

NORTH AMERICAN ASSOCIATION
OF CENTRAL CANCER REGISTRIES, INC.

**NAACCR Annotated Bibliography
of Research and Publications:
Multi-Registry Cancer
Incidence and Mortality Studies
in the United States and Canada**

February 2012



Acknowledgements

North American Association of Central Cancer Registries, Inc. (NAACCR) would like to thank its members, the population-based central cancer registries throughout North America, for submission of their cancer incidence data to NAACCR. Through voluntary participation in the annual NAACCR Call for Data, incidence data from up to 78 cancer registries in the United States and Canada are evaluated each year for timeliness, accuracy, and completeness. The number of registries meeting the NAACCR data quality standards for inclusion in an aggregated database grows each year. NAACCR staff, NAACCR committees, and individual researchers use the aggregated database, called CINA Deluxe, to conduct surveillance and epidemiologic research and to continually evaluate the comparability and quality of the data. The research and publications generated from these analyses reflect the efforts of many NAACCR volunteers representing a broad spectrum of cancer registries and cancer surveillance organizations in the United States and Canada. We appreciate the dedication of these professionals to use this valuable national resource to study the cancer burden in North America and to enhance our understanding of risk, etiology, and diversity in cancer occurrence.

Copies of most NAACCR publications are available on the NAACCR website and may be downloaded free of charge at www.naacrr.org.

Further information can be obtained by contacting the NAACCR Executive Office at 2121 West White Oaks Drive, Suite B, Springfield, Illinois 62704-7412 or (217) 698-0800 or info@naacrr.org.

Suggested citation: Hinds RA (ed). *NAACCR Annotated Bibliography of Research and Publications: Multi-Registry Cancer Incidence and Mortality Studies in the United States and Canada*. Springfield, IL: North American Association of Central Cancer Registries, February 2012.

We would like to acknowledge the Centers for Disease Control and Prevention (CDC) for staff support under cooperative agreement 5U58DP001803 awarded to NAACCR. The contents are the sole responsibility of the authors and do not necessarily represent the official views of the CDC.

Report Design: The Scientific Consulting Group, Inc.

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Statistical Monographs and Other Data Reports

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Howe HL (ed). **Cancer Incidence in North America, 1988-1991.** Sacramento, CA: North American Association of Central Cancer Registries, April 1995.

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Howe HL. **Recommendations for Public Use Files of National Cancer Data.** Sacramento, CA: North American Association of Central Cancer Registries, November 1997.

Howe HL. **Report of the CINA Deluxe Beta Test Results.** Sacramento, CA: North American Association of Central Cancer Registries, March 2000.

Chen VW, Howe HL, Wu XC, Hotes J, Correa C (eds). **Cancer in North America, 1992-1996, Volume One: Incidence.** Sacramento, CA: North American Association of Central Cancer Registries, April 2000.

Chen VW, Howe HL, Wu XC, Hotes J, Correa C (eds). **Cancer in North America, 1992-1996, Volume Two: Mortality.** Sacramento, CA: North American Association of Central Cancer Registries, April 2000.

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Chen VW, Howe HL, Wu XC, Hotes J, Correa C (eds). **Cancer in North America, 1993-1997, Volume Two: Mortality.** Sacramento, CA: North American Association of Central Cancer Registries, April 2000. [www.naaccr.org/DataandPublications/PreviousCINAPubs.aspx. Last accessed February 8, 2012.]

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Wu XC, Hotes J, Fulton JP, Cormier M, Correa C, McLaughlin CC, Kosary C, Howe HL, Chen VW (eds). **Cancer in North America, 1995-1999, Volume Three: NAACCR Combined Cancer Incidence Rates.** Springfield, IL: North American Association of Central Cancer Registries, April 2002. [www.naaccr.org/DataandPublications/PreviousCINAPubs.aspx. Last accessed February 8, 2012.]

Hotes J, Wu XC, McLaughlin C, Roney D, Lake A, Cormier M, **Chen VW**, Howe HL, Holowaty E, Fulton JP (eds). **Cancer in North America, 1996-2000. Volume One: Incidence.** Springfield, IL: North American Association of Central Cancer Registries, April 2003. [www.naaccr.org/DataandPublications/PreviousCINAPubs.aspx. Last accessed February 8, 2012.]

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NAACCR. **2002 NAACCR Workshop Report: Data Security and Confidentiality.** Springfield, IL: North American Association of Central Cancer Registries, May 2002. 56 pp. [www.naaccr.org/DataandPublications/EpiReports.aspx. Last accessed February 8, 2012.]

Howe HL, Carozza S, O'Malley C, Dolecek TA, Finch JL, Kohler B, West D, Liu L, Schymura MJ, Williams M, Abe T, Agovino P, Chen VW, Firth R, Harkins D, Hotes J, Lake A, Roney D, Suarez L (eds). **Cancer Incidence in U.S. Hispanic/Latinos, 1995-2000.** Springfield (IL): North American Association of Central Cancer Registries, December 2003. [www.naaccr.org/DataandPublications/PreviousCINAPubs.aspx. Last accessed February 8, 2012.]

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Ellison JH, Wu XC, Howe HL, McLaughlin C, Lake A, Firth R, Sullivan SK, Roney D, Cormier M, Leonfellner S, Kosary C (eds). **Cancer in North America, 1998-2002. Volume Four: Cancer Incidence in U.S. Hispanic/Latino Populations.** Springfield, IL: North American Association of Central Cancer Registries, April 2005. [www.naaccr.org/DataandPublications/PreviousCINAPubs.aspx. Last accessed February 8, 2012.]

Phillips JL (ed). **Summary Stage: Data Effects of the Changes in 2000.** Springfield, IL: North American Association of Central Cancer Registries, December 2003. [www.naaccr.org/DataandPublications/DataQuality.aspx. Last accessed February 9, 2012.]

The Surveillance, Epidemiology, and End Results (SEER) Program developed SEER Summary Stage 2000 (SSS2000) to address issues related to directly coded summary stage and discrepancies in summary stage classification being identified between direct and indirect coding procedures. All of the changes to the extent of disease coding system (EOD) that occurred between 1977 and 2000 were incorporated into the modified SSS2000. The *Summary Stage: Data Effects of the Changes in 2000* was written for registries that coded SSS2000 directly. Selection of cancer sites to include in the study was based on: (1) changes between SSS1977 and SSS2000 (colon cancer had none and thus was excluded); (2) completeness of staging information (melanoma was excluded due to expected high frequency of missing data from records of diagnosis and treatment occurring outside the registry's reporting infrastructure); and (3) absence of other external factors that might affect time trends (prostate cancer was excluded based on regional variation in screening

affecting the stage trends). As a result, invasive carcinomas of the lung and female breast were selected for the study. Cases were randomly sampled from three volunteer central registries. The change from SSS1977 to SSS2000 is only one factor affecting longitudinal use of the two Summary Stage coding systems. Although the Kappa statistics showed good-to-excellent agreement beyond chance between the registry records and the reabstracted SSS1977, all three central registries did have some discrepancies. The abstractors in the study often were required to assign codes based on a strict interpretation of SSS1977 that was inconsistent with their own experience. Finally, few central registries provided extensive field training in the coding of SSS1977.

Greenlee R. **Evaluation of Methods to Estimate & Compare Race/Ethnicity Specific Cancer Incidence Rates Using Combined Central Cancer Registry Data.** Springfield, IL: North American Association of Central Cancer Registries, June 2004. [www.naaccr.org/DataandPublications/EpiReports.aspx. Last accessed September 9, 2010.]

There is considerable interest in routinely reporting cancer incidence data for racial/ethnic groups, in addition to white or black, as part of general surveillance summaries and site-specific investigations. Such reports can detect disparities in magnitude, severity, or trends of disease, and can help shape group-specific prevention and control strategies. There are concerns, however, with the quality of rate estimates for racial/ethnic groups using multi-registry aggregated data, including geographic variation in the accuracy of race-specific population counts and in the classification of incident cancer cases by race. When selecting registries to include in group-specific rates, a fundamental tension exists between interests of accuracy and interests of precision and comparability. A preferred approach has not been identified, and different strategies have been employed in recent analyses of Cancer in North America (CINA) data. Based on descriptive studies of ovarian and breast cancer, this project evaluates the influence of alternative geographic selection strategies on race/ethnicity-specific incidence rates, confidence intervals, and interracial comparisons. Changes in age-specific and age-adjusted rates, as well as rates stratified by tumor behavior and summary stage, are quantified. Rates and rate ratios are compared statistically. The working hypothesis is that there will not be meaningful differences under the various approaches, and that study inferences will remain unchanged.

Athas W. **Quality Assessment Of CINA Deluxe, 1995-1999 Morphology Data.** Springfield, IL: North American Association of Central Cancer Registries, January 2004. [www.naaccr.org/DataandPublications/DataQuality.aspx. Last accessed February 9, 2012.]

A quality assessment study of *CINA Deluxe, 1995-1999 Morphology Data* was conducted for all invasive cancers and *in situ* breast cancer. Using SEER-Stat, ICD-O-2 histology and tumor grade data from 14 participating National Program for Cancer Registries (NPCR) registries were collectively compared to those from seven Surveillance, Epidemiology, and End Results (SEER) Program registries selected to reflect the age, gender, and racial structure of the NPCR case population. A total of 2,040,435 microscopically confirmed cancers were available for analysis. Principal findings were:

- Overall microscopic confirmation rates were 94% for both NPCR and SEER. With the exception of leukemia, site-specific frequencies of microscopic confirmation were similar for NPCR and SEER.
- NPCR and SEER each coded 0.5% of all cancers combined to Neoplasm Not Otherwise Specified (NOS) and 3% to Carcinoma NOS. NPCR coded a comparatively higher percentage of total cancers as Squamous cell carcinoma NOS and Adenocarcinoma NOS.
- Site-specific frequency distributions of histologic group were similar for NPCR and SEER.
- Site-specific frequency distributions of common histologic type were similar for NPCR and SEER, particularly for the major cancers.
- The site-specific frequency of tumor grading was similar for NPCR and SEER, with the exception of *in situ* breast cancer.
- Site-specific frequency distributions of tumor grade were similar for NPCR and SEER, and largely indistinguishable for many of the commonly graded cancers, including prostate, urinary bladder, colon, rectum, corpus, and invasive breast.

Howe HL. **Evaluation of NHIA Submissions for 1997-2001.** Springfield, IL: North American Association of Central Cancer Registries, January 2005. [www.naaccr.org/DataandPublications/EpiReports.aspx. Last accessed February 9, 2012.]

In December 2003, the NAACCR Call for 1995-2001 Data required that all submitting registries run the NAACCR Hispanic Identification Algorithm (NHIA) on the file and the 5 years, 1997-2001, were used to evaluate the outcomes of the algorithm in registries throughout the United States. This evaluation was conducted in anticipation of NAACCR publishing rates for Latinos annually, beginning with the December 2004 NAACCR Call for Data submission for the 2005 *Cancer in North America*. Fifty-one registries submitted a data file and only four did not run NHIA. For 26 registries,

this was the first time that NHIA had been run. Of the 47 registries that ran NHIA, four registries encountered execution problems. Among the 43 registries that correctly ran NHIA, seven registries had rates that were inconsistent with rates produced by other registries. Among these seven, data from two registries produced rates that were too low. Neither registry had attained the NAACCR data quality standard for completeness (i.e., at least 90 percent), which may contribute to the lower incidence rates. Data from five registries produced rates that appeared to be too high, three of the states with extremely small numbers of Latino cases, which apparently were not able to produce a stable estimate, even over a 5-year period. NHIA is a useful and generally reliable method to enhance the ethnic identification of the U.S. Latino population. NHIA will continue to be evaluated to improve the validity of indirect assignment of a Latino ethnicity.

Howe HL, Jamison M, Havener L, Chen VW, Ries L, et al. **Site-Specific Comparison of Summary Stage 1977 and Summary Stage 2000 Coding.** Springfield, IL: North American Association of Central Cancer Registries, Inc. November 2005. [www.naacr.org/DataandPublications/DataQuality.aspx. Last accessed February 9, 2012.]

This assessment uses data from the Surveillance, Epidemiology, and End Results (SEER) Program to examine selected site-specific impacts for the most common cancer types of all cases diagnosed in 1998-2001 where differences in indirect assignment to either a summary stage 1977 or a summary stage 2000 code would occur using the more detailed extent of disease coding system (EOD) as a basis for staging. Cases were indirectly coded to summary stage twice using EOD: once based on the 1977 rules and the second based on the 2000 rules.

Havener LA. **The 2005 Summary of Quality Assessments of CINA Deluxe.** Springfield, IL: North American Association of Central Cancer Registries, Inc. February 2006. [www.naacr.org/DataandPublications/DataQuality.aspx. Last accessed February 9, 2012.]

Data used for cancer incidence statistics are reviewed annually and certified when they meet NAACCR standards for high-quality incidence data. However, as uses of the data submitted to NAACCR expand beyond calculation of incidence statistics and data files are made available to researchers for analytic and surveillance research, the need to expand data evaluation has become apparent. Therefore, all researchers granted access to use NAACCR's CINA Deluxe are asked to provide a report of their review of the quality of the file as it pertains to their proposed project.

In addition, staff conduct *ad hoc* assessments of CINA Deluxe regarding data elements that have suspected or potential data quality concerns that could affect information of interest to the membership. This report includes summaries from two quality assessment reviews of the Cancer in North America (CINA) Deluxe dataset.

Ellison JH, Wu XC, McLaughlin C, Lake A, Firth R, Cormier M, Leonfellner S, Carozza SE, Roney D, Howe HL, Kosary C (eds). **Cancer in North America, 1999-2003. Volume One: Incidence.** Springfield, IL: North American Association of Central Cancer Registries, May 2006. [www.naaccr.org/DataandPublications/PreviousCINAPubs.aspx. Last accessed February 8, 2012.]

Ellison JH, Wu XC, McLaughlin C, Lake A, Firth R, Cormier M, Leonfellner S, Carozza SE, Roney D, Howe HL, Kosary C (eds). **Cancer in North America, 1999-2003. Volume Two: Mortality.** Springfield, IL: North American Association of Central Cancer Registries, May 2006. [www.naaccr.org/DataandPublications/PreviousCINAPubs.aspx. Last accessed February 8, 2012.]

