Welcome and Acknowledgments

NPCR Planning Committee
- Rana Bayakly, Nathan Husky, Debbie Lemons, Anne Llewellyn
- Deirde Rogers, Martin Whiteside, Melanie Williams
- Linda Mulvihill, Joan Phillips

Sponsors
- American Cancer Society
- National Cancer Registrars Association
- Lance Armstrong Foundation

Posters
Programs
CSB staff
This is National Cancer Registrars Week

National Cancer Registrars Week
April 13–17, 2009

Cancer Registrars...
Rock Solid

1340 Braddock Place | Suite 203 | Alexandria, VA 22314 | 703.299.6640 | www.ncra-usa.org
Value of National Cancer Surveillance

- Guide planning, implementation, and evaluation of cancer control programs at a national, local and state level
- Describe cancer patterns in special populations and investigate rare cancers
- Identify and document disparities
- Provide data for prioritization of health resources
- Advance clinical, epidemiologic, and health services research
United States Cancer Statistics

- National cancer statistics
- 96% Population Coverage
- Collaboration, CDC, NCI, NAACCR
- State, regional, and national data
- Rates for whites, blacks, Asians/Pacific Islanders (A/PI), American Indians/Alaska Natives (AI/AN), Hispanics, and children

http://www.cdc.gov/uscs
Annual Report to the Nation

- Update of death and incidence cancer rates
- 2008 report
  - First time report documented decline in cancer incidence
  - Special focus on tobacco-related cancers
  - State and regional differences in lung cancer trends
  - Collaboration between CDC, NCI, North American Association of Central Cancer Registries (NAACCR), ACS

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**Background**

The American Cancer Society, the Centers for Disease Control and Prevention (CDC), the National Cancer Institute (NCI), and the North American Association of Central Cancer Registries (NAACCR) collaborate annually to provide updated information on cancer occurrence and trends in the United States. This year’s report includes trends in lung cancer incidence and death rates, tobacco use, and tobacco control by state of residence.

**Methods**

Information on invasive cancers was obtained from the NCI, CDC, and NAACCR and information on mortality from the CDC’s National Center for Health Statistics. Annual percentage changes in the age-standardized incidence and death rates (2000 US population standard) for all cancers combined and for the top 15 cancers were estimated by joinpoint analysis of long-term (1975–2005) trends and by least squares linear regression of short-term (1996–2005) trends. All statistical tests were two-sided.

**Results**

Both incidence and death rates from all cancers combined decreased statistically significantly (P < .05) in men and women overall and in most racial and ethnic populations. These decreases were driven largely by declines in both incidence and death rates for the three most common cancers in men (lung, colorectum, and prostate) and for two of the three leading cancers in women (breast and colorectum), combined with a leveling off of lung cancer death rates in women. Although the national trend in female lung cancer death rates has stabilized since 2003, after increasing for several decades, there is prominent state and regional variation. Lung cancer incidence and death rates among women increased in 18 states, 16 of them in the South or Midwest, where, on average, the prevalence of smoking was higher and the annual percentage decrease in current smoking among adult women was lower than in the West and Northeast. California was the only state with decreasing lung cancer incidence and death rates in women.

**Conclusions**

Although the decrease in overall cancer incidence and death rates is encouraging, large state and regional differences in lung cancer trends among women underscore the need to maintain and strengthen many state tobacco control programs.

J Natl Cancer Inst 2006;100:1672-1694
MMWR Surveillance Summary

- Collaboration with Office of Smoking and Health
- Findings emphasize need for ongoing surveillance
  - Identify populations at greatest risk
  - Evaluate effectiveness of targeted tobacco control programs and policies
Monitoring Success of Public Health Programs

- Agency for Healthcare Research and Quality’s National Healthcare Quality Report
  - NPCR contributes data for three cancer measures for stage at diagnosis
  - [http://www.ahrq.gov/qual/qrdr07.htm](http://www.ahrq.gov/qual/qrdr07.htm)
Contributions to Science and Research

HPV associated cancers

◆ Baseline data to measure the impact of HPV vaccine and cervical cancer screening programs

◆ More HPV-associated cancers occur in the cervix than any other site – about 10,800 per year.

