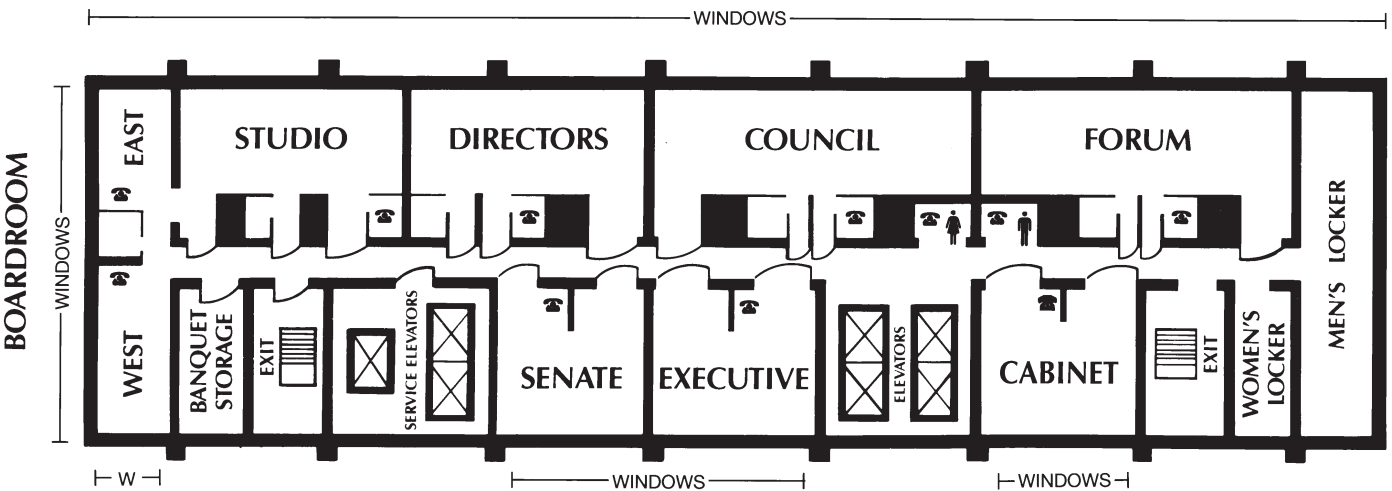


Floor Plans

GENERAL INFORMATION

Hilton Portland & Executive Tower

THIRD FLOOR



NAACCR
2012 CONFERENCE
final program



FRIDAY, JUNE 1 PRE-CONFERENCE

8:30 am - 6:00 pm Statistical Methods for Population-Based Cancer Survival Analysis (Day 1)
Faculty:
Paul W. Dickman, Department of Medical Epidemiology and Biostatistics, Karolinska Institutet, Stockholm, Sweden
Paul C. Lambert, Department of Health Sciences, University of Leicester, UK & Department of Medical Epidemiology and Biostatistics, Karolinska Institutet, Stockholm, Sweden
Course Organizer:
C. Johnson, Cancer Data Registry of Idaho
BROADWAY I AND II

SATURDAY, JUNE 2 PRE-CONFERENCE

8:30 am - 5:30 pm Basic SEER*Stat Software Training
C. Kosary, NCI
GALLERIA NORTH

9:00 am - 6:00 pm Statistical Methods for Population-Based Cancer Survival Analysis (Day 2)
C. Johnson, Cancer Data Registry of Idaho
BROADWAY I AND II

12:30 pm - 5:15 pm Central Cancer Registries: A Review Short Course (Day 1)
H. Menck, FACE
COUNCIL SUITE

SUNDAY, JUNE 3 PRE-CONFERENCE

8:00 am - 5:00 pm Board of Directors Meeting
GALLERIA NORTH

8:00 am - 12:00 pm CDC Registry Plus/Link Plus Workshop
J. Rogers, Cancer Surveillance Branch, Division of Cancer Prevention and Control, Centers for Disease Control and Prevention
FORUM SUITE

8:15 am - 4:45 pm Central Cancer Registries: A Review Short Course (Day 2)
H. Menck, FACE
COUNCIL SUITE

8:30 am - 5:30 pm Advanced SEER*Stat Software Training
C. Kosary, NCI
BROADWAY III

9:00 am - 3:00 pm Hands-On Geocoding for Cancer Registries
NAACCR GIS Committee
BROADWAY IV

9:00 am - 6:00 pm Statistical Methods for Population-Based Cancer Survival Analysis (Day 3)
C. Johnson, Cancer Data Registry of Idaho
BROADWAY I AND II

1:00 pm - 5:00 pm CDC EDITS Workshop
J. Rogers, Cancer Surveillance Branch, Division of Cancer Prevention and Control, Centers for Disease Control and Prevention
FORUM SUITE

MONDAY, JUNE 4 PRE-CONFERENCE

7:00 am - 8:30 am Board of Directors Meeting
GALLERIA NORTH

8:00 am - 12:00 pm SEER*Prep Software Training
C. Kosary, NCI
COUNCIL SUITE

9:00 am - 7:00 pm Registration
GRAND BALLROOM FOYER

1:00 pm - 5:00 pm Exhibit Set-up
GRAND BALLROOM

1:00 pm - 5:00 pm Poster Set-up
PARLORS

5:00 pm - 6:30 pm Exhibitor Showcase Poster Preview
Be sure to connect with your colleagues at our new Exhibitor Showcase and Poster Preview. Visit vendors, preview posters, have a nibble, and enter a door prize give-away drawing. Cash bar available.
GRAND BALLROOM

8:30 am - 7:00 pm COMMITTEE MEETINGS

8:30 am - 9:30 am CINA Editorial Subcommittee
FORUM SUITE

8:30 am - 10:30 am Uniform Data Standards and Information Technology Committees Combined Meeting
BROADWAY III AND IV

10:30 am - 11:30 am EDITS Workgroup
BROADWAY III AND IV

10:30 am - 12:30 pm GIS Committee
GALLERIA NORTH

10:30am - 12:30 pm	Data Evaluation and Certification Committee BROADWAY I AND II
11:30 am - 5:00 pm	Assisted Reproductive Technology and the Risk of Childhood Cancer GALLERIA SOUTH
1:00 pm - 3:00 pm	Education Committee FORUM SUITE
1:00 pm - 3:00 pm	Interoperability Ad Hoc Committee BROADWAY III AND IV
3:00 pm - 4:00 pm	Race and Ethnicity Workgroup DIRECTORS SUITE
3:00 pm - 4:30 pm	Board/SMO Meeting GALLERIA NORTH
3:00 pm - 5:00 pm	Data Use and Research Committee BROADWAY I AND II
4:00 pm - 6:00 pm	Registry Operations Committee FORUM SUITE
4:30 pm - 5:30 pm	Cancer Registration Steering Committee Meeting (CRSC) GALLERIA NORTH
5:30 pm - 7:00 pm	Collaborative Stage Governance Meeting BROADWAY III AND IV
5:30 pm - 6:30 pm	Confidentiality Subcommittee BROADWAY I AND II
6:00 pm - 7:00 pm	Data Use and Research Committee's Survival Analysis Work Group DIRECTORS SUITE

TUESDAY, JUNE 5

CONFERENCE DAY 1

6:30 am - 8:00 am	Breakfast GRAND BALLROOM
7:00 am - 5:00 pm	Registration GRAND BALLROOM FOYER
7:00 am - 5:00 pm	Exhibits Open GRAND BALLROOM AND PARLORS
7:00 am - 5:00 pm	Posters GRAND BALLROOM AND PARLORS
8:00 am - 8:30 am	Opening Ceremonies and Welcome Donald Shipley, MS (Cancer Control Program Manager Oregon Public Health Division) PAVILION BALLROOM

Plenary Session #1

PAVILION BALLROOM

8:30 am - 10:00 am	NAACCR's 25th Anniversary: Past, Present, and Future <i>Moderator: Thomas C. Tucker, PhD, MPH (Kentucky Cancer Registry)</i> Historical Perspectives of Cancer Surveillance in North America: 25 Years of Progress <i>Donald Austin, MD, MPH (Professor Emeritus, Department of Public Health and Preventive Medicine, Oregon Health Science University)</i> International Perspectives of Cancer Registration: Global Initiatives and Future Directions <i>David Forman, PhD, (Head, Cancer Information Section, International Agency for Research on Cancer)</i>
10:00 am - 10:30 am	Break / Poster Viewing / Exhibits GRAND BALLROOM AND PARLORS

Plenary Session #2

PAVILION BALLROOM

10:30 am - 12:00 pm	Bridges to the Future: Communicating Cancer Surveillance Data <i>Moderator: Vivien Chen, MPH, PhD (Louisiana State University Director, Louisiana Tumor Registry)</i> Making Cancer Survival Statistics More Relevant for Clinicians, Patients, and the General Public <i>Paul Dickman, PhD (Department of Medical Epidemiology and Biostatistics, Karolinska Institutet Stockholm, Sweden)</i> Improving the Social Impact of Cancer Registry Data Through Infographic Thinking <i>Christina Clarke, PhD, MPH (Research Scientist, Cancer Prevention Institute of California)</i> <i>Matthew Kreuter, PhD (Director, Health Communication Research Laboratory, Washington University)</i> <i>Heather Corcoran, MFA (Professor, Sam Fox School of Design, Washington University)</i>
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12:00 pm - 1:30 pm Lunch (on your own)

12:00 pm - 1:30 pm MTC Registry Luncheon (Sponsored Lunch Meeting - United BioSource, by invitation)
FORUM SUITE

Concurrent Session #1

1:30 pm - 3:00 pm

Section A: GEOCODING METHODS

GALLERIA I

Moderator: D O'Brien

- 01 Cancer Registry Geocoding Services Standardization
D.W. Goldberg, University of Southern California
- 02 Accuracy and Precision of the NAACCR Geocoder
R.L. Sherman, University of Miami
- 03 A Google Maps Mashup for Cancer Case Geocoding
F.P. Boscoe, New York State Cancer Registry
- 04 Strategies for Increasing Geocoding Accuracy
D. Rust, Kentucky Cancer Registry

Section B: INNOVATIVE APPROACHES TO COLLECTING TREATMENT DATA

GALLERIA II

Moderator: F Ross

- 05 Toward Achieving More Complete Treatment Information - What Can Be Obtained From Resubmitted Hospital Data?
A. Kahn, New York State Cancer Registry
- 06 Cancer Reporting from Radiation Treatment Centers
A.R. Houser, C/NET Solutions, PHI
- 07 Pro-Active Reporting of Physician Medical Claims Data: Capturing Complete Treatment Data and Identifying Physician Office Missed Cases
J. MacKinnon, University of Miami
- 08 Validation of SEER Treatment Data Using Medicare Claims
A.M. Noone, NCI

Section C: ANALYTIC EPIDEMIOLOGY I

GALLERIA III

Moderator: D Turner

- 09 Estimating Probability of Death for Cancer Patients: In Presence of Competing Risks
N. Howlader, NCI
- 11 Estimating the Loss in Expectation of Life Due to Cancer Using Flexible Parametric Survival Models
T. M.L. Andersson, Department of Medical Epidemiology and Biostatistics, Karolinska Institutet
- 12 Relative Survival of Colorectal and Breast Cancer Cases in Maine
S. Nazare, University of Southern Maine/Maine CDC

Section D: DATA USE AND RESEARCH

BROADWAY I AND II

Moderator: M Williams

- 13 Unstaged Cancer in the United States: A Population-Based Look at Demographic, Socioeconomic, and Geographic Variables as Predictors of Staging
K. Herget, University of Utah
- 14 Linking the 1991 Census to the Canadian Cancer Registry to Advance Knowledge About Cancer in First Nations and Métis Adults in Canada
D. Withrow, Cancer Care Ontario
- 15 A Novel Method for Multiple Mediation Analysis – With Application to Analyze Racial Disparity in Breast Cancer Mortality
Q. Yu, Louisiana State University Health Sciences Center
- 16 A Composite Index of Socioeconomic Status for Controlling the Confidentiality of Cancer Registry Data
K. Cronin, NCI



Section E:

DATA COLLECTION AND RESEARCH

BROADWAY III AND IV

Moderator: A Stewart

- 17 Enhancing Cancer Registries for Comparative Effectiveness Research: Development of an Infrastructure for Data Collection
C.R. Ehemann, Cancer Surveillance Branch, Division of Cancer Prevention and Control, CDC
- 18 Project HAN, A Data Collection Study Within the Hospice, Adult Living, and Nursing Home Community, NC Central Cancer Registry
C. Rao, NC Central Cancer Registry
- 19 Treatment Summaries for All! An Expanded Role for Central Cancer Registries
R.K. Rycroft, Colorado Central Cancer Registry
- 20 Developing a Tracking System to Ensure Completeness of CER Required Data Items
D. Rousseau, Hospital Association of Rhode Island

3:00 pm - 3:30 pm Break / Poster Viewing / Exhibits
GRAND BALLROOM AND PARLORS

Concurrent Session #2

3:30 pm - 5:00 pm

Section A:

IMPROVING DATA QUALITY THROUGH ELECTRONIC METHODS

GALLERIA I

Moderator: F Michaud

- 21 Analysis of Time and Effort Required to Collect Data for 2004 Collaborative Stage Site-Specific Factors
H. M. Kim, Emory University, Rollins School of Public Health
- 22 Data Quality Control by Using SAS Enterprise Guide
Y. Ren, ICF International
- 23 Algorithms for Logical Checking Multiple Data Items in Monitoring and Improving Data Quality
L. Sun, SEER Program, NCI
- 24 Enhancing Data Quality Through Automation
C. Moody, California Cancer Registry/Public Health Institute

Section B:

CANCER SURVIVAL ANALYSIS AND INTERPRETATION

GALLERIA II

Moderator: N Lozon

- 25 Where Wisconsin Cancer Patients Die: Observations and Practical Implications
R.L. Borchers, Wisconsin Cancer Reporting System
- 26 Estimating Expected Survival Probabilities for Relative Survival Analysis - Exploring the Impact of Including Cancer Patient Mortality from the Calculations
P. W. Dickman, Karolinska Institutet

- 27 How Can We Make Cancer Survival Statistics More Useful for Patients and Clinicians – An Application Using Localized Prostate Cancer in Sweden
S. Eloranta, Department of Medical Epidemiology and Biostatistics, Karolinska Institutet

- 28 Evaluating NAACCR Survival Data for Fitness for Use
H. Weir, CDC

Section C:

GEOGRAPHIC AND SPATIAL RESEARCH

GALLERIA III

Moderator: R Sherman

- 29 Overcoming Small Numbers in a Small State: Vermont's Approach to Cancer Mapping
J. Kachajian, Vermont Department of Health
- 30 Comparing Spatial Patterns Using Hierarchical Bayes Models
L. Zhu, NCI/SEER
- 31 Geographic Variation in Thyroid Cancer Incidence in Ontario, Canada: 2003-2007
E. Candido, Cancer Care Ontario
- 32 Geocoding Reference Data Quality Assessment Strategies at North Carolina CCR
C. Klaus, NC Central Cancer Registry

Section D:

USING CANCER SURVEILLANCE DATA FOR PUBLIC HEALTH POLICY

BROADWAY I AND II

Moderator: L Coleman

- 33 Supporting Public Health Unit Analyses of Cancer Registry Data
B. Theis, Cancer Care Ontario
- 34 The Impact of Georgia Smoking Prevalence Trend on Georgia Lung Cancer Incidence and Mortality by Year 2020
V. Davis, Georgia Comprehensive Cancer Registry
- 35 Making the Case for Chronic Disease Prevention Policies Using Ontario Cancer Registry Data
B. Theis, Cancer Care Ontario

Section E:

INNOVATIVE APPROACHES TO DATA COLLECTION

BROADWAY III AND IV

Moderator: L O'Connor

- 36 Consolidating Health Providers' Data into a Relational Database System for the North Carolina Central Cancer Registry
L. Carrasco, Lineberger Comprehensive Cancer Center
- 37 Using Mixture Cure Models to Estimate Biological Cure
M. Stedman, NCI

38 New Challenges in Cancer Surveillance: Oral Treatments for Cancer
L.T. Penberthy, VCU Massey Cancer Center

39 Using Cancer Surveillance Data to Advance Science: Monitoring for a Potential Safety Signal for Approved Drugs through Linkage Studies
D. Harris, RTI Health Solutions

5:00 pm - 5:30 pm Appalachia Cancer Survival Study Meeting
GALLERIA I

5:30 pm - 6:00 pm CONCORD-2 Working Group (North America) Meeting
GALLERIA I

6:00 pm - 9:00 pm Opening Reception
PAVILION BALLROOM

WEDNESDAY, JUNE 6

CONFERENCE DAY 2

6:30 am - 9:00 am Breakfast
GRAND BALLROOM

7:00 am - 8:00 am GIS Committee Walk/Run
MEET IN HOTEL LOBBY

7:00 am - 12:30 pm Exhibits Open
GRAND BALLROOM

7:00 am - 12:30 pm Posters
GRAND BALLROOM AND PARLORS

7:00 am - 12:30 pm Registration
GRAND BALLROOM FOYER

2:00 pm - 3:30 pm NPCR Data Quality Evaluation Meeting
GALLERIA I

Plenary Session #3

PAVILION BALLROOM

9:00 am - 10:30 am **Bridges to the Future:
Collecting Clinically Relevant Data**
*Moderator: Susan Gershman, MPH, PhD,
CTR (Director, Massachusetts Cancer
Registry)*

Creation of CCOs in Oregon:
Plans and Progress
*Sean P. Kolmer, MPH
(Assistant Health Policy Advisor,
Office of Governor Kitzhaber)*

Plenary Session #3 continued

National System Performance Reporting
*Heather Bryant, MD, PhD, CCFP, FRCPC
(Vice President, Cancer Control,
Canadian Partnership Against Cancer)*

10:30 am - 10:45 am Break / Poster Viewing / Exhibits
GRAND BALLROOM AND PARLORS

Concurrent Session #3

10:45 am - 12:15 pm

Section A:
DATA QUALITY: CANCER STAGING

GALLERIA I

Moderator: K Ward

40 Comparison of Directly Coded Summary Stage 2000 and Derived Summary Stage 2000 Using Data from NPCR for Breast and Colon Cancer Cases
R. Wilson, CDC

41 Improving Stage at Diagnosis Data Through Imputation
B. Das, Westat

42 The 2011 Collaborative Stage Reliability Study Results for Cancers of Lung, Breast, Colon and Prostate
J. Ruhl, NCI/SEER

43 Evaluation of a Pan-Canadian Cancer Staging Program
E. Taylor, Canadian Partnership Against Cancer

Section B:
AUTOMATING DATA COLLECTION PROCESSES

GALLERIA II

Moderator: S Vann

44 Getting the Most Out of Web Plus™ File Upload and Download Features in Tennessee
R. Tenney, Tennessee Cancer Registry

45 It's About Time . . . for ICD-10-CM Implementation
L. Infrerra, California Cancer Registry



- 46 Bridging the Discharge Data Gap: National Harmonization and Education Efforts
S. Jones, Centers for Disease Control and Prevention

- 47 Automated Tumor Consolidation: The Florida Algorithm
G. Levin, Florida Cancer Data System

Section C: RECORD LINKAGES

GALLERIA III

Moderator: R Pinder

- 48 Integrating LinkPlus with Registry Non-Hospital Casefinding Operations
J. Jacob, Kentucky Cancer Registry
- 49 Data Linkages Supporting Occupational Cancer Surveillance
M. A. Harris, Occupational Cancer Research Centre, Cancer Care Ontario
- 50 Enhance Cancer Care Surveillance Using Hospital Discharge Data
L. Zhang, Nebraska Department of Health and Human Services, Nebraska Cancer Registry
- 51 Standardized Data Exchange and Linkage Between Cancer Registries and Breast and Cervical Cancer Screening Programs Using Standardized Tools from the Centers for Disease Control and Prevention
K. K. Thoburn, Northrop Grumman

Section D: ANALYTIC EPIDEMIOLOGY II

BROADWAY I AND II

Moderator: B Theis

- 52 The Real Cancer Problem in Hinkley
J. W. Morgan, Loma Linda University School of Public Health
- 53 The Mystery of Ontario's Unusually High Pancreatic Cancer Survival
D. Nishri, Cancer Care Ontario
- 54 Storm Brewing: Cancer in Manitoba's First Nations
D. Turner, Cancer Care Manitoba

- 55 Cancer Clusters in the US – What Do the Last Twenty Years of State and Federal Investigations Tell Us?
M. Goodman, Emory University, School of Public Health

Section E: EDUCATION AND TRAINING

BROADWAY III AND IV

Moderator: M Dryden

- 56 Building Bridges with Hospital Registries: Louisiana Experience
V. W. Chen, Louisiana Tumor Registry
- 57 Educational Outreach - A Glimpse into FCDS Current and Future Education Plans
S. Peace, Florida Cancer Data System
- 58 Educate Me: Implementing a Web-Based Training, Assessment, and Intervention Program
M. Potts, Fred Hutchinson Cancer Research Center
- 59 Leaders Are Trained not Born: Characteristics of Effective Leadership Training
C. L. Kosary, NCI

12:15 pm - 12:30 pm Break / Poster Viewing / Exhibits
GRAND BALLROOM AND PARLORS

12:30 pm - 2:00 pm Awards Luncheon
Join your colleagues for our Annual Awards Luncheon on a new day (Wednesday). We will hold the NAACCR Annual Business Meeting immediately following the Awards Luncheon.
PAVILION BALLROOM

2:00 pm - 3:30 pm NAACCR Business Meeting
PAVILION BALLROOM

2:00 PM - 3:30 pm NPCR Data Quality Evaluation Meeting
GALLERIA I

THURSDAY, JUNE 7

CONFERENCE DAY 3

6:30 am - 9:00 am Breakfast
GRAND BALLROOM

7:00 am - 10:30 am Registration
GRAND BALLROOM FOYER

7:00 am - 12:30 pm Exhibits Open
GRAND BALLROOM

7:00 am - 12:30 pm Posters
GRAND BALLROOM AND PARLORS

7:15 am - 7:45 am Cancer-Rates. Info Users Group Meeting
GRAND BALLROOM

8:00 am - 9:00 am Birds of a Feather:
Information Overload – Any Way Out?
GALLERIA II



Plenary Session #4

PAVILION BALLROOM

9:00 am - 10:00 am

Deliberations on the Future of Collaborative Stage

*Moderator: Betsy A. Kohler, MPH, CTR
(Executive Director, NAACCR)*

Update: CS Summit Data Element Review Work Group
*(Liz Ward, PhD
American Cancer Society)*

Update: CS Summit Evaluation and Simplification Work Group *(Brenda Edwards, National Cancer Institute)*

Concept Development: CS Lite
(Christie Ehemann, Cancer Surveillance Branch, Division of Cancer Prevention and Control, CDC and/or Kevin Ward, Metro Atlanta SEER Registry)

Results from CSv2 Reliability Study
(Lynda Douglas, CDC/NPCR and/or Jennifer Ruhl, NCI/SEER)

10:00 am - 10:15 am

Break / Exhibitor and Poster Viewing
GRAND BALLROOM AND PARLORS

Concurrent Session #4

10:15 am - 11:45 am

Section A:

COLLABORATIVE STAGE RELIABILITY STUDY RESULTS

GALLERIA I

Moderator: D Morrell

- 60 An Introduction to the 2011 Collaborative Stage Reliability Study
P. Jamison, NIH/NCI/SEER
- 61 The 2011 Collaborative Stage Reliability Study Results for Other Common Cancer Sites
G. Lee, Cancer Care Ontario



- 62 The 2011 Collaborative Stage Reliability Study Results for New and Complex Schemas
J. L. Phillips, NCDB

- 63 The 2011 Collaborative Stage Reliability Study Results, Summary and Future Plans
L. Douglas, CDC/NPCR

Section B:

ASSESSING COLLABORATIVE STAGE

GALLERIA II

Moderator: M Adamo

- 64 Assessing Completeness of CSv2 Site Specific Factor Data Items in Louisiana
V. W. Chen, Louisiana Tumor Registry, Louisiana State University Health Sciences Center School of Public Health
- 65 Data Quality Assessment of CSV1 in Canada: Building a Bridge to CSV2
K. Boyuk, Cancer Care Nova Scotia
- 66 Evaluating Unknown Stage by Collaborative Staging Components and Surgery Status for Colon Cancer - NAACCR Data Assessment Workgroup
M. C. Hsieh, Louisiana Tumor Registry
- 67 Template Assessing Data Quality for CINA Deluxe
*B. Wohler, Florida Cancer Data System
(Presenter TBD)*

Section C:

TRENDS IN CANCER INCIDENCE AND MORTALITY

GALLERIA III

Moderator: D Nishri

- 68 Cancers with Increasing Incidence Trends in the United States: 1999 - 2008
E. Simard, American Cancer Society
- 69 Examining the Rise of Kidney Cancer Incidence Rates Based on Tumor Size in SEER 9 (1983-2008)
J. Chotalia, Louisiana Tumor Registry



70 The Effect of Changing Hysterectomy Prevalence on Trends in Endometrial Cancer, SEER 1992-2008
A.M. Noone, NCI

71 Trends in Endometrial Cancer Incidence, Mortality, and Survival by Race and Histology with an Adjustment for the Prevalence of Hysterectomy, SEER 1992-2008
P. Jamison, NCI/SEER

Section D:

ANALYTIC EPIDEMIOLOGY III

BROADWAY I AND II

Moderator: *L. Biazio*

72 Sociodemographic Factors Predicting Non-Receipt of Guideline-Concordant Chemotherapy Among Locoregional Breast Cancer Women Under Age 70 Years
X.C. Wu, Louisiana Tumor Registry/School of Public Health, LSU Health Sciences Center

73 Update of the Burden of Potentially HPV-Associated Cancers in the United States: 2004-2008
X. C. Wu, Louisiana Tumor Registry/School of Public Health, LSU Health Sciences Center

74 Demographic Predictors of Delayed Stage Colorectal Cancer Diagnosis in California, 2004-2008
J. W. Morgan, Loma Linda University School of Public Health

75 Associations of Colorectal Cancer Incidence and Mortality Rates by Poverty and Urbanization in Georgia
V. Davis, Georgia Comprehensive Cancer Registry

Section E:

DATA INTEGRATION AND UTILIZATION

BROADWAY III AND IV

Moderator: *N. Lozon*

76 The Death Clearance Process: What Do We Gain From Our Efforts?
M.J. Schymura, New York State Cancer Registry

77 Rapid Quality Reporting System: Real-Time Use of Cancer Registry Systems to Monitor the Quality of Cancer Care
A.K. Stewart, American College of Surgeons

78 Using Text Fields to Determine Out of State Diagnoses in Central Cancer Registries
L. Soloway, New York State Cancer Registry

79 The Saskatchewan Cancer Registry: Uses, Opportunities and Challenges
G. Narasimhan, Epidemiology Department, Saskatchewan Cancer Agency

11:45 - 12:30 pm Poster Viewing / Exhibits
GRAND BALLROOM AND PARLORS

11:45 am - 12:45 pm Lunch (on your own)

12:30 pm All Posters must be removed from boards

12:30 - 1:30 pm Exhibits and Poster Tear Down
GRAND BALLROOM AND PARLORS

Plenary Session #5

PAVILION BALLROOM

Moderator: *Maureen MacIntyre, MHSA*
(*NAACCR Board President, CancerCare Nova Scotia*)

12:45 pm - 1:45 pm Future of Collaborative Stage: Interactive Panel Discussion

1:45 pm - 2:00 pm Break

Concurrent Session #5

2:00 - 3:30 pm

Section A:

INITIATIVES IN INFORMATICS

GALLERIA I

Moderator: *M. Green*

80 Automated Cancer Data Extraction and Rapid Case Ascertainment from Text-Based Electronic Pathology Reports
G. Cernile, Artificial Intelligence In Medicine, Inc.