Ellison JH, Wu XC, McLaughlin C, Lake A, Firth R, Cormier M, Leonfellner S, Carozza SE, Roney D, Howe HL, Kosary C (eds). **Cancer in North America, 1999-2003. Volume Three: Combined.** Springfield, IL: North American Association of Central Cancer Registries, May 2006. [www.naaccr.org/DataandPublications/PreviousCINAPubs.aspx. Last accessed February 8, 2012.]

Ellison JH, Wu XC, McLaughlin C, Lake A, Firth R, Cormier M, Leonfellner S, Carozza SE, Roney D, Howe HL, Kosary C (eds). **Cancer in North America, 1999-2003. Volume Four: Hispanic/Latino.** Springfield, IL: North American Association of Central Cancer Registries, May 2006. [www.naaccr.org/DataandPublications/PreviousCINAPubs.aspx. Last accessed February 8, 2012.]

Wu XC, McLaughlin C, Lake A, Firth R, Leonfellner S, Cormier M, Cardinez C, Kosary C, Roney D, Howe HL. **Cancer in North America, 2000-2004. Volume One: Incidence.** Springfield, IL: North American Association of Central Cancer Registries, May 2007. [www.naaccr.org/DataandPublications/PreviousCINAPubs.aspx. Last accessed February 8, 2012.]

Wu XC, McLaughlin C, Lake A, Firth R, Leonfellner S, Cormier M, Cardinez C, Kosary C, Roney D, Howe HL. **Cancer in North America, 2000-2004. Volume Two: Mortality.** Springfield, IL: North American Association of Central Cancer Registries, May 2007. [www.naaccr.org/DataandPublications/PreviousCINAPubs.aspx. Last accessed February 8, 2012.]

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Wu XC, McLaughlin C, Lake A, Firth R, Leonfellner S, Cormier M, Cardinez C, Kosary C, Roney D, Howe HL. **Cancer in North America, 2000-2004. Volume Four: Hispanic/Latino.** Springfield, IL: North American Association of Central Cancer Registries, May 2007. [www.naaccr.org/DataandPublications/PreviousCINAPubs.aspx. Last accessed February 8, 2012.]

Zeig-Owens R, Knowlton R, Gershman ST, Howe HL. **CINA Highlights of Cancer Incidence and Mortality in the United States and Canada, 2000-2004.** Springfield, IL: North American Association of Central Cancer Registries, October 2007. [www.naaccr.org/DataandPublications/PreviousCINAPubs.aspx. Last accessed February 9, 2012.]

The purpose of this report is to present the highlights of both cancer incidence and mortality data from the Cancer in North America report for 2000-2004. This report includes information on the more common cancers that occur in Canada and the United States, such as female breast, prostate, lung and bronchus, and colon. There is also discussion of some cancers that occur at lower rates, such as melanoma, cervical cancer, and testicular cancer. Incidence and death rates for males and females for these cancers are compared between the two countries.

Havener LA. **The 2007 Summary of Quality Assessments of CINA Deluxe.** Springfield, IL: North American Association of Central Cancer Registries, Inc. September 2007. [www.naaccr.org/DataandPublications/DataQuality.aspx. Last accessed February 9, 2012.]

Data used for cancer incidence statistics are reviewed annually and certified when they meet NAACCR standards for high-quality incidence data. However, as uses of the data submitted to NAACCR expand beyond calculation of incidence statistics and data files are made available to researchers for analytic and surveillance research, the need to expand data evaluation has become apparent. Therefore, all researchers granted access to use the NAACCR analytic files, referred to as CINA Deluxe, are asked to provide a report of their review of the quality of the file as it pertains to their proposed project. In addition, staff conduct *ad hoc* assessments of CINA Deluxe regarding data elements that have suspected or potential data quality concerns that could affect information

of interest to the membership. This report includes summaries from quality assessment reviews of the CINA Deluxe dataset as well as reviews from researchers.

Howe HL, Lake A, Firth R, Lehnerr M, Bayakly R, Copeland G, Wu XC, Stroup A, Roney D (eds). **Cancer in North America, 2001-2005. Volume One: Combined Cancer Incidence for the United States and Canada.** Springfield, IL: North American Association of Central Cancer Registries, Inc. May 2008. [www.naaccr.org/DataandPublications/PreviousCINAPubs.aspx. Last accessed February 9, 2012.]

Howe HL, Lake A, Firth R, Lehnerr M, Bayakly R, Copeland G, Wu XC, Stroup A, Roney D (eds). **Cancer in North America, 2001-2005. Volume Two: Registry-Specific Cancer Incidence in the United States and Canada.** Springfield, IL: North American Association of Central Cancer Registries, Inc. May 2008. [www.naaccr.org/DataandPublications/PreviousCINAPubs.aspx. Last accessed February 9, 2012.]

Howe HL, Lake A, Firth R, Lehnerr M, Bayakly R, Copeland G, Wu XC, Stroup A, Roney D (eds). **Cancer in North America, 2001-2005. Volume Three: Registry-Specific Cancer Mortality in the United States and Canada.** Springfield, IL: North American Association of Central Cancer Registries, Inc. May 2008. [www.naaccr.org/DataandPublications/PreviousCINAPubs.aspx. Last accessed February 9, 2012.]

Copeland G, Lake A, Firth R, Lehnerr M, Bayakly R, Wu XC, Stroup A, Russell C, Schymura M, Hofferkamp J, Kohler B (eds). **Cancer in North America: 2002-2006. Volume One: Combined Cancer Incidence for the United States and Canada.** Springfield, IL: North American Association of Central Cancer Registries, Inc. June 2009. [www.naaccr.org/DataandPublications/PreviousCINAPubs.aspx. Last accessed February 9, 2012.]

Copeland G, Lake A, Firth R, Lehnerr M, Bayakly R, Wu XC, Stroup A, Russell C, Schymura M, Hofferkamp J, Kohler B (eds). **Cancer in North America: 2002-2006. Volume Two: Registry-Specific Cancer Incidence in the United States and Canada.** Springfield, IL: North American Association of Central Cancer Registries, Inc. June 2009. [www.naaccr.org/DataandPublications/PreviousCINAPubs.aspx. Last accessed February 9, 2012.]

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Copeland G, Lake A, Firth R, Bayakly R, Wu XC, Stroup A, Russell C, Boyuk K, Niu X, Schymura M, Hofferkamp J, Kohler B (eds). **Cancer in North America: 2003-2007. Volume One: Combined Cancer Incidence for the United States and Canada.** Springfield, IL: North American Association of Central Cancer Registries, Inc. May 2010. [www.naaccr.org/DataandPublications/PreviousCINAPubs.aspx. Last accessed February 9, 2012.]

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Copeland G, Lake A, Firth R, Wohler B, Wu XC, Stroup A, Russell C, Boyuk K, Niu X, Schymura MJ, Hofferkamp J, Kohler B (eds). **Cancer in North America: 2004-2008. Volume One: Combined Cancer Incidence for the United States and Canada.** Springfield, IL: North American Association of Central Cancer Registries, Inc. May 2011. [www.naaccr.org/DataandPublications/CINAPubs.aspx. Last accessed February 9, 2012.]

Copeland G, Lake A, Firth R, Wohler B, Wu XC, Stroup A, Russell C, Boyuk K, Niu X, Schymura MJ, Hofferkamp J, Kohler B (eds). **Cancer in North America: 2004-2008. Volume Two: Registry-Specific Cancer Incidence in the United States and Canada.** Springfield, IL: North American Association of Central Cancer Registries, Inc. May 2011. [www.naaccr.org/DataandPublications/CINAPubs.aspx. Last accessed February 9, 2012.]

Copeland G, Lake A, Firth R, Wohler B, Wu XC, Stroup A, Russell C, Boyuk K, Niu X, Schymura MJ, Hofferkamp J, Kohler B (eds). **Cancer In North America, 2004-2008. Volume Three: Registry-Specific Cancer Mortality in the United States and Canada.** Springfield, IL: North American Association of Central Cancer Registries, Inc. September 2011. [www.naaccr.org/DataandPublications/CINAPubs.aspx. Last accessed February 9, 2012.]

Research Reports

Howe HL. **Population-based cancer registries in the United States.** In: Howe HL (ed). *Cancer Incidence in North America, 1988-1990*. Springfield, IL: North American Association of Central Cancer Registries, April 1994. [www.naaccr.org/DataandPublications/EpiReports.aspx. Last accessed February 9, 2012.]

Using information from *Cancer Incidence in the United States, 1988-1989* and a telephone survey of non-participating registries that were operational in 1988, administrative and descriptive analyses were conducted. Common features among all U.S. registries were presented as were some distinguishing characteristics.

Roffers SD. **Case completeness and data quality assessments in central cancer registries and their relevance to cancer control.** In: Howe HL (ed). *Cancer Incidence in North America, 1988-1990*. Springfield, IL: North American Association of Central Cancer Registries, April 1994. [www.naaccr.org/DataandPublications/DataQuality.aspx. Last accessed February 9, 2012.]

This is a report of the activities of the Cancer Surveillance and Control Program of the Public Health Institute in association with the American Association of Central Cancer Registries.

Chen VW. **Should we or shouldn't we compare cancer incidence rates among registries?** In: Howe HL (ed). *Cancer Incidence in North America, 1988-1991*. Sacramento, CA: North American Association of Central Cancer Registries, April 1995, pp V-1 - V-7. [www.naaccr.org/DataandPublications/DataQuality.aspx. Last accessed February 9, 2012.]

A frequent question addressed to central cancer registries is how local rates compare with the national average. Before performing a comparative analysis, an assessment of data comparability and appropriateness of comparisons must be conducted. This article discusses the importance of case definition, case ascertainment completeness, resolution of duplicate tumor reports, missing information on reported cases, and the comparability of populations with regard to age, race, cancer screening participation, prevalence of risk factors, and urbanicity in interpreting such comparative analyses.

Fulton JP and Howe HL. **Evaluating the incidence-mortality ratios in estimating completeness of cancer registration.** In: Howe HL (ed). *Cancer Incidence in North America, 1988-1991*. Sacramento, CA: North American Association of Central Cancer Registries, April 1995. [www.naaccr.org/DataandPublications/DataQuality.aspx. Last accessed February 9, 2012.]

This article describes the method for assessing completeness of cancer registration across central cancer registries in North America. Several cancer types were selected representing differences in the degree of difficulty in case reporting. The incidence-mortality ratios broadly reflected known differences in the difficulty in achieving complete case ascertainment. However, substantial variances in these ratios were evident among Surveillance, Epidemiology, and End Results (SEER) Program registries, known for superb case completeness suggesting real differences in the incidence-mortality ratio may exist among central cancer registries in North America. Therefore, the ratios should not be used to compute estimates for the absolute completeness of cancer registration, but they can be helpful in the evaluation of case completeness in local areas.

Chen VW, Wu XC, Andrews PA, Howe HL, Fulton JP, Correa CN, Roffers SD. **Comparative analysis of lung cancer incidence rates in the United States.** In: Howe HL, et al. (eds). *Cancer Incidence in North America, 1988-1992*. Sacramento, CA: North American Association of Central Cancer Registries, April 1996, pp V-1 - V-14. [www.naaccr.org/DataandPublications/EpiReports.aspx. Last accessed February 9, 2012.]

Geographic variations of lung cancer mortality have been observed since the 1950s. Differences in incidence have not been available outside of the Surveillance, Epidemiology, and End Results (SEER) Program areas until recently. Using data submitted to NAACCR for 1988-1991, three-to-fourfold differences in white populations were found among registries, ranging from 50% higher and 50% lower than the U.S. rates as determined by the SEER Program. Large geographic variations were identified; this information is important for cancer control programs in high-risk states.

Fulton JP, Wingo P, Jamison M, Roffers SD, Howe HL, Chen VW. **Exploring the effects of death certificate follow-back on cancer registration.** In: Howe HL, et al. (eds). *Cancer Incidence in North America, 1988-1992*. Sacramento, CA: North American Association of Central Cancer Registries, April 1996, pp VI-1 - VI-8. [www.naaccr.org/DataandPublications/DataQuality.aspx. Last accessed February 9, 2012.]

Using data from 1988-1991, the effect of death certificate follow-back on cancer registration and particularly completeness of case reporting was explored. Death clearance practices were compared with four indicators of data quality for 35 U.S. registries. These included proportion of cases with histologic confirmation; proportion of death certificate only cases; incidence-to-mortality rate ratios; and incidence rates. The authors conclude that the extent of death certificate follow-back is a robust indicator of data quality, strongly linked to indicators of case completeness.

Carozza SE, Chen VW, Wu XC, Lehnherr M, Derrick L, Riley R, Correa CN, Ortiz-Rios E, Ender J. **Childhood cancer incidence in North America, 1988-1992.** In: Howe HL, et al. (eds). *Cancer in North America, 1989-1993, Volume One: Incidence*. Sacramento, CA: North American Association of Central Cancer Registries, April 1997, pp V-1 - V-13. [www.naaccr.org/DataandPublications/EpiReports.aspx. Last accessed February 9, 2012.]

This report describes cancers diagnosed among children in the United States and Canada from 1988-1992, with special attention to variations across race, gender, and age. Incidence data from 24 U.S. registries and 11 Canadian registries met the high-quality criteria in effect at the time and were included in the analysis. Incidence data were evaluated for the major sites of childhood cancers. Although rates were higher for white children than black and boys than girls for all sites combined, these patterns were not observed in most of the specific cancer types. Canadian data generally mirrored the data for U.S. white children.

Fulton JP, Correa C, Hirschenberger W, Howe HL, Krauthem K, Parker S, Zahniser C. **Urbanization and cancer incidence, United States, 1988-1992.** In: Howe HL, Lehnherr M (eds). *Cancer Incidence in North America, 1989-1993*. Sacramento, CA: North American Association of Central Cancer Registries, April 1997, pp VI-1 - VI-9. [www.naaccr.org/DataandPublications/EpiReports.aspx. Last accessed February 9, 2012.]

In the early 1950s, large geographic differentials existed among county-level, site-specific cancer mortality rates. For many cancers, strongly urban counties had higher mortality rates than moderately urban counties; while for some counties, the reverse was true. By the early 1970s, many

of these differentials had diminished substantially. Geographic variation in site-specific cancer incidence rates were explored using state-level data for 1988-1992. For this time period, cancer incidence differentials appeared to be inconsequential for many cancer sites, using state rates. Even with this crude measure of urbanicity, some differentials persisted and might be the focus of future epidemiologic studies.

