NAACCR 2010 CONFERENCE final program





Renewed Collaboration: A Modern Paradigm for Cancer Surveillance

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

Québec City, QC, Canada June 19 - 25, 2010 Hilton Québec and Québec City Convention Centre





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Grant Information



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NAACCR 2010 CONFERENCE final program and abstract book



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Exhibitors and Sponsors continued

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■ Exhibitor

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Welcome to NAACCR 2010





Bonjour Mes Amis:

Bienvenu au Québec! On behalf of the Board of Directors and the Program Committee, we welcome you to Québec City as the host of the 2010 Annual Scientific Conference of the North American Association of Central Cancer Registries, Inc. (NAACCR).

In keeping with previous years, the Program Committee has set out to establish a high quality agenda for the benefit of conference participants. The theme for the 2010 NAACCR conference, "Renewed Collaboration: A Modern Paradigm for Cancer Surveillance," was selected in the context of emerging opportunities throughout North America to apply new cancer control interventions, placing a greater need on more timely and diverse surveillance information products. However, the ability to provide relevant information to a broad range of stakeholders is a demanding responsibility. To address such needs, the sharing of resources and knowledge is essential. Central to these advancements is a belief in the role of collaboration; relationships, joint initiatives and mutual learning can be leveraged to enhance the capacities and contributions of each partner such that the collective work is greater than the sum of individual parts. The program for the 2010 NAACCR conference is designed to explore the role, opportunities and challenges in collaboration.

Our plenary sessions will commence with a keynote address from Dr. Simon Sutcliffe, who has lead efforts in the creation of collaborative platforms in Canada and internationally. Dr. Jon Kerner will then focus on the importance and role of knowledge translation, followed by Dr. Steven Clauser who will present examples of knowledge translation in practice. To discuss the use of innovation in achieving collaboration, Dr. John Srigley will outline its application in the area of synoptic pathology. Similarly, a short video presentation on the Terry Fox story will

demonstrate the power of a creative idea in which the dream of one immensely dedicated individual has been converted to true hope and reality for everyone. A new format will also see a current topic, the process for determining new data elements, debated by Andrew Stewart and Dr. Melanie Williams as the final Plenary session. We are looking forward to this new and exciting format.

Concurrent sessions for oral and poster abstract presentations have been selected to support the overall conference theme through the development of tracks in the following topic categories: Data Collection; Collaborative Staging; Data Analysis and Use; Knowledge to Action, Action to Knowledge; Informatics; and an Open Session.

In addition to the scientific program, we urge you to take time to enjoy the many points of interest in Québec City. Its warm culture and historic buildings provide a memorable setting, especially given the celebration of St. Jean-Baptiste on June 24th.

Best wishes during your stay and interactions in Québec!

Johanne Castonguay

Co-Chair, 2010 NAACCR Conference

J-0: harme Carlanguay

President of the Board

Association québécoise des registraires en oncologie (AQRO)

Les Merv

Co-Chair, 2010 NAACCR Conference Chronic Disease Surveillance Division

Public Health Agency of Canada

Message from the President

Dear Friends and Colleagues,

Welcome to the 2010 NAACCR Annual Conference, "Renewed Collaboration: A Modern Paradigm for Cancer Surveillance."

I would especially like to thank Johanne Castonguay and Les Mery, co-chairs of this year's Program Committee, and their staff at the Association Québécoise des Registraires en Oncologie (AQRO) and the Public Health Agency of Canada for organizing an outstanding program. Many thanks also go out to the other members of the Program Committee. The program contents underscore the value of the data we collect and generate, as well as the need for us to be responsive to the medical and research communities.

This year's schedule allows us to participate in more committee meetings, which I hope you will find useful. Another exciting, new feature is the debate format of the fourth plenary session. As in past years, we are offering a number of informative preand post- conference workshops, many of which are back by popular demand.

It's especially exciting to be in this beautiful, old-world city. I hope you'll have an opportunity to spend some time exploring Québec but don't let its charms entice you away from our wonderful program!

Merci beaucoup!

Maria J. Schymura, PhD President



While the benefits of collaboration are generally well recognized, clearly articulated and sustained multi-organizational commitments are difficult to achieve. The objective of the 2010 NAACCR conference is to explore how existing and future cancer surveillance activities can collaborate across disciplines, jurisdictions and organizations in order to enhance relationships, joint initiatives, and mutual learning.

The keynote address, 'Working Together to Advance Cancer Control: Essential Principles, Challenges and Opportunities,' will examine the role of collaboration in the context of cancer control while also serving as a call to action among NAACCR members. To further expand on key aspects of collaboration, two plenary sessions will focus on the role of Knowledge Translation and Innovation, respectively. The theme of knowledge translation will discuss issues such as the involvement of multidisciplines and their application to cancer surveillance. The theme of innovation will review examples that have inspired change among large groups through the use of new approaches to obtain shared benefits and results. A final plenary topic will debate perspectives on the governance of selecting new data elements in cancer surveillance.

NAACCR Board 2009-2010

2009 - 2011



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American Joint Committee on Cancer



CONFERENCE REGISTRATION INFORMATION

The Conference Registration and Information Desk is located near the 2000A Meeting Room and is open during the following days and times:

Monday, June 21st 9:00 am to 7:00 pm Tuesday, June 22nd 7:00 am to 5:00 pm Wednesday, June 23rd 7:00 am to 12:30 pm Thursday, June 24th 7:00 am to 11:30 am

Course Registration desks are located near the meeting rooms.

Any inquiries about the conference, social functions, etc., may be answered by approaching 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 ensure you wear your name badge to all social events.

PLENARY/BREAKOUT SESSIONS

All Plenary Sessions and the Business Meeting will take place in the 2000A Meeting Room of the Québec City Convention Centre.

OPENING RECEPTION

Tuesday, June 22nd, 2010.

The welcome reception will be held in the Portes Kent/St. Louis rooms at the Hilton Québec at 7:00 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 2010 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 2000BC Meeting Room of the Québec City Conference Centre.

We would like to encourage all delegates to take the opportunity to visit the exhibits and posters to become familiarized with some of the latest advances and research in the field. They will be available at these times:

EXHIBIT HOURS

Tuesday, June 22 7:00 am to 5:00 pm Wednesday, June 23 7:00 am to 12:00 pm Thursday, June 24 7:30 am to 10:15 am

CYBER CAFÉ

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

ROOM LOCATION

Please note that activities for the NAACCR 2010 Conference will be held at both the Hilton Québec (HQ) and the Québec City Convention Centre (QCCC). These designations will follow after each room location in the program schedule.

CONFERENCE EVALUATIONS

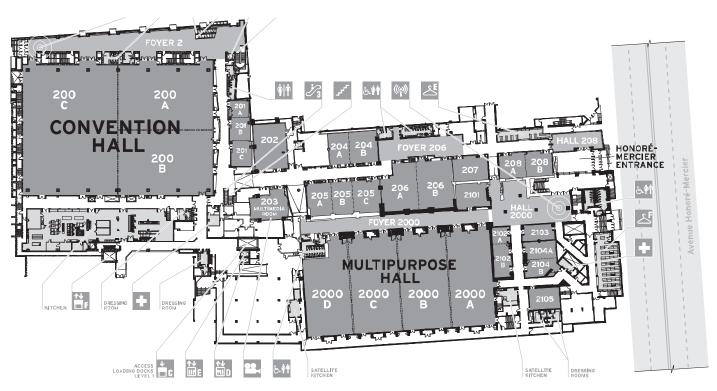
2010 conference evaluations will be available in electronic format only. Please visit www.naaccr.org/annualconference to complete your evaluation. All delegates will be emailed reminders and links to the evaluation forms after the conference.



Floor Plans **GENERAL INFORMATION**

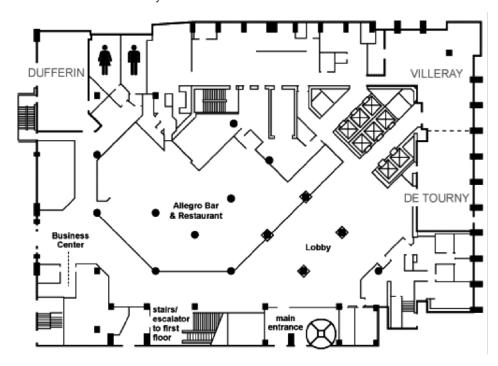
Québec City Convention Centre (QCCC)

Convention Centre - Level 2



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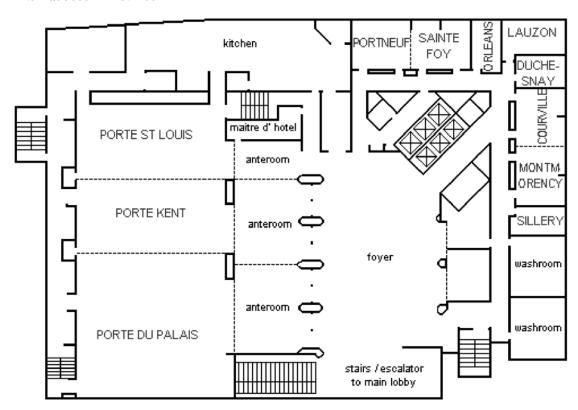
Hilton Québec-Lobby Level



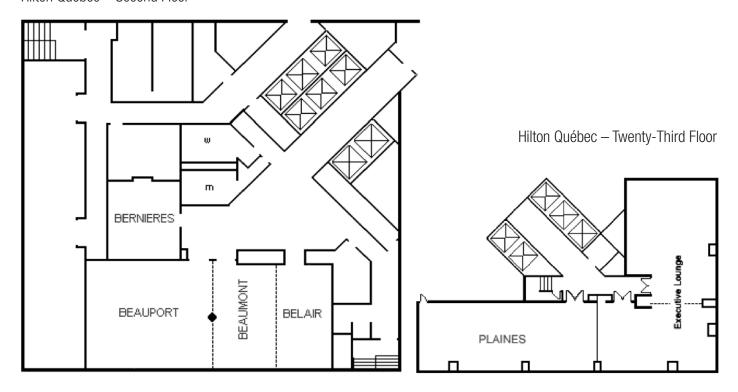
Floor Plans **GENERAL INFORMATION**

Hilton Québec (HQ) continued

Hilton Québec - First Floor



Hilton Québec - Second Floor



NAACCR 2010 CONFERENCE final program



Room locations are listed immediately after activity, ie. - SAINTE-FOY / PORTNEUF, HQ or ROOM 206B, QCCC, etc.

SATURDAY, JUNE	19	PRE-CONFERENCE
----------------	----	----------------

Basic SEER*Stat Software Training 8:30 am - 5:30 pm

Carol Kosary (NCI)

SAINTE-FOY / PORTNEUF, HQ

SUNDAY, JUNE 20 PRE-CONFERENCE

CDC Registry Plus Link Plus Workshop 8:00 am - 12:00 pm

Scott VanHeest (CDC)

COURVILLE / MONTMORENCY, HQ

8:00 am - 5:00 pm NAACCR Board Meeting

DE TOURNY, HQ

8:30 am - 5:30 pm Advanced SEER*Stat Software Training

Carol Kosary (NCI)

SAINTE-FOY / PORTNEUF, HQ

12:30 pm - 5:45 pm Central Cancer Registries:

A Review Short Course - DAY 1

Herman Menck (Los Angeles Cancer

Surveillance Program)

COURVILLE / MONTMORENCY, HQ

1:00 pm - 5:00 pm CDC EDITS Workshop

Scott VanHeest (CDC)

LAUZON, HQ

MONDAY, JUNE 21 PRE-CONFERENCE

7:00 am - 9:00 am NAACCR Board Meeting

DE TOURNY, HQ

8:00 am - 4:45 pm Central Cancer Registries:

> A Review Short Course - DAY 2 Herman Menck (Los Angeles Cancer

Surveillance Program)

COURVILLE / MONTMORENCY, HQ

9:00 am -7:00 pm Registration

2000A FOYER, QCCC

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

2000BC, QCCC

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

2000BC, QCCC

9:00 am - 6:00 pm	COMMITTEE MEETINGS
9:00 am - 10:00 am	Race and Ethnicity Workgroup LAUZON, HQ
9:00 am - 10:00 am	Data Use and Research Committee BELAIR, HQ
10:00 am - 11:00 am	Registry Ops ORLEANS, HQ
11:00 am - 12:00 pm	EDITS Workgroup BELAIR, HQ
11:00 am - 12:00 pm	Pathology Data Workgroup LAUZON, HQ
11:00 am - 1:00 pm	SMO/BOARD PLAINES, HQ
1:00 pm - 2:00 pm	CRSC PLAINES, HQ
1:00 pm - 2:00 pm	2010 Implementation Workgroup of UDS ORLEANS, HQ
2:00 pm - 3:00 pm	Education Committee BELAIR, HQ
2:00 pm - 3:00 pm	Interoperability Ad Hoc Committee ORLEANS, HQ
3:00 pm - 4:00 pm	CINA Editorial Subcommittee ORLEANS, HQ
3:00 pm - 4:00 pm	GIS Committee BELAIR, HQ
4:00 pm - 5:30 pm	Data Evaluation and Certification Committee ORLEANS, HQ
4:00 pm - 5:00 pm	Uniform Data Standards and Information Technology Committees Combined Meeting BELAIR, HQ
5:00 pm - 6:00 pm	Confidentiality Committee BELAIR, HQ

TUESDAY, JUNE 22 CONFERENCE DAY 1

6:30 am - 8:00 am Breakfast

2000BC, QCCC

NAACCR 101: Meet the Board and 7:00 am - 8:00 am

Committee Chairs

New member? Want to learn more about NAACCR? Join us for an informal and informative session. You will learn about NAACCR activities, how to participate in NAACCR committees, and the overall scope of the organization. The NAACCR website will be demonstrated and you will

have a chance to chat with Board

Members and Chairs. ROOM 206B, QCCC

7:00 am - 5:00 pm Registration

2000A FOYER, QCCC

7:00 am - 5:00 pm **Exhibits**

2000BC, QCCC

7:00 am - 5:00 pm **Posters**

2000BC, QCCC

8:00 am - 8:45 am Opening Ceremonies and Welcome

Johanne Castonguay, Les Mery and

Betsy Kohler 2000A, QCCC

Moderator: B Kohler

Québec Ministry of Health 8:45 am - 9:00 am

Antoine Loutfi, MD, Director

Direction de la lutte contre le cancer

2000A, QCCC

Moderator: J Castonguay

9:00 am - 10:00 am **KEYNOTE ADDRESS**

Working Together to Advance Cancer Control: Essential Principles, Challenges

and Opportunities Simon Sutcliffe, MD 2000A, QCCC

Moderator: L Merv

10:00 am - 10:30 am Break

2000BC, QCCC

Plenary Session #1:

2000A, QCCC

10:30 am - 12:00 pm KNOWLEDGE TRANSLATION

Moderator: B. Edwards

10:30 am - 11:15 am Knowledge to Action, Action to

Knowledge . . . Putting it All Together

Jon Kerner, PhD

11:15 am - 12:00 pm Population-Based Strategies to Enhance

Surveillance Research: SEER-Medicare

Data Linkages Steven Clauser, PhD

12:00 pm - 1:30 pm Lunch on own / Poster Viewing

2000BC, QCCC

Concurrent Session #1

1:30 pm - 3:00 pm

■ Section A:

DATA COLLECTION:

DATA QUALITY, CONTROL AND STANDARDS PART I

206B, QCCC

Moderator: J Ewing

001 NPCR-AERRO'S Clinic/Physician Office (CPO) Reporting

to Registries Project J Rogers, CDC

002 Improving Cancer Mortality Data for American Indians and

Alaska Natives in the US DK Espey, CDC

003 Evaluation of Data Accuracy of the Prostate Cancer

Registry at the Singapore General Hospital HH Huang, Singapore General Hospital

004 Mind the Gap - A Review of the Completeness and

Accuracy of Non-Surgical Treatment Data Found in

Hospital-Based Registries

AK Stewart, American College of Surgeons

Section B:

DATA COLLECTION:

INNOVATIVE APPROACHES AND ADVANCES PART I

207, QCCC

Moderator: F Ross

005 CDC-NPCR'S National Interstate Data Exchange

Application System (N-Ideas) RJ Wilson, CDC

006 Challenges to the Data Analyst in Working with the

NAACCR v12 Record Layout DK O'Brien, Alaska Cancer Registry

007 Centralized Resource for Genomics Research

DJ Dale, University Health Network

008 The Use of a New Completeness Measure and its

Application R Dewar, Cancer Care Nova Scotia

Section C:

DATA ANALYSIS AND USE: ANALYTIC EPIDEMIOLOGY PART I 2101, QCCC

Moderator: R Alvi

- 009 Application of Multiple Imputation for Missing Data in the Pre-Invasive Cervical Cancer Study B Huang, University of Kentucky
- 010 Measuring the Effect of Including Multiple Cancers in Survival Analyses LF Ellison, Statistics Canada
- 011 The Unique SES Disparity of Cancer Incidence Among California's Hispanic Population D Yin, Public Health Institute
- 012 A Web-Based Interactive Query System to Calculate Survival for Recently Diagnosed Cancer Patients A Percy-Laurry, NCI
- Section D:

DATA ANALYSIS AND USE: RECORD LINKAGE

2102AB, QCCC

Moderator: F Michaud

- 013 Enhancing Research Capacity of Cancer Registries and Other Administrative Health Databases Towards Studying Access to Quality Colorectal Cancer Services R Urquhart, Cancer Care Nova Scotia
- 014 Using Claims and Discharge Data to Better Assess Quality of Cancer Care Among the Medicaid Population MJ Schymura, New York State Department of Health
- 015 Concordance of Colorectal Treatment Information Between a Central Cancer Registry and Medicaid Claims FP Boscoe, New York State Cancer Registry
- 016 Improved Patient Matching in Wisconsin: Productivity Gains from New Approaches to Patient De-Duplication and Death Linkage RL Borchers, Wisconsin Office of Health Informatics
- Section E:

KNOWLEDGE TO ACTION, ACTION TO KNOWLEDGE: CANCER SURVEILLANCE IN THE FUTURE PART I

2104AB, QCCC

Moderator: M Spayne

- 017 NPCR-AERRO'S Cancer Control and Data Use (CC&DU) Project J Rogers, CDC
- 018 Pan-Canadian Cancer Surveillance and Epidemiology Networks B Candas, Canadian Partnership Against Cancer

- 019 The Canadian Partnership Against Cancer's (The Partnership's) Surveillance and Epidemiology Networks: Knowledge Translation in the Colorectal Network (CRCNET) B Theis, Cancer Care Ontario
- 020 Streamlining Research Collaboration with State Cancer Registries D Hurley, South Carolina Central Cancer Registry

■ Section F:

INFORMATICS: STANDARDS

2105, QCCC

Moderator: A MacLean

- 021 Structured Reporting In Anatomic Pathology For Cancer Surveillance M Kennedy, College of American Pathologists
- 022 Cancer Pathology Electronic Reporting Standards, New NAACCR Volume V - With Specimen Information JN Harrison, New York State Cancer Registry
- 023 National Program of Cancer Registries -Advancing E-Cancer Reporting and Registry Operations Project (NPCR-AERRO): Discharge Data Project S Thames, CDC
- 024 Steps Taken by a Central Cancer Registry (CCR) with Limited Resources to Improve Data Security and Maintain Patient Confidentiality J Jackson-Thompson, Missouri Cancer Registry University of Missouri

3:00 pm - 3:30 pm Break 2000BC, QCCC

Concurrent Session #2

3:30 pm - 5:00 pm

■ Section A:

DATA COLLECTION:

DATA QUALITY, CONTROL AND STANDARDS PART II

206B, QCCC

Moderator: MJ King

- 025 Assessing the Reliability and Validity of Primary Payer Information in Central Cancer Registry Data C Verrill, CDC
- 026 Address Validation to Resolve Geocoding Issues at the Central Registry AR Houser, C/Net Solutions, Public Health Institute
- 027 Implementing an On-line Tracking System® (OSTS®) for Collaborative Research Projects with Cancer Registries L Holtby, Propel Centre for Population Health Impact, University of Waterloo

028 Highlights from the New 2010 SEER Program Manual: **Process and Content** MB Adamo, NCI

■ Section B:

DATA COLLECTION:

INNOVATIVE APPROACHES AND ADVANCES PART II

207, QCCC

Moderator: M Green

029 A National Standard for Stage in Canada: Early Results from Selected Canadian Provinces for Collaborative Stage in Breast and Colorectal Cancer R Dewar, Cancer Care Nova Scotia

030 Collaboration Re-Imagined (CA) S Fuchslin, California Cancer Registry

031 Collaboration Re-Imagined (NC/CCR) C Rao, North Carolina Central Cancer Registry

032 Collaboration Re-Imagined (SK/CA) H Stuart, Saskatchewan Cancer Agency

■ Section C:

COLLABORATIVE STAGE: IMPLEMENTATION AND FACILITATED **DISCUSSIONS**

2101, QCCC

Moderator: M MacIntyre

Invited Speaker

Stories from the Front Lines M Potts, Seattle Cancer Registry

033 Looking from the Inside Out: Evaluating the 2010 Data Changes Implementation B Gordon, C/NET Solutions, California Cancer Registry

Invited Speaker

Planning for the Future of Collaborative Stage C Bura, American College of Surgeons

■ Section D:

DATA ANALYSIS AND USE: ANALYTIC FPIDEMIOLOGY PART II 2102AB, QCCC

Moderator: M Lemieux

034 Évolution du Cancer du Col de L'utérus chez les Jeunes Femmes Adultes au Québec, 1983 à 2006 R Louchini, MSSS

035 The Gist on G.I.S.T. B Wohler, FCDS, University of Miami Miller School of Medicine 036 Increase in the Use of Double Mastectomy for the Treatment of Early-Stage Breast Cancer in California CR Morris, California Cancer Registry, Public Health Institute

037 CP3R Reports for Population-Based Studies F Ross, Kentucky Cancer Registry

■ Section E:

KNOWLEDGE TO ACTION. ACTION TO KNOWLEDGE: CANCER SURVEILLANCE IN THE FUTURE PART II

2104AB, QCCC

Moderator: S Gershman

038 The Canadian Partnership Against Cancer's Surveillance and Epidemiology Networks: A Brave New World for Cancer Surveillance Products. Exhibit #1: The Cancer Survival and Prevalence Analytic Network (CSPAN). D Turner, CancerCare Manitoba / University of Manitoba

039 The Canadian Partnership Against Cancer's Surveillance and Epidemiology Networks: A Brave New World for Cancer Surveillance Products. Exhibit #2: Colorectal Cancer Network (CRCNET) LD Marrett, Cancer Care Ontario / University of Toronto

040 Canadian Partnership Against Cancer's Surveillance and Epidemiology Networks: A Brave New World for Cancer Surveillance Products. Exhibit #3: The Cancer Projection Analytic Network (C-PROJ) J Hatcher, Alberta Health Services

041 The Canadian Partnership Against Cancer's Surveillance and Epidemiology Networks: The C-Span Methodology Working Group Journey: Decisions Along the Way K Fradette, CancerCare Manitoba / University of Manitoba

5:00 pm - 6:30 pm Poster Viewing 2000BC, QCCC

7:00 pm - 9:00 pm Opening Reception

PORTES KENT / ST. LOUIS, HQ

WEDNESDAY, JUNE 23 CONFERENCE DAY 2

6:30 am - 8:00 am Breakfast 2000BC, QCCC

7:00 am - 8:00 am Birds Of A Feather Round Table Discussion

"What Did We Learn From 2010?"

Susan Gershman

(Massachusetts Cancer Registry) / Rich Pinder (Los Angeles Cancer

Surveillance Program)

206B, QCCC

7:00 am - 12:00 pm Exhibits

2000BC, QCCC

7:00 am - 12:30 pm Registration

2000A FOYER, QCCC

Plenary Session #2:

2000A. QCCC

8:30 am - 9:30 am **INNOVATION**

Moderator: M MacIntyre

8:30 am - 9:15 am Population Level Synoptic Cancer

> Pathology Facilitates Timely Prognostic Factor Analysis and Quality Indicator

Reporting John Srigley, MD

9:15 am - 9:30 am The Terry Fox Story

9:30 am - 10:00 am Break

2000BC, QCCC

Concurrent Session #3

10:00 am - 11:30 am

■ Section A:

DATA COLLECTION:

INNOVATIVE APPROACHES AND ADVANCES PART III

206B, QCCC

Moderator: M Beaupre

- 042 Set-Oriented Searching of Cancer Cheklist Data J Golabek, AIM Inc.
- 043 Inter-Registry Record Linkage Without Releasing Patient Level Data: Examining the Feasibility of Establishing a National Clearinghouse Using One-Way Data Encryption JA MacKinnon, University of Miami
- 044 Automated Coding of Key Case Identifiers from Text-Based Electronic Pathology (E-Path) Reports E Durbin, Kentucky Cancer Registry
- 045 Successes and Challenges In Population-Based Electronic Pathology (E-Path) Reporting T Gal, Kentucky Cancer Registry
- Section B:

DATA COLLECTION:

OCCUPATIONAL AND ENVIRONMENTAL DATA

207, QCCC

Moderator: B Kohler

046 Collection and Use of Industry and Occupation Data I: Opportunities and Challenges D Deapen, University of Southern California

- 047 Collection and Use of Industry and Occupation Data II: Overview and Goals RD Cress, California Cancer Registry/Public Health Institute
- 048 Collection and Use of Industry and Occupation Data III: Cancer Surveillance Findings Among Construction Workers GM Calvert, NIOSH/CDC
- 049 Collection and Use of Industry and Occupation Data IV: Development of Training Materials to Improve Occupational Data Collection in Cancer Registries SE Luckhaupt, NIOSH/CDC
- Section C:

DATA ANALYSIS AND USE: GEOGRAPHIC INFORMATION SYSTEMS AND MAPPING APPLICATIONS PART I

2101, QCCC

Moderator: R Sherman

- 050 Mapping Late Stage Breast Cancer Rates to Improve Local Cancer Control Efforts L Agustin, USC/Keck School of Medicine
- 051 Evaluating Methods for Preserving Confidentiality During the Release of Records Incorporating Address or other GeoData A Curtis, USC College of Letters
- 052 Using the Rapid Inquiry Facility (RIF) to Investigate the Association Between Lung Cancer Incidence and Air Borne Pollutants from Steel and Iron Foundries in Hamilton, Ontario S Wanigaratne, Cancer Care Ontario
- 053 Liver Cancer and Immigration: Small Area Analysis of Incidence Within Ottawa and the Greater Toronto Area, 1999 to 2003.

T Norwood, Cancer Care Ontario

■ Section D:

DATA ANALYSIS AND USE:

TRENDS IN CANCER INCIDENCE AND MORTALITY PART I

2102AB, QCCC

Moderator: R Rycroft

054 Colorectal Cancer Trends in Florida Hispanics: Data from the Hispanic Monograph — A Florida Cancer Data System (FCDS) Publication MN Hernandez, Florida Cancer Data System (FCDS),

University of Miami Miller School of Medicine, Sylvester Comprehensive Cancer Center

055 Variations in Cancer Incidence and Mortality Among Neighborhoods in Boston, MA, 2001-2005 R Knowlton, Massachusetts Department of Public Health Cancer Registry

- 056 Incidence of HPV Associated Head and Neck Cancers by Sub-Site Among Diverse Racial/Ethnic Populations in the U.S. LE Cole, Louisiana Tumor Registry / Louisiana State University Health Sciences Center School of Public Health
- 057 Esophageal Cancer in Canada, 1986-2006: Trends by Morphology and Anatomical Location M Otterstatter, Centre for Chronic Disease Prevention and Control, Public Health Agency of Canada
- Section E:

KNOWLEDGE TO ACTION, ACTION TO KNOWLEDGE: APPLICATIONS IN CANCER CONTROL PART I 2104AB, QCCC

Moderator: M Schymura

- 058 Using Surveillance and Other Data to Report on the Status of Cancer Control in Canada - the System Performance Initiative at the Canadian Partnership Against Cancer (CPAC) M Spayne, Canadian Partnership Against Cancer
- 059 Cancer Survival According to Insurance Status in Kentucky HK Weir, CDC
- 060 Factors Contributing to High Death Rates Among Black Women with Breast Cancer in Louisiana XC Wu, Louisiana Tumor Registry, LSU Health Sciences Center
- 061 Utah Cancer Control Program: The Impact of Breast Cancer Screening through the Breast and Cervical Cancer Screening Program A Stroup, Utah Cancer Registry, University of Utah
- Section F:

LANGUAGE TRANSLATION: COLLEGE OF AMERICAN PATHOLOGIST PROTOCOLS 2105, QCCC

Moderator: J Castonguay

Invited Speakers

062 Considerations in Modeling and Mapping the College of American Pathologists Electronic Cancer Checklists (CAP eCC) A Pitkus, College of American Pathologists

11:45 am - 1:45 pm **NAACCR Business Meeting**

Join us for the 2010 NAACCR Business Meeting. Beverages and complimentary light refreshments will be available for those who attend. We will cover NAACCR's fiscal status, committee progress, bylaws amendments, and announce the certification of registries.