81 Standardizing Cancer Pathology Reporting: Promoting Interoperability Through Collaboration
A. Kwiatkowski, Canadian Partnership Against Cancer

82 Using Claims to Capture Missing Hematologic Malignancies from Community Oncology Providers
L. T. Penberthy, VCU Massey Cancer Center

83 Interoperability Between the CAP Electronic Cancer Checklists (eCC) and Collaborative Staging (CS)
R. Moldwin, College of American Pathologists

Section B:

CAPTURING INFORMATION FROM ELECTRONIC REPORTING SOURCES

GALLERIA II

Moderator: *M J King*

84 Capturing EMR Data for Cancer Care Research and Validation of Registry Data: A Florida Case Study
M. Hernandez, Florida Cancer Data System, University of Miami, Miller School of Medicine

85 A New Approach: Using Electronic Health Records to Capture Unreported Cases and Missing Data
J. Jackson-Thompson, University of Missouri

86 XML - How it Impacts NAACCR
R. Pinder, USC School of Medicine

- 87 National Program of Cancer Registries - Meaningful Use (MU) of Electronic Health Records (EHRs): Clinic/Physician Office (CPO) Reporting to Registries
W. Blumenthal, Centers for Disease Control and Prevention

Section C:
ANALYTIC EPIDEMIOLOGY IV

GALLERIA III

Moderator: E Candido

- 88 Survival of Patients with Hematological Malignancies in Sweden
P. W. Dickman, Karolinska Institutet
- 89 Building New Data Bridges - Opioid Use Among Nova Scotia Cancer Patients
G. Walsh, Cancer Care Nova Scotia
- 90 Using the Standard Incidence Ratio (SIR) to Investigate a Potential Link between Cancer Incidence and a Chemical Spill in North Pole, Alaska
D. K. O'Brien, Alaska Cancer Registry
- 91 Cancer Among Hispanics in New Mexico, 1981-2008
A. Meisner, New Mexico Tumor Registry, University of New Mexico

Section D:
USING DATA FOR CANCER PREVENTION AND CONTROL

BROADWAY I AND II

Moderator: R Rycroft

- 92 Innovative Uses of Cancer Registry Data: Estimating the Number Of Young Breast Cancer Patients at Risk Of Infertility Due to Cancer Treatments
A.K. Fink, ICF International
- 93 Data Integration and Utilization at the Markey Cancer Center
T.S. Gal, Kentucky Cancer Registry
- 94 Overview of Small Cell Prostate Cancer in the United States: Its Incidence, Clinicopathological Characteristics and Survival
L. Sun, NCI
- 95 The New Unified Cancer Registration Service for England
A. Murphy, Cambridge University Hospital

Section E:
RESULTS OF OUR EFFORTS

BROADWAY III AND IV

Moderator: R Otto

- 96 Comparative Analysis of Stage and Other Prognostic Factors among Urethral, Ureteral, and Renal Pelvis Malignant Tumors
S. Negoita, Westat

- 97 Is Reporting of PV & RHDs from Non-Hospital Settings Essential?
S. Lai, University of Kansas Medical Center; Kansas Cancer Registry

- 98 Cancer Risk in a Hospitalized Cohort of Patients with Systemic Sclerosis in California
A. Parikh-Patel, California Cancer Registry - Public Health Institute

- 99 A New Approach for Accurately Projecting the Future Burden of Cancer
M.C. Otterstatter, Public Health Agency of Canada

3:30 pm - 3:45 pm Break
PAVILION BALLROOM

3:45 pm - 4:30 pm NAACCR Showcase
The NAACCR Showcase will highlight current NAACCR projects and upcoming innovative work of The Association.
Moderator: Betsy A. Kohler
NAACCR Executive Director
PAVILION BALLROOM

NAACCR Geocoder
Daniel W. Goloberg, PhD
University of Southern California
Using NAACCR Data to Identify Cancer Disparities
Thomas C. Tucker, PhD, MPH
Kentucky Cancer Registry
PAVILION BALLROOM

4:30 pm - 4:45 pm Invitation to 2013 Conference
Melanie Williams, PhD
Texas Cancer Registry

4:45 pm - 5:00 pm Closing Remarks
Donald Shipley, MS
(Cancer Control Program Manager
Oregon Public Health Division)
PAVILION BALLROOM

5:00 pm Adjournment for the Day

FRIDAY, JUNE 8

POST-CONFERENCE

9:00 am - 3:00 pm Using Census 2010/American Community Survey Data for Cancer Surveillance
NAACCR GIS Committee
BROADWAY I

NAACCR
2012 CONFERENCE
poster listing



Poster Listing

POSTERS

- P-01** Modeling Reporting Delay in the NPCR Data
X Dong
- P-02** Defining the Burden of Cancer among Small Asian Populations in Wisconsin
M Foote
- P-03** The Impact of Veterans Affairs Cancer Reporting in New Hampshire
B Riddle
- P-04** Prevalence of Comorbid Medical Conditions among Elderly Colorectal Cancer Patients in the National Cancer Data Base and the SEER-Medicare Database
C Lin
- P-05** Use of the Collaborative Stage Data Collection System in Survival Analyses: An Initial Review
AK Stewart
- P-06** How Data Collection Cycle Affects Survival Calculations
JL Phillips
- P-07** Linking Cancer Registry Data to Perform Outcomes-Based Comparative Effectiveness Research (CER)—Florida, 2011
J Feldman
- P-08** CCR versus NAACCR: Bridging the Gap with Standard Setters
G Noonan
- P-10** Expanding Cancer Registry Data Collection for Comparative Effectiveness Research: Logistical Issues
MO Celaya
- P-11** Development of an Automated Consolidation Algorithm to Resolve Inconsistent Dates of Diagnosis from Multiple Sources
X Zhang
- P-12** Missing Stage Information for Prostate Cancer Cases – Too Much Reliance on Collaborative Stage?
MJ Schymura
- P-13** Borderline Ovarian Tumors – to Collect or Not to Collect?
MJ Schymura
- P-14** Rates and Recent Trends in Squamous Cell Carcinomas of the Lip, U.S.
J Cleveland
- P-15** Enhancing Cancer Registries for Comparative Effectiveness Research: A CDC/NPCR Approach
D Butterworth
- P-16** Do Not Contact Me! Characteristics of Cancer Patients Refusing Registry Contact
J Harrell
- P-17** Insights into Brain and CNS Tumor Epidemiology among the Chronologically Advantaged in the US Population
TA Dolecek



- P-18** Progressing Towards 21st Century Informatics Innovation in New Brunswick Canada – EHR & Cancer Registry
S Leonfellner
- P-19** Estimating the Costs of a Data Breach: An Exercise at the New Hampshire State Cancer Registry
B Riddle
- P-20** Baseline Evaluation of Pathology Report Completeness and Format on Breast, Lung, Colorectal and Prostate Cancer Specimens in New Brunswick 2007-2008
S Leonfellner
- P-21** Health Indicators for Nova Scotia First Nations Communities: the Tui'kn Initiative
R Dewar
- P-22** Obesity and Cancer in Massachusetts, 2005-2009
A MacMillan
- P-23** Reporting Practices and Challenges from Non-Hospital Facilities and Physicians for Death Follow Back of Death Clearance in Maryland
W Ross
- P-24** Health-Adjusted Age Tool to Inform Age to Stop Screening
H Cho

- P-25** Developing a National Interstate Data Exchange Application System (N-IDEAS) for NPCR: A CMMI Approach
K Zhang
- P-26** Linking Data from the National Health Interview Survey (NHIS) and the Florida Cancer Data System (FCDS): Project Update
LA McClure
- P-27** Finding a Path to Becoming a Survival Registry
N Cole
- P-28** Which County is it? When Reported County Does Not Match Geocoded County
RL Sherman
- P-30** Non Small Cell Lung Cancer (NSCLC) Incidence Rates, Treatments and Survival Based on Tumor Size: A Comparative Analysis for State of Louisiana (LA) to the Rest of the United States (RON)
J Chotalia
- P-31** Public Health Surveillance and Research: Evolution of the Cancer Registry Data Set
I Zachary
- P-32** A Revised SAS Macro for Computing the Charlson Score
MR Stedman
- P-33** Receipt of Breast Cancer Treatment among White and Black Medicare Beneficiaries
A White



- | | |
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| <p>P-34 Building Bridges - the CBTRUS Experience with Advocacy Organizations
<i>C Kruchko</i></p> <p>P-35 Electronic Pathology Project in North Carolina Central Cancer Registry
<i>J Bostic</i></p> <p>P-36 Data Quality Evaluation Using MART Guided Generalized Linear Mixed Model – with Application to Evaluate the SEER Cancer Staging Data
<i>Y Fan</i></p> <p>P-37 State-Specific Endometrial Cancer Incidence Rates Corrected for Hysterectomy Prevalence
<i>R Siegel</i></p> | <p>P-38 Utah Cancer Small Area Report, 2011: On the Road to Improved Collaboration and Where Cancer Registries, Cancer Surveillance, and Public Health Intersect for Cancer Control and Prevention
<i>M Balough</i></p> <p>P-39 Receipt of Guideline-Recommended Work-Up among Breast Cancer Patients in Louisiana
<i>XR Li</i></p> <p>P-40 Using Population-Based Cancer Surveillance and Vital Records to Document Improved Outcomes for Multiple Myeloma
<i>CL Wiggins</i></p> <p>P-41 Spatial Cluster Analysis of Female Breast Diagnosis in Missouri: Using GIS and Spatial Analyst Functions
<i>F Williams</i></p> |
|--|--|



NAACCR
2012 CONFERENCE

oral abstracts

concurrent session 1



01

**CANCER REGISTRY GEOCODING SERVICES
STANDARDIZATION**

D Goldberg,¹ C Kosary,² C May,³ B Kohler,⁴ J Whitley⁴

¹University of Southern California, Los Angeles, CA; ²National Cancer Institute, Bethesda, MD; ³Information Management Services, Silver Spring, MD; ⁴North American Association of Central Cancer Registries, Springfield, IL

Geocoding is a critical tool used in cancer surveillance and control activities because it provides the geographic context within which researchers and policy-makers can investigate how environment and socio-demographic characteristics of populations and services are associated with human health outcomes. Historically, the geocoding process has been performed by each individual registry using a variety of in-house custom-built or commercial tools without a single set of consistent geocoding methods or reference data sources. The unfortunate result of this scenario is that geocoded data consolidated at regional and national levels are of widely varying quality and may be in some cases incomparable. This talk will describe the efforts currently underway by the University of Southern California, NAACCR, NCI, and IMS aimed at addressing these challenges through the development and deployment of a standardized and freely-available geocoding system provided for NAACCR registries.

Notes _____

02

ACCURACY AND PRECISION OF THE NAACCR GEOCODER
R Sherman,¹ D Lee¹

¹University of Miami, Miami, FL

Cancer maps are a useful and popular tool for aiding public health policy and for targeting public health activities to areas of high need. However, public health practitioners often focus solely on the map and subsequent results rather than on the quality of the underlying, geocoded data. Despite geocoding documentation stating 100% match at the street level, it is imprudent to assume the result is error free. The geocoding process is subject to uncertainty because error can be introduced at any of the multiple steps. Currently, there is no standard metric for describing the quality of a geocode and often even the simplest, the geocoding match rate, is unreported in the published articles. NAACCR uses items #365 and #366 (Census Tract Certainty and GIS Coordinate Quality) to guide researchers on the quality of individual geocode cases. But the hierarchy assumption of these variables, e.g. that a street level match is always more precise than a zip code level match, does not always apply. NAACCR is currently unveiling a free geocoder available through MyNAACCR to enable standardization of geocoding among the central cancer registries. This system was tested for accuracy against a test set of Florida cancer cases as well as an environmental data set with known longitude/latitudes determined by GPS. The accuracy of the NAACCR geocoder is compared to a national fee-for-service geocoder. Because the NAACCR geocoder is not proprietary, the cancer surveillance community will have some leverage in determining the type and extent of the meta data returned with each geocode. One available metric which describes the distance the case lies within, for instance the geographic size of the zip code, is compared to the known locations from the environmental data set used for testing. The applicability and implications for use of this geocoding quality metric in cancer research will be discussed.

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03

A GOOGLE MAPS MASHUP FOR CANCER CASE GEOCODING

F Boscoe,¹ D Goldberg²

¹New York State Cancer Registry, Albany, NY; ²University of Southern California, Los Angeles, CA

Many free map-based web sites are available that can assist in the geocoding of cancer cases. Typically these sites do not return the census information (namely, tract and block) that is collected by central cancer registries. Using the Google Maps application programming interface (API), we developed a web site ‘mashup’ to perform this function. We constructed polygons for each census block in New York State from the 2010 Census TIGER files, and superimposed these onto the standard Google Maps view. Upon locating a residence on the map, users can click to see the county, town, tract, block group, block, and latitude/longitude coordinates of the location. An additional keystroke pastes these values directly into the New York State Cancer Registry database. This ‘mashup’ is best suited for geocoding cases that did not geocode through an automated process but that have some useable address information, or in instances where it is imperative to have an accurate rooftop location, such as studies of environmental exposures. It also is a useful geographic reference tool generally, and could be adapted to locate school districts, legislative districts, city wards and precincts, or any other kind of geographic area.

Notes _____

04

STRATEGIES FOR INCREASING GEOCODING ACCURACY

D Rust¹

¹Kentucky Cancer Registry, Lexington, Kentucky

Geocoding is a method of defining geographical coordinates, latitude and longitude, given street addresses or postal codes. The geolocation of patient addresses at diagnosis provides important information for cancer surveillance and cancer control. To obtain this geodata the Kentucky Cancer Registry (KCR) uses Envinsa, a geocoder, to geocode patient addresses; however, because of the rural nature of Kentucky, a significant proportion of patient mailing addresses obtained from medical records cannot be geocoded to a street level geolocation. Due to the high population in rural areas, geocoding strategies tend to fail at retrieving accurate results of approximately 28% of Kentucky cancer cases. A significant issue is the availability of PO Box mailing addresses instead of street addresses. Lastly, typographical errors and misspellings can degrade the ability to accurately geocode records. The inaccurate reporting of patient addresses is a significant challenge to the geocoding process. The KCR is employing a number of strategies to overcome these pitfalls and retrieve more accurate geocoding data. Following the lead of the Atlanta SEER Registry, the KCR has obtained voter registration files that include both mailing and residential addresses for all registered voters. Link Plus, a CDC record linkage software, is used to match patient addresses with voter registration mailing addresses. For matching patients KCR geocodes voter registration residential addresses. Using this method the KCR was able to increase rural geocoding accuracy by 2-3%. The KCR has also implemented Melissa Data geocoding service, and it was able to geolocate addresses Envinsa could not. Melissa Data also provides an address scrubbing application which standardizes addresses according to USPS standards and corrects certain typographical errors and misspellings. Utilizing such strategies allows cancer registries to continue to be supported by reliable geolocation data.

Notes _____

05

TOWARD ACHIEVING MORE COMPLETE TREATMENT INFORMATION-WHAT CAN BE OBTAINED FROM RESUBMITTED HOSPITAL DATA?

A Kahn,¹ T Hinman,¹ C Sherman,¹ M Schymura¹
¹NYS Cancer Registry, Albany, NY

In an effort to reduce the rate of cases with unknown treatment information, and improve the quality and accuracy of first course treatment data, the New York State Cancer Registry (NYSCR) requested hospitals to resubmit abstracts for 2008 and 2009 analytic cases. Resubmitted abstracts were received in June 2011, accounting for approximately 70% of the initial 2008 and 2009 hospital submissions. Most (80%) resubmissions were from Commission on Cancer (CoC)-accredited facilities. Resubmitted abstracts were matched to original reports on facility ID, patient accession number, name and birth date. Approximately 30% of resubmitted abstracts contained treatment information not originally reported, mainly in the areas of radiation treatment, chemotherapy, and hormone therapy. Almost 40% (n=3,131) of resubmitted records that originally reported radiation therapy as recommended were updated to specific codes for either type of radiation or reason for no radiation. Close to 3% (n=3,972) of records that originally reported none or unknown chemotherapy were updated to specific chemotherapy codes or to codes indicating why chemotherapy was not administered. The percent of records indicating that hormone therapy had been administered increased from 9.7% to 12.3%. Cancers of the prostate, breast, lung, thyroid and bone marrow were most affected. The impact on consolidated information was less dramatic, due to reporting from multiple facilities per case. The percent of cases with totally unknown treatment values was not impacted since these are cases with lab only, death certificate only, or physician office only reports.

Conclusions: Additional first course treatment information is obtained in the resubmission process. Most changes were found in the reporting of chemotherapy, hormone therapy, or radiation treatment.

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06

CANCER REPORTING FROM RADIATION TREATMENT CENTERS

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If trends of the past decade are at all predictive of things to come, we will be seeing a revolution in cancer reporting technologies in the near future. Although central cancer registries might eventually retrieve all data from ‘the cloud’, we are not there yet. We are faced with collecting as much information as possible from various types of facilities while trying to minimize the impact on those facilities and on our own registries. The New York State Cancer Registry (NYSCR) has been receiving data electronically, in the NAACCR Volume II standard format, from standalone treatment facilities. But it has been difficult to apply hospital reporting requirements to non-hospital facilities. This is likely due to a lack of comprehensive information in the facilities’ medical records and/or the absence of highly-trained registrars in the non-hospital setting. NYSCR and C/NET Solutions are examining what information is available at radiation treatment centers and how this information can best be collected, edited, and transmitted to the central registry.

Methods: We will examine medical records currently in use at several standalone facilities, selected to be representative in terms of patient load and software support. We will compare the information contained in the records to the set of data items currently required by the National Program of Cancer Registries, for certification by NAACCR, and for inclusion in Cancer in North America. We will also analyze the impact of applying standard data quality edits to these records. We will summarize our findings and present recommendations for a standard (interim) model for cancer reporting from such facilities.

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07

PRO-ACTIVE REPORTING OF PHYSICIAN MEDICAL CLAIMS DATA: CAPTURING COMPLETE TREATMENT DATA AND IDENTIFYING PHYSICIAN OFFICE MISSED CASES.

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Background: As a result in the change in the diagnosis and management of some cancers, a growing number of cancer cases are not entering a hospital setting therefore these cancers and complete first course treatment may be missing. The solution used in Florida is to capture data directly from the attending physician. Florida has over 900 licensed ‘Oncology’ physicians, making this a challenging operation.

Methods: Florida, using a modified version of an automated software system for processing billing data which uses a validated methodology to capture coded data directly from the private physician’s office allowing for the incorporation of the expanded treatment data into the statewide surveillance system. Using funding from the CDC’s Comparative Effectiveness Research has allowed FCDS to develop this methodology. Florida physicians submit a copy of their ‘837’ medical billing claim to FCDS immediately after they submit the claim to the insurance company for processing. The claims data are uploaded to the FCDS via an SSL connection and processed through the *MD Office Automated Software*. The software consolidates the person/tumor data, parses the 837 data into 56 specific NAACCR fields, crosswalks the CPT, HCPCS and ICD9 codes into NAACCR standards and creates a NAACCR record. The output NAACCR record is uploaded to the FCDS system and will either augment an existing record or creates a new record if the person/tumor does not exist.

Results: Automated capture of billing data from community oncology practices offers an opportunity to efficiently and effectively supplement critical missing data for cancer surveillance-treatment provided in the outpatient setting. The use of such data offers an incentive for physicians to participate through automating the follow up process for them, and offering the opportunity to monitor key quality indicators, thus making such reporting a collaborative effort between practices and the central registry.

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08

VALIDATION OF SEER TREATMENT DATA USING MEDICARE CLAIMS

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Background: The Surveillance, Epidemiology, and End Results (SEER) program is committed to providing high quality data for cancer research. As more patients receive cancer treatment in the outpatient setting, the collection of complete treatment data is becoming increasingly difficult. The linkage of SEER data to Medicare claims provides an opportunity to validate and assess the completeness of cancer treatment information collected by SEER using the health claims for Medicare beneficiaries as the gold standard. This analysis evaluates the completeness and validity of chemotherapy and radiation therapy data collected by SEER for 7 major cancers and of hormone therapy data for prostate cancer.

Methods: Patients age 65 years or older and diagnosed with breast, prostate, colorectal, pancreas, lung, ovary or bladder cancer from 2000 to 2006 were included from SEER data. Treatment from SEER was dichotomized (Yes vs. No). Treatment from Medicare was determined by at least one claim for treatment within 12 months after diagnosis. Sensitivity, specificity, positive predictive value (PPV) and negative predictive value (NPV) were calculated to quantify the concordance between SEER and Medicare using Medicare as the gold standard.

Results: The sensitivity of SEER data to identify treatment was higher for radiation therapy compared to chemotherapy or hormone therapy. Specifically, the sensitivity to identify chemotherapy was 68%, radiation therapy was 79%, and hormone therapy (prostate only) was 69%. The sensitivity varied by tumor type and patient characteristics. For all treatment types, the PPV was high indicating that among patients identified as having received treatment in SEER the majority also had Medicare claims (Chemotherapy: 90%, Radiation: 95%, Hormone: 86%).

Conclusion: This analysis provided measures of completeness and validity of SEER treatment data. These measures will inform SEER data release policy and whether these data should be used in studies.

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09

ESTIMATING PROBABILITY OF DEATH FOR CANCER PATIENTS: IN PRESENCE OF COMPETING RISKS

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Background: Prognosis is the most sought after measure following the diagnosis of cancer. The readily available prognosis measures from cancer registry data are generated as the five-year survival probability based on the relative survival (RS) method. For patients, however, survival probability produced by the RS method has diminishing value as competing causes of death (e.g., heart disease, diabetes) are not accounted for in the calculation.

Objective: We propose to calculate 5-year probability of death from a given cancer, death from causes other than cancer (i.e., other causes) in conjunction with overall survival probability stratified by age and stage at diagnosis for leading cancers in the US. Subgroup analysis by comorbid conditions for the older adults (age 75-84) will also be presented.

Method: We used registry data from the Surveillance, Epidemiology, and End Results (SEER) Program. The analysis cohort included patients with malignant cancer diagnosed from 2001-2007 where the last day of follow-up was December 31, 2008. The life-table method was used for calculation.

Result: For localized screen detected cancers such as female breast, the probability of death from cancer is low compared to that of other causes (e.g. In 65-74 year-olds, probability of breast cancer death was 1% vs. 10% for other-causes). However for distant stage, probability of death due to breast cancer remains high regardless of age at diagnosis. For cancers with poor prognosis such as lung cancers, other causes play less of a role on the mortality rates, as death due to cancer is high.

Conclusion: Probability of death from cancer compared to other causes varies substantially by cancer type, age, stage, and comorbid conditions. Because people live in the presence of other causes of death, providing statistics to understand the risks posed by cancer and by competing comorbidities is important to help treatment decisions.

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11

ESTIMATING THE LOSS IN EXPECTATION OF LIFE DUE TO CANCER USING FLEXIBLE PARAMETRIC SURVIVAL MODELS

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A useful summary measure for survival data is the expectation of life, which can be calculated by obtaining the area under a survival curve. The loss in expectation of life is the difference between the expectation of life in the general population and the expectation of life in a diseased population. This measure is used little in practice as its estimation generally requires extrapolation of both the expected (general-population) survival and the observed survival (of the cancer patients).

The extrapolation of the expected survival is fairly straightforward, but assumptions have to be made for the observed survival. One way is to assume a parametric distribution for the observed survival, but it is difficult to find a statistical distribution that captures the underlying shape of the survival function. An alternative is to make assumptions for the relative survival, by assuming that the excess mortality has reached zero (statistical cure) or has stabilized to a constant. The extrapolation using relative survival is more stable and reliable. Hakama and Hakulinen showed how this could be done for life tables. By using a flexible parametric approach for estimating the excess mortality we can estimate the loss in expectation of life for individual level data.

We have evaluated our extrapolation approach using Swedish data and results agree well with observed data. Results will be presented for a variety of cancer sites. We are developing user friendly software to enable estimation of the loss in expectation of life.

The loss in expectation of life provides a measure of the impact a cancer has on society, is useful for measuring cancer control progress and for resource allocation in cancer prevention and control. This easily-interpretable measure is rarely reported because it is not available in software commonly used for relative survival analysis. We believe this measure should be routinely reported and with the availability of our software, we hope it will be.

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12

RELATIVE SURVIVAL OF COLORECTAL AND BREAST CANCER CASES IN MAINE

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Maine has higher overall age-adjusted cancer incidence and mortality rates compared to other states¹. There is an existing gap in knowledge about the survival of cancer patients in Maine. The Maine Cancer Registry linked with NDI for the first time in 2011 and thus felt ready for a study of survival. In this study we calculated 5-year relative survival (RS) rates for colorectal cancer (CRC) and female breast cancer. We focused on these cancers due to the availability of standards for screening and treatment. We explored geographic and age-specific variation in 5-year RS rate. We included 2,263 CRC and 6,270 female breast cancer patients with 'in situ' or 'local' stage (grouped as 'early stage') by 2000 SEER Summary staging system during 1/1/2001 to 12/31/2008. We calculated 5-year RS rates of these cancer patients using SEER*Stat (Ver.7.0.5). Survival analysis was stratified by public health district and age at diagnosis. We found that early stage CRC patients in the Midcoast health district had almost 50% higher 5-year RS rate compared to patients in the Western health district. Also, the 5-year RS was higher among early stage CRC patients under 65 years old at diagnosis compared to those 65 years and above, but the difference was not statistically significant. Females with early stage breast cancer from the Midcoast district had 25% higher 5-year RS rate compared to those from the Downeast district although this was not statistically significant. However, females with early stage breast cancer and less than 65 years old at diagnosis had significantly higher [74% (67.9% - 78.8%)] 5-year RS compared to those aged 65 years and above [59% (52.9% - 64.2%)]. Geographic location at the time of diagnosis had significant influence on 5-year RS of early stage CRC patients. Age at diagnosis played an important role in 5-year RS rate of early stage female breast cancer patients in Maine. ¹ 1999 - 2008 Cancer Incidence, CDC WONDER Online Database; 2011.

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13

UNSTAGED CANCER IN THE UNITED STATES: A POPULATION-BASED LOOK AT DEMOGRAPHIC, SOCIOECONOMIC, AND GEOGRAPHIC VARIABLES AS PREDICTORS OF STAGING

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Background: Investigators typically group unstaged cancers with late stage cancers, but unstaged cancers not follow the same patterns as staged cancers. Little is known about the characteristics of patients who have cancers that are unstaged at diagnosis. **Purpose:** The aim of this study was to identify the demographic, socioeconomic, and geographic factors that are associated with the likelihood of being unstaged at diagnosis. **Methods:** Analysis was conducted on SEER 12 data for cancers diagnosed from 1992-2008. A total of 2,241,829 cancers were examined, of which 134,552 (6%) were unstaged. A logistic regression model analyzed the likelihood of having an unstaged cancer when controlling for socioeconomic, geographic, and demographic variables. A principal component was calculated to control for socioeconomic status (SES) at the county level. **Results:** Males were more likely than females to have cancers that were unstaged at diagnosis (OR=1.35, 95% CI: 1.33-1.37). Hispanic whites more likely to be unstaged at diagnosis compared to non-Hispanic whites (OR=1.28 95% CI: 1.25-1.31). Relative to non-Hispanic whites, African Americans (OR=1.30, 95% CI: 1.28-1.33), Asians (OR=1.34, 95% CI: 1.31-1.37), and American Indians (OR=1.25, 95% CI: 1.15-1.37) were all more likely to be unstaged. Individuals living in rural (OR=1.16, 95% CI: 1.10-1.22) or urban (OR=1.11, 95% CI: 1.08-1.14) counties were more likely to not be staged at diagnosis compared to those living in metropolitan counties. People living in counties with the lowest SES were more likely to be unstaged at diagnosis compared to those living in counties with the highest SES (OR=1.30, 95% CI: 1.28-1.32). **Conclusion:** Individuals who have cancers that are unstaged at diagnosis vary from individuals diagnosed with staged cancers, and investigators should evaluate these differences before combining or removing these cases for analysis.

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14

LINKING THE 1991 CENSUS TO THE CANADIAN CANCER REGISTRY TO ADVANCE KNOWLEDGE ABOUT CANCER IN FIRST NATIONS AND MÉTIS ADULTS IN CANADA

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Background: There is a paucity of information about cancer burden in First Nations and Métis people in Canada. A study of cancer in Ontario First Nations people showed rising incidence rates and poor survival, but there are no comparable data for Canada as a whole.

Purpose: To estimate cancer incidence and survival in First Nations and Métis (FNM) people compared to non-Aboriginal Canadians over the period 1992-2008.

Methods: A cohort of adults aged 25+ in the 1991 Long Form (about 15% of the population) Census of Canada was probabilistically linked to the Canadian Cancer Registry (1992 to 2003). Mortality data (1991 to 2006) have been linked previously. The linked sample (to be updated to 2008 data) will be used to estimate and compare cancer incidence rates in First Nations, Métis and non-Aboriginal Canadians by region of Canada, age group, sex and type of cancer. The number of strata will depend on sample size for individual cancers and populations. Population-specific 5-year relative survival will be estimated using life tables created from the linked file.

Results: There are about 62,000 adults who reported either FN ancestry or are registered under the Indian Act of Canada and 12,000 who reported Métis ancestry in the census sample, along with 2.6 million non-Aboriginal Canadian adults. We expect 5000 cancers in FN and 1000 in Métis over the 17 year follow-up period.

Conclusions: Analysis will be conducted over the next 6 months and preliminary results will be available for presentation.

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15

A NOVEL METHOD FOR MULTIPLE MEDIATION ANALYSIS– WITH APPLICATION TO ANALYZE RACIAL DISPARITY IN BREAST CANCER MORTALITY

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Background: Multiple regression models have been used to identify factors associated with specific disease outcomes. Although ORs describe the strength of association (relative risk) for each factor, the contribution from individual factors has not been widely measured because of methodology challenges in mediation analysis with nonlinear models, multiple mediators and various types of variables. The objective of this study was to apply our newly developed statistical method on cancer registry data to explore contributive factors to racial disparity in breast cancer mortality.

Methods: We proposed the measurement methods for total effect (TE), direct effect (DE) as well as indirect effect (IE). The relative mediation effect (RE) was defined as a ratio of indirect effect for each mediator over total effect (i.e., . We applied the method to 1,374 breast cancer cases from a pattern of care study. The outcome variable was all causes of death (alive, death) at the end of 3rd year after diagnosis, and explanatory variables were race, age at diagnosis, insurance status, marital status, tumor stage, grade, tumor size, comorbidity, surgery, radiation, chemotherapy, and receptors-specific hormonal therapy.

Result: Receptor-specific hormonal therapy (RE=40.8%, p<.0001), insurance status (RE=24.5%, p=0.025), stage (RE=23.9%, p=0.006), and tumor size (RE=20.9%, p=0.01) as well as age (RE=-18%, p=0.016) had a significant mediation effect on the relationship between race and the mortality.

Conclusion: Difference in receptor-specific hormonal therapy explained the majority of racial differences on the mortality. Higher mortality among blacks than whites were also attributable to large tumor size, late stage diagnosis, as well as insurance status.

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16

A COMPOSITE INDEX OF SOCIOECONOMIC STATUS FOR CONTROLLING THE CONFIDENTIALITY OF CANCER REGISTRY DATA

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Despite the increasing need for socioeconomic status (SES) data to describe cancer health disparities, this information is not routinely available from cancer registries. A promising alternative is to use measures based on social and economic aspects of the area in which a patient resides. For the Surveillance, Epidemiology, and End Results (SEER) Program data, the lowest level of geography for which these measures are available is census tract. Although they are the preferred bases of SES measures, the risks of disclosing the census tract in which a patient resides, and consequently the identity of a patient is high when releasing as few as three census tract measures in addition to the information already made available, such as demographics and county of residence. A single composite SES index has the potential advantage of providing comprehensive summary of the multidimensional nature of SES without incurring additional risk of disclosure. The authors constructed two composite SES indices based on SES measures identified in Krieger et al. (2002) and Yost et al.(2001) separately to investigate their associations with the incidence and survival of primary cancers. Using factor analysis each index was constructed at two time points for SEER 17 areas using census tract data from 2000 Census Summary File 3 and 2005-2009 American Community Survey 5-Year estimates. Analyses of overall cause-specific survival and cancer incidence rates as well as those for each racial groups indicated that the Krieger's and Yost's indices perform similarly and similar gradients were detected with categories generated by quintiles and tertiles.

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17

ENHANCING CANCER REGISTRIES FOR COMPARATIVE EFFECTIVENESS RESEARCH: DEVELOPMENT OF AN INFRASTRUCTURE FOR DATA COLLECTION

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Introduction: The National Program of Cancer Registries received American Recovery and Reinvestment Act (ARRA) funding to create specialized cancer registries (SCR) with enhanced data collection to address comparative effectiveness research questions. **Objective:** To develop methodology and create an infrastructure that could be implemented by the ten SCRs, which were tasked with expanding registry operations to collect data on biomarkers, chemotherapy, hormone therapy and biologic response modifiers. **Methods:** Based on the four key questions related to treatment of breast, colon, and rectum cancers as well as chronic myeloid leukemia, the necessary additional data items were determined and a data dictionary developed. Collaborations between SCRs were established to approach common vendors to customize their software to accommodate additional data items. Training materials were developed and shared between SCRs to train cancer reporters on the new data items. A web-based information sharing portal was developed to facilitate communication and sharing of materials between the SCRs. Procedures for submitting and resolving technical assistance requests were established. Quality control methods were established by the creating of additional edits and consolidation guidelines. **Results:** We will present preliminary data on the collection of the additional data items, including indicators of completeness. Key areas requiring technical assistance and early lessons learned will be discussed. **Implications:** Patient-centered comparative effectiveness research is a growing focus and cancer registries have the potential to play a key role in providing the data for this research.