Carozza SE, Chen VW, Wu XC, Fulton JP, Hutton MD, Jumaan A, Lehnherr M, Punyko J. **Recent changes in lung cancer incidence for selected states and metropolitan areas.** In: Chen VW, Wu XC, Andrews PA (eds). *Cancer in North America, 1990-1994*. Sacramento, CA: North American Association of Central Cancer Registries, April 1998, pp V-1 - V-16. [www.naacr.org/DataandPublications/EpiReports.aspx. Last accessed February 9, 2012.]

The purpose of this study was to expand national information on lung cancer incidence for 1989-1993 to encourage NAACCR registries to use their data in cancer control and prevention programs within their areas. The data revealed distinct geographic variation on rates in trends in lung cancer incidence rates; this information is useful for local efforts in cancer control and prevention.

Porter R, Correa CN, Fulton JP, Howe HL, Newton C, Nowak J, Roffers SD. **Exploring the internal consistency of registry data on stage of disease at diagnosis.** In: Chen VW, Wu XC, Andrews PA (eds). *Cancer in North America, 1990-1994*. Sacramento, CA: North American Association of Central Cancer Registries, April 1998, pp VI-1 - VI-12. [www.naacr.org/DataandPublications/DataQuality.aspx. Last accessed February 9, 2012.]

Cancer registry information on stage of disease at diagnosis is very important information. To date, it has not been subjected to evaluation in NAACCR's standard set of computerized edits. The objective of the study was to evaluate the internal consistency of stage of diagnosis for breast cancer cases in four states: Arizona, Louisiana, Rhode Island, and Illinois for the period 1990-1995. A framework for identifying and correcting coding errors is described for breast cancer.

Fulton JP, Lehnherr M, Hutton M, Jumaan AO, Wingo PA, Chen VW, Punyko J, Carozza SE, Wu, XC. **Geographic variability in prostate cancer incidence trends, United States, 1989-1994.** In: Chen VW, et al. (eds). *Cancer in North America, 1991-1995, Volume One: Incidence*. Sacramento, CA: North American Association of Central Cancer Registries, April 1999, pp V-1 - V-10.

Although recent data for areas within the Surveillance, Epidemiology, and End Results (SEER) Program indicate both consistent trends in prostate cancer incidence rates and variability in the absolute magnitude of those rates, these patterns have not been evaluated in other areas of the United States. Prostate cancer incidence rates were evaluated for 1989-1994 to assess the extent of the geographic variability in the trends of prostate cancer incidence rates. Similar trends and variability were found as reported from the SEER Program.

Parrish P, Fulton JP, Correa CN, Roffers SD, Jackson N, Newton C, O'Connor L, Perkins C, Porter R, Tucker T, Weir H. **Exploring the internal consistency of registry data on stage of disease at diagnoses: part II cancer of the prostate.** In: Chen VW, et al. (eds). *Cancer in North America, 1991-1995, Volume One: Incidence*. Sacramento, CA: North American Association of Central Cancer Registries, April 1999, pp VI-1 - V-14.

Using prostate cancer incidence data from six states/metropolitan areas (Arizona, California, Illinois, Louisiana, Rhode Island, and Metropolitan Atlanta), the internal consistency of summary stage data was evaluated to determine whether a guideline could be developed to assess data submitted to NAACCR. A framework for identifying and correcting coding errors is described for prostate cancer, using the same approach as described for breast cancer, as mentioned above.

Fulton JP, Wu XC, Carozza SE, Greenlee R, Liu L, Steele B, Chen VW. **Variation in colorectal cancer incidence among states and metropolitan areas in the United States, 1991-1995.** In: Chen VW, et al. (eds). *Cancer in North America, 1993-1997, Volume One: Incidence*. Springfield, IL: North American Association of Central Cancer Registries, April 2000, pp V-1 - V-6.

Data from 36 states and metropolitan areas were used to describe geographic variation in age-adjusted colorectal cancer incidence rates in the United States. Potential determinants of identified variability were obtained from NAACCR, the U.S. Census, and the Behavioral Risk Factor Surveillance System. These included case ascertainment completeness, racial composition, age structure, urbanization, and colorectal cancer screening. The findings, being ecologic in nature, are described as merely suggestive of potential hypotheses for future analytic research.

Fulton JP, Parrish P, Roffers SD, Correa CN, Jackson N, O'Connor L, Perkins C, Newton C, Clutter G. **Exploring the internal consistency of registry data on stage of disease at diagnosis: part III suggestions for an edits metafile.** In: Chen VW, et al. (eds). *Cancer in North America, 1993-1997, Volume One: Incidence.* Springfield, IL: North American Association of Central Cancer Registries, April 2000, pp VI-1 - VI-7.

This report is the third in the series (first breast in 1998; prostate in 1999). The current report focuses on internal consistency of registry data on stage of disease at diagnosis for all cancers combined, with specific suggestions for outputs from the standard computer edit package, EDITS.

Howe HL, Fulton JP, Tucker TC, Kohler B. **Adopting the HL7 standard for cancer registry work: clarifying unresolved issues.** In: Chen VW, et al. (eds). *Cancer in North America, 1993-1997, Volume One: Incidence.* Springfield, IL: North American Association of Central Cancer Registries, April 2000, pp VII-1 - VII-6.

Ten members of NAACCR were interviewed about their perceptions of the unresolved practical and policy issues related to the adoption of HL7 by central cancer registries. Eight groups of issues emerged and are described. The authors conclude that when weighing the appropriateness of HL7 application to cancer registries, the registries must go beyond the technical aspects of translation and implementation and consider the practical, administrative, and managerial issues related to its successful implementation. They recommend that NAACCR continue to study these issues with the goal of formulating a strategic plan for the use of HL7 in cancer registry systems.

Fulton JP, Chiaverini L, Roffers S, Curran D, Parrish P, Clutter G, Hall I, Jamison M, Newton C. **The collection and use of occupation and industry data by NAACCR member registries.** In: Wu XC, et al. (eds). *Cancer in North America, 1995-1999, Volume Three: NAACCR Combined Incidence.* Springfield, IL: North American Association of Central Cancer Registries, April 2002, pp IV-1 - IV-8.

This paper presents the results of a survey of NAACCR member registries to evaluate the data collection, coding, and use of industry and occupation information. A response rate of 77% was achieved. The survey delineated a number of inadequacies in the availability, coding, and ultimately use of these data. Improvements to data quality are suggested based on suggestions by survey respondents.

Howe HL and Hotes JL. **Use of override flags in the 1995-1999 CINA file submission.** In: Hotes JL, et al. (eds). *Cancer in North America, 1996-2000, Volume Three: NAACCR Combined Incidence*. Springfield, IL: North American Association of Central Cancer Registries, April 2003, pp IV-1 - IV-5. [www.naacr.org/DataandPublications/DataQuality.aspx. Last accessed February 9, 2012.]

The purpose of this report was to describe the use of nine specific override flags on the data file submitted to NAACCR for 1995-1999. The feasibility for establishing guidelines for a reasonable use of override flags was evaluated. The report concluded that there was no reasonable standard that could be established for setting override flags based on the data set; however, the use of override flags should be continued to be monitored. Registries with outlier values for setting override flags should be contacted to clarify the methods used in reconciliation of edits errors.

Howe HL. **Urban-rural gradients in cancer incidence and mortality in the United States.** Springfield, IL: North American Association of Central Cancer Registries, August 2004. [www.naacr.org/DataandPublications/EpiReports.aspx. Last accessed February 9, 2012].

This study describes urban-rural gradients in cancer incidence and mortality in the United States. The 1995-1999 NAACCR data set covering 34% of the U.S. population and 2.1 million cancer cases and 1996-99 cancer deaths for the United States as compiled by the National Vital Statistics System were used for the analyses. Cancer incidence and death rates were calculated by sex, site, race, and Beale category. The Beale urban-rural continuum assigns U.S. counties into 1 of 10 categories based on population count, proximity to larger metropolitan areas, and work commuting patterns. The gradients in rates of the site- and sex-specific cancer rates by Beale categories were compared using linear regression and were considered statistically significant at $p < 0.05$, with the adjusted R^2 used to explain the strength of the gradient. Furthermore, several area socioeconomic measures for the white population were examined for their linear association with the Beale urban-rural indicator. Statistically significant urban-rural trends occurred similarly for age-adjusted cancer incidence and cancer death rates. Nearly all incidence trends declined from urban to rural areas, with the exception of lip cancer in males and lung and oral cavity cancers in females. The gradients in age-adjusted cancer death rates had more increasing urban-rural trends than did cancer incidence rates. The increasing trends for deaths included cancers of the lip, liver, and lung, and non-Hodgkin lymphoma in males and cancers of the cervix and breast, and non-Hodgkin lymphoma in females. The urban-rural measure correlated strongly with all area socio-economic status (SES) indicators.

Research Publications

Howe HL. **Comparability and compatibility: issues in combining data from central cancer registries.** *Top Health Inf Manage.* 1997 Feb;17(3):29-34. PMID 10165385.

Before combining or comparing data from different registries, one should consider similarities and differences in data collection methods, data quality, and underlying populations. What are important population demographic differences? What about differences in data quality: How can these be measured and evaluated? What factors can affect data compatibility? How can one assess data comparability? If registries are compatible, are they always comparable? Are comparable data from registries compatible data? When data are combined, what issues should be considered to determine whether the combined result is meaningful? These are some of the common questions that need to be addressed to determine whether and when data from different registries should be combined or compared.

Tucker TC, Howe HL, Weir HK. **Certification for population-based registries.** *J Reg Manag.* February 1999;26(1):24-27.

This paper describes the criteria used in the NAACCR Registry Certification Program, which annually reviews a cancer registry's incidence data file for completeness, accuracy, and timeliness. This review is used to assess whether the data are appropriate for use in the computation of incidence rates.

Howe HL. **Data aggregation from multiple registries: issues and advantages.** *J Reg Manag.* February 2000;27(1):9-14.

Data aggregation is important for comparisons for a number of reasons described in this article. Guidelines are described for assessing data quality from all participants, the appropriateness of aggregation of data from various programs; and appropriate uses of a multi-registry data file.

Tucker TC and Howe HL. **Measuring the quality of population-based cancer registries: the NAACCR perspective.** *J Reg Manag.* 2001;28(1):41-5.

This paper describes the NAACCR program of Registry Certification, which evaluates cancer registry data annually for completeness, accuracy, and timeliness in producing cancer incidence rates. The evaluation approach is described, as is NAACCR's commitment to helping all cancer registries achieve standards that reflect high-quality data.

Wu XC, Chen VW, Steele B, Ruiz B, Fulton JP, Liu L, Carozza SE, Greenlee R. **Subsite-specific incidence rate and stage of disease in colorectal cancer by race, gender, and age group in the United States 1992-1997.** *Cancer.* 2001 Nov 15;92(10):2547-54. PMID 11745188.

Subsite-specific incidence rates of colorectal cancer vary considerably by age, gender, and race. This study used the largest aggregation of cancer incidence data in the United States to examine subsite-specific incidence rates of colorectal cancer and the relation of stage of disease to anatomic subsites by race, gender, and age group. Data on the incidence of invasive colorectal cancer were obtained from 28 population-based central cancer registries. Age-specific and age-adjusted rates and stage distributions were analyzed by subsite, race, and gender. Differentials in stage of disease by subsites indicate a need for a targeted effort at early detection of cancer in the proximal colon. Risk factors and higher risk populations for colorectal cancers in each subsite need to be studied further to guide actions for improving the efficacy of screening.

Wu XC, Chen VW, Steele B, Roffers S, Klotz JB, Correa CN, Carozza SE. **Cancer incidence in adolescents and young adults in the United States, 1992-1997.** *J Adolesc Health.* 2003 Jun;32(6):405-15. PMID 12782451.

The purpose of this paper was to examine cancer incidence patterns among adolescents and young adults in the United States. Cancer incidence data from 26 population-based central cancer registries for 1992-1997 were used. Individual cancers were grouped into specific diagnostic groups and subgroups using an integrated classification scheme. The integrated scheme was developed for this study and was based on the most commonly used schemes in population-based epidemiologic studies: Surveillance, Epidemiology, and End Results Program's site groups, International Classification of Childhood Cancer, and International Agency for Research on Cancer's Histological Groups for Comparative Studies. Percent distributions and age-specific incidence rates per million population were computed for adolescents (ages 15-19 years) and young adults (ages 20-24 years) by gender. The data for 26,010 cancer cases were examined. Among 15-19-year-olds, the five

most common cancers were Hodgkin's disease, leukemia, cancer of the brain and other nervous system, bone cancer, and non-Hodgkin's disease. Among 20-24 year olds, the five most common cancers were Hodgkin's disease, testicular cancer, thyroid cancer, melanoma of the skin, and leukemia. The proportions and rates of the histologic subtypes for most of the common cancers changed with advancing age. For example, among 15-19 year olds, acute lymphocytic leukemia accounted for approximately 60% of leukemias in males and 50% in females. Among 20-24 year olds, however, the corresponding percentages of acute lymphocytic leukemia were 37% in males and 31% in females. For ovarian cancer, the germ cell tumor was the most common subtype (54.6% of all ovarian cancers) among 15-19 year olds. In contrast, ovarian carcinoma was the predominant subtype (70.4%) among 0-24 year olds. For both age groups, the incidence rates of nodular Hodgkin's disease, melanoma of the skin, and thyroid cancer were significantly greater in females than in males. Cancer incidence patterns among adolescents and young adults are distinctive. In these age groups, a transition from predominantly pediatric histologic subtypes to adult subtypes was observed for Hodgkin's disease, leukemia, ovarian cancer, and soft tissue sarcoma. Gender differences were found for Hodgkin's disease, melanoma of the skin, and thyroid cancer.

Goodman MT, Howe HL. **Descriptive epidemiology of ovarian cancer in the United States, 1992-1997.** *Cancer.* 2003 May 15;97(10 Suppl):2615-30. PMID 12733127.

Ovarian cancer is the fifth most commonly diagnosed cancer among women in the United States. Similar to breast and endometrial cancers, ovarian cancer is more common among women in northern and central Europe, and in North America compared with Africa, South America, and Asia. In the United States, substantial racial and ethnic variations have been observed in the incidence of ovarian cancer. This analysis substantiates higher risk of ovarian cancer among white women and women who are not Hispanic than among black, American Indian, Asian/Pacific Islander, and Hispanic women. A review of the epidemiology and risks for ovarian cancer is provided, as is a complete and detailed description of the methodology used in all the ovarian cancer projects included in the *Cancer Supplement*. The article also includes a brief summary of each of the papers generated from the research group.