2000A, QCCC

1:45 pm - 5:00 pm Free Afternoon

THURSDAY, JUNE 24 CONFERENCE DAY 3

6:30 am - 8:00 am Breakfast

2000BC, QCCC

7:00 am - 7:45 am

Walking/Running Event Hosted by GIS Committee MEET IN HOTEL LOBBY

7:00 am - 11:30 am

Registration 2000A FOYER, QCCC

7:30 am - 10:15 am

Exhibits 2000BC, QCCC

Concurrent Session #4

8:30 am - 10:00 am

■ Section A:

DATA COLLECTION:

INNOVATIVE APPROACHES AND ADVANCES PART IV

206B, QCCC

Moderator: D Dale

- 063 Utility of Hospital Discharge Data for Registry Enhancement R Sherman, FCDS, University of Miami
- 064 The Registry Plus Suite of Software: Affordable, State-ofthe-Art Tools for Central Cancer Registry Data Collection and Processing KK Thoburn, Northrop Grumman
- 065 Abstract Plus Version 3: Security Standards Upheld D Farmer, Northrop Grumman
- 066 NPCR-AERRO: ePath Reporting S Baral, Northrop Grumman
- Section B:

DATA COLLECTION: TRAINING NEEDS AND EDUCATION

207. QCCC

Moderator: P Adamo

- 067 Just JING it! A Cost-Effective Method to Document Procedures and Produce Training Materials M Potts, Fred Hutchinson, Cancer Research Center, Cancer Surveillance System
- 068 A Review of CSv2 S Vann, NAACCR
- 069 Finding the Cancer Registrars of the Future, the Rhode Island Cancer Registry Internship Training Program D Rousseau, Rhode Island Cancer Registry
- 070 Experience With An NCRA Webinar Series For Collaborative Stage (CSv2) Training HR Menck, University of Southern California

■ Section C:

DATA ANALYSIS AND USE: GEOGRAPHIC INFORMATION SYSTEMS AND MAPPING APPLICATIONS PART II

2101, QCCC

Moderator: R Pinder

- 071 Trends and Patterns of Childhood Cancer Incidence in the US, 1995-2009 L Zhu, NCI
- 072 Cancer and the Medically Underserved In Missouri: A GIS Approach to Identifying Cancer Disparities by Primary Care Physician Shortage Areas K Pena-Hernandez, Informatics Institute / Missouri Cancer Registry / University of Missouri
- 073 Thyroid Cancer, Early Detection and Environmental Factors in Ontario: A Small-Area Analysis E Holowaty, Cancer Care Ontario / Dalla Lana School of Public Health, University of Toronto
- Section D:

DATA ANALYSIS AND USE:

TRENDS IN CANCER INCIDENCE AND MORTALITY PART II

2102AB, QCCC

Moderator: B Thesis

- 074 Rising Incidence Trends and Ethnic Patterns of Breast Cancer Among Asian-American Women L Liu, Los Angeles Cancer Surveillance Program, University of Southern California
- 075 The Changing Face of Cancer In Canadian Adolescents and Young Adults P De, Canadian Cancer Society
- 076 Predication of Cancer Incidence and Mortality in Canada L Xie, Public Health Agency of Canada
- 077 Using the Accuracy of Cancer Mortality (ACM) Study to Evaluate Uterine Cancer Survival in California JH Bates, California Cancer Registry/Public Health Institute
- Section E:

KNOWLEDGE TO ACTION, ACTION TO KNOWLEDGE: APPLICATIONS IN CANCER CONTROL PART II

2104AB, QCCC

Moderator: B Candas

- 078 Access to Care in Rural Northern New England MO Celaya, New Hampshire State Cancer Registry, Dartmouth Medical School
- 079 Using Registry Data to Inform Community Action: Melanoma and Non-Melanoma Skin Cancer in Saskatchewan, Canada, 1998-2007 R Alvi, Saskatchewan Cancer Agency

- 080 A Case Study in Translating Surveillance Data to Understandable and Actionable "Citizen Data" TH Bounds, East Tennessee State University
- 081 Working with Canadian Cancer Registries to Determine the Unmet Needs of Cancer Survivors and their Support Persons: Benefits and Challenges S Filsinger, CancerCare Manitoba

■ Section F:

INFORMATICS: INTEROPERABILITY

2105, QCCC

Moderator: A MacLean

- 082 NPCR-AERRO'S Partnership with IHE: Ensuring Cancer's Connectivity with the EMR/EHR S Thames, CDC
- 083 Interoperability Questions and Issues: Assessing Implications of the NAACCR Clinical Data Interoperability Pilot Project J Martin, Virginia Cancer Registry
- 084 College of American Pathologists Electronic Cancer Checklists (CAP ECC): Cancer Pathology Data Flow Into Cancer Registry Systems J Rogers, CDC
- 085 The Public Health Grid (PHGRID): What is it and How can it Support Cancer Surveillance Activities? S Thames, CDC

10:00 am - 10:30 am Break

2000BC, QCCC

10:15 am - 11:00 am Exhibit Break Down

2000BC, QCCC

Concurrent Session #5

10:30 am - 12:00 pm

■ Section A:

DATA COLLECTION:

DATA QUALITY, CONTROL AND STANDARDS PART III

206B, QCCC

Moderator: J Rogers

- 086 A New Edit for Identifying Potential Gender Misclassification in Central Cancer Registry Databases F Boscoe, New York Cancer Registry
- 087 Workflow Management, What Does it All Mean? How the California Cancer Registry Used 'Project Management' Tools to Create a Production Environment and Our Results G Halvorson, California Cancer Registry
- 088 Determinants of Collaborative Staging Input Items Availability: Maryland Experience 2004-2008 S Negoita, Westat

- 089 From Quality Control Challenges to Process Improvement Opportunities *W Roshala, California Cancer Registry*
- Section B:

DATA COLLECTION:

INNOVATIVE APPROACHES AND ADVANCES PART V

207, QCCC

Moderator: MJ King

- 090 Abstract Plus Version 3: Ad-Hoc Report Wizard D Farmer, Northrop Grumman
- 091 The Reporting of VHA Data to a Central Cancer Registry S Van Heest, CDC, NPCR
- 092 Estimating Average Annual Percent Change (AAPC) for Trend Analysis *L Clegg, NCI*
- 093 ICD-9-CM Updates and U.S. Adoption of ICD-10-CM Coding Standard: Major Changes in Health Information Coding Practice and Implications for Cancer Surveillance J Ruhl, NCI SEER
- Section C:

COLLABORATIVE STAGE:

APPLICATIONS THROUGH ANALYTIC USE

2101, QCCC

Moderator: R Wilson

- 094 CSv2 Training: So Many Data Items, So Little Time K Vance, California Cancer Registry
- 095 Frequency and Determinants of Missing Data in Collaborative Stage Site-Specific Variables Recently Added to SEER *M Goodman, Emory University, Rollins School of Public Health*
- 096 Inter-Rater Reliability Assessment and Electronic Collaborative Stage Data Collection in Ontario B Li, Cancer Care Ontario
- 097 National Staging Advisory Committee Supporting Surveillance *DJ Dale, University Health Network*
- Section D:

DATA ANALYSIS AND USE:

TRENDS IN CANCER INCIDENCE AND MORTALITY PART III

2102AB, QCCC

Moderator: D Stinchcomb

- 098 Exploring the Impact of Immigration on Cancer Incidence in Toronto, Ontario *D Nishri, Cancer Care Ontario*
- 099 Descriptive Features and Trends in the Incidence of Borderline Ovarian Tumors in California CR Morris, California Cancer Registry, Public Health Institute

- 100 Going Against the Tide: The Increasing Incidence of Colorectal Cancer among Korean Americans in California, 1988-2007 JH Bates, California Cancer Registry, Public Health Institute
- 101 The Final Word on the Increase in Melanoma Incidence: It's Not Due to Screening! M Cockburn, USC/Keck School of Medicine

■ Section E:

KNOWLEDGE TO ACTION, ACTION TO KNOWLEDGE: APPLICATIONS IN CANCER CONTROL PART III

2104AB, QCCC

Moderator: L Ellison

- 102 Increasing Efficiency of Statewide Registry Software Maintenance and Updates J Jacob, Kentucky Cancer Registry
- 103 Cancer Data Ignites Research and Programs for Alaska Native People A Stroup, (Utah Cancer Registry, University of Utah) presenting on behalf of J Kelly, Alaska Native Tribal Health Consortium
- 104 Cancer Surveillance and Cancer Genetics: Statewide Collaboration in Utah A Stroup, Utah Cancer Registry, University of Utah
- 105 Does the Interruption in the Decrease of Lung Cancer Rates below Age 50 in the US Vary According to Level of State Tobacco Control Activities? A Jemal, American Cancer Society
- Section F: OPEN SESSION

2105, QCCC

Moderator: J Martin

- 106 Cancer Patterns among Hispanics and Length of Stay in the U.S. PS Pinheiro, University of Nevada Las Vegas
- 107 Multilevel Modeling of Melanoma Incidence Using Combined NPCR and SEER Data CJ Johnson, Cancer Data Registry of Idaho
- 108 Overview of Melanoma Incidence in the United States: Methods *M Watson, CDC*
- 109 Association of Demographic Characteristics with Anatomic Stage/Prognostics Groups in Prostate Cancer S Negoita, Westat

12:00 pm - 1:30 pm Luncheon and Awards Ceremony

2000A, QCCC

1:30 pm - 2:00 pm Break

Plenary Session #3

2000A, QCCC

2:00 pm - 3:00 pm

NAACCR SHOWCASE

Moderator: Betsy A. Kohler, MPH, CTR

NAACCR Executive Director

2:00 pm - 2:15 pm

The Inclusion of Poverty-Rate Quantiles in CINA Deluxe: A Call for Participation

Francis Boscoe, PhD

New York State Cancer Registry

2:15 pm - 2:30 pm

Update: Susan G. Komen for the Cure

Network Path Distance Study

Myles Cockburn, PhD

Los Angeles Cancer Surveillance Program

2:30 pm - 2:45 pm

Summary Stage 2000: Directly Coded

vs. Derived

Xiao-Cheng Wu, MD Louisiana Tumor Registry

2:45 pm - 3:00 pm

Showing and Sharing:

Making Data More Accessible

Andy Lake IMS, Inc. and

Susan Gershman, PhD

Massachusetts Cancer Registry

3:00 pm - 3:30 pm

Break

Plenary Session #4

2000A, QCCC

3:30 pm - 4:30 pm

POINT COUNTERPOINT

Moderator: Thomas C. Tucker, PhD Debators: Melaine Williams. PhD and

Andrew Stewart, MA

4:30 pm - 4:45 pm

Invitation To 2011 Meeting Thomas C. Tucker, PhD and

Frances Ross, CTR

4:45 pm - 5:00 pm

Closing Ceremonies

Johanne Castonguay, Les Mery and

Betsy Kohler

FRIDAY JUNE 25 POST CONFERENCE

8:30 am - 5:00 pm Continuous Process Improvement

> and Managing Change Lilia C. O'Connor SAINT-FOY/ PORTNEUF, HQ

8:30 am - 5:00 pm The 2010 Hematopoietic and Lymphoid

> Neoplasm Project: What It Means for Central Registries NCI/SEER

Course information is on SEER website: http://seer.cancer.gov Please visit the site above for alerts and registration announcements.

BEAUMONT/ BELAIR, HQ





NAACCR 2010 CONFERENCE poster listing



- P-01 The Canadian Partnership Against Cancer's (CPAC) Surveillance And Epidemiology Networks: Investigating The Quality Of Cancer Registry Data In Canada. Part I: Completeness, Accuracy, Timeliness M Wang
- P-02 Considering the Collection of Follow-Up Data by a Central Cancer MO Celaya
- P-03 Completeness of Population-Based Cancer Registry in Taiwan C-J Chiang
- P-04 Guidance for Resolving Conflicting Race Information from Multiple Sources FP Boscoe
- P-05 Automating Business Rules to Optimize Data Quality C Moody
- P-06 The Canadian Partnership Against Cancer's (The Partnership's) Surveillance and Epidemiology Networks: Investigating the Quality of Cancer Registry Data in Canada Part II: Comparability E Candido
- P-08 Use of Records from a Reference Pathology Laboratory to Enhance Electronic Reporting of Hematological Malignancies C Wiggins
- P-09 Canadian Partnership Against Cancer's (The Partnership) Cancer Surveillance and Epidemiology Networks: Investigating Short-Term Cancer Projection Methods for Use by Canadian Cancer Registries ZZ Qiu
- P-10 Integrated Electronic Case-Finding I Hands

- P-11 Towards the Fully-Electronic Transmission of Pathology Data into the Manitoba Cancer Registry (MCR): e-Path Year 1 in Review A Downey-Franchuk
- P-12 Crossing Boundaries for Central Cancer Registry Professionals M Mesnard
- P-13 Cancer and the Environment: Development of Methods to Prioritize Carcinogens, Estimate Exposures and Evaluate Public Health Risks for the People of Ontario M Pahwa
- P-14 The Massachusetts Cancer Registry's Information Corner E Prestosa
- P-15 How We Made Our Training Dollars Stretch M Dryden
- P-16 The Saskatchewan Cancer Control Report -Profiling Cancer Stage, 1988-2007 G Narasimhan
- P-17 Design a Computer-Based User Interface for Pathology Reporting in a Cancer Center: Design Principles and Implementation W Shi
- P-18 Survival Difference between Black and White Men with Invasive Prostate Cancer In Louisiana XR I i
- P-19 Health Insurance Status Affects Staging and Influences Treatment Strategies in Patients with Hepatocellular Carcinoma M Whiteside
- P-20 Effect of Race and Socioeconomic Status on Breast Cancer Treatment in Louisiana P Ranganath





- P-21 Improved Data Analysis and Dissemination Using Bayesian Spatial Modeling S Cherala
- P-22 Nationwide Cancer Incidence in Taiwan, 2002-2006 F-Z Chang
- P-23 Using Artificial Intelligence Software to Assist In Documenting Personalized Medicine Testing Practises G Cernile
- P-24 Disparities in Breast Cancer Prognostic Factors by Race, Insurance Status, and Education CE DeSantis
- P-25 Incidence of Cervical Cancer Among Women Under 40 Years Old in the United States M Watson
- P-26 Burden of Cholangiocarcinomas in the United States, 1999-2006 M Watson
- P-27 Calculating Distances Between Address at Time of Diagnosis and Radiation Facilities in California HA Hodges
- P-28 Linkage with State Medicaid Data for Case-Finding Purposes. Is it Worth the Effort? EA Miller
- P-29 An Investigation of Self-reported Cancers from a Cohort Study Where no Record was found at the State Registry of Residence G Fraser
- P-30 The Variety of Experience in Working with 35 U.S. Cancer Registries: Matching Adventist Health Study-2 (AHS-2) and Registry Data G Fraser
- P-31 Record Linkage between Cancer Registry and Hospital Discharge Data S Cherala

- P-32 Public Health Surveillance Collaboration: Establishing a Linkage Algorithm with Cancer Registries for the Forteo Patient Registry D Harris
- P-33 Death Matching with Link Plus Version 2 Reduced Time and Cost and Increased the Number of Good Matches, in Comparison to a Legacy In-house System G Giacco
- P-34 Utilizing Hospital Discharge and Emergency Department Data to Develop a Sickle Cell Disease (SCD) Cohort to Evaluate Cancer Burden, California, 1991-2007 A Brunson
- P-35 An Open Source Probabilistic Record Linkage System C Khor
- P-36 Validating Cancer Screening Results: Linking Utah Breast and Cervical Cancer Screening Program Data with the Utah Cancer Registry CJ Harrell
- P-37 Linking Missouri Cancer Registry (MCR) Data with the Social Security Death Index (SSDI) F Williams
- P-38 Incidence Trends for Preventive and Early Detection Cancer in Kentucky B Huang
- P-39 The Impact of the Benign Brain Tumor Cancer Registries Amendment Act on Brain Tumor Incidence and Trends In The USA BJ McCarthy
- P-40 Trends in Gastric Cancer Incidence Rates among American Indians in New Mexico, 1981-2007 C Wiggins
- P-41 Cancer Disparities by Race and Ethnicity in Nebraska G Lin





- P-42 Cancer Trends in Nevada's Urban, Rural and Frontier Communities J Symanowski
- P-43 The Hispanic Monograph A Florida Cancer Data System (FCDS) Publication of Hispanic Cancer Trends in Florida LE Fleming
- P-44 Trends in the Incidence Rates and Histology of DCIS in Los Angeles County, 1990-2007 M Pike
- P-45 Changing Incidence of Esophageal Cancer Subtypes in Relation to Changing Prevalence of Risk Factors in Ontario S Bahl
- P-46 Cancer and Place of Death in New Hampshire B Riddle
- P-47 Co-Morbidities among Female Breast Cancer Patients in Florida, 2000-2008 AS Babu
- P-48 Descriptive Epidemiology of Ovarian Cancer in Massachusetts B Backus
- P-49 Trends in Childhood Cancer Incidence and Mortality in Canada D Mitra
- P-50 The Canadian Partnership Against Cancer's (The Partnership's) Surveillance and Epidemiology Networks: Colorectal Cancer In Ontario by Anatomic Subsite
- P-51 Thyroid Cancer Incidence Trends in New Jersey, 1979-2006 X Niu



- P-52 Surveillance of Cancer in Young People in Canada (CYP-C): A Renewed System K Hutchings
- P-53 National Health Interview Survey (NHIS)-Florida Cancer Data System (FCDS) Data Linkage Project DJ Lee
- P-54 A Feasibility Study in Obtaining Paraffin Embedded Breast Tumor Tissue from California Hospitals M Brown
- P-55 Childhood Cancers in New York: Who Gets Treated and/or Reported by Members of the Children's Oncology Group (COG)? AR Kahn
- P-56 Expanding the Reach of Canadian Cancer Statistics to a Clinical Audience H Chappell
- P-57 Canadian Partnership Against Cancer's (The Partnership) Cancer Surveillance and Epidemiology Networks: Knowledge Translation as a Component of a Pan-Canadian Surveillance Network on Cancer **Projections** A Colguhoun
- P-58 Improving the Understanding and Standardization of the Canadian Cancer Data Set G Noonan
- P-59 NPCR-AERRO: The Multi-Source Glossary S Van Heest
- P-60 From Surveillance to Research: A Central Cancer Registry (CCR) Strives to Improve Participation in Research Projects While Protecting Human Subjects J Jackson-Thompson





oral abstracts

concurrent session 1



NPCR-AERRO'S CLINIC/PHYSICIAN OFFICE (CPO) REPORTING TO REGISTRIES PROJECT

<u>J Rogers</u>¹, W Blumenthal¹, W Scharber², S Thames¹, M Agrawal²

¹Centers for Disease Control and Prevention, Atlanta, GA, United States; ²Northrop Grumman, Atlanta, GA, United States

Background: The National Program of Cancer Registries -Advancing E-Cancer Reporting and Registry Operations (NPCR-AERRO) is a collaborative project within the CDC-NPCR to position the cancer surveillance community to take advantage of the electronic health record (EHR) for cancer surveillance. Until recently, complete and high quality cancer reporting has been achieved primarily through reporting from hospital cancer registries. However, advances in medicine now allow patients to obtain care outside the hospital setting. Data collection from other sources, such as physician offices, is often not as consistent with reporting. This leads to underreporting of certain types of cancers, typically those now diagnosed and treated outside the hospital setting. Purpose: To develop standards, methods, and tools for, and test the implementation of, electronic clinician reporting from CPO Electronic Medical Records (EMRs) to cancer registries. Methods: Convened workgroup with participants representing central and hospital cancer registries, clinic/physician office representatives, professional organizations, government agencies, software vendors, and other stakeholders. The activities of the workgroup will include: development of models and use cases to describe the processes needed to implement the reporting; identify and develop standards; and pilot test implementation. Results: This presentation will describe the activities completed to date, the lessons learned, and the next steps.

002

IMPROVING CANCER MORTALITY DATA FOR AMERICAN INDIANS AND ALASKA NATIVES IN THE US

<u>DK Espey</u>¹, MA Jim¹, HK Weir¹, D Haverkamp¹, N Cobb¹ ¹Centers for Disease Control and Prevention, Atlanta, GA, USA; ²Indian Health Service, Albuquerque, NM, USA

Background: Misclassification of American Indians/Alaska Natives (Al/AN) as non-Al/AN occurs in cancer surveillance and vital statistics data. Linkages of cancer registry data with Indian Health Service (IHS) patient registration data have improved cancer incidence estimates. Linkages of death records with IHS can also improve mortality estimates for cancer and other health events for Al/AN. Purpose: To improve race classification of Al/AN in state death records. Methods: A total of 8,855,141 death certificates from 1990-2003 were submitted from 14 states where 62% of the Al/AN population reside. These records were linked probabilistically with national IHS registration data. Results: The death certificate race codes indicated 103,185 Al/AN deaths over the 14-year period. The IHS database linked to 87,927 death records. Of these, 16,986 did not have Al/AN race recorded on the death certificate bringing the total AI/AN deaths to 120,171, a misclassification rate of 14% (range 2% to 41%). This linkage, though helpful, was hampered by differing data formats and coding schemes submitted by the states, often varying by year for the same state - and missing data. Conclusions: Routine linkages of death records with IHS data can improve data completeness and allow more accurate descriptions of cancer and other mortality patterns in AI/AN populations. A project linking the National Death Index and IHS is underway to address issues encountered in the state level linkages.

Notes	Notes

EVALUATION OF DATA ACCURACY OF THE PROSTATE CANCER REGISTRY AT THE SINGAPORE GENERAL HOSPITAL

H Huang¹, N Uy¹, H Sim¹, T Chong¹, J Yuen¹, C Cheng¹, W

¹Singapore General Hospital, Singapore, Singapore

Objectives: In order to improve data quality of prostate cancer in the Urological Cancer Registry (UCR) at Singapore General Hospital, we evaluated the accuracy of data registration of prostate cancer, and its compliance to the international standards of US Commission on Cancer (CoC).

Methods: Capture-recapture methods were used to assess the accuracy of the registration. There were 2360 prostate cancer cases registered in the registry from 1980 to 2007. A total of 257, or 10.9%, prostate cancer cases were randomly selected from the registry database and were re-abstracted by an Urologist and a qualified cancer registrar.

Results: The results showed that accuracy rates were as follow: 99.6% for date of birth; 98.8% for date of diagnosis; 96.5% for prostate-specific antigen at diagnosis; 94.6% for Gleason score at first positive biopsy for prostate cancer (transrectal / transurethral route); 88.3% for clinical staging; 97.3% for cancer status at last follow up; and 100% for survival status at last follow up.

Conclusions: Accuracy rate of clinical staging was 88.3% compared to the CoC standard requirement of 90%. Thus the existing registry does not fully meet the CoC Standard at the moment, which will be an area we will strive to improve with the recruitment of more qualified cancer registry staff.

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004

MIND THE GAP - A REVIEW OF THE COMPLETENESS AND ACCURACY OF NON-SURGICAL TREATMENT DATA FOUND IN HOSPITAL-BASED REGISTRIES

A K Stewart¹, J Banasiak¹, M Kalinin¹, C Eichenberger¹, E G Gay¹, D P Winchester^{1,2}

¹American College of Surgeons, IL, USA; ²Northshore University Health System, IL, USA

In 2009, the CoC initiated a chart review process to independently assess and monitor the completeness and accuracy of data reported to the NCDB and used to report quality of care measures for breast and colorectal cancer. In advance of each accreditation site survey up to 25 cases are selected for review by the NCDB. Registries are notified electronically and directed to assemble charts and abstracts for each case. Site surveyors are provided case-specific review directives. Administration of unreported adjuvant radiation, chemotherapy and hormone therapy, timing of reported adjuvant therapy, documentation of reported considered but un-administered treatment, and completeness of tumor characteristic information including tumor size, nodal metastases and hormone receptor status are all possible foci for review. Results of the chart review are reported electronically by surveyors following each site visit and are matched to the reported case record triggering the review. During 2009, a total of 392 surveys were conducted; 5,712 breast and colon cases were reviewed. This presentation will describe operational aspects of the chart review process; findings summarizing the extent of agreement or discordance between data reported to the NCDB and information discovered through the chart review process; and comment specifically on the challenge of ascertaining information on treatment modalities administered in the ambulatory setting and implications for cancer registries.

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CDC-NPCR'S NATIONAL INTERSTATE DATA EXCHANGE APPLICATION SYSTEM (N-IDEAS)

<u>RJ Wilson</u>¹, KB Zhang¹, J Rana¹, M Huston¹, D Radune¹ CDC, Atlanta, GA, United States

BACKGROUND: Data exchange among central cancer registries (CCRs) is essential to assure complete and timely data are available to accurately evaluate the burden of cancer in support of comprehensive cancer control efforts. Advances in computer technology enable the development of a national interstate cancer data exchange system. PURPOSE: To facilitate interstate data sharing and improve public health surveillance through more efficient central cancer registry operations. METHODS: The N-IDEAS applications was developed in two tiers: The client application and a tracking database to monitor the application. The client application performs appropriate computer edit checks, automatically creates separate encrypted files, uploads the encrypted files, and downloads and decrypts files. The second tier provides a tracking database with the capability to track the frequency with which CCRs are exchanging data and the quality of data being exchanged. RESULTS: In the initial deployment phase, a select number of registries tested the application with full release to all registries during the next phase. CONCLUSIONS: Standardizing the process by which CCRs exchange data has the potential to improve the overall quality and completeness of the incidence data, streamline operations, and reduce the amount of staff time to carry out interstate data exchange activities.

006

CHALLENGES TO THE DATA ANALYST IN WORKING WITH THE NAACCR V12 RECORD LAYOUT

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The implementation of the NAACCR v12 Record Layout will present many challenges to the cancer registry community. Vendors and registry programmers will have to add additional data items to their central registry database and accommodate the new date format and longer text fields. The new longer record length of 22,824 characters will be especially challenging to the registry Data Analyst, who uses a text editor to view and perform simple edits of data files and uses MS Access to perform advanced file edits. Many text editors will truncate or wrap the new longer record length. One that does not is TextPad (www.textpad.com). It can be purchased for a nominal fee; a fully functional version is available to download for evaluation. Reviewing and editing a file in MS Access poses more of a challenge. One solution is to develop an Access import/export specification that combines many data items so that the total number is less than 255. Another solution is to use ODBC linkage. The Data Analyst creates an empty database (e.g. in MS SQL) for the registry's database software. Using Access, ODBC linkages to the database tables are then created and the software's import routine is run to upload the file. After edits are completed, the software's export routine is run to regenerate the file. The new NAACCR Record Layout will require some modifications of operating procedures, but fortunately there are software tools available to the Data Analyst to accomplish this goal.

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CENTRALIZED RESOURCE FOR GENOMICS RESEARCH

DJ Dale¹, H Begley¹, J Brierley¹, P Shaw¹ ¹University Health Network, Toronto, Ontario, Canada

The University Health Network (UHN) Biobank stores excess tumour tissue donated for future research by patients undergoing surgical procedures. It is one of the largest hospital biospecimen repositories in Canada. Currently there is limited clinical data associated with the biospecimens. A recent institutional project studying the genomics of colon cancer patients necessitated the identification of over 900 cases of tumour tissues with detailed clinical annotation. Princess Margaret Hospital, part of UHN, operates a hospital based cancer registry. A partnership was formed between the Registry and the Biobank to annotate the biospecimens with existing

One of the purposes was to identify Stage II and III colon cancer cases with a recurrence within four years of diagnosis (bad outcome) that could then be selected for biomarker studies using tissue microarray technology. In addition to data on the bad outcome cases, detailed clinical data is required on good outcome Stage II and III along with all Stage I and IV cases. This newly designed database of 905 patients currently contains: Stage I-116 cases, Stage II-239, Stage III-271, and Stage IV-279.

clinical data and to gather extensive recurrence and follow up

This collaborative project will facilitate the creation of a clinical and biospecimen database including colon cases accrued over a ten year period. This partnership through the colon cancer initiative has built a foundation for future site specific research.

Notes

008

THE USE OF A NEW COMPLETENESS MEASURE AND ITS APPLICATION

R Dewar¹, V Bu¹, M MacIntyre¹ ¹Surveillance and Epidemiology Unit, Cancer Care Nova Scotia, Halifax, NS, Canada

Many methods have been proposed for estimating cancer registration completeness, each with strengths and limitations. Multiple methods are often combined to evaluate case completeness.

The 'Flow' method (Bullard, 2000), which models temporal flow of information from diagnostic facility to central registry, is a recent and novel addition to this armamentarium. It has been used in registry data quality evaluation, but deserves wider use.

This method was used to evaluate registry completeness by age, cancer type, extent of disease and time period, for the Nova Scotia Cancer Registry. Results for reporting patterns, before and after changes to registry operations provide evidence that new ascertainment methods have improved completeness. The estimated proportion of missing hematologic cases 12 months after diagnosis has diminished (20% to 12%). Other measures are either contradictory, or have poor statistical power to address the evaluation of new registry procedures. Estimating missing proportions over the same time period for other cancer types suggests registry operation changes were mostly specific to those malignancies at which they were targeted.

The 'Flow' method will be introduced and guidelines discussed for its application in central cancer registries.

Bullard J, Coleman MP, Robinson D, et al 'Completeness of cancer registration: a new method for routine use' Br J Cancer. 2000 82 (5) 1111-16

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APPLICATION OF MULTIPLE IMPUTATION FOR MISSING DATA IN THE PRE-INVASIVE CERVICAL CANCER STUDY

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Background: Missing data is a serious problem in the preinvasive cervical cancer study, especially for race. Using the complete case (CC) method to analyze the data may lead to biased estimates. Multiple imputation (MI) has been demonstrated to be a powerful tool to handle missing data in many scientific fields. Purpose: The purpose of this study is to investigate if race is associated with cervical cancer histological type (particularly AIS), and examine if MI will improve the estimates of the analysis. Methods: A total of 3,843 pre-invasive cervical cancer cases were collected from three registries - KY, LA and MI. Descriptive analysis and multivariate analysis were performed using both the CC method and the MI method. Results: Missing race varied significantly among the three states. Only 68.7% of cases had complete data. The estimates of race were 80.3% White, 18.3% African-American and 1.5% for other using the CC method, and 81.7%, 16.9% and 1.4% using the MI method. The logistic regression showed that Whites had a 3.71 (95%) CI 1.59-8.64) times higher risk for AIS than African-Americans using the CC method and a 2.16 (95% CI 1.05-4.47) times higher risk for AIS using the MI method. Conclusion: It was surprising to see higher risk of AIS for Whites compared to African-Americans. Further research is needed to understand the etiology of the results. Quantitative differences in estimates between the two methods were found. MI likely improved the accuracy of the estimates.

010

MEASURING THE EFFECT OF INCLUDING MULTIPLE CANCERS IN SURVIVAL ANALYSES

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Background: The wisdom of including only first primary cancers in survival analyses has recently come into question because it may lead to biased comparisons of survival between cancer registries, or over time within a single registry.1,2

Purpose: To examine the impact on Canadian survival estimates of including multiple primaries in the analyses. Methods: Data from the Canadian Cancer Registry (CCR; 1992-) were record linked to the Canadian Vital Statistics Death Database to determine mortality follow-up. Five-year relative survival estimates for those 15-99 at diagnosis were derived using all cases and then first primary cases only. The pre-1992 tumour history of persons on the CCR, if any, was obtained by linking the CCR to a predecessor database. Results: The impact will be measured across a large number of cancers: at different stages in the maturation of the CCR; within specific age groups; and after age-standardization of the results.

Implications: The inclusion of subsequent primaries in survival analyses may increasingly be adopted as standard practice. It is important that the impact on survival estimates be measured and conveyed to users.

References:

¹ Brenner H, Hakulinen T. Patients with previous cancer should not be excluded in international comparative cancer survival studies. Int J Cancer 2007; 121: 2274-2278. ² Rosso S, De Angelis R, Ciccolallo L, et al. Multiple tumours in survival estimates. Eur J Cancer 2009; 45: 1080-1094.

lotes	Notes

THE UNIQUE SES DISPARITY OF CANCER INCIDENCE AMONG CALIFORNIA'S HISPANIC POPULATION

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¹Public Health Institute, Sacramento, California, United States; ²UC Davis Medical Center, Davis, California, United States

Background: Disparities in cancer care by socioeconomic status (SES) or by race/ethnicity have been widely recognized. However, few studies have examined SES effects on cancer incidence within racial/ethnic groups.

Purpose: The objective of the study is to describe SES disparity of cancer incidence within each of four major racial/ethnic groups (non-Hispanic white, black, Hispanic, and Asian/Pacific Islander). Focus will be given to the uniqueness of SES disparity of cancer incidence among the Hispanic population.

Methods: Invasive cancers of five major sites diagnosed from 1998 through 2002 in California (n=284,738) were included. A composite area-based SES indicator was used to quantify SES level, and Relative Index of Inequality (RII) was used to measure SES gradient of cancer incidence within each racial/ethnic group.

Results: For female breast cancer and prostate cancer, SES gradients were in the same direction for all groups, with the largest gradient among Hispanics. Compared to non-Hispanic whites, SES gradients of lung and colorectal cancer incidence were in the opposite direction for Hispanics. **Implications**: Hispanics account for a large proportion of the projected population growth in both California and the U.S; the unique relationship of SES and cancer incidence within this group has important implications on cancer control efforts, especially primary prevention.

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012

A WEB-BASED INTERACTIVE QUERY SYSTEM TO CALCULATE SURVIVAL FOR RECENTLY DIAGNOSED **CANCER PATIENTS**

A Percy-Laurry¹, R Feuer¹, R Hankey³, L Cynkin¹, E Waters¹, C Mylks¹, B Killam², D Campbell³, S Scoppa³, S Gilkeson⁴ ¹National Cancer Institute, Bethesda, MD, United States; ²User-Centered Design, Inc., Ashburn, VA, United States; ³Information Management Systems, Inc., Silver Spring, MD, United States; 4Scott Gilkeson - User-Centered Software Design, Takoma Park, MD, United States

The Cancer Survival Query System (CSQS) developed by the National Cancer Institute is a web-based interactive system designed to provide survival predictions based on populationbased data from the Surveillance, Epidemiology, and End Results (SEER) Program. The online system generates information on a cancer patient's survival, characterizing the patient including comorbidity, after the input of data from a physician. The CSQS provides the probabilities of dying of cancer, other causes, and surviving for various points in time subsequent to diagnosis. By looking at cancer and comorbidity simultaneously, it is possible to obtain a more accurate assessment of survival.

The prototype design of CSQS uses SEER survival data on prostate and colo-rectal cancer sites, adapted for individual prognosis. Other cancer sites will be incorporated into the system in the future. The CSQS uses data from diagnosis years 1994-2005 from 13 SEER registries representing 20.3% of the US population.

The development of the CSQS has involved clinician participation, focus group discussions, interviews and usability testing with cancer advocacy groups, patients and oncologists. The research findings collected from physician interviews frequently reported the use of online tools for prognosis data. Physicians feel that this type of tool could be useful if presented with proper sensitivity, and in the context of other relevant information.

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ENHANCING RESEARCH CAPACITY OF CANCER REGISTRIES AND OTHER ADMINISTRATIVE HEALTH DATABASES TOWARDS STUDYING ACCESS TO QUALITY COLORECTAL CANCER SERVICES

R Urquhart¹, J Bu^{1,2}, M MacIntyre², R Dewar², E Grunfeld^{3,4}
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Institute for Cancer Research, Toronto, ON, Canada; ⁴Dept of
Family and Community Medicine, University of Toronto,
Toronto, ON, Canada

Purpose: Developing tools to measure access to and quality of colorectal cancer (CRC) services along the care continuum.

Methods: All patients diagnosed with CRC between 01Jan01-31Dec05 were identified through the Nova Scotia Cancer Registry (NSCR). Colloborating with the NSCR, a chart review was instituted to stage all cases, as Canadian registries are only beginning to capture population based staging. The cohort was anonymously linked to several large administrative databases, including hospital discharge abstracts, physicians' billings, and cancer center, pharmacare, and census data. To facilitate initial and ongoing linkages, dataset custodians agreed to create a unique study ID held at the NSCR. Additional datasets (palliative care, radiology, breast and cervical cancer screening) and chart review data have been used to enhance the original linkage. Results: 3501 patients comprise the study cohort. Descriptive analyses were completed for the diagnostic, surgery, and treatment periods. This presentation will include findings from access (wait times, inequity analysis) and quality (quality indicators, adherence to practice guidelines) analyses, and note variations over time and between subpopulations.

Conclusions: Linking data from a range of sources permits a detailed examination of care events across the continuum and the measurement of access and quality for entire populations. Building collaborations is key to enabling wider data capture and linkage mechanisms.