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PROJECT HAN, A DATA COLLECTION STUDY WITHIN THE HOSPICE, ADULT LIVING AND NURSING HOME COMMUNITY, NC CENTRAL CANCER REGISTRY

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Overview and goals: Through the Death Clearance process we found a large percent of the death certificates indicated the individual expired in the care of Hospice, Adult Living or Nursing Homes. Once the Death Certificate is submitted to the CCR it is approximately two years old. This not only starts the arduous task of requesting information about the case from the HAN facilities but can produce frustration from the facilities being asked or the inability for the facility to produce the information needed. The goal of Project HAN is to reduce the amount of cases coming to Death Clearance from these facilities and, therefore, improve data quality and completeness. Another benefit of the project is to develop a contact list at the facility level as well as create awareness that their information is important to the goals of the CCR and the State of North Carolina.

Communications and training: The process includes contact with State Associations who have collaborated with the CCR to ensure their members understand the goals of and the reasons for the project. Identification of corporate entities who manage multiple sites has enabled the project to move forward quickly and has reduced the initial numbers of communications needed to implement the process.

A Web site was utilized to house an on-line, on-demand training module as well as general information about the project, forms to be utilized for reporting, FAQs, and more.

Expected Outcomes: The CCR expects more complete data, lower Death Clearance numbers and reduced manpower hours to manage the Death Clearance process; improved awareness and communication between the CCR and the HAN facilities; better information on cancer incidence in North Carolina.

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TREATMENT SUMMARIES FOR ALL! AN EXPANDED ROLE FOR CENTRAL CANCER REGISTRIES

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Background: A 2005 Institute of Medicine report highlighted the need for cancer patients to receive a written document outlining treatments they received and plans for future care- a Treatment Summary and Survivorship Care Plan (TS/SCP). Uptake in oncology practices has been slow for numerous reasons, but the growing number of survivors has created a high demand for these documents. The American College of Surgeons (ACoS) 2012 Program Standards now require accredited hospitals to distribute plans to all cancer patients treated in their facilities by 2015.

Purpose: The Colorado Central Cancer Registry (CCCCR) Survivorship Program is an effort to develop TS/SCPs that are pre-populated with clinical data, reducing the time and effort required by oncologists to produce the documents. This project is intended to educate patients, provide concise information to physicians, and assist hospitals with meeting ACoS standards.

Methods: With the assistance of a multidisciplinary advisory board, the CCCR has developed TS/SCPs for breast and colorectal cancer survivors. Data from the cancer registry are uploaded into a modified version of CDC's Web Plus software. Oncologists selected for the pilot log in to complete the documents and then provide them to patients. Program evaluation involved satisfaction surveys of the survivors, oncologists, and PCPs.

Results: The presentation will include a summary of program development, a demo of the new module within Web Plus, and display of the final TS/SCPs. Preliminary data from the satisfaction surveys will also be presented.

Implications: Collaborating with oncology practices to provide TS/SCPs to survivors is an example of how central cancer registries can take on an expanded public health role. Because the infrastructure for this project was built with Web Plus, other state cancer registries will be able to implement this program in their states, thus contributing to the standardization of cancer survivorship care in the U.S.

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DEVELOPING A TRACKING SYSTEM TO ENSURE COMPLETENESS OF CER REQUIRED DATA ITEMS

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The Rhode Island Cancer Registry was one of 10 central cancer registries selected to participate in the Comparative Effectiveness Research Core Activity project designed to create specialized registries that would increase and improve data collection within the NPCR. The project involves the collection of standard and non-standard data items with the focus on breast, colorectal and chronic myeloid leukemia cases diagnosed in 2011. It became apparent that required data items were dispersed in multiple source documents and institutions and that a tracking system would have to be developed to document required data had been collected.

A review of possible data collection methods revealed that the most effective method would be to utilize well trained auditors to begin the initial data collection while hospital and non-hospital data collectors transitioned into collecting non-standard data items. Auditors were selected and trained and underwent a clinical training period using cases on file with the Rhode Island Cancer Registry that were diagnosed in 2009. Collection of 2011 data was begun in July of 2011. However it became apparent that patients enrolled in the project visited multiple hospital and non-hospital treatment centers. In order to maximize the time auditors spent collecting new data it was decided to create a tracking system that would clearly indicate if required data items had been collected, when collection was completed, if collection was no longer required and where treatment was done. It was felt that the use of a data collection tracking system would eliminate time wasted reviewing source documents multiple times that contained no additional information.

The tracking system developed by Comparative Effectiveness Research Core Activity staff provides a mechanism to measure completeness of data collection for required standard and non-standard data items and will eliminate time wasted reviewing source documents multiple times.

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ANALYSIS OF TIME AND EFFORT REQUIRED TO COLLECT DATA FOR 2004 COLLABORATIVE STAGE SITE-SPECIFIC FACTORS

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Background: The objectives of the current study were to examine and quantify the amount of time and effort required to collect data on collaborative stage (CS) site-specific factors (SSF) for six selected cancer sites: breast, prostate, colon/rectum, testes, head and neck and lymphoma.

Methods: Information for each SSF was collected from 40 cancer registrars who were asked to score the degree of difficulty ranging from 1 (lowest) to 5 (highest), identify the main data sources, and estimate the average time required for each variable of interest. The reported degree of difficulty and amount of required time were examined in relation to various registrar and facility-related characteristics. Additional analyses evaluated the association between reported amounts of time and effort and the percentage of missing data in the SEER data for the period 2004-2008.

Results: According to the registrars' reports, data collection for CS SSF requires a median of 2-3 minutes with a range of 1-15 minutes. Variables most commonly reported to be associated with the greatest difficulty of obtaining the necessary information (score ≥4) were International Prognostic Index (SSF3) for lymphoma (80% of responses) and molecular studies of regional lymph nodes (SSF5) for breast cancer (44% of responses). These two variables were among CS SSF with the highest percentage of missing information (90% or more) in the SEER data. Additional analyses evaluating responses according to registrar experience and facility characteristics will be presented.

Conclusions: Our results indicate that for certain CS SSF the amount of effort required for data collection and the proportion of missing data are so high that these variables can be of little use for population-based research. The main reported barrier to data completeness was the availability of information in the medical records. The practical implications of our findings with respect to existing and future CS SSF need to be explored.

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DATA QUALITY CONTROL BY USING SAS ENTERPRISE GUIDE

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Background: The National Program of Cancer Registries Cancer Surveillance System (NPCR-CSS) is designed to collect, process, evaluate, enhance, analyze and disseminate cancer incidence data submitted to CDC by NPCR grantees. In addition, ICF currently also provides support in producing datasets for *United States Cancer Statistics* (USCS). All these activities require strict data quality control procedures. SAS is powerful software used extensively in industry and research. This presentation will demonstrate how the SAS Enterprise Guide 4.2. was implemented in data quality control systems for our Pre-Edit alarming system and the USCS data validation.

Methods: The Pre-Edit Verification system is a SAS-based system that performs an initial validation check on the data submitted by NPCR-CSS grantees. This initial validation check determines the file record layout version, checks the consistency of data variables, identifies disqualifying data elements (such as the data fields for personal identifiers), and provides summary statistics including temporary SAS files, a report and several Excel workbooks. In addition, a data validation system was developed that includes more than 50 individual specifications for the USCS data production.

Both systems were developed by experienced developers by using SAS Enterprise Guide. Since both systems were implemented in SAS Enterprise Guide, it empowered non-technical users with SAS "Guided Analytics", allowing them to manipulate data, create reports and graphs, and conduct ad-hoc analysis, without writing any code.

Conclusion: By using SAS Enterprise Guide, a system was developed to perform sophisticated QC analyses, but also allowed non-technical users do simple data manipulation, statistical analysis, and distribute reports. With the point-and-click interfaces of Enterprise Guide, non-technical QC staff completed many of these tasks on their own and conducted QC analyses more efficiently.

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ALGORITHMS FOR LOGICAL CHECKING MULTIPLE DATA ITEMS IN MONITORING AND IMPROVING DATA QUALITY
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Background and purpose: Availability and accuracy of multiple data items in a given data set are critical for data quality evaluation and scientific study. This presentation introduces a logical checking system aimed to monitor and improve data missing and accuracy.

Materials and Methods: The system was composed of a relational database and a set of algorithms in SQL and SAS categorized and indexed by cancer sites (prostate, breast, colon and lung) and demographics, diagnosis, histology, staging, treatment, follow-up and vital status. SEER 17 research data submitted on 2010 was used for logical data checking. Below are the examples of an application of the algorithm.

Results: Using the diagnosis-staging algorithm, we found that among 262,238 prostate cancer men diagnosed at 2004 and afterwards, 55,497 (21.2%) men were missing all three key data points, PSA, clinical staging and Gleason score, while the availability of these three variables is required in almost all prostate cancer clinical studies. In the same cohort, 43,004 (16.4 %) PSA levels were 0.1 ng/ml or below. Using the logical survival checking algorithm we identified problematic cases with pretreatment PSA <10 ng/ml, biopsy Gleason score <8, diagnostic stage of T1cNOMx and died of prostate cancer within 5 years of diagnosis). These cases should be reviewed. Stratifying the rates of data missing and problematic cases by registry, year at diagnosis, cancer sites and key data items, we can not only provide a case listing to the registry as a data quality reference, but also identify the patterns for missing individual and multiple data, timing patterns (temporary or persistent), and overall data quality evaluation.

Conclusions: This novel approach will improve data monitoring and data quality, and impact many aspects of the cancer registry community, such as design and implementation of the algorithms, analysis on data availability, and targeted training based on data missing patterns.

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ENHANCING DATA QUALITY THROUGH AUTOMATION
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Background: California Cancer Registry (CCR) reduced visual editing of incoming Admissions from 100% to 40%. This required a new approach to verifying the quality of 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 using Class of Case as the key data field for this determination. CTRs developed rule sets to evaluate the Class of Case assignment for each Admission. Programmed code was developed that would auto-correct Class of Case or related fields when specified conditions existed. Auto-correcting Class of Case is the short-term goal, while eventually automating the manual consolidation process is the long-term goal.

Results: Presentation will provide attendees with updates to California's Business Rules Management Solutions (BRMS) rule writing project. Currently, project has implemented Class 49 and Class 38 rule sets. Automation rules for Class 00, 10-30 and 43 are in various stages of development. General automation rules modeled after existing edits have also been developed. Schema specific auto-change rules were developed for three sites with additional sites currently in development. Presentation will provide post-implementation status of the implemented rule sets and discuss future directions.

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WHERE WISCONSIN CANCER PATIENTS DIE: OBSERVATIONS AND PRACTICAL IMPLICATIONS

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Understanding the extent and nature of cancer morbidity in specific populations requires reference to survival and mortality. Central cancer registries link patient records with associated death records. Length of survival, death cause and comorbidities are case attributes for which death certificate data is indispensably informative. Satisfactorily complete and correct patient-decedent matching is a challenge. Consider change, variants and errors in subject identifiers. Improved length of survival increases the possibility that a patient will assume another name (e.g., through marriage or re-marriage) or state of residence (through permanent out-migration.) Furthermore, social and cultural changes such as the increased use of non-hospital hospice programs may contribute to declining rates at which cancer patients die in hospitals (for several reasons an advantageous type of informant for death-certificate-only (DCO) case follow-up by registries.) How far are patient residences at diagnosis from places of death? Can incidence cases be matched with deaths when State of residence changes during survival? How does the changing rate of hospital deaths for cancer patients affect options for DCO follow-up? This presentation will address these issues through a review of death place type and location relative to Wisconsin residences at diagnosis of patients accessioned during the last two decades. The U.S. Center for Health Statistics has customarily returned to the State only records for any decedents characterized by death in Wisconsin or others dying elsewhere if officially regarded as residents of Wisconsin. Patient-decedent linkage has been extended beyond this limit through utilization of the Social Security Death Index. Analysis will be presented concerning the geographical relationship of diagnosis residences relative to death places and types, based on State death files. Implications for improved patient-decedent linkage will also be discussed.

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ESTIMATING EXPECTED SURVIVAL PROBABILITIES FOR RELATIVE SURVIVAL ANALYSIS - EXPLORING THE IMPACT OF INCLUDING CANCER PATIENT MORTALITY FROM THE CALCULATIONS

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Relative survival is a widely used measure of cancer patient survival, defined as the observed survival of the cancer patients divided by the expected survival of a comparable group from the general population, free from the cancer under study. In practice, expected survival is usually calculated from general population life tables. Such estimates are known to be biased since they also include mortality from the cancer patients, but the bias is ignored since mortality among individuals with a specific cancer is thought to constitute only a small proportion of total mortality. Using the computerised population registers that exist in Sweden we had the unique opportunity to calculate expected survival both including and excluding individuals with cancer, and thereby estimate the size of the bias arising from using general population estimates. We also evaluated a simple method to adjust expected survival probabilities estimated from general population statistics as an aid to researchers who do not have access to computerised registers of the entire national population. Our results show that the bias is sufficiently small to be ignorable for most applications, notably for cancers with high or low mortality and for younger age groups. However, the bias in relative survival estimates can be greater than 1 percent unit for older age groups for common cancers and even larger for all sites combined. For example, the bias in 10-year relative survival for men aged 75+ diagnosed with prostate cancer was 2.6 percent units, which we think is of sufficient magnitude to warrant adjustment.

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HOW CAN WE MAKE CANCER SURVIVAL STATISTICS MORE USEFUL FOR PATIENTS AND CLINICIANS – AN APPLICATION USING LOCALIZED PROSTATE CANCER IN SWEDEN

S Eloranta,¹ J Adolfsson,² P C Lambert,^{1,3} P Stattin,^{4,5} O Akre,⁶ T M L Andersson,¹ P W Dickman¹

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Studies of prostate cancer survival typically report statistics that assume patients are immune to death from causes other than cancer. This hypothetical construct is called net survival and is useful for applications such as comparing survival between countries/regions where it is desirable to correct for differences in non-cancer mortality. In a clinical setting, non-cancer deaths are important to consider when communicating prognosis and planning treatment. Our study highlights how estimates of cancer patient survival should be interpreted and discusses why some measures are more relevant to clinicians and patients than others.

We present risk group- and treatment-specific survival among 23,353 men with intermediate or high risk localized prostate cancer using data from the Swedish National Prostate Cancer Register. Crude probabilities of death due to prostate cancer (i.e., accounting for non-cancer deaths) were estimated using flexible parametric models adapted for relative survival. Among patients managed conservatively in the intermediate risk group the proportion estimated to have died from prostate cancer within ten years after diagnosis was 4.6% (95% CI:1.9%-7.4%) for men aged 60 years at diagnosis and 3.9% (95% CI:1.9%-6.0%) for 80-year-olds. In the high risk group the proportions were 17.0% (95% CI:10.4%-23.6%) and 14.4% (95% CI:11.0%-17.8%) respectively. For hormonally treated men in the intermediate risk group, the corresponding proportions were 27.6% (95% CI:20.8%-34.4%) and 12.2% (95% CI:9.0%-15.4%) for the two ages respectively. In the high risk group younger age was even more strongly associated with higher cancer mortality.

We suggest that estimates of crude survival are of greater value for risk communication as they account for non-cancer deaths. Even if such estimates are not available, clinicians should be aware that estimates of net survival are hypothetical construct that need to be interpreted accordingly.

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EVALUATING NAACCR SURVIVAL DATA FOR FITNESS FOR USE

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Background: Population-based cancer survival data can help monitor cancer control activities. The Surveillance, Epidemiology and End Results (SEER) Program routinely link their data with the National Death Index (NDI) to improve death ascertainment. More recently, the National Program of Cancer Registries (NPCR) has begun encouraging NPCR registries to link their data with the NDI. In 2010, NAACCR member registries (SEER and NPCR) were requested to include follow-up data (date of last contact, vital status and cause of death) with their annual submission. The NAACCR Survival Analysis Workgroup has been charged with evaluating and analyzing these data.

Purpose: To evaluate registry data for fitness for use in population-based survival analyses.

Methods: Registries that linked 2002-2006 diagnosis data with the NDI were eligible for analysis. Registries were evaluated for accuracy and completeness of vital status and follow-up data and registry characteristics relevant to the interpretation of survival data (e.g % multiple primaries, % microscopically confirmed, etc.). Data were compared to SEER-11 data.

Results: 24 NPCR registries were eligible for analysis. Among registry characteristics: 1 registry reported no clinical cases; 2 mature registries (operational before 1995) reported a low percentage of multiple primaries. Among deceased patients: 6 registries reported no day of last contact; 1 registry reported a high percentage of missing month of last contact; 4 registries reported no cause of death. Relative survival analyses will be performed on data from 23 registries (excluded registry with missing month of last contact).

Conclusion: Suppression of date and cause of death information may reflect issues related to confidentiality or state laws. Registry characteristics which impact the interpretation will be discussed with respect to results. Issues of data quality will be discussed. Standards for aggregating the data will be proposed.

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OVERCOMING SMALL NUMBERS IN A SMALL STATE:
VERMONT’S APPROACH TO CANCER MAPPING

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Background: A number of concerns have been raised by individuals regarding the number of cancers in their communities. There is a need to evaluate how the number of cases observed in a community compares with the number expected. However, Vermont’s small number of cases and population present challenges for community-level analysis. Several approaches to standardized incidence ratio (SIR) calculation and web-based mapping were evaluated. Existing methodology did not meet our need to correct for multiple comparisons or being easy to use.

Purpose: The study’s purpose is threefold: (1) to provide increased access to cancer incidence data; (2) to increase the efficiency of staff time spent addressing community concerns; and (3) to better understand the cancer burden at the community level. **Methods:** The Vermont Cancer Registry geocoded the 2001 – 2008 diagnosis years using ESRI ArcGIS. SIR’s were computed at the community level, using the false discovery rate (FDR) method for multiple comparisons. Data are displayed using Instant Atlas. Consensus on methodology was reached among statisticians, cancer registry personnel, department leadership, and the Environmental Public Health Tracking (EPHT) Program.

Results: SIR’s for non Hodgkin lymphoma, colorectal, female breast, prostate, and lung cancer were calculated at the community level. A web-friendly report using a dashboard style (bar charts, table, and map) is used to display the results. Results of the significance testing (comparing the community to the State) are included. Data are downloadable and are appropriately suppressed to maintain confidentiality and rate stability. **Conclusions:** Vermont has found that it is possible to both address small number limitations and display data at the community level, without going to very large geographies (i.e., counties). The FDR method is recommended due to the number of comparisons being made and the possibility of finding a seemingly significant difference by chance alone.

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COMPARING SPATIAL PATTERNS USING HIERARCHICAL
BAYES MODELS

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Background: When new cancer registry data become available every year, we are interested in finding out 1) whether there are areas with higher or lower cancer rates than expected in the new data, and 2) how the spatial patterns in cancer counts or rates are different from the expected or what were in the past.

Methods: A hierarchical Bayes modeling approach is developed that takes into account the impact of potential risk factors, as well as spatial and temporal random effects in predicting cancer counts or rates. The approach will be applied in white female lung cancer mortality rates to test the method in detecting the known pattern changes.

Implication: The approach has a broad application in comparing spatial pattern changes in cancer incidence counts, rates, and stage at diagnosis.

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GEOGRAPHIC VARIATION IN THYROID CANCER INCIDENCE IN ONTARIO, CANADA: 2003-2007

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Background: Thyroid cancer incidence is rising more rapidly than any other cancer in Ontario, Canada, with a particularly sharp increase seen in females from the late 1990s to the early 2000s. Rising incidence has been attributed to improved detection of small tumours but it has been suggested that changing population demographics or exposure to emerging risk factors may also play a role. **Purpose:** To examine geographic variation in female thyroid cancer incidence in Ontario and explore its relation with socio-demographic factors and diagnostic imaging service availability. **Methods:** All female cases of thyroid cancer were extracted from the Ontario Cancer Registry, 2003-2007 (N=7,179). Age-standardized incidence rates (1991 Canadian population standard) were calculated by health region. Socio-demographic factors including data on immigration were obtained from Canadian census data. Diagnostic imaging service availability was estimated from physician billing claims obtained from the Ontario Health Insurance Plan database, 2003-2007. Incidence rates per 100,000 were then correlated with the prevalence of socio-demographic factors and rates of diagnostic service availability per 100,000 at the health region level. **Results:** Significant variation in female thyroid cancer incidence exists across health regions in Ontario. Incidence rates are highest in the health regions that encompass the Greater Toronto Area; an area that contains Ontario's large teaching hospitals, over 50% of its endocrinologists, and the majority of its immigrant population. Preliminary results show positive and significant correlations between health region-specific incidence rates and both the percent immigrant population and rates of diagnostic service availability. **Conclusions:** Preliminary findings are consistent with the hypothesis that the rising incidence of thyroid cancer is being influenced by both changing population demographics and greater diagnostic detection.

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GEOCODING REFERENCE DATA QUALITY ASSESSMENT STRATEGIES AT NORTH CAROLINA CCR

C Klaus,¹ L Carrasco²

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Recent research has demonstrated the modeling of geographic uncertainty due to reference data error in geocoding processes. As a result, there is increasing evidence that demonstrates the impact of poor geocoding quality on the analysis of health related research, and resultant constraints on drawing conclusions with these data. CCRs face several challenges when assessing, and perhaps mitigating the uncertainty in reference data used for geocoding. Some of these challenges include limited staff resources, and establishing practical goals that will have an impact on quality of geocodes. A set of methods that estimate error parameters inherent to spatial data are proposed, along with strategies used at North Carolina CCR for evaluating and quantifying the error of address points, parcels and street centerlines, that can be propagated into case records through the geocoding process.

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SUPPORTING PUBLIC HEALTH UNIT ANALYSES OF CANCER REGISTRY DATA

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Background: Ontario Cancer Registry data are disseminated on SEER*Stat CDs to public health unit analysts, who are mandated to assess current health status of their local regions, including cancer incidence. A working group with representation from the provincial cancer and public health agencies, and the provincial association of public health epidemiologists, collaboratively provided opportunities for analytic support.

Purpose: To support public health analysts in using cancer registry data to inform programs and report on cancer in their regions.

Methods: We collaborated to present two one-day workshops to inform public health unit analysts on cancer registration, aspects of Ontario Cancer Registry data, and to lead them through analytic exercises. We asked attendees about their willingness to provide peer mentorship for cancer registry data analysis.

Results: 43 analysts, including representation from 25 of the 36 Ontario public health units, attended one of the two workshops. Pre- and post-workshop questions showed a substantial increase in attendees' assessment of their ability to use SEER*Stat for their work. Attendees indicated a preference for more active demonstration of methods, more workshop mentors, advanced training and a mechanism for regular updates on cancer data. 14 attendees subsequently formed a SEER*Stat Cancer Mentorship Group, which has established a web page with names and contact information, frequently asked questions and answers, a link to the workshop slide presentations, and a list of recently produced local health unit cancer reports and other resources.

Implications: Collaboration meant that we were able to provide workshop content, venue, publicity, registration and evaluation, and has resulted in a peer mentorship group and increased local analytic capacity; all these should improve the quality of registry data analysis within a local/regional context.

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THE IMPACT OF GEORGIA SMOKING PREVALENCE TREND ON GEORGIA LUNG CANCER INCIDENCE AND MORTALITY BY YEAR 2020

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Background: Tobacco use is the leading preventable cause of disease and premature death. About 18% of adults in Georgia smoke cigarettes and about 87% of lung cancer deaths among men and 70% of lung cancer deaths among women in Georgia are due to smoking. Other cancers such as oral cavity, esophageal, laryngeal, cervical, stomach, renal pelvis, urinary bladder, and acute myelogenous leukemia (AML) have been associated with tobacco use. From 2004-2008, the age-adjusted incidence rate for all tobacco related cancers (TRC) in Georgia was 291/100,000 while the mortality rate was 176/100,000.

Methods: Adult smoking prevalence (1985-2009) was obtained for adults aged 35 years and older using the Georgia Behavioral Risk Factor Surveillance System. Georgia cancer incidence (1998-2008) and mortality (1990-2007) were analyzed for all TRCs for adults aged 35 years and older. An average annual percent change was determined and used to project lung cancer rates through 2020.

Results: From 1985-1993, the prevalence of smoking among Georgians declined by an average of 3% per year in males and 0.2% in females. These changes correspond to a lung cancer incidence decline of 2.2% in males and an increase of 0.4% in females for the years 2001-2008. Lung cancer mortality rates declined by 2.2% in males and by 0.8% in females for the years 2000-2007. Therefore by 2020, Georgia lung cancer incidence rates are projected to decrease from 179 to 162/100,000 in males and increase from 107 to 114/100,000 in females. Additionally, lung cancer mortality rates are projected to decrease from 188 to 110/100,000 in males and decrease from 77 to 69/100,000 in females.

Conclusions: The lung cancer mortality rates projected in this study are far from meeting the Healthy People 2020 goal (46/100,000). Full implementation of comprehensive tobacco control programs would lead to significant reductions in tobacco-related morbidity and mortality.

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MAKING THE CASE FOR CHRONIC DISEASE PREVENTION POLICIES USING ONTARIO CANCER REGISTRY DATA

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Background: Two provincial agencies, Cancer Care Ontario and Public Health Ontario, prepared a joint submission to government recommending population-level action, for chronic disease prevention, on tobacco, alcohol, physical inactivity and unhealthy eating.

Purpose: To use Ontario Cancer Registry and other available data to illustrate the burden of chronic disease in Ontario, as context for prevention recommendations.

Methods: We investigated data availability for illustrating the burden in Ontario of cancer, cardiovascular disease, diabetes and chronic respiratory disease.

Results: Anticipated growth in numbers of new cases could be readily provided only for cancer (for which the contribution of future population growth, population aging, and cancer risk, could all be quantified) and for diabetes. Cancer incidence data show an increase from ~30,000 cases in 1982 to over 80,000 by 2016. We used Ontario mortality data to illustrate that 79% of 2007 Ontario deaths were from chronic disease and that of those, 38% were from cancer. Some expert and stakeholder feedback indicated a strong preference for incidence data, as more compelling than mortality information.

Implications: The availability of good-quality cancer incidence data is valuable for effectively initiating population-level action on chronic disease prevention. It also points to data gaps for other major chronic disease categories for which similar registration, although somewhat challenging to implement, would provide useful information.

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CONSOLIDATING HEALTH PROVIDERS' DATA INTO A RELATIONAL DATABASE SYSTEM FOR THE NORTH CAROLINA CENTRAL CANCER REGISTRY

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The North Carolina Central Cancer Registry (NCCCR) collects, processes, and analyzes data on all cancer cases diagnosed among the state's residents. The analyses performed by the NCCCR are used in research, state resources targeting across the state, education, and risk awareness campaigns. NAACCR also uses the data collected by NCCCR to provide nationwide estimates of cancer incidence. The sources of health providers' data are hospitals of the state as well as physicians. Some of the most recurrent issues with providers datasets collected from different independent sources are the large number of redundant records, incorrect or incomplete facility names and invalid addresses. In particular, the lack of a central repository of providers' data has represented an obstacle for NCCCR staff in gathering and processing cancer incidence data. With that in mind, NCCCR staff designed, created and implemented a relational database system to serve as a single source of health providers' data. The database was designed and created with a strong indexing approach to consolidate redundant information from the providers' data sources. This database has data entry and reporting capabilities enabled by a graphical user interface. We describe the database conceptualization and design, consolidation of data sources, maintenance approach, graphical user interface and uses. We also describe aspects considered for future integration.

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USING MIXTURE CURE MODELS TO ESTIMATE BIOLOGICAL CURE

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Background: With advancing technology and treatment options more patients are surviving their cancer and there is increasing interest in measuring cancer cure rates. Mixture cure models use aggregate data at the population level to measure the biological cure rate, or proportion of patients that will have the same expected mortality as the general population. Since accurate estimation of the cure fraction can be problematic in mixture cure models advisement is needed to assess the reliability of the cure estimate from these models.

Purpose: To investigate criteria to assess the reliability of estimates from mixture cure models.

Methods: We applied parametric mixture models in CANSURV software to estimate biological cure rates in patients from the SEER registries diagnosed with multiple cancer types between 1975 and 2008.

Results: We investigate the criteria for the confidence interval and identifiability of the cure parameter and survival time for 10 different cancer sites. Biological cure rates, median survival, and gain in life expectancy are presented by stage and age group. We identify areas of limitation in obtaining cure fraction estimates for certain cancer sites.

Conclusions: Based on our criteria cure fraction can be estimated for a limited number of cancer sites. Also, the mixture cure model is more reliable for late stage compared to early stage disease. In late stage disease there is shorter median survival time and we can observe the tail of the distribution from follow-up data. With longer survival times, estimates are less reliable because the tail cannot be observed. Specific recommendations will be given for implementing these models in cancer research.

References: Huang L, Cronin KA, Johnson KA, Mariotto AB, Feuer EJ. Improved survival time: what can survival cure models tell us about population-based survival improvements in late-stage colorectal, ovarian, and testicular cancer? Cancer. 2008 May 15;112(10):2289-300.

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NEW CHALLENGES IN CANCER SURVEILLANCE: ORAL TREATMENTS FOR CANCER

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Background: Capturing complete information on the initial course of therapy for cancer remains a challenge to cancer registries. New methods for capturing traditional systemic therapy are being evaluated such as the use of claims data and linkage with the electronic health record. However, the increasing use of oral agents for cancer represents a new and growing challenge. Oral treatments for cancer are being increasingly provided as prescriptions filled at the outpatient pharmacy. These agents will represent 25% of all systemic cancer therapy by 2015. Currently, there is no existing mechanism to capture oral therapies for cancer treatment. Capturing these data are critical for both health and financial reasons. While the overall health care costs for use of oral agents may be lower than for traditional office-based administration, there are significant direct costs to the patient that may create barriers to further exacerbate disparities in access to treatment among the uninsured or underinsured.

Results: There are several potential mechanisms to capture these treatments. These include: use of billing data which typically do not include prescription-based agents. Linkage with the practice EHR, yet prescriptions may not be captured discretely and may capture only that the drug was prescribed not actual usage. E-prescribing systems are another source but the data are not universally available. An opportunity that would address these issues is to work with existing Controlled Substance e-reporting systems. These are in existence in every state and include mandated electronic reporting from all pharmacies. These existing system might be efficiently leveraged to include reporting of cancer treatment drugs for linkage with the existing registry data.

Conclusions: Home-based systemic therapy must become a component of the cancer surveillance system in order to completely address an existing critical gap in reporting of cancer treatment.

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USING CANCER SURVEILLANCE DATA TO ADVANCE SCIENCE: MONITORING FOR A POTENTIAL SAFETY SIGNAL FOR APPROVED DRUGS THROUGH LINKAGE STUDIES

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Background: The Forteo Patient Registry linkage study is an example of a regulatory commitment for a postmarketing safety study that incorporates data from participating state cancer registries in the US to monitor for a potential safety signal. Initiated in July 2009, the Registry is a cohort of patients who have taken teriparatide (Forteo) and voluntarily provided information through a simple, one-time enrollment process during a 5-year enrollment period. To estimate the incidence of osteosarcoma, patient information is linked with all participating state cancer registries in each of 12 years.