Goodman MT, Correa CN, Tung KH, Roffers SD, Wu XC, Young JL, Wilkins LR, Carney ME, Howe HL. **Stage at diagnosis of ovarian cancer in the United States, 1992-1997.** *Cancer.* 2003 May 15;97(10 Suppl):2648-59. PMID 12733130.

Symptoms of ovarian cancer are generally non-specific and delays in diagnosis are commonplace. Little has been published on factors that influence the stage at ovarian cancer diagnosis such as age, histology, or ethnic/racial group. This paper describes the stage-specific rates of ovarian cancer by racial and ethnic group.

Chen VW, Ruiz B, Killeen JL, Cote TR, Wu XC, Correa CN. **Pathology and classification of ovarian tumors.** *Cancer.* 2003 May 15;97(10 Suppl):2631-42. PMID 12733128.

Knowledge of the embryology and microscopic anatomy of the ovary is fundamental to the understanding of the various cancer types originating in this organ. This paper focuses on key developmental events and anatomic features of ovarian cancer.

Roffers SD, Wu XC, Johnson CH, Correa CN. **Incidence of extraovarian primary cancers in the United States, 1992-1997.** *Cancer.* 2003 May 15;97(10 Suppl):2643-7. PMID 12733129.

The pathological distinction between cancer of the ovary and cancer of extraovarian tissue can be difficult, and the potential for misclassification of primary ovarian cancer is a concern in epidemiological studies. This paper describes the incidence and distribution of three subsets of extraovarian tumors that have similar symptoms, appearance, and microscopic spread as ovarian cancer.

Hall HI, Tung KH, Hotes J, Logan P. **Regional variations in ovarian cancer incidence in the United States, 1992-1997.** *Cancer.* 2003 May 15;97(10 Suppl):2701-6. PMID 12733135.

International comparisons show the highest ovarian cancer incidence among white females in northern and western Europe and in North America. Ovarian cancer incidence rates are generally lower in Asian and African nations. Little information is available regarding the geographic variation in the incidence of ovarian cancer within the United States. This paper evaluates variations in incidence rates for ovarian cancer within four U.S. regions by ethnic and racial group.

Howe HL, Weinstein R, Hotes J, Kohler B, Roffers SD, Goodman MT. **Multiple primary cancers of the ovary in the United States, 1992-1997.** *Cancer.* 2003 May 15;97(10 Suppl):2660-75. PMID 12733131.

Given the rarity of ovarian cancer, little information is available concerning multiple primaries of the ovary, especially among women who are not white. Differences among women with single and multiple primaries by grade, stage, histology, and common syndromes or combination of tumor types are discussed in this paper.

Goodman MT, Howe HL, Tung KH, Hotes J, Miller BA, Coughlin SS, Chen VW. **Incidence of ovarian cancer by race and ethnicity in the United States, 1992-1997.** *Cancer.* 2003 May 15;97(10 Suppl):2676-85. PMID 12733132.

Ethnic variation in the incidence of cancer makes possible a variety of comparisons that can contribute to the general understanding of cancer etiology and responses to therapy. Such descriptive studies have been useful in generating not only causal hypotheses, but also useful prevention strategies. Racial and ethnic differences in the incidence of ovarian cancer have been reported, but these have been limited to specific geographic areas in the United States. In this paper, ethnic-specific incidence patterns are discussed.

Howe HL, Tung KH, Coughlin S, Jean-Baptiste R, Hotes J. **Race/ethnic variations in ovarian cancer mortality in the United States, 1992-1997.** *Cancer.* 2003 May 15;97(10 Suppl):2686-93. PMID 12733133.

An estimated 13,900 women in the United States will die in 2001 from ovarian cancer, the most fatal cancer of the female genital tract. Although this statistic is alarming, only a few descriptive studies of ovarian cancer mortality in the U.S. population have been reported. This paper describes ovarian cancer mortality by ethnic and racial group.

Young JL, Wu XC, Roffers SD, Howe HL, Correa CN, Weinstein R. **Ovarian cancer in children and young adults in the United States, 1992-1997.** *Cancer.* 2003 May 15;97(10 Suppl):2694-2700. PMID 12733134.

Ovarian cancer is rare among children, adolescents, and young adults. Accordingly, little has been published regarding ovarian cancer incidence among girls and young women. This paper describes ovarian cancer incidence among the young (0-24 years of age) by ethnic and racial group.

Hall I, Jamison P, Fulton JP, Clutter G, Roffers S, Parrish P. **Reporting cutaneous melanoma to cancer registries in the United States.** *J Am Acad Dermatol.* 2003 Oct;49(4):624-30. PMID 14512907.

The aim of this study was to assess the completeness of melanoma reporting in the United States. Data provided by central cancer registries were used to calculate age-adjusted, average annual incidence rates and were compared by time period (1992-1994, 1995-1997), stage, and program (Surveillance Epidemiology and End Results [SEER] and National Program of Cancer Registries [NPCR]). Completeness was measured with an incidence/mortality ratio. Incidence rates among whites for 1995-1997 from SEER registries ranged from 11.8 to 33.9 per 100,000 population; 18 of 40 NPCR registries were within this range. For 1992-1994, 8 of 30 NPCR registries were within the range of SEER incidence rates. NPCR registry incidence rates were generally higher for 1995-1997 than 1992-1994. The percentage of cases of localized melanoma did not increase substantially in most SEER registries over the study period, but some NPCR registries had substantial increases. Among NPCR registries that had incidence rates comparable with those of SEER in 1995-1997, the incidence/mortality ratios were generally lower among NPCR registries than SEER registries. Although melanoma incidence rates are generally increasing, part of the increases in incidence rates reported by NPCR registries over the study time period are likely due to increased case ascertainment and reporting.

Howe HL, Edwards BK, Young JL, Shen T, West DW, Hutton M, Correa CN. **A vision for cancer surveillance in the United States.** *Cancer Causes Control.* 2003 Sep;14(7):663-72. PMID 14575364.

A comprehensive framework for cancer surveillance spans the entire lifespan and is capable of providing information on risk, burden, disparity, cost, cancer care, survival, and death. Cancer incidence, the point in the continuum at which a healthy individual becomes a cancer patient, has a strong, well-developed system to produce information about newly diagnosed cancer cases. However, in the future this system must be enhanced and integrated with other cancer surveillance networks to provide timely information on the burden of newly diagnosed patients with respect to various cross-cutting population characteristics to define, monitor, and reduce incidence, disparity, and other differences noted among groups.

Howe HL, Weinstein R, Schult T, Kohler B, Hotes J. **Registering multiple primary tumors in central cancer registries.** *J Reg Manag.* 2003;30(4):113-116.

Coding rules for multiple primary tumors are complex and may diminish data reliability. The purpose of this study was to assess the reliability and utility of reports of multiple primary cancers among breast cancer cases. A NAACCR dataset for tumors diagnosed from 1994-1998 was used. Within each registry, all tumors were linked by patient identification number to determine the history of primary tumors for individuals. Once linked, patients with one breast cancer and another primary tumor were extracted. For these cases, data recorded for sex, race, ethnicity, and sequence number were compared among the multiple primary tumor reports. A full 10% of the sample was lost by the omission of 2 registries with pervasive errors in sequence number assignment, resulting in 327,537 records of invasive breast cancers. Of the 62,394 multiple primary patients, 24,273 had multiple primaries diagnosed during the 5-year interval. Of these, 32 tumors had an unknown sequence number; 1,953 patients had the first tumor incorrectly coded as a single primary; and 158 records were sequenced incorrectly. Inconsistencies were also found in race, ethnicity, and sex identification, but these were few. It was concluded that some data quality problems existed; however, routine quality assurance registry operations produced a reasonable accurate and useful patient-linked file.

Young JL, Ward KC, Wingo PA, Howe HL. **The incidence of malignant non-carcinomas of the female breast.** *Cancer Causes Control.* 2004 Apr;15(3):313-9. PMID 15090726.

Demographic and tumor characteristics of all malignant non-carcinomas of the breast, including the lymphomas and myelomas, were the focus of this investigation. Twenty-six U.S. population-based registries identified 363,801 newly diagnosed malignant breast cancers among women during the time period 1994-1998. Of these, 4,625 (1.3%) were reported simply as cancer, not otherwise specified; 357,775 (98.3%) were of epithelial origin (carcinomas or adenocarcinomas); and the remaining 1,401 (0.4%) were non-epithelial in origin. All but nine of the non-epithelial breast cancers were some form of soft tissue sarcoma. The most common non-epithelial cancer was malignant phyllodes tumor, which accounted for 61% of these diagnoses. In addition to the 363,801 malignant cancers classified to the breast, another 613 tumors arose in the breast but were classified as myelomas or lymphomas: two as solitary myelomas, two as Hodgkin lymphoma and the remaining 609 as non-Hodgkin lymphoma. The median age of females with a non-epithelial cancer (53) was 10 years younger than that of women with an epithelial

cancer. The age-adjusted incidence rate per 100,000 females was 0.51 for non-epithelial cancers compared to 127.05 for epithelial cancers. Adding the myelomas and lymphomas, which are traditionally included with the hematopoietic cancers, to the incidence rates for breast cancer would increase the rate by less than 0.2 per 100,000.

Howe HL. **The North American Association of Central Cancer Registries.**

In: Hutchison CL, Menck HR, Burch M, Gottschalk R (eds). *Cancer Registry Management: Principles and Practice*. Alexandria, VA: National Cancer Registrars Association, 2004, pp 387-394.

A history of the organization, with a current description of the structure, objective, and major activities, is described for this registry management text.

Wingo PA, Jamison PM, Young JL, Gargiullo P. **Population-based statistics for women diagnosed with inflammatory breast cancer (United States).**

Cancer Causes Control. 2004 Apr;15(3):321-8. PMID 15090727.

The purpose of this study was to use population-based information to describe the demographic and tumor characteristics of inflammatory breast cancer (IBC) – the most aggressive form of this disease. IBC cases diagnosed during 1994 through 1998 were reported to 26 population-based cancer registries covering approximately 40% of the U.S. population. Rates were expressed per 100,000 female population and age-adjusted to the 2000 U.S. population. Ninety-five percent gamma confidence limits were estimated for the rates. Among the 3626 women diagnosed with IBC during 1994-1998, the majority were 40-59 years old. Most tumors were diagnosed at a regional (68.9%) or distant (25.3%) stage and were poorly differentiated (49.4%). The rate of IBC was 1.3 per 100,000 for all races combined. Black women had the highest risk (1.6) and Asian and Pacific Islander women the lowest (0.7). IBC is an extremely rare form of breast cancer. More precise diagnostic criteria are needed to distinguish it from less aggressive forms of the disease. Future studies should use a population-based design and collect detailed clinical information, including the presence of erythema, edema or peau d'orange appearance of the skin, and other clinical signs of disease.

Hotes JL, Ellison LF, Howe HL, Friesen I, Kohler B. **Variation in breast cancer counts using SEER and IARC multiple primary coding rules.** *Cancer Causes Control*. 2004 Mar;15(2):185-91. PMID 15017131.

The purpose of this study was to determine breast cancer case counts, on a given data set, using both Surveillance, Epidemiology, and End Results (SEER) Program and International Agency for Research on Cancer (IARC)

multiple primary coding rules and to describe differences, if any, by age at diagnosis, histology, stage at diagnosis, laterality, and grade. SEER and IARC multiple primary coding rules were applied to a data set provided by NAACCR. Only registries whose data met high quality data standards for the time period studied (1994-1998) and whose permission was obtained were included. Percentage differences were calculated using IARC counts as the base. Using IARC multiple primary rules resulted in 2.4% fewer cases. Among females, the highest percent changes by category were: age group – 80-84 year-olds (3.4%); histology – inflammatory breast cancer (4.6%); stage – distant (3.1%); grade – well differentiated (3.0%). Among males, the highest percent changes by category were: age group – 80-84 year-olds (1.7%); histology – for intraductal and lobular breast carcinoma in combination (4.8%); stage – distant (3.0%); grade – well differentiated (1.8%). Overall differences were generally unaffected when examined by laterality. Breast cancer case counts are dependent on the multiple primary coding rules used.

Perkins CI, Hotes J, Kohler BA, Howe HL. **Association between breast cancer laterality and tumor location, United States, 1994-1998.** *Cancer Causes Control.* 2004 Sep; 15(7):637-45. PMID 15280621.

Cancer is more likely to be diagnosed in the left breast than the right, but the reasons for this are undetermined. Left-sided predominance has not been evaluated for some demographic groups or by tumor location. Laterality was analyzed among 419,935 incident unilateral breast cancers from 26 population-based cancer registries participating in NAACCR, covering 40% of the U.S. population. Logistic regression assessed the independent contribution of race, ethnicity, age, histology, stage, and location to laterality. Breast cancer was about 5% more likely to be diagnosed in the left breast than the right, a finding that was generally consistent across demographic groups and tumor types. Men showed left-sided predominance, which was statistically significant for invasive tumors and nonsignificant for *in situ* disease. Among women, tumors in the upper-outer quadrant, where one-third of cancers are located, occurred with equal frequency in the left and right breast, while those in the lower quadrants were about 10% more likely to occur in the left breast. The observation that the left breast is at greater risk of cancer than the right may not apply to tumors arising in the upper-outer quadrant. The identification of physiologic, pathologic, or immunologic differences between the lower, but not upper, left and right breasts may assist in explaining breast cancer laterality.

Wu X, Chen VW, Martin J, Roffers S, Groves FD, Correa CN, Hamilton-Byrd E, Jemal A. **Subsite specific colorectal cancer incidence rates and stage distributions among Asians/Pacific Islanders in the United States, 1995-1999.** *Cancer Epidemiol Biomarkers Prev.* 2004 Jul;13(7):1215-22. PMID 15247133.