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014

USING CLAIMS AND DISCHARGE DATA TO BETTER ASSESS QUALITY OF CANCER CARE AMONG THE MEDICAID POPULATION

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¹New York State Department of Health, Albany, NY, United States; ²Dana Farber Cancer Institute, Boston, MA, United States; ³Centers for Disease Control and Prevention, Atlanta, GA, United States

Central cancer registries are well positioned to measure how well cancer care adheres to guidelines promoted by professional organizations. Capacity to accomplish this may be limited by incomplete ascertainment of treatments received in ambulatory settings. By augmenting registry data through linkage with insurance claims files and discharge records (hospital inpatient and outpatient, ambulatory surgery center), it becomes possible to more accurately assess concordance with treatment guidelines. We report on adherence to six cancer care quality measures based on linkages constructed between the New York State Cancer Registry, the New York State Medicaid program, and state discharge records using cancer cases diagnosed between 2004 and 2006 with follow-up through 2008. The measures involve age and stage appropriate receipt of radiation therapy, tamoxifen or third generation aromatase inhibitor, and adjuvant chemotherapy for breast cancer; receipt of adjuvant chemotherapy for colon cancer; and receipt of radiation therapy and adjuvant chemotherapy for rectal cancer. Preliminary results suggest that the information gained from the non-registry sources substantially improves our ability to assess quality of cancer care.

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CONCORDANCE OF COLORECTAL TREATMENT INFORMATION BETWEEN A CENTRAL CANCER REGISTRY AND MEDICAID CLAIMS

FP Boscoe¹, MJ Schymura¹, CG Sherman¹, K Chen², PJ Roohan³, D Schrag²

¹New York State Cancer Registry, Menands, NY, United States; ²Dana Farber Cancer Institute, Boston, MA, United States; ³New York State Dept. of Health, Albany, NY, United States

New York State Cancer Registry (NYSCR) data was linked to enrollment and claims data from the New York State Medicaid program to better assess cancer care among the economically disadvantaged. The linkage revealed that approximately 25% of over 300,000 patients diagnosed between 2004 and 2006 were enrolled in Medicaid for one or more months between 2002 and 2008. One of the principal aims of the linkage was to determine the concordance between treatment information in the registry and treatment information available through Medicaid claims. Approximately 4,000 cases with a primary colorectal tumor in both the NYSCR and Medicaid files were identified and compared. For those who received surgery, the information was uniquely on the Medicaid record about 5% of the time. For those who received radiation, the information was uniquely on the Medicaid record about 20% of the time. Similar analysis for chemotherapy is ongoing. Treatment delay and receipt of care from multiple facilities, both of which are characteristic of Medicaid recipients, account for much of the missing information. In particular, the missing radiation treatment information often reflected treatment that was administered many months after diagnosis and at not at the diagnosing facility. We will use these findings to prioritize facilities for education regarding reporting and for ongoing work evaluating cancer care for underserved populations.

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016

IMPROVED PATIENT MATCHING IN WISCONSIN: PRODUCTIVITY GAINS FROM NEW APPROACHES TO PATIENT DE-DUPLICATION AND DEATH LINKAGE

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¹Wisconsin Office of Health Informatics, Madison, WI, USA

Do central cancer registry (CCR) patient records refer to the same person? Does a death certificate or other type of external record refer to that cancer patient? The minimization of case duplicates and the correct linkage of CCR records with external ones are critically import but often challenging labor-intensive tasks. Matching records which share the benefit of correct names, birthdates, and social security numbers is a very welcome but not always available opportunity.

Techniques have been developed at the Wisconsin Cancer Reporting System to enhance the person matching process using knowledge of typographical and other commonly made data entry errors and variant naming and name recording practices. Algorithms for disaggregation and un-scrambling text, characteristically absent in probabilistic methods will be described and evaluated.

A variety of cost effective, non-proprietary approaches to improved match sensitivity and selectivity will be presented. Match counter-evidence as well as positive evidence have also been developed with hitherto seldom used data such as race, marital status, telephone numbers and standardized address data.

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NPCR-AERRO'S CANCER CONTROL AND DATA USE (CC&DU) PROJECT

<u>J Rogers</u>¹, W Blumenthal¹, S Thames¹, J Phillips¹, T Fairley¹ ¹Centers for Disease Control and Prevention, Atlanta, GA, United States

Background: The National Program of Cancer Registries-Advancing E-Cancer Reporting and Registry Operations (NPCR-AERRO) is a collaborative project within the CDC-NPCR to position the cancer surveillance community to take advantage of the electronic health record (EHR) for cancer surveillance. Purpose: To determine how electronic reporting of cancer data and adoption of the EHR can impact use of cancer surveillance data, such as improved timeliness and data quality for better trend analysis. Methods: Convened workgroup to model how cancer data are used for current and future needs, identify data sources and/or data elements not previously available, and model feedback mechanisms between data use and cancer surveillance. Completed workgroup activities include: classified current and potential users of cancer surveillance data; examined short- and longterm data needs; identified how cancer surveillance data are used to inform health and administrative decisions: identified existing and new knowledge products; and reviewed data items currently available in the EHR, and identified cancer data gaps. Based on the results of these activities, the workgroup will develop recommendations for improvements to the format of the EHR, and/or data collection and dissemination standards to aid in the use of cancer-related statistical data. Results: This presentation will describe the activities completed to date, the lessons learned, and the next steps in the project.

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018

PAN-CANADIAN CANCER SURVEILLANCE AND EPIDEMIOLOGY NETWORKS

B Candas¹, J Shin¹

¹Canadian Partnership Against Cancer, Toronto, Canada

BACKGROUND: With the 2007 funding of a Canadian Strategy for Cancer Control and establishment of the Partnership, there is a greater demand for increased timeliness, quality, and breadth of surveillance products to better inform and monitor cancer control.

PURPOSE: To meet this need, the Partnership is implementing an innovative model of cancer surveillance: pan-Canadian Cancer Surveillance and Epidemiology Networks.

METHODS: Four proposals were selected to create networks of multi-provincial and multi-disciplinary teams providing scientific expertise, effective training of analysts, high-level of collaboration within and between organizations, and knowledge translation (KT) strategies.

RESULTS: The networks address: the entire continuum of colorectal cancer, survival and prevalence methodologies, projection methodologies, and palliative care. National coverage is achieved with the involvement of the vast majority of provincial cancer registries/agencies. End-users and decision makers are involved in defining the information products to be developed. The networks are actively producing surveillance products, training end users and enhancing dialogue.

CONCLUSION: Networks will experiment with a variety of innovative approaches, scopes and KT practices. The impact of the networks will be evaluated in order to guide future development of this initiative.

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THE CANADIAN PARTNERSHIP AGAINST CANCER'S (THE PARTNERSHIP'S) SURVEILLANCE AND **EPIDEMIOLOGY NETWORKS: KNOWLEDGE** TRANSLATION IN THE COLORECTAL NETWORK (CRCNET) B Theis¹, E Candido¹, C Silverman¹, K Fradette², D Turner^{2,3}, LD Marrett^{1,4}

¹Cancer Care Ontario, Toronto, ON, Canada; ²CancerCare Manitoba, Winnipeg, MB, Canada; ³University of Manitoba, Winnipeg, MB, Canada; ⁴University of Toronto, Toronto, ON, Canada

Background: CRCNet is conducting a systematic, comprehensive examination of the burden of colorectal cancer in Canadian provinces. Four networks funded by the Partnership consulted with expert advisors to develop a joint Knowledge Translation (KT) Framework for Canadian Cancer Surveillance. The CRCNet KT Strategy follows from this framework. Purpose: To produce colorectal cancer surveillance information that is useful to end-users – decision-makers, policy-influencers and health practitioners - and to build capacity and collaboration in the Canadian cancer surveillance analytic community.

Methods: We are engaging decision-makers (cancer agency senior management), the funding body (the Partnership), policy- influencers in the Canadian Cancer Society, and health practitioners via group or individual meetings, to discuss their current and potential uses of colorectal cancer surveillance data and to get feedback on information products. We are building capacity amongst cancer surveillance analysts through training workshops, webinars, and technical support.

Results: We will summarize end-users' suggestions for analysis, content, and presentation of information products as well as analysts' feedback on workshops and webinars and identified analytic learning needs.

Conclusion: Early experience in implementing our KT strategy may suggest refinements to methods of end-user engagement and capacity building.

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020

STREAMLINING RESEARCH COLLABORATION WITH STATE CANCER REGISTRIES

D Hurley¹, M Ehlers¹, J Savoy¹, S Bolick-Aldrich¹ ¹South Carolina Central Cancer Registry, SC Dept. of Health & Environmental Control, Columbia, SC, United States

Background- State cancer registries enable public health professionals to study cancer more efficiently and effectively (e.g., burden, trends, survival). Providing high quality data and cancer data expertise are key in filling data requests and participating on collaborative research projects. However, if the application and approval processes for release of data or the researcher's responsibilities once data are received are not well-defined or well-understood; delays and tension can occur and limit future data use. Purpose- To promote data use/collaboration between central cancer registries and researchers by streamlining the application and approval processes, by providing a thorough understanding of the functions and limitations of registries as collaborators and by promoting best practices for working together. Methods-Developed policies and guidelines for working with a CCR, updated existing data application to include elements to ensure applicants understand the data request process in order to submit a complete application. Results- 5 new documents: Essential Functions & Limitations of the Central Cancer Registry, Best Practices for Working with the Central Cancer Registry, Data Use Promotion Letter, Data Application, and Protocol Checklist.

Conclusion- Clear communication and streamlining the data request and collaborative research processes not only promote data use, but also create a more successful and rewarding collaborative research experience for everyone.

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STRUCTURED REPORTING IN ANATOMIC PATHOLOGY FOR CANCER SURVEILLANCE

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The time has come to move from paper to electronic structured reporting in pathology. Electronic reporting tools will dramatically facilitate incorporation of cancer checklist information into the healthcare workflow. This need for structured reporting in anatomic pathology continues to grow. The benefits of structured reporting, especially in terms of cancer surveillance will be discussed. The most recent CAP cancer checklists will be explained in terms of changes to the checklists, their electronic structure, mappings to CS, SNOMED CT and ICD-O3, and what to expect in future CAP cancer checklist releases.

In addition to the CAP Cancer checklists, there will also be an overview of the work in structured reporting in anatomic pathology being carried out in Integrating the Healthcare Enterprise (IHE) Anatomic Pathology Work Group, an international initiative that creates frameworks for passing vital health information seamlessly – from application to application, system to system, across multiple healthcare enterprises. IHE intends to publish a white paper on structured reporting in anatomic pathology that will become an IHE Integration Profile (IP). This IP is based on the CAP Cancer Checklists as well as input from other countries that have also developed national cancer checklists. Ways for cancer registrars to become involved in IHE will also be discussed.

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022

CANCER PATHOLOGY ELECTRONIC REPORTING STANDARDS, NEW NAACCR VOLUME V – WITH SPECIMEN INFORMATION

JN Harrison¹, for the NAACCR Pathology Data Work Group² ¹New York State Cancer Registry, Albany, New York, United States; ²Canada and United States

The first uniform data standards for electronic reporting by pathology laboratories to central cancer registries were issued by the North American Association of Central Cancer Registries (NAACCR) in Sept. 2000. Since then the electronic reporting recommendations have gone through many updates. In the most recent version of NAACCR's Volume V, the Health Level 7 (HL7) section has been upgraded to include HL7 Version 2.5.1, rather than the more widely used HL7 Version 2.3.1 for message transmission. The NAACCR Pathology Data Work Group (WG) decided to define the standard using HL7 Version 2.5.1 for two reasons: 1) the HL7 organization no longer actively supports the HL7 Version 2.3.1 and 2) the specimen segment in HL7 Version 2.5.1 allows for a more robust transmission of specimen information. The focus of the new implementation guide (Volume V) is the traditional text-based pathology report with guidance on specimen handling—three use cases with corresponding HL7 sample messages are provided: 1) a single reporting source sending information on multiple specimens, 2) a service model, where one reporting source may send the specimen for accessioning to a second or third reporting source, and 3) a more elaborate version of the service model which includes consults. The WG also developed a profile for validation of HL7 messages using the Messaging Work Bench. This presentation will provide specific examples of these and related updates, including an overview of the available tools.

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NATIONAL PROGRAM OF CANCER REGISTRIES -ADVANCING E-CANCER REPORTING AND REGISTRY OPERATIONS PROJECT (NPCR-AERRO): DISCHARGE DATA PROJECT.

S Thames¹, C McCants², W Scharber² ¹Centers for Disease Control and Prevention, Atlanta, GA, United States; ²Northrop Grumman, Atlanta, GA, United States

The National Program of Cancer Registries - Advancing Ecancer Reporting and Registry Operations Project (NPCR-AERRO) is a collaborative effort to advance automation of cancer registration by developing a set of cancer surveillance models, requirements, and products that identify and describe consistent processes and data reporting standards. Hospital discharge data and claims data are rich sources of data that could provide central cancer registries with a large portion of information for cancer surveillance reporting needed to fulfill their congressional reporting requirements. The goals of the NPCR-AERRO Discharge Data Project are to collaborate with the national organizations such as the National Association of Health Data Organizations that manage the hospital discharge and claims data standard to identify and recommend modifications to the existing standard that will meet cancer registry data needs and define the standard for reporting hospital discharge and claims data to state central cancer registries. This presentation will provide a background of activities performed to date as well as an update on current standards, consensus building and anticipated next steps to developing a common data standard for reporting hospital discharge and claims data.

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024

STEPS TAKEN BY A CENTRAL CANCER REGISTRY (CCR) WITH LIMITED RESOURCES TO IMPROVE DATA SECURITY AND MAINTAIN PATIENT CONFIDENTIALITY

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Background: States and provinces/territories maintain CCRs that collect demographic, tumor and treatment data on new cases of cancer, using text and standard codes in a standard layout. CCRs must meet national standards for completeness, timeliness and quality; maintain data security; and protect patient and provider confidentiality, often with limited resources. Purpose: Describe steps one CCR took to assess and improve the security of data, systems and processes. Methods: We reviewed security processes/procedures and requested that the University's IT security team audit our systems and business practices (hard drive security, data flow, applications, firewall issues with individual computers, hardening operating system, laptop encryption, desktop risks). Web-based reporting, our most vulnerable area, was selected for the first phase. Results: We developed an inventory of all systems (web servers, file servers, etc.); set up an annual review of data security measures; changed paper handling practices; arranged for security awareness training for staff; and updated manuals. The initial web-based reporting system audit ran 52 hours and found 4 high-risk vulnerabilities plus a number of medium-risk issues; these have now been fixed by CDC's Web Plus development team. Results of audited systems will be presented. Conclusions: Frequent review of security processes/ business practices is needed to maintain data security. Many improvements have minimal cost; others need funding.

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Oral Abstracts	TUESDAY - CONCURRENT SESSION
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oral abstracts

concurrent session 2



ASSESSING THE RELIABILITY AND VALIDITY OF PRIMARY PAYER INFORMATION IN CENTRAL CANCER REGISTRY DATA

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Payer source information enables researchers and policy makers to assess disparities in healthcare coverage, patterns of care, and health outcomes including survival. As it is currently collected and reported, the utility of Primary Payer at Diagnosis (NAACCR Item #630) is uncertain. Concerns about this information include variations in reporting and consolidation practices; whether all relevant payer sources are represented; whether the information is associated with diagnosis or treatment; and the inability to track changes in insurance coverage after diagnosis. In our study we examined a sample of 2,450 prostate cases and 1,450 ovarian cases in four state registries to evaluate the validity and reliability of Primary Payer at Diagnosis as compared to reabstracted data from the reporting source medical records, and to each registry's statewide hospital discharge database. We characterized measurements of agreement between central registry data and re-abstracted/discharge data, and determined the feasibility of collecting additional payer information. We also calculated the proportion of cases where primary payer status changed between diagnosis and first course of treatment. This evaluation of registry operations will offer recommendations for the collection of information on primary payer at diagnosis.

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026

ADDRESS VALIDATION TO RESOLVE GEOCODING ISSUES AT THE CENTRAL REGISTRY

AR Houser¹, HA Hodges²

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In 2008 the California Cancer Registry (CCR) submitted nearly 200,000 cases to a geocoding vendor and received georeferenced patient addresses on 93.7% of those cases before manual review, leaving 14,540 cases to be reviewed and recoded manually. Even after removing PO Boxes, more than 7000 cases remained to be reviewed. Efforts to improve addressing coding at the hospital registry level by training have had minimal impact on this success rate. Borchers, et al., (Wisconsin Cancer Reporting System) have proposed an interactive system for capturing valid addresses at the time of data entry, but the size of the database required to make that available in California is too large for effective distribution and installation at hundreds of hospitals, and the number of cases received by the CCR makes it problematic to apply the system interactively. We have taken some of Borchers' concepts to develop a tool for applying this technology as a batch process to the screening and resolution of invalid addresses in California. We will discuss the design of this tool and its potential for becoming part of the CCR standard procedures.

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IMPLEMENTING AN ON-LINE TRACKING SYSTEM® (OSTS©) FOR COLLABORATIVE RESEARCH PROJECTS WITH CANCER REGISTRIES

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Background: To protect confidentiality of participant information, legislated regulations prohibit the release of patient information to researchers, thus transferring the time and cost required for research activities to Cancer Registry staff. University of Waterloo (UW) research staff developed an On-line Survey Tracking System® (OSTS®) for a study assessing the unmet needs of cancer survivors conducted concurrently with two Canadian population based cancer registries. OSTS® was developed to protect patient confidentiality and improve the efficiency of tracking study activities between registries and researchers.

Purpose: This presentation will describe OSTS® and discuss benefits and challenges of implementing a system to suit the needs of registry and research staff.

Methods/Results: OSTS[©] is a web-based interface that generates participant Study ID numbers for easy linkage to Registry files yet prevents researchers from seeing patient information. OSTS[©] provides a central location for tracking study activities that both researchers and Registry staff can follow. OSTS[©] generates daily reports for monitoring response rates by gender, cancer type, etc. to determine adequacy of sampling.

Conclusions: By implementing a system like OSTS[®] we can improve the efficiency of collecting data and tracking study activities while sharing information between registry and research staff. As we integrate cancer practice, surveillance and research, such systems will become invaluable.

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028

HIGHLIGHTS FROM THE NEW 2010 SEER PROGRAM MANUAL: PROCESS AND CONTENT

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Background: The SEER Program Manual contains coding and abstracting instructions for cases and data items reported to the SEER Program. The manual was last updated in 2007. The 2010 edition of the manual coincides with some significant changes for the cancer registry community.

Purpose & Methods: The 2010 manual was developed using an innovative process to catalogue proposed changes and employed a collaborative revision process.

Results: The presentation will provide an overview of the revisions made and

descriptions of the revision processes. Topics to be covered include

Background on the SEER Program Manual

Process used to identify and catalogue proposed changes

Process used to revise the manual

Overview of the 2010 revisions

Conclusion: The SEER Program Manual is a reference and a resource that is widely used throughout the cancer registry community. Revisions to this manual impact SEER and other registries. The latest edition of the manual benefits from innovative methods used to identify and catalogue potential changes, and from the collaborative process used to update the manual.

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A NATIONAL STANDARD FOR STAGE IN CANADA: EARLY RESULTS FROM SELECTED CANADIAN PROVINCES FOR COLLABORATIVE STAGE IN BREAST AND COLORECTAL **CANCER**

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Cancer registries have been operating on a population basis in most Canadian provinces for over 40 years. However, stage at diagnosis information has not been available on a population basis, although there are limited series in some provinces. To fill this acknowledged gap, Canada established its first stage collection standard in 2003.

Collaborative Stage (CS) version 1 became operative in Canadian provincial/territorial registries (PTCRs) starting with cases diagnosed in 2004. CS Implementation has been staggered across PTCRs, but several are now able to report on CS variables for cases across multiple incidence years. In this report, we describe stage completeness, and CS summary stage distribution for Nova Scotia (NS), Prince Edward Island (PE) and Manitoba (MB) for colorectal and breast cancer patients for the period 2004 - 2007 (2005-07 for PE), and compare the observed stage distribution with that reported for the SEER registries for a corresponding period.

The proportions of later stage (stage III or higher) colorectal cancers in NS, MB and PE where slightly higher (45%, 52% and 51% resp.) than in the SEER 13 registries for 2004 (41%). Proportions unknown or not available were somewhat lower (6%, 9% and 4% for NS, MB and PE resp.) vs 11% for SEER. Availability of Canadian stage data is an important contribution to enhancing cancer surveillance and as completeness expands greater opportunities will arise to understand stage-based patterns and trends.

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030

COLLABORATION RE-IMAGINED (CA)

S Fuchslin¹, J Pine¹

¹California Cancer Registry, California, United States

An international collaborative partnership group consisting of Canadian and American jurisdictions (SK/CA/NC) is working together on a joint mission against cancer in ways not previously imagined. Each partner brings the willingness to share resources, best practices, governance, and technology to discuss solutions for common benefit. This requires each partner to discuss long standing business practices, collaborate and adapt to new ways of collecting/processing data. The group has expanded the breadth and depth of what is possible and will improve the registry application (Eureka) and processes used. California Cancer Registry's (CCR) journey began with the internal collaboration between eight regional registries into one common platform implementing standards compliance. As these efforts evolved, the technology evolved as well into one of the most advanced registries available. Jurisdictions such as Mexico, North Carolina (NC), and Saskatchewan (SK) have discussed possibilities for collaboration, in areas such as process analysis, governance, technology and resource sharing. These possibilities have been realized, starting in 2007 with the North Carolina Central Cancer Registry, and in 2009 with the Saskatchewan Cancer Registry. The ability to partner, share a vision and to realize advancements in 'how we do our job', automate manual steps and improve research capabilities are some of the areas that the partnership has achieved, now, and in the next two to four years.

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COLLABORATION RE-IMAGINED (NC/CA)

J Sammerson¹, C Rao¹

¹Central Cancer Registry, Raleigh, North Carolina, United States

An international collaborative partnership group consisting of Canadian and American jurisdictions (SK/CA/NC) is working together on a joint mission against cancer in ways not previously imagined. Each partner brings the willingness to share resources, best practices, governance, and technology to develop solutions for common benefit. This requires each partner to discuss long standing business practices, collaborate and adapt to new ways of collecting/processing data. The group has expanded the breadth and depth of what is possible and will improve the registry application (Eureka) and processes used. The North Carolina Central Cancer Registry's (NC) and California Cancer Registry (CCR) began their partnership in 2006. NC's key contributions have been threefold. 1. Direct hospital case abstraction into NC CCR's database, eliminating the need for manual file upload as cases are abstracted directly. This eliminates edit errors on file upload as the software system requires that edit errors be fixed before system acceptance. 2. Data Miner functionality equips users with point and click data querying capability, providing a solution to database queries without the user having prior SQL programming knowledge. All required NAACCR fields are at the users' disposal allowing for customized queries where results can be saved, modified and shared. 3. Direct file upload by the hospital abstractor directly into the central registry by those not directly abstracting into the system.

032

COLLABORATION RE-IMAGINED (SK/CA)

H Stuart¹, K Guedo¹

¹Saskatchewan Cancer Agency, Regina, Saskatchewan, Canada

An international collaborative partnership group consisting of Canadian and American jurisdictions (SK/CA/NC) is working together on a joint mission against cancer in ways not previously imagined. Each partner brings the willingness to share resources, best practices, governance, and technology to develop solutions for common benefit. This requires each partner to discuss long standing business practices, collaborate and adapt to new ways of collecting/processing data. The group has expanded the breadth and depth of what is possible and will improve the registry application (Eureka) and processes used. The Saskatchewan Cancer Agency (SCA) and the California Cancer Registry (CCR) established a partnership in the fall of 2009, with a focus on three areas - 'People, Process and **Technology**'. People: joint efforts in process review, technology and Lean Six Sigma. Process: review of current processes patient/case registration, final diagnosis, follow up processes and death clearance. Technology: 'patient centric' data model (event driven, data oriented) based on enhancements and application improvements. The Future: Offers an opportunity to provide a long term solution that is web based allowing for enhanced research capabilities and provides a hybrid solution (central registry and hospital entry that is data driven) that is the most advanced solution available. Solution meets / exceeds key attributes of the 2009 NAACCR Roundtable - "Transforming Registries".

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LOOKING FROM THE INSIDE OUT: EVALUATING THE 2010 DATA CHANGES IMPLEMENTATION

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Most would agree that this year's data changes are the most intense since converting to FORDS or ICDO-2. This year there was much planning and heroic efforts by teams across the country to pin down specifications and prepare software and training. Now we need look at the status of the roll out and see what we can learn. We will examine the timeline from when it was first imagined to what we have now. We will check off a number of initial measures to see how we fare, such as: Timeliness of completion of specifications for each of the major components (e.g., CS schemas, date formats, dictionary, hematopoietic db)?

Commitment of national organizations to the 2010 implementation?

Availability of the required national tools (CSv2, AJCC, Edits, testing, help files)?

Quality and timing of registrar training?

Quality of the testing of components?

Communication to states on the substance and progress of the 2010 standards completion to allow for early planning and implementation?

What states are now in production for 2010 cases?

We will conduct an informal query with a non-scientific sample of states to help answer these questions. This not a formal review but rather an example of how one might do one. We will bring our own viewpoint, as members of several NAACCR standards and CSV2 committees, as a provider of hospital software and national registry tools, including the 2010 EDITS tools revision, and as a part of the California Cancer Registry.

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034

ÉVOLUTION DU CANCER DU COL DE L'UTÉRUS CHEZ LES JEUNES FEMMES ADULTES AU QUÉBEC, 1983 À 2006

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Au Québec, la vaccination contre les virus du papillome humain a débuté en 2008, principalement en milieu scolaire. Bien que l'impact de cette vaccination sur l'incidence du cancer du col utérin risque de ne pas être perceptible avant une vingtaine d'années, la participation élevée des adolescentes à la vaccination pourrait peut-être avoir un impact plus rapide que prévu chez les femmes plus jeunes. Il apparaît donc pertinent de documenter les taux d'incidence du cancer du col utérin dans cette population, en tenant compte de la morphologique, puisqu'il existe un lien entre la morphologique et les génotypes de VPH inclus dans le vaccin.

La population à l'étude est composée des jeunes femmes âgées de 20 à 44 ans atteintes du cancer du col utérin entre 1983 et 2006. Les morphologies ont été stratifiées en 3 catégories. Pour chaque catégorie, le taux standardisé d'incidence a été calculé en utilisant la population du Canada en 1991 comme référence.

On dénombre 3261 femmes âgées de 20 à 44 ans atteintes de cancer du col, dont 62 % sont de type de carcinomes épidermoïdes et 21 % de type d'adénocarcinomes. Au cours de la période à l'étude, le taux de cancer du col a diminué de 30 % chez les jeunes adultes. Par contre, le Québec observait une forme stable pour les carcinomes épidermoïdes et une augmentation de 80 % pour les adénocarcinomes.

Ces statistiques serviront comme taux de référence pour mesurer l'impact de la vaccination sur le taux d'incidence du cancer du col.

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THE GIST ON G.I.S.T.

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Beginning in 2001, Gastrointestinal stromal tumors (GIST) was given a proper ICD03 code. Since then, 1,203 have been reported in Florida. GIST are considered rare tumors that occur throughout the digestive tract, anywhere from the esophagus to the rectum or in the abdominal cavity. Originally GISTs were thought to be from muscle or nerve cells, but in the last 20 years it was discovered that they actually originate from the interstitial cells of Cajal (ICC) located in the walls of the GI tract. Currently there is some debate regarding whether or not all GISTs should be considered malignant. Some clinicians and pathologists have suggested that the term "benign GIST" be discarded as there is no such thing as a "benign" GIST. Current reporting guidelines state that only records that mention malignancy somewhere in the record are reportable. Leading to the question, should we be collecting information on all GISTs whether or not it is stated to be malignant? We will present descriptive epidemiology on GISTs in Florida and the U.S. with regard to site, age at dx, sex, race, ethnicity and stage. In light of the debate on "benign" GISTs we will also be discussing reportability problems, implications and possible solutions.

036

INCREASE IN THE USE OF DOUBLE MASTECTOMY FOR THE TREATMENT OF EARLY-STAGE BREAST CANCER IN **CALIFORNIA**

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Background. Among women diagnosed with early-stage breast cancer in California, the use of breast- conserving surgery (BCS) increased steadily during the last decade. However, there is growing concern that a trend towards double mastectomies among women eligible for breast conservation may be on the

Objective. The objective of this study was to uncover recent trends in surgical treatment of women diagnosed with earlystage breast cancer in California, with a special focus on the use of double mastectomy.

Methods. The study population included 111,701 women diagnosed with American Joint Committee on Cancer stages 0-II breast cancer. Logistic regression and chi-square test for trends were used to evaluate changes in the proportion of women receiving BCS, unilateral mastectomy, or double mastectomy, with removal of the unaffected breast.

Results. From 2000 through 2005, the use of BCS increased from 66.9% to 73.3%, while the proportion of unilateral mastectomies decreased from 30.3% to 23.3%. During the same period, receipt of double mastectomy increased from 2.8% to 3.4% (OR = 1.24, p = 0.002). However, between 2005 and 2009, the proportion of women receiving double mastectomies increased from 3.4% to 6.1% (OR = 1.8, p < 0.000).

Conclusion. The use of double mastectomy among women diagnosed with early-stage breast cancer in California increased significantly during recent years. More research is needed to determine reasons behind this disconcerting trend.

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CP3R REPORTS FOR POPULATION BASED STUDIES

F Ross¹, J Jacob¹

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The American College of Surgeons (ACoS) provides specifications for Cancer Program Practice Profile Reports (CP3R) which offer hospitals comparative information to assess adherence to standard of care therapies for certain major cancers. While this information can be used by individual providers to monitor the care provided to their patients, such information is also valuable to assess standards of care in populations represented in central cancer registries. The Kentucky Cancer Registry (KCR) has created reports based on the CP3R guidelines in their cancer registry software called CPDMS.NET and is using the results at the central registry for population-based patterns of care studies.

KCR has translated report specifications into queries that include all reporting sources at the central registry. The results are used to generate study groups for statistical analyses. For example, KCR created a report aimed at measuring compliance with the standard treatment guideline for Stage III colon cancers. A report of eligible patients was generated for 2007 colon cancers which identified cases compliant and noncompliant with the treatment guidelines. KCR used this report to initiate a pattern of care (POC) study. The POC study followed back on each noncompliant case to determine if chemotherapy was actually given but not reported to the central registry or not given at all. Differences in the compliant vs. noncompliant groups may then be explored by age, race, gender and geography.

038

THE CANADIAN PARTNERSHIP AGAINST CANCER'S SURVEILLANCE AND EPIDEMIOLOGY NETWORKS: A BRAVE NEW WORLD FOR CANCER SURVEILLANCE PRODUCTS. EXHIBIT #1: THE CANCER SURVIVAL AND PREVALENCE ANALYTIC NETWORK (CSPAN).

D Turner^{1,2}, K Fradette^{1,2}, H Lu¹, R Koscielny¹ ¹CancerCare Manitoba, Winnipeg, MB, Canada; ²University of Manitoba, Winnipeg, MB, Canada

Objective: As one of The Canadian Partnership Against Cancer's Surveillance and Epidemiology Networks, CSPAN is producing cancer survival and prevalence products in way that maximizes uptake by key audiences.

Methods: CSPAN is using an approach grounded in knowledge translation (KT) to produce cancer survival and prevalence products (traditional reports plus a suite of programs to aid in standardized methods) for use by the Canadian cancer control community. While the basic statistical concepts (for survival and prevalence) are well-known, the use of KT in this environment is novel: the ultimate "users" of the products are engaged in the concepts, design and implementation. CSPAN is also investigating new approaches to the "old" methods, e.g., using multiple primaries vs first primaries in survival analysis.

Results: We have two types of "audiences": senior surveillance analysts and groups of policy "influencers" (the users of the statistics). Engagement by the methodologists has been outstanding and analytic approaches are aligning. Early feedback from policy influencers has also been positive. Details of our methods, output, and engagement success will be shared in this session.

Conclusions: The engagement of various audiences in CSPAN's work is advancing cancer surveillance's methods and utility by key audiences.

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THE CANADIAN PARTNERSHIP AGAINST CANCER'S (THE PARTNERSHIP'S) SURVEILLANCE AND EPIDEMIOLOGY NETWORKS: A BRAVE NEW WORLD FOR CANCER SURVEILLANCE PRODUCTS. EXHIBIT #2: COLORECTAL CANCER NETWORK (CRCNET)

LD Marrett^{1,2}, B Theis¹, E Candido¹, P Sanchez-Romeu¹, D Nishri¹, G Walsh³

¹Cancer Care Ontario, Toronto, ON, Canada; ²University of Toronto, Toronto, ON, Canada; 3Cancer Care Nova Scotia, Halifax, NS, Canada

Background: Standardized and useful approaches to analysing and reporting on colorectal cancer (CRC) trends and risk factors are needed to support newly implemented provincial screening programs.

Purpose: As part of the Partnership's surveillance and epidemiology networks initiative, CRCNet aims to:

- 1. create high-quality information products useful to target audiences (policy-influencers, decision-makers and health practitioners) for informing and monitoring cancer control progress for colorectal cancer; and
- 2. increase capacity for cancer surveillance analysis and information product development.