Objective: To describe the outcomes, challenges, and resources associated with implementing a multiyear, multistate data linkage study in the US, where no nationwide linkable central cancer registry exists.

Methods: We explore the resources and processes associated with registry recruitment and study approval relative to those required for the conduct of the study (i.e., linkage).

Results: In 2009, cancer registries in all 50 states plus the District of Columbia were invited to participate. In 2011, a total of 37 state cancer registries, covering 85% of the US population aged 18 years and older, participated in the second annual linkage. Of the remaining registries, 2 are currently seeking local approvals and 12 refused or were unable to participate. The level of effort for the registries to perform the linkage was described by registry personnel as “minimal.” However, the estimated resources required by the researchers to secure registry participation were deemed extensive.

Conclusion: Linking with a large proportion of state cancer registries is feasible but requires significant effort and resources on the part of the external researcher and cooperation by multiple individuals at each participating cancer registry.

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COMPARISON OF DIRECTLY CODED SUMMARY STAGE 2000 AND DERIVED SUMMARY STAGE 2000 USING DATA FROM NPCR FOR BREAST AND COLON CANCER CASES

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Background: There has been growing concern about the increased workload needed to capture and record all data elements required by CSV2 and the potential increases in the number of cases with an unknown stage. To relieve some of the workload for data collectors, CDC's NPCR allowed NPCR registries to report Summary Stage 2000 either derived through the CSV2 system (DeSS2000) or directly coded (SS2000) beginning with cases diagnosed in 2012. Directly coded Summary Stage is to be relied on when use of the full CSV2 system is not practical.

Purpose: To determine concordance between SS2000 and DeSS2000 in classifying cancer stage, determine the agreement rate, and to identify patterns of disagreement.

Methods: After the annual NPCR call for data, three NPCR registries provided an electronic file containing supporting stage text data for female breast and colon cancer cases. For each case, CTRs were blinded to the submitted DeSS2000 and SS2000. CTRs used the text to code SS2000 and abstract the CSV2 data items to derive DeSS2000. The re-coded CSV2 data items and DeSS2000 were compared with the submitted data and to the directly coded SS2000. The amount of time required for both coding systems was tracked.

Results: The agreement rate, patterns of disagreement, and time study results will be presented to show the potential effect on the quality and completeness when the two staging systems are used interchangeably.

Conclusions/Implications: Using both staging systems may allow flexibility for data collectors to capture an appropriate and high quality stage to meet reporting requirements, while reducing the workload burden.

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IMPROVING STAGE AT DIAGNOSIS DATA THROUGH IMPUTATION

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Stage at Diagnosis is an important variable for any researcher working with cancer incidence data. Unless stage is properly adjusted for, it is very difficult to get a correct estimate of statistics that are important to cancer control researchers and policy makers. Stage is itself a composite variable that is assigned by the cancer registry collecting the data based on preset rules depending on tumor and disease characteristics. If some of these characteristics are absent in the medical record then stage cannot be assigned and may be set to missing which typically means that the case would be dropped during analysis. Recently there has been interest in imputing some of the missing characteristics that comprise stage so as not to lose these cases. There is also concern that the proportion of missing data elements may not be evenly distributed across stage categories and thus, working only with complete cases may give biased estimates of true population statistics. In this project we look at prostate cancer data from SEER. Note that out of 145,499 patients diagnosed with malignant tumors of prostate in SEER coverage regions, 10.1% did not receive an AJCC 6 Stage Group. Moreover, when the collaborative stage data elements are used to assign the NCCN risk group, the risk cannot be fully assessed for 25% of cases because of missing data. In addition, the most powerful predictor of prostate cancer survival, which is the Gleason score, is missing for 8% of the patients diagnosed in the five most recent years. Thus this major cancer site is a good candidate for imputation. We use the AutoImpute procedure and software developed by Westat to fill in the missing values and examine the feasibility and consequences of using imputed stage information.

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THE 2011 COLLABORATIVE STAGE RELIABILITY STUDY RESULTS FOR CANCERS OF LUNG, BREAST, COLON AND PROSTATE

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Background: In September 2011, standard setters in the cancer community collaborated to implement an on-line reliability study to test the consistency of coding for 17 cancer schemas (sites) for Collaborative Stage Version 0203 (CSv2). The top four cancer sites were the only sites assessed in previous CS Reliability Studies in 2005 and 2008.

Purpose: This presentation will describe the results of the 2011 Reliability Study for these four cancers that represent 50% of the cancer burden in the United States with reference to results from the previous studies. Changes to the CS coding system based on the 2005 and 2008 reliability studies will be reviewed to assess progress over time.

Approach: Focus will be on the data items that have been collected since the beginning of CS in 2004. Additional review will be on the new SSF's that were added to CSv2 in 2007. The response patterns and issues discovered during reconciliation will be used to describe where there are problems.

Implications: Data from this study will be used to improve the documentation and education for the CS system.

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EVALUATION OF A PAN-CANADIAN CANCER STAGING PROGRAM

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Background: In 2008, the Canadian Partnership Against Cancer launched the National Staging Initiative (NSI) to address long standing issues within Canada regarding the collection of Stage data. The objective of the \$20 million dollar program was to achieve a 90% Collaborative Stage data capture rate for all new Breast, Colorectal, Lung and Prostate cancer cases diagnosed on or after January 1st 2010 through funding of key e-health infrastructure upgrades at the provincial level. This objective was to be realized before March 31st 2012, and the achievements of the NSI to be determined through an evaluation.

Purpose: To present on the methodology, findings and lessons learned from an evaluation of the National Staging Initiative.

Methods/Approach: Evaluation components: A Baseline Assessment conducted in 2008/2009 to determine methods and disease sites being staged, ability of Provincial Territorial Cancer Registries (PTCR's) to access e-health data to facilitate efficient staging, a Progress Assessment conducted in 2011/12 which was an update to the Baseline Assessment to measure changes in the PTCR landscape, and an outside evaluation by a third party which will involve all key stakeholders within the NSI. Each of the Baseline Assessment and Progress Assessment is comprised of ten indicators, and in some cases fifty to sixty subsections for select indicators. Data used will be from the 2008 diagnosis year, as well as 2009 and 2010.

Results: Results from the Baseline Assessment and Progress Assessment will be presented to demonstrate outcomes of the NSI. In addition, portions of the third party assessment will be presented including feedback from stakeholders; lessons learned, as well as overall findings.

Conclusions: The evaluation of the NSI is a unique opportunity to share the outcomes of a pan-Canadian \$20 million dollar effort to upgrade PTCR's to support Collaborative Stage, and the pilot implementation of electronic synoptic pathology in Canada.

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GETTING THE MOST OUT OF WEB PLUS FILE UPLOAD AND DOWNLOAD FEATURES IN TENNESSEE

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Progressively more central cancer registries (CCRs) are taking advantage of new, secure, cost-effective avenues for electronic transmission of information. Web Plus is a free, Web-based application used to collect cancer data securely over the public Internet. Because data are entered and transmitted over the World Wide Web, the need to distribute and maintain software at the facilities or offices using Web Plus is eliminated. Web Plus supports four main functions: online abstraction, file upload, file download, and follow-back.

The file upload and download features in Web Plus enable CCRs to securely receive and transmit files of any type. Using the Web Plus file upload feature, facilities can submit files of abstracts in the NAACCR format, or other files in any format. Uploaded NAACCR files are run through edits validation upon upload, and both error and data quality reports are available after upload. Non-NAACCR files of any type can be uploaded. In addition the file download features of Web Plus, added to the program in 2009, allow CCRs to post files for download by facilities. Files for download are posted by facility allowing for the posting of different files for different facilities. Web Plus file download features have been used for a variety of purposes including interstate data exchange, exchange of data files for linkage such as for linkage with the Indian Health Services administrative database, distribution of communications and training materials, and even distribution of other software.

The Tennessee Cancer Registry (TCR) first implemented Web Plus in 2006 and immediately began using the file upload feature to replace outdated facility reporting practices such as submission of data on CD-ROM. Since then, the TCR has made extensive use of the Web Plus file transmission features. This presentation will include an overview of the file upload and download features in Web Plus and description of unique, effective use of these features by the TCR.

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IT'S ABOUT TIME . . . FOR ICD-10-CM IMPLEMENTATION

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This presentation will present an overview of ICD-10-CM including why it is needed, when it will be implemented, and why it matters for cancer surveillance and cancer registrars. ICD-10-CM is a clinical modification of the International Statistical Classification of Diseases and Related Health Problems, 10th revision (ICD-10), published in 1992 and used in the United States since 1999 for cause of death coding by central cancer registries. Due to advances in medical science, more accurate and specific disease coding is needed, and ICD-10-CM provides that detailed specificity to diagnosis coding. Implementation of ICD-10-CM is scheduled for October 1, 2013. ICD-10-CM is used for cancer registry casefinding lists and in comorbidity coding. Resources for cancer registries will be discussed including ICD-10-CM casefinding lists and crosswalks between ICD-9-CM, ICD-10, ICD-O-3, and ICD-10-CM. The general equivalency mappings (GEMs) will be defined, and their relationship to crosswalks to cancer registry data will be explained. Beginning with NAACCR record layout version 12.2 (v12.2), the ten comorbidity data items can be submitted in ICD-9-CM or ICD-10-CM. The presentation will describe the organization of the codes. Information on how registries have implemented collection of the comorbidity codes in ICD-10-CM will be discussed.

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BRIDGING THE DISCHARGE DATA GAP: NATIONAL HARMONIZATION AND EDUCATION EFFORTS

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Background: Hospital discharge data (HDD) and claims data are rich resources that could provide central cancer registries (CCR) with a large portion of information needed to fulfill their reporting requirements. NAACCR Interoperability AdHoc Committee formed the Discharge Data Workgroup (WG) to focus on HDD and CDC focused attention in this area in collaboration with the registry community.

Purpose: The CDC Cancer Surveillance Branch contracted with the National Association of Health Data Organization (NAHDO) to assist the cancer community in developing a better understanding of data collected, standards used for collection, and appropriate uses of the HDD. The goal of NAACCR Discharge Data WG is to explore opportunities with existing discharge datasets and work with appropriate organizations responsible for those data sets to facilitate transmissions and to include additional data items for cancer surveillance.

Methods: CDC worked with NAACCR Discharge Data WG to provide results of the NAHDO gap analysis that compared data standards for cancer registry and discharge data systems. The NAACCR Discharge Data WG reviewed results and made recommendations that harmonized the two systems and identified potential educational opportunities. The work products were shared with NAACCR Semantic Data WG.

Results: The NAACCR Semantic Data WG formed a subgroup to develop educational webinars and data harmonization techniques that enabled exchange and use of data between the two systems. This work produced several educational webinars provided to the cancer registry and discharge data communities; distributed NAHDO and NAACCR statement on collection and use of personal identifiers; recommendations on use of discharge data elements in CCRs; and guidance on collecting payer typology.

Conclusions: This presentation will provide an overview of work the CDC, NAACCR, and NAHDO accomplished with the registry community around the use of HDD to meet CCR data needs.

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AUTOMATED TUMOR CONSOLIDATION: THE FLORIDA ALGORITHM

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Background: Tumor consolidation has always been a very visual review process. No standards or consensus best practices have been developed to accomplish this extremely burdensome process. Florida has developed field level tumor consolidation rules, a computer algorithm and integrated it into registry operations.

Purpose: Development of the algorithm was designed to reduce the burden of registry consolidators and increase consistency and efficiency.

Methods: Each consolidated tumor field was reviewed by a team of CTRs, including tumor information, stage, and treatment. Business rules were developed for each of these fields along with QC review flags. A list of review flags were developed for conditions that will require visual review by consolidators. The software was developed as a set of .NET dll's separating the database access from the algorithms, so that the core can be shared with other registries. Each review flag was then reviewed by the team validating the need for a visual review. The results from the consolidation were run through Call for Data Edits with excellent results. The algorithm was then integrated into daily registry operations.

Results: The resources required to consolidate tumor data was significantly reduced. Use of automated consolidation with QC review flags allows routine discrepancies to be resolved via business rules. The review flag methodology allows QC Staff to focus on discrepancies in need of a resolution. Incidence rates were consistent with rates prior to the implementation of the algorithm.

Conclusions: Automated tumor consolidation is possible. Next steps will be to offer it to NAACCR for a workgroup to evaluate it with the goal of evolving the algorithm for use in the United States and Canada.

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INTEGRATING LINKPLUS WITH REGISTRY NON-HOSPITAL CASEFINDING OPERATIONS

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As part of the Kentucky Cancer Registry's (KCR) case finding operations, linkages are performed between the central registry and data sources from non hospital facilities (NHF) such as physicians' offices, free standing clinics and pathology laboratories. This helps the KCR identify potentially missed cases that may not have come from hospitals that directly report to the central registry. The KCR identified areas with NHF case finding operations that needed to be improved upon such as reducing the man hours involved in the logistics of data preparation and instead, allow registrars to focus their efforts towards the clerical review of the linkage results. The KCR believed that these changes would make the overall process more efficient and accurate. In order to achieve this, we decided to design custom software that allowed us to integrate LinkPlus into an automated work flow process. We will describe how the integration with LinkPlus was performed and highlight the scalability of our approach. We will also discuss some of the challenges with integrating LinkPlus into an automated work flow model and novel solutions to address these through innovative design methods and technologies. Registrars have reported that work time for a standard NHF matching procedure has been reduced significantly with higher rates of accuracy and results on linkages. We will highlight these improvements through comparisons of linkage results and registrar feedback between the former and current processes. This process has been so successful that the KCR is planning to adopt the work flow model for other linkage studies against the central registry.

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DATA LINKAGES SUPPORTING OCCUPATIONAL CANCER SURVEILLANCE

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Occupational carcinogen exposures impose a significant burden of cancer in working populations. At least 60 occupational carcinogens have been identified by the International Agency for Research on Cancer (IARC) with a further 100 agents suspected to cause cancer. Other occupational exposures have yet to be fully studied for carcinogenicity. High quality cancer registries allow measurement and tracking of cancer outcomes, but information on occupational exposures is lacking. This presentation describes a program of work at the Occupational Cancer Research Centre (OCRC, Toronto, Canada) aiming to link occupational exposure information to existing cancer registries. Statistics Canada recently linked data from the 1991 Census of Population (long form, which includes contemporary occupation and industry) to the Canadian Cancer Database (the national cancer registry), yielding an occupational cohort of approximately 2.1 million Canadians employed outside the home, representing approximately 15% of the Canadian working population 25 and over. The standardized occupational and industrial categorizations derived from census data include approximately 500 occupations and 300 industries, allowing the application of job exposure matrices. Pilot efforts led by OCRC scientists demonstrate the utility of this dataset through preliminary studies of welding and lung cancer, occupation and ovarian cancer, sino-nasal cancer and wood dust, and cancer risks for firefighters using Cox proportional hazards modelling. The second pilot project to be described entails the linkage of time-loss claims to the Ontario Workplace Safety and Insurance Board (WSIB) to the Ontario Cancer Registry to create a dynamic surveillance cohort enriched with workers in industries where both injuries (the likely cause of claims) and exposures of interest (such as shift work, exhaust and dust) are common. Together, these efforts create new ways to surveil and evaluate links between occupation and cancer.

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ENHANCE CANCER CARE SURVEILLANCE USING HOSPITAL DISCHARGE DATA

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State cancer registries are available for the 50 states and the District of Columbia. Incidence and mortality information from a state cancer registry has been routinely used for cancer surveillance. While previous studies using cancer registry data have made significant contributions to cancer incidence and staging surveillance, the demand for cancer care surveillance become more and more important, as the national priority moved from disease surveillance to eliminating disparities in cancer care. However, most registry data have incomplete treatment information, which makes it especially difficult to investigate cancer care disparity. In this study, the Nebraska Cancer Registry (NCR) data was linked with the Nebraska hospital discharge data (NHDD) for treatment surveillance. The purpose of the current study is to develop a protocol and best practice of probabilistic linkage between NCR and NHDD, and to make an initial assessment of data linkage procedure and results. In Nebraska, 100% of radiation therapies (RT) are hospital based, and a majority of chemotherapies (CT) are also administered in outpatient settings associated with hospitals. The linkage of NCR and NHDD produced a population-based data source that cover both Medicare and non-Medicare patients. Information from the linked dataset can be used for treatment surveillance, and clinical epidemiology and health services research because non-cancer related diagnoses, more detailed cancer-related treatments and cost of cares can all be derived.

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STANDARDIZED DATA EXCHANGE AND LINKAGE BETWEEN CANCER REGISTRIES AND BREAST AND CERVICAL CANCER SCREENING PROGRAMS USING STANDARDIZED TOOLS FROM THE CENTERS FOR DISEASE CONTROL AND PREVENTION.

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Background: NPCR central cancer registries (CCRs) are required to conduct annual linkages with the Breast and Cervical Cancer Early Detection Program (BCCEDP) in their locale. As of 2010, NPCR-funded registries are required to maintain and submit special BCCEDP linkage status fields to the CDC to help monitor the linkages, follow-up on missed cases, and support studies of outcomes of cancer patients diagnosed through the BCCEDPs. CDC distributed guidance that included a framework for conducting these linkages, but due to the variation in practices across CCRs and BCCEDPs, no standard best practices existed.

Purpose: To facilitate annually required data linkages between CCRs and BCCEDPs.

Methods: Develop a standardized approach to the linkages that will take advantage of existing standardization within both the CCRs and the BCCEDPs.

Results: 1) A format for standardized data exchange between CCRs and BCCEDPs was developed which is comprised of the NAACCR Volume II Record Layout with BCCEDP fields included in the State/Requestor area of the layout; 2) A standard data extract was added to the BCCEDP Cancer Screening and Tracking system software (CaST) so that all CCRs will receive data in the same file format from their BCCEDP; 3) Standard data mapping and linkage configurations were developed for the Registry Plus Data File Mapper Plus and Link Plus programs; 4) Link Plus was enhanced to allow for export of linkage results in NAACCR file format; 5) CaST was enhanced to accept the customized NAACCR file format and facilitate the assimilation of the linkage results returned to the BCCEDP.

Conclusions: 1) Standardized data formats facilitate data exchange between the 2 programs for annual linkage; 2) The standardized data tools developed facilitate the annual linkages and ease of use of the data by both programs; 3) Annual linkages can be conducted in a timely, effective manner and all parties involved can more easily meet their linkage requirements.

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THE REAL CANCER PROBLEM IN HINKLEY

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Background: Hinkley, a desert community in California, was the focus of a \$330 million legal settlement and the Erin Brockovich Movie that alleged a cancer excess produced by chromium 6 (Cr(VI)) contamination of groundwater by a public utility.

Objectives: We sought to assess observed and expected new cancer counts in Hinkley using population-based cancer registry data to determine whether a cancer excess occurred.

Methods: Counts of new cancers and 19 subtypes were obtained from the California Cancer Registry for 1996-2008. Indirect standardization yielded expected counts adjusted for demographic characteristics. Ratios of observed to expected counts defined standardized incidence ratios (SIR) with 95% confidence intervals (CI).

Results: Observed counts for all cancers (SIR=0.91;CI=0.78-1.04) and 12 cancer types did not differ significantly from expected counts. The cervix cancer count was above (SIR=2.83;CI=1.82-5.86) and prostate cancer below (SIR=0.65 CI=0.40-0.98) the expected number. The digestive cancer count was notably lower than the expected number (SIR=0.72;CI=0.48-1.03). No nasopharyngeal or pancreatic cancers were identified. Although the observed count was lower than the expected, colorectal cancer showed advanced diagnostic stage relative to the county, region, and state. Review of Census 2000 data revealed lower median household and family income and smaller percentages of college graduates and persons earning graduate/professional degrees in Hinkley, compared to county and state.

Conclusions: Consistent with three previous assessments covering 1988-2008, these findings do not identify a generalized cancer excess in Hinkley. Higher cervix and lower prostate cancer occurrence than expected counts are consistent with underutilization of cancer screening in Hinkley. Delayed diagnosis of colorectal cancer in Hinkley provides further evidence of a cancer screening deficit in Hinkley that may also exist in other remote desert communities.

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THE MYSTERY OF ONTARIO’S UNUSUALLY HIGH PANCREATIC CANCER SURVIVAL

D Nishri¹

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The Cancer Survival and Prevalence Analytic Network (C-SPAN) has brought together like-minded individuals from across Canada to discuss data quality and methodological issues important to survival, and has estimated relative survival across provinces, time periods and cancers by sex and age group for 1, 3, 5 and 10 years after diagnosis using Canadian Cancer Registry data. While the results were fairly consistent across provinces for most cancers and time periods, for pancreatic cancer, Ontario stood out: In 2004-06, the period 5-year relative cancer survival estimate was 10.2, while the other provinces’ estimates ranged from 3.4 to 5.9. To better understand this result, two approaches will be employed. First, Ontario’s pancreatic survival estimates will be compared to those from the other provinces to determine if any of the available factors (province, sex, age group, time period, years since diagnosis, cohort or period method) explain the observed variation. Next, a variety of methods, such as simulations and multiple imputation, will be used to explore the relative importance of suspected data quality issues in Ontario’s pancreatic cancer incidence. There are several data quality issues that could inflate survival estimates: missing death certificates, too many Death Certificate Only cases, incorrect diagnosis dates and inclusion of out-of-scope patients. In a passive cancer registry such as the Ontario Cancer Registry, such issues may be more common, and their impact can be magnified for more fatal cancers. Finally, an attempt will be made to generalize these findings to survival estimates for other cancers in Ontario.

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STORM BREWING: CANCER IN MANITOBA’S FIRST NATIONS

D Turner,^{1,2} B Elias,² A Demers,^{1,2} M Hall,² E Kliwer,¹ G Musto,¹ L Hart,³ K Avery-Kinew,³ G Munro,³ C Kasper,⁴ D Malazdrewicz,⁴ M Sagan,⁵ P Martens²

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Background: Although historically rare, cancer is an increasing concern among Canada’s First Nations (FNs). However, lack of a FNs identifier in key data sources has constrained efforts to fully quantify the issue. In our province (Manitoba), a network of university researchers, FNs provincial and tribal organizations and federal and provincial governments collaboratively produced a FNs flag for studies using the Manitoba Cancer Registry and other health administrative databases.

Objective: To identify FNs in the Manitoba Cancer Registry, and to describe incidence and mortality trends from 1984 to 2008 for FNs compared to non-FNs by sex, as a basis for additional population-based cancer research and identification of cancer control needs.

Methods: A combination of deterministic and probabilistic record linkage of the federal Indian Registry System database with the Manitoba Population Health Registry resulted in a de-identified file for FNs, which was later linked to the cancer registry at CancerCare Manitoba. Relative risk was determined by comparing cancer incidence in FNs to that for all other Manitobans.

Results: Linkage was successful in 93% of records, a 50% increase in our ability to distinguish FNs for health research studies. While age-standardized cancer incidence has remained fairly stable for non-FNs Manitobans over 25 years for all invasive cancers combined, rates in the FNs population have increased dramatically over time and are now approximating the rates found in the non-FNs population. A similar trend was apparent for cancer mortality (all sites and specific sites).

Conclusions: Cancer is increasing for FNs in Manitoba. The direction of the recent trend combined with additional information showing substantially-increased risk factor rates for Manitoba’s FNs, illustrate the looming cancer control issues in this population.

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CANCER CLUSTERS IN THE US – WHAT DO THE LAST TWENTY YEARS OF STATE AND FEDERAL INVESTIGATIONS TELL US?

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Background: Cancer clusters garner considerable public and legislative attention, and there is often an expectation that cluster investigations in a community will reveal a causal link to an environmental exposure. At a 1989 national conference on disease clusters it was reported that cluster studies conducted in the 1970s and 1980s rarely, if ever, produced important findings. In subsequent two decades states and the federal government continued to investigate cancer clusters and new methodologies and protocols had been developed. However, to our knowledge there has not been a systematic review of the cluster investigations to ascertain whether these investigations contributed to our understanding of cancer etiology or advanced in any way cancer prevention and control.

Methods: We reviewed publicly-available cancer cluster investigation reports since 1990, obtained from literature searches and by canvassing all 50 states and the District of Columbia. Investigations were categorized with respect to cancer type(s), hypothesized exposure, whether the perceived cluster was confirmed, and conclusions about a link between the cancer of concern and the hypothesized environmental exposure(s).

Results: We reviewed 428 investigations conducted in 38 different states and evaluating 567 cancer categories of concern. An increase in incidence was confirmed for 72 (13%) of 567 cancer categories (including the category “all sites”). Three clusters were linked (with variable degree of certainty) to hypothesized exposures, but only one investigation revealed a clear cause.

Conclusions: It is fair to state that extensive efforts to find causes of community cancer clusters have not been successful. There are fundamental shortcomings to our current methods of investigating community cancer clusters. We recommend a multi-disciplinary national dialogue on creative, innovative approaches to understanding when and why cancer and other chronic diseases cluster in space and time.

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BUILDING BRIDGES WITH HOSPITAL REGISTRIES: LOUISIANA EXPERIENCE

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Background: Collaborative relationship between central and hospital registries can be less than ideal. Hospital registries often consider the state’s only interest is to obtain cancer cases from them but with nothing to offer in return.

Purpose: This presentation shares the Louisiana Tumor Registry (LTR) experience of a long process of building bridges and harmonization with hospitals.

Methods: To optimize limited resources within the registry community under recent economic conditions, LTR and hospitals develop common interest and goals. LTR shares education resources and training materials such as recorded webinars free to hospital registrars, supports partial funding for the state cancer registrars’ annual meeting to provide their needed CE hours, facilitates access to online death information from state vital records, shares follow-up information that LTR obtains from numerous linkages with state and national databases as well as provides software upgrade for electronic reporting. Recently LTR developed a Hospital Sharing Web Application that allows hospital registries to “read” the consolidated records in LTR database management system for cases that they have submitted to obtain additional information on stage, tumor markers, treatment and follow-up.

Results: These shared resources have built a strong and trustful relationship between LTR and hospital registries. Hospitals are now more cooperative in submitting complete, timely and high quality data and are more willing to facilitate and participate in LTR special studies.

Implications: Central registries can build bridges with hospitals which will lead to collaborative relationships and shared benefits.

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EDUCATIONAL OUTREACH - A GLIMPSE INTO FCDS CURRENT AND FUTURE EDUCATION PLANS

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Background: FCDS has been focusing intently on enhancing and coordinating Education and Training Outreach Programs for the past two years. Since all central registries play a role in education and training for registrars in their state it is important to ensure all registrars and all central registry staff receive the training they need at the level they can understand (new registrar, 2nd year registrar, experienced CTR).

Methods: FCDS makes extensive use of web casts and teleconferences to conduct statewide education. The training process involves Examples of the scope and depth of presentations include; FCDS Annual Meeting (2 days), FCDS Monthly Webcasts, NAACCR Monthly Webinars, monthly staff in-services, monthly FCDS EDITS Metafile Update, FCDS On-Line Abstractor Training Course, and outreach webcasts for special audiences.

Results: FCDS has achieved variable results on education and training, depending upon topic of interest, method of presentation (in-person, live, webinar, recorded webinar, topic of interest, availability of participants).

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EDUCATE ME: IMPLEMENTING A WEB-BASED TRAINING, ASSESSMENT, AND INTERVENTION PROGRAM

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For several years, hospital registrars in the SEER reporting region of northwest Washington State have requested that we bring their new staff onsite for several months to train them in the same manner as we train our central registry staff. We were unable to accommodate these onsite training requests; however, we recognized the need for both new and experienced hospital registrars to receive timely training. To address this need, we collaborated with educators and a software development company to produce a web-based training program: Educate Me with a Case a Day.

The Educate Me training program is available 24/7. Registrars have many demands on their time and schedules, so we wanted to provide a “complete training session” in 10 to 20 minutes, such that registrars could fit this activity into their day based on their own schedules, not ours. Registrars are presented with a case scenario. They code the case and then immediately receive the answers with detailed rationales explaining how the coded values were obtained.

Educate Me provides the means for registrars to apply the theory learned in various other training venues, such as webinars, state association meetings, and the NCRA and NAACCR annual conferences.

Our goal is to help every registrar in our region have relevant training to help them do their job better today than they did yesterday. Their improved ability to apply abstracting and coding principles results in more complete and higher quality abstracts, ultimately reducing the effort required by our medical editors in case consolidation.

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LEADERS ARE TRAINED NOT BORN: CHARACTERISTICS OF EFFECTIVE LEADERSHIP TRAINING

C L Kosary¹

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Although some may insist that in order to be a good leader an individual must be born with specific personality traits a quick search of the web is all that is needed to find the very large number of books, articles, we sites, and training programs all claiming that they can increase a participant's leadership effectiveness. With so many choices to choose from when an organization is making decisions regarding offering training in this area the question becomes how to be a wise and informed consumer. Drawing on the current literature on leadership training this presentation will discuss the characteristics which have been found to be most effective in the development of leadership ability. The presenter will also discuss her thoughts and experiences as a member of a cohort currently going through the National Cancer Institute's Senior Executive Enrichment and Development (SEED) program. The presentation will conclude with ideas and suggestions for the ways in which both formal and informal methods of training leaders could be utilized within the cancer registry community.

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AN INTRODUCTION TO THE 2011 COLLABORATIVE STAGE RELIABILITY STUDY

P Jamison,¹ L Douglas,² G Lee,³ J Phillips,⁴ J Ruhl¹

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Background: In September 2011, standard setters in the cancer community collaborated to implement an on-line reliability study to test the consistency of coding for 17 cancer schemas (sites) for Collaborative Stage Version 0203 (CSv2).

Purpose: Stage is one of the most important clinical features used to describe the cancer burden in a population. As the community puts increasingly scarce resources into the collection of these data, it is important to measure their quality and consistency.

Approach: The schemas in the reliability study were selected to represent five groups of cases: the big four (lung, breast, colon, prostate), other common cancers (e.g., bladder, melanoma of the skin, ovary), cancers with new schemas, complex schemas, and sites using the schema discriminator. The study was open for 4 weeks to allow for wide participation from the registry community and each participant completed a minimum of 10 cases selected to be representative of the five groups of interest. Each case consisted of the core staging data items (e.g., primary site, histology, laterality, size) and the site specific factors (SSF's). Approximately 350 participants completed the cases in each group for a total participation of over 1300 registrars. The goal is 85% or greater agreement with the preferred answer. Preliminary results indicate that of the big four, the lung cases presented the most challenge for the registrars. Agreement for the SSF's for the big four was better for breast and prostate than for colon. This introductory talk will focus on the background and process for the reliability study and a few overarching results.

Implications: It is important to use these results to improve the documentation and education for CS as the community continues to refine the system to collect this important data item.

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THE 2011 COLLABORATIVE STAGE RELIABILITY STUDY RESULTS FOR OTHER COMMON CANCER SITES

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¹Cancer Care Ontario, Toronto, Ontario; ²CDC/NPCR, Atlanta, GA; ³NCI/SEER, Bethesda, MD; ⁴NCDB, Chicago, IL

Background: In September 2011, standard setters in the cancer community collaborated to implement an on-line reliability study to test the consistency of coding for 17 cancer schemas (sites) for Collaborative Stage Version 0203 (CSv2).