◆ About 7,400 potentially HPV-associated cancers of the oral cavity and oropharynx per year
Cancers among American Indians and Alaskan Natives: 1999-2004

- Indian Health Service data linked to cancer surveillance data
- Incidence rates for cancers of the stomach, liver, kidney, gallbladder, nasopharynx, and cervix were higher among AI/AN persons compared to non-Hispanic whites.
- For AI/AN persons overall, breast, colorectum, cervix and prostate cancers were diagnosed at more advanced stages than in non-Hispanic whites.
Other Publications


Cancer Surveillance Data

◆ Division is challenged by:
  ● Internal and external partners
  ● Researchers
  ● Federal legislators

◆ To improve:
  ● Completeness
  ● Timeliness

◆ And Expand
  ● Use of data for research, health measures
  ● Type of data collected and analyzed
HHS and CDC Collaborations

- National Breast and Cervical Early Detection Program
- National Comprehensive Cancer Control Program
- Office of Smoking and Health (NCCDPHP)
- Office of Women’s Health
- Division of Sexually Transmitted Disease Prevention
- Division of Oral Health
- National Center for Environmental Health
- National Center for Health Statistics
- National Cancer Institute
- Agency for Health Care Research and Quality
- National Center for Public Health Informatics
- Agency for Toxic Substance and Disease Registry
- Indian Health Service
External Collaborations

- National Cancer Registrars Association
- American Cancer Society
- American Joint Committee on Cancer
- Central Brain Tumor Registry of the United States
- College of American Pathologists
- North American Association of Central Cancer Registries
Objective:

- Increase the number of new uses of surveillance data to address current and newly emerging issues

Strategy:

- Develop and communicate a Data Release and Data Use Plan
Data Release and Data Use Plans

- Development of plans will be a multi-step process
- Data quality component
  - Expand use of data variables through quality reviews and analyses
- Prepare for more data analyses outside of the Division and outside of CDC
- Communicate with Programs
Data Release and Data Use Plans

- Establish data use categories and procedures that everyone is aware of
  - What type of data use is routine?
  - What type of data use requires notification of registries?
  - What type of data use requires additional permission?
  - What are procedures for each?
Factors to Consider for Data Requests

- What type of data (aggregated, individual record level) is being requested
- Published in USCS previously
- County, State, or National level
- Will it be published
- Who is conducting analyses
- Other concerns?
- Sample data requests from this year
  - Decisions made on a case by case basis based on general guidelines
  - Can we categorize and establish standard practices?
Data for Surveillance Use:
NPCR aggregated data & published in USCS

◆ Example
  ● Request from ACS to provide aggregated cancer case counts by selected primary sites and age for global burden of cancer
    ◆ No states were identified
    ◆ Data would be aggregated with other North American countries

◆ State permission?
  ● Not sought

◆ Appropriate attribution?
  ● Yes
Data for Surveillance Use:
NPCR aggregate & not published in USCS

◆ Example
  ● Breast cancer stage measure for GPRA/PART measure
    ◆ No states were identified
    ◆ Stage data are not presented in USCS

◆ State permission?
  ● Not sought

◆ Appropriate attribution?
  ● Yes
Data for Surveillance Use: state-level data & published in USCS

- Example
  - MMWR on tobacco-related cancers (state-level maps)
    - Different data presentation for data presented in tabular format in USCS

- State permission?
  - Not sought, but concept was discussed prior to publication at PD meeting

- Appropriate attribution?
  - Yes
Data for Surveillance Use: state-level data & not published in USCS

◆ Example
  ● Request from Program Director to provide distribution of stage data by state
    ◆ For use to test regression modeling to assess cancer burden patterns
      • Test using state-level data to determine applicability
      • Final model and presentation would use county-level data in Tennessee

◆ State permission?
  ● Yes, via blast e-mail

◆ Appropriate attribution?
  ● Yes
Data for Research Manuscripts

- Division of Cancer Prevention and Control
  - Proposals presented to NPCR Data Users Group
    - Chair: Umed Ajani
    - Representation from each branch
    - If input is desirable from Programs the topic is presented to the Scientific Workgroup
    - County level data – special permission
  - Next steps – other CDC Divisions