Methods: CRCNet is a collaboration of cancer registries in 8 provinces (Alberta, Saskatchewan, Manitoba, Ontario, Québec, Nova Scotia, Prince Edward Island and Newfoundland & Labrador), led by Ontario. A standardized protocol, including rigorous assessment of registry comparability; common definitions, algorithms and reporting templates; and analyst training, is being implemented in all registries. An explicit knowledge translation (KT) strategy involving frequent engagement of target audiences is being carried out. Results: CRCNet is progressing on all fronts. Details will be shared.

Conclusions: CRCNet's engagement of collaborators, analysts and stakeholders and a systematic approach to analysis and training will have a lasting benefit on surveillance analysis and KT capacity in Canada.

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CANADIAN PARTNERSHIP AGAINST CANCER'S (CPAC) CANCER SURVEILLANCE AND EPIDEMIOLOGY NETWORKS: A BRAVE NEW WORLD FOR CANCER SURVEILLANCE PRODUCTS. EXHIBIT #3: THE CANCER PROJECTION ANALYTIC NETWORK (C-PROJ)

J Hatcher¹, M Wang¹, Z Qiu¹, Z Jiang¹, A Colquhuon¹, C Normandeau¹

¹Alberta Health Services, Edmonton, AB, Canada

Background: Multiple methods for cancer projections are currently used across Canada. Standard methods need to be evaluated for production of projection statistics that can be used by key stakeholders.

Objective: As part CPAC's analytic network initiative, C-PROJ aims to produce cancer incidence and mortality projections products in a consistent way that maximizes uptake by key audiences. increase cancer surveillance analytical capacity among the provincial registries

Methods:. C-PROJ is a collaboration among six provinces (British Columbia, Alberta, Saskatchewan, Manitoba and Nova Scotia) which is investigating the best methods for short and long term projections that are generally applicable across Canada. Collaboration among the analysts across the country will ensure alignment of methodologies. The Knowledge Translation activities are designed to ensure that the products are useful to both analysts (Software programs) and decision makers (reports and other media)

Results: There is engagement in for this project from both analysts and decision makers, at both the provincial and national level. Details of our methods, output, and engagement success will be shared in this session.

Conclusions: The engagement of various audiences in C-PROJ's work is advancing cancer surveillance's methods and utility by key audiences for advancing cancer control in Canada.

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THE CANADIAN PARTNERSHIP AGAINST CANCER'S (THE PARTNERSHIP'S) SURVEILLANCE AND EPIDEMIOLOGY NETWORKS: THE C-SPAN METHODOLOGY WORKING GROUP JOURNEY: DECISIONS ALONG THE WAY

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Background: The Cancer Survival and Prevalence Analytic Network (C-SPAN) is bringing Canadian analysts together to develop standard approaches to cancer survival and prevalence analysis in Canada. Thus far, the C-SPAN Methodology Working Group has reached several decision points relating to relative survival analysis.

Purpose: We will examine the impact of methodological decisions relating to choice of life tables, inclusion of first primaries or multiple primaries, multiple primary coding rules, and method of confidence interval calculation.

Methods: Using data from two Canadian provinces (Manitoba and Alberta), relative survival estimates will be compared to determine the individual and collective impact of (a) including only first primary tumours or multiple primaries in survival analysis; (b) using life tables prepared by each province or standard life tables used to generate Canadian Cancer Statistics' survival estimates; (c) using the SEER/CCR multiple coding rules employed in each province or converting each registry's data to IARC multiple primary rules; and (d) confidence interval calculation.

Results: A comparison of the impact of different choices will be examined within and between the two provinces, across time, and cancer sites. Analysis will also be stratified by age and gender.

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oral abstracts

concurrent session 3



SET-ORIENTED SEARCHING OF CANCER CHEKLIST DATA J Golabek¹, M Matan¹

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The reporting of tumor characteristics is tending toward synoptic format—a collection of questions and answers describing tumors in terms of size, histologic type, grade, nodal involvement, biomarker assay results, and other pertinent characteristics. The College of American Pathologists provides standardized checklists for each of the various types of cancers. Each checklist contains somewhere between 20 and 40 variables and values coded to the SNOMED CT vocabulary. Should the trend toward synoptic reporting continue it is expected that cancer databases will eventually contain hundreds of thousands of values describing the characteristics of different tumors.

Searching such databases poses a challenge for non-technical users. Not only is the volume of the data daunting but examining relationships between subsets of the data requires programmatic techniques. We describe an innovative approach that allows users to quickly create simple sets of cancer data and to manipulate these datasets in a graphical Venn-diagram manner to inspect differences, similarities, and generate more complex datasets without the need for database programming.

The presentation will describe techniques for building cancer checklist databases and methods for data presentation, navigation, and manipulation for the non-technical user. The objective is to make cancer checklist data accessible and usable for research applications.

043

INTER-REGISTRY RECORD LINKAGE WITHOUT RELEASING PATIENT LEVEL DATA: EXAMINING THE FEASIBILITY OF ESTABLISHING A NATIONAL CLEARINGHOURSE USNING ONE-WAY DATA ENCRYPTION

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Background: Many cancer patients move from one registry jurisdiction to another. Often times, a different "permanent residence" at diagnosis is listed and therefore, the cancer can become an 'incident' case in multiple CCR's resulting in overestimation of cancer in the respective states and at the national level.

Purpose: A central database could link and identify the potentially duplicate cancers. However due to patient confidentiality, the release of patient level identifiers is not feasible for many CCR's. We have examined the use of one-way encryption of patient level identifiers to overcome this limitation. One-way encryption cannot be un-encrypted unlike two-way encryption.

Methods: One-way encryption converted the patient identifiers into a series of characters called hashes and then deterministically compared them using a series of 10 passes. This project linked Florida's 160,000 mortality records against 1.2 million consolidated patient records.

Results: Approximately 99% of the records were linked deterministically using one-way encryption with fewer than 0.0002% false positives. The linkage took less than one minute per pass to run.

Implications: Using this innovative approach to de-duplicating cases between CCR's may allow CCR's to share their deidentified data with a central clearing database, resulting for more accurate data by eliminating non-incident cases from the respective CCR's which in turn will provide more accurate national data.

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AUTOMATED CODING OF KEY CASE IDENTIFIERS FROM TEXT BASED ELECTRONIC PATHOLOGY (E-PATH) **REPORTS**

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The volume of E-Path reports transmitted to cancer registries are increasing at a phenomenal pace; however, the utility of text based E-Path reports remain limited until reviewed and coded by cancer registrars. Automated coding of key case identifiers such as site, histology, behavior, grade and laterality could enhance E-Path for rapid case ascertainment, case finding and earlier estimates of cancer incidence rates. The Kentucky Cancer Registry (KCR) and Artificial Intelligence in Medicine, Inc. are collaborating on a project sponsored by the SEER Program to evaluate the use of AI technology for automated coding of these data elements.

Two software tools, AutoCode and Synoptex have been developed to identify topography and morphology codes and extract the data items defined by the College of American Pathologists (CAP), from free text pathology reports. These tools use natural language processing to accomplish their tasks; however they do not take into account all factors on which registrars base coding decisions. This project seeks to enhance the technology by incorporating heuristics based on cancer registrar domain knowledge. Using the five data elements described above, the objective is to improve coding performance to make the system useful at the cancer coding stage of registry operations.

KCR has provided e-path reports and feedback from registrars to build the knowledge and rule base for Coding Assistant. Study methods and preliminary results will be presented.

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045

SUCCESSES AND CHALLENGES IN POPULATION BASED **ELECTRONIC PATHOLOGY (E-PATH) REPORTING**

T Gal¹, E Durbin¹

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With support from the Surveillance, Epidemiology and End Results (SEER) program, the Kentucky Cancer Registry (KCR) has implemented E-Path reporting in a large number of hospital path labs and small freestanding path labs. KCR has also implemented e-path from national labs through CDC's Public Health Information Network (PHIN). As a result, KCR is approaching complete population based E-Path reporting for all histologically confirmed cancer diagnoses.

In order to fully utilize E-Path reports, a number of sophisticated tools are required at the central registry. KCR has implemented an E-Path repository based upon the Health Level Seven (HL7) 2.3.x message structure as defined by NAACCR Standards Volume V. In addition, a search engine interface and an E-Path viewer have also been developed. These tools have enabled KCR to use the E-Path repository for central registry case-finding and pathology based research studies. KCR is also integrating E-Path case-finding into the web based registry system provided by KCR to all non-federal hospitals in Kentucky.

Complete and well defined HL7 standards have been published by NAACCR since December 2005, yet non-compliant vendor implementations remains an obstacle to E-Path utilization. This presentation will describe KCR's successes and challenges in establishing e-path reporting, development of the necessary tools and utilization of E-Path in registry operations.

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COLLECTION AND USE OF INDUSTRY AND OCCUPATION DATA I: OPPORTUNITIES AND CHALLENGES

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¹University of Southern California, Los Angeles, CA, United States; ²California Cancer Registry, Sacramento, CA, United States; ³National Institute for Occupational Safety and Health Centers for Disease Control and Prevention, Cincinnati OH, United States

Background: The Cancer Registries Amendment Act of 1992 specifies that "information on the industrial or occupational history of the individuals with cancer" be collected by registries which receive federal funding support. This provision was controversial at the time and remains so. The data collected under this provision have been little used.

Purpose: In this presentation we will review the strengths and weaknesses of industry and occupation (I&O) data from the central registry.

Methods: We have reviewed characteristics of I&O data collected by the California Cancer Registry since 1988. We also reviewed published epidemiologic literature for opportunities to compare results from the registry data with more extensive research.

Results: We find that I&O data collected by the California Cancer Registry are sufficiently valid to be used for hypothesis generation and occupational cancer risk surveillance. We will describe methods that will substantially enhance the completeness of these data.

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047

COLLECTION AND USE OF INDUSTRY AND OCCUPATION DATA II: – OVERVIEW AND GOALS

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Background: In 2007, the Centers for Disease Control funded the National Institute for Occupational Safety and Health (NIOSH) to work with the California Cancer Registry (CCR) on a pilot study to explore the feasibility of coding of industry and occupation (I&O) information contained in CCR records. Purpose: The goals of the project were to develop an autocoding program to assign codes to I&O text fields in registry records, to use these data to calculate incidence rates and standardized rate ratios for major cancer sites for various construction occupations, and to demonstrate the usefulness of this coding to other cancer registries.

Methods: CCR staff provided I&O text strings (literals) for coding by NIOSH staff, and the autocoding program was enhanced with the new codes..

Results: Now in year three of this pilot, of the nearly three million cases in the CCR database (diagnosed 1988-2007), the proportion assigned I&O codes has increased to 78.4% allowing preliminary analysis of the association between occupation and cancer. However, a high proportion of records (>50%) do not have enough data in I&O text fields to code industry beyond "unemployed/unknown" or "retired."

Conclusion: Future plans include developing a training module to educate cancer registrars on locating this I&O information in medical records. The CCR also is initiating a project to enhance the CCR research database with I&O information extracted from electronic death records.

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COLLECTION AND USE OF INDUSTRY AND OCCUPATION DATA III: CANCER SURVEILLANCE FINDINGS AMONG CONSTRUCTION WORKERS

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Construction workers are currently or have historically been exposed to several known or suspected carcinogens including silica, solvents, paints, diesel exhaust, wood dust, and lead. There is interest in estimating and comparing the burden of cancer in construction workers. Data from the California Cancer Registry (CCR) were used to compare cancer incidence rates between construction workers and all other workers, and incidence rate ratios (IRRs) were calculated. Numerator data were provided by CCR and denominator data were obtained from the Current Population Survey. A matched case-control design was also used to examine the risk of various cancers among construction workers. Cases were subjects identified by CCR with the cancer of interest. Controls were individuals identified by CCR with cancers not thought to be related to employment in the construction industry. Between 1988 and 2008, a total of 57,794 cancer cases were identified by CCR with construction as the industry the patient engaged in for most of their life. Among those 15-64 years of age, the rate of all cancers combined was lower for construction workers (IRR=0.73). However, construction workers had increased rates of plural, laryngeal, lung, liver and esophageal cancers. Trends, cancer rates among various construction occupations, and case/control study findings will be presented. This work documents an important, ground-breaking new tool to conduct occupational cancer surveillance.

049

COLLECTION AND USE OF INDUSTRY AND OCCUPATION DATA IV: DEVELOPMENT OF TRAINING MATERIALS TO IMPROVE OCCUPATIONAL DATA COLLECTION IN CANCER **REGISTRIES**

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Between 4-20% of cancer deaths have been attributed to occupation, and virtually no industry is spared from potential occupational carcinogens. Central cancer registries have the potential to be a rich source of data for examining associations between occupation and cancer; but, despite a mandate to collect occupational data, the estimated proportion of cancer registry records that contain usable occupational data varies by state, ranging from 15-64%.

The goal of this project is to improve the capture of occupational data from medical and administrative records to increase the validity of using these data for surveillance and research, with the ultimate goal of decreasing the incidence of cancers related to occupational exposures.

We will do this by: 1) Observing and talking with registrars to see how they collect occupational data and identify best practices; 2) Reviewing previous work in this area; 3) Working with NAACCR to develop a web-based training module for cancer registrars; and 4) Testing and evaluating the training module.

We will present an outline of the proposed content of the webbased training module for cancer registrars, based on our background work with registrars and registries.

This project will help to overcome many of the perceived barriers to collecting occupational information in a systematic, standardized and efficient manner, and ultimately improve the capacity of all central registries to use occupational data in epidemiologic research.

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MAPPING LATE STAGE BREAST CANCER RATES TO IMPROVE LOCAL CANCER CONTROL EFFORTS

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Geographic Information System (GIS) can be used to understand disparities in cancer control and better target areas in need of prevention intervention. The Patient Education and Community Outreach Center (PEOC) at the University of Southern California/Norris Comprehensive Cancer Center (USC/NCCC) analyzed cancer incidence data using kernel density estimation (KDE) to create density maps showing patterns of late-stage or invasive breast cancer diagnosis in the 8 Service Planning Areas (SPA), and at a finer geographical resolution, in Los Angeles County (LAC).

Overall, Metro, South, East and South Bay had disproportionately high levels of invasive breast cancer diagnoses. Patterns of late stage disease varied substantially by area and race/ethnicity. Among Latino and Black women, the highest density of invasive and late stage breast cancer was concentrated in areas poorly represented by local screening and clinical services.

Findings from this study will assist partnership development efforts to engage cancer prevention and control organizations, including those that offer treatment and clinical trials, and encourage the use of evidence-based programs, to target highdensity areas. We will continue to monitor geographical distributions over time so that we can determine if partnership efforts are able to make long term differences to the distribution of late stage disease.

051

EVALUATING METHODS FOR PRESERVING CONFIDENTIALITY DURING THE RELEASE OF RECORDS INCORPORATING ADDRESS OR OTHER GEODATA

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Spatially aggregating cancer registry data (e.g. producing rates at the census tract level) is not a perfect means of protecting confidentiality: it is often possible to combine publicly-available geographical data with cancer rates to re-engineer locations of individual cancer cases, compromising confidentiality. Moreover, spatial aggregation undoubtedly hides important local variation in cancer incidence that could be used to target cancer control efforts.

We used Registry breast cancer incidence data (initially transposed in space to protect the confidentiality of the actual points for this exercise), aggregated at various spatial resolutions, tested the probability of successful re-engineering, and assessed the impact on geospatial patterns of the various methods of masking confidentiality. We provided groups of lay persons with commonly available geographical tools to aid them in regenerating the original incident locations, and determined their success in doing so.

Data aggregated above 1km square grid level were rarely successfully re-engineered, and the spatial patterns of disease based on that aggregation showed clear patterns of breast cancer risk that were not obvious from census tract-based mapping. We provide recommendations on how best to balance the concern of protecting geoconfidentiality of cancer data, while maintaining the ability to conduct relevant spatial analysis.

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USING THE RAPID INQUIRY FACILITY (RIF) TO INVESTIGATE THE ASSOCIATION BETWEEN LUNG CANCER INCIDENCE AND AIR BORNE POLLUTANTS FROM STEEL AND IRON FOUNDRIES IN HAMILTON, ONTARIO

S Wanigaratne¹, E Holowaty^{1,2}, T Norwood¹, S Harris^{1,2,3}, P Brown^{1,2}

¹Cancer Care Ontario, Toronto, Ontario, Canada; ²Dalla Lana School of Public Health, Toronto, Ontario, Canada; ³Occupational Cancer Research Centre, Toronto, Ontario, Canada

GIS tools, such as the RIF, enable rapid examination of spatial relationships in public health. The RIF conducts disease mapping using robust spatial statistical methods and risk analysis in relation to suspected environmental hazards. The steel industry, present in Hamilton since 1910, has reported substantial emissions of carcinogens, such as benzene, to the environment. The study outlined here builds on an analysis conducted in 1988, and will assess whether carcinogenic releases from the steel industry are associated with risk of lung cancer. The spatial unit of analysis is the dissemination area, akin to the US census block group.

The spatial patterns of lung cancer for both sexes in the City of Hamilton will be examined using a cross sectional design employed by the RIF. Lung cancer Standardized Incidence Ratios (SIRs) will be smoothed using Bayesian hierarchical models and adjusted for small area estimates of smoking, areal estimates of income, migration and employment in processing, manufacturing and utilities. Secondly, risk analysis will be conducted, calculating lung cancer SIRs for modeled exposure bands adjusting for the same confounders. Statistical significance will be evaluated using the chi square tests for homogeneity and linear test for trend, across the bands of exposure.

The RIF is valuable for quickly identifying cancer excesses in small areas, investigating risks from suspected environmental hazards, and generating hypotheses for future study.

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053

LIVER CANCER AND IMMIGRATION: SMALL AREA ANALYSIS OF INCIDENCE WITHIN OTTAWA AND THE GREATER TORONTO AREA, 1999 TO 2003.

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While liver cancer is rare, its incidence is growing and it is highly fatal. In the United States from 1973-2006, age-adjusted liver cancer rates more than doubled. In Ontario, since 1980, liver cancer incidence has increased 2 to 3% annually and its mortality rate has increased the most rapidly of any cancer.

In a recent study, investigators analyzed liver cancer incidence by the 35 Ontario health units and located clusters of higher standardized incidence rates in Ottawa and the Greater Toronto Area. Immigration (data from Canadian Community Health Survey, cycle 1.1, 2001) was an important factor explaining the spatial variation of liver cancer within Ontario, corroborating findings from other North American studies.

To identify whether spatial patterns exist at the finest geographical unit available for Census data and to determine if immigration is an important contributing factor at this level, liver cancer incidence rates are calculated by small areas for 1999-2003 using Ontario Cancer Registry data. Bayesian hierarchical models are employed to estimate the association of sociodemographics and liver cancer, while properly accounting for overdispersion and spatial autocorrelation.

Preliminary results show clear spatial patterns and significant clusters of higher liver cancer incidence within Toronto. Small area analyses allow researchers to identify at risk populations, evaluate risk factors, and assist planners with health services utilization.

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COLORECTAL CANCER TRENDS IN FLORIDA HISPANICS: DATA FROM THE HISPANIC MONOGRAPH — A FLORIDA CANCER DATA SYSTEM (FCDS) PUBLICATION

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Hispanic colorectal cancer (CRC) rates historically have been lower than for non-Hispanic Whites (NHW) in the US. Purpose: To understand the cancer burden of Florida Hispanics and differences in outcomes based on the diversity of Hispanic subgroups. The FCDS has created a Monograph focusing on the cancer outcomes of Florida Hispanics diagnosed between 1989-2006. Methods: The Hispanic Origin Identification Algorithm was applied to the FCDS data in order to reduce misclassification as to ethnic designation. Primary cancer site and histology data were categorized based on SEER site groups. Cancer incidence trends between 1989-2006 were conducted using the Joinpoint regression model. Results: Trends in CRC have been higher for Hispanics compared to NHW since the mid 1990s. More troubling was a consistent significant increase in the incidence of distant stage CRC in Hispanics (annual percent change [APC] of 1.26% and 0.90% in males and females), while rates in NHW decreased significantly during the same time period (APC -1.36% and -1.28%). This is a particular public health concern given that CRC is a screenable cancer and could imply an associated increase in CRC-related mortality among Florida Hispanics. Current (2008) Florida Behavioral Risk Factor Surveillance System reports report significantly lower rates of CRC screening in Hispanic adults 50 years of age and older relative to NHW. Comprehensive CRC screening programs targeting the Florida Hispanic population are warranted.

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055

VARIATIONS IN CANCER INCIDENCE AND MORTALITY AMONG NEIGHBORHOODS IN BOSTON, MA, 2001-2005

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Objectives. This study presents the differing cancer incidence and mortality rates and stages at diagnosis among the socially, racially, and ethnically diverse neighborhoods of Boston, MA. Methods. Using census tract and zip code data, 15 neighborhoods in Boston were identified. Standardized incidence ratios (SIRs) and standardized mortality ratios (SMRs) for 22 cancers and all invasive cancers, based on MA rates, were calculated for each neighborhood by sex. Stage at diagnosis for each neighborhood for colorectal, female breast, and prostate cancers was compared to the state. Census data on racial/ethnic, linguistic percentages and poverty levels by neighborhood were examined as well. Results. While each neighborhood had cancers with significantly elevated SIRs and SMRs, the type of cancer varied by neighborhood. For example, melanoma SIRs were significantly elevated in white, non-Hispanic (NH) neighborhoods while prostate cancer SIRs were significantly elevated in black, NH neighborhoods. Stage at diagnosis for colorectal, prostate, and female breast cancer were also significantly elevated in a few neighborhoods. Conclusions. There are clear variations of cancer incidence and mortality among the diverse neighborhoods of Boston. This

mortality among the diverse neighborhoods of Boston. This study examines these variations in relation to race/ethnicity, poverty levels and stage at diagnosis.

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INCIDENCE OF HPV ASSOCIATED HEAD AND NECK CANCERS BY SUB-SITE AMONG DIVERSE RACIAL/ETHNIC POPULATIONS IN THE U.S.

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Background: Head and neck cancer (HNC) incidence, mortality and survival rates are known to vary by sex and race, with men and African Americans disproportionately affected. Established etiologic factors for HNC include tobacco and alcohol exposure, with a recent implication of human papillomavirus (HPV) in the pathogenesis of HNC. Objective: This study describes the epidemiology of HNC in North America, examining the variation of rates by race and anatomic sub-site. Cancer sites were further grouped according to proclivity for HPV infection. Methods: Using NAACCR's CINA deluxe file, HNC incidence data for 1995-2005 from all US cancer registries that met high quality data standards were used to calculate age-adjusted incidence rates by sex, race, sub-site, and HPV grouping. Annual percent change (APC) was calculated for HPV groupings by subsite and race. Findings: Consistent with previous findings, males and Non-Hispanic Blacks (NHB) experienced greater HNC incidence. With respect to APC trend analyses, a significant increase in HNC incidence has been observed among the HPVassociated sites between 1995 and 2005. In contrast, non-HPV associated sites experienced a significant decrease in HNC incidence in the same time period. When stratified by race, the increase in APC was mainly seen in Non-Hispanic Whites and Hispanics, while the APC of HNC for NHB decreased for all subsites. These results suggest treatment implications for HNC related to sub-sites associated with HPV.

057

ESOPHAGEAL CANCER IN CANADA, 1986-2006: TRENDS BY MORPHOLOGY AND ANATOMICAL LOCATION

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Background: The prevention and control of esophageal cancer in Canada is limited: incidence and mortality rates are stable and 5-year survival is low. Although differing trends by morphology have been reported elsewhere, trends in Canada are unknown. Purpose: To explore esophageal cancer incidence, mortality and survival in Canada by morphological type and anatomical location. Methods: Cancer incidence and mortality (ages 15+ years) were obtained from the Canadian Cancer Registry, the National Cancer Incidence Reporting System, and the Canadian Vital Statistics Death databases for 1986-2006. Trends (annual percent change) and 5-year relative survival ratios (RSR) were estimated separately for adenocarcinoma and squamous cell carcinoma, and by location (upper, middle, or lower third). Results: Annual age-standardized incidence rates for esophageal cancer in 2002-06 were 6.1 and 1.7 per 100,000 for males and females, respectively. Esophageal adenocarcinoma incidence rose by 3.8% per year in 1986-2006—the steepest increase (4.9% per year) occurred in the lower region—while squamous cell carcinoma incidence declined by 3.3% per year (both sexes). The predicted 5-year RSR was 14% in 2003-05, roughly a 3% unit increase since 1992-94. Conclusions: Although esophageal cancer is rare in Canada, the incidence of esophageal adenocarcinoma has doubled in the last 20 years, which may reflect the increasing prevalence of obesity and gastroesophageal reflux disease in Canada.

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USING SURVEILLANCE AND OTHER DATA TO REPORT ON THE STATUS OF CANCER CONTROL IN CANADA – THE SYSTEM PERFORMANCE INITIATIVE AT THE CANADIAN PARTNERSHIP AGAINST CANCER (CPAC)

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Background: In Canada, healthcare services and cancer control occur on a provincial/territorial basis. Although Canada has a strong registry system, there is no national approach to reporting on performance across the cancer control system. In 2007, CPAC was funded to implement a national cancer control strategy. One priority was to report on cancer system performance.

Objectives: Using system performance indicators, report on the status of cancer control in Canada.

Methods: In 2008, CPAC's system performance steering committee identified 17 high-level pan-Canadian indicators to begin to report on the status of cancer control in Canada. A subset of indicators was presented in national webinars to gain feedback on presentation of data. Results of the indicators were reported in four regional workshops across the country in June/July 2009. During the first year the System Performance Initiative worked collaboratively with provincial partners to move forward an understanding of the system.

Results: Data were gathered from three national databases and directly from provinces. Analyses included provincial results, time trends and social determinants data where possible. Highlights of selected indicators will be presented.

Conclusion: Pan-Canadian cancer system performance indicators have been developed following a collaborative process. Ways of deepening indicators into the future have been identified, as well as steps for moving forward.

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059

CANCER SURVIVAL ACCORDING TO INSURANCE STATUS IN KENTUCKY

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Background: cancer survival in the US differs by race and socioeconomic status (SES). Most studies have used ecologic measures of SES. Disparities appear to result from financial barriers to early diagnosis and treatment. Access to care may be a particular problem for the uninsured in Kentucky. Among residents diagnosed 1995-1998, 3-year survival following prostate, breast, colon, rectum and lung cancer was lower among uninsured compared to privately insured patients. The relationship between insurance, race and SES was not investigated.

Purpose: This study will extend these findings and examine the relationship between survival and insurance type, race and SES.

Methods/Results: 5-year relative survival estimates for residents diagnosed 1995-2006 with cancer of the breast, cervix uteri, colon, rectum, lung or prostate will be used to examine the relationship between insurance type, SES, race, stage, gender and treatment using multi-variable excess hazard models. SES-specific life tables will be used to adjust for background mortality. Conclusions/Implications: The findings from this study may help target cancer control activities within the State of Kentucky.

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FACTORS CONTRIBUTING TO HIGH DEATH RATES AMONG BLACK WOMEN WITH BREAST CANCER IN LOUISIANA

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Background: Breast cancer death rates have decreased in the past 15 years in the nation for white and black women. However, in Louisiana, the decreases occurred only among white women while the rate among black women has not changed significantly. Methods: Data were from the CDC-NPCR Patterns of Care Study. A total of 1,004 white and 723 black women diagnosed with breast cancer in 2004 were randomly selected. Data from hospital medical records were supplemented with information from physicians. Chi-square test and Cox proportional hazard model were used. Results: Compared with whites, blacks were more likely to be diagnosed with later-stage and more aggressive breast cancers and less likely to receive guideline-concordant therapies. Overall, the 5-year survival rate was lower for blacks (72%) than whites (80%). The risk of death from all causes was 70% higher for blacks than whites if adjusted for age only. When stage, tumor characteristics, and comorbidity were adjusted with age, the racial difference declined to 26%. Additional adjustment for treatment reduced the difference to 11% (p>0.05). After controlling insurance with the above factors, the difference was no longer significant (hazard ratio= 1.02, 95% CI=0.79-1.31). Conclusion: The high breast cancer death rates among blacks are attributable to both modifiable and non-modifiable factors. Increasing early detection, adherence to guideline therapies, and equal access to health care would reduce the racial disparities.

061

UTAH CANCER CONTROL PROGRAM: THE IMPACT OF BREAST CANCER SCREENING THROUGH THE BREAST AND CERVICAL CANCER SCREENING PROGRAM

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Background: The Utah Breast and Cervical Cancer Screening Program (BCCSP), in partnership with the CDC and Local Health Departments, promotes early detection of breast and cervical cancer by offering eligible women free pap tests, mammograms, and pelvic and breast exams. The BCCSP targets Utah women with limited access to screening. The BCCSP hopes to improve detection rates and prevent late stage diagnosis; thereby, decreasing the number of women who die from BC. Purpose: Evaluate the effectiveness of the BCCSP in improving BC detection rates and early detection. Methods: Detection rates for the BCCSP were compared to statewide estimates. Stage at diagnosis among women initially screened (via mammography) by BCCSP were compared to women who underwent diagnostic mammography through the State Medicaid program (MBCCTA) from 7/2001 to 6/2008. Results: BCCSP detected a larger number of BC than was expected for all women aged 40-64 and among non-Hispanic women. BCCSP detected approximately 5 cases per 1,000 women, whereas statewide estimates were 3.5 cases per 1,000 women. Among BCCSP screened women, nearly 29% were diagnosed with Stage I and 10% with Stage IV BC. While, nearly 24% of MBCCTA women were diagnosed with Stage IV and only 8% with Stage I BC. 26% of BCCSP screened women were diagnosed with Stage I BC. Discussion: The BCCSP has been effective in improving detection and early diagnosis of BC among Utah women who have little or no access to screening resources.

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CONSIDERATIONS IN MODELING AND MAPPING THE COLLEGE OF AMERICAN PATHOLOGISTS ELECTRONIC **CANCER CHECKLISTS (CAP ECC)**

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Many considerations are necessary in transforming the updated CAP Cancer Protocols into the CAP eCC in ensuring they are optimally designed for the interoperability of information necessary for cancer reporting. Aspects of the CAP Pathology Electronic Reporting Taskforce (PERT) mapping team's work on modeling data elements for electronic representation, transmission and coding in cancer reporting will be discussed. This interdisciplinary panel of cancer experts has considered the needs of the pathologist and cancer registrar especially with mapping the CAP eCC data elements to Collaborative Staging 2.0 data elements, including Site Specific Factors. The result will be the seamless flow of cancer data elements for interoperability form the pathology report to the cancer abstract including the integration of clinical decision support features.

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oral abstracts

concurrent session 4



UTILITY OF HOSPITAL DISCHARGE DATA FOR REGISTRY **ENHANCEMENT**

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Background: Survival analysis using cancer registry data is difficult, particularly for many NPCR registries, due to lack of active follow-up (resulting in early censoring of cases) and limited covariates for adjustments, due to incomplete treatment variables and information on co-morbidities. Florida Cancer Registry (FCDS) historically links with state discharge data as a case-finding source. Due to a recent agreement between FCDS and Florida Agency for Health Care Administration (AHCA), FCDS data was linked with "all cause" AHCA discharge data. Methods: This pilot study evaluated using a linked dataset between FCDS and AHCA for enhancement of FCDS data. FCDS cases (SSN known, alive, and dxed 1981-2007) were linked with AHCA with a deterministic match on SSN against three AHCA files for 2008: ambulatory surgery, ER, and inpatient encounters. The data was evaluated for accuracy of linkage and improvement of incomplete FCDS data items. Co-morbidity algorithms were developed for the AHCA data and an in-house matrix was used to identify missed treatment information. Results: Nearly 17% of registry cases linked with AHCA, increasing by dx year to over a 50% link for dx year 2007. Of unknown FCDS data, 98% of race, 97% of ethnicity, 100% of dob, and 100% of sex were known in AHCA. Implications: Despite issues, such as inadequate linkage capacity and years of available data, linking with hospital discharge datasets can improve registry data.

Notes

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THE REGISTRY PLUS SUITE OF SOFTWARE: AFFORDABLE, STATE-OF-THE-ART TOOLS FOR CENTRAL CANCER REGISTRY DATA COLLECTION AND PROCESSING.

KK Thoburn¹, S Baral¹, T Rawson², J Seiffert¹, D Gu³, D Farmer¹, S Stein¹, P Kim¹, S Van Heest², JD Rogers² ¹Northrop Grumman, Atlanta, GA, United States; ²Centers for Disease Control and Prevention (CDC), National Program of Cancer Registries (NPCR), Atlanta, GA, United States; 3Science Applications International Corporation, Atlanta, GA, United States

Registry Plus is a suite of publicly available, free-of-charge software programs used for collecting and processing central cancer registry (CCR) data. Developed by the CDC-NPCR, Registry Plus currently includes 8 applications: Abstract Plus, Web Plus, eMaRC Plus, Data file Mapper Plus, Prep Plus, CRS Plus, Link Plus and Registry Plus Online Help. The software can be used separately or together for both routine and special data collection.