Purpose: Previous reliability studies have focused only on the lung, breast, colon and prostate. The 2011 study included 1 case each for other common cancer sites: bladder, brain, kidney parenchyma, melanoma skin, ovary and thyroid. These sites are usually included in the top 10 cancers within the United States and Canada and with the complexity of changes to the CS system, it was decided to study these sites as well to get a better overall representation of CS.

Approach: The response patterns and comments provided by participants will be used to highlight problem areas. Since these sites have not been studied before, additional review will be done on all Site Specific Factors with a focus on those that are determined to be problematic.

Implications: It is important to use these results to improve the documentation and education for the CS system.

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THE 2011 COLLABORATIVE STAGE RELIABILITY STUDY RESULTS FOR NEW AND COMPLEX SCHEMAS

J Phillips,¹ L Douglas,² P Jamison,³ G Lee,⁴ J Ruhl³
¹NCDB, Chicago, IL; ²CDC/NPCR, Atlanta, GA; ³NCI/SEER, Bethesda, MD; ⁴Cancer Care Ontario, Toronto, Ontario

Background: In September 2011, standard setters in the cancer community collaborated to implement an on-line reliability study to test the consistency of coding for 17 cancer schemas (sites) for Collaborative Stage Version 0203 (CSv2).
Purpose: Seven sites were selected for study because of the complexity of the changes (Corpus, Testis), use of the SSF25 Discriminator (Esophagus-GE Junction, Pharyngeal Tonsil), and schemas first introduced in CSv2 (GIST [Gastro-intestinal stromal tumors], Merkel Cell Carcinoma, NET [Neuro-endocrine tumors]). The intent was to identify the circumstances that particularly challenged participants. Each of the groups of cases presented for coding included 1 case from each of these 3 sets.
Approach: The response patterns and comments provided by participants during the reconciliation phase will be used to describe where coding problems occurred and the nature of the more troublesome items. Where type of training or amount of experience with CS affects the extent of coding difficulties, that effect will be described.
Implications: Data from this study will be used to direct revisions to the CS manual and to training procedures.

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THE 2011 COLLABORATIVE STAGE RELIABILITY STUDY RESULTS, SUMMARY AND FUTURE PLANS

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Background: In September 2011, standard setters in the cancer community collaborated to implement an on-line reliability study to test the consistency of coding for 17 cancer schemas (sites) for Collaborative Stage Version 0203 (CSv2).
Purpose: Our basic purposes for doing the CSv2 Reliability Study were to 1) Assess the accuracy and consistency with which registrars are able to use CSv2, version 0203 and 2) Use information to refine CSv2 rules, documentation and training for all organizations with training and, education, which includes coordinating efforts.
Approach: Using the data analysis of the results of over 1000 participants, we will summarize the patterns of incongruence and determine areas where more education is needed.
Implications: The data from this study will drive education for CSv2 in the future as well as help direct future directions of the CSv2 Governance Committee. The CSv2 Governance Committee oversees all projects and teams working on CSv2.

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ASSESSING COMPLETENESS OF CSV2 SITE-SPECIFIC FACTOR DATA ITEMS IN LOUISIANA

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Background: Effective in 2010, all CoC-hospitals and SEER registries are required to collect Collaborative Stage version 2(CSV2) site-specific factors (SSF). Many SSFs are non-anatomic but clinically relevant information. They include lab values and tumor markers as well as other prognostic/predictive factors which influence clinical decision-making and outcomes. These new additional data items have taken enormous resources to abstract but their availability and completeness have not been systematically evaluated at the population level.

Purpose: The objective of this study is to assess the completeness of CSV2 SSFs for selected common cancer sites in a population-based cancer registry.

Methods: Cancer cases of breast, prostate, colon and lung as well as melanoma of the skin that diagnosed in 2010 among Louisiana residents were analyzed. We calculated the proportion of cases with unknown/missing (i.e. non-informative) values for each SSF. To identify patterns we grouped SSFs into the following categories: stage-related, standard of care tests, prognosis and predictive factors. The determinants of missing/unknown data were then examined by demographic factor, geographic area and hospital type.

Results: Wide variations of percent missing were noted among the SSFs, ranging from less than 1% to 97%. In general, SSF related to staging (TNM or anatomic stage/prognostic group) and lab tests for standard of care (ER, PR, HER/2, Gleason score) were relatively complete. New lab tests and molecular studies had higher % missing values. Detailed results on determinants of missing data will be presented.

Implications: Given limited resources in registry community, selective and conditioned collection of CSV2 SSF should be considered.

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DATA QUALITY ASSESSMENT OF CSV1 IN CANADA: BUILDING A BRIDGE TO CSV2

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Canada adopted Collaborative Staging (CS) as the standard for stage data collection effective 2004 incidence year. Scope and timing of CS adoption by provinces and territories (PTCR) and into the national Canadian Cancer Registry (CCR), has varied with each jurisdiction moving ahead as time and resources allowed. In an effort to encourage the pace of CS implementation, in 2008 the Canadian Partnership Against Cancer (CPAC) developed the National Staging Initiative (NSI). The NSI provided targeted funding and in return PTCRs agreed to collect complete CS stage data for at least the four most common cancers (breast, lung, colorectal and prostate) and submit the data to the CCR no later than the 2010 data year. By 2010, the Canadian Council of Cancer Registries (Council), the governing body for the CCR, recognized that stage data submission were increasing, with some PTCRs reporting data starting in the 2004 incidence year. In 2010 Council established a working group to review the quality of the stage data being submitted to the CCR for the 2004-2008 incidence cycles as reported using CSV1. The working group included senior coders, registry Directors, statisticians and analysts. An oncologist was consulted for specific analyses and technical support was provided by Statistics Canada. This presentation will outline the findings from the quality assessment analysis of the 2004-2008 stage data submitted to the CCR as well as recommendations for action and future monitoring of this data. Key metrics examined included; stage data completeness, at both the PTCR and national levels; CS derived TNM Stage group distributions by cancer type, year and PTCR. The template of this assessment will be used as a starting point to examine the CSV2 data for 2010 coming in the CCR as of March 2012. The information gained from this assessment can be used not only in Canada but can be bridged into the USA or any other jurisdiction using CS as the standard for stage collection.

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EVALUATING UNKNOWN STAGE BY COLLABORATIVE STAGING COMPONENTS AND SURGERY STATUS FOR COLON CANCER – NAACCR DATA ASSESSMENT WORKGROUP
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Background: The NAACCR Data Assessment Workgroup found that the percentage of unknown Collaborative Staging (CS) derived Summary Stage (SS) cases varied substantially by registry. The objectives of this study are to (i) examine how each of three CS components (tumor extension, lymph node status, and metastasis at diagnosis) is related to unknown stage status and (ii) identify whether no surgery was one of the underlying causes for unknown stage status among colon cancers.
Methods: The 401,724 invasive colon cancer cases diagnosed in 48 U.S. state registries in 2004-2007 were obtained from the 1995-2007 CINA Deluxe file. Autopsy, death certificate only, lymphoma and leukemia were excluded. Registries were categorized to three groups based on percentage of unknown stage cases: low (<4%), medium (4-7%), and high (>7%). **Results:** Overall, 25,829 colon cases (6.4% of invasive colon cancers) were reported with unknown stage; percentage varied from 2.1% to 19.0% among registries. Of those, 74.6% had unknown information on all three CS components, 16.2% was solely due to unknown CS extension, 9.1% was due to two unknown CS components. The majority (78.6%) of unstaged colon cases had either none or unknown surgery. Registries in the high category of unknown stage cases had 27.6% of unstaged colon cases (3,645 cases) had a cancer surgery; of these cases, 15% had unknown tumor extension only. For the low or medium unknown stage registries, percentages of unknown stage cases having a surgery performed were much lower (16.0% and 16.9%, respectively). **Conclusion:** About 25% of unknown stage cases have at least one known CS component. Determination of tumor extension relies on a primary site surgery. No surgery is the main reason for unknown stage; 59% of unknown stage cases did not receive a cancer directed surgery. High percentages of unknown stage cases with primary surgery performed for registries with high unknown stage cases indicates possible abstracting and coding issues.

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TEMPLATE ASSESSING DATA QUALITY FOR CINA DELUXE
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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 group has been hard at work over the last several months drafting a data quality template that is both easy to read and understand. This presentation will discuss the process that the group went through, current format of the template and also present the data quality profile filled out for a handful of variables pertaining to cancer stage from the CINA Deluxe dataset.
Methods: The group worked through several rough drafts of a template using CS derived stage data. Drafts of the template were presented to both the DURC & DECC committees for their feedback.
Results: The current templates consist of the following variables: Date when produced, variable examined, filters (exclusion criteria), years covered, cancer sites, citation, number of registries included, references (such as data dictionary), and tables. The tables contain the 25-75% percentile, minimum, median, maximum, upper whisker and the number of registries outside upper whisker by diagnosis year. The variable of interest (such as stage) is also broken down by age, race/ethnicity, diagnostic confirmation, type of report source and urban/rural continuum by diagnosis year as well.
Discussion: It is hoped that the researchers using CINA Deluxe will find the templates a useful tool to aid them in planning their analysis.

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CANCERS WITH INCREASING INCIDENCE TRENDS IN THE UNITED STATES: 1999 – 2008

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Background: Despite declines in incidence rates for the most common cancers, rates for some cancers have recently increased, including cancers of the pancreas, liver, thyroid, and kidney and melanoma of the skin, as well as esophageal adenocarcinoma, and subsites of oropharyngeal cancer associated with human papillomavirus (HPV) infection. We evaluated trends in rates by sex, race/ethnicity, and age group to inform prevention and research activities.

Methods: Population-based data from 41 states (covering approximately 86% of the U.S.) compiled by the North American Association of Central Cancer Registries were used to examine trends in age-standardized rates from 1999–2008 for the seven cancers listed by demographic characteristics. Joinpoint regression was conducted to determine the average annual percent change in rates over time.

Results: Rates for HPV-related oropharyngeal cancer, esophageal adenocarcinoma, and melanoma of the skin increased significantly only in white men and women, except for esophageal adenocarcinoma, which also increased in Hispanic men. Liver cancer rates significantly increased among white, black, and Hispanic men and in black women only. In contrast, rates for thyroid and kidney cancers significantly increased among men and women in all racial/ethnic groups, except American Indian/Alaska Native men. Rates steeply increased for liver and HPV-related oropharyngeal cancers among men aged 55-64 years. Notably, rates of HPV-related oropharyngeal cancer in men and thyroid cancer in women were higher in those aged 55-64 versus 65+years.

Conclusions: Reasons for these increasing trends in incidence rates are unclear, although the rising prevalence of obesity may partly contribute to increases for esophageal adenocarcinoma and cancers of the pancreas, liver, and kidney. Changes in screening and imaging procedures are also likely to be important. Additional research is needed to determine the underlying reasons for these increasing trends.

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EXAMINING THE RISE OF KIDNEY CANCER INCIDENT RATES BASED ON TUMOR SIZE IN SEER 9 (1983-2008)

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Introduction: Kidney cancer was the 9th most commonly diagnosed malignancy and the 12th most common cause of cancer death in 2007 in the US. Incidence rates of kidney cancer have steadily increased over three decades, although the mortality rates have decreased in the last decade. Stage-specific incidence rates of kidney cancer indicate that the trends may be partially attributable to increased detection of asymptomatic tumors. The objective of this study was to examine incidence trends of kidney cancer by anatomic site and tumor size.

Methods: The 1983-2008 incidence data were from the 9 registries of Surveillance, Epidemiology, and End Results program. We calculated incidence trends for kidney , renal pelvis and ureter cancers and examined incidence trends of kidney cancer by tumor size (<2 cm, 2.0-3.9 cm, 4.0-5.9 cm, 6.0-7.9 cm, 8.0-9.9 cm, and ≥10.0 cm).

Results: Incidence rates of kidney cancer steadily increased from 7.8 per 100,000 in 1983 to 14.4 in 2008, whereas rates of renal pelvis and ureter cancer remained similar over time, 1.9 in 1983 vs. 1.6 in 2008. Although the increase in kidney cancer incidence occurred for all tumor size groups, the highest increase was observed for small tumor size groups (2-3.9 cm followed by 4-5.9 cm).

Conclusion: Differences in incidence trends of kidney cancer from renal pelvis and ureter cancer suggest that other unknown factors may play an important role in the increase of kidney cancer incidence rates. Further studies are needed to identify other contributing factors of kidney cancer incidence.

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THE EFFECT OF CHANGING HYSTERECTOMY PREVALENCE ON TRENDS IN ENDOMETRIAL CANCER, SEER 1992-2008

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Background: Women who have had a hysterectomy are no longer at risk for endometrial cancer (EC). Furthermore, hysterectomy is a common procedure performed in the United States and varies by age, race, and geographic region. The impact of population adjustment for hysterectomy on EC rates and trends was evaluated.

Methods: To obtain more accurate incidence rates for EC, women who are no longer at risk for the disease were removed from the population. Hysterectomy prevalence was used to adjust EC rates and trends by age and race. Data from the Behavioral Risk Factor Surveillance System (BRFSS) was used to estimate hysterectomy prevalence for states containing SEER registries. The population was adjusted for each age, race, and calendar year strata. To illustrate the effect, age-adjusted EC incidence rates were analyzed from 1992 to 2008 for Non-Hispanic white and black women before and after adjustment for hysterectomy using data from the Surveillance, Epidemiology, and End Results (SEER) Program, covering 14% of the population.

Results: Overall hysterectomy prevalence ranged from 24% to 51% among white women and from 37% to 73% among black women. Prevalence increased by age but declined over time for both races and most age groups. The decline was largest for younger and white women. The impact of hysterectomy adjustment on the age-adjusted incidence rates changed over time and was greater for black women. Specifically, the age-adjusted rates were about 70% higher after hysterectomy adjustment for white women and about 95% higher for black women.

Conclusions: Hysterectomy prevalence varied by race, age, and calendar year. If the population count is not adjusted for women who have had a hysterectomy and are no longer at risk for EC, the EC cancer rates are greatly underestimated and the differences in rates and trends by race may be misinterpreted.

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TRENDS IN ENDOMETRIAL CANCER INCIDENCE, MORTALITY, AND SURVIVAL BY RACE AND HISTOLOGY WITH AN ADJUSTMENT FOR THE PREVALENCE OF HYSTERECTOMY, SEER 1992-2008

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Background: Among women with endometrial cancer, black women have lower incidence, but higher mortality and lower survival than white women. Understanding these differences is hampered by the lack of adjustment for hysterectomy prevalence which varies by race and time period.

Methods: We analyzed 80,000 white, black, Asian/Pacific Islander (API), and Hispanic women from the Surveillance, Epidemiology, and End Results (SEER) Program diagnosed with microscopically confirmed endometrial cancer (EC) between 1992 and 2008. Cases were grouped into three histologic subtypes to compare the disease burden by age and race for the more aggressive Type II EC with Type I EC and with all other histologies combined. Incidence both unadjusted and adjusted for hysterectomy prevalence, mortality, and survival were examined.

Results: Approximately 15% of white and black women are diagnosed at less than 50 years of age; the figure is 28% among API and Hispanic women. The percentage of the aggressive Type II EC is more than twice as high among women over 50 compared to younger women. Black women have the highest incidence rate of Type II EC and other histologies combined which have a poorer prognosis. Trend data show an increase in the incidence of EC among API women across all histologic subtypes. The incidence of Type I and Type II EC is stable among black and white women although the rate of Type I EC appears to be trending upward among black women. When adjusted for hysterectomy prevalence, the incidence rate for black women is higher than for white women in recent years.

Conclusion: The use of hysterectomy adjusted population data alters incidence rates and trends for endometrial cancer. Further work is needed to determine the appropriate use of these more exact denominator adjusted incidence rates when examining trends in female genital cancers.

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SOCIODEMOGRAPHIC FACTORS PREDICTING NON-RECEIPT OF GUIDELINE-CONCORDANT CHEMOTHERAPY AMONG LOCOREGIONAL BREAST CANCER WOMEN UNDER AGE 70 YEARS

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Background: The guidelines for chemotherapy primarily apply to women under 70 years old because there is insufficient data to support recommendations for older women. We examined how selected sociodemographic factors predict non-receipt of guideline-concordant chemotherapy among women under age 70. **Methods:** We analyzed data from 4,452 locoregional breast cancer cases diagnosed in 2004 from the Centers for Disease Control and Prevention's Breast and Prostate Cancer Data Quality and Patterns of Care study. Sociodemographic variables 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. Predictors of guideline-concordant (receiving/not receiving) adjuvant chemotherapy, according to National Comprehensive Cancer Network Guidelines, were explored using logistic regression. **Results:** Overall, 24% of women under age 70 did not receive guideline-concordant chemotherapy care. Significant predictors of non-guideline concordant chemotherapy included Medicaid-insurance (Odds Ratio [OR]=0.64; 95% Confidence Interval [CI], 0.47-0.88), living in high-poverty areas (OR=0.70; 95%CI, 0.54-0.90), and treatment at non-CoC hospitals (OR=0.70; 95%CI, 0.55-0.89) adjusting for age, registry, and clinical variables. The ORs remained similar after adjusting for other sociodemographic variables. **Conclusions:** Guideline recommended chemotherapy is not disseminated proportionally in the community. Socioeconomically disadvantaged women under age 70 are more likely to receive non-guideline concordant chemotherapy. Target actions need to be taken to ensure high-quality care for all cancer patients.

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UPDATE OF THE BURDEN OF POTENTIALLY HPV-ASSOCIATED CANCERS IN THE UNITED STATES: 2004-2008

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Vaccines are available to protect against 2 oncogenic types of human papillomavirus (HPV) responsible for at least 70% of cervical cancers worldwide. Increased understanding of the role of HPV and the availability of the HPV vaccine has focused attention on cervical, vulvar, vaginal, penile, anal, and oropharyngeal cancers due to their association with HPV. This presentation describes the burden of potentially HPV-associated cancer in the US. Incidence data from NPCR and SEER 2004-2008 were analyzed, using predefined case definitions to examine invasive cancers. An average of 33,370 potentially HPV-associated cancers per year occurred, (rate 10.8 per 100,000); 12,080 among males (rate 8.1) and 21,290 among females (rate 13.2). Cervical cancer was the most common of these cancers, with an average of 11,967 cases per year; oropharyngeal cancer was the second most common, with an average of 11,726 cases per year (2,370 among females and 9,356 among males). The rate of anal cancer among females was 57% higher than among males (1.8 vs. 1.2). The rate of oropharyngeal cancer among males was over 300% higher than among females (6.2 vs. 1.4). We also calculated estimated counts of HPV-associated cancers by multiplying the average annual counts of potentially HPV-associated cancers by the percent of cancers attributable to HPV, based on previous literature. There were 25,900 cancers estimated to be HPV-associated annually; 18,000 among females and 7,900 among males. Cervical and oropharyngeal were the most common of these, with an estimated 11,500 cervical cancers and 7,400 oropharyngeal cancers (5,900 among men and 1,500 among women). Ongoing surveillance of these cancers can help monitor any eventual impact of HPV vaccination, as well as cervical cancer screening programs/strategies. Methods used to estimate HPV-associated cancers will be presented so that interested registry staff can replicate analyses in their respective states.

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DEMOGRAPHIC PREDICTORS OF DELAYED STAGE COLORECTAL CANCER DIAGNOSIS IN CALIFORNIA, 2004-2008

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Purpose: We sought to distinguish roles of selected demographic variables and bowel segments as predictors of delayed vs. early stage colorectal cancer in California.
Methods: Demographic and anatomic variables for 66,806 *in situ* and invasive colorectal cancers (CRC) were extracted from the California Cancer Registry for 2004-2008 and analyzed using logistic regression as delayed (Stage II-IV) vs. early (*in situ* and Stage I) diagnostic stage.
Results: Odds ratios (OR) for binary stage categories comparing age <40 (OR=2.58; 95% CI=2.26-2.94), 40-49 (1.71; 95%=1.60-1.83) and 75+ (1.05; 1.02-1.09) relative to 50-74 years were computed. Compared with non-Hispanic whites, ORs for stage categories were: 1.05; 0.99-1.13 (non-Hispanic blacks), 1.08; 1.02-1.13 (Hispanics), and 1.05; 1.00-1.10 (Asian/Other). Females had higher odds of delayed diagnosis (1.09; 1.06-1.13) than males. Descending ORs were measured for successively lower vs. highest SES quintiles (OR_{4:5}=1.08; 1.03-1.14, OR_{3:5}=1.13; 1.08-1.19, OR_{2:5}=1.18; 1.12-1.24, and OR_{1:5}=1.21; 1.14-1.28; Trend p <0.0001).
Conclusions: Younger and older than age 50-74; females; Hispanic ethnicity; right vs. left, proximal vs. distal, cecum plus appendix vs. distal bowel segment contrasts, and each of the lower SES quintiles vs. highest SES each independently predicted delayed CRC diagnosis. Sequentially lower SES represented the most robust predictor of delayed CRC diagnosis, independent of other covariates. Approximately 77% of delayed diagnoses were in non-Hispanic whites and Asian/Others, two groups frequently neglected in intensified screening. Triple the number of delayed stage cases in California would have been targeted for intensified screening using the two lowest SES quintiles rather than targeting that fails to also include Asian/Other and non-Hispanic whites. These findings reveal that a community SES index provides a superior and egalitarian targeting method for intensified CRC screening.

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ASSOCIATIONS OF COLORECTAL CANCER INCIDENCE AND MORTALITY RATES BY POVERTY AND URBANIZATION IN GEORGIA.

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Background Colorectal cancer is the third most common cause of cancer incidence and mortality among men and women. From 2004-2008, nearly 10,000 men and 9,300 women were diagnosed with colorectal cancer. Age-adjusted colorectal cancer incidence rates were 56/100,000 among men and 40/100,000 among women. Nearly 3,400 men and 3,300 women died of colorectal cancer, with age-adjusted mortality rates of 20 and 14/100,000, respectively. The purpose of this study was to examine the effect of poverty and urbanization on colorectal cancer rates in order to target screening efforts. **Methods** The 2005 county poverty level data were obtained from the U.S. Census Bureau and categorized into 3 groups: low poverty (<10% of county's population below federal poverty level), medium (10-19% below), and high poverty (>=20% below). The 2003 rural-urban continuum codes were obtained from the U.S. Department of Agriculture and categorized based on degree of urbanization and population size. Age-adjusted incidence and mortality rates were examined by re-categorizing counties based on urbanization and poverty level. **Results** Sixty-percent of Georgia counties were classified as either medium or high poverty rural counties. Incidence rates for males living in medium (59 /100,000) and high (61/100,000) poverty rural counties were significantly higher than for males living in low poverty large metro counties (51/100,000). Mortality rates for males living in high poverty rural counties (24/100,000) were significantly higher than for males living in low poverty large metro counties (18/100,000). Incidence and mortality rates for females living in medium and high poverty rural areas were higher than for females living in low poverty large metro counties, but the difference was not significant. **Conclusions** Regardless of race, medium and high poverty counties have higher colorectal cancer incidence and mortality rates. Screening and education efforts should be targeted towards counties in those areas.

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THE DEATH CLEARANCE PROCESS: WHAT DO WE GAIN FROM OUR EFFORTS?

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Each year, central cancer registries use a considerable amount of resources for their death clearance process. This poster will: 1) demonstrate the variability of followback resolution from different types of reporting facilities in New York; 2) illustrate how much additional information is typically obtained from those followbacks which are potential multiple primary cases and; 3) emphasize some of the key issues that the New York State Cancer Registry (NYSCR) continues to encounter during the followback process.

The 2009 New York Vital Records' death file was matched to the NYSCR database and 3,458 cases did not match. Of these, there were 2,740 patient non-matches and 718 primary site non-matches. Some cases were sent to multiple sources for resolution, so 4,298 followbacks were sent (2,159 were sent to hospitals and 2,139 were sent to physicians). By November 2011, hospitals had provided responses for approximately 98% of the followbacks and physicians had provided responses for approximately 31% of the followbacks. Of the hospital followbacks, 60% were submitted as missed cases, 14% were deleted because patient's record did not include a reportable cancer, 13% were determined to have been previously reported and the code on the death certificate did not reflect a missed primary, 9% were not reported because the specific hospital had not treated the patient's cancer (however, some of these might have been submitted by another hospital/physician), 2% were not reported because the record could not be found and 2% had not been resolved. Of the physician followbacks, 17% were submitted as missed cases, 13% were not reported because the physician did not have information about the patient or did not treat the cancer, 1% were deleted because the patient did not have cancer and 69% had not been resolved.

Specific results from registries' current death clearance procedures are vital in order to inform the NAACCR Death Clearance Process.

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RAPID QUALITY REPORTING SYSTEM: REAL-TIME USE OF CANCER REGISTRY SYSTEMS TO MONITOR THE QUALITY OF CANCER CARE

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Background: Over the past three years the NCDB has developed and field tested a web-based prospective quality of cancer care reporting tool using nationally endorsed quality of care measures for breast and colorectal cancer. This reporting tool provides real-time year-to-date and retrospective hospital-level performance rates for as many as six measures to CoC accredited cancer programs. **Design:** The Rapid Quality Reporting System (RQRS) is a real-time quality reporting system that feeds back process performance and case level reports to hospitals using data from cancer registries. NAACCR data transmission standards and the use of registry EDITS software streamline case management to ensure local registry data are synchronized with data in the RQRS. The RQRS uses this information to provide diagnostic tools allowing hospitals to review and compare performance rates with other hospitals based on patient demographics and hospital characteristics. Prospective case monitoring systems provide e-mail notifications and web reports to ensure cases are actively monitored to better assure delivery of evidence-based care. Ambulatory radiation and medical oncology treatment data are updated in a timely manner thus providing the hospital a more current performance rate. Patient treatment summary documents are also available for local hospital use for patient navigators, and can be edited to provide specific patient information and can serve as the beginning of a customized patient survival report. **Results:** The RQRS has been available, on a voluntary basis, to all CoC accredited cancer programs since September 2011. This presentation will review the structural design and reporting capabilities of the RQRS and will describe the implications for central registry collection of non-surgical treatment data and the effect of this system on hospital performance rates as broad adoption of the system by CoC accredited programs is anticipated.

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USING TEXT FIELDS TO DETERMINE OUT OF STATE
DIAGNOSES IN CENTRAL CANCER REGISTRIES.

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Background: Because of the mobile nature of the New York population and the worldwide reputation of New York hospitals, many non-residents are reported to the New York State Cancer Registry (NYSCR). To identify these, we decided to examine the test fields of cases on the NYSCR database for references to other countries.

Methods: All text fields were scanned for occurrences of country names using the index function in SAS 9.2 (Cary, NC). We then eliminated various common combinations of text strings found in the text that indicated non-country values such as: “Beth Israel” (a hospital); “Dr. Jordan”; “Jamaica, NY” and “Cuba, NY”; and “Vietnam veteran” references. We then manually reviewed the cases and the accompanying text to determine if the case was actually diagnosed in New York or the patient was not a resident of New York at the time of diagnosis.

Results: We found 1668 cases in which there were references in the text to a foreign country. Of these, 54% were found to be non-New York residents at the time of diagnosis or non-New York diagnoses.

Conclusions: Scanning text included in source files may be an important factor in determining whether or not a person was diagnosed and/or lived in New York at the time of diagnosis. This has implications for various types of analysis as public reports of incidence rates are limited to state residents and we often limit our studies to those who live in New York State as well.

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THE SASKATCHEWAN CANCER REGISTRY: USES,
OPPORTUNITIES AND CHALLENGES

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In Saskatchewan, legislative authority to conduct cancer surveillance resides with the Saskatchewan Cancer Agency (SCA). A part of the SCA, the Saskatchewan Cancer Registry (SCR) is a vital source of information on cancer epidemiology and in planning cancer services in the province. As a repository of incidence, follow-up and mortality data, the role of the registry has changed considerably since its inception in 1932. Along with typical surveillance activities the SCR has been used to evaluate cancer screening delivery, describe the extent of cancer burden in the community (e.g. prevalence), monitor the effectiveness of cancer control activities, calculate resource allocation and projections as well as to predict and interpret changes in incidence. The data collected is of a high quality with an estimated < 2% loss to follow-up. The objectives of this presentation are as follows: (1) to document the development of the SCR; (2) describe the uses of registry data citing representative examples; (3) to outline the current process followed by researchers in requesting data; and (4) to identify opportunities and challenges as we move forward. This presentation will serve to inform key stakeholders including clinicians, administrators, managers and other users of the potential presented by a provincially complete cancer registration process, how they can use this data and its limitations.

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concurrent session 5



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AUTOMATED CANCER DATA EXTRACTION AND RAPID CASE ASCERTAINMENT FROM TEXT-BASED ELECTRONIC PATHOLOGY REPORTS

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Electronic pathology reporting (E-Path) has automated the identification of reportable cancers from text based pathology reports with a high degree of accuracy: 99% sensitivity and 98% specificity (based on field testing). The volume of cases reported to cancer registries has increased dramatically since 2005; however, to extract the relevant tumor information, the text reports must still be interpreted by humans. This bottle neck limits the identification of candidates for studies and clinical trials. We present an approach that uses natural language and knowledge based processing to identify relevant tumor information in free text pathology reports and converts this information into standard form for database processing. The software identifies the anatomical site and surgical procedure presenting the tumor information as a synoptic list. Software assist allows quick verification of the location of each item of information within the text. Search agents then match patient and tumor characteristics to study criteria. This system automatically analyzes new pathology reports and, when matched, a notification (email) is activated and the reports are set aside for review. Any number of searches and subscribers can be defined, as well as the reporting cycle for each study. A prototype is installed at several central cancer registries to routinely identify cases for various studies. A quality assessment of the system is underway by the Georgia Cancer Registry and AIM to determine the accuracy of the system's ability to correctly identify cases. Time and labor savings affected by the system are also being quantified. Results from 6 months of system use will be presented. Initial assessments indicate significant savings.

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STANDARDIZING CANCER PATHOLOGY REPORTING: PROMOTING INTEROPERABILITY THROUGH COLLABORATION

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¹Canadian Partnership Against Cancer, Toronto, Ontario

Background: The Canadian Partnership Against Cancer (*the Partnership*) launched the National Staging Initiative (NSI) in 2008 to collect national population-based stage data for new cancer cases diagnosed on or after January 1, 2010. Pathology was identified as a critical component of the NSI.

Purpose: The Partnership recognized the need to standardize pan-Canadian cancer pathology reporting to enable complete data collection and improve interoperability. Endorsement and maintenance of these standards is essential for adoption.

Approach: Key approaches to promotion of adoption and implementation include endorsement of the CAP Cancer Protocols as pan-Canadian content standards for cancer pathology reporting; identification of the protocols as Canadian Approved Standards; coordination of Pathologist and Vendor-led education sessions; establishment of expert panels and assignment of Canadian representatives to the CAP Cancer Protocol Review Panels. The Partnership continues to collaborate with standards organizations such as NAACCR, CAP, AJCC, and Canada Health Infoway to support standards maintenance.