- NPCR-funded states, NCI, and ACS
  - Proposals presented to NPCR Small Data Release Workgroup
    - Chair: Reda Wilson
  - Next steps – external researchers
Updates
Data Items - 2010
for NAACCR Volume II, Required Status Table

- NPCR evaluation of existing and new data items
  - Draft of initial proposed items to NPCR Scientific Working Group
  - Developing revised draft combination of required, required as available or supplemental/recommended list of variables
  - New draft proposal to SWG and NPCR registries
    - Conference call with SWG
    - Conference call with NPCR registries
- NPCR information to NAACCR by end of May
Coordinated Call for Data

- **2009 Coordinated Data Submission**
  - all registries submitted 2007 data to CDC in Jan. 2009
  - May need to improve process – forms for example
  - Would like feedback from states – will provide more details and timelines soon
  - Contact: Reda Wilson df08@cdc.gov
Coordinated Call for Data
NPCR-CSS 2010 Timeline
Diagnosis Years: 1995-2008

<table>
<thead>
<tr>
<th>Data Submission</th>
<th>Submission Dates</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diagnosis years 1995-2007 all programs</td>
<td>11/1/09 – 12/1/09</td>
</tr>
<tr>
<td>Diagnosis year 2008 all programs</td>
<td>1/1/10 – 2/1/10</td>
</tr>
</tbody>
</table>
Number of cases from VA reported by year of diagnosis

- Registry A
- Registry B
- Registry C
- Registry D
- Registry E
- Registry F
- Registry G
2009 VHA Data Request Submission:

- 40 registries sent in the SAS dataset with VHA data
- 4 registries indicated that they received all VHA cases
- 7 states reported less than 10 cases for 2006
- 16 registries about level or increased reporting
- 23 registries had decreased reporting
- Further analyses underway
Program Evaluation Instrument

- Survey from May 4 – May 15
- Web-based survey
- Conducted every two years
- Contractor: Macro, Inc.
- Few changes from previous survey
- Results will be on Web following survey analysis
- Contact: Jean Ewing  jfe7@cdc.gov
Linkage with National Death Index

◆ Important priority for NPCR
  • Only about 1/3 of registries have linked and submitted data

◆ Training at NAACCR meeting

◆ New CSB contacts:
  • Umed Ajani  uajani@cdc.gov
  • Cheryll Thomas  CCTThomas@cdc.gov
Project contacts:

◆ INCA- Interactive Cancer Atlas
  ◆ A web based, interactive GIS application that generates user defined maps
◆ Web-based Geoserver
  ◆ To provide geocoding capacity to all states
  ◆ To standardize geocoding methods and address verification.
◆ Analysis of cancer incidence and county level socioeconomic measures
◆ Evaluation of census tract information for data quality as provided in NPCR dataset for use in SES analyses
◆ Contact Simple Singh  sdsingh@cdc.gov or Umed Ajani  uajani@cdc.gov
Project Contacts:

◆ Primary Payer Project
  ● Goal: Evaluate the validity and reliability of Primary Payer at Diagnosis
  ● Participating states: Massachusetts, Florida, Oklahoma, and Georgia
  ● Contact: Castine Verrill hhe2@cdc.gov

◆ Electronic Pathology (ePath) Reporting
  ● PHINMS installed and tested in 22 states
  ● Testing completed
  ● LabCorp to begin implementation with states
  ● Contact: Sandy Thames SThames@cdc.gov
Healthcare Information and Management Systems Society (HIMSS) – Integrating the Healthcare Enterprise (IHE) Collaboration

- Healthcare industry and national standards
- Present cancer registry & pathology use-cases/needs
- Foster working relationships with software vendors
- Goal: communicate needs to greater healthcare community & engage partners in implementation activities

Contact: SThames@cdc.gov
The Future

- Melanoma monograph – MSaraiya@cdc.gov
- Camp Lejeune Study – ATSDR
- Polycythemia Vera project
- Survival analysis – NPCR
- Environmental Public Health Tracking