This study examined subsite-specific colorectal cancer incidence rates and stage distributions for Asians and Pacific Islanders (API) and compared the API data with data for whites and African Americans. Data included 336,798 invasive colorectal cancer incident cases for 1995 to 1999 from 23 population-based central cancer registries, representing about two-thirds of the API population in the United States. Age-adjusted rates, using the 2000 U.S. standard population, and age-specific rates and stage distributions were computed by anatomic subsite, race, and gender. Age-adjusted colorectal cancer incidence rates were significantly lower in API than in white and African-American populations, particularly for proximal colon cancer in which rates were 40% to 50% lower in API males and females. However, a significantly (10%) higher rectal cancer incidence rate was found in API males than in African-American males. Increases in age-specific rates with advancing age were more striking for proximal colon cancer than for distal colon and rectal cancers in white and African-American populations, while age-specific rates were similar for different subsites in API with parallel increases with advancing age, especially in API males. Similar to white and African-American persons, in API, proximal colon cancers (32% to 35%) were less likely to be diagnosed with localized stage compared with distal colon (38% to 42%) and rectal (44% to 52%) cancers. The patterns of subsite-specific colorectal cancer incidence in API, especially API males, differ from those of whites and African-American populations. Similar to white and African-Americans, a lower percentage of localized disease in API for proximal colon cancer than for distal colon and rectal cancers was observed.

Aldrich TE. **Review: Quality assessment of CINA Deluxe, 1995-1999 morphology data, 2004.** *J Reg Management.* 2004;31(3):111.

Dr. Aldrich reviewed the report of Dr. Will Athas comparing in-depth site-morphology agreement between the two national U.S. cancer programs: the National Cancer Institute's Surveillance, Epidemiology, and End Results and the Centers for Disease Control and Prevention's National Program of Cancer Registries. The report can be found on the NAACCR website.

Howe HL, Weinstein R, Alvi R, Kohler B, Ellison JH. **Women with multiple primary breast cancers diagnosed within a five year period, 1994-1998.** *Breast Cancer Res Treat.* 2005 Apr;90(3):223-32. PMID 15830135.

Women diagnosed with a primary breast cancer are at higher risk for a second primary. Few studies have focused on a comparison of women with single breast primary cancers and women with multiple primary breast cancers. The 1994-1998 NAACCR dataset aggregated from high quality registries representing more than one-third of the U.S. population provides a unique opportunity to examine the incidence of multiple primary breast cancers in a large population. Using this multi-registry dataset, the incidence pattern of malignant synchronous (within 2 months) and short-term metachronous (from 3 months to 60 months) multiple primaries and single primary breast cancers by demographic and tumor characteristics was described. Synchronous multiple primary tumors were more similar in age, stage, and tumor grade to single breast tumors than they were to short-term metachronous tumors. The short-term metachronous tumors did not resemble either the synchronous tumors or the single primaries. These findings may indicate that while synchronous multiple primaries may have treatment implications different from single primaries, their etiology may be similar to single breast primaries. Further, they may actually be multi-centric single primaries. The 2-month interval between multiple primaries is arbitrary and may not distinguish between the synchronous tumors and those occurring within 12 months of the index tumor. The rules for defining and counting breast primaries have implications for interpretation of incidence rates and temporal trends. These data also suggest the need for standard definitions for multiple primary breast tumors among clinicians, pathologists, and surveillance epidemiologists.

Wu XC, Groves FD, McLaughlin CC, Jemal A, Martin J, Chen VW. **Cancer incidence patterns among adolescents and young adults in the United States.** *Cancer Causes Control.* 2005 Apr;16(3):309-20. PMID 15947883.

An examination of the changing proportions and age-specific rates of epithelial vs. non-epithelial cancers with advancing age from 15-49 years by race and gender was conducted.

McLaughlin CC, Wu XC, Jemal A, Martin HJ, Roche LM, Chen VW. **Incidence of noncutaneous melanomas in the United States.** *Cancer.* 2005 Mar 1;103(5):1000-7. PMID 15651058.

Description of the epidemiology of noncutaneous melanoma has been hampered by its rarity. This report is the largest in-depth descriptive analysis of incidence of noncutaneous melanoma in the

United States, using data from NAACCR. Pooled data from 27 states and one metropolitan area were used to examine the incidence of noncutaneous melanoma by anatomic sub-site, gender, age, race and geography (northern/southern and coastal/non coastal) for cases diagnosed between 1996 and 2000. Percent distribution by stage of disease at diagnosis and histology was also examined. Between 1996 and 2000, 6,691 cases of noncutaneous melanoma (4,885 ocular and 1,806 mucosal) were diagnosed among 851 million person years at risk. Ocular melanoma was more common among men compared to women (6.8 cases per million men compared to 5.3 cases per million women, age-adjusted to the 2000 U.S. population standard), whereas mucosal melanoma was more common among women (2.8 cases per million women compared to 1.5 cases per million men). Rates of ocular melanoma among whites were more than eight times higher than among blacks. Rates of mucosal melanoma were approximately two times higher among whites compared to blacks. In contrast to cutaneous melanoma, there was no apparent pattern of increased noncutaneous melanoma among residents of southern or coastal states, with the exception of melanoma of the ciliary body and iris. Despite their shared cellular origins, both ocular and mucosal melanomas differ from cutaneous melanoma in terms of incidence by gender, race and geographic area.

Joslyn SA, Foote ML, Nasser K, Coughlin SS, Howe HL. **Racial and ethnic disparities in breast cancer rates by age: NAACCR breast cancer project.** *Breast Cancer Res Treat.* 2005 Jul;92(2):97-105. PMID 15986118.

The purpose of this study was to examine age-specific rates of breast cancer incidence among racial and ethnic groups in the United States. Subjects were 363,801 women diagnosed with invasive breast cancer diagnosed during 1994-1998 and reported in the NAACCR data set. Variables analyzed included race, ethnicity, 5-year age group (from 10 years through 85+ years), and stage at time of diagnosis (localized, regional, distant). Incidence rates per 100,000 women were calculated for each 5-year age group and stratified by stage. Rate ratios and 95% confidence intervals were calculated by comparing each racial group with whites and Hispanics with non-Hispanics. Black women experience significantly higher breast cancer incidence up to the age of 40 years and significantly lower incidence after age 50 compared with white women of the same ages. This is called the "crossover" effect. This shifting burden of higher incidence occurs at ages 35-39 for localized stage and at ages 55-59 for regional stage. For distant stage, black women of all ages experience higher incidence compared with white women. Similar crossover effects do not exist for American Indian (AI) or Asian/Pacific Islander (API) women compared with white women. Both AI and API women have significantly lower incidence of breast cancer compared

with white women, and Hispanic women have significantly lower incidence compared with non-Hispanic women. This study highlights racial and ethnic differences in breast cancer incidence rates among U.S. women. The crossover effect between black and white women, particularly the lower incidence of localized stage disease diagnosed in older black women, is a significant phenomenon that may be associated with screening practices and has implications for public health planning and cancer control initiatives to reduce racial/ethnic disparities.

Jemal A, Ward E, Wu X, Martin HJ, McLaughlin CC, Thun MJ. **Geographic patterns of prostate cancer mortality and variations in access to medical care in the United States.** *Cancer Epidemiol Biomarkers Prev.* 2005 Mar;14(3):590-5. PMID 15767335.

Striking geographic variation in prostate cancer death rates have been observed in the United States since at least the 1950s; reasons for these variations are unknown. The authors examined the association between geographic variations in prostate cancer mortality and regional variations in access to medical care, as reflected by the incidence of late-stage disease, prostate-specific antigen (PSA) utilization, and residence in rural counties. Mortality data from the National Center for Health Statistics, 1996 to 2000, and incidence data from 30 population-based central cancer registries from NAACCR, 1995 to 2000, were analyzed. Ecological data on the rate of PSA screening by registry area were obtained from the 2001 Behavioral Risk Factor Surveillance System. Counties were grouped into metro and nonmetro areas according to Beale codes from the Department of Agriculture. Pearson correlation analyses were used to examine associations. Significant correlations were observed between the incidence of late-stage prostate cancer and death rates for Whites ($r = 0.38$, $P = 0.04$) and Blacks ($r = 0.53$, $P = 0.03$). The variation in late-stage disease corresponded to about 14% of the variation in prostate cancer death rates in White men and 28% in Black men. PSA screening rate was positively associated with total prostate cancer incidence ($r = 0.42$, $P = 0.02$) but inversely associated with the incidence of late-stage disease ($r = -0.58$, $P = 0.009$) among White men. Nonmetro counties generally had higher death rates and incidence of late-stage disease and lower prevalence of PSA screening (53%) than metro areas (58%), despite lower overall incidence rates. These ecological data suggest that 10% to 30% of the geographic variation in mortality rates may relate to variations in access to medical care.

Adelman AS, McLaughlin CC, Wu XC, Chen VW, Groves FD. **Urbanisation and incidence of acute lymphocytic leukemia (ALL) among United States children ages 0-4.** *Br J Cancer.* 2005 Jun 6;92(11):2084-8. PMID 15886703.

Incidence of acute lymphocytic leukemia (ALL) among children under 5 years of age was examined utilizing data from 24 population-based cancer registries in the United States. Age-specific incidence rates for ALL (and for comparison, acute nonlymphocytic leukemia [ANLL] and non-Hodgkin's lymphoma [NHL]) among white children under 5 years of age were compared across four levels of urbanization: large and small metropolitan counties, and adjacent and nonadjacent rural counties. Among white males, incidence of ALL decreased with decreasing degrees of urbanization (two-sided trend $P = 0.008$), such that rates were significantly lower in the most remote rural counties than in the most populous metropolitan counties (RR = 0.71, CI = 0.59-0.85). No rural-urban gradient in the incidence of ALL was observed among white females, nor was any such gradient in incidence of ANLL or NHL detected among whites of either gender. Rates among blacks and Asians/Pacific Islanders (APIs) residing in metropolitan counties were also compared; blacks had lower incidence of ALL than white persons, and API persons had a lower incidence of ALL than white persons (RR = 0.78, CI = 0.63-0.97). Regardless of race, males had higher incidence of ALL than females, while ANLL rates did not vary by gender.

Wu X, Chen VW, Ruiz B, Andrews P, Su LJ, Correa P. **Incidence of esophageal and gastric carcinomas among American Asians/Pacific Islanders, Whites, and Blacks: subsite and histology differences.** *Cancer.* 2006 Feb 1;106(3):683-92. PMID 16388522.

The authors examined subsite-specific and histology-specific esophageal and gastric carcinoma incidence patterns among the Asian/Pacific Islander (API) population in the United States and compared them with those among whites and blacks. Data on newly diagnosed esophageal and gastric carcinomas during 1996-2000 were obtained from 24 population-based central cancer registries, representing approximately 80% of the API population in the United States. Age-adjusted rates, using the 2000 U.S. standard population, and age-specific rates were computed by anatomic subsite, histology, race, and gender. The difference in the age-adjusted rates between API and other races were examined using the two-tailed z statistic. Greater than 75% of esophageal carcinomas among APIs, both males and females, were squamous cell carcinoma. Adenocarcinoma accounted for <20% of all esophageal carcinomas. This pattern was similar to that among blacks but was completely opposite to that among whites. The rate of esophageal squamous cell carcinoma was 81% higher among API males compared with white males, but it was 64%

less compared with black males. The rates of esophageal adenocarcinoma were significantly lower among API than among both whites and blacks both males and females. The majority of gastric carcinomas among API were noncardia adenocarcinoma, whereas cardia adenocarcinoma accounted for only 11% of gastric carcinomas among API males and 6% of gastric carcinomas among API females. The age-adjusted incidence rate of cardia adenocarcinoma was 23% lower among API males compared with white males, but it was 26% higher compared with black males. In contrast, the rates of noncardia adenocarcinoma among API were approximately 3.7 times the rate among whites for both males and females and 33% higher than the rate among blacks. Subsite-specific and histology-specific incidence patterns of esophagogastric carcinoma among API differ from those among whites and blacks. The reasons for significantly higher rates of noncardia adenocarcinoma among API compared with whites and blacks warrant further investigation.

Smigal C, Jemal A, Ward E, Cokkinides V, Smith R, Howe HL, Thun M. **Trends in breast cancer by race and ethnicity: update 2006.** *CA Cancer J Clin.* 2006 May-Jun;56(3):168-83. PMID 16737949.

Approximately 212,920 new cases of invasive breast cancer, 61,980 *in situ* cases, and 40,970 deaths are expected to occur among U.S. women in the year 2006. The continuing increase in incidence (all stages combined) is limited to white women over age 50; recent trends are stable for African-American women over age 50 and white women under age 50, and decreasing for African-American women under age 50. Although incidence rates (all races combined) are substantially higher for women age 50 and over compared to women under age 50, approximately 23% of breast cancers are diagnosed in women under age 50. Below age 35, age-specific incidence rates are slightly higher among African-Americans compared to whites, but then cross over so that whites have substantially higher incidence at all later ages. However, death rates in African-American women remain 37% higher than in whites, despite lower incidence rates. Continued progress in the control of breast cancer will require sustained and increased efforts to provide high quality screening, diagnosis, and treatment to all segments of the population.

Goodman MT, Tung KH, Wilkens LR. **Comparative epidemiology of breast cancer among men and women in the United States, 1996 to 2000.** *Cancer Causes Control.* 2006 Mar;17(2):127-36. PMID 16435090.

Few investigations of breast cancer among men have been conducted because of the relative rarity of this malignancy. The objective of this analysis was to compare the demographic, pathological, and clinical

features of breast cancer among men and women. Breast cancer among 6,379 men and 744,275 women was identified through 34 U.S. population-based registries in the United States during the period 1996 to 2000. These registries were estimated to represent 69% of the U.S. population. Age-adjusted incidence rates (AAIR) were calculated per million population using counts derived from the 2000 U.S. census. The AAIR of breast cancer among men (16.6) was substantially lower than the incidence among women (1,557.7). Rates of breast cancer among black men were higher than among white and Asian-Pacific Island men, in contrast to women among whom rates in whites exceeded those among other ethnic groups. Similar to women, breast cancer rates among non-Hispanic men were 50% greater than among Hispanic men. Ductal cancer was the most common histologic type diagnosed in both sexes. The incidence of lobular cancer was rare in men, but Paget's disease and papillary carcinoma occurred with lower relative frequency in women than in men. Lobular breast cancers were less common among black men and women than among other ethnic groups. *In situ* breast cancer was diagnosed in 10.8% of men and 16.2% of women. Localized breast cancer was the most common stage at diagnosis in both sexes and all ethnic groups, although women were more likely than men to be diagnosed at a localized stage. Cancer was 10% more likely to be diagnosed in the left breast than the right breast among men compared to 4% in women. In spite of the rare incidence of breast cancer in men, the descriptive epidemiology of this malignancy is surprisingly similar to that in women. An explanation for the greater relative incidence of breast cancer in black men is a research challenge.