Results: The Partnership has had much success and was able to facilitate the endorsement of the CAP Cancer protocols as pan-Canadian content standards for cancer pathology reporting by the Canadian Association of Pathologists (CAP-ACP), and to assign Canadian representatives to CAP's Cancer Committee and Protocol Review Panels. Maintenance of the standards is being addressed through engagement of site-specific multidisciplinary expert panels. The Partnership, with CAP-ACP, has partnered with pathology communities from the US, UK, and Australasia to form the International Collaboration on Cancer Reporting (ICCR) to collaborate on internationally-harmonized core datasets for cancer pathology.

Conclusions: Adoption of structured pathology reporting in Canada will enable better patient care, improve data quality, create efficiencies and enable interoperability.

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USING CLAIMS TO CAPTURE MISSING HEMATOLOGIC MALIGNANCIES FROM COMMUNITY ONCOLOGY PROVIDERS

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¹VCU Massey Cancer Cetner, Richmond, VA

Background: Cancer diagnoses and treatments are moving increasingly to the outpatient setting, increasing the risk of missing incident cancers. Because of diagnostic methods, new treatment modalities, and frequency of watchful waiting, hematologic malignancies in particular are more likely to remain unreported or to be reported after a substantial lag time. We evaluated an automated system for capturing cancers and treatments from community oncology practices to address this gap in cancer surveillance.

Methods: We developed a software to screen, store and report information on cancer and its treatment using standardized claims data from 5 oncology practices representing 30 physicians in North Carolina and Virginia. We matched all data with the central registries in each state. We performed independent abstraction from practice medical records on a sample of 247 randomly selected unmatched and unreported cases. We used the validation data to extrapolate the potential annual missed caseload per physician and for the U.S. in total.

Results: There were 1,935 hematologic malignancies identified during the study period. The overall match rate was 58.2% with substantial variation by hematologic disease. Based on the validation set using incidence, reportability, and billing diagnosis accuracy, we estimate that there are approximately 3.4 cases per year per oncologist that remain unreported. The estimated US total missed cases may be as much as 47,000.

Conclusion: As the migration to the outpatient setting for diagnosis and treatment for cancer continues, it will be critical to assure that we are capturing cases such as the hematologic malignancies likely missed through traditional surveillance methods. The medical oncology practice has been over looked as a potential source for reporting of missed cases. Thus, leveraging standardized electronic data such as claims may be an efficient method to provide information on these otherwise unreported cancers.

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INTEROPERABILITY BETWEEN THE CAP ELECTRONIC CANCER CHECKLISTS (ECC) AND COLLABORATIVE STAGING (CS)

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Background/Purpose: The College of American Pathologists (CAP) produces cancer checklists to aid pathologists in the complete and standardized reporting of cancer diagnoses. CAP also produces a computer implementable XML version of the checklists known as the CAP electronic Cancer Checklists (eCC). Ideally, eCC data elements would map directly to Collaborative Staging (CS) data elements, so that eCC data could flow directly into cancer registry databases.

Approach: Recently, the CAP eCC team, CAP's Pathology Electronic Reporting Committee (PERT), the CAP Cancer Committee, the American College of Surgeons CS Team, the Centers for Disease Control and Prevention (CDC) and NAACCR have been engaged to work together to better harmonize the data elements in the CAP eCC with those in the CS schema tables. The project team will evaluate the possibility of harmonizing the CS schema groups (currently numbering 153) with the 81 current eCC checklists. A versioning mechanism to keep the eCC and CS data elements change-resistant and synchronized also will be investigated.

Results: Many eCC data elements have been modified and expanded in recent releases to better conform to the CS data elements used in cancer registries. New sections for "Primary Tumor Site" and "Additional Sites Involved by Tumor" were added to many checklists. Work has begun to harmonize the schemas for prostate, stomach and melanoma. An analysis of informatics models suggests several areas for improvement, particularly with approaches to CS XML schema production and versioning.

Conclusions: Harmonization of CS and eCC will likely require significant changes to the content and informatics models of both CS and the eCC. Progress toward this goal will be presented.

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CAPTURING EMR DATA FOR CANCER CARE RESEARCH AND VALIDATION OF REGISTRY DATA: A FLORIDA CASE STUDY

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Background: Current cancer registry data provide incomplete information to determine treatment efficacy, delays and overall quality of care. The Florida Cancer Data System (FCDS) sought to develop methods to accept and process hospital EMRs for patients diagnosed with invasive cancers for a targeted study, and evaluate existing FCDS cancer data.

Methods: Electronic patient records from a large health care system consisting of nine hospitals were abstracted for 2007 – 2010 admissions. A trigger event using ICD-9CM invasive cancer codes were utilized to identify patient records. Together with hospital staff, the FCDS reviewed and identified EMR data elements most closely related to NAACCR standard data items and treatment information. Electronic medical records were transmitted via secure FTP, processed in a relational database, and linked to FCDS data. Text-based pathology data were processed using an algorithm to identify cancer-relevant records for analysis.

Results: A total of 253,570 patient encounter records were triggered and transmitted to the FCDS from the hospital EMR system. Records represented patient data for every hospital encounter. Patient data included detailed treatment such as chemotherapy, radiation and surgery, pathology, discharge reports, medication list, and demographic data. Hospital records consisted of both discrete and text data elements.

Conclusion: Hospital EMR data provide more granularity for patient treatment information and hospital encounters and can include critical treatment trends as well as add high quality data to research. A limitation of the project is that the transmission and processing methodology was specific to the capabilities of the hospital EMR system, which may not be similar across hospital systems. This will be less limited as EMR systems incorporate more standardized formats such as CDAs and HL7s.

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A NEW APPROACH: USING ELECTRONIC HEALTH RECORDS TO CAPTURE UNREPORTED CASES AND MISSING DATA

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Background: All US states have laws requiring facilities to report new cancer cases to a central cancer registry (CCR). Capturing cases diagnosed in physician offices or small-caseload hospitals and obtaining complete treatment information are among challenges facing CCRs. Informatics and American Recovery and Reinvestment Act of 2009 (ARRA) funding of special projects by the Centers for Disease Control and Prevention National Program of Cancer Registries (CDC-NPCR) through ICF Macro offers the possibility of improving data quality and case completeness.

Objectives: Describe how the Missouri Cancer Registry and Research Center (MCR-ARC) is obtaining previously unreported cases and treatment information through use of electronic health records (EHRs).

Methods: We entered into a sub-contract with ICF Macro that outlined major activities to be accomplished and time frames. We targeted specific oncology practices and partnered with the Missouri Health Information Technology (MO HIT) Assistance Center to identify EHR vendors and physician offices implementing approved vendor EHRs. We also entered into a contract with QuantumMark to obtain diagnostic imaging text from CT scans and MRIs using software developed by Artificial Intelligence in Medicine (AIM).

Results: We are bringing previously unreported cancer cases directly into MCR from physician office EHRs and hospital radiology department. In 2012 the project will be expanded to include an acute care hospital that previously submitted copies of medical records for abstraction by the CCR.

Conclusions/Implications: Underreporting of cases is largely due to lack of human and financial resources. Funding to improve infrastructure and import data directly from EHRs can improve data quality and completeness; provide data needed for public health surveillance; and facilitate comparative effectiveness and other research.

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XML - HOW IT IMPACTS NAACCR

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For years clinical and research data sources have been moving to standardize transmission formatting using the popular XML (Extensible Markup Language) specification. This talk will present some of the various flavors and solutions we are adopting today, and also discuss the NAACCR plans to transform the familiar export record format into an XML tag based layout.

I plan to allow adequate time during the session for questions and comments. To help anticipate questions and topics, give feedback and to download the final slides for the talk prior to Portland, please visit <http://via.usc.edu/xml>

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NATIONAL PROGRAM OF CANCER REGISTRIES-MEANINGFUL USE (MU) OF ELECTRONIC HEALTH RECORDS (EHRs): CLINIC/PHYSICIAN OFFICE (CPO) REPORTING TO REGISTRIES

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Background: Historically, complete and high quality cancer surveillance data has relied primarily on reporting from hospital cancer registries. The need to capture data from outpatient settings has become more important as cancer care is increasingly being provided outside of hospitals. Without complete reporting from physician offices, there is under-reporting of certain types of cancers and treatments. EHRs provide a powerful tool for automation of cancer reporting from these providers.

Purpose: To develop standards, methods, and tools, and test the implementation of, electronic reporting from CPO EHRs to cancer registries.

Methods: As a result of efforts across the cancer registry community, cancer reporting to public health registries by “eligible providers” was proposed by the Health Information Technology (HIT) Policy Committee of the Office of the National Coordinator for Health Information Technology (ONC) to the Centers for Medicare & Medicaid Services (CMS) for consideration of inclusion in Stage 2 of MU. NPCR-AERRO CPO workgroup developed documents to specify the process and standard format for physician reporting from EHRs.

Results: Through a NAACCR workgroup, the documents developed were combined to form a single Implementation Guide for Physician Reporting to Cancer Registries. We expect that this Guide will be recommended by the HIT Standards Committee for eligible providers to meet the MU cancer reporting objective. Electronic Mapping, Reporting, and Coding software (eMaRC Plus) has been enhanced to enable registries to receive and process these reports.

Conclusions: This presentation will provide: a status update on the cancer reporting objective in MU; an overview of the Implementation Guide; accomplishments from testing/demonstrating with vendors; information on eMaRC Plus’s ability to receive and process physician reports; and next steps for cancer registries to be prepared for physician implementation of reporting from EHRs.

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SURVIVAL OF PATIENTS WITH HEMATOLOGICAL MALIGNANCIES IN SWEDEN

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We present a summary of key findings from a series of recent studies investigating survival of patients diagnosed with hematological malignancies in Sweden 1973-2009 with follow-up to the end of 2010. Survival has improved substantially over the last four decades and significant improvements are still being seen. These figures provide a reference level for the survival that can be achieved in a population-based setting with universal health care.

We illustrate, for example, major improvements in survival of patients up to 79 years of age diagnosed with chronic myeloid leukaemia, mainly due to increasing use of imatinib mesylate. The elderly still have poorer outcome, partly because of a limited use of imatinib mesylate.

Advances in therapy for patients with limited and advanced-stage Hodgkin lymphoma have contributed to an increasing cure rate. In addition, our findings suggest that patients diagnosed with Hodgkin lymphoma up to 65 years of age during the last decade reach a point of statistical cure, suggesting that long-term treatment-related mortality has been all but eliminated. We previously reported (Kristinsson *et al*, *JCO*, 2007) improvements in 5- and 10-year survival for patients diagnosed with multiple myeloma up to 2003, although improvements were restricted to patients younger than 70 (5-year survival) or 60 (10-year survival). Extending the study to 2009 shows continued improvements, but also clear evidence of improving 1-year and 5-year survival among patients aged 80 years and over. We applied cure models to study survival of patients diagnosed with acute myeloid leukaemia and believe that this methodological approach can provide valuable insights. A dramatic improvement in the cure proportion was seen in younger patients, whereas improvement in older ages was mainly within the survival of the ‘uncured’.

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BUILDING NEW DATA BRIDGES - OPIOID USE AMONG NOVA SCOTIA CANCER PATIENTS

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Opioid analgesics (e.g. morphine, hydromorphone) are the mainstay of drug therapy for moderate to severe cancer-related pain. Surveillance of their use is essential to identify potential issues for health professionals, health care organizations and policy makers, and promote safe, appropriate and cost-effective pharmacotherapy.

This study describes prescription of opioid analgesics to all Nova Scotia (NS) cancer patients receiving these medications from 2005 – 2009, through linkage of two data sets. All NS residents diagnosed with cancer from 1991 onward, living in NS during the period 2005 – 2009 were included. Two disease periods were examined: time of diagnosis (TOD) and end of life (EOL). Data was provided by *Cancer Care Nova Scotia Cancer (CCNS)* and the *Nova Scotia Prescription Monitoring Program (NSPMP)*. CCNS operates the NS Cancer Registry, housing data on all residents diagnosed with cancer. NSPMP data contains details on all prescription opioid analgesics dispensed in NS community pharmacies.

Opioid use patterns will categorize patients as either chronic, episodic or non-users at TOD and EOL. Descriptive statistics will outline patterns of opioid dispensing at TOD and EOL by demographic and clinical characteristics. Levels of opioid use will be described in terms of oral morphine equivalents. Multivariate regression models will be used to compare the likelihood of dispensing opioids by demographic and clinical characteristics.

This study is the first of its kind in NS and will provide a true understanding of opioid use in the cancer population. Currently, no baseline data exists to assist key stakeholders who manage this component of cancer care. This information will allow stakeholders to identify focus areas for improving cancer pain management and target areas for ongoing monitoring.

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USING THE STANDARD INCIDENCE RATIO (SIR) TO INVESTIGATE A POTENTIAL LINK BETWEEN CANCER INCIDENCE AND A CHEMICAL SPILL IN NORTH POLE, ALASKA

D O'Brien¹

¹Alaska Cancer Registry, Anchorage, AK

The Alaska Cancer Registry has been working with the Section of Epidemiology's Environmental Public Health Program in investigating potential health risks of a chemical spill in the town of North Pole, Alaska. The spill occurred at the Flint Hills North Pole Refinery, and the chemical is called solfolate, which is used in the refining of gasoline. There have been several spills of this chemical in the past and it is detectable in the area's groundwater, impacting some private drinking water wells. Solfolane isn't regulated by the EPA, and not much is known about the long-term health implications of exposure. A map of the delineated solfolane plume showed that it was almost entirely contained within the North Star Borough's Census Tract 16 and is over half the size of the census tract. Therefore, ACR used this census tract as the basis for this study. ACR determined the number of observed cancer cases for this census tract, calculated the number of expected cancer cases, and used the Standard Incidence Ratio (SIR) statistical significance test to determine if the difference between the two numbers was statistically significant. As part of determining the observed cases, PO Box addresses and ungeocodable addresses (25% of the total) had to be manually researched for a physical address. To calculate the expected cases, age-specific incidence rates were calculated for 18 individual age groups for the State of Alaska and multiplied by the US Census population of each age group for the census tract. The resulting expected numbers of cases by age group were summed to get the total expected cases per year. Over a 12-year period of 1996-2007, there were 117 expected cases and 127 observed cases. To determine if the excess of 10 cases was not just due to chance, the SIR was calculated and determined to be 108.4, with a confidence interval (CI) of 89.6-127.3. Because the CI includes the value of 100, the excess of 10 cases is not considered to be statistically significant.

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CANCER AMONG HISPANICS IN NEW MEXICO, 1981-2008
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Background: New Mexico (NM) has the largest percentage of Hispanics (46.3%) in the U.S, of which 83% are native-born with claims to mostly Spanish and Mexican ancestry.

Purpose: This epidemiological study will describe cancer in NM Hispanics using data from the New Mexico Tumor Registry (NMTR), a population-based cancer registry.

Methods: Average annual age-adjusted incidence rates (per 100,000) were calculated by direct method for the time period 2004-2008, and were adjusted to the 2000 US standard population. Temporal changes in incidence rates were evaluated for years 1981-2008 using joinpoint regression.

Results: The overall cancer incidence rate is lower among Hispanics compared to NHW and the U.S., all races combined. Hispanics are about half as likely as NHW to be diagnosed with lung and bronchus, oral cavity and pharynx, urinary bladder, and thyroid cancers. Although most cancer types are lower among NM Hispanics than their NHW counterparts, liver and intrahepatic bile duct, and stomach cancer are twice as high. In general, the most common types of cancer have increased over the past 30 years for Hispanics; however, incidence rates are still lower than NHW.

Conclusion: Cancer has emerged as a major cause of morbidity and mortality among Hispanics in NM. Surveillance data from the NMTR is an important tool for describing the burden of cancer, increasing awareness, and identifying targets for cancer control efforts for NM Hispanics. Given the unique population in NM, culturally-sensitive cancer prevention programs must be developed.

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**INNOVATIVE USES OF CANCER REGISTRY DATA:
ESTIMATING THE NUMBER OF YOUNG BREAST CANCER
PATIENTS AT RISK OF INFERTILITY DUE TO CANCER
TREATMENTS**

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Increasingly, cancer surveillance data is being used to advance science, policy and public health. As part of the Affordable Care Act passed by Congress in March 2010, the Centers for Disease Control and Prevention (CDC) was directed to address breast cancer in young women. Infertility due to cancer treatments is a particular concern among young women, therefore, the objective was to estimate the number of young breast cancer patients who are at risk for cancer-related infertility by developing a conceptual model accounting for key factors in determining cancer-related infertility. The key factors were national statistics of cancer incidence in young women, estimates of receipt of hormone therapy and chemotherapy, estimates of the impact of chemotherapy on future fertility and estimates of future birth expectations. There is no one data source with the capacity to address all the factors. Therefore, we combined multiple surveillance and survey data sources to achieve our objective. Specifically, we obtained national breast cancer incidence among women aged 15-44 from CDC's National Program of Cancer Registries (NPCR) and the National Cancer Institute's Surveillance Epidemiology and End Results Program. Additional treatment information was obtained from NPCR's Breast and Prostate Cancer Data Quality and Patterns of Care Study and CDC's National Survey of Family Growth provided estimates of future birth expectations. The results of this study can be used to reinforce the need for oncologists to discuss the impact cancer treatment may have on young women's fertility and to gauge the potential demand for fertility counseling and possible preservation so that fertility providers, insurance companies and policy makers can make informed decisions about the value and importance of access to such services. This project highlights the impact that cancer registry data can have on improving the survivorship experience of young women with breast cancer.

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**DATA INTEGRATION AND UTILIZATION AT THE MARKEY
CANCER CENTER**

T S Gal^{1,2}

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Collaboration between the Kentucky Cancer Registry (KCR) and the Markey Cancer Center at the University of Kentucky has been crucial for both parties in order to achieve success in fighting cancer. Multiple staff and faculty serve double appointments at the two institutions and the informatics group at KCR has recently become the Shared Informatics Core of the Markey Cancer Center. One of the key corner stones of this close collaboration is the data management services that KCR provides to the Markey Cancer Center. Based on the data management services provided by KCR, a data warehouse was formed in 2010. The data warehouse collects and processes data from various sources, such as the central registry, the state wide electronic pathology reporting system, electronic medical records from multiple hospitals in the state, and other clinical and research data. The data is linked on patient level. Patient identifiers are separated from the rest of the data and stored securely for future linking purposes. KCR serves as an honest broker to provide data to customers with adequate authorization. Each data request goes through a formal review process to make sure that patient privacy is not violated. The KCR informatics group is in the process of finalizing a data governance policy that will address authorization and privacy issues through the data management process. This policy is aimed to simplify data access by creating standard operating procedures that can be vetted through the IRB letting KCR perform honest broker services without requesting IRB reviews for each project separately. The data warehouse has been proved to be a useful tool for the Markey Cancer Center. There have been multiple research grants submitted and awarded recently that utilize the data management services provided by KCR, such as rapid case ascertainment or biospecimen annotation.

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OVERVIEW OF SMALL CELL PROSTATE CANCER IN THE UNITED STATES: ITS INCIDENCE, CLINICOPATHOLOGICAL CHARACTERISTICS AND SURVIVAL
L Sun,¹ L Dickie,¹ C Johnson,¹ J Ruhl,¹ M Adamo,¹ S Altekruse,¹ J Su,¹ J Li,² M H Chen,³ A D'Amico⁴
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Background and Purpose: An overall picture about small cell prostate cancer remains unclear, mainly due to the difficulty to obtain a large sample. This study used the population based SEER database that covers approximately 26% of the total US population to characterize its pathological features.

Materials and Methods: Small cell prostate cancer men were retrieved. Race, age at diagnosis, year of diagnosis, PSA, cell histology, Gleason score, multiple primary tumor status, tumor stage and survival were analyzed using nonparametric methods and multivariate regressions.

Results: Among 843,896 prostate cancer men diagnosed between 1973 and 2008, 364 (0.043%) were with small cells. The racial percentage was 317 (87.1%) white men, 27 (7.4%) African Americans, 19 (5.2%) others, and 1 (0.3%) unknown. The median incidence over the total prostate cancer cases per year in past 36 years was 0.045% (IQR: 0.036 – 0.053). The median age was 72 (IQR: 65-80). There were 340 (93.4%) cases with small cell carcinoma NOS, 23 (6.3%) was mixed, and 1 (0.3%) was intermediate cell. Among 276 cases with tumor staging, 61 (22.1%) were T3-4 diseases, and 152 (55.1%) had metastatic disease. In 208 men with Gleason score, 179 (86.1%) had Gleason score 8-10. Among 71 men with PSA, the median PSA was 5.1 ng/ml (IQR: 2.7 – 12.4). There was no statistical difference in the PSA between the groups with and without metastatic disease ($p = 0.5161$). There were 222 (61.8%) men died of prostate cancer. Cox regression showed that older age (RR: 2.44, $p = 0.001$), T4 stage or with metastasis (RR: 2.31, $p = 0.035$) and Gleason score >7 (RR: 2.706, $p = 0.008$) were independent risk factors for death-free survival.

Conclusions: Small cell prostate cancer is highly rare and risky with short survival. It is usually diagnosed at low PSA level and advanced stage with metastasis. The findings indicate a need of a new strategy specific for its screening, early detection and optimal clinical intervention.

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THE NEW UNIFIED CANCER REGISTRATION SERVICE FOR ENGLAND
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In the near future, the care of patients with cancer will require good quality Cancer Registration to help separate the variety of molecular abnormalities in tumours; to achieve this you need a large population and a high quality dataset.

In order to raise standards of staging data to the best in the country, a single National Cancer Registration system is being rolled out, using the Eastern Cancer Registration and Information Centre (ECRIC) system EnCORE.

The vision is to provide near real-time, cost effective, comprehensive data collection and quality assurance over the entire cancer pathway on all patients treated in England. This will create a single high quality dataset that can be used for patient care, quality assurance, safety and performance management, audit, research and outcome monitoring.

This is more than just creating a single national database; it is about changing cancer registration practice in England, to achieve consistent data processing. The Encore system combines multiple electronic data records that are patient and tumour specific and from different hospitals so that registrars can view them together; this increases accuracy and speed and prevents duplication of work. Keyword highlighting aids the reading of complex pathology reports and source specific validations improve the quality of the data before, during and post registration.

A central data clearing house and processing service has been created which is easily expandable with improved data access and timely feedback to clinical teams along with seamless links to cancer screening. This will form the basis of integral support for National Cancer Audits, and Research and also the creation of extensive datasets for site specific registries.

By the end of 2012 all cancer registries in England will be using EnCORE, creating a data resource unmatched anywhere else in the world, with a population of 44 Million and recording every cancer in England; approximately 350,000 per year.

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COMPARATIVE ANALYSIS OF STAGE AND OTHER PROGNOSTIC FACTORS AMONG URETHRAL, URETERAL, AND RENAL PELVIS MALIGNANT TUMORS

S Nagoita,¹ M Dunn,¹ V Ralda¹
¹Westat, Rockville, MD

Background: Urinary tract (UT) malignant tumors include neoplastic lesions that arise in kidney parenchyma, renal pelvis, ureter, urinary bladder, and urethra. Age, sex, and race are among the determinants of UT cancer incidence and mortality. Stage at diagnosis, tumor histology and WHO grade predicts survival. Currently, the Collaborative Stage (CS) system classification of UT tumors is based solely on the site of primary tumor.

Purpose: This investigation aims to research whether the extension and dissemination of tumors arising at certain UT sites (urethra, ureter and renal pelvis) varies enough to warrant the use of two CS schemas. In addition, we will investigate whether histology alone or in combination with primary site is a strong prognostic factor that should be included in the definition of UT CS schemas.

Methods: SEER 17 Database will be use to select microscopically confirmed UT tumors (C659, C669, C680) diagnosed between years 2004 and 2009. Tumor anatomic extension (measured by the depth of tumor invasion) will be stratified by age, sex, race and compared by primary site, histology, and WHO grade. Similarly, the proportion of cases with disseminated disease will be compared by primary site, histology, and WHO grade. Survival of localized disease patients will be presented by site-histology combinations, while adjusting for demographics and treatment.

Results: Annually, there are approximately 1,700 UT tumors of interest reported to the SEER program. The majority of these tumors are assigned to KidneyRenalPelvis (88%). Proportion localized disease is similar for KidneyRenalPelvis (32%) and Urethra (30%). Crude five-year observed survival of patients diagnosed with localized disease is not significantly different between KidneyRenalPelvis and Urethra tumors.

Conclusion: From the cancer surveillance perspective, empirical data raise questions on the usefulness of current primary site-based classification of UT tumors.

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IS REPORTING OF PV & RHDS FROM NON-HOSPITAL SETTINGS ESSENTIAL?

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Under-reporting of polycythemia vera (PV) and hematopoietic diseases (RHDs) have been documented due to reasons including missed cases in non-hospital settings. In this report we described the extent of missed PV & RHDs cases by non-hospital based hematologists, oncologists, and primary care physicians (PCPs).

Kansas Cancer Registry is one of the three state central registries awarded by NPCR to develop best approaches to increase non-hospital reporting of PV and RHDs. Non-hospital based physicians were identified using a myriad of databases including NPI, KS Board of Healing Arts Physicians Database, KCR Physicians Database, and Internet Physicians Searches. A survey was mailed followed by phone contact to validate their in- and out-patient affiliation status. PCPs were selected based on population-density and the geographic locations to identify cases that were potentially missed due to a lack of access to hematologists and/or oncologists. Only 2010 diagnosed cases were included in this report.

A total of 20 clinics (9 PCPs and 11 hematology/oncology clinics) and 2 singleton hematology/oncology practices were recruited for the study. Only 13/20 clinics had patients records whose ICD-9CM codes met the criteria of being reportable cancers (189,843 records). A net of 3,662 records (3,356 patients) which were retained after removing duplicates were reviewed by the facilities. A total of 238 full abstracts were received and 203 were true non-hospital setting cases (5 from PCPs). The top 3 leading frequently used ICD-9CM codes that were found not reportable were myelodysplastic syndrome, unspecified, essential thrombocythemia and PV.

Our study found PV and RHDs can potentially be missed if non-hospital hematology, oncology, and PCP clinics were not involved in case reporting to central cancer registries. The extent of missed cases also depends on abstractors' coding training and facility coding practices.

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CANCER RISK IN A HOSPITALIZED COHORT OF PATIENTS WITH SYSTEMIC SCLEROSIS IN CALIFORNIA

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Previous cohort studies have reported increased risks of several cancer types among patients with systemic sclerosis (SS), although many of these have suffered from limited power and generalizability. We conducted a retrospective cohort study to examine cancer risk in a hospitalized cohort of SS patients in California via electronic linkage of cancer registry and patient discharge data over the period 1991-2009. Patients with a diagnosis of SS in the patient discharge database were followed up for cancer using registry data. Person-years of follow up were calculated for each individual. Time from the first hospitalization with a diagnosis of SS to one of the following three events was calculated: date of cancer diagnosis, date of death, or December, 31, 2010. Site-specific standardized incidence ratios (SIRs) and 95% confidence intervals (95% CI) were calculated to compare observed to expected numbers of cancers based on age, race and sex specific incidence rates in the California population. The 9,633 SS patients were observed for 61,160 person-years. A total of 564 cancers occurred within the observation period. Cohort members also had two- to three-fold significantly increased risks of cancers of the stomach, pancreas, kidney, thyroid, and brain, relative to the general California population. Risk of vagina/vulva cancer in the cohort was elevated (SIR: 5.4, 95% CI: 2.7, 9.4). Significantly increased risks of lung cancer (SIR: 1.6, 95% CI: 1.3, 1.9), non-Hodgkin's lymphoma (SIR: 1.6, 95% CI: 1.3, 1.9) and Hodgkin's lymphoma (SIR: 11.0, 95% CI: 3.0, 28.2) were also observed in the cohort. Results stratified by race and age will also be presented and potential biologic mechanisms underlying these relationships will be discussed. To our knowledge, this is the largest cohort study of cancer in patients with systemic sclerosis to date.

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A NEW APPROACH FOR ACCURATELY PROJECTING THE FUTURE BURDEN OF CANCER

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Background: Accurate projections of the future burden of cancer are essential for public health planning. Recent work shows that a new method for cancer projections, vector autoregressive (VAR) models, is more accurate for long-term predictions than current standard approaches. Despite their wide use in other fields, VAR models are essentially unknown among cancer data analysts.

Purpose: To illustrate the use of VAR models for long-term cancer projections and explore their unique contribution to our understanding of historical and future cancer trends.

Methods: Provincial and national incidence data (1971-2008) were obtained for >20 cancer types from the Canadian Cancer Registry. VAR models were fit to observed data and used to project annual numbers of cancer cases for all provinces and cancer types. Projection accuracy and precision, as well as model diagnostics, were examined for variations on the basic VAR model.

Results: Several aspects of VAR models are adjustable, depending on the projection scenario of interest. Particularly, (1) Bayesian approaches (BVAR models) permit finer age groups and the calculation of age standardized rates; (2) diagnostic statistics (AIC, BIC) allow a formal mechanism for selecting the best model; and (3) the problem of projecting from sparse historical data can be remedied by combining VAR and simple average methods.

Conclusions: VAR models have excellent potential for accurately projecting the future burden of cancer and clearly warrant further development and use.

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Poster Sessions

P-01

MODELING REPORTING DELAY IN THE NPCR DATA

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Background: Reporting delay happens when a cancer case is not reported to a cancer registry within the allowed reporting window. The direct impact of such a delay is underestimation of cancer incidence in more recent diagnosis years. However, previous published cancer incidence cases and rates estimated with the NPCR-CSS data were not adjusted for reporting delays. Previous studies have shown that there are two factors affecting reporting delay adjustment in cancer reporting: reporting delay and reporting error. In 2005, NCI published a method that estimated reporting delay distribution and delay error distribution jointly. The net between the two distributions is used to adjust reporting delay.

Purpose: The purpose of this study is to find appropriate, yet flexible, approaches to estimate reporting delay distribution for NPCR-CSS data with comparable performance as provided by the NCI models.

Methods: The reporting delay distribution in this study is defined as the cumulative net probabilities between reporting delay and reporting error where the reporting delay is less than or equal to delay time. The generalized linear mixed model was used to predict probability density function. The variance of reporting delay distribution was estimated with nonparametric Greenwood's formula adapted from lifetime table method.

Results: Our study showed that the NCI's algorithm did not apply to the reporting trend of NPCR-CSS data very well, especially when random covariates were introduced into the model. Preliminary results using fixed effect model will be presented.

Implications: Reporting adjustment will enhance the accuracy of national cancer incidence reporting and thus provide a more complete picture for cancer surveillance for public health purpose.