Registry Plus offers CCRs software solutions for all levels of data reporting. The online abstracting capability of Web Plus is suitable for reporting from physicians' offices and other lowvolume reporting sources, while the file upload feature is used for electronic submission of data from all other reporting sources, along with the offline abstraction capability of Abstract Plus. In addition, Abstract Plus supports facility and CCR coder audits, and Web Plus supports follow-back and interstate data exchange efforts. The file mapping functions of eMaRC Plus and Data File Mapper Plus are used to map files received by CCRs in formats other than NAACCR format. Once received, data are cleaned and edited with Prep Plus, and then consolidated and maintained using CRS Plus. Link Plus is then used to detect duplicates within, or to link external files to, the CCR database.

This presentation will include an overview of the entire suite, including descriptions of implementation in United States CCRs and the benefits of using the applications.

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ABSTRACT PLUS VERSION 3: SECURITY STANDARDS UPHELD.

D Farmer¹, S Stein¹, J Rogers², S Van Heest² ¹Northrop Grumman, Atlanta, GA, United States; ²Centers for Disease Control and Prevention (CDC), Atlanta, GA, United States

NPCR program standards require registries to have data security procedures in place to ensure cancer registry data are available only to those who need to use it for legitimate purposes. Controlling access to data helps ensure patient privacy and data confidentiality. Abstract Plus v3 has improved software features to uphold security standards, including formbased authentication, options to configure password attributes, challenge questions for user password reset, role-based access, Microsoft SQL Server database options, and user passwords stored and encrypted using a one-way hash method. Abstract Plus requires users to have an ID and password to access the system. On initial login, the user enters a standard password that must be changed along with answering the required number of challenge questions. The administrator configures the password attributes to enforce password complexity, require new passwords be different from historical passwords, set new password expiration to force users to change their passwords after a specified time interval, and set the number of challenge questions required. The MS SQL Server database option offers inherent security features and the default Microsoft Access option offers password-protected, encrypted databases preventing access from outside the application. This presentation will include an overview of the security features of Abstract Plus v3, and discuss how to optimize them to meet your security needs.

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NPCR-AERRO: EPATH REPORTING

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The National Program of Cancer Registries - Advancing E-Cancer Reporting and Registry Operations (NPCR-AERRO) initiated a pilot project with a large national laboratory and 18 state cancer registries to transmit electronic pathology reports to central cancer registries (CCR) using NAACCR's implementation guide for pathology laboratory electronic reporting as the standard for developing the HL7 message. A CDC developed application, PHINMS, was adopted for the secure transmission of messages from the laboratory to CCRs and a new application, eMaRC Plus, was developed to process HL7 messages in central cancer registries. As a result of this initiative, several states are now receiving HL7 daily message feeds from Labcorp, and other states are using/evaluating eMaRC Plus for the processing of electronic pathology reports. With the success of the pilot implementation, NPCR-AERRO is initiating additional laboratory and CCR implementations. Also, eMaRC Plus has been enhanced to improve the accuracy of coding suggestion of site and histology, and new functionalities have been added with feedback from several CCRs.

This presentation will provide an overview of the status of the pilot implementation with Labcorp, the status of additional laboratory and registry participation, discuss new functionality added to eMaRC Plus, and present results on the accuracy of eMaRC Plus' filtering of relevant cancer reports and computerassisted coding for histology.

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JUST JING IT! A COST-EFFECTIVE METHOD TO DOCUMENT PROCEDURES AND PRODUCE TRAINING MATERIALS

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Registries need to actively identify ways to provide both training and procedural documentation in a cost-effective manner. Traditionally, most in-house training in cancer registration occurs on-the-job, in one-on-one situations. Trainers who show other staff members how to perform various tasks are the best choices for preparing screencasts as an alternative to lengthy written procedures that demonstrate the use of a computer application or to provide narration to a PowerPoint presentation.

The Cancer Surveillance System at the Fred Hutchinson Cancer Research Center, the Seattle-Puget Sound SEER registry, began using Camtasia Studio by Techsmith in June 2009 to document four major computer applications. Four trainers within the Seattle registry produced 204 screencasts. This project took a total of 240 hours to complete.

A well-indexed screencast library could supplement or replace traditional written procedures as well as capture the one-on-one verbal training information for present and future new hires. The world of cancer registration has become increasingly complex and most people need to hear training information several times. The screencast library fills this need in a cost-effective manner.

068

A REVIEW OF CSV2

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The purpose of this presentation is to inform NAACCR registrants of the goals and objectives of the CSv2 Education and Training Team during the implementation phase of CSv2. Discuss briefly the role of the standard setters, other professional organizations, software vendors and the registrar in the implementation of CSv2. Discuss the training opportunities provdied to membership to date, as well as future training opportunites currently being considered. Provide information on the opportunities to present questions through the Inquiry and Response system, as well as the affect of this process on the CSv2 training module. Discuss the future goals and objectives of the CSv2 Education and Training team, as related to NAACCR registrants.

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FINDING THE CANCER REGISTRARS OF THE FUTURE, THE RHODE ISLAND CANCER REGISTRY INTERNSHIP TRAINING PROGRAM

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Hospital and central cancer registries are finding difficult to fill open positions. When Rhode Island experienced a statewide cancer registry workforce shortage it became apparent that the Rhode Island Cancer Registry (RICR) would have to develop a program to identify and train the cancer registrars of the future for both hospitals the central registry. Given the limited number of cancer registrars needed in Rhode Island the development of college based training program was impractical. The RICR decided to develop an internship program that would introduce potential cancer registrars to the principles of cancer registration through the use of classroom lecture, exercises and clinical experience in hospital cancer registries and the RICR. Clinical experience included case finding, follow-up and an introduction to abstracting in the hospital setting.

The goals of the RICR Internship Program is to provide interns with the real cancer registry experience needed to determine if they will pursue certification and to be able to assume cancer registry duties that do not require the skill set of a CTR.

The RICR Internship program has attracted sufficient interest to warrant the formation of a second class and plans are being made to provide interns who have completed the program with additional training in abstracting, coding and staging

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EXPERIENCE WITH AN NCRA WEBINAR SERIES FOR **COLLABORATIVE STAGE (CSV2) TRAINING**

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Background: Significant change in the abstracting and coding of Collaborative Stage is being introduced starting in 2010.

Purpose: Share experience with developing and presenting a large webinar series.

Methods: A series of twelve CSv2 webinars was started in September, 2009, aimed at the 4000+ NCRA members, and other interested 'parties. As the series progressed, explicit procedures were developed, as necessary, to facilitate adequate preparation. Procedural steps included: 1) cost analysis and pricing, 2) procurement of webinar software, 3) speaker recruitment, 4) marketing and student recruitment, 5) registration, 6) speaker training and practice, 7) Distribution of student course materials, 8) solicitation of student questions, 9) speaker responsibilities, and 10) solicitation and analysis of student evaluations.

Results: The level of favorable response of the students, staff, and the presenter was assessed; primarily with regard to subject matter, presenter expertise and adequacy of the webinar methodogy,. Specific feedback will be overviewed.

Conclusions: 1) Student evaluation of the usefulness of the training appeared closely related to the reputation and expertise of the presenter. 2) Staffing for successful planning and conduct for webinars is easy to under-estimate. 3) Class size significantly effects workload. 4) The webinars were reasonably effective, but are characterized by some limitations.

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TRENDS AND PATTERNS OF CHILDHOOD CANCER INCIDENCE IN THE US, 1995-2009

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The American Cancer Society publishes Cancer Facts & Figures every year to provide estimated incidence rates and case counts for the coming year. Childhood cancer incidence was also reported since 2007, but there is no report on patients with age 15-19 or combined age 0-19, or major subsites of childhood cancer. There may be different patterns of socioeconomic status and geography in children from those for adult cancer. Therefore, it is necessary to develop models to evaluate and predict childhood cancer incidence for varying age groups in the whole country. A generalized linear mixed effects model is applied on observed childhood cancer case counts reported in the CINA Deluxe Custom dataset over 1995-2006 to predict case counts and incidence rates for every U.S. state and the U.S. total. Covariates included are measures of income, education, housing, urban/rural status, health insuance coverage, smoking, obesity and cancer screening. Temporal trends and spatial distribution patterns are compared among different subpopulations and cancer subsites. The resulting predictions will provide annual estimates for states that did not provide data, and projections ahead in time to the current calendar year for every state and the U.S. total. These projections fill in the gaps in cancer registry to provide complete count and rate estimates for all states, regions, and the U.S. total for the coming year.

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072

CANCER AND THE MEDICALLY UNDERSERVED IN MISSOURI: A GIS APPROACH TO IDENTIFYING CANCER DISPARITIES BY PRIMARY CARE PHYSICIAN SHORTAGE **AREAS**

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Background: While great efforts have been made to diagnose and treat cancer, it remains one of the world's most prevalent diseases. The American Cancer Society estimates that 1,479,350 new cancer cases and 562,340 deaths from cancer will occur in the US in 2009. Previous research has revealed that medically underserved populations are at higher risk of being diagnosed with late-stage cancer. Rural populations also face financial, physical and cultural barriers that prevent them from obtaining effective health care.

Purpose: To further understand factors that influence cancer disparities.

Methods: We evaluated external factors that may contribute to cancer disparities by using the Instant Atlas™ geographical information system (GIS) mapping tool. We examined cancer incidence data for Missouri, BRFSS regions and counties for 7 major sites and all sites for three 3-year periods (1998-2000; 2001-2003; 2004-2006) and for all 9 years (1998-2006). We compared incidence data with Health Resources and Services Administration (HRSA) primary care physician shortage areas.

Results: Preliminary findings for colon cancer reveal that 5 rural counties with a high incidence of late-stage colon cancer also have a shortage of primary care physicians. Implications: GIS can be a vital tool in understanding health disparities and identifying potential solutions.

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THYROID CANCER, EARLY DETECTION AND **ENVIRONMENTAL FACTORS IN ONTARIO: A SMALL-AREA ANALYSIS**

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Thyroid cancer is relatively uncommon, but its incidence is rising rapidly across North America. This increase has been attributed to more sensitive methods of early detection but it has also been hypothesized that endocrine-modulating chemicals and environmental carcinogens are contributing to this increase.

Our study demonstrates the use of a GIS-based approach to spatio-temporal surveillance of thyroid cancer, from 1989 to 2008. This study uses different Census geographic units.

Common geostatistical techniques to describe global and local clustering using various geographic units are applied; Bayesian random effects models are implemented to produce smoothed maps of thyroid cancer. Adjustment for spatio-temporal utilization patterns of diagnostic thyroid procedures will also be done. Then, residual clustering will be assessed and its implications discussed.

Preliminary work over the recent interval, 1999-2003, confirms strong spatial autocorrelation at the county level for female thyroid cancer. Areas of higher risk are mainly in the lower Great Lakes region, an area known historically to be goitrogenic. Early work has confirmed the feasibility of a GIS-based approach for rapidly assessing spatial patterns of thyroid cancer, including detection of residual spatial aggregation following adjustment for areal indicators of medical screening activity. The results of more detailed analyses and maps will be presented and interpreted.

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074

RISING INCIDENCE TRENDS AND ETHNIC PATTERNS OF BREAST CANCER AMONG ASIAN-AMERICAN WOMEN

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Background: Asian-American women in general display a much lower breast cancer incidence rate as compared to their non-Hispanic (NH) white counterparts. However, this masks an important heterogeneity in breast cancer risk among Asian women living in the US.

Materials and methods: Using data from the Los Angeles Cancer Surveillance Program for 1972-2007, we analyzed the age-adjusted and age-specific incidence rates of invasive breast cancer in Chinese, Japanese, Filipina, Korean, and NH white women in Los Angeles County, California.

Results: Increasing incidence trends of invasive breast cancer were found in all racial/ethnic groups throughout the 1980s and 1990s. The increases in Japanese and Filipinas were more substantial than those in Chinese and Koreans, fast approaching the risk level of NH whites. In early 2000s, a declining incidence trend was observed for NH whites and Japanese, while the upward trends continued for Filipinas, Chinese, and Korean. By 2007, Filipinas had the highest breast cancer risk among Asian-Americans, surpassing Japanese. Japanese and Filipinas born in 1930s and later displayed a risk level much closer to that of NH whites than their Chinese and Korean counterparts.

Conclusion: Risk for invasive breast cancer varies markedly by ethnic group among Asian-American women. The variations underline the significance of environmental determinants on the development of breast cancer. Targeted efforts against breast cancer are needed for Asian-Americans.

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THE CHANGING FACE OF CANCER IN CANADIAN ADOLESCENTS AND YOUNG ADULTS

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Background: Adolescents and young adults (AYAs) with cancer, aged 15-29 years, are a largely understudied population.

Objectives: To examine the trends in cancer incidence, mortality, and survival in Canadian AYAs with cancer.

Methods: The numbers of new cases and deaths among those aged 15 to 29 years were obtained from the population-based Canadian Cancer Registry (for years 1992-2006) and the Canadian Vital Statistics Death databases (for years 1991-2005). Age-standardized incidence (ASIR) and mortality (ASMR) rates, annual percent changes (APC), and observed 5-year survival were calculated.

Results: An average annual ASIR of 347.2 per million (1,068 cases per year) was observed for 2002-2006. More young females than males had cancer in this age group. The ASIR increased between 1997 and 2006 (APC: males 0.9%; females 1.7%), mostly due to significant increases in thyroid cancer in females and testicular cancer in males. An average annual ASMR of 43.9 per million was observed for 2002-2006. The ASMR declined between 1996 and 2005 (APC: males -3.2%; females -1.7%). Predicted 5-year survival for 2001-2005 of 85% was 5% higher than for 1992-1996; survival ranged by cancer type from 68-99%. Conclusion: The number of AYAs living with cancer continues to increase, owing to rising incidence and improved survival for many leading cancers. Thus, it is increasingly important to understand the unique physical, social and psychological challenges facing this age group.

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076

PREDICATION OF CANNCER INCIDENCE AND MORTALITY IN CANADA

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BACKGROUND: Projections of cancer incidence and mortality are vital for health planning and evaluation. While estimates of the future cancer burden in Canada have been conducted, a rigorous approach has not been established.

PURPOSE: To develop short- and long-term projection methodologies in order to produce long-term cancer incidence and mortality trends for the major cancer sites by sex, region, and age in Canada.

METHODS: Cancer incidence data were from the Canadian Cancer Registry (since 1992) and the National Cancer Incidence Reporting System (1969-1991). Deaths due to the cancer were identified from the Canadian Mortality Database. Population estimates were obtained from national censuses and forecasts. The following forecasting approaches will be compared using observed data: multiplicative age-period-cohort models; power model; Bayesian simulations; spline models; spatial-temporal model; short-base models and mixed models. The number of future cases/deaths and age-standardized rates will be projected up to 2030.

RESULTS: Short and long-term projections will be presented. Results comparing the various models will be presented for the most common cancer sites. Projections based on small numbers will comprise a key focus of the analysis.

CONCULSION: The comparison of methodologies will contribute towards the standardization of national forecasting methods and training in cancer surveillance.

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USING THE ACCURACY OF CANCER MORTALITY (ACM) STUDY TO EVALUATE UTERINE CANCER SURVIVAL IN **CALIFORNIA**

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The accuracy of cancer mortality and survival statistics depends upon the accuracy of underlying cause of death (UCOD) coded on death certificates. Misclassification of uterine cancer on death certificates has been noted in previous studies that may impact the accuracy of mortality and survival statistics for this cancer. This study uses more current data from the Accuracy of Cancer Mortality (ACM) study to examine the degree of misclassification of uterine cancer on death certificates and the potential impact on survival statistics.

The California Cancer Registry (CCR) /ACM linked database identified 1937 women diagnosed with uterine cancer from 1993 to 1995 who subsequently died from cancer between 1993 and 2004. These cases were examined for concordance of the primary cancer site recorded in the CCR and the primary cancer site recorded on the death certificate. The CCR/ACM data identified discordance in 315 cases (16%) where uterine cancer was the only cancer noted in the registry database, but the UCOD was attributed to another cancer site and so possibly misclassified. Cause-specific survival statistics for uterine cancer will be calculated first using existing mortality data, and then using the ACM database where the potentially misclassified cases are re-classified as uterine cancer deaths to examine the potential impact of misclassification on survival statistics for uterine cancer.

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078

ACCESS TO CARE IN RURAL NORTHERN NEW ENGLAND

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Background: A collaborative team from three states in Northern New England evaluated quality of care for breast and colon cancer. Cancer data from Maine, New Hampshire and Vermont showed differences in oncology care for breast and colon cancer patients between rural and urban areas. This joint initiative explores the potential for multi-state cooperation to enhance cancer surveillance in a geographic region.

Purpose: The aim of this study is to evaluate state-specific data versus regional aggregate data to show the power is stronger when the three states' data are combined.

Methods: Using cancer registry records for diagnosis years 2003-2004 in ME, NH, and VT, we compare individual state results with results from the aggregate, tri-state dataset and determine if significant differences exist between rural and urban breast and colon cancer patients and their care.

Results: Analysis for breast cancer patients will include the use of breast conserving surgery, sentinel and axillary lymph node dissection, and radiation therapy by rural/urban residence. Among colon cancer patients, we will assess rural and urban patient care characteristics including surgical treatment, lymph node sampling, and adjuvant chemotherapy.

Conclusions: The success of this regional collaborative initiative is exemplary in demonstrating the benefits and opportunities for multi-state cooperation in cancer surveillance, especially when common geographic and population characteristics are shared.

Notes

USING REGISTRY DATA TO INFORM COMMUNITY ACTION: MELANOMA AND NON-MELANOMA SKIN CANCER IN SASKATCHEWAN, CANADA, 1998-2007

T Zhu¹, R Alvi¹

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Background: Skin cancer including non-melanoma and melanoma (NMSC and MSC) is the most commonly diagnosed cancer in Canada. In 2007, 73,600 Canadians were diagnosed with skin cancer with 2921 new cases in Saskatchewan (SK). Skin cancer is primarily attributed to ultraviolet radiation exposure and is preventable.

Purpose: Use SK cancer registry (SCR) data to foster collaboration between health stakeholders to promote sun safety awareness. Establish a Skin Cancer Prevention Coalition (SCPC) to promote sun safety awareness.

Methods: The SCR is one of the oldest cancer registries in the world (est.1932). The SCR is unique as it collects both NMSC and MSC data. Incidence and detailed GIS analyses were performed on NMSC and MSC data from 1998 to 2007 and presented to the SCPC.

Results: 26519 cases of skin cancer (MSC & NMSC) from 1998 to 2007 in SCR were identified. The SIR's for Melanoma in females were statistically significantly higher in some health regions compared to others (P<0.05). The trend of SIR's on NMSC was lower in the north vs. the south of SK. The results will help SCPC teams make informed decisions on skin cancer prevention messages and strategies for SK. Collaboration fueled by SCR data has lead to opportunities for skin cancer prevention across many different disciplines.

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080

A CASE STUDY IN TRANSLATING SURVEILLANCE DATA TO UNDERSTANDABLE AND ACTIONABLE "CITIZEN DATA"

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The NC, TN, and VA central registries, and faculty in the School of Public Health at East Tennessee SU, are collaborating on a project. Goals are to 1) characterize incidence in tri-state Appalachian counties; 2) query relationships between socioeconomic status and cancer; and 3) evaluate data quality, focusing on missing data. An extension of the study is to prepare analyses that local cancer prevention and control groups can use.

The flow of surveillance information, whether it is epidemiological data or technical advice, usually is one-way, from central registries to consumers. Rarely do registry staff query audiences about whether they actually use data, how to make data intelligible and actionable, or how to integrate data into community-based participatory research.

This presentation builds on the study and on lessons from presentations to rural Virginia audiences which have, as intertwined objectives, 1) providing locally useful data and 2) learning from audiences what they understand, what they struggle with, and what their data needs are. The Virginia Cancer Plan Action Coalition, which develops and pursues the state-wide cancer control plan, organized the meetings and the Virginia Cancer Registry provided the presentations. The talk will explain how these presentations inform both the audience and the presenter, important lessons about explaining statistics and their uses, and key steps in translating surveillance data into usable "citizen data".

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WORKING WITH CANADIAN CANCER REGISTRIES TO DETERMINE THE UNMET NEEDS OF CANCER SURVIVORS AND THEIR SUPPORT PERSONS: BENEFITS AND **CHALLENGES**

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Background: The number of cancer survivors is rapidly increasing due to more effective treatments and an aging population. Research to describe the prevalence and predictors of survivors' unmet needs is critical for health care planning and resource allocation. Population based cancer registries provide the only means of recruiting representative samples of survivors for these studies but privacy legislation poses challenges for registry based research.

Purpose: To test a methodology for recruiting and surveying a representative sample of cancer survivors and their support persons from population based cancer registries.

Methods: Three Canadian cancer registries initially selected a random sample of survivors according to study eligibility criteria. Deceased and those not wanting to be contacted were removed and the representativeness of the sample was compared to the survivor registry population before mailing prenotification letters, preparing survey packages, and sending two follow-up reminders.

Results: Survey return and completion rates were moderate (48% to 67%). Representativeness of the final study sample differed from the population by province and response rate. Conclusions: Appropriate and feasible methodologies for conducting population level research with cancer registries are critical to improve cancer control. The results, benefits and challenges of the registry-research partnership will be discussed.

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082

NPCR-AERRO'S PARTNERSHIP WITH IHE: ENSURING CANCER'S CONNECTIVITY WITH THE EMR/EHR.

S Thames¹, W Scharber², W Blumenthal¹ ¹Centers for Disease Control and Prevention, Atlanta, GA, United States; ²Northrop Grumman, Atlanta, GA, United States

Background:

The National Program of Cancer Registries - Advancing E-Cancer Reporting and Registry Operations (NPCR-AERRO) is a collaborative project within the CDC-NPCR to position the cancer surveillance community to take advantage of the electronic health record (EHR) for public health surveillance of cancer. As cancer surveillance relies on clinical information to meet its objectives, it is critical that the community participate in and implement processes that take advantage of the rapid changes in electronic health information management. Through its three year participation in the Health Information and Management Systems Society's Integrating the Healthcare Enterprise (HIMSS-IHE), NPCR-AERRO has identified several existing profiles and authored two primary profiles that can be used by the healthcare community to report cancer diagnoses to central, population-based registries. These profiles address standards, processes and/or content for reporting cancer cases from anatomical pathology laboratories and from clinics/physician offices.

This presentation will explain NPCR-AERRO's connection to ehealth initiatives, describe the profiles related to reporting to cancer registries, and discuss activities for implementing the profiles.

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INTEROPERABILITY QUESTIONS AND ISSUES: ASSESSING IMPLICATIONS OF THE NAACCR CLINICAL DATA INTEROPERABILITY PILOT PROJECT

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The NAACCR Board of Directors charged the Clinical Data Working Group (CD WG) with considering format alternatives to the current column de-limited flat file. Settling on HL7 Clinical Document Architecture (HL7 CDA) as a promising alternative, the WG developed a prototype file format and associated transmission utilities, and tested the results at two central registries. The WG attended to NAACCR's priority to achieve syntactic and semantic interoperability with existing and emerging standards for electronic health records (EHR).

This presentation goes beyond the technical details of the CDA project to consider broader issues. NAACCR will need to understand, address, and explain such issues to achieve interoperability. 1) How will interoperable cancer software integrate with complex EHR environments? 2) With which new partner organizations must NAACCR cooperate? 3) How can NAACCR accommodate vendor, hospital registry, central registry, and national perspectives? 4) How will NAACCR's function as the clearinghouse for surveillance data standards evolve as relationships with non-surveillance EHR partners develop? 5) Developing educational materials will be complicated; what planning is necessary?

These issues will require thoughtful, competent assessments. Examining processes, results, and CD WG recommendations to the NAACCR Board will help illuminate the lay of the land ahead. Will NAACCR be ready?

084

COLLEGE OF AMERICAN PATHOLOGISTS ELECTRONIC CANCER CHECKLISTS (CAP ECC): CANCER PATHOLOGY DATA FLOW INTO CANCER REGISTRY SYSTEMS

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The College of American Pathologists (CAP) has developed site-specific cancer protocols and checklists with the intent to improve the quality and completeness of cancer pathology reports. These checklists have recently been updated to be consistent with TNM 7th Edition and to include relevant collaborative stage (CS) data concepts. The American College of Surgeons has incorporated these checklists into their certification process. To enhance the value of these checklists, CAP has developed an electronic version, electronic Cancer Checklists (eCC), for implementation by anatomical pathology (AP) laboratory information systems (LIS) which will promote the use of an interoperable tool for submitting cancer pathology reports.

This tool and the capability to submit cancer pathology reports with data item values are having an impact on a network of cancer registry related areas. This presentation will focus on the data flow from the AP laboratory using the eCC into the cancer registry database. Discussion highlights include the decision to use the CAP Cancer Checklists within a laboratory, the status of the Checklists in certification programs, the eCC output format, interoperable transmission standards, mappings to NAACCR data items, and cancer registry software to receive and parse eCC cancer pathology reports, as well as software to electronically convert the CAP checklists data items into the NAACCR data items.

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THE PUBLIC HEALTH GRID (PHGRID): WHAT IS IT AND HOW CAN IT SUPPORT CANCER SURVEILLANCE ACTIVITIES?

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¹Centers for Disease Control and Prevention, Atlanta, GA, United States; ²Northrop Grumman, Atlanta, GA, United States

Background: Public health and cancer surveillance face significant challenges, including collection of public health data in separate disparate systems, development and use of noninteroperable systems, and limited access to health care data needed for public health. The CDC's National Center for Public Health Informatics (NCPHI) and its partners have researched the technical feasibility of deploying Grid architecture to resolve information management challenges within public health practice. Purpose: To explore the feasibility of using Grid technology to meet data reporting and processing requirements in the cancer surveillance community and among cancer data providers. Specific Grid services will be identified for development and pilot implementation among the cancer surveillance community and data exchange partners. Methods: Over the past year, the CDC's NPCR has worked with the NCPHI to become familiar with the PHGrid architecture. Through this collaboration, NPCR has identified several Grid services that will be useful in reporting and processing cancer data within Central Cancer Registries, pathology laboratories, and other partners. Results: This presentation will provide a detailed description of what PHGrid is and how it will be interoperable with other Grid environments, such as caBIG. Specific conceptualized Grid services will be described that demonstrate the potential uses of Grid technology for cancer surveillance to meet program requirements.

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Oral Abstracts	THURSDAY - CONCURRENT SESSION 4
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oral abstracts

concurrent session 5



A NEW EDIT FOR IDENTIFYING POTENTIAL GENDER MISCLASSIFICATION IN CENTRAL CANCER REGISTRY **DATABASES**

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Standard sex-site edits are routinely used by central registries to identify cases that must be reviewed; but sex-specific diagnoses account for fewer than 15% of reported cases, leaving registries to rely on visual editing for the identification of most sex coding errors. We decided to develop a new program that could be used to flag suspicious name/sex combinations for manual review. Names that are highly correlated with gender(e.g., "Mary" and "Thomas") are occasionally misclassified to the opposite sex. Problems can also arise because of spelling mistakes with names such as "Francis/Frances" and "Jean/Gene". Finally, the use of male and female first names can change by decade. For example, the first name "Rosario" was typically male in 1900, but became a female name in 1940. Using the New York State Cancer Registry and the Social Security Administration database of the 1000 most popular male and female first names for each decade from 1890-2008, we were able to flag those entries that had predominately male or female first names but the opposite sex for the sex field. This was done separately for each decade to account for changes in name usage. Our preliminary results identified 8,285 cases, out of 2,476,579 (0.3%), with improbable first name/gender combinations (incorporating 1,495 names) that will need manual review. This new edit is both more sensitive and more specific than other edits, making it a useful tool for central cancer registries to flag records for review.

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087

WORKFLOW MANAGEMENT, WHAT DOES IT ALL MEAN? HOW THE CALIFORNIA CANCER REGISTRY USED 'PROJECT MANAGEMENT' TOOLS TO CREATE A PRODUCTION ENVIRONMENT AND OUR RESULTS.

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Workflow management includes a broad range of activities to ensure that organizational goals are consistently being met in an effective and efficient fashion. Very broadly, one aspect of workflow management is to monitor the quality, which includes specifying a performance standard, monitoring and measuring results, comparing the results to the standard and then making adjustments as necessary. Therefore, workflow management often includes substantial measurement and analysis of internal processes. One of these measures is the use of a production calendar.

The California Cancer Registry (CCR) developed the yearly production calendar based on the NAACCR Central Cancer Registry Calendar of operations for our project scheduling. The production calendar focuses on monitoring data quality, national data submission tasks, the processing of interstate, ACTUR and VA records. The production calendar is critical in assigning the major functions of yearly production by defining the tasks, and timing for such activities as Geocode, Death Clearance, and Linkages with external files.

The CCR's use of a production calendar has helped to improve and define the production tasks within the registry. Streamlining the responsibilities and clarifying the roles of every employee within the process. With use of a production calendar for work flow management, the CCR can more easily determine where improvements can be made to increase efficiency and to improve the quality.

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DETERMINANTS OF COLLABORATIVE STAGING INPUT ITEMS AVAILABILITY: MARYLAND EXPERIENCE 2004-2008

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Collaborative Staging (CS) data elements have been used since 2004 to collect information on cancer anatomic extent and dissemination. CS data items serve as input data for the derivation of AJCC Stage Group and SEER Summary Stage. Availability of CS input data items is critical for the accurate determination of stage. This study presents patterns and trends related to the availability of CS data items as observed among abstracts received by the Maryland Cancer Registry (MCR). The investigation focused on abstracts received by the MCR for tumors diagnosed between 2004 and 2008 that passed state reporting requirements and NPCR/NAACCR Core Edits. Since type of reporting source was expected to be the strongest determinant of data availability, the analysis was conducted separately for hospital and non-hospital reports, by diagnosis year. In addition to analyzing all cancer abstracts, data availability trends were compared for certain frequent cancer types (e.g., prostate, lung, etc). The analysis aimed to identify CS data availability patterns by demographic characteristics and hospital accreditation status/category. For the study period, the availability of CS Extension increased from 85% to 95% among hospital abstracts, and from 18% to 47% among non-hospital abstracts. Public health practitioners and researchers should consider the potential bias introduced by the association of CS data availability with the type of reporting source and patient demographics.

089

FROM QUALITY CONTROL CHALLENGES TO PROCESS **IMPROVEMENT OPPORTUNITIES**

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In 2000, the California Cancer Registry (CCR) established an accuracy rate of 97% on selected data items in order to provide consistency in the visual editing process and to quantify the accuracy of cancer data from cancer reporting facilities. Visual editing was performed on 100% of the abstracts. In February 2008, due to further reduction in state funding, the CCR implemented a random sampling of cases for visual editing, reducing the percentage of cases undergoing visual editing from 100% to 40%. The remaining 60% of cases bypass the visual editing process, unless a case has edits. In order to monitor the quality of the data in the cases bypassing visual editing, recoding audits were implemented using the Recoding Audit Module within the Eureka database. This tool provides the ability to select criteria for quickly conducting a recoding audit. The results of the recoding audits performed will be discussed, including identifying the most common coding discrepancies and the subsequent action items. Educational modules are developed, focusing on the most common coding discrepancies identified for each site audited, with Continuing Education Credit provided. The same site can be re-audited at a later date to evaluate the efficacy of the education and training efforts. By utilizing a combination of visual editing and recoding audit/education approach, the CCR is able to carefully monitor, evaluate and where needed, implement methods to improve the quality of the data.

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ABSTRACT PLUS VERSION 3: AD-HOC REPORT WIZARD.

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Background/Purpose: Abstract Plus v3 software provides flexible abstracting and audit features. To support this flexibility, ad-hoc, user-designed reporting capability has been added to offer users the option of enhanced data analysis.

Approach: The software contains a Report Wizard, which guides users in creating, managing, and running customized reports. Both abstracting and audit data are available through the wizard. The wizard can be used to create simple or complex reports, including cross-tab, hierarchical, and charts.

Results: The Abstract Plus Report Wizard provides a friendly Graphical User Interface (GUI), which does not require an indepth knowledge of Sequel Query Language (SQL). The GUI allows the user to manage and preview a report to ensure the desired design and all relevant information are captured. With training provided, users will be able to use the wizard to define the report query, data source, necessary calculations, formatting of records, and layout instructions. Reports can be designed to work with both Microsoft Access and the Microsoft SQL Server database options of Abstract Plus v3.

Conclusions: This presentation will include an overview of the Abstract Plus Report Wizard, including the components used to design a report, and illustration of how the wizard can be used to meet a variety of unique reporting needs.

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THE REPORTING OF VHA DATA TO A CENTRAL CANCER REGISTRY

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Background: Data security is a top priority for all central cancer registries, and involves securing data for those who need to use it for a legitimate purpose. Controlling access to cancer data helps ensure patient privacy and data confidentiality, and is required by various federal agencies. These general requirements are described on both the North American Association of Central Cancer Registries, Inc. (NAACCR, Inc.), and National Program of Cancer Registries (NPCR) websites. In October 2009, the Veterans Health Administration (VHA) released Directive 2009-046 regarding the release of VHA cancer registry data to state cancer registries. This directive changes the procedures required to successfully obtain VHA cancer registry data.