Boscoe FP, Schymura MJ. **Solar ultraviolet-B exposure and cancer incidence and mortality in the United States, 1993-2002.** *BMC Cancer.* 2006 Nov 10;6:264. PMID 17096841.

An inverse relationship between solar ultraviolet-B (UV-B) exposure and non-skin cancer mortality has long been reported. Vitamin D, acquired primarily through exposure to the sun via the skin, is believed to inhibit tumor development and growth and reduce mortality for certain cancers. The analysis of this relationship was extended to include cancer incidence as well as mortality, using higher quality and higher resolution data sets than have typically been available. More than 3 million incident cancer cases between 1998 and 2002 and 3 million cancer deaths between 1993 and 2002 in the continental United States were regressed against daily satellite-measured solar UV-B levels, adjusting for numerous confounders. Relative risks of reduced solar UV-B exposure were calculated for 32 different cancer sites. For non-Hispanic whites, an inverse relationship between solar UV-B exposure and cancer incidence and mortality was observed for 10 sites: bladder, colon, Hodgkin lymphoma, myeloma,

other biliary, prostate, rectum, stomach, uterus, and vulva. Weaker evidence of an inverse relationship was observed for six sites: breast, kidney, leukemia, non-Hodgkin lymphoma, pancreas, and small intestine. For three sites, inverse relationships were seen that varied markedly by sex: esophagus (stronger in males than females), gallbladder (stronger in females than males), and thyroid (only seen in females). No association was found for bone and joint, brain, larynx, liver, nasal cavity, ovary, soft tissue, male thyroid, and miscellaneous cancers. A positive association between solar UV-B exposure and cancer mortality and incidence was found for anus, cervix, oral cavity, melanoma, and other non-epithelial skin cancer. This paper adds to the mounting evidence for the influential role of solar UV-B exposure on cancer, particularly for some of the less-well studied digestive cancers. The relative risks for cancer incidence are similar to those for cancer mortality for most sites. For several sites (breast, colon, rectum, esophagus, other biliary, vulva), the relative risks of mortality are higher, possibly suggesting that the maintenance of adequate vitamin D levels is more critical for limiting tumor progression than for preventing tumor onset. These findings are generally consistent with the published literature, and include three cancer sites not previously linked with solar UV-B exposure to the author's knowledge: leukemia, small intestine, and vulva.

Carozza SE, Howe HL. **Patterns of cancer incidence among U.S. Hispanics/Latinos, 1995-2000.** *Cancer Causes Control.* 2006 Oct;17(8):1067-75. PMID 16933057.

Current and comprehensive data on cancer incidence in U.S. Latinos has been limited. Using a standardized approach to uniformly assign Hispanic/Latino race/ethnicity to cancer records, data from 15 central cancer registries, representing more than 85% of the U.S. Latino population, were included in the analysis. Average annual age-adjusted incidence rates and standard errors were calculated for Hispanic, non-Hispanic white, and non-Hispanic black males and females. To compare cancer incidence among Hispanic and non-Hispanic populations, standardized incidence ratios (SIRs) also were calculated. Latino populations had overall lower incidence for all cancers combined and for the four leading cancers (breast, prostate, lung and colorectal) than non-Hispanic populations; however, cancers of lesser impact in non-Hispanic populations (liver, gallbladder, stomach, penis and cervix) were more commonly diagnosed among Latinos. Understanding the patterns of cancer incidence in this diverse racial/ethnic minority group can serve to both stimulate research into the unique behaviors, exposures, and genetics that drive cancer risk among Latinos and to direct prevention and control efforts tailored to this population.

Howe HL, Lake AJ, Shen T. **Method to assess identifiability in electronic data files.** *Am J Epidemiol.* 2007 Mar 1;165(5):597-601. Epub 2006 Dec 20. PMID 17182982.

The authors developed the Record Uniqueness (RU) software program to assess electronic data files for risk of confidentiality breach based on unique combinations of key variables. The underlying methodology utilized by the RU program generates a frequency distribution for every variable selected for analysis and for all combinations of the variables selected. In addition, the program provides the regression coefficient that designates the relative contribution of each variable to the unique records on the data file. The authors used RU to evaluate a NAACCR research data set with 4.67 million cases from 34 population-based cancer registries for 1995-2001. To illustrate the process and utility of RU, they described the evaluation process of the confidentiality risk of adding a county-based socioeconomic measure to the research file. The RU method enables one to be assured of record confidentiality, provides flexibility to adjust record uniqueness thresholds for different users or purposes of data release, and facilitates good stewardship of confidential data balanced with maximum use and release of information for research. RU is a useful data tool that can quantify the risk of confidentiality breach of electronic health databases, including reidentifiability of cases through triangulation of information or linkage with other electronic databases.

Goodman MT, Yamamoto J. **Descriptive study of gallbladder, extrahepatic bile duct, and ampullary cancers in the United States, 1997-2002.** *Cancer Causes Control.* 2007 May;18(4):415-22. Epub 2007 Jan 30. PMID 17264972.

Few investigations of biliary tract (gallbladder, extrahepatic bile duct, ampulla of Vater) cancers have been conducted because of the relative rarity of these malignancies. The objective of this analysis was to compare the demographic, pathological, and clinical features of biliary tract cancers among men and women. Biliary tract cancers among 11,261 men and 15,722 women were identified through 33 U.S. population-based registries during the period 1997-2002. These registries were estimated to represent 61% of the U.S. population. Age-adjusted incidence rates (AAIR) were calculated per 100,000 population using counts derived from the 2000 U.S. Census. The AAIR for gallbladder cancer among men (0.82 per 100,000) was significantly lower than the AAIR among women (1.45 per 100,000). By contrast, rates for extrahepatic bile duct and ampullary cancers were significantly higher among men (0.93 per 100,000 and 0.70 per 100,000, respectively) than among women (0.61 per 100,000 and 0.45 per 100,000, respectively). White men and women had significantly lower AAIRs for gallbladder cancer compared with other racial-ethnic groups, with the highest rates among Hispanics, American Indian-Alaska

Natives, and Asian-Pacific Islanders(API). API and Hispanics of both sexes had the highest AAIRs for extrahepatic bile duct and ampullary cancers. Ampullary tumors were more likely to be diagnosed at a localized or regional stage than were cancers of the gallbladder and extrahepatic bile duct. API men and women tended to have more unstaged cancers than other groups. This population-based study suggests distinct etiologies of anatomic subsites of biliary tract cancer and caution against analytic investigations of all biliary tract cancers combined.

Wu X, Chen VW, Andrews PA, Ruiz B, Correa P. **Incidence of esophageal and gastric cancers among Hispanics, non-Hispanic whites and non-Hispanic blacks in the United States: subsite and histology differences.** *Cancer Causes Control.* 2007 Aug;18(6):585-93. Epub 2007 Apr 4. PMID 17406989.

The authors examined subsite- and histology-specific esophageal and gastric cancer incidence patterns among Hispanics/Latinos and compared them with non-Hispanic whites and non-Hispanic blacks. Data on newly diagnosed esophageal and gastric cancers for 1998-2002 were obtained from 37 population-based central cancer registries, representing 66% of the Hispanic population in the United States. Age-adjusted incidence rates (2000 U.S.) were computed by race/ethnicity, sex, anatomic subsite, and histology. The differences in incidence rates between Hispanics and non-Hispanics were examined using the two-tailed z-statistic. Squamous cell carcinoma accounted for 50% and 57% of esophageal cancers among Hispanic men and women, respectively, while adenocarcinoma accounted for 43% among Hispanic men and 35% among Hispanic women. The incidence rate of squamous cell carcinoma was 48% higher among Hispanic men (2.94 per 100,000) than non-Hispanic white men (1.99 per 100,000) but about 70% lower among Hispanics than non-Hispanic blacks, for both men and women. In contrast, the incidence rates of esophageal adenocarcinoma were lower among Hispanics than non-Hispanic whites (58% lower for men and 33% for women) but higher than non-Hispanic blacks (70% higher for men and 64% for women). Cardia adenocarcinoma accounted for 10-15% of gastric cancers among Hispanics, and the incidence rate among Hispanic men (2.42 per 100,000) was 33% lower than the rate of non-Hispanic white men (3.62 per 100,000) but 37% higher than that of non-Hispanic black men. The rate among Hispanic women (0.86 per 100,000), however, was 20% higher than that of non-Hispanic white women (0.72 per 100,000) and 51% higher than for non-Hispanic black women. Gastric non-cardia cancer accounted for approximately 50% of gastric cancers among Hispanics (8.32 per 100,000 for men and 4.90 per 100,000 for women), and the rates were almost two times higher than for non-Hispanic whites (2.95 per 100,000 for men and 1.72 per 100,000 for women) but about the

same as for non-Hispanic blacks. Subsite- and histology-specific incidence rates of esophageal and gastric cancers among Hispanics/Latinos differ from non-Hispanics. The incidence rates of gastric non-cardia cancer are almost two times higher among Hispanics than non-Hispanic whites, for both men and women. The rates of gastric cardia cancer are lower among Hispanics than non-Hispanic whites for men but higher for women. The rates of esophageal and gastric cardia adenocarcinomas are higher among Hispanics than non-Hispanic blacks.

Goodman MT, Hernandez BY, Shvetsov YB. **Demographic and pathological differences in the incidence of invasive penile cancer in the United States, 1995-2003.** *Cancer Epidemiol Biomarkers Prev.* 2007 Sep;16(9):1833-9. PMID 17855702.

Penile cancer is an uncommon malignancy, so few descriptive or analytic studies have been reported in the literature. The objective of this analysis was to describe the distribution of penile cancer in the United States by demographic, pathologic, and clinical features. Penile cancer among 6,539 men was identified through 29 population-based registries in the United States during the period 1995-2003. These registries were estimated to represent 68% of the U.S. population. Age-adjusted incidence rates were calculated per million population using counts derived from the 2000 U.S. census. A subset of nine registries was used to examine time trends in penile cancer between 1973 and 2003. Squamous cell carcinomas were the most common histologic type of penile cancer, representing 93% of all malignancies. Hispanic men had the highest age-adjusted incidence rates per million for penile cancer (6.58 per million), followed by Blacks (4.02 per million), Whites (3.90 per million), American Indians (2.81 per million), and Asian-Pacific Islanders (2.40 per million). The highest rates of penile cancer were found among Hispanic men (46.9 per million) and Black men (36.2 per million) of ages \geq 85 years. Penile malignancy was rare among males under age 20 years. Time trend analysis supported a significant decrease in the incidence of penile cancer for Blacks (annual percent change, -1.9%) and Whites (annual percent change, -1.2%). The majority (61%) of penile cancers were diagnosed at a localized stage among all racial and ethnic groups, although Hispanic and Black men tended to be diagnosed at more advanced stages than Whites. No racial or ethnic differences in tumor grade were identified. The incidence of penile cancer was highest in the South (4.42 per million) and lowest in the West (3.28 per million) of the United States. The highest age-adjusted incidence rate was found among Black men in the South (4.77 per million) and the lowest rate among Asian-Pacific Islanders in the West (1.84 per million). This analysis showed

significant racial/ethnic and regional variation in the incidence of penile cancer. The high rate of penile cancer among Hispanic and Southern Black men suggests differences in risk factors for this malignancy, such as circumcision, hygiene, or human papillomavirus exposure.

Carozza SE, Li B, Elgethun K, Whitworth R. **Risk of childhood cancer associated with residence in agriculturally intense areas of the United States.** *Environ Health Perspect.* 2008 Apr;116(4):559-65. PMID 18414643.

The potential for widespread exposure to agricultural pesticides through drift during application raises concerns about possible health effects to exposed children living in areas of high agricultural activity. We evaluated whether residence in a county with greater agricultural activity was associated with risk of developing cancer in children <15 years of age. Incidence data for U.S. children 0-14 years of age diagnosed with cancer between 1995 and 2001 were provided by member registries of NAACCR. The authors determined percent cropland for each county using agricultural census data and used the overall study distribution to classify agriculturally intense counties. Odds ratios and 95% confidence intervals were estimated for all ages and 5-year age groups for total cancers and selected cancer sites using logistic regression. Results showed statistically significant increased risk estimates for many types of childhood cancers associated with residence at diagnosis in counties having a moderate to high level of agricultural activity, with a remarkably consistent dose-response effect seen for counties having $\geq 60\%$ of the total county acreage devoted to farming. Risk for different cancers varied by type of crop. Although interpretation is limited by the ecologic design, in this study the authors were able to evaluate rarer childhood cancers across a diverse agricultural topography. The findings of this exploratory study support a continued interest in the possible impact of long-term, low-level pesticide exposure in communities located in agriculturally intense areas.

Yamamoto JF, Goodman MT. **Patterns of leukemia in the United State by subtype and demographic characteristics, 1997-2002.** *Cancer Causes Control.* 2008 May;19(4):379-90. Epub 2007 Dec 7. PMID 18064533.

Efforts to prevent leukemia have been hampered by an inability to identify significant risk factors. Exploring incidence patterns of leukemia subtypes by sex and race/ethnic group may generate new etiologic hypotheses and identify high-risk groups for further study. Data from NAACCR for 1997-2002 were used to assess patterns of leukemia incidence by subtype, sex, age, race and ethnicity. A total of 144,559 leukemia cases were identified, including 66,067 (46%) acute and 71,860 (50%) chronic leukemias. The highest rates of acute myeloid leukemia

with and without maturation were observed in Asian-Pacific Islanders (API). Hispanics had a higher incidence of acute lymphocytic leukemia, particularly in childhood, and promyelocytic leukemia than did non-Hispanics. African-Americans had the highest rates of HTLV-1 positive adult T-cell leukemia/lymphoma. A sharp increase in the incidence of chronic myeloid leukemia was observed for both APIs and Hispanics, 85 years and older. Known risk factors are unlikely to explain the observed disparities in leukemia incidence. Further studies of differences in environmental and genetic risk factors in these populations by specific leukemia subtype may provide clues to the etiologies of these malignancies.

Das B, Clegg LX, Feuer EJ, Pickle LW. **A new method to evaluate the completeness of case ascertainment by a cancer registry.** *Cancer Causes Control.* 2008 Jun;19(5):515-25. Epub 2008 Feb 13. PMID 18270798.