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P-02

DEFINING THE BURDEN OF CANCER AMONG SMALL ASIAN POPULATIONS IN WISCONSIN

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Background: There are approximately 15 million Asian Americans living in the United States, and they represent the fastest growing populations in the country. Many studies demonstrate that cancer incidence patterns among Asians are heterogeneous, but cancer statistics for Asian subgroups are not routinely available.

Purpose: Wisconsin has a very small but somewhat diverse Asian population (Hmong, Chinese, Asian Indian/Pakistani, Filipino, Vietnamese, Japanese). Reporting completeness for Asian subgroups is estimated to be much lower than for White and Black races. Increasing interest in granular race and ethnicity data requires a balance between: 1) aggregation of multiple small populations and 2) separation of subgroups to make variations apparent.

Methods: This report summarizes data on cancer incidence and stage at diagnosis for the largest Asian group in Wisconsin, Hmong and Whites as a referent group. We focused the analysis on the 4 most common cancers (prostate, breast, lung, colon/rectum) and the 3 more common sites among Asian Americans (stomach, liver, cervix).

Results: In Wisconsin, Hmong are diagnosed at later stages than are Whites. Between 1995 and 2008, only 27% of cancers diagnosed in Wisconsin's Hmong were detected at the local stage, compared to 46% among Whites. The Hmong community had lower proportions of lung, breast and prostate cancers, but higher proportions of cervical, stomach and liver cancers.

Implications: Possible disparities in cancer incidence between specific Asian subgroups in Wisconsin were identified for several cancers. The observed variation in cancer sites and unfavorable patterns of stage at diagnosis suggest a need for cancer control interventions in selected groups.

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Poster Sessions

P-03

THE IMPACT OF VETERANS AFFAIRS CANCER REPORTING IN NEW HAMPSHIRE

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The August 2007 Department of Veterans Affairs (VA) Veterans Health Administration (VHA) VHA DIRECTIVE 2007-023 effectively stopped the transmission of all VA cases to central cancer registries until new data security standards were met and new Data Use Agreements were established. In New Hampshire, this resulted in a four year gap in cancer reporting by the VA. The last transmission received by NHSCR from its local facility was in July 2007. Like many central registries, NHSCR had previously been receiving cases from the in-state facility but not from the VA facilities in adjacent states and beyond. NHSCR executed a new DUA with the VA in June 2011. In August 2011, NHSCR received from the VHA a transmission covering all NH residents in the VA central system, 1964-2011 covering 24 facilities; 79% of cases were from just 2 facilities in NH and VT. This single transmission provides the opportunity to examine the impact of VA cases on the incidence age adjusted rates in our state. We propose to examine age-adjusted incidence rates with and without VA cases to see if it alters our understanding of the burden of cancer in New Hampshire. We will look at the age-adjusted incidence, and the age, site and stage distribution of cases with and without VA data. We will further examine how many tumor records are reported only by a VA facility and how many were also reported by a non-VA facility.

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P-04

PREVALENCE OF COMORBID MEDICAL CONDITIONS AMONG ELDERLY COLORECTAL CANCER PATIENTS IN THE NATIONAL CANCER DATA BASE AND THE SEER-MEDICARE DATABASE

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Background: The National Cancer Data Base (NCDB) is a national hospital-based cancer registry, jointly sponsored by the American College of Surgeons and American Cancer Society. Approximately 70% of newly diagnosed cancers in the US are captured in the database. In 2003, NCDB began collecting data on comorbidities.

Purpose: To compare the prevalence of comorbid medical conditions among elderly colorectal cancer (CRC) patients in NCDB to the prevalence in a similar population of patients in the SEER-Medicare database.

Methods: In both datasets, we selected patients who were aged 66 or older, with Medicare as primary payer, first primary invasive CRC diagnosed during 2006–2007, carcinoma histology, stages I–IV and who resided in counties that exist in both datasets. The final sample size was 11298 in NCDB and 16554 in SEER-Medicare. Fifteen Charlson-Deyo comorbid conditions were identified through a search of diagnosis and/or procedure codes. Two methods for identifying comorbid conditions within four months of diagnosis were used for SEER-Medicare: index admission vs. index claim (inpatient, outpatient, or community physician visit). Comorbid conditions in the NCDB were identified through a search of ten comorbidity and complication fields. Comorbidity prevalence in the two datasets was compared with chi-square statistics. Charlson-Deyo comorbidity score was compared with t-tests.

Results: Using the index admission or claim, the prevalence of most comorbid conditions in NCDB was not significantly different from the prevalence in SEER-Medicare. The prevalence of CHF, chronic pulmonary disease, rheumatologic disease, mild liver disease, and renal disease was significantly lower in NCDB than SEER-Medicare ($p < .05$). Comorbidity scores were significantly different between NCDB and SEER-Medicare ($p < .0001$).

Conclusions: Using similar data collection methods, the prevalence of all comorbid conditions was similar in NCDB and SEER-Medicare.

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Poster Sessions

P-05

USE OF THE COLLABORATIVE STAGE DATA COLLECTION SYSTEM IN SURVIVAL ANALYSES: AN INITIAL REVIEW

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Background: The Collaborative Stage Data Collection System introduced a novel mechanism by which registries can record a fixed set of objective inputs from which AJCC staging elements and stage group, as well as SEER Extent of Disease, can be derived. To date, no known systematic assessment of survival statistics using CS derived stage group has been performed.

Purpose: Survival analyses are common in epidemiologic and clinical uses of cancer registry data. The purpose of this study is to assess the consistency and comparability of calculated 5-year survival rates stratified by physician staged AJCC stage group with that of the registry based CS derived AJCC stage groups for common and rare tumors as well as high and low mortality cancers.

Methods: The National Cancer Data Base has collected cases staged by CS since 2004. The NCDB currently has over 2 million case reports with five year vital status follow-up diagnosed in 2004 and 2005 reported from Commission on Cancer accredited programs. Staging information by the AJCC 6th edition has been reported for these cases via both CS and physician reported AJCC staging.

Analysis: Site-specific, stage-stratified, 5-year observed and relative survival rates for selected tumor types will be calculated. Comparison of results using both staging methodologies will be presented.

Implications: This study will be used to determine whether survival analyses stratified by CS Stage Group can reliably be included in published NCDB data in the future. Additionally, population based registries, which have historically used SEER EOD schemas to report outcomes, may determine whether CS derived AJCC stage groups can be useful in outcomes analyses.

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P-06

HOW DATA COLLECTION CYCLE AFFECTS SURVIVAL CALCULATIONS

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Background: When the NCDB originated, a 5-year data collection cycle was adopted in order to obtain 5-year follow-up data for survival calculation without requiring resubmission of all diagnosis years annually. However, a substantial portion of reports lacked 5 years' worth of follow-up at the time data were submitted during the 5th calendar year after the year of diagnosis, resulting in a high rate of case-censoring in 5th year calculations. Programs that made submissions in the 6th year were far more likely to have follow-up for 5 or more years. However, the 5-year collection cycle meant that those updated cases were not required to be resubmitted for an additional 5 years. Consequently, in 2011 NCDB implemented a data collection cycle in which all new and updated cases diagnosed since the program's Reference Date are submitted annually.

Purpose: This study was implemented to evaluate effects of the new submission cycle on case-censoring and stage-specific survival rates.

Methods: NCDB receives over 1 million case reports per diagnosis year from Commission on Cancer accredited programs. Programs are required to follow these cases annually, and the reports for cases diagnosed 2004-2010 that were added or updated since the last NCDB Call for Data along with the reports for unchanged cases already in the NCDB database will constitute the case pool. Sites will be selected to represent short- and long-term survival and relatively rare and common disease. Stage is based on CS derived AJCC 6th edition stage group.

Analysis: Site-specific percentages of cases with Date of Last Contact at least 1, 2, 3, 4 and 5 years following the Date of Initial Diagnosis; site- and stage-specific percentages of case-censoring; and calculated site- and stage-specific observed and expected survival rates will be presented.

Implications: This study will be used to determine which diagnosis years can reliably be included in published NCDB data in the future.

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P-07

LINKING CANCER REGISTRY DATA TO PERFORM OUTCOMES-BASED COMPARATIVE EFFECTIVENESS RESEARCH (CER)—FLORIDA, 2011

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Background: National cancer data collection requirements summarize treatment data in gross categories, making it impossible to use incidence registry data alone for robust outcomes-based CER. Florida hospitals and physicians are required to report patient information to the Florida Cancer Data System (FCDS). FCDS collected granular cancer treatment information by linking patient pathology and incidence data with detailed treatment data from hospitals and physician offices to investigate patient outcomes.

Methods: Five counties (Broward, Miami-Dade, Palm Beach, Orange, and Hillsborough) were selected as project target sites. FCDS surveyed select hospital abstractors to obtain information about their electronic data reporting practices. FCDS staff then conducted onsite case validation to collect hospital records and medical claims information for demographic and treatment data for patients diagnosed with breast, colorectal and CML cancers in 2011. The Florida DOH and FCDS completed data linkages with the Agency for Health Care Administration to analyze statewide cancer co-morbidity data. Cancer patient data were enhanced with medication therapies. Medical claims data allow FCDS to follow-back to providers for remaining data gaps. The DOH and FCDS staff performed physician outreach.

Results: 22 of 23 hospitals surveyed use an ERM or hospital information system, 75% of hospital EMR systems use discrete data combined with scanned images (using no national standard). Medical claims data represent a nationally recognized standard for coding diagnoses and medical procedures and also provide the majority of data necessary for complete cancer abstracts. Despite outreach, physician reporting is low, resulting in missed cases and incomplete treatment information.

Implications for Public Health: Enhanced medical data linkages will institute ongoing data-capture for rates of completed therapy needed to achieve better treatment outcomes and perform outcomes-based research.

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P-08

CCR VERSUS NAACCR: BRIDGING THE GAP WITH STANDARD SETTERS

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Background: The Canadian Cancer Registry (CCR) is a national dynamic administrative survey established in 1992, which contains person-oriented information on cancer incidence, mortality and stage from the thirteen provincial/territorial cancer registries (PTCRs). In order to harmonize the standards for collection of data elements with the standards and guidelines used by NAACCR a subcommittee of the Data and Quality Management Committee (DQMC) compared which NAACCR standards, variables and possibly edits could or may be adopted in Canada.

Purpose: To harmonize where possible the standards and variables for the collection and reporting of cancer data elements.

Method: The Resolution Issues Group a subcommittee of the DQMC has been working on a NAACCR/CCR comparison by examining each variable in the CCR with NAACCR variables and recommending the adoption of the NAACCR standard or continue with the CCR standard.

Results: A report will be produced identifying the differences and showing a comparison between NAACCR and CCR data variables.

Conclusions: This initiative will generate a final report recommending a consistent set of data element standards and ideally in future, a standard set of edits to be available to all Provincial & Territorial Cancer Registries in a portable stand alone software program that they can run through their data before submitting to the Canadian Cancer Registry.

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Poster Sessions

P-10

EXPANDING CANCER REGISTRY DATA COLLECTION FOR COMPARATIVE EFFECTIVENESS RESEARCH: LOGISTICAL ISSUES

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In 2010, New Hampshire was among ten state registries selected as Specialized Cancer Registries for expanded activities as part of the Comparative Effectiveness Research (CER) program and data collection is underway. We will share our experience with New Hampshire's expanded scope of work, highlighting our approach to addressing the challenges and progress through May 2012.

First, to our knowledge, we have developed the first inter-state collaboration whereby one state (NH) funds Certified Tumor Registrars to work within another state registry (MA). Approximately 15% of New Hampshire's cancer cases are only reported to us via Massachusetts Cancer Registry. We will describe the practical issues that arose in developing this collaboration and how we are addressing them, including aspects of data security, state law, and establishing a remote working relationship with contractors and another state registry.

Second, we are working to implement pathology laboratory cancer case filtering using Artificial Intelligence in Medicine (AIM, Inc) software at a large local hospital laboratory. This project has been well received by both the administration and hospital registrars. We will describe how we are addressing logistical issues implementing this project, including data security and ownership, competing with other priorities for computing services within the hospital, as well as practical issues with the customization of the software at a new site.

Finally, we proposed a statewide biomarker surveillance system resembling the annual pathology review that we use to validate case finding. Hospitals have agreed to provide these data. We will describe the mechanics of how biomarker data are reported from external laboratories to local hospitals.

Our New Hampshire CER project provides valuable experience and suggests novel approaches to address inter-state data sharing, electronic pathology data filtering, and biomarker surveillance.

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P-11

DEVELOPMENT OF AN AUTOMATED CONSOLIDATION ALGORITHM TO RESOLVE INCONSISTENT DATES OF DIAGNOSIS FROM MULTIPLE SOURCES

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Although each tumor has one valid date of diagnosis, two or more inconsistent dates are often received from different reporting sources. Resolving these inconsistencies can be a labor-intensive task. To our knowledge, no algorithms for the consolidation of diagnosis dates have been published. The New York State Cancer Registry (NYSCR) has developed such an algorithm and would like to share it with other registries. The algorithm was developed through many iterations of a trial and error process. The preliminary algorithm was designed based on our knowledge and past experience; tested using the tumors diagnosed during 2003-2009; modified based on the results of manual review from a random sample of tumors; and tested again. The reported date of diagnosis, class of case, service type (a NY-specific item similar to Type of Reporting Source), date of first contact and the previously consolidated date of diagnosis were considered in the algorithm. Among 209,907 tumors with inconsistent dates from ≥ 2 sources in the NYSCR, the algorithm resolved the inconsistent dates for ~96% of the tumors, leaving ~4% of the tumors for manual review. Of the resolved tumors, there was ~98% agreement between the algorithm-derived diagnosis year and the original consolidated diagnosis year, ~88% agreement for diagnosis year and month, and ~76% agreement for diagnosis year, month, and day. A sample of 381 tumors was then randomly selected from the tumors where there was disagreement between the algorithm-derived dates and the original consolidated dates. These were reviewed by an experienced senior coding supervisor, who found that the algorithm-derived date was correct ~77% of the time, the originally consolidated date was correct ~14% of the time, and neither was correct ~9%. These results suggest that the application of an automated algorithm not only saves time and labor but also improves the quality of tumor date of diagnosis.

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P-12

MISSING STAGE INFORMATION FOR PROSTATE CANCER CASES – TOO MUCH RELIANCE ON COLLABORATIVE STAGE?

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The New York State Cancer Registry (NYSCR) ranks highest among registries in the percent of prostate cancer cases with unknown derived summary stage (dSS), 17.6% for 2004-2008, excluding DCO and autopsy cases. Our objective was to assess the reasons for this unfortunate distinction.

The NYSCR does not require non-hospital reporting sources to report collaborative stage (CS), which we hypothesized as the main reason for the high percent of unknown dSS. Using the type of reporting source variable, only 40.7% of prostate cancer cases diagnosed 2004 to 2008 were hospital inpatients; 29.7%, 22.0%, 4.1% and 3.5% were reported by radiation treatment centers, outpatient sources, physicians, and laboratories, respectively. The percent unknown dSS varied by type of reporting source. It was 8.3% for hospitals; 31.4% for radiation treatment centers; 4.4% for outpatient sources; 35.5% for physicians; and 69.6% for laboratories. Missing dSS was not directly related to a specific missing CS element required to derive dSS. For the prostate cancer cases missing dSS, directly coded summary stage (SS) was available for 21.6% of cases, clinical AJCC stage for 22.3%, and pathologic AJCC for 1.9%. In total, 31.0% of prostate cancer cases missing dSS had some usable stage information, thus reducing the percent of cases missing any stage information to 12.1%, which is still fairly high. In order to obtain more complete stage information for prostate cancer, all stage information, not only CS, should be considered and consolidated into a composite stage variable. To further improve the completeness of stage data for prostate cancer will require more active work on the part of the NYSCR and consequently more resources.

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P-13

BORDERLINE OVARIAN TUMORS – TO COLLECT OR NOT TO COLLECT?

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With the implementation of ICD-O-3, fourteen ovarian tumor morphology terms (or five codes) were reclassified as borderline and became non-reportable, and a new borderline code was added. The New York State Cancer Registry (NYSCR) is among the few registries that have continued to collect borderline ovarian tumors. Our objective was to determine whether to continue doing so, using disease survival in our evaluation. More than 200 borderline ovarian cancer cases are reported to the NYSCR annually. While the incidence of ovarian cancer is decreasing, the incidence of borderline ovarian tumors appears to be increasing. For this study we included all microscopically confirmed ovarian tumors, diagnosed between 1996 and 2009, with behavior codes 1 and 3. The mean age at diagnosis for borderline tumors was significantly younger than for invasive tumors (49 vs. 61). Tumor behavior was not associated with race. Five-year relative survival varied by behavior and stage; it was 98.2% for borderline tumors and 90.5% for invasive tumors diagnosed at localized stage. To eliminate the effect of multiple primaries, we restricted further analyses to women with only one tumor. Among women with only one borderline ovarian tumor, 25.1% of deaths were attributed to ovarian cancer, while 44.7% of deaths were attributed to any cancer. Since the underlying cause of death is frequently misclassified, it is likely that almost all of the cancer deaths were due to ovarian cancer. We consulted a limited number of gynecologic-oncologists regarding whether to keep collecting borderline ovarian tumors and received a unanimous affirmative in reply. In light of their response and our findings, we will continue to collect these tumors.

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Poster Sessions

P-14

RATES AND RECENT TRENDS IN SQUAMOUS CELL CARCINOMAS OF THE LIP, U.S.

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Background: Squamous cell carcinoma of the lip is strongly related to cumulative lifetime exposure to the sun. This study updates the incidence rates of lip cancers overall and by selected factors in the US using the most recent data through 2008

Methods: Data from CDC's NPCR and NCI's SEER Program, covering 100% of the US population, were used to examine the incidence of invasive lip cancers diagnosed during 2004-2008 by subsite, sex, age, race, Hispanic ethnicity, region and stage. Incidence trends from 1999-2008, covering 90% of the US population, were also examined.

Results: During 2004 – 2008, 8953 cases of lip cancers were identified for an average annual count of 1791 (rate 0.58 per 100,000). Lip cancer accounted for 10% of oral cavity cancers. The majority (63.9%) occurred on the lower, external portion of the lip (67.3% among males and 52.4% among females). Incidence rates were higher among whites (0.64 per 100,000) than blacks, American Indians/Alaskan Natives, or Asian or Pacific Islanders (0.05, 0.32, 0.07 per 100,000 respectively); higher among non-Hispanics than Hispanics (0.61 and 0.26 per 100,000, respectively); and highest for persons living in the West region (0.73 per 100,000). Rates were about 4 times higher among males than females. Incidence increased with age with the highest rates found among persons 80 years and older (3.9 per 100,000). Most lip cancers were diagnosed in the localized stage, followed by regional and distant stages. From 1999-2008 the overall rate of lip cancers steadily declined from 0.90 per 100,000 in 1999 to 0.53 in 2008 (Annual Percentage Change (APC) -6.22%).

Conclusions: Most lip cancers in the US occur on the lower, external portion of the lip and among men in comparison to women. Rates have declined over the last decade likely associated with decreased sun exposure and smoking rates and increased use of UV lip protection

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P-15

ENHANCING CANCER REGISTRIES FOR COMPARATIVE EFFECTIVENESS RESEARCH: A CDC/NPCR APPROACH

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Background: This ARRA-funded project responds to the need for data to support comparative effectiveness research (CER) (or patient-centered healthresearch) on cancer outcomes. The Institute of Medicine's *Initial National Priorities for Comparative Effectiveness Research* identifies seven priorities focused on cancer outcomes. To measure these outcomes, data systems must provide timely, high-quality data on treatment regimes, co-morbidity, prognostic biomarkers, and other significant determinants. Central cancer registries (CCRs) play a significant role in the development of this data infrastructure.

Purpose: The purpose of this project is to establish Specialized Cancer Registries by enhancing data collected through a subset of NPCR-funded CCRs for CER. Outcomes will include a dataset to be used for CER and other research.

Methods: Through an open, competitive process, CDC/NPCR selected 10 CCRs as Specialized Cancer Registries (CORE) to develop sustainable methods to enhance cancer registry data in supporting CER through additional data collection, training, methodological development, and the expansion of electronic reporting. Six Special Projects were also selected to explore innovative public health applications of particular concern to CDC/NPCR: 1) Improving race/ethnicity data; 2) Developing innovative uses of cancer registry data; and 3) Implementing electronic reporting from clinic and physician offices.

Results: The presentation will include project organization, major activities and early success stories of the CORE CER and Special Projects.

Implications: Data collected from this project will permit a more detailed evaluation of CER questions identified by CDC and the Agency for Healthcare Research and Quality. The methodologies developed under this project will enhance the NPCR-funded central cancer registries and contribute to national cancer surveillance and prevention goals.

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Poster Sessions

P-16

DO NOT CONTACT ME! CHARACTERISTICS OF CANCER PATIENTS REFUSING REGISTRY CONTACT

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Background: A key problem facing cancer registries and researchers are patients who refuse registry contact. Patients who request never to be contacted by the registry are excluded from all active follow-up contact, patient contact studies, and patient identifiable cancer research.

Purpose: The purpose of this study is to examine the characteristics of cancer patients who have actively requested never to be contacted by the Utah Cancer Registry (UCR).

Method: Patients who request never to be contacted by the UCR are flagged as a “do not contact” with a do not contact reason of “patient requested no contact”. We analyzed the tumor records of these patients looking at the distribution by race, ethnicity, gender, age at diagnosis, cancer site, stage at diagnosis, diagnosis year, county of residence at diagnosis, vital status, and marital status at diagnosis.

Result: 626 patients (666 tumors) requested no registry contact. Over 95% of these patients are non-Hispanic White with a near equal gender distribution (52% female and 48% male); 18% were less than 40 years of age at diagnosis, and over 56% were age 55 or older at diagnosis. The leading five cancer sites were prostate (18%), breast (16%), colorectal (12%), female genital (11%), and skin (11%). No other cancer site accounted for more than 6% of the distribution. A majority of tumors were local stage at diagnosis. Over 85% resided in urban counties at diagnosis. Nearly 50% were diagnosed with cancer within the last 10 years.

Conclusion: Patients requesting no registry contact are largely representative of the Utah Cancer Registry population, which suggests that “do not contacts” are randomly distributed. Selection bias is a perennial concern for researchers; however, the representativeness of the patients requesting never to be contacted by UCR suggests that selection bias is not an issue with the Utah Cancer Registry population.

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P-17

INSIGHTS INTO BRAIN AND CNS TUMOR EPIDEMIOLOGY AMONG THE CHRONOLOGICALLY ADVANTAGED IN THE US POPULATION

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On January 1st, 2011 and every single day over the next 19 years more than 10,000 Baby Boomers have reached or will reach the age of 65, a fact that highlights the aging of the US population. This population trend undoubtedly will have a profound impact on disease patterns including those involving brain and CNS tumor incidence, mortality, and survival prompting an evaluation of population-based cancer registry data. The study was based on data from cases diagnosed with brain and CNS tumors (ICD-O-3 primary sites: C70.0-C72.9, C75.1-C75.3) in the Central Brain Tumor Registry of the United States (CBTRUS) twenty-one state population-based cancer registries analytic data set, 2004-2007 (n=81,085) and the Surveillance Epidemiology End Results Program (SEER) thirteen registry research data file, 1992-2008 (n=18,870). Incidence rates of malignant and non-malignant tumors were compared and contrasted for six age groups including 0-19, 20-39, 40-59, 60-69, 70-79, and 80+ years using CBTRUS. Trends and survival among the chronologically advantaged group (60+ years) were further examined for malignant tumors using SEER. All analyses were conducted using SEER*Stat v.7.0.5. Incidence rates for all combined, malignant, and non-malignant tumors were observed to progressively increase for each advancing age group with the highest rates observed for 80+ years with only one exception; malignant rates were not significantly different between the age categories 70-79 and 80+ years. Trend analyses for malignant brain tumor rates by age category showed a statistically significant decrease for 60-69, no change for 70-79, but a statistically significant increase among those 80+ years of age. Survival was poorest in the oldest 80+ year category which is of importance given the increasing incidence trend for this respective group. Such an increase will require attention to approaches needed to treat and care for those diagnosed with brain and CNS tumors in this population subgroup.

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Poster Sessions

P-18

PROGRESSING TOWARDS 21ST CENTURY INFORMATICS INNOVATION IN NEW BRUNSWICK CANADA-EHR & CANCER REGISTRY

S Leonfellner,¹ A Wang,¹ B Zhang,¹ A O'Brien,¹ T Foster,¹ E Kumar,¹ R Savoie¹

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The New Brunswick Cancer Network (NBCN) began its journey into the world of cancer informatics in July 2008 when the Canadian Partnership Against Cancer (CPAC) – the federally-funded organization leading the implementation of Canada’s cancer control strategy – began working with provinces, territories and national partners on the National Staging Initiative (NSI). The intent of the initiative was to achieve national population-based Collaborative Stage (CS) capture for cases of Canada’s four most common cancers (breast, prostate, lung and colorectal) diagnosed on or after January 1, 2010. With project funding provided by CPAC, NBCN embarked on a plan to enhance stage capture in NB by purchasing lab tools that can utilize the College of American CAP Cancer Protocols (CCP’s). The radical prostatectomy CCP and the invasive breast, lung and colorectal resections CCPs’ were selected because they provided the most complete staging information for these 4 leading cancers in NB which account for about 55-57% of new cancer cases and deaths each individual year.

Objectives 2008-2012

The project objectives are to:

1. Implement synoptic pathology reporting tools into hospital lab information systems that can utilize the computerized versions of the four CCP’s (i.e.; electronic cancer checklists or eCC’s);
2. Bring all pathology reports into the interoperable Provincial Electronic Health Record (EHR). The EHR in NB integrates patient clinical data from all NB hospital systems into the “One Patient, One Record” so that there is a single point of web based viewing; and,
3. Provide registry access to the EHR for all reports required to assign CS stage including diagnostic imaging, blood lab and pathology reports that will replace faxing.

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P-19

ESTIMATING THE COSTS OF A DATA BREACH: AN EXERCISE AT THE NEW HAMPSHIRE STATE CANCER REGISTRY

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Following a risk assessment undertaken at Dartmouth College, NHSCR performed a planning exercise to estimate what a data breach might cost our supporting institution. The Ponemon Institute publishes annual report on the costs of a data breach. There are data breach liability calculators on the web. The potential costs include internal investigation, notification and crisis management, and regulatory compliance. The poster will take publically available information and apply to NHSCR to generate some rough estimates of the potential cost of a data breach. Estimates of the costs of data breach are one tool in generating support for data security.

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Poster Sessions

P-20

BASILINE EVALUATION OF PATHOLOGY REPORT COMPLETENESS AND FORMAT ON BREAST, LUNG, COLORECTAL AND PROSTATE CANCER SPECIMENS IN NEW BRUNSWICK 2007-2008.

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Background In November 2009, a pilot study was conducted to assess the baseline state of pathology reporting in NB and to evaluate the completeness in a sample of pathology reports using CAP - required data items as the content standard.

Study design: A cross-sectional survey was conducted using eligible pathology reports from all eight labs (seven health zones) in NB to assess report format and completeness based on CAP required data items in 2007-2008 before project implementation.

Methods: A simple random sample of eligible pathology reports was taken from each of the four cancer sites and by seven health zones. To keep statistical power or precision across all labs, all of the pathology reports in the smaller zones were included for each cancer site. A random selection of eligible pathology reports was taken for larger health zones. The NB Discharge Abstract Database was used to obtain a list of eligible invasive cancer surgery procedures done in 2007-2008 for breast, prostate, lung and colorectal cancers. A registered and certified medical laboratory technologist reviewed the pathology reports for completeness and pathology report format.

Statistical analysis: Odds ratio and associated 95% confidence interval were used to measure the difference between pathology report format (narrative vs. synoptic) and completeness. Sampling selection weights were considered in the logistic regression model to obtain more accurate parameter estimates. All analyses were performed using SAS version 9.1.

Results: The NB pilot study showed that of the approximately 685 pathology reports reviewed from all eight labs in NB for the four leading cancer surgeries, 71% were in narrative format and 29% were in synoptic format. The completeness using CAP standards for all four cancers was relatively higher when the report format was synoptic, especially for lung, colorectal and breast cancer.

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P-21

HEALTH INDICATORS FOR NOVA SCOTIA FIRST NATIONS COMMUNITIES: THE TUI'KN INITIATIVE

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Among the challenges facing First Nations peoples in Canada, the absence of health surveillance data for their communities is a barrier to understanding and gaining control of health planning. Five First Nations communities on Cape Breton Island, Nova Scotia have installed Electronic Patient Record (EPR) systems in each of their community health clinics. Health practitioners serving these communities use these systems to maintain patient profiles, and to facilitate billing to the provincial Medical Services Insurance (MSI) program. The Tui'kn Initiative started in 2004 to develop these separate EPRs into a single Client Registry which could be linked to provincial administrative health data sources, in order to provide community-based health indicators within a framework that would allow comparisons over time, and to the wider Cape Breton and Nova Scotia populations.

To fully enumerate the populations encompassed by the five communities, three datasets were linked: the communities' own EPRs; the provincial MSI database; and a list of First Nations' individuals living in Nova Scotia, registered in the national database of Indian and Northern Affairs Canada (the INAC database). The resulting Client Registry (CR) was then available to be linked to several different health outcome or utilisation databases available at the provincial level.

This presentation will describe the challenges of the linkage activity required for the project and the partnerships created as a result, to make this work a sustainable resource. Results will focus on the types of health indicators that were derived from the linkage to datasets held by Cancer Care Nova Scotia, namely the cancer registry, and the Cervical Cancer Prevention Program database. The impact of the First Nations' guiding principles of Ownership, Control, Access and Possession (OCAP) on the way individual- and aggregate-level data is managed will be described.

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Poster Sessions

P-22

OBESITY AND CANCER IN MASSACHUSETTS, 2005-2009

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Background: Obesity has become recognized as a major public health challenge. While it is commonly known that obesity increases the risk of heart disease, stroke, high blood pressure and diabetes, many are still unaware that obesity can affect cancer risk. There is a growing body of evidence that being overweight or obese increases risk of certain types of cancer.

Purpose: To compile relevant data that can inform Cancer Control educational efforts and public health policy around the topic of obesity and cancer, and serve as a baseline from which future progress and trends can be monitored. Data include the incidence of obesity-related cancers in Massachusetts, overweight/obesity prevalence, and other health behaviors associated with either obesity such as diet and physical activity, or cancer (screening for example).

Methods: The Massachusetts Cancer Registry, in collaboration with the Behavioral Risk Factor Surveillance Program and the Comprehensive Cancer Control and Prevention Program are compiling Massachusetts-specific incidence rates on obesity-related cancers, and measures of health behaviors. Profiles will be created that will include age-adjusted rates for 2005-2009 for five types of obesity-related cancers including post-menopausal breast, colon, endometrial, adenocarcinoma of the esophagus and renal cell carcinoma, and BRFSS data on percent overweight/obese, and cancer screening prevalence. Profiles will describe incidence and BRFSS measures for Massachusetts as a whole and by Massachusetts regions.