Purpose: To assist central cancer registries in general understanding of data security, and how to address VHA Directive 2009-046 to obtain VHA central cancer registry data.

Methods: This presentation will discuss data security in a central cancer registry, and provide approaches to address current VHA directives to obtain VHA data.

Results/Conclusions: VHA Directive 2009-046 provides the most current policy on the release of VHA central cancer registry data to the state cancer registries to ensure a complete understanding of the national cancer burden.

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ESTIMATING AVERAGE ANNUAL PERCENT CHANGE (AAPC) FOR TREND ANALYSIS

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Background. Trends for different groups often have different change points, making comparison problematic. Purpose. We introduce a new measure, the average annual percent change (AAPC), to summarize and compare trends. Methods. We apply the AAPC estimator to SEER data to illustrate the new method and its utilities in trend comparisons, and its advantages over conventional methods that estimate annual percent change (APC) over fixed intervals using linear regression.

Results. AAPC takes into account the trend changes, whereas conventional methods do not and can lead to erroneous conclusions. Additionally, when the trend is constant over the entire time interval of interest, the AAPC has the advantage of reducing to the conventional methods. Moreover, because the estimated AAPC can take JoinPoint results over the entire data series, any selected subinterval within a single time period will yield the same trend estimate—i.e., AAPC will be equal to the estimated trend from JoinPoint regression for that time partition. Conclusions. We recommend using the AAPC for summarizing and comparing trends over a specified time interval. We have incorporated the AAPC estimation into JoinPoint regression analysis software program for characterizing trends in cancer rates. The software reports and compares AAPCs directly as an integral part of results from JoinPoint regression analyses. AAPC has been used in the Annual Report to the Nation and Cancer Statistics Review.

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093

ICD-9-CM UPDATES AND U.S. ADOPTION OF ICD-10-CM CODING STANDARD: MAJOR CHANGES IN HEALTH INFORMATION CODING PRACTICE AND IMPLICATIONS FOR CANCER SURVEILLANCE

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Historically cancer surveillance programs have used ICD-9-CM, ICD-10 and other recognized coding standards for casefinding, case matching, record linkage and other purposes. ICD-9 and ICD-10 are updated bi-annually; however, cancer registrar coding references seldom follow suit. Other resources, such as ICD-O-3 to ICD-9 and ICD-10, also tend to be outdated. During the 2008 update of the NCI SEER casefinding list, staff identified several areas directly affected by ICD-9-CM and ICD-10 coding. The 2009 casefinding list was updated in parallel with the release of ICD-9-CM coding standard changes & will be released the first week of January 2010. The reference manuals ICD-9-CM to ICD-10 and ICD-10 to ICD-9-CM are also being updated to match the 2010 casefinding list.

Using the Center for Medicaid and Medicare Services (CMS) website and the General Equivalency Mappings (GEM), all codes on the 2009 casefinding list were mapped from ICD-9-CM to ICD-10 and ICD-10 to ICD-9-CM. The 2010 updated ICD-9-CM to ICD-10 and ICD-10 to ICD-9-CM will be available electronically. Starting in 2011, this will also include the ICD-10-CM codes. In preparation for the adoption of ICD-10-CM, NCI SEER will create a working group to prepare for the major changes to the coding standards with plans to support the cancer registry and cancer surveillance community starting in 2011 through 2014. The goal is to have a standardized casefinding list used by all standard setters.

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CSV2 TRAINING: SO MANY DATA ITEMS, SO LITTLE TIME K Vance¹

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The California Cancer Registry represents one NPCR state and three SEER Cancer Registries. Collaboration, resource sharing, and project management principles established the framework to approach CSv2 statewide training for approximately four hundred registrars. The result will be a series of one day trainings to be offered at various locations throughout the state to train and ready cancer registrars and central registry staff for the CSv2 implementation. Each training will use the same agenda that includes software demonstration, presentations, and materials. Questions from each training will be collated, categorized, and submitted to the CSv2 I&R. Responses will be formally distributed using the CCR statewide memo mechanism. Registrars will receive feedback on the new CSv2 changes and data items through the CCR's central system's electronic visual editing reports. These reports will document data items needing clarification and training needs. This training template will be used to present additional CSv2 training on sites not covered in the initial training.

095

FREQUENCY AND DETERMINANTS OF MISSING DATA IN COLLABORATIVE STAGE SITE-SPECIFIC VARIABLES RECENTLY ADDED TO SEER

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The objectives of the current study were to examine and quantify the frequency of missing information for the variables added since 2004 and to evaluate factors associated with incomplete data. All collaborative stage site-specific variables for all types of cancers reported to the SEER program since 2004 were included in the analysis. The frequency of missing data for each variable was calculated. Multivariate analyses, in which the outcome measures (missing information) were expressed as a binary variable, were performed using logistic regression models. The hypothesized determinants of missing data included various patient-, disease-, and reporting-related characteristics. The proportions of cases with missing data ranged from less than 1% to 100%. Patients over 80 years of age were more likely to have missing data. There was a decrease in the frequency of missing data over time. We found no discernable association between patients' race and the probability of missing data. Our analyses also showed substantial variability of the proportions of missing data across registries.

The presented study is the first step in evaluating the completeness of the collaborative stage site-specific variables and identifying factors associated with missing information. Further research will evaluate the amount of time and effort required to obtain data for different variables at the level of the reporting facility.

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INTER-RATER RELIABILITY ASSESSMENT AND **ELECTRONIC COLLABORATIVE STAGE DATA COLLECTION** IN ONTARIO

BLi¹, GLee¹, MJ King¹, E Holowaty¹, R Rahal¹, K Milnes¹, J Ross¹, M Yurcan¹

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The success of Ontario's Collaborative Staging Initiative will rely on the quality of the stage data abstracted by Cancer Care Ontario's (CCO) trained abstractors. An inter-rater reliability (IRR) study was conducted to estimate the agreement across all abstractors for derived TNM Stage Group. Random samples of hospital charts for total 198 newly diagnosed cases of breast, colorectal (CRC), lung, and prostate cancer were selected. Multirater agreement scores were generally "Good" or "Very Good" for the derived TNM stage group for each cancer site, whether measured as crude agreement scores (range: 86% - 93%), or as chance-corrected Krippendorff Alpha scores (range: 0.69 -0.85). Agreement scores were generally higher for colorectal and prostate cancer cases than for breast and lung cases. In particular, when classifying stage group as Known vs Unknown, the Alpha score was "Poor" for breast (□=0.25), while for the other three sites agreement was 'Good' (range: 0.65 - 0.67). When all unknown values were removed from the analysis, the Alpha scores increased substantially, and were at "Very Good" agreement (range: 0.76 - 0.92), which suggests the cases with unknown stage group assignment are major contributors to disagreement among abstractors. The reliability assessment revealed a reasonable level of agreement. Additional education of CS abstractors was undertaken based on the IRR study findings, especially addressing rules that affect the assignment of "Unknown" value.

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NATIONAL STAGING ADVISORY COMMITTEE SUPPORTING **SURVEILLANCE**

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The Canadian Partnership Against Cancer (the Partnership), formed a National Staging Advisory Committee in March 2009 to support the National Staging Initiative (NSI). The purpose of the NSI is to capture population based collaborative stage (CS) for breast, prostate, colorectal and lung reportable cancer cases beginning with diagnosis year 2010. The mandate of the Committee is to: I) Strengthen the capture of stage across Canada by coordinating activities among national and provincial organizations. II) Advise on the new standards related to staging. III) Form linkages with AJCC, UICC and CAP. IV) Foster the awareness, education, collection and use of high quality staging data in Canada. The membership includes; epidemiology, medical, radiation and surgical oncology, pathology, information technology and cancer registry operations. The Committee developed recommendations to the Canadian Council of Cancer Registries in relation to timelines, education needs and the assessment, implementation and clinical relevance of CS site specific factors. This committee works very closely with the Partnership's National Pathology Standards Committee who has been instrumental in endorsement of the CAP checklists across Canada. The Committee developed a communication strategy to inform all Physician groups across Canada of the changes to TNM 7th edition. The committee plans to continue to monitor and audit the implementation and impact of CS and TNM 7th edition over the next year.

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EXPLORING THE IMPACT OF IMMIGRATION ON CANCER INCIDENCE IN TORONTO, ONTARIO

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Over the past 50 years, Toronto has become one of the most multicultural cities in the world; according to the 2006 census, 50% of Toronto's population is foreign-born. There have also been dramatic shifts in immigrant origins from European to Asian countries. Six cancers have been identified as having clusters centered on Toronto: liver, stomach and thyroid incidence rates are higher than the provincial rate, while lung, colorectal and melanoma incidence rates are lower. However, it is difficult to quantify the impact of immigration on Toronto's cancer rates because race/ethnicity is not recorded in the Ontario Cancer Registry and birthplace information is limited. In this presentation, we will discuss several possible strategies for investigating the influence of immigration on incidence rates for the six cancers of interest, including comparisons to cancer rates in countries of origin, using available birthplace data, imputing ethnicity through surnames, and employing the methods used by other researchers such as:

Chen Y et al (2008) Cluster of liver cancer and immigration: A geographic analysis of incidence data for Ontario 1998-2002. Int J Health Geographics 7:28

McCoy HV et al (1992) Effects of migration on cancer incidence and resources for prevention and treatment in Florida. Public Health Rep 107:389

Zurriaga O et al (2008) Spatio-temporal evolution of female lung cancer mortality in a region of Spain, is it worth taking migration into account? BMC Cancer 8:35

099

DESCRIPTIVE FEATURES AND TRENDS IN THE INCIDENCE OF BORDERLINE OVARIAN TUMORS IN CALIFORNIA

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Background. Ovarian cancer is increasingly recognized as a heterogeneous disease. The distinction between invasive and borderline, or low malignant potential (LMP), tumors is determined by histopathologic features, and there is still controversy on whether they represent two entirely different entities. Although LMP tumors are included as detected cancers in large ovarian cancer screening trials in the US and UK, few registries in the US collect information on LMP ovarian tumors. Purpose. The objective of this study was to describe epidemiologic features and temporal trends in the incidence of LMP ovarian tumors in California, and to contrast these features with those from invasive ovarian cancer.

Methods. The study population included 9,081 LMP ovarian tumors diagnosed from 1988 through 2008 and reported to the California Cancer Registry. Descriptive measures were obtained and trend analysis was performed using joinpoint regression. Results. Women were diagnosed with LMP tumors at a median age of 46 years (median age for invasive tumors was 63). Compared to invasive ovarian tumors, the incidence of LMP tumors among Hispanic women was much higher: 15.2% and 23.6% of tumors, respectively. While epithelial ovarian cancer incidence decreased, the incidence of LMP increased significantly in California during the period.

Implication. California is in a unique position to study LMP tumors which may offer valuable insight into the pathogenesis of ovarian cancer.

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GOING AGAINST THE TIDE: THE INCREASING INCIDENCE OF COLORECTAL CANCER AMONG KOREAN AMERICANS IN CALIFORNIA, 1988-2007

JH Bates¹, BM Hofer¹, SL Kwong² ¹California Cancer Registry/Public Health Institute, Sacramento, CA, United States; ²California Department of Public Health, Sacramento, CA, United States

Colorectal cancer (CRC) incidence rates have decreased substantially over the past twenty years. This study evaluated variations in CRC burden among the 6 major Asian subgroups in California: Chinese, Filipino, Japanese, Korean, South Asian and Vietnamese using data from the California Cancer Registry (CCR). Previous studies have documented that important differences exist in the cancer burden among Asian subgroups that are masked by aggregated statistics for Asian/Pacific Islanders (APIs).

Colorectal cancer incidence trends and annual percent change (APC) were calculated for cases diagnosed in California from 1988-2007 overall and for Asian subgroups. Overall, colorectal cancer incidence rates declined significantly among all men (APC = -1.8%) and women (-1.4%), and among API men (-1.3%) and women (-0.5%). Among Asian subgroups, Chinese, Japanese, and South Asian men and women also experienced a significant decline in CRC incidence. In stark contrast to the declines seen in other groups, however, CRC incidence increased sharply among Koreans, with an APC of 11% for men and 7% for women. These results are consistent with survey data showing that Korean Americans have a low prevalence of colorectal cancer screening utilization that has actually declined in recent years. These findings demonstrate the importance of examining subgroups individually, and can be used to target outreach and education efforts for CRC screening.

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THE FINAL WORD ON THE INCREASE IN MELANOMA INCIDENCE: IT'S NOT DUE TO SCREENING!

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It is unclear whether or not recent increases in melanoma incidence are "real" (ie as a result of increasing sun exposure, or perhaps increased use of tanning beds), or simply a result of more vigorous screening efforts. This issue needs to be resolved: if the increase is "real", we need to determine which behaviors or exposures are responsible, and better target prevention activities; if the increase is due to screening, this implies screening is successful, resulting in the notification of melanomas we wouldn't otherwise discover.

Past efforts to directly assess the impact of screening have evaluated tumor thickness trends over time. Thinner tumors are more likely to have been detected by screening. However, most Registry datasets suffer from the same problem: thickness values are missing for up to 40% of the data, making evaluation of time trends largely futile.

In Los Angeles, we have access to much more complete melanoma thickness data. We supplemented our data with pathology review to further improve completeness, and rule out tumors that most likely were not screen detected.

In cases diagnosed 1992-2007 we reduced the proportion of tumors with uninformative data from 22.5% to less than 10%. Analyses of time trends by tumor thickness clearly showed that all thicknesses of tumors are increasing at the same rate, effectively ruling out any substantial effect of screening on melanoma incidence trends. Efforts to improve melanoma primary prevention are needed.

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INCREASING EFFICIENCY OF STATEWIDE REGISTRY SOFTWARE MAINTENANCE AND UPDATES

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The Kentucky Cancer Registry (KCR) maintains a web based cancer registry application called CPDMS.NET for all non federal hospitals that report to the KCR. Timely updates to this software enhance the central registry's ability to ensure uniform, high quality data standards. The KCR recently changed its software release practices to provide updates, perform maintenance, and address user requests much more frequently than in the past. Historically, the KCR updated software 4-6 times a year that included several, large changes. The KCR has adopted a biweekly release schedule while reducing the number of changes in each release. This has allowed for quicker turnaround time of user-initiated feature requests, better manageability of periodic maintenance, and increased user satisfaction. Deployment has been simplified and automated with the help of the open source tool, Apache Ant. Both data and source code updates are handled with a single invocation. The new software update model follows a two-phase rollout system. The first phase applies updates to internal databases at the KCR for one week of integration testing. After this first week, the second phase deploys the same updates to the rest of the databases for external users. A short scheduled down time is maintained for both phases where hardware updates or disaster planning can occur. This presentation will outline the KCR's new software release practices and how these changes have enhanced efficiency at the central registry.

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CANCER DATA IGNITES RESEARCH AND PROGRAMS FOR ALASKA NATIVE PEOPLE

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Colorectal cancer (CRC) is the most frequently diagnosed cancer among Alaska Native (AKN) people, and the second leading cause of cancer death. Incidence of CRC among AKN is more than twice that in US Whites and mortality due to CRC is 80% higher than US Whites . Alaska Natives lead the nation in high regional rates of colorectal cancer among US American Indians and Alaska Natives. Challenges to reducing the mortality rate include: remote communities without road systems, low colon cancer screening rates, little education in prevention, cultural differences, behavioral risk factor differences and possibly genetic differences.

Alaska Native Tumor Registry contains detailed information on cancer diagnosed in Alaska Naïve people since 1969. Data on colorectal cancer patterns and trends have supported further research and programs aimed at reducing colorectal cancer mortality in this population. The presentation will include data on colorectal cancer incidence and mortality, colorectal cancer research and programs including immunochemical FOBT and DNA mismatch repair research, a prospectively followed cohort, family history project, and CRC screening initiatives.

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CANCER SURVEILLANCE AND CANCER GENETICS: STATEWIDE COLLABORATION IN UTAH

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United States

Background/Purpose: The Resource for Genetic and Epidemiologic Research (RGE) was established by the State of Utah to facilitate data collection, storage, study and dissemination of medical and related information to reduce morbidity and mortality. The Utah Cancer Registry (UCR) and RGE operate under the auspices of the Utah Department of Health to achieve these state goals.

Methods: One resource developed to meet these goals is the Utah Population Database (UPDB). It includes genealogy records, Utah vital records (births, marriages, divorces, fetal deaths, and deaths), Utah and Idaho cancer records, social security death index, driver license, voter registration and inpatient discharge records on 7 million persons from about 1800-2008. In addition, UPDB has been linked to the University of Utah Hospital/Clinic and Intermountain Healthcare Hospital/Clinic records.

Results/Conclusion: The combination of these data results in the ability to describe extensive, multigenerational family histories that can be studied to identify heritable cancer and other diseases. The UPDB helped to facilitate the Huntsman Cancer Institute's development of high-risk cancer clinics, which play an instrumental part in the advancement of cancer genetics, epidemiology, and cancer control. Additionally, the recent development of a pre-research query tool allows investigators to search a subset of UPDB to ascertain a potential study cohort for genetic and clinical research.

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DOES THE INTERRUPTION IN THE DECREASE OF LUNG CANCER RATES BELOW AGE 50 IN THE US VARIES ACCORDING TO LEVEL OF STATE TOBACCO CONTROL ACTIVITIES?

A Jemal¹, E Ward¹

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Background: We previously reported that the decrease in lung cancer rates below age 50 in the U.S. was interrupted in cohorts born between 1950-1960, particularly in women, in part because of increased initiation of smoking in these cohorts. However, the extent to which this interruption varies by level of state tobacco control activities/policies is unknown.

Method: We examined trends in lung cancer death rates from 1992 to 2006 among non-Hispanic white and black men and women aged 20-49 by join point analysis in three groups of states with varying levels of tobacco control activities: California, a state with strong tobacco control policies; New York and New Jersey, states with modest tobacco control policies; and six tobacco growing states in the south (Georgia, Kentucky, North Carolina, South Carolina, Tennessee, and Virginia) with weak tobacco control policies.

Results: Among whites, lung cancer death rates in young adults continued to decrease in California and New Jersey and New York, whereas rates increased in tobacco growing states, especially in women aged 40-49. Among blacks, death rates continued to decrease in all categories of states for men; for women, however, rates continued to decrease only in California, while they increased in New Jersey and New York and remained unchanged in the tobacco growing states.

Conclusions: The interruption in reduction of lung cancer rates below age 50 were largely confined to tobacco growing states, especially in whites.

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CANCER PATTERNS AMONG HISPANICS AND LENGTH OF STAY IN THE U.S.

<u>PS Pinheiro</u>¹, SL Gomez², M Williams³, EA Miller³, S Easterday³, A Hansen⁴, S Moonie¹

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In general, U.S. Hispanics have lower cancer rates than both non-Hispanic Blacks and Whites. Notable exceptions are cervix, liver and stomach cancers among others. After immigration, their cancer patterns become more similar to those of non-Hispanic populations. Among some Hispanic subgroups an increase in incidence of the most common cancers (e.g., lung, breast, and colorectal cancers) is apparent in the same immigrating generation.

Contributing to these changes, rates for some risky behaviors for cancer (smoking, alcohol use, high BMI) seem to increase with acculturation specifically among Hispanics. For example, obesity rates among foreign-born Asians or Blacks do not differ depending on length of stay in the US. Among foreign-born Hispanics, however, living 5 years or more in the U.S. translates into increased rates of obesity compared to more recent arrivals. Change in the occurrence of breast cancer among Hispanics according to length of stay has been shown in a Californian population, but other cancers have not been studied.

We aim to characterize the incident cancer patterns and stage at diagnosis among Hispanics, cross-sectionally for years 2000-2006, in two populations, Nevada and Texas, according to length of stay and nativity in the U.S. . Registry data on birthplace will be analyzed, and, for cases without birthplace, previously utilized and validated registry tools based on birthplace and year of acquisition of social security number will be utilized.

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MULTILEVEL MODELING OF MELANOMA INCIDENCE USING COMBINED NPCR AND SEER DATA

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Melanoma is the deadliest form of skin cancer, and will claim about 8,650 lives in the US in 2009. Risk factors for melanoma include light skin color, ultraviolet (UV) exposure and high socioeconomic status (SES). Individual-level UV exposure and SES data are not available from US cancer registries. This study will use multilevel models to explore variation in melanoma incidence in the US by area-level SES and UV exposure, controlling for race/ethnicity. Incidence data from a subset of population-based cancer registries that participate in the NPCR and SEER programs will be used in this study. The data will have a multilevel structure with the lowest level consisting of age by sex by county case count "cells". Cells will be nested within counties, and county measures will include SES and UV exposure. SAS PROC GLIMMIX will be used to fit multilevel mixed models of melanoma incidence and will account for potential spatial autocorrelation. State of residence at the time of diagnosis will be included as a random effect in the models. Preliminary results using SEER data with a subset of the explanatory variables show that melanoma rates vary significantly by age, location, and county-level SES and UV exposure. Results using combined NPCR and SEER data and the full set of explanatory variables will be presented. This study will provide important information on variation in cutaneous melanoma incidence in the US.

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OVERVIEW OF MELANOMA INCIDENCE IN THE UNITED STATES: METHODS

M Watson¹, C Johnson², R Sherman³, C Thomas¹, M Cockburn⁴, H Weir¹, J Jackson-Thompson⁵, V Chen⁶, M Saraiya¹ ¹Centers for Disease Control and Prevention, Atlanta, GA, United States; ²Cancer Data Registry of Idaho, Boise, ID, United States; ³Florida State Cancer Registry, Miami, FL, United States; ⁴USC/Keck School of Medicine, Los Angeles, CA, United States; ⁵Missouri Cancer Registry, Columbia, MO, United States; ⁶Louisiana Tumor Registry, New Orleans, LA, United States

Melanoma incidence rates vary widely by population, but to date most reports have only included, at most, 26% of the US population. In collaboration with partners from state cancer registries, academia, the American Cancer Society and the National Cancer Institute, the Centers for Disease Control and Prevention (CDC) is producing a supplement on melanoma incidence in the United States covering recent years (up to 2006). By using combined NPCR and SEER data, this effort is the first large analysis of melanoma incidence covering a majority of the US population. Such broad population coverage allows for a comprehensive examination of melanoma incidence patterns, and an in-depth examination of issues related to the quality and completeness of data collection and reporting of melanoma incidence data. A steering committee, made up of lead authors and experts, provided input on topics such as histology definitions, race/ethnicity categories, and helped standardize criteria for the analysis and interpretation of the data. Preliminary results show that melanoma rates varied widely by age and race/ethnicity. Age-adjusted incidence rates ranged from 0.3 (age 0-14 years) to 64.6 (65+ years) per 100,000; Non-Hispanic whites had the highest rate (21.6) while blacks had the lowest (1.1). The results of this study will provide important information on the burden of melanoma in the US.

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ASSOCIATION OF DEMOGRAPHIC CHARACTERISTICS WITH ANATOMIC STAGE/PROGNOSTICS GROUPS IN PROSTATE CANCER

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Association of demographic characteristics with anatomic stage/prognostics groups in prostate cancer. The 7th edition of AJCC Staging Manual introduced major changes to the staging of prostate carcinomas. Prostatic Specific Antigen (PSA) and Gleason Score (GS) have been added to T, N, and M elements to define stage groups. The number of stage groups was increased from four to five. This study aims to describe anatomic stage/prognostic group (AS/PG) distribution of prostate adenocarcinomas by age category, race and ethnicity, and to discuss the re-distribution of cases among stage groups between AJCC staging manual editions (6th v.7th). Prostate adenocarcinomas diagnosed between 2004 and 2006 were selected from the SEER 17 Registries Database. Derived AJCC T, N, and M data elements were used in combination with PSA and GS to assign the AS/PG. The new AS/PG distribution was compared to the old (anatomic based-only) stage group distribution by demographic factors. The proportion of cases diagnosed at AS/PG I increased dramatically from less than 1% to approximately 23%. This is because most tumors identified by needle biopsy for elevated PSA were downstaged from stage II to stage I. The remaining stage II tumors will be re-assigned to either AS/PG IIA (47% of all adenocarcinomas) or AS/PG IIB (19%). No race-specific pattern was observed, but the distribution was associated with age category. AJCC 7th edition brings significant changes to prostate cancer stage distribution.

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Oral Abstracts	THURSDAY - CONCURRENT SESSION		
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NAACCR 2010 CONFERENCE

posters 01 - 60



P-01

THE CANADIAN PARTNERSHIP AGAINST CANCER&RSQUO:S (CPAC) SURVEILLANCE AND EPIDEMIOLOGY NETWORKS: INVESTIGATING THE QUALITY OF CANCER REGISTRY DATA IN CANADA. PART I: COMPLETENESS, ACCURACY, TIMELINESS

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Background: The Partnership's three multi-province, registrybased surveillance and epidemiology networks (CRCNet, C-SPAN, C-PROJ) have been established to address issues in coordination, data access, and analytic capacity to inform and monitor cancer control in Canada. Data quality assessment is a top priority since the validity and comparability of these analyses across provinces relies heavily on the underlying data quality and the quality control procedures in place.

Purpose: To assess the accuracy, completeness, and timeliness of cancer registry data in Canada.

Method: Based on a comprehensive literature review and common practice, data quality indicators and their standards have been identified to examine four key aspects: the completeness, accuracy, timeliness and comparability of cancer registry data. Data quality information on completeness, accuracy, timeliness are collected from existing reports from Statistics Canada and administered questionnaires.

Results: A data quality protocol for Canadian cancer surveillance has been compiled to give detailed explanation and justification for each indicator. Part I is presenting results of the completeness, accuracy and timeliness among registries. Part II will address the results of comparability.

Conclusion: The data quality assessment will inform the data quality improvement initiative cross Canadian cancer registries and will ensure high quality surveillance products.

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P-02

CONSIDERING THE COLLECTION OF FOLLOW-UP DATA BY A CENTRAL CANCER

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Background: Monitoring cancer survival is an important function of population-based cancer registries. Central cancer registries may do this by conducting follow-up of cancer cases, which entail the collection of several variables, such as date last seen, vital status, cancer status, and recurrence. The New Hampshire State Cancer Registry, however, is an incidence-only registry, meaning that no follow-up information is collected after a case is initially reported.

Purpose: To examine the feasibility of obtaining current vital status and tumor status information on cancer patients. Our ultimate goal is to achieve a current follow-up rate based on the SEER standard.

Methods: We will examine date last seen, vital status and cancer status for cases diagnosed during 2000 through 2007. Passive follow-up will be performed on cases with no current follow-up information. We will attempt to demonstrate the methods available for central registries to meet the SEER follow-up standard, even in settings in which follow-up is not carried out, such as with incidence-only central cancer registries.

Results: Our analysis will include an evaluation of the frequency of records with and without current follow-up data.

Conclusion: Cancer survival data are important to evaluate cancer survival and outcomes. This study will attempt to show that survival data can be captured without the arduous process of active follow-up.

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P-03

COMPLETENESS OF POPULATION-BASED CANCER REGISTRY IN TAIWAN

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Background: The Taiwan Cancer Registry (TCR), a populationbased cancer registry, was founded in 1979 and became a compulsory system by the implementation of Cancer Control Act of 2003, which legally requires hospitals with greater than 50-bed capacity providing outpatient and hospitalized cancer care to report all newly diagnosed malignant neoplasms to the registry. In this study, we attempt to describe the completeness of TCR database after the Cancer Control Act enacted. Methods: Taiwan has several social infrastructures, such as citizenship ID numbers, cancer registry database, death certificate database, catastrophic illnesses database (included in health insurance program since 1995), and cancer screening programs for cancers in oral, colon and rectum, breast, and cervix uteri. With these tools, cancer registry is conducted very efficiently with excellent quality indices. After the active trace-back process, follow-back cases were included in the registry database except for the death certificate only (DCO) and unreported cases. Results: The completeness of TCR database increased from 91.28% in 2001 to 97.82% in 2007. The DCO% had a decreasing trend from 4.18% in 2001 to 1.40% in 2007. The mortality/incidence (M/I) ratio slightly decreased. The reporting timeliness improved from 24 months to 17 months. Conclusion: These findings reveal that the quality of Taiwan Cancer Registry is quite well.

Notes

P-04

GUIDANCE FOR RESOLVING CONFLICTING RACE INFORMATION FROM MULTIPLE SOURCES

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There is no established method to determine which race code is accurate when a patient has conflicting race data from different reporting sources. We developed and tested four rules to address this issue. The more-specific rule chooses a more specific code over a less specific one, such as code 04 (Chinese) over code 96 (Asian, NOS) or 99 (unknown). The majority rule chooses the race that appears on a majority of independent reporting sources. The class-of-case rule prioritizes sources based on class of case, under the presumption that closer contact with a patient yields more accurate race coding. The most-current rule picks the most recent source, under the presumption that data collection tends to improve over time. We settled on applying the rules in this order after a detailed review of alternative orderings. For 1,362,647 cases in the registry diagnosed between 1995 and 2008, 158,188 (11.6%) had sources with conflicting races. Of these, the more-specific rule resolved 134,165 (84.8%), the majority rule resolved 9,176 (5.8%), the class-of-case rule resolved 13,412 (8.5%) and the most-current rule resolved 1,435 (0.9%). The newly resolved race code differed from the previously consolidated value in 9,524 cases (6% of the cases with conflicting codes). Our results are preliminary and still under review. We plan to extend this approach to other data items with conflicting sources.

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P-05

AUTOMATING BUSINESS RULES TO OPTIMIZE DATA **QUALITY**

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Background: California Cancer Registry (CCR) reduced visual editing of incoming Admissions from 100% to 40%. A new approach to verifying the quality of the data in our database was needed. A management decision was made to create a business model for implementing automated business rules as a quality control tool.

Methods: Core project team members were assembled consisting of a Project Manager, skilled CTR's and software Programmer. Through collaborative efforts between Team members, a module for developing automated business rules was created. Initial efforts were directed at verifying Admission level information as analytic or non-analytic. The data field "Class of Case" was used as the key data field for this determination. By collaborating with programmers, programmed code was developed that would auto-correct Class of Case or related fields when specified conditions existed. Long term project goal is to eventually automate the manual consolidation process.

Results: Pre-implementation analysis of Class 8 Admissions in the database revealed a 5% error rate. Post-implementation analysis of Class 8 Admissions will be performed by running a series of queries on each condition of the rule set. Presentation will include results of post-implementation analysis.

P-06

THE CANADIAN PARTNERSHIP AGAINST CANCER'S (THE PARTNERSHIP'S) SURVEILLANCE AND EPIDEMIOLOGY NETWORKS: INVESTIGATING THE QUALITY OF CANCER REGISTRY DATA IN CANADA PART II: COMPARABILITY

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Background: The Partnership's three multi-provincial, registrybased surveillance analytic networks strive to build analytic capacity across Canada and develop a standardized approach for analyzing, interpreting, and reporting on cancer. With the aim for standardization, the networks are undertaking a rigorous data quality assessment, including an investigation into the comparability of registry data over time and across registries. Purpose: To assess the comparability of cancer registry data and practices in Canada.

Methods: Key indicators for comparability were identified by reviewing guidelines developed by national and multi-national cancer registry associations and incorporated into the larger data quality assessment protocol (see Part I). Data on comparability will be collected for provincial cancer registries using existing reports and interview administered questionnaires with cancer registry managers.

Results: We will present results of the comparability among registries for indicators related to methods for registering cases, including coding changes over time, and methods for determining dates (birth, diagnosis, death) and geography (diagnosis, death), ascertaining vital status, resolving data inconsistencies, and documenting stage.

Conclusion: Knowledge of cancer registry comparability will facilitate the standardization of methods for cancer surveillance in Canada and the interpretation of inter-provincial comparisons of surveillance data.

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P-08

USE OF RECORDS FROM A REFERENCE PATHOLOGY LABORATORY TO ENHANCE ELECTRONIC REPORTING OF HEMATOLOGICAL MALIGNANCIES

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Electronic reporting of pathology records (E-Path) is a useful tool for the accurate and timely identification of cases for cancer surveillance. We conducted an NCI-sponsored project to evaluate and enhance an existing E-Path system. Approximately 1,000,000 electronic records were obtained from a regional reference pathology laboratory with expertise in the diagnosis of hematological malignancies; these reports represented all cases reviewed by the laboratory during the time period 2002-2007, and included both cancer and non-cancer diagnoses. These records represented standard anatomical pathology reports, as well as reports from specialized diagnostic tests, including those that identify specific genetic markers and chromosomal aberrations relevant to the diagnosis of hematological cancers. These reports were linked with records from the populationbased New Mexico Tumor Registry to assist in identifying which reports were associated with hematological malignancies. We applied existing E-Path lexicon to identify laboratory records that were associated with cases of hematological malignancies. Through systematic review of these records, we identified new words and phrases that were associated with hematological malignancies, and characterized which types of laboratory reports were most useful in identifying such cases. In this presentation, we will summarize results from this study and will outline our methodology for ongoing assessment and improvement of E-Path lexicon.