Epidemiologic research into cancer and subsequent decisionmaking to reduce the cancer burden in the population are dependent on the quality of available data. The more reliable the data, the more confident one can be that the decisions made would have the desired effect in the population. NAACCR certifies population-based cancer registries, ensuring uniformity of data quality. An important assessment of registry quality is provided by the index of completeness of cancer case ascertainment. NAACCR currently computes this index assuming that the ratio of cancer incidence rates to cancer mortality rates is constant across geographic areas within cancer site, gender, and race groups. NAACCR does not incorporate the variability of this index into the certification process. The authors proposed an improved method for calculating this index based on a statistical model developed at the National Cancer Institute to predict expected incidence using demographic and lifestyle data. They calculated the variance of the index using statistical approximation and used the incidence model to predict the number of new incident cases in each registry area, based on all available registry data. Then, they adjusted the registry-specific expected numbers for reporting delay and data corrections. The proposed completeness index is the ratio of the observed number to the adjusted prediction for each registry. The authors calculated the variance of the new index and proposed a simple method of incorporating this variability into the certification process. Better modeling reduces the number of registries with unrealistically high completeness indices. A fuller picture of registry performance is provided by incorporating variability into the certification process.

Rollison DE, Howlader N, Smith MT, Strom SS, Merritt WD, Ries LA, Edwards BK, List AF. **Epidemiology of myelodysplastic syndromes and chronic myeloproliferative disorders in the United States, 2001-2004, using data from the NAACCR and SEER programs.** *Blood.* 2008 Jul 1;112(1):45-52. Epub 2008 Apr 28. PMID 18443215.

Reporting of myelodysplastic syndromes (MDSs) and chronic myeloproliferative disorders (CMDs) to population-based cancer registries in the United States was initiated in 2001. In this first analysis of data from NAACCR, encompassing 82% of the US population, the authors evaluated trends in MDS and CMD incidence, estimated case numbers for the entire United States, and assessed trends in diagnostic recognition and reporting. Based on more than 40 000 observations, average annual age-adjusted incidence rates of MDS and CMD for 2001 through 2003 were 3.3 and 2.1 per 100,000, respectively. Incidence rates increased with age for both MDS and CMD ($P < .05$) and were highest among whites and non-Hispanics. Based on follow-up data through 2004 from the Surveillance, Epidemiology, and End Results (SEER) Program, overall relative 3-year survival rates for MDS and CMD were 45% and 80%, respectively, with males experiencing poorer survival than females. Applying the observed age-specific incidence rates to U.S. Census population estimates, approximately 9,700 patients with MDS and 6,300 patients with CMD were estimated for the entire United States in 2004. MDS incidence rates significantly increased with calendar year in 2001 through 2004, and only 4% of patients were reported to registries by physicians' offices. Thus, MDS disease burden in the United States may be underestimated.

Goodman MT, Shvetsov YB. **Incidence of ovarian, peritoneal, and fallopian tube carcinomas in the United States, 1995-2004.** *Cancer Epidemiol Biomarkers Prev.* 2009 Jan;18(1):132-9. PMID 19124490.

The objective of this analysis was to describe the distribution of pelvic carcinomas in the United States by demographic, pathologic, and clinical features. Carcinomas of the ovary ($n = 112,541$), peritoneum ($n = 6,458$), and fallopian tube ($n = 3,479$) were identified through 24 population-based registries in the United States during the period 1995 to 2004. Age-adjusted incidence rates were calculated per million population using counts derived from the 2000 U.S. Census. The age-adjusted incidence rate for ovarian carcinoma (119.9 per million) was substantially higher than for peritoneal (6.78 per million) or fallopian tube (3.72 per million) carcinomas. White women had the highest rates for all three malignancies. Rates for peritoneal carcinoma were lowest among Black women (2.88 per million) and rates for fallopian tube carcinoma were lowest among Hispanic women (2.45 per million). Serous carcinomas were the most commonly diagnosed histologic type for all anatomic sites.

Peritoneal carcinomas were diagnosed at later ages (mean, 67 years) and more advanced stages (85% regional/distant) compared with fallopian tube carcinomas (mean, 64 years; 62% regional/distant) and ovarian carcinomas (mean, 63 years; 76% regional/distant). Incidence for all three pelvic carcinomas was lowest in the South. Time trend analyses between 1973 and 2005 exhibited a significant decline in ovarian carcinoma incidence and rises in the rates of peritoneal and fallopian tube cancers. Similarities in the incidence patterns for ovarian, peritoneal, and fallopian tube carcinomas support the likelihood of a common molecular pathogenesis.

Goodman MT, Shvetsov YB. **Rapidly increasing incidence of papillary serous carcinoma of the peritoneum in the United States: Fact or artifact?** *Int J Cancer*. 2009 May 1;124(9):2231-5. PMID 19127596.

Papillary serous carcinoma of the peritoneum (PSCP) has been recognized for almost 5 decades, but little is known about the etiology or pathogenesis of this uncommon malignancy. The objective of this analysis was to examine trends in the incidence of PSCP in the United States. Invasive PSCP cases (N = 4,389) were identified through 24 population-based registries in the United States during the period 1995-2004. Incidence rates were calculated per million population. PSCP is a disease of older women, with few cases diagnosed before the age of 40 years. The incidence of PSCP was 64% lower among black women and 47% lower among Asian-Pacific Islander women compared with white women. Rates among Hispanic women were 39% lower than among non-Hispanic women. The majority of PSCP (68%) was diagnosed at a distant stage, underscoring the difficulty of diagnosing this malignancy. The incidence of PSCP has increased dramatically during the past decade in the United States with the greatest rise (>13% per year) among non-Hispanic and white women. This trend was more pronounced among older women and women with early stage disease. The incidence of PSCP shows substantial racial and ethnic diversity. The increase in the rate of PSCP among all racial and ethnic groups during the 10-year observation period is cause for some alarm. Although the reason for this temporal trend is unknown, some of the increase may be attributable to reclassification of ovarian carcinoma to the peritoneum.

Hao Y, Jemal A, Zhang X, Ward EM. **Trends in colorectal cancer incidence rates by age, race/ethnicity, and indices of access to medical care, 1995-2004 (United States).** *Cancer Causes Control.* 2009 Jun 19;20(10):1855-1863. PMID 19543799.

Colorectal cancer (CRC) incidence rates in the United States have decreased rapidly since 1998. This is largely thought to reflect increases in utilization of CRC screening through detection and removal of adenomatous polyps. However, the extent to which the decrease varies by age, race/ethnicity, and differences in access to medical care is largely unknown. Temporal trends in CRC incidence rates were examined from 1995 to 2004 by regression analysis according to age (50-64, ≥ 65), race/ethnicity (whites, African Americans, and Hispanics), and categories of county-level indicators of access to care (poverty, primary care physician supply [PCP], uninsured rate [age 50-64], and metro/nonmetro areas) using incidence data from 19 cancer registries, covering about 53% of the U.S. population. Changes in colorectal endoscopic screening and fecal occult blood stool test (FOBT) from 1995-1997 to 2002-2004 for the same set of county-level indicators were also analyzed, using data from the Behavioral Risk Factor Surveillance System (BRFSS). Among whites, CRC incidence rates decreased significantly from 1998 through 2004 in age ≥ 65 , but not in age 50-64 in counties with high uninsured or poverty rates, fewer PCPs, or in nonmetro areas. Among African Americans or Hispanics, rates did not decrease in age 50-64 in general and age ≥ 65 in counties with high poverty rates, low PCP supply, and nonmetro counties (African Americans). Colorectal endoscopic screening rates increased significantly among whites in both age groups, but not among Hispanics (aged 50-64 in general and aged ≥ 65 residing in high poverty counties) or African Americans residing in counties with higher uninsured rates (age 50-64), low PCP supply, high poverty rates, and nonmetro counties (age ≥ 65). FOBT rates remained unchanged during the study time period. These results suggest that individuals residing in poorer communities with lower access to medical care have not experienced the reduction in CRC incidence rates that have benefited more affluent communities; these disparities may be related to health care access barriers to colorectal endoscopic screening.

Hausauer AK, Keegan TH, Chang ET, Glaser SL, Howe H, Clarke CA. **Recent trends in breast cancer incidence in US white women by county-level urban/rural and poverty status.** *BMC Med.* 2009 Jun 26;7:31. PMID 19558637.

Unprecedented declines in invasive breast cancer rates occurred in the United States between 2001 and 2004, particularly for estrogen receptor-positive tumors among non-Hispanic white women over 50 years. To understand the broader public health import of these reductions among

previously unstudied populations, the authors utilized the largest available U.S. cancer registry resource to describe age-adjusted invasive and *in situ* breast cancer incidence trends for non-Hispanic white women aged 50 to 74 years overall and by county-level rural/urban and poverty status. They obtained invasive and *in situ* breast cancer incidence data for the years 1997 to 2004 from 29 NAACCR population-based cancer registries. Annual age-adjusted rates were examined overall and by rural/urban and poverty of patients' counties of residence at diagnosis. Joinpoint regression was used to assess trends by annual quarter of diagnosis. Between 2001 and 2004, overall invasive breast cancer incidence fell 13.2%, with greater reductions among women living in urban (-13.8%) versus rural (-7.5%) and low- (-13.0%) or middle- (-13.8%) versus high- (-9.6%) poverty counties. Most incidence rates peaked around 1999 then declined after second quarter of 2002, although in rural counties, rates decreased monotonically after 1999. Similar but more attenuated patterns were seen for *in situ* cancers. Breast cancer rates fell more substantially in urban and low-poverty, affluent counties than in rural or high-poverty counties. These patterns likely reflect a major influence of reductions in hormone therapy use after July 2002 but cannot exclude possible effects due to screening patterns, particularly among rural populations where hormone therapy use was probably less prevalent.

Greenlee RT, Howe HL. **County-level poverty and distant stage cancer in the United States.** *Cancer Causes Control.* 2009 Aug;20(6):989-1000. Epub 2009 Feb 7. PMID 19199061.

Late stage cancer at diagnosis increases the likelihood of cancer death. The relation of county-level poverty with late stage cancer for 18 anatomic sites was evaluated using data from NAACCR. Stratified analysis and logistic regression were applied to 2 million incident cancers (1997-2000) from 32 states representing 57% of the United States. For 12 sites, higher county poverty significantly increased the odds of late stage [adjusted odds ratio (95% confidence interval), comparing highest to lowest county poverty: larynx 2.4 (1.8-3.2), oral cavity 2.2 (1.8-2.7), melanoma 2.0 (1.5-2.8), female breast 1.9 (1.7-2.2), prostate 1.7 (1.5-1.9), corpus uteri 1.6 (1.3-1.9), cervix 1.6 (1.3-2.1), bladder 1.6 (1.2-2.1), colorectum 1.4 (1.3-1.5), esophagus 1.3 (1.1-1.7), stomach 1.3 (1.1-1.5), and kidney 1.3 (1.1-1.5)]. With some exceptions, county poverty associations with stage were comparable across gender and race, but stronger among metropolitan cases. A few differences by age may reflect screening patterns. In this large population-based study, higher county poverty independently predicted distant stage cancer. This held for several non-screenable cancers, suggesting improved area economic

deprivation, including access to and utilization of good medical care, might facilitate earlier diagnosis and longer survival even for cancers without practical screening approaches.

Barnholtz-Sloan J, Patel N, Rollison D, Kortepeter K, MacKinnon J, Giuliano A. **Incidence trends of invasive cervical cancer in the United States by combined race and ethnicity.** *Cancer Causes Control.* 2009 Sep;20(7):1129-38. Epub 2009 Mar 1. PMID 19253025.

The aim of this study was to better understand national patterns of invasive cervical cancer (ICC) incidence by race and ethnicity in order to develop appropriate ICC prevention policies. Age-adjusted and age-specific ICC incidence rates were calculated by combined race/ethnicity, making distinct the Hispanic/all races category from three other non-Hispanic (White, Black and other) racial categories. There was a significant downward trend in ICC incidence during both time periods for every combination of race/ethnicity (p -value <0.05) except Hispanic/all races during 1995-1999. Non-Hispanic/Black and Hispanic/all races women had significantly higher incidence rates of ICC compared to non-Hispanic/White women. ICC incidence peaked much earlier for non-Hispanic/White women (35-44 years of age) compared to any other racial/ethnic group. Non-Hispanic (White, Black and other) women had lower rates of adenocarcinoma and squamous cell carcinoma compared to Hispanic/all races women. Non-Hispanic/Black and Hispanic/all races women were more likely to be diagnosed at late stage or unstaged at diagnosis than non-Hispanic/White women. Although ICC incidence decreased significantly over the last 10 years, Black or Hispanic U.S. populations continue to have the highest ICC incidence compared to Non-Hispanic/Whites, highlighting the need for improved health literacy and social support to ensure their equal access to ICC screening and human papillomavirus (HPV) prevention including HPV vaccination.

Howe HL, Lake A, Schymura MJ, Edwards BK. **Indirect method to estimate specific Hispanic group cancer rates.** *Cancer Causes Control.* 2009 Sep;20(7):1215-26. PMID 19609690.

Several states with large Hispanic populations have historically served as the source for U.S. Hispanic cancer incidence rates, with aggregation of data across all states limited by different methodologies to identify Hispanic persons. Now with data available for more than 85 percent of the U.S. Hispanic population, state rates suggest regional diversity in their Hispanic cancer profiles. The authors tested an approach of using a surrogate indicator of county residential homogeneity for Hispanic groups, based on the 2000 U.S. Census. The indicator used the counts of specific Hispanic residents compared to the total Hispanic population in

the county to define counties with homogenous Hispanic populations. From these data, counties were aggregated into homogeneity categories for each Hispanic group, and defined thresholds and rules were defined for allocating Hispanic persons to a specific Hispanic group. It was possible to use county demographic data in many counties to meaningfully attribute a specific Hispanic ethnicity to incident cancer cases based on homogeneity thresholds. Cancer rates for the U.S. Hispanic population describe a profile of high rates of cancers of the liver, gallbladder, cervix (female), stomach, and lower rates of the cancers of the lung, female breast, and prostate compared with the non-Hispanic white population. In general, rates among U.S. Mexicans are lower than the U.S. Hispanic rates, while rates for Puerto Ricans and Cubans are higher than the U.S. Hispanic rates. Additional variations among the three Hispanic groups were also evident. The approach yielded reasonable and useful information to explore etiologic differences among the populations, as well as to develop relevant cancer control interventions. However, direct identification of specific Hispanic ethnicity in medical records and annual Census estimates of these populations would be preferable if they ever became available.