Results/ Conclusion: The percentage of Massachusetts adults who are obese increased from 20.7% in 2005 to 21.8% in 2009. Patterns in incidence for the 5 identified cancers vary by cancer type and by socio-demographic population composition. Colonoscopy screening statewide increased for both sexes from 2005-09, but decreased in the Central and Metro West regions for females, and decreased for Western and Central regions for males for this period.

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P-23

REPORTING PRACTICES AND CHALLENGES FROM NON-HOSPITAL FACILITIES AND PHYSICIANS FOR DEATH FOLLOW BACK OF DEATH CLEARANCE IN MARYLAND

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Background: Death clearance is defined as the process of matching registered deaths in a population against reportable conditions in the central cancer registry database. All deaths with a reportable condition mentioned as a cause of death which are not found in the central cancer registry are Death Certificate Only (DCO) cases. These cases require follow back to facilities and physicians to obtain additional information. NPCR and NAACCR Standard V.c.2, DCO cases must represent 3% or fewer of total cases in the registry database. The Maryland Cancer Registry (MCR) conducted an extensive follow back to hospital facilities and non-hospital facilities, including nursing homes, hospice, and physician offices.

Purpose: The aim to assess the reporting practices of non-hospital reporters because they may have fewer trained staff in cancer registration.

Methods: Westat matched patients and tumors of Maryland residents who died in 2009 to the MCR database of reported cancers using SAS programming. Facilities and physicians were followed back to identify the reportable tumors listed on the death certificate but not found in the MCR database. Hardcopy forms were mailed. Data received from reporters that met the minimum requirements to clear DCO status were inputted into the MCR database.

Results/ Conclusion: This presentation will describe the reporting practices of non-hospital facilities and physician reporters; compare the quality and completeness of non-hospital reporting with hospital reporting; and identify the most common reporting issues among non-hospital facilities and physician reporters. We will also discuss the challenges to following back non-hospital reporting facilities and physicians as well as lessons learned.

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Poster Sessions

P-24

HEALTH-ADJUSTED AGE TOOL TO INFORM AGE TO STOP SCREENING

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Background: A critical question in public health policy is at which age screening for cancer should stop. The benefits of early detection and treatment decline sharply with age because older persons are more likely to die from comorbid conditions or competing causes of death. Some of the guidelines, for the age to stop screening are based on life expectancy. The objective in this study is to estimate life expectancies and a “health-adjusted age” for people without cancer taking into account comorbid conditions.

Methods: A random 5% sample of Medicare beneficiaries residing in the SEER areas and not diagnosed with cancer (SEER-Medicare database, 1992-2005) was utilized. ICD-9-CM codes recorded in claims were used to identify 16 comorbid conditions, and comorbidity score were calculated. We used Cox proportional hazards model to estimate the life tables by specific comorbidity profiles and calculated the health-adjusted age by comparing the estimated life tables with the decennial 2000 US life tables.

Results: The mapping of the health-adjusted age by sex, race and the comorbidity groups for chronological age from 66 to 90 showed that the health-adjusted ages are younger for healthy individuals, similar for individuals with low/medium comorbidity and older for individuals with high comorbidity compared to their chronological age. Individual with CHF had the lowest survival among the frequent comorbidities (diabetes, COPD and CHF), suggesting worse life expectancy compared to the US average population.

Conclusions: The estimated survival probabilities differ by comorbidity profiles. The health-adjusted age can be used by physicians to determine if a person with a given age and comorbidity is below or above the stop age recommended by screening guidelines. It will provide useful information for guideline development and assessment of potential impact of implementation on over diagnose (or other harms).

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P-25

DEVELOPING A NATIONAL INTERSTATE DATA EXCHANGE APPLICATION SYSTEM (N-IDEAS) FOR NPCR: A CMMI APPROACH

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Background: The state cancer registry collects cancer data regardless of where the cases were diagnosed or treated. The exchange of data between cancer registries is important to ensure data completeness and evaluation. The information technology solution using N-IDEAS provides a way of secure data exchange. By following the Capacity Maturity Model Integration (CMMI) process improvement approach throughout the software development life cycle (SDLC), we implemented a solution to help provide a quality product.

Purpose: The N-IDEAS provides technical assistance to facilitate secure data exchange between state cancer registries. The system provides monitoring and tracking of data exchange for CDC reporting. CMMI standards were followed to streamline development process.

Method: An n-tier solution with .Net technologies and XML web services was used. The system followed NIST standards for security and Advanced Encryption Standards (AES) to encrypt data. Encrypted data were sent over HTTPS protocol, which made the data exchange more secure. The CMMI approach for project management, requirement, design and quality were followed for proper documentation and clear understanding of the system. A pilot implementation of the project has been tested with selected NPCR-funded registries.

Results: The output of the project is an easy-to-use secure data exchange system. The presentation will include a summary of the CMMI approach and a demo of how the system works in a real-world registry setting.

Implications: The N-IDEAS is another product developed for CDC/NPCR that can be widely used to help cancer registries in their data collection and operation improvement efforts. The CMMI approach for the product development will ensure timely delivery of product that meets the users’ requirements.

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Poster Sessions

P-26

LINKING DATA FROM THE NATIONAL HEALTH INTERVIEW SURVEY (NHIS) AND THE FLORIDA CANCER DATA SYSTEM (FCDS): PROJECT UPDATE

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Background: Previously our study team completed a trial linkage between data from the 1987 National Health Interview Survey (NHIS) of the National Center for Health Statistics (NCHS) and the Florida Cancer Data System (FCDS) database. We then undertook a full linkage of 1986-2009 NHIS data and the entire FCDS database. " has been linked to other national administrative records, this linkage provides a highly enriched source for cancer surveillance research.

Purpose: The purpose of this project is to assess the feasibility and logistics of linking national population-based survey data with individual state cancer registries. The ultimate goal 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.

Methods: Employing a probabilistic algorithm through LinkPlus version 2, we conducted a linkage between 1986-2009 NHIS data and 1981-2010 FCDS data using Social Security number, name, date of birth, and sex. Matching scores were assigned to identify true, false, and questionable matches. All questionable matches were reviewed manually.

Results: There were 1,913,210 NHIS records submitted for linkage to 2,520,333 FCDS records, resulting in a total of 10,406 matched cases that represent NHIS participants diagnosed with cancer in Florida prior to or subsequent to their NHIS interview. The de-identified, linked data will be deposited in the secure NCHS Research Data Center (RDC) to be analyzed by approved researchers.

Conclusions: Results from this linkage indicate this is a feasible and worthwhile research endeavor. Similar linkages conducted by other central cancer registries would represent an unparalleled data resource for evaluating cancer risk factors, screening behaviors, and healthcare assess and utilization in a large sample of cancer patients.

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P-27

FINDING A PATH TO BECOMING A SURVIVAL REGISTRY

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Background: The majority of NPCR-funded registries are incidence only but many, including the Missouri Cancer Registry and Research Center (MCR-ARC) have the goal of becoming survival registries. Like other registries, we continue to have occasional discussions about the need to become a survival registry in order to have outcome data needed to better serve public health and research interests. Staff express concerns about the additional work needed to become a survival registry.

Purpose: Identify steps to become a survival registry. **Methods:** MCR-ARC will survey central cancer registries to determine whether survival (other than SEER) or incidence. Follow-up questions will be tailored to their classification. Questions for survival registries will focus on how registries moved from incidence to survival (or were they always a survival registry); identify barriers and challenges registries; learn methods registries use to keep data current; ascertain costs involved in maintaining a survival registry; and how registries perceive the quality and completeness of their data. For incidence registries, the focus will be on finding out if the registries are planning to become survival registries; the challenges and barriers registries face; anticipated costs; and perceived benefits.

Results: We will present results of the surveys as well as information from our own gap analysis, utilizing survey results to assist with completion of the gap analysis. The gap analysis will include a description of the present situation along with factors required to achieve the objective of becoming a survival registry and highlight existing gaps that need to be filled.

Conclusion: We will use the results of the surveys to inform us in developing a survival registry strategic plan. Survival registries with high-quality, complete and timely data provide added value to researchers and public health professionals.

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Poster Sessions

P-28

WHICH COUNTY IS IT? WHEN REPORTED COUNTY DOES NOT MATCH GEOCODED COUNTY

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Florida Cancer Data Systems (FCDS) currently reports county level cancer rates based on the county denoted by the reporting facility. However, the process of geocoding cancer cases can often result in a change or “improvement” from one county to another—most often to a contiguous county or sometimes one in close proximity. This represents a problem with publishing cancer rates by county—which county is it? Do the geocode based rates represent an improvement or introduce additional error?

Moving from reported county for rates to geocoded county for rates resulted in a loss as great as 60% for one Florida county and a gain as high as 120% for another. The change in rates varies by county over time with the biggest impact on medium size counties. The rates also are impacted due to the level of geocoding coverage—some counties have a higher geocoding rate than others.

We postulated a “move” to a contiguous county was often based on zip codes crossing county lines. And a move to a county in close proximity is often the result of the facility’s county being reported instead of the patients. And, although this scenario is less common, we hypothesized that a cancer case reported in a county quite far from the geocoded county resulted from either data entry error or geocoding error. But how do we know? FCDS is considering publishing cancer rates based on geocoded county. But as we considered this change, we needed to understand the characteristics of cancer cases that are reported and geocoded to different counties. There are a variety of implications from changing how we publish county rates—including caveats that must be written in annual reports and the allusion of dramatic changes in rates for counties with cancer cluster concerns.

This presentation details the characteristics of “moving” cases and the tests the above assumptions.

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P-30

NON SMALL CELL LUNG CANCER (NSCLC) INCIDENCE RATES, TREATMENTS AND SURVIVAL BASED ON TUMOR SIZE: A COMPARATIVE ANALYSIS FOR STATE OF LOUISIANA (LA) TO THE REST OF THE UNITED STATES (RON)

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Although the incidence of lung cancer has been decreasing in the United States over the years, there has been no significant improvement in survival. The survival rates of NSCLC vary depending upon tumor size and initial treatment. Access to care is a key predictive factor to successful treatment of lung cancer. LA, a state recently ranked 49th yet again for health care, experiences a high degree of lung cancer mortality. We examined NSCLC incidence, comparing tumor size, treatment and survival in LA compared to the rest of the United States.

Methods: Using SEER*Stat we analyzed data on NSCLC cases from 2004-2008. Variables included in the analyses were age, gender, race, stage, tumor size (< 2cm, 2-3.9cm, 4-5.9cm, 6-7.9cm, 8-9.9cm, >10cm), histology, year of diagnosis, type of treatment, SEER registry.

Results: A total of 153,469 NSCLC cases were reported from 2004 to 2008 in all SEER registries. LA had significantly* higher incidence rates of NSCLC than the RON for all tumors >2cm. LA males had significantly higher incidence rates for all tumor sizes than RON, while females in LA had significantly higher incidence rates for all tumor sizes >2cm than RON. We observed significantly lower rates for Blacks to be diagnosed with tumor sizes <2cm in LA than in RON. Blacks were less likely to receive any type of surgery for NSCLC tumor sizes <4cm than whites in both regions. Blacks were significantly more likely to receive radiation for tumor sizes >6cm in LA than whites, while this trend was observed for tumor size >2cm for blacks in RON. The relative 5-year survival rates were lower for LA than RON for whites (16% vs. 18.6%) and for blacks (12.9% vs. 15.5%).

Conclusion: LA experiences significantly higher incidence rates of RON for NSCLC. We also found racial disparities in treatment received based on tumor size. More studies from diverse populations are needed to address racial disparities in treatment and survival.

*Significance level p<0.05

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Poster Sessions

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PUBLIC HEALTH SURVEILLANCE AND RESEARCH: EVOLUTION OF THE CANCER REGISTRY DATA SET

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Background: Cancer registries have a long-standing history in data collection and carry a wealth of information that is not used to its full potential. Cancer registry data needs to be more visible and available for use to increase the cancer registries' use and role in the public health field. Cancer registries have developed a minimum core dataset that started with 25 required data elements that is now up to over 200 required data elements. In order to meet research and ongoing needs registry data needs, accurate, timely and complete registry data needs to be made available in a timely manner. **Purpose:** To identify the development of cancer registry data set over time from 1985 to 2010. Cancer Registries do collect a vast amount of information and data fields (>200) but when asked to provide data sometimes fall short due to data elements that are requested that are not collected. **Methods:** A literature review and review of cancer registry requirements was conducted to analyze and show the evolution of the cancer registry dataset over time. We searched Ovid Medline, Pub med and Compendex with the Medical Subject headings public health, cancer registry, clinical dataset, standards. **Discussion:** The cancer registry dataset has evolved from as minimal as 25 data elements to over 200 required data fields. Do we need that many data elements to fulfill the requirement for public health, surveillance and research? **Results and Conclusions:** The cancer registry data set as is now does not meet researchers' needs, the data collected is not available in the time needed to conduct research and may not have what the researcher needs when available. Because of these two major drawbacks and the barrier to access cancer registry data, cancer registry data is not used to its full potential. Most cancer registries have by now more than 10 years of research quality data available, that can serve and significantly contribute and provide for current research.

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P-32

A REVISED SAS MACRO FOR COMPUTING THE CHARLSON SCORE

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Background Statement: The Charlson score is a widely used method for measuring the burden of comorbid illnesses in patient populations. SAS macros developed by the NCI (the NCI index) estimate the Charlson score from insurance claims data and these macros enable researchers to measure comorbidity in the SEER-Medicare population. **Purpose:** To determine if revising the NCI index changes our estimate of the prevalence of comorbid conditions in cancer patients. **Methods/ Approach:** We perform a descriptive analysis comparing disease ascertainment with 4 different versions of the SAS macro: (1) the original NCI index (CPTs and ICD-9s), (2) the NCI index without CPT codes (ICD-9s only), (3) the NCI index with updated ICD-9 codes (old CPTs, new ICD-9s) and (4) the NCI index with updated ICD-9 codes and no CPT codes (ICD-9s only). The 4 versions of the index are applied to claims data from SEER-Medicare patients with a diagnosis of lung, prostate, breast, or colorectal cancer between 1/1/92 and 12/31/96. **Results:** We present the frequency of disease ascertainment by NCI index version and cancer site. There are 16 different comorbid conditions included in computing the Charlson score. Updated ICD-9 codes were available for 10 of the 16 conditions. Only 3 of the 16 conditions relied on CPT codes for disease confirmation. **Conclusions:** Because codes evolve over time it is important to reassess and revise the comorbidity algorithm to reflect updates in the codes and to improve estimation of comorbid disease. **References:** Klabunde CN, Legler JM, Warren JL, Baldwin LM, Schrag D. A refined comorbidity measurement algorithm for claims-based studies of breast, prostate, colorectal, and lung cancer patients. *Annals of Epidemiology*. 2007 Aug;17(8):584-90. National Cancer Institute, Health Services and Economics Branch. SEER Medicare: Calculation of Comorbidity Weights. Available at: <http://healthservices.cancer.gov/seermedicare/program/comorbidity.html>

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Poster Sessions

P-33

RECEIPT OF BREAST CANCER TREATMENT AMONG WHITE AND BLACK MEDICARE BENEFICIARIES

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Background: Racial disparities in breast cancer treatment among Medicare beneficiaries have been documented in the literature. This study aimed to determine whether racial disparities exist among white and black female Medicare beneficiaries in Alabama, one of the poorest US states.

Methods: From a linked dataset that included breast cancer cases from the Alabama Statewide Cancer Registry and fee-for-service claims from Medicare, we identified 2,251 white and black females, aged 66 years and older, who were diagnosed with stages I-III breast cancer (ICD-O-3 codes C601-C609) from January 1, 2000 to December 31, 2002. Standard therapy for breast cancer was defined based on the National Comprehensive Cancer Network Clinical Practice Guidelines. Generalized Estimating Equation (GEE) models were used to determine whether there were significant differences in having initiated or completed treatment between whites and blacks after adjusting for confounders.

Results: Among women diagnosed with breast cancer, 61.9% of whites and 65.3% of blacks had mastectomy (p=0.27); 34.7% of whites and 29.9% of blacks had breast conserving surgery (lumpectomy, p=0.12). Among those who had a lumpectomy, 78.0% of whites and 82.7% of blacks started adjuvant radiation therapy (p=0.33) and 81.3% of whites and 86.6% of blacks completed adjuvant radiation therapy (p=0.29.) For women with tumors over 1 centimeter, whites and blacks were equally likely to start (17.1% of whites and 19.7% of black; p=0.34) and complete (48.7% of whites and 50.0% of black; p=0.87) adjuvant chemotherapy. There were still no differences between whites and blacks after adjusting for confounders using GEE.

Conclusion: No racial differences were found in guideline-specific breast cancer treatment or treatment completion. Future studies should examine whether similar results hold in other poor US states and if other disparities (e.g. stage at diagnosis) still exist.

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P-34

BUILDING BRIDGES - THE CBTRUS EXPERIENCE WITH ADVOCACY ORGANIZATIONS

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In July 1992, the Central Brain Tumor Registry of the United States (CBTRUS) was incorporated as a 501 c (3) nonprofit research organization in Illinois and celebrates its twentieth anniversary in 2012. For three years prior to this historic date, the Committee Investigating Cancer Registration of Primary Brain Tumors worked under the auspices of the American Brain Tumor Association, the oldest brain tumor advocacy organization in the United States. The initial funding for the Committee work was provided by the fledgling Ride for Kids organization which later became the Pediatric Brain Tumor Foundation. It was a time when health advocacy was intense most notably from the AIDS and breast cancer advocates. Advocates from the brain tumor patient community learned from these advocate trail blazers and made their own contributions. The aims of this presentation are as follows: (1) to describe the events and experiences with advocacy organizations that have resulted in the improvement in brain cancer registration; (2) to promote descriptive epidemiology studies of brain and central nervous system tumors using population-based cancer registry data; and, (3) to recognize the contributions that these advocacy organizations have made to CBTRUS and the stakeholder scientific and lay communities over the last twenty years.

Notes _____

Poster Sessions

P-35

ELECTRONIC PATHOLOGY PROJECT IN NORTH CAROLINA CENTRAL CANCER REGISTRY

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The complexity of cancer registration has increased over the past few years with the high demands for quality cancer data. Ongoing enhancement of cancer registry practices and operations improve data collection and methods for processing data. The North Carolina Central Cancer Registry (NC CCR) initiated ePath reporting in June 2008 to facilitate encrypted transmission of cancer data from pathology laboratories for the purpose of electronic case-finding. As of December 2011, 18 of 30 identified Pathology laboratories report to the CCR and about 65% of all the pathology reports are received electronically. To date, the CCR has received 50,000 + electronic pathology reports from 18 labs. The CCR is making tremendous progress in recruiting more and more pathology labs to report to the registry via ePath.

Presently, CCR uses three systems to integrate the pathology reports into the CCR's Eureka database, Public Health Information Network Messaging System (PHINMS) is used for secure transmission of data from pathology lab to CCR; the CDC's eMARC PLUS software is used to process, filter, auto-encode and auto populate data into the NAACCR abstract format; and, the Parser developed by Public Health Institute is used to parse Pathology report data and integrate it into the Eureka database.

This presentation will focus on the NC CCR's intricate integration of the three systems, the progress achieved amidst ongoing challenges and the future of case-finding through this ePath mechanism.

Notes _____

P-36

DATA QUALITY EVALUATION USING MART GUIDED GENERALIZED LINEAR MIXED MODEL – WITH APPLICATION TO EVALUATE THE SEER CANCER STAGING DATA

Y Fan,¹ Q Yu,¹ X Wu¹

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Proportions of unknown stage cases differ substantially by cancer registry. The objective of this study is to identify predictors of unknown stage cervical cancer cases. This information may help registries implement target actions to improve the quality of stage data.

We analyzed data on 40,618 cervix cancer cases diagnosed in 2004-2008 from 32 registries that met the NAACCR's high data quality criteria. The outcome variable was stage vs. unknown stage. Explanatory variables included age at diagnosis, race/ethnicity, type of reporting source, diagnostic confirmation, metro/non-metro residence, year of diagnosis, histology type, and registry as well as county-level poverty, education, and unemployment. We first used Multiple Additive Regression Trees to identify significant predictors of unknown stage and interactions, and then generalized linear mixed model for further inference.

Significant predictors of unknown stage were diagnostic confirmation, histology type, and type of reporting source ($p < .01$). Cases with unknown or no microscopic confirmation, non-specific histology type, or non-hospital reporting source were more likely ($p < 0.01$) to be of unknown stage than their counterparts. The effect of reporting sources on unknown stage varies across registries ($p < .01$). After controlling for the significant predictors, proportions of unknown stage cases were still significantly higher for five registries indicating other factors may play an important role. Age at diagnosis, race/ethnicity, metro/non-metro residence, year of diagnosis, and registry, as well as county-level poverty, education, and unemployment were not significantly associated with unknown stage.

Diagnostic confirmation, histology type, and type of reporting source explain the majority of variations in proportion of unknown stage of cervical cancer cases by registry. Registries that have unpredictably higher proportion of unknown stage cases may have operational or other issues.

Notes _____

Poster Sessions

P-37

STATE-SPECIFIC ENDOMETRIAL CANCER INCIDENCE RATES CORRECTED FOR HYSTERECTOMY PREVALENCE

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Background: Endometrial cancer incidence rates that are uncorrected for hysterectomy prevalence vary widely by state. The extent to which this pattern is affected by geographic differences in hysterectomy prevalence is unknown.

Methods: We estimated corrected endometrial cancer incidence rates by state using incidence data from CDC's NPCR and NCI's SEER Program, as reported by NAACCR, and hysterectomy prevalence data from BRFSS. We then analyzed the correlation between the corrected rates and state obesity prevalence.

Results: Endometrial cancer incidence rates unadjusted for hysterectomy prevalence were lowest in the South, which has the highest rate of hysterectomy, and highest in the Northeast, which has the lowest rate of hysterectomy. After correcting for state-specific hysterectomy prevalence, endometrial cancer incidence rates increased substantially; these increases were larger for Southern than for Northeastern states.

Conclusion: Endometrial cancer incidence rates adjusted for state hysterectomy prevalence provide a more accurate representation of the true burden of disease.

Notes _____

P-38

UTAH CANCER SMALL AREA REPORT, 2011: ON THE ROAD TO IMPROVED COLLABORATION AND WHERE CANCER REGISTRIES, CANCER SURVEILLANCE, AND PUBLIC HEALTH INTERSECT FOR CANCER CONTROL AND PREVENTION.

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Background: The Utah Cancer Registry (UCR) has provided support to the Utah Department of Health (UDOH) for over 25 years, helping the UDOH to lower the burden of cancer through surveillance, education and awareness, policy development, implementation of community-based interventions, and screening.

Purpose: Reporting by small area highlights the relative burden of cancer in Utah communities. As the cost of cancer fatalities, hospitalizations, and treatment increases each year, this report can help decision makers and stakeholders determine how to best allocate limited resources and focus on communities in need.

Methods: The report presents screening, incidence, and mortality data for top six cancers in Utah (female breast and cervical, prostate, colorectal, melanoma, and lung). Screening data were derived from the 2004-2008 Utah Behavioral Risk Factor Surveillance System, 2005-2007 incidence data were provided from UCR, and 2005-2009 mortality data from the State Office of Vital Records. Small areas were defined using ZIP code boundaries, but limited geographically and statistically to health district boundaries while conforming to established political city/town boundaries and reflecting homogeneous communities. Population counts were in the range of 40,000-60,000.

Results: The report was released by the UDOH on November 29, 2011. It provides detailed summaries, tables, and maps by cancer topic. The benefits of the report, with specific focus on the top three most common cancers in Utah, will be discussed in detail.

Conclusions/Implications: Small area data can bolster evidence-based community health plans and target specific populations for prevention programs. This will reduce costs by focusing efforts on specific communities rather than larger, more heterogeneous areas. Analyzing data at this level can assist states in strengthening prevention programs to better allocate available funds and set appropriate targets for cancer prevention and control.

Notes _____

Poster Sessions

P-39

RECEIPT OF GUIDELINE-RECOMMENDED WORK-UP AMONG BREAST CANCER PATIENTS IN LOUISIANA

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Background: The NCCN guidelines recommend certain breast cancer work-up tests for staging and treatment planning. Because data on work-up tests are not routinely collected by cancer registries, the use of guideline-recommended work-up tests in the community and its variation by sociodemographic factors are unknown. This study examined receipt of guideline-recommended work-up tests by sociodemographic factors among breast cancer patients.

Methods: The 1,012 stages I, II breast cancer patients diagnosed in 2004 in Louisiana were from CDC-NPCR Pattern of Care study. We examined the association of recommended work-up tests (i.e., liver function, chest x-ray, bilateral mammogram, and receptor status (ER/PR) and HER-2 status with race, age, insurance, census-tract poverty and education, urban/rural status, hospital type, and comorbidities.

Results: Overall, 43% of patients received liver function test, 68% chest-X-ray, 92% bilateral mammogram, 96% ER/PR test, and 87% Her-2 test. The predictors of receipt of liver function test were moderate/severe comorbidity, living in rural areas, and diagnosis at COC hospitals. The predictors of the use of chest X-ray test were moderate/severe comorbidity, Medicaid insurance and living in high education areas. Use of ER/PR and Her-2 tests was comparable across sociodemographic and comorbidity groups.

Conclusions: The majority of the breast cancer patients received bilateral mammogram, ER/PR and Her-2 tests. The use of liver function test and chest x-ray was relatively low. Comorbidity predicts use of liver function test and receipt of chest x-ray.

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P-40

USING POPULATION-BASED CANCER SURVEILLANCE AND VITAL RECORDS TO DOCUMENT IMPROVED OUTCOMES FOR MULTIPLE MYELOMA

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Background: Improved survival of young patients (< 65 years) with multiple myeloma (MM) has resulted from usage of oral melphalan and prednisone, autologous stem cell transplantation and introduction of the novel agents (thalidomide, bortezomib and lenalidomide). We utilized population-based data cancer surveillance data and vital records to characterize trends in MM incidence, mortality, and survival over three decades in the United States.

Methods: Myeloma incidence rates and survival estimates for the time period 1973-2008 were calculated with records from the National Cancer Institute's Surveillance, Epidemiology, and End Results (SEER) Program. Records of all deaths due to myeloma in the United States during the study period were obtained from the National Center of Health Statistics. Annual age-adjusted and age-specific incidence and mortality rates were calculated by the direct method and were standardized to the age-distribution of the projected US population for calendar year 2000. Temporal changes in annual age-adjusted incidence and mortality rates were assessed with joinpoint regression techniques. Myeloma cause-specific survival curves were generated by the Kaplan and Meier product-limit method. Cox proportional hazards model was used to assess univariate and multivariate predictors of myeloma cause-specific survival.

Results: Myeloma incidence rates were generally increasing or stable during the period 1973-2008; there were no statistically significant declines in myeloma incidence rates during this period. In contrast, statistically significant declines in mortality rates were documented in each age group after the mid-point of the study period. Improvements in myeloma cause-specific survival were documented at all ages, though magnitude of such gains decreased with age.

Conclusions: Novel therapies are contributing to improved survival for MM patients of all ages.

Notes _____

Poster Sessions

P-41

SPATIAL CLUSTER ANALYSIS OF FEMALE BREAST DIAGNOSIS IN MISSOURI: USING GIS AND SPATIAL ANALYST FUNCTIONS

F Williams,¹ C Barnett,¹ J Jackson-Thompson,¹ D O'Brien,¹ S Jeanetta¹

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Background: The stage at cancer diagnosis has a tremendous impact on type of treatment, recovery and survivor. In most cases the earlier the cancer is detected and treated the higher the survival rate for the patient. Various studies have indicated disparities in access to primary care especially access to screening services like mammogram for early detection.

Purpose: To examine the role of spatial access to health care services on incidence of female breast cancer in Missouri over time taking into account available clinics and hospitals.

Method: The main data source was the five year cancer data (2004-2008) on all Missourian females diagnosed with breast cancer from the MCR-ARC taking into account the Surveillance Epidemiology and End Results (SEER) staging categories: (1) *in-situ*, (2) localized, (3) regional, (4) distant and (5) unknown. Geostatistical analysis was used to compute the proportions of female breast cancer cases in each county diagnosed at early and late stages. The addresses of all clinics and hospitals were also geocoded and used to calculate patient travel time from one point of a provider to another.

Results: Eight of the top 10 total late stage incidence cases per county by population were in rural areas. In addition, even though there are 180 screening centers, access to these services are not evenly distributed. A Euclidean analysis also showed that the distance travel to health care providers for services vary from 9.1 miles to 77.2 miles.

Conclusion: Women living in areas with limited access to health care services are more likely to be diagnosed with late stage breast cancer.

References: American Cancer Society. (2011). Cancer prevention and early detection facts and figures. Atlanta, GA: American Cancer Society, Inc.

Wang, F., McLafferty, S., Escamilla, V. & Luo, L. (2008). Late-stage breast cancer diagnosis and and health care access in Illinois. *Professional Geographer*, 60 (1), 54–69.

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Poster Sessions

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*The Texas Cancer Registry,
Texas Department of State Health Services
and the
Cancer Prevention and Research Institute of Texas
welcome the
2013 NAACCR Annual Conference
to
Austin, Texas, June 8-14, 2013.*

PROGRAM GUIDE . . . at a glance



		Monday, June 4, 2012	Tuesday, June 5, 2012	Wednesday, June 6, 2012	Thursday, June 7, 2012				
 Early Morning	7:00 am	NAACCR BOD Meeting	Opening & Welcome	Run/Walk	Birds of a Feather	7:00 am			
	8:00					8:00			
	8:30					8:30			
	9:00					9:00			
	9:30					9:30			
	10:00	Committee Meetings All Day	Plenary 1: NAACCR's 25th Anniversary: Past, Present, and Future	Plenary 3: Bridges to the Future: Collecting Clinically Relevant Data	Plenary 4: Deliberations on the Future of Collaborative Stage	10:00			
	10:15					10:15			
	10:30					10:30			
	10:45					10:45			
	11:00					11:00			
	11:15		Plenary 2: Bridges to the Future: Communicating Cancer Surveillance Data	Break 	Break 	Concurrent Session 4	11:15		
	11:30						11:30		
	11:45						11:45		
	12:00 pm						12:00 pm		
	12:15						12:15		
 Lunch	12:30		Lunch (on your own)	Break	Lunch (on your own)	12:30			
	12:45					12:45			
	1:00					Poster/Exhibit Setup All Afternoon	Concurrent Session 1	Plenary 5: Future of Collaborative Stage: Interactive Panel Discussion	1:00
	1:30								1:30
	1:45								1:45
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	4:00					4:00			
	4:30		Adjourn	Concurrent Session 2		Invitation to 2013 Conference	4:30		
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-  Plenary Sessions
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-  BOD & Committee Meetings
-  Poster/Exhibit Setup
-  Other Sessions
-  Awards Luncheon
-  Break/Lunch