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P-09

CANADIAN PARTNERSHIP AGAINST CANCER'S (THE PARTNERSHIP) CANCER SURVEILLANCE AND EPIDEMIOLOGY NETWORKS: INVESTIGATING SHORT-TERM CANCER PROJECTION METHODS FOR USE BY **CANADIAN CANCER REGISTRIES**

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Background: Accurate cancer projections help in developing policies for effective cancer control, which include utilizing resource, prioritizing prevention activities, and evaluating the impact of certain interventions.

Purpose: The partnership's cancer projection network aims to investigate, evaluate and identify appropriate methodologies for short term (<=5 years) projections of cancer incidence/mortality for Canada, and the provinces/territories.

Methods: Cancer incidence/mortality can be predicted by extrapolating past trends using statistical regression models. Covariates used in these models are age and/or calendar year for short-term projection. Age effects and age-specific (or common) trends have most impact on projected results. The selection of historical data used for identifying trends plays an important role. We propose two methods: (i) Hybrid method, which incorporates the spirits of average, joinpoint and log-linear regression method as appropriate, (ii) Markov chain Monte Carlo (MCMC) method, which is derived from the Bayesian age-periodcohort modeling and the state-space modeling methods. Results: For Alberta cancer data 1983 - 2007 the Hybrid method outperformed those traditionally used approaches in most cancer sites, while the MCMC method is even better than the Hybrid method for small cancer sites, but computationally

Discussion: The rationales of the developed methods are discussed based on the trend analysis and validation analysis.

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P-10

INTEGRATED ELECTRONIC CASE-FINDING

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In many cancer registries, cases are identified and abstracted from a combination of sources, including pathology reports, patient discharge lists, and patient billing information. These case-finding sources often start out in electronic form, but are copied into manually curated spreadsheets or printed onto paper lists before assignment to an abstractor. A more efficient method of processing would be to include the electronic versions directly into the case abstraction process and automatically distribute the caseload across a group of abstractors. The Kentucky Cancer Registry has begun to integrate electronic pathology reports and hospital EMR data directly into its web-based cancer registry software, in use at both the central registry and all non-federal reporting hospitals in Kentucky. As a result, we hope to reduce the time and effort necessary to identify and record new cancer cases. Furthermore, we have developed a simple way to balance the caseload and monitor progress across a group of abstractors. In this presentation we will discuss the progress, challenges, and future enhancements of our integrated electronic case-finding system. We will outline use cases from the point of view of case-finder and abstractor, discuss our technical infrastructure for receiving and storing electronic case-finding data sources, and summarize our automated record linkage methods. Additionally, we will talk about how security and confidentiality are maintained across hospitals.

P-11

TOWARDS THE FULLY-ELECTRONIC TRANSMISSION OF PATHOLOGY DATA INTO THE MANITOBA CANCER REGISTRY (MCR): E-PATH YEAR 1 IN REVIEW.

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Background: Through National Staging Initiative (NSI) funding from CPAC (2008-2012), the MCR is engaged in the Manitoba Cancer Stage Information Initiative (MCSII). One of the key objectives of the MCSII is to improve the timeliness of data transfer through electronic transmission of pathology data (ePath).

Methods/Approach: Manitoba's ePath system feeds labgenerated HL7 pathology reports into AIM's casefinding software, which then flow into the MCR's reportable/nonreportable intake streams. Once Registry staff associate each reportable pathology report with a new or existing patient record, the case proceeds to the abstracting queue for coding and staging.

Results: In the first year of the project, we connected 3 of the 6 labs to the MCR using ePath. While there are preferred industry standards for transmitting ePath data, there has been a spectrum of readiness at our partner labs. By implementing an internationally-recognized project management process the MCSII has effectively engaged stakeholder communities, mitigated risk, managed change and integrated continuous improvement through on-going quality control activity, keeping us on track (often exceeding expectations), under considerable budgetary constraint.

Conclusions: This presentation will highlight a range of lessons learned that we have experienced in the first year of the MCSII ePath project and touch on how the MCR is starting to realize tangible efficiencies in intake processing and workflow.

Notes	Notes

P-12

CROSSING BOUNDARIES FOR CENTRAL CANCER REGISTRY PROFESSIONALS

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Is a CTR really just a Cancer Registrar? There are a wide variety of areas in applied cancer research, where the skills and experience of Central Cancer Registry professionals are extremely valuable. In the workplace community of an employeeowned research organization, there are multiple ongoing projects which require the skill level of a central cancer registry professional to perform. Having experience in processes related to quality assurance, data management or writing edit logics, has proven to be an asset to many study areas. The Prostate, Lung, Colon & Ovarian Cancer Screening Trial required central registry professionals to perform quality assurance on forms completion related to diagnostic evaluation and treatment information. The role of central registry professionals in National Lung Screening Trial has been to abstract diagnostic workup from medical records as well as to provide accurate staging information. This has also been done from a quality assurance standpoint to be sure the data from each screening center is accurate. Other studies requires central registry professionals to review cancer records from all over the world to ensure accuracy of data collection methods, abstract a wide variety of information from diagnosis to treatment, or to be an "expert" contributor to developing study proposals. In conclusion, this presentation will highlight the contributions a central cancer registry professional can make as part of applied cancer research teams.

P-13

CANCER AND THE ENVIRONMENT: DEVELOPMENT OF METHODS TO PRIORITIZE CARCINOGENS, ESTIMATE EXPOSURES AND EVALUATE PUBLIC HEALTH RISKS FOR THE PEOPLE OF ONTARIO

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It has been long recognized that environmental exposures may contribute to the burden of cancer. More recently, reports of exposures to endocrine-modulating chemicals and associations with some hormonally related cancers have elevated public and governmental concern. Further, Scientists and Health officials must be able to respond to reports of possible cancer clusters, many of which are believed to be environmental in origin. To address some of these concerns, place them into context, and ultimately reduce exposures to important carcinogens, Cancer Care Ontario Scientists are developing a framework to rank environmental carcinogens for the province. As part of the work, carcinogens will be identified based on existing lists of known, probable and possible carcinogens, and provincial exposure data (current and historical) for contaminants in air, water, soil and human biomonitoring will be collected. This information will be used to assist in carcinogen ranking. This work will proceed in collaboration with others, such as CAREX Canada, involved in ranking and/or prioritizing carcinogens for other provinces. In addition, a public health tracking tool for future small area mapping and spatial analysis of environmental exposures, cancer outcomes (from the Ontario Cancer Registry), and their possible associations will be developed. The framework and public health tracking tool will be piloted in a community in Ontario with well known industrial emissions of carcinogens.

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P-14

THE MASSACHUSETTS CANCER REGISTRY'S INFORMATION CORNER

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Objective. The Massachusetts Cancer Registry continuously works to enhance communication between the central registry operations staff and hospital registrars.

Methods. For the past eleven months MCR's operations staff have produced the Information Corner, which is a monthly enewsletter that provides coding exercises and MCR updates to hospital registrars at 69 reporting facilities. The Information Corner focuses on collaborative staging site specific factors, tumor size, histology coding, coding tips, death clearance updates, treatment issues, multiple primaries, previews of 2010 data changes, and many other issues. Many of the exercises are based on coding issues that the MCR operations staff note as they process cancer incidence data.

Results. The Information Corner has received rave reviews from Massachusetts' hospital registrars. It does take time to organize and produce, but it's definitely an efficient way to keep connected to our reporting facilities.

Conclusions. Better communication results in more timely, complete, and quality cancer incidence data.

P-15

HOW WE MADE OUR TRAINING DOLLARS STRETCH M Dryden¹

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Background: In today's economic climate training dollars are hard to find. With shrinking budgets and overworked staff our training efforts began to take a back seat to other seemingly more pressing needs. Attending a week long training class is a good alternative, but for some students it is too much information crammed into a relatively short time span. We needed something innovative and different that would be stimulating and motivating, but wouldn't break our budget.

Approach: Our solution: partner with NAACCR training staff. We worked with Jim Hofferkamp of the NAACCR office and together developed a program that specifically targeted areas with which our staff needed hands on training.

Results: Newly hired regional registry staff that participated in this training had nothing but positive feedback to this approach.

Conclusion: Working with NAACCR Education/Training staff to customize training for our regional registry staff was a huge success. It provided a cost effective way to train multiple staff in cancer reporting and central registry concepts in a timely, manageable way. This method could also be combined with local hospitals that have similar training needs and the cost could be shared. In addition it can be tailored to your registries specific needs. The possibilities are endless and the benefits are great. We were able to train new staff quickly and efficiently with seemingly little to no effort on our part.

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P-16

THE SASKATCHEWAN CANCER CONTROL REPORT -PROFILING CANCER STAGE, 1988-2007

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In Saskatchewan (SK), legislative authority to conduct cancer surveillance resides with the SK Cancer Agency (SCA).

The SCA's surveillance activities use data from the SK Cancer Registry (SCR). Two strengths of the SCR are its comprehensive follow-up (less than 2% loss to follow-up) and its longevity (1932). The SK Cancer Control Report describes the burden of cancer and its change over time.

The report presents standard information along with a different special topic each year. The special topic in our next issue will be cancer stage distribution using Collaborative Stage (CSv1). As a combined measure, CSv1 describes the extent of disease at diagnosis for clinical and epidemiological purposes. The SCR implemented CSv1 starting in 2005.

In this report we will provide CSv1 specific analysis for Breast, Colorectal (CRC), Lung, and Prostate cancers. Stage distribution by site, age, and time will be presented. In addition, stage specific relative survival will be presented (where possible). Analysis of CRC stage distribution is especially useful as the SCA embarks on a population-based screening program.

Publications such as this, with a wide audience including health care providers, government agencies and the lay public, showcase the use of the population based SCR for cancer control.

P-17

DESIGN A COMPUTER-BASED USER INTERFACE FOR PATHOLOGY REPORTING IN A CANCER CENTER: DESIGN PRINCIPLES AND IMPLEMENTATION

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The solution to many of the problems of the computer-based recording of the pathology report has been elusive, largely due to difficulties in the capture of those data elements that comprise the records of the free text report of pathologists' findings. Reliable input of data has proven to be more complex than originally envisioned by early work in the field. This has led to more research and development into better data collection protocols and easy to use human-computer interfaces as support took. This design is a computer enhanced interactive and structured vocabulary record of the findings designed to provide ease of user input and to support organization and processing of the data characterizing these findings. (6,8) The primary design objective of the system is to develop and evaluate a interface designs for recording reports from the pathologist review in an attempt to overcome some of the deficiencies in this major component of the individual record of diagnoses.

KEY WORDS: pathology; record; system; pathology report; interactive interface; structured vocabulary; object-oriented; GUI.

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P-18

SURVIVAL DIFFERENCE BETWEEN BLACK AND WHITE MEN WITH INVASIVE PROSTATE CANCER IN LOUISIANA

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Background: The incidence rate of prostate cancer was 44% higher and mortality rate was 133% higher among blacks than whites in 2002-2006. This study identifies factors that contribute to high mortality among blacks in Louisiana.

Methods: A total of 2,000 Louisiana men diagnosed with prostate cancer in 2004 were randomly selected for the CDC-NPCR Pattern of Care study. Data were abstracted from hospital and non-hospital medical records, supplemented with data on follow-up and census tract-level socioeconomic status (SES). The proportional hazards model was used to compare risk of death from all causes for blacks with whites.

Results: Stage distributions were comparable between blacks and whites. Blacks were more likely to have high recurrence risk tumors than whites (32% vs. 26%). There is no significant racial difference in surgery and watchful waiting as treatment of choice. Blacks were less likely than whites to receive radiotherapy (33% vs. 39%) and more likely to receive hormone therapy (43% vs. 39%). The 5-year survival rate was significantly lower among blacks than whites (77% vs. 81%). After adjusted for age, tumor characteristics, treatment, health insurance and marital status, and SES, the risks of death from all causes no longer differ between blacks and whites.

Conclusion: Racial difference in tumor recurrence risk, treatment, health insurance and marital status, and SES contribute substantially to the lower survival rate of black men in Louisiana

P-19

HEALTH INSURANCE STATUS AFFECTS STAGING AND INFLUENCES TREATMENT STRATEGIES IN PATIENTS WITH HEPATOCELLULAR CARCINOMA

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Lack of health insurance is associated with poorer outcomes in patients with cancers amenable to early detection. The effect of insurance status on hepatocellular carcinoma (HCC) presentation stage and treatment outcomes has not been examined. We examined the effect of health insurance status on stage of presentation, treatment strategies, and survival in patients with

HCC diagnosed between January 2004 and December 2006 were selected, 680 patients, and stratified by insurance status: 208 with private insurance, 356 with government insurance (non-Medicaid), 75 with Medicaid and 41 uninsured. Logistic, Kaplan-Meier, and Cox models tested the effects of demographic and clinical covariates on the likelihood of having surgery or chemotherapy and on survival.

Medicaid and uninsured patients were more likely to be male, African-American, and reside in an urban area (all p≤0.022). The uninsured were more likely to present with Stage IV disease (p=0.005). After adjusting for demographics and tumor stage, Medicaid and uninsured patients were less likely to receive surgical treatment (p≤0.004), but were just as likely to be treated with chemotherapy (p≥0.243). Survival was significantly better in privately insured patients and in those treated with surgery or chemotherapy (all p≤0.006). Demographic adjusted risk of death was doubled in the uninsured (p=0.005).

Uninsured patients with HCC are more likely to present with latestage disease and have poorer survival.

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P-20

EFFECT OF RACE AND SOCIOECONOMIC STATUS ON BREAST CANCER TREATMENT IN LOUISIANA

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Socioeconomic status (SES) is associated with utilization of screening, stage at diagnosis, cancer treatment and prognosis. Higher mortality rate of breast cancer among blacks in Louisiana may be related to racial differences in SES. We examine the effect of SES on this racial difference in breast cancer stage and treatment.

Methods:Using data from the CDC-NPCR Pattern of Care Study for breast cancer, 1772 women diagnosed with breast cancer in 2004 in Louisiana were selected by stratified random sampling. Demographics, stage and treatment information was obtained by medical record review and verified with physicians. Census tract level data was used to determine SES. Chi Sq test and logistic regression were used.

Results: Black women and women living in areas with low SES (high poverty and low education) were more likely to be diagnosed with late stage disease than their counterparts. Black women and low SES women were less likely to receive radiation after BCS for Stage I/II and more likely to receive mastectomy without radiation. When adjusted for each other, age, stage and tumor characteristics, only effect of SES remains significant. Also there is no significant effect of race and SES on adjuvant chemotherapy or hormonal therapy.

Conclusion: Our study shows that the effect of race on treatment pattern in Louisiana is mainly mitigated by SES and other factors. Addressing these factors will help in eliminating disparities in breast cancer treatment and prognosis.

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P-21

IMPROVED DATA ANALYSIS AND DISSEMINATION USING BAYESIAN SPATIAL MODELING

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Background: There are many challenges in measuring the burden of disease using traditional epidemiological methods. The major barriers that frequently prevent measuring burden at local level are: data is often unreliable due to small numbers with limited ability to measure behavioral health outcomes; and data is not analyzed to answer specific questions that include socioeconomic, cultural, and geographic influences.

Purpose: Our purpose through this work is to examine the feasibility of using the spatial modeling methods to address the barriers like small numbers or rare events.

Methods: We plan to use Bayesian models in spatial smoothing. Spatial smoothing "pools" information from neighboring areas to produce more stable estimates of rates for each area and to identify any spatial patterns in the data. We will examine the New Hampshire State Cancer Registry data from 1997 to 2006 and using software called WinBUGS to process the data, and generate the smoothed rates. Using this software we will attempt to fit Bayesian model using the selected covariates and spatial smoothing and present the results in the form of maps.

Results: Using these new statistical methods we will explain some of the perceived clusters and various other uses of this methodology and its use in the disease surveillance and follow up.

Conclusion: In conclusion small-area analysis helps to provide better and reliable disease rate information to communities and thus helps to improve public health.

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P-22

NATIONWIDE CANCER INCIDENCE IN TAIWAN, 2002-2006 F-Z Chang¹, T-H Hsu¹, C-J Chiang¹, S-C Hsiao¹, S-L Koong¹ Bureau of Health Promotion, Department of Health, Taiwan, Xinzhuang City/Taipei County, Taiwan; ²Graduate Institute of Preventive Medicine, College of Public Health, National Taiwan University, Taiwan, Zhongzheng Dist./Taipei City, Taiwan

Backgrounds: Cancer has become the leading cause of death in Taiwan since 1982. For cancer surveillance, the Department of Health established a reporting system of new cancer cases in 1979, which can not only monitor the incidence of cancers but also provide cancer control strategies and programs. The purpose of this study was to describe the major cancer incidences in Taiwan.

Methods: The Taiwan Cancer Registry (TCR) is a population-based registration system. The data used in this analysis was provided by TCR database from 2002 to 2006. Cancer incidence rates were calculated by age, gender and cancer sites. All rates are listed per 10⁵ populations and were age-standardized to the 2000 WHO standard population.

Results: There were 339,897 new cancer case diagnosed in 2002-2006. The most incidence cases of cancer site was liver which was also the most cases in male (total 49,537 and male 35,518). Breast cancer had the highest incidence cases among female (30,172 cases). The age-standardized incidence rate (ASR) for all cancer combined was 264.4. The highest ASR in Taiwan for females was breast cancer (ASR 46.2) and for males was liver cancer (ASR 56.0). The overall 5-year observed survival rate is 42.7%.

Conclusion: In order to fight cancer and decrease cancer mortality rate, the central government provides cancer screening and treatment improving programs. Through these strategies we hope to achieve the promotion of the quality of medical care for cancer patients.

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P-23

USING ARTIFICIAL INTELLIGENCE SOFTWARE TO ASSIST IN DOCUMENTING PERSONALIZED MEDICINE TESTING PRACTISES.

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Personalised medicine requires gene- or protein testing to identify candidates with the factor of interest, thus allowing physicians to select appropriately targeted therapy. Human epidermal growth factor receptor-2 (HER2) testing to direct trastuzumab treatment in breast cancer (BC) patients is a well established example of personalised medicine. We evaluated HER2 testing patterns in a retrospective cohort of BC patients. In Ontario, tumour pathology information available from electronic pathology reports is highly variable due to the many acronyms used to describe HER2, type of test and test result.

We modified AIM's Synoptex software to automatically extract the HER2 data elements from BC pathology reports. Synoptex is a software tool that uses natural language and AI processing techniques to reduce free text pathology reports to data elements defined by the College of American Pathologists. The extracted information was reviewed by a trained reviewer and verified or modified to ensure accuracy. Results were stored in a database for analysis and compared for accuracy between individual users and the computer.

The system was able to distinguish either genetic or protein HER2 tests using common terminology, and can appropriately assign a test result. The software facilitates rapid data capture approx. six times faster and reduces opportunity for human error. Detailed experience and results with the software will be discussed.

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P-24

DISPARITIES IN BREAST CANCER PROGNOSTIC FACTORS BY RACE, INSURANCE STATUS, AND EDUCATION

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Black women are more likely to be diagnosed with advanced stage and other less favorable breast cancer prognostic factors than white women; however, little is known about the extent to which socioeconomic position account for these differences. Our study included 193,969 women diagnosed with breast cancer during 2004-05 in the National Cancer Database. We examined the effects of race, insurance status, and educational attainment on the likelihood of being diagnosed with breast cancers that have less favorable prognostic factors and the contribution of insurance and education on the black-white differences in these factors. Compared to white women, black women are more likely to be diagnosed with breast tumors that are less differentiated, ER-PR-, lymph node positive, large in size, and metastatic. Adjustment for insurance and educational attainment explained 31%-39% of the differences in tumor size and metastasis, but only 14% of the differences in grade and hormone receptor status. Uninsured women and women in less educated areas were also more likely to have tumors with poor prognostic factors. Insurance and education explained a substantial proportion of the black-white differences in tumor size and metastasis. Extending health insurance coverage to all women, as well as reducing socioeconomic disparities, environmental, and social inequities could reduce disparities in prognosis and survival among black and socioeconomically disadvantaged women.

P-25

INCIDENCE OF CERVICAL CANCER AMONG WOMEN **UNDER 40 YEARS OLD IN THE UNITED STATES**

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Cervical cancer incidence has declined since the advent of screening through Pap testing; incidence in young women is very rare and not well characterized. We describe the incidence of invasive cervical cancer among females under 40 years of age in the US by age, race/ethnicity, and histology using data from CDC's NPCR and NCI's SEER Program. Data from 45 registries, covering 90.4% of the U.S. population for 1999-2005 were included. (Final presentation will include 2006 data.) Rates were calculated in SEER*Stat and expressed per 100,000 females. Among females younger than 40, 22,441 cases of invasive cervical cancer were diagnosed during 1999-2005. Among females younger than 20 years of age, an average of fewer than 20 cases per year were diagnosed; most of these cases were non-carcinomas, suggesting an etiology other than HPV. Rates of cervical cancer increased from 1.5 for ages 20-24 to 6.2 for ages 25-29, and continued to increase with age up to 14.3 at age 35-39. The results of this study demonstrate that the incidence of cervical cancer in females under 25 is very low, but increases with age. Also, detailed information on cervical cancer among young women is provided. Comprehensive nationwide, population-based cancer registry data enable the examination of cancer among younger age groups, and in populations where cancer is rare.

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BURDEN OF CHOLANGIOCARCINOMAS IN THE UNITED STATES, 1999-2006

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Cholangiocarcinoma (CC) is a rare cancer of the bile duct with low survival rates. Intrahepatic CCs (ICC) arise from the intrahepatic bile ducts; extrahepatic CCs (ECCs) arise from bile ducts outside of the liver. To date, this rare cancer has not been well characterized in the US. Data from CDC's NPCR and NCI's SEER Program, covering 88% of the U.S. population, were used to examine invasive CC incidence from 1999-2006. Analyses were limited to CCs using specific histology and site codes. Ageadjusted (2000 US standard) rates of invasive CC incidence were examined by age, race, Hispanic ethnicity, and gender and expressed per 100,000 population. There were 26,180 cases of invasive CC from 1999-2006; 10,981 ICCs and 15,199 ECCs. The overall CC incidence rate was 1.29; 0.54 for ICCs and 0.75 for ECCs. The highest rate of both ICC and ECC was among Asian/Pacific Islanders (API) (rates of 0.79 and 1.15, respectively) and lowest among blacks (0.45 and 0.65). ICC and ECC rates were higher among males (0.62 and 0.93) than females (0.47 and 0.62). The Northeast census region had increased rates of ICC (0.60) and ECC (0.83) compared to other census regions. These results confirm previous reports of CC distribution by gender and race/ethnicity, yet provide unique information on histology-specific and geographic incidence. The ability to characterize the burden of rare cancers highlights an important use of population-based cancer registry data covering a large proportion of the US.

P-27

CALCULATING DISTANCES BETWEEN ADDRESS AT TIME OF DIAGNOSIS AND RADIATION FACILITIES IN CALIFORNIA

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Prior research has shown that the distance between a patient's residence and their nearest radiation facility is associated with receipt of adjuvant radiation for breast and colorectal cancers. As part of a larger study of the impact of contextual factors on disparities in cancer care and survival, we conducted an analysis to determine whether distance to radiation facilities explained racial/ethnic disparities in the receipt of adjuvant radiation for breast and colorectal cancer in California. Between 1996 and 2006, the California Cancer Registry (CCR) obtained latitude and longitude values for patient addresses at time of diagnosis for over 1 million individuals. The histologically confirmed, first primary female breast cancer cases and male and female colorectal cancer cases were parsed from the dataset. The distance between each breast cancer and colorectal cancer case and the nearest radiation facility offering oncology services was calculated. We will discuss the GIS methodology of determining the nearest radiation facility influences treatment and disparities in cancer care.

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P-28

LINKAGE WITH STATE MEDICAID DATA FOR CASE-FINDING PURPOSES. IS IT WORTH THE EFFORT?

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In order to ensure comprehensive and quality cancer data, cancer registries must incorporate data from a variety of sources. Early stage cancers, such as prostate, breast, colon and melanoma, have been difficult to fully ascertain because they do not always reach typical cancer reporting sources (i.e. hospitals or cancer treatment centers). The Texas Cancer Registry (TCR) obtained 2007-2008 inpatient and outpatient Texas Medicaid claims data in an attempt to improve the quality and completeness of particular data fields and evaluate case completeness by identifying potential cases that were not reported to the Registry. Using diagnosis codes, we will determine the possible utility of Medicaid data to improve completeness of known under-reported cancer sites. In the Medicaid files, there were 613,351 outpatient and 17,448 inpatient claims that had an ICD-9 code between 140 and 239 (neoplasm). Of those, there were 61,883 female breast, 23,520 prostate, 20,256 colon, and 3,114 melanoma outpatient claims and 890 breast, 170 prostate, 617 colon, and 26 melanoma inpatient claims. Using Link Plus software, we will conduct a probabilistic linkage between Medicaid and TCR data and examine how many matches occur, which sites most commonly matched, and of the cancer-related Medicaid claims that did not match, examine the provider type and specialty. This analysis is intended to inform both the TCR and other registries about the usefulness of state Medicaid data for case-finding.

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P-29

AN INVESTIGATION OF SELF-REPORTED CANCERS FROM A COHORT STUDY WHERE NO RECORD WAS FOUND AT THE STATE REGISTRY OF RESIDENCE

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Adventist Health Study-2 (AHS-2) is a nation-wide diet-cancer cohort study (N=96,000) that must match study data with all U.S. and Canada cancer registries. Agreements are now completed with 26 registries. Here, we begin validating the completeness of cancer ascertainment for this study. A substudy consists of 397 AHS-2 subjects living in CA, OR, WA, ID, UT or AZ, who reported a recent cancer diagnosis on a biennial question-naire but where we could not identify a corresponding registry record. This was for the period 2002-2005 (or 2006 in some states). There were 885 incident cancers successfully matched from these states during the same period. Telephone contact was attempted with a random sample of 94 from the 397 subjects. This was not immediately possible in 18 subjects. Of the others, 11 were deceased, in 48 the tumor was clearly benign/non-existent, and in 17 (based on treatment) a cancer seemed likely. We will attempt to obtain and report the relevant medical records at the meeting. Death certificate information for 6 of the deceased found cancer as the cause of death in four. Of the 17 possible cancers, two had been diagnosed in a state not their state of residence. In conclusion, we will need to obtain medical records in about 30% of situations where a cancer is reported but not matched. The biennial questionnaire may be the only source of 8% of cancers, if all medical records obtained subsequently confirm a cancer. This study will be extended to other states.

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P-30

THE VARIETY OF EXPERIENCE IN WORKING WITH 35 U.S. CANCER REGISTRIES: MATCHING ADVENTIST HEALTH STUDY-2 (AHS-2) AND REGISTRY DATA

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AHS-2 is a nation-wide diet-cancer cohort that requires matching with all U.S. cancer registries. Agreements are now completed with 26, and under negotiation in another 10. So far only 2 registries have temporarily declined the match. Matching has been completed at least once with 16 registries. Applications varied from 0 to 28 pages. The time from submission to completed agreement averaged 19.2 weeks (3 to 138). In 18/26 states the new laptop used for the match was accepted as payment. In others the cost was \$0 to \$4500, sometimes limiting us to one match during follow-up. The usual matching model is a visit to the registry by a trained AHS-2 programmer (22/30 states) who matches using Link-Plus software. Levels of oversight by registry staff are highly variable. 6 states required that the registry perform the match working by telephone with AHS-2 personnel. Two states sent their whole relevant database to us electronically so matching was at Loma Linda. One registry required a new HIPAA-style agreement from all AHS-2 subjects in that state (we lost about 30% of subjects). Lawyers became involved with agreements in 4 states, slowing progress. Some states do not record telephone #'s, a variable used in our matching procedure. Availability of different variables by deidentified state will be reported. Despite frustrations, matching with nearly all cancer registries is feasible and usually inexpensive. Registry staff are mostly helpful and anxious to participate.

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P-31

RECORD LINKAGE BETWEEN CANCER REGISTRY AND **HOSPITAL DISCHARGE DATA**

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Background: Linking records in different datasets allows researchers to connect different parts of the life experience of individuals. However, most health datasets lack unique identifiers and have limited personal identifying information. This impedes the possibility of conducting research through record linkage.

Purpose: Our purpose is to examine the feasibility of matching records between cancer cases in the New Hampshire State Cancer Registry and cancer patients in the hospital discharge data in New Hampshire.

Methods: We plan to use: Hospital inpatient data, 2000-2007, with breast and colorectal cancer diagnosis in any of the diagnostic fields; and NHSCR cancer incidence data, 2000-2007, New Hampshire residents only, with any cancer diagnosis. Data fields co-existing in the two datasets are used in the linkage.

Results: Results of the linkage will be stratified by demographic and geographic factors for comparisons. The overall results will be presented for Breast and Colorectal Cancers.

Conclusion: It is critical that unique identifiers or more identifying information available in health datasets is crucial to improve record linkage for health research. This study will provide an opportunity to show where we can improve record linkage for cancer data in our next step toward making New Hampshire cancer registry into a follow up registry and also to improve health care research

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P-32

PUBLIC HEALTH SURVEILLANCE COLLABORATION: ESTABLISHING A LINKAGE ALGORITHM WITH CANCER REGISTRIES FOR THE FORTEO PATIENT REGISTRY

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Background: A voluntary prospective registry of patients treated with Forteo will complement the ongoing Osteosarcoma Surveillance Study conducted by RTI Health Solutions (RTI-HS). We will enroll patients for 5 years, collecting basic identifying information and the last four digits of the social security number one time only, and follow them through linkage with US population-based cancer registries annually for up to 12 years to identify cases of osteosarcoma. Since registrants will not be providing their full social security number, it will be essential to perform linkages consistently.

Objective: To establish a uniform probabilistic linkage algorithm for participating cancer registries.

Methods: We will develop a linkage algorithm from information collected during patient enrollment (name, date of birth, sex, address, telephone number, race, ethnicity, and last 4 digits of social security number) using Link Plus software. Prior to implementation, the algorithm will be pretested with up to 4 cancer registries to enhance the specificity and usability.

Results: We will share the resultant linkage algorithm for use by participating cancer registries, the challenges encountered during development and testing, and the resolutions.

Conclusions: Establishing a uniform linkage algorithm ensures that cases of osteosarcoma among registrants are captured during the linkage period, allowing for accurate estimation of the incidence of osteosarcoma among registrants.

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P-33

DEATH MATCHING WITH LINK PLUS VERSION 2 REDUCED TIME AND COST AND INCREASED THE NUMBER OF GOOD MATCHES, IN COMPARISON TO A LEGACY IN-HOUSE SYSTEM.

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Since the 1970's UT MD Anderson Cancer Center has relied on an in-house mainframe based program to match files from the Texas BVS with patients from the hospital based registry. Recently the Texas BVS has sent a number of additional files to catch-up for a backlog over the last year. This has resulted in an increased load for our staff in the cancer registry and prompted us to seek new efficiencies.

A typical weekly file from the Texas BVS contains over 4,000 deaths. This file is linked with over 207,000 patients with a malignancy who were alive at last contact. Using the output match from the legacy system, the follow-up representative then had to manually review over 250 potential matches to obtain 75+ true matches and then manually enter the data to the registry database. Over the course of a year this constitutes an estimated 156 work hours or nearly 20 days.

Running Link Plus version two in parallel resulted in a 16% increase in true matches with a 90% reduction in manual reviews and, using the export utility, a 100% reduction in data entry. Potentially, the number of hours for review by a follow-up representative over the course of a year has been has been reduced to 15. This saving in time and cost has been utilized to reduce a backlog in death verification.

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P-34

UTILIZING HOSPITAL DISCHARGE AND EMERGENCY DEPARTMENT DATA TO DEVELOP A SICKLE CELL DISEASE (SCD) COHORT TO EVALUATE CANCER BURDEN, CALIFORNIA, 1991-2007

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Introduction: SCD is genetic hematologic disorder resulting in wide-ranging clinical complications. Primary therapy for SCD is suspected of increasing cancer risk. The methodology described was developed to investigate cancer risk in this population using the California Cancer Registry (CCR). There is no disease registry for SCD; therefore we created a SCD prevalence database for linkage.

Methods: Patient discharge (PDD) and emergency admissions (EDD) data from the California Office of Statewide Health Planning and Development (OSHPD) was used. The PDD averages 3.8 million records while the EDD averages 8.6 million records per year. All 25 diagnostic fields of the PDD and EDD were queried for ICD-9 codes (286.6X and 282.41, 282.42). After removing invalid SSN, we used SSNs to capture all admission (with and without a SCD diagnostic code). Patient identifiers were used to link cohort to the CCR using the probabilistic AutoMatch program.

Results: 120,958 SCD-related admissions were captured in the PDD and 20,050 SCD related admissions were captured in the EDD files. 10,346 individuals with SCD were found in the PDD and 3,662 in the EDD were identified. Ultimately, 550 SCD patients were matched to the CCR with a first primary invasive cancer. Conclusion: Procedures described here allowed us to maximize the number of SCD patients and admissions from the OSHPD data systems; and made it possible to evaluate this group's cancer burden.

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AN OPEN SOURCE PROBABILISTIC RECORD LINKAGE SYSTEM

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Most central cancer registries use external tools to link records between two different data sources or deduplicate their registry. These tools require many manual steps that cannot be easily automated. For example, records must be exported from databases into files and results must be incorporated back into the central registry once the linkage is complete. To address these limitations, we have incorporated an open source, probabilistic record linkage system into the Kentucky Cancer Registry (KCR) central registry software. This system handles a variety of inputs including multiple database platforms, file formats, and web-service data sources. As in other linkage software, our linkage engine is configured with blocking parameters, matching parameters, algorithm-specific settings, and cutoff scores. However, our linkage engine also supports custom blocking, matching, and scoring algorithms. Taking advantage of this feature, we have implemented matching algorithms for social security number, dates, and value-specific fields such as sex and race. In addition, overall scores for a matched pair are calculated from weighted scores we obtain from the Expectation-Maximization algorithm. We also take advantage of common linkage routines such as Soundex encoding and Jaro-Winkler partial string scoring. In this presentation we discuss our motivations for building the record linkage system, our development process, and a comparison of its accuracy to other record linkage software.

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P-36

VALIDATING CANCER SCREENING RESULTS: LINKING UTAH BREAST AND CERVICAL CANCER SCREENING PROGRAM DATA WITH THE UTAH CANCER REGISTRY

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Background: The Utah Cancer Control Program (UCCP), in partnership with the Centers for Disease Control and Prevention (CDC) and Utah's Local Health Departments, promotes early detection of breast and cervical cancer by offering eligible women free pap tests, pelvic exams, clinical breast exams, instruction on self-breast examination, and a voucher for a free mammogram.

Purpose: UCCP data was linked to the Utah Cancer Registry (UCR) to verify cancer diagnoses and staging information.

Methods: UCCP demographic and cancer information was provided to UCR for linkage. Records were linked by social security number, name, and date of birth using SAS (v 9.1.3). Non-matches were reviewed manually.

Results: Of the 914 UCCP cancer records submitted, 97% successfully linked with UCR (70% linked on all three criteria, 25% linked on two criteria, and 2% linked after manual review). Of the manually reviewed cases, 42% were determined to match. Non-linked cases could not be verified as reportable cancers to the UCR.

Discussion: Linking cancer control program data with state cancer records is a reliable method for verifying cancer information. It also provides an avenue for program evaluation, which may include a comparison of staging in rarely screened and frequently screened clients as well as an assessment of treatment and survival outcomes of program participants. Results from the UCCP-UCR linkage are reported to the CDC as part of the biannual data submission.

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P-37

LINKING MISSOURI CANCER REGISTRY (MCR) DATA WITH THE SOCIAL SECURITY DEATH INDEX (SSDI)

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Record linkage is the process of bringing together information from more than one source on the same patient. Linkage with national databases such as the SSDI and the National Death Index is essential for incidence registries that would like to become survival registries. The studies purpose is to improve the quality and completeness of data in the MCR database. MCR linked cancer records on all Missourians from 2001 & 2006 with single-year SSDI files downloaded from the National Program of Cancer Registries-Central Cancer Registry document server. The two cancer files were linked to single-year SSDI files from the year of diagnosis to the most recent SSDI file available (Jan. 2001 - June 2009, and Jan. 2006 - June 2009). The linkage took into account the matching and blocking variables (Last, First & Middle name, SSN, Birth Date, Address at diagnosis, etc). We then reviewed the result manually to check for discrepancies. Using a cut-off value of 7, we observed that on average most true matches stopped at 22.5. We also discovered that out of 81,344 total linkages, 26,601 (32.70%) were true and 54,375 (66.85%) were false and 328 (0.40%) were uncertain matches. Linking registry's data with national databases provide an accurate method to determine people who are truly dead or alive. It also provides opportunity for registries to correct any discrepancies in the database as well update their cases vital status to ensure survival analysis.

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P-38

INCIDENCE TRENDS FOR PREVENTIVE AND EARLY DETECTION CANCER IN KENTUCKY

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Background: Kentucky has one of the highest cancer incidence and mortality rates in the U.S. Substantial efforts through various cancer prevention and early detection programs in Kentucky have been made to reduce the burden from cancer.

Objective: The aim of the study is to investigate how incidence rates of selected cancers have changed over time, in order to better understand effectiveness of cancer prevention and early detection efforts.

Methods: Age-adjusted rates for colorectal cancer, female breast cancer, prostate cancer and invasive cervical cancer in KY 1995-2006 were calculated. Trends of rates and rate ratios (early-stage vs. late-stage) were also examined.

Results: Rates for early-stage prostate cancer (In situ, stage I&II) have increased steadily over the study period. The rates of invasive cervical cancer have dropped consistently. A favorable upward trend of the rate ratios for breast cancer was found prior year 2004. No clear trends were observed for the rates and the rate ratios for colorectal cancer.

Conclusions: The efforts towards cancer prevention and early detection have contributed the increasing diagnosis for early stage prostate cancer and the decreasing invasive cervical cancer rates. The change of coding rule in year 2004 may have impacted the rates for breast cancer. Further research will be necessary to better understand the cancer burden for breast and prostate cancer in Kentucky.

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P-39

THE IMPACT OF THE BENIGN BRAIN TUMOR CANCER REGISTRIES AMENDMENT ACT ON BRAIN TUMOR INCIDENCE AND TRENDS IN THE USA

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Public Law 107-206 expanded primary brain and CNS tumor data collection to include non-malignant behavior in diagnosis year 2004. CBTRUS collaborating registries collected nonmalignant tumors prior to 2004, but collection and reporting were not consistent. The study investigated changes in patterns of reported incidence of brain tumors pre-2004 and for 2004-2006. Data from 13 population-based state cancer registries were collected on all primary brain tumors from 1995-2006. The incidence of non-malignant brain tumors increased over time (6.13, 7.35, 9.23, 11.64/100,000 for the years 95-97, 98-00, 01-03, and 04-06, respectively) while malignant tumor rates were stable. The non-malignant contribution to total brain tumors increased on average from 50% pre-2004 to 61% for 2004-06 for an 11% difference (registry range: 4% - 20%). The average annual percent change (APC) showed a significant increase for non-malignant (7.1) and all (3.1) brain tumors pre-2004, while malignant tumors significantly decreased (-0.8). Malignant and non-malignant brain tumor incidence did not change from 2004 to 2006. Data collected pre-2004 underestimated the true incidence of non-malignant brain tumors. The increasing incidence in non-malignant brain tumors pre-2004 was likely due to factors associated with changes in reporting requirements and legislative inconsistencies that influenced ascertainment. In the future, brain tumor incidence should be evaluated beginning with diagnosis year 2004.

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TRENDS IN GASTRIC CANCER INCIDENCE RATES AMONG AMERICAN INDIANS IN NEW MEXICO, 1981-2007

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Incidence rates for gastric cancer in the United States declined dramatically during the twentieth century for reasons that are still not well understood. In New Mexico, gastric cancer incidence rates for American Indians have historically been much higher than rates among the state's Hispanic and non-Hispanic white populations. Further, gastric cancer incidence rates remained high among American Indians in New Mexico well into the 1980's despite declining rates in the United States and among New Mexico's Hispanic and non-Hispanic white populations. Gastric cancer incidence rates finally declined among American Indians in New Mexico in the 1990's and early 2000's - but remain well above rates for other populations in the state. This presentation will focus on changing patterns of gastric cancer incidence rates among American Indians in New Mexico – rates for Hispanic and non-Hispanic whites from this region will serve as a comparison.

P-41

CANCER DISPARITIES BY RACE AND ETHNICITY IN NEBRASKA

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This study intends to identify and document cancer disparities by race and ethnicity in Nebraska between1991 and 2005, which provides evidence for updating the Nebraska Cancer Prevention Plan.

Based on Nebraska Cancer Registry data for the last 15 years, we examined and synchronized cancer status and trends at the same period in terms of incidence, staging, and survival with an emphasis on incidence, either by cancer site or by geography by exclusive racial/ethnic groups. In general, differences in the incidence among major cancer sites, such as breast, colorectal, lung, prostate by race and ethnicity, exhibit patterns and trends similar to those at the national level. In addition, differences in early stage diagnoses and five-year survival rates favoring non-Hispanic whites remain throughout the study period. Overall, Nebraska's non-Hispanic Blacks and American Indians had the highest rate of late-stage cancer at diagnosis and the lowest fiveyear survival rate of all racial and ethnic groups. Our results also show that program efforts for small populations may not be measureable. Recommended actions such as data quality and screening improvement and further study are discussed. In addition, this study suggest that outcomes from major programs that are either directly or indirectly related to cancer control and cancer disparity can be assessed with evidencebased health disparity measures based on the registry data.

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CANCER TRENDS IN NEVADA'S URBAN, RURAL AND FRONTIER COMMUNITIES

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Cancer is the 2nd leading cause of death for Nevadans. In 2005, 10,366 new cases of cancer were diagnosed in Nevada (NV) and 4,238 cancer deaths were reported (NPCR, 2005). In 2009 there will be 12,020 new cancer cases identified in NV and 4,600 cancer deaths (ACS, 2009). NV is the 5th most geographically disparate state in the nation (UHF, 2009), which may have led to health disparities. Nevada Cancer Institute is working on a CDC funded project to provide statistics to support the 2010 update of NV's Comprehensive Cancer Plan. This project collaborates with the NV Office of Health Statistics and Surveillance. Analyses will be conducted on the six most commonly diagnosed cancers in NV. This poster will show selected results from our analyses focusing on regional similarities and disparities in cancer burden. Cancer statistics will be obtained from the NV Central Cancer and Death Registries among other data. Incidence and mortality will be analyzed by demographic, geographic, and disease factors. Cancer Registry data will be linked to Census data by zip code. Regional US and national data will be compared with NV data. Reports will illustrate relevant behavioral data.

American Cancer Society. (2009). Cancer facts and figures 2009. National Program of Cancer Registries. (2005). United States Cancer Statistics.

United Health Foundation (2009). Ranking of US states by health indicators.

P-43

THE HISPANIC MONOGRAPH - A FLORIDA CANCER DATA SYSTEM (FCDS) PUBLICATION OF HISPANIC CANCER TRENDS IN FLORIDA

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Background: Hispanics are the fastest growing minority population in the US. FCDS has created a Monograph focusing on the cancer experience of Florida Hispanics. Methods: The data were all cancer cases residing in Florida diagnosed between 1989-2006. The Hispanic Origin Identification Algorithm was applied to the FCDS data (Pinheiro 2008). Primary cancer site and histology data were categorized according to SEER site groups. The top 10 cancers among all Florida residents for 2006 were selected, as well as additional cancers traditionally elevated in Hispanics. Cancer incidence trends between 1989-2006 were conducted using joinpoint regression model. Results: Cancer rankings among Hispanic and non-Hispanic White males were similar for the top four cancers. Proportionally, male Hispanics had lower melanoma and bladde rates, and higher proportions of non-Hodgkin lymphoma, liver and stomach cancers. For Hispanic females, the top five were breast, colorectal, lung and bronchus, uterus, and thyroid, with a higher proportion of cervical cancer, but lower of melanoma. Although Hispanics and non-Hispanic Whites had decreasing trends in overall cancer rates, the decrease was greater for non-Hispanic Whites. Implications: Rates for cervical, liver, stomach, non Hodgkins' lymphoma, and thyroid cancers are elevated in the Hispanics. Cancer rate trend decreases were greater for non-Hispanic White population, indicating the existence of health disparities between the two groups.

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P-44

TRENDS IN THE INCIDENCE RATES AND HISTOLOGY OF DCIS IN LOS ANGELES COUNTY, 1990-2007

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Ductal carcinoma in situ (DCIS) the most common non-invasive lesion of the breast increased dramatically with the widespread introduction of screening mammography. We have studied the trends in DCIS by histologic type in Los Angeles County from 1990 through 2007. The age-adjusted rates of DCIS increased 71% from 1990-92 to 1999-2001 and remained stable from then to 2005-07. The peak incidence of DCIS shifted from age 70-74 in the period 1990-95 to 65-69 in 1996-1998 and has remained in the 65-69 year age group since that time: the incidence rates in both age groups increased but the rise was much sharper in the 65-69 year age group (age 65-9: from 44.8/100,000 to 69.2; age 70-74: 51.9 to 65.6). The trend in the age-adjusted incidence rate of DCIS by histological type showed that the increase occurred mainly in the non-comedo histology group. The incidence rate in the comedo histology group increased from 5.5 in 1990-92 to 7.4 in 1993-95 and has been decreasing since that time to 3.0 in the period 2002-2007. The reason for this decline in this most serious form of DCIS is unclear. It may be a change in pathology 'fashion' combined with the reduction in DCIS NOS and calls for a detailed pathology review. Another aspect requiring detailed review is the increase in the percentage of DCIS with larger tumor size (≥2 cm) and higher grade (grade III and IV) - size:18.9% in 1990-92 to 36.9% in 2005-07; grade: 27.3% to 45.4%.

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P-45

CHANGING INCIDENCE OF ESOPHAGEAL CANCER SUBTYPES IN RELATION TO CHANGING PREVALENCE OF RISK FACTORS IN ONTARIO.

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Background: Esophageal cancer is an uncommon but highly fatal cancer. While overall incidence of esophageal cancer has been stable over the past two decades, the main subtypes – esophageal adenocarcinoma (EAC) and esophageal squamous cell carcinoma (ESCC) – show opposing trends.

Objective: To evaluate the influence of risk factor trends on incidence patterns of EAC and ESCC.

Methods: Age-standardized incidence rates for esophageal subtypes were calculated from the population-based Ontario Cancer Registry. Data on risk factors were extracted from national and provincial surveys.

Results and interpretation: EAC increased dramatically at 4% per year while ESCC incidence declined at 2% per year from 1981 to 2005. EAC has now become the most common type of esophageal cancer in Ontario. An increase in the prevalence of obesity may explain part of the rise. Obesity is associated with EAC (but not with ESCC) and has been on the rise in Ontario since at least the1980s (16% of adults were obese in 2007 compared to <10% in the 1980s). Canada-wide data suggest that obesity has been increasing since the 1970s. Smoking increases the risk of both subtypes but the risk is much higher for ESCC. Reductions in smoking observed in Ontario (since at least mid 1980s) and Canada (since mid 1960s in males and 1980s in females) may partly explain long-term fall in ESCC. An improved understanding of other risk factors in relation to EAC is needed to aid in the prevention of this lethal cancer.

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CANCER AND PLACE OF DEATH IN NEW HAMPSHIRE B Riddle¹

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The New Hampshire Statistical Death File, 1987-2007, records place of death along with cause of death. This longitudinal data set provides a look at where decedents with cancer died and to examine the impact place of death has on cancer surveillance activities. Over the last 20 years, a number of trends have influenced where people die. One trend is rapidly aging population. In the US people over 65 increased 12% from 1990 to 2000. A second trend is rise in acceptance in hospice care and a strong desire to die outside a hospital. The US Census reports that people 65 years and over living in nursing homes declined from 5.1 percent in 1990 to 4.5 percent in 2000. In 1987, about 61% of cancer deaths in NH occurred in a hospital but by 2007 the number was 29%. A third trend is a small increase in life expectancy after a diagnosis of cancer. The American Cancer Society reports that "cancer death rates dropped 19.2% among men during 1990-2005 and 11.4% among women during 1991-2005." This study will answer the following questions about cancer and place of death in NH: How has where people die changed over time? Do cancer patients die in different places than others? How has age at death changed by place of death? Is place of death associated with certain kinds of cancer? The poster will report the results of this study.

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CO-MORBIDITIES AMONG FEMALE BREAST CANCER PATIENTS IN FLORIDA, 2000-2008

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Background: Breast cancer is the most common cancer among females in Florida. Though the incidence and mortality rates are decreasing, it remains a threat among blacks. Co-morbid conditions are an important factor of determining treatment and the prognosis and are under-studied.

Purpose: The study explores the co-morbid conditions among female breast cancer patients between 2000 and 2008. Disparities in co-morbidity will be examined.

Methods: Florida data from the AHCA for the years 2000 to 2008 were analyzed. Females were grouped into: <40 years, 40-64 years, and 65+ years, whites and blacks. The frequently reported co-morbid conditions were identified. The sums of comorbidity were calculated and were grouped into: no co-morbidity, 1 to 3 conditions, and over 4 conditions. Cross tabulations were performed by age and race groups. Results: Between 2000 and 2008, 43,787 females were hospitalized for breast cancer. The commonly reported co-morbid conditions in Florida were hypertension, diabetes, lipid metabolism disorders, hypothyroidism, CVD, and COPD. The percentage of having one to three co-morbid conditions was higher among the older age groups and among blacks. The percentage of having hypertension and diabetes was significantly higher among whites.

Conclusion: The percentage of having higher co-morbid conditions could be a possible explanation for the threat among blacks.

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DESCRIPTIVE EPIDEMIOLOGY OF OVARIAN CANCER IN MASSACHUSETTS

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Purpose: Ovarian cancer was the eighth leading cancer diagnosed in females and the fifth leading cause of cancer deaths among females in Massachusetts (MA). The Incidence and mortality rates were 8% and 2% higher in MA than nationally. This prompted an interest in the descriptive statistics using MA data.

Methods: Counts and incidence rates were used for histology, staging, and race/ethnicity charts using 2001-2005 and 1990-1994 periods. Incidence and mortality rates were plotted and annual percent change was calculated for 1982-2005 and probabilities were calculated for 1996-2005.

Results: Age-adjusted incidence and mortality trends decreased about 0.7% per year over time and incidence peaked later in life. White, non-Hispanics had the highest incidence and mortality rates among race/ethnicity groups. Over 50% of ovarian cases were found at the distant stage and over 80% were epithelial tumors. The probability of developing and dying from ovarian cancer over the lifespan (0-85 years) was 1.6% and 1.1%.

Discussion: There is no single factor that can explain these ovarian cancer epidemiology trends. However, changes in gynecological procedures and medications over time could help explain some of the patterns seen.

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TRENDS IN CHILDHOOD CANCER INCIDENCE AND MORTALITY IN CANADA

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BACKGROUND: Cancer is the leading cause of disease related deaths in children in Canada. Despite the public health importance of childhood cancer, few published reports exist.

PURPOSE: To examine patterns of cancer incidence and mortality in Canadian children aged 0-14 years by diagnostic group, age, sex and geography, from 1984 to 2006.

METHODS: Cancer incidence data was obtained from the Canadian Cancer Registry and the National Cancer Incidence Reporting System and classified according to the diagnostic categories of the International Classification of Childhood Cancer (3rd edition). Mortality data was obtained from the Canadian Vital Statistics Death Database. Rates were age-standardized to the 1991 Canadian population. Trends, including changepoints, were determined using the Joinpoint Regression Program.

RESULTS: On average, 850 children are diagnosed with cancer in Canada each year and 135 died of their disease. The most common types of childhood cancer are leukemia (33%), central nervous system tumours (20%) and lymphomas (12%). Since 1985, overall incidence of childhood cancer has remained relatively stable (144 to 159 cases per 1,000,000), while mortality rates have dramatically declined (from 41 to 21 cases per 1,000,000).

CONCLUSION: The study provides health care providers, researchers, and policy makers detailed information on childhood cancer on which to base future decisions.

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THE CANADIAN PARTNERSHIP AGAINST CANCER'S (THE PARTNERSHIP'S) SURVEILLANCE AND EPIDEMIOLOGY NETWORKS: COLORECTAL CANCER IN ONTARIO BY ANATOMIC SUBSITE

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Background: The Partnership's three multi-provincial, registrybased surveillance analytic networks have been established to build analytic capacity across Canada and develop a standardized approach for analyzing, interpreting, and reporting on cancer. The Colorectal Cancer Network aims to provide information on colorectal cancer in Canadian provinces. Analytic algorithms are being developed initially using Ontario data.

Purpose: To report on colorectal cancer incidence in Ontario by anatomic subsite, sex and age group as baseline for a provincial colorectal screening program.

Methods: Data were extracted from the Ontario Cancer Registry and analyzed with SEER*Stat and Joinpoint software. Source records were reviewed to reduce the proportion of registry records with unassigned subsite.

Results: We present incidence and mortality proportions and trends from the early 1980s by anatomic subsite (left and right colon, rectum) and sex and for several age groups, including the screening target age group, 50-74.

Conclusion: Preliminary analyses suggest that left colon and rectal cancer rates differ by sex in magnitude and trend.

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THYROID CANCER INCIDENCE TRENDS IN NEW JERSEY, 1979-2006

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Background: Thyroid cancer incidence increased during the past two decades in New Jersey and the U.S. This study investigates the incidence trends and birth cohort effects using data from the New Jersey State Cancer Registry.

Methods: A total of 15,576 invasive thyroid cancer cases were included in the analysis. Joinpoint regression was used to discern the trends by gender, race, age groups and histological types, and age-specific incidence rates by birth cohort were generated to investigate the birth cohort effects. We also examined thyroid cancer incidence by socioeconomic index.

Results: Between 1979 and 2006, the New Jersey thyroid cancer age-adjusted incidence rate increased over 300%, with a larger increase in women of 380%. The thyroid cancer rate became increasingly higher in New Jersey than in the U.S. after 1999. White men and women had higher thyroid cancer incidence than black men and women. Among men and women, respectively, thyroid cancer rates increased by 3.3% and 3.0% a year between 1979 and 1996 and by 10.9% and 8.2% a year between 1996 and 2006. Each gender and age group experienced an increase, with the steepest increases in women 60-69 years old. Incidence rates increased in most birth cohorts. The age-adjusted thyroid cancer incidence rates vary by socioeconomic index.

Conclusions: The observed increasing trends in thyroid cancer in New Jersey warrant further investigation to understand the causes of the increases and to assist in cancer control.

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SURVEILLANCE OF CANCER IN YOUNG PEOPLE IN CANADA (CYP-C): A RENEWED SYSTEM

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BACKGROUND: The Canadian Childhood Cancer Surveillance and Control Program was created in 1993 to advance knowledge regarding cancer in young people. To contribute towards cancer control in Canada, an enhanced population based surveillance system of childhood cancer has been renewed (CYP-C).

PURPOSE: Outline the rationale, current status and next steps of the surveillance system.

METHODS: The CYP-C surveillance system will include Canadian children, aged 0-14, diagnosed with a malignant cancer beginning in 1995. Information on eligible cases will be collected from diagnosis for five years. Data will be collected using a remote, internet based application. National analysis will focus on patterns of incidence and survival by diagnosis, stage, risk category and extent of disease. Time between key health care events, initial treatment plans and short and medium term outcomes will be described.

RESULTS: Approximately 850 children are diagnosed with cancer each year in Canada. Lessons learned regarding selection, engagement and implementation of data collection elements and tools will be presented. An overview of data quality and access procedures will be provided and an outline of program governance and stakeholder involvement.

CONCLUSION: This multi-centre, multi-partner program was successful in renewing and revising a childhood cancer surveillance system which will be used to develop and evaluate cancer control activities in Canada's young people.

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

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Background: This Pilot Demonstration Project is designed to demonstrate and evaluate the feasibility of performing a record linkage between the National Health Interview Survey (NHIS) of the National Center for Health Statistics (NCHS) and the Florida Cancer Data System (FCDS) databases.

Purpose: The Project will assess the feasibility of linking NCHS national population-based survey data with individual state cancer registries and to establish the logistics involved in conducting such linkages with individual state cancer registries. This linkage will provide highly enriched data for incident cancer cases who participated in the NHIS. Linking the NHIS survey participants' demographic, socio-economic, health conditions, health care utilization, health insurance, and health behaviors with the FCDS cancer incidence cases.

Methods: Human Subjects clearance has been obtained, and procedures for secure data linkage and secure transfer of data to the NCHS Research Data Center (which will serve as the data repository) have been developed. The initial linkage will use 1987 NHIS data with the entire FCDS database and will be completed by Spring 2010, with plans to expand the linkage to the other NHIS Survey years.

Implications: The ultimate goal of the proposed Pilot Study is to develop a model for conducting linkages between NCHS population-based Surveys, and the CDC National Program of Cancer Research and the National Cancer Institute-supported SEER Cancer Registries within the US.

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A FEASIBILITY STUDY IN OBTAINING PARAFFIN EMBEDDED BREAST TUMOR TISSUE FROM CALIFORNIA HOSPITALS

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The California Cancer Registry (CCR) conducted a feasibility study to ascertain whether the relationship with California hospitals could be expanded to include the acquisition of paraffin embedded breast tumor tissue. Thirteen university-based and community hospitals across the state were selected for participation. Eighty-five percent of hospitals agreed to provide specimens. One university-based hospital insisted that we apply to their Institutional Review Board (IRB). Two facilities had only biopsy tissue available on the selected patients, while two others said they could not find their selected patient's specimens, although they confirmed that those patients were diagnosed at their facilities. None of the selected facilities refused participation, but two large hospitals, one university-based, ignored multiple requests from our Administrative Assistant to speak to someone about obtaining specimens for this study. Despite this, we consider this study a success. This small study allowed the CCR to document, compare and contrast procedures for obtaining paraffin embedded breast tumor tissue by hospital type; to document costs and assess the efficiency of procedures used in the feasibility study for future activities. Our primary recommendation is that pathology departments of academic institutions, large non-academic hospitals and health care systems are informed of this effort and encouraged to enter into an agreement with the CCR to facilitate this process.

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CHILDHOOD CANCERS IN NEW YORK: WHO GETS TREATED AND/OR REPORTED BY MEMBERS OF THE CHILDREN'S ONCOLOGY GROUP (COG)?

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The Caroline Pryce Walker Conquer Childhood Cancer Act of 2008 mandates the establishment of a "national childhood cancer registry" that shall "include an actual occurrence within weeks of the date of such occurrence." In order to evaluate some of the implications of this act, we studied the current reporting of childhood cancers to the NYSCR. Of particular interest are the percent of these cancers reported by COG members; referral patterns involving all childhood cancers; and time lags of reporting.

For this study, we identified each diagnosis reported for children age zero through nineteen and included each related source. The New York members of the COG were identified from CureSearch.org, the COG's website. Cases were categorized by International Classification of Childhood Cancer, Third Edition (ICCC-3) groupings.

There were 2087 childhood cancer cases reported among New York residents for 2007-2008 diagnoses. Eighty-three percent had been reported by at least one COG member hospital. Of the remaining 346 cases, 27 had been reported through inter-state agreement and might have been seen by a COG member in a different state. The presentation will include analyses of COG representation by type of cancer, by patient characteristics, and by penetration of COG facilities. It will also include analyses of: time between diagnosis and initial contact; time between diagnosis and treatment; and time between initial contact and submission of case report to the NYSCR.

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EXPANDING THE REACH OF CANADIAN CANCER STATISTICS TO A CLINICAL AUDIENCE

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Background: The Canadian Cancer Statistics (CCS) is an annual national surveillance report geared towards researchers, health professionals, and policy makers. It provides detailed information about cancer incidence, mortality and other measures of cancer burden of the most common types of cancer in Canada.

Purpose: To expand the reach and impact of cancer surveillance information in Canada, particularly in the clinical setting.

Methods: In 2008, the Canadian Cancer Society began a mutually beneficial partnership through a memorandum of understanding with the Canadian Medical Association Journal (CMAJ). A series of peer-reviewed articles of varying lengths and cancer topics were developed by members of the CCS steering committee. Surveillance data were interpreted and presented for a broad and largely clinical audience of CMAJ.

Results: 3 peer-reviewed articles have been published to date in CMAJ through this process including short pieces on mesothelioma and childhood cancer, and a, a State of the Nation on cancer statistics in 2008. Each presented surveillance data as well as important, topic-related clinical considerations. Based on the success of these papers, the memorandum of understanding was renewed in 2009 and additional topics are currently being developed.

Conclusions: This project demonstrates how strategic partnerships can help disseminate cancer surveillance information to a broader audience.

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CANADIAN PARTNERSHIP AGAINST CANCER'S (THE PARTNERSHIP) CANCER SURVEILLANCE AND EPIDEMIOLOGY NETWORKS: KNOWLEDGE TRANSLATION AS A COMPONENT OF A PAN-CANADIAN SURVEILLANCE NETWORK ON CANCER PROJECTIONS

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Background: The pan-Canadian Cancer Projection Network will assess cancer incidence and mortality trends and will implement standardized methodologies to predict future cancer burden across the country. A knowledge translation framework was developed to address the gap between surveillance and provincial/national end-user target audiences that include decision-makers and policy-makers.

Purpose: Knowledge translation activities are being undertaken to maximize the use of surveillance cancer projection products by target audiences and ultimately increase the potential impact of network products on cancer control initiatives.

Methods: As part of the Partnership's cancer surveillance and epidemiology network initiative, a knowledge translation framework was developed and applied by respective networks. Key province-specific target audiences were identified and primary end-users were selected. Through active and on-going stakeholder engagement, the needs of each end-user were assessed and the best delivery mechanism of network results established.

Results: Collaboration with end-users helped identify what cancer projection information would be useful, as well as how and at what time this information would be best presented. Details about knowledge translation methods used, outcomes to date, and future plans will be presented.

Conclusions: Knowledge translation processes are necessary to ensure that stakeholder-specific surveillance products are relevant and informative.

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IMPROVING THE UNDERSTANDING AND STANDARDIZATION OF THE CANADIAN CANCER DATA SET

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Background: The Canadian Cancer Registry (CCR) is a dynamic administrative survey established in 1992, which contains person-oriented information on cancer incidence, mortality and stage from all thirteen provincial/territorial cancer registries (PTCRs). The demand for standardized data in Canada has intensified due to increased surveillance and research activities. Specific Canadian Council of Cancer Registries (CCCR) data elements were flagged as lacking coherence across the country. The Data and Quality Management Committee, the PTCRs and the CCR collaborated to identify variation in standards of practice in the collection and interpretation of these data elements. Purpose: 1. To document past and current PTCRs practice in order to facilitate DQMC discussions to determine if any rule and/or standard changes or further rationale to enhance clarity are required. 2. To create a document that will assist physicians, researchers and standard setters with the interpretation of national level data.

Method: Survey disseminated to PTCRs and subsequent inperson meeting to discuss and document variance.

Results: Presented as a process improvement document that will be distributed nationally to improve clarity at the PTCR level and for researchers who are interpreting this data.

Conclusions: This initiative will contribute to a more coherent and comprehensive population database in Canada allowing for expanded research and surveillance opportunities.

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NPCR-AERRO: THE MULTI-SOURCE GLOSSARY

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Background: The Centers for Disease Control and Prevention (CDC) National Program of Cancer Registries - Advancing Ecancer Reporting and Registry Operations (NPCR-AERRO) has recently developed an interactive web-based application that allows users to search and view NPCR-AERRO related glossary terms and definitions and submit comments. NPCR-AERRO's Messaging, Standards, and Vocabulary workgroup transformed a glossary into a database, with the ability to consolidate definitions from various sources into one place for each term, and designate alternate term wording (abbreviations and synonyms). The North American Association of Central Cancer Registries, Inc. (NAACCR, Inc.) does not have a consolidated glossary and has expressed interested in using the NPCR-AERRO multi-source glossary.

Purpose:. The Multi-Source Glossary provides a central location to find definitions for terms used in the workplace that combines glossaries from multiple sources with the goal to reduce misunderstanding of terms when diverse groups communicate. Methods: The glossary is a web-based tool with a SQL Server database that allows users to search for and view terms, definitions, and sources.

Results: This presentation will provide an overview of how the multi-source glossary was developed, and training on how to maximize the application.

Conclusion: The Multi-Source Glossary can have an impact on how the cancer registry community does business in the next several years.

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FROM SURVEILLANCE TO RESEARCH: A CENTRAL CANCER REGISTRY (CCR) STRIVES TO IMPROVE PARTICIPATION IN RESEARCH PROJECTS WHILE PROTECTING HUMAN SUBJECTS

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Background: The Missouri Cancer Registry (MCR), like many CCRs funded by CDC's National Program of Cancer Registries (NPCR), has as its primary focus activities related to public health surveillance. After meeting NAACCR certification standards and NPCR requirements since 1998, MCR embarked on an NCIfunded case-control study of breast cancer survivors with Washington University in St. Louis. The participation rate for controls was 69%; the rate for cases was < 35%.

Purpose: To improve case participation in future studies by: 1) examining participation of target groups (older women; inner city and rural women; African-American women); and 2) identifying barriers to participation.

Methods: We examined study records for all 4,171 women who met eligibility criteria for the period 1/1/07 through 5/31/09. Results: Of women who met initial eligibility requirements, 151(3.8%) were excluded due to death, disability or inability to speak English. Of the 4,020 women who remained eligible, 1,200 (30%) signed all 3 forms; 1,727 (43%) refused to participate; 323 (8%) could not be contacted; and 770 (19%) did not complete any/all forms. Comparing women who participated with those who refused, women age 25-49 were over-represented (27% v 13%) while women age ≥ 65 and African-American women were under-represented (29% v 52%; 6% v 11%).

Conclusions: Target populations were under-represented. Primary barriers were lack of accurate current address and classification as a high-risk study.

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NAACCR 2010 CONFERENCE final program









Québec City, QC, Canada June 19 - 25, 2010

Hilton Québec and Québec City Convention Centre