Wu XC, Andrew P, Chen VW, Groves FD. **Incidence of extranodal non-Hodgkin lymphomas among whites, blacks, and Asians/Pacific Islanders in the United States: anatomic site and histology differences.** *Cancer Epidemiol.* 2009 Nov;33(5):337-46. Epub 2009 Oct 22. PMID 19853554.

Extranodal non-Hodgkin lymphoma (NHL) accounts for much of the increase in NHL incidence in the past 3 decades in the United States, but its descriptive epidemiology is scarce in the literature. Incidence data for the years 1999-2003 were analyzed from 38 population-based cancer registries, covering 82% of the U.S. population. The authors grouped anatomic sites of extranodal NHLs according to the Surveillance, Epidemiology, and End Results (SEER) Program site recodes, and histology subtypes according to the nested classification of lymphoid neoplasms developed by the Pathology Working Group of the International Lymphoma Epidemiology Consortium. Blacks and Asians/Pacific Islanders (API) experienced incidence rates about the same as or lower than whites for B-cell extranodal NHL as a whole and most of its histologic subtypes. The significant exceptions were: API men had a 40% higher rate of marginal zone lymphoma (MZL) than white men, and API women had a 12% higher rate of diffuse large B-cell lymphoma (DLBCL) than white women. The rates of all T-cell extranodal NHLs combined and peripheral T-cell lymphoma (PTCL) among black women exceeded those of white women by 46% and 18%, respectively. Blacks also had higher rates of mycosis fungoides (MF) than whites (28% higher for men and 99% higher for women). The most common sites of extranodal NHL are stomach, skin,

and oral cavity and pharynx. Compared with whites, blacks had either lower or similar incidence of NHL for all sites except skin for women while APIs had higher rates of NHL of the stomach, nose/nasal cavity/middle ear, colorectum (women only), and brain (men only). Age was associated with race- and sex-specific differences in histology-specific incidence rates. While blacks and APIs had lower or similar overall incidence rates for extranodal NHL, they experienced excessive rates in some subtypes. Blacks had higher rates of the two most common types of T-cell extranodal NHL and APIs had higher rate of the two common types of B-cell types than whites. Distinct race-specific patterns in histology- and site-specific incidence of extranodal NHL may implicate racial differences in risk factor exposure and/or genetic predisposition.

Greenlee RT, Goodman MT, Lynch CF, Platz CE, Havener LA, Howe HL. **The occurrence of rare cancers in U.S. adults, 1995-2004.** *Public Health Rep.* 2010 Jan-Feb;125(1):28-43. PMID 20402194.

Rare cancers have been traditionally understudied, reducing the progress of research and hindering decisions for patients, physicians, and policy makers. The descriptive epidemiology of rare cancers was evaluated using a large, representative, population-based dataset from cancer registries in the United States. More than 9 million adult cancers diagnosed from 1995 to 2004 in 39 states and two metropolitan areas were analyzed using the Cancer in North America (CINA) dataset, which covers approximately 80% of the U.S. population. The authors applied an accepted cancer classification scheme and a published definition of rare (i.e., fewer than 15 cases per 100,000 per year). Age-adjusted incidence rates and rare/non-rare incidence rate ratios were calculated using SEER*Stat software, with analyses stratified by gender, age, race/ethnicity, and histology. Sixty of 71 cancer types were rare, accounting for 25% of all adult tumors. Rare cancers occurred with greater relative frequency among those who were younger, nonwhite, and of Hispanic ethnicity than among their older, white, or non-Hispanic counterparts. Collectively, rare tumors account for a sizable portion of adult cancers, and disproportionately affect some demographic groups. Maturing population-based cancer surveillance data can be an important source for research on rare cancers, potentially leading to a greater understanding of these cancers and eventually to improved treatment, control, and prevention.

Roche LM, Wu XC, Chen V, Hamilton-Byrd E, Groves FD, Jemal A, Martin HJ, McLaughlin CC. **Cutaneous melanoma incidence and survival among black, Asian and Pacific Islander, and white populations in the United States.** *Clinical Medicine Insights: Dermatology*. 2010;3 15-24. doi: 10.4137/CMD.S5173.

Cutaneous melanoma incidence and survival among U.S. blacks, Asian-Pacific Islanders (API) and whites were examined. Frequency distributions and age-adjusted incidence rates (cases per 100,000) by race, sex, anatomic subsite, histology and stage (frequency distribution only) and age-specific incidence rates were calculated for primary invasive cutaneous melanoma diagnosed in 1995–2001 from 36 U.S. population-based cancer registries (n = 138,725). Rate ratios with 95% confidence intervals comparing anatomic subsite and histology rates among APIs and blacks with whites were calculated. Five-year cause-specific survival rates by sex, race and histology were calculated using data from 17 Surveillance, Epidemiology and End Results (SEER) Program registries. API and black incidence rates were lower than the white rate for males (2.1 and 1.2, respectively, versus 20.6) and females (1.6 and 0.9 versus 13.6). Within each sex-race group, incidence rates generally increased with age; the increase was greatest for white males. Rate ratios for anatomic subsites and histologies were statistically significantly low, except black male and female and API male rate ratios for acral lentiginous histology. Five-year cause-specific survival rates were lowest for black males and females (77%), followed by API males (79%) and API females (84%). Further elucidation of risk factors for cutaneous melanoma in blacks and APIs and for the acral lentiginous histology in all races could assist in the design of measures to prevent and detect cutaneous melanoma.

Research in Progress

Cutaneous Malignant Melanoma (CMM): Differences in Epidemiology Between U.S. Adults and Children, 1995-2002. Lisa Paddock.

This study proposes a two-part analysis looking at data quality and data use. The investigators will compare age and body site, histology, gender, grade and summary stage to help elucidate the differences between childhood and adult cutaneous malignant melanoma (CMM) and prepubertal and postpubertal children. CMM cases will be identified from the CINA Deluxe database for the years 1995-2002. SEER*Stat software will be used to calculate frequencies and percentages for reporting source for children and adults for SEER versus other registries over the seven-year time interval. A two sample t-test will be used to compare the differences between percentages. SEER*Stat will also be used to calculate age-specific CMM incidence rates for children and adults by gender. Gender-specific frequencies and percentages will be calculated for children and adults for body site, race, grade, stage, and histology to evaluate differences between adults and children for each using age-specific incidence rates.

Projecting Estimates of Cancer Incidence for Every U.S. State Both Spatially and Temporally. Ahmedin Jemal, Yongping Hao.

The spatio-temporal Poisson mixed-effects regression model has been used for the prediction for every U.S. state for the years 1995-2003. Results have been investigated the superiority of this model-based method compared to the old method used to produce the American Cancer Society's (ACS) *Cancer Facts & Figures* projections. Based on evidence that the new method produces more accurate estimates of the number of new cancer cases for the years and areas for which data are available for comparison, the ACS has elected to use it to estimate the number of new cancer cases in *Cancer Facts & Figures 2007* and in *Cancer Statistics, 2007*. We have successfully projected estimates of cancer incidence for every U.S. state in 2007 using diagnosis data during 1995-2003. In the years to come, the researchers

will continue to project estimates of the number of new cancer cases for every U.S. state using the updated CINA data and provide results through *ACS Cancer Facts & Figures* and *Cancer Statistics*, which are published annually.

Epidemiology of Head and Neck Cancer Sub-Sites among Different Racial and Ethnic Populations in the United States. Edward Peters.

This research proposal will describe the epidemiology of head and neck cancer (HNC) in the United States, with NAACCR database files for aggregate cancer incidence in the United States. Because HNC has a fairly low incidence and prevalence in North America, utilization of the CINA Deluxe data is perhaps the only approach that will yield sufficient sample sizes to allow a meaningful examination of HNC distribution by sub-site and race/ethnicity. The researchers will estimate site-specific incidence and prevalence of HNC for a variety of diverse racial and ethnic populations, with further comparisons of human papillomavirus (HPV) associated HNC sites to non-HPV associated cancer sites. The study will be descriptive in nature, and provide valuable information to identify incidence discrepancies that can serve as a foundation for further etiologic research into HNC.

Hematopoietic Cancers in the Hispanic Population in the United States. Maria Schymura, Francis Boscoe.

The investigators propose to use the CINA Deluxe file to describe patterns of hematopoietic cancers among the primary Hispanic subgroups in the United States (Mexican, Puerto Rican, Cuban, Dominican, Central American and South American). Overall, rates of these cancers among Hispanics are lower than those for white non-Hispanics, which was the basis for excluding them from detailed discussion in the most recent *Report to the Nation* focused on Hispanic populations. But substantial variations in the occurrences of these cancers between Hispanic subgroups exist, particularly when leukemic subtypes are considered. For example, Schymura et al. found that rates of acute lymphocytic leukemia (ALL) among Mexicans and Central and South Americans were roughly double those of non-Hispanic whites, but this was not true for Puerto Ricans or Cubans. In contrast, rates of chronic lymphocytic leukemia (CLL) were half those of non-Hispanic whites for each of Hispanic groups. The proposed project will allow these and other key findings to be updated, expanded, and published using more current and complete data.

Combined Cancer Incidence Rate Study of 3 US States and 3 Canadian Provinces: A Descriptive Epidemiology Study. Bruce Riddle.

The purpose of this project is to produce an aggregate cancer incidence report for three northeastern states-Maine, New Hampshire, and Vermont-and three neighboring Canadian provinces-Nova Scotia, New Brunswick, and Prince Edward Island-as a first step to develop a consortium to study cancer rates in northeastern North America.

Cancer in the Appalachian Regions of North Carolina, Tennessee, and Virginia, 2004-2006. Toni Herring Bounds.

This study will describe the incidence for five cancer types (lung, colorectal, female breast, cervical and prostate) reported to the state cancer registries of North Carolina, Tennessee, and Virginia for the years 2004-2006. Comparisons will be made between the Appalachian and non-Appalachian regions of each state and the combined Tri-state Appalachian and non-Appalachian regions. Cancer mortality rates for the same sites for years 2004-2006 will also be compared.

Incidence of Small Bowel Cancer in the United States, 1995-2007. Marc T. Goodman.

As in past analyses, the CINA and Cancer in U.S. Hispanics/Latinos (CIUSHL) files provide an extraordinary opportunity to conduct descriptive analyses in a large and well-defined cancer registry network. In the proposed investigation the investigators will examine ethnic and racial variation in small bowel cancer by age at diagnosis, sex, anatomic sub-site, histology, and geographic area in the United States. This analysis may provide the basis for future collaborative population-based case-control studies.

Recent Changes in Incidence Rates of Ovarian Cancer: Relationship to Patterns of Use of Hormone Replacement Therapy. Mark E. Sherman.

The researchers will examine incidence rates of ovarian, tubal, and peritoneal cancers for the period 1998-2007. Both hormone replacement therapy (HRT) use (current, initiation and discontinuation) and ovarian cancer incidence rates may vary by a number of factors including, race, age, and region. The researchers will attempt to consider these factors in their analysis. Specifically, they will seek to determine whether ovarian cancer rates were highest among groups of women with the highest prevalence of HRT use and fell the most over time among groups with the highest rates of discontinuation of HRT use.

Comparison of Patients Captured in the National Cancer Data Base with Those in Population-Based Central Registries. Anthony Robbins.

The primary purpose of this study is to compare the case counts and characteristics of patients in the National Cancer Data Base (NCDB) database with those in the NAACCR database of population-based cases from NAACCR gold- and silver-certified registries.

Comparisons of cancer incidence and mortality for rural vs. urban counties in Pennsylvania and rural United States. Samuel M. Lesko.

In 2010, cancer is expected to overtake heart disease as the leading cause of death worldwide. In the United States, one in two males and one in three females will be diagnosed with cancer over their lifespan. The National Institutes of Health estimated the total annual cost of cancer in the United States (including all treatment costs and lost worker productivity due to illness) was \$228 billion in 2008. The American Cancer Society estimated that the number of new cancer cases diagnosed in 2010 in the United States was 1,529,560, with 75,260 (5%) of these occurring within Pennsylvania. The estimated number of deaths due to cancer in 2010 was forecasted to be 569,490 for the United States, with 28,690 (5%) of these deaths occurring within Pennsylvania. According to the state cancer registries, (see <http://statecancerprofiles.cancer.gov/incidencerates>), the average annual incidence rate during 2002-2006 in Pennsylvania for cancers of all sites was 496.5 for every 100,000 people, which ranks Pennsylvania as having the 8th highest cancer incidence rate of all states in the United States. The cancer mortality rate (see <http://statecancerprofiles.cancer.gov/deathrates>) during the same time period was 191.1 for every 100,000 people, ranking Pennsylvania as having the 16th highest cancer death rate of all states in the United States.

Data Quality Control through Nonlinear Association Analysis of Unknown Staged Cancer Cases. Qingzhao Yu.

Cancer stage describes the extent of cancer and how far it has spread from its origin at diagnosis. Stage data collected by population-based cancer registries have been used to examine variations in stage distribution across different populations, monitor trends in stage, and evaluate the effectiveness of early detection programs. Unfortunately, not all cancer cases are staged in cancer registry databases. Proportions of unknown stage cases vary substantially by registry and cancer sites. Using 2005-2007 incidence data from population-based cancer registries, the Data Assessment Work Group of the NAACCR Data Use and Research

Committee found wide variation in proportion of unknown stage cases by type of cancer. These proportions varied from 0.58% - 11.3% for breast cancer, 0.50% - 20.7% for prostate cancer, 1.8% - 19.1% for colorectum cancer, 1.9% - 20.7% for lung cancer, and 0 - 14.1% for cervix cancer.

Hodgkin Lymphoma Incidence in the United States by Age, Race and Ethnicity. Denise R. Lewis.

Hodgkin lymphoma (HL) accounts for approximately 12 percent of the incident cancer burden among young adolescents and young adults aged 15 to 29 years old (Bleyer et al. 2006). Although many are familiar with the classic age distribution of HL with a bimodal distribution and a first peak among those 20 to 25 years of age, a decline in incidence in the 40 to 50 year age range, and a second peak in the mid 70's, this distribution may not hold for all raceethnic groups. In 1992, the Surveillance Epidemiology and End Results (SEER) Program expanded the race-ethnic classification to include Hispanic ethnicity and Asian/Pacific Islander race. SEER data indicate a statistically significant increase in HL for Asian Pacific Islander females from 1992 to 2006 (Lewis 2011). Therefore, it is important to consider subpopulation changes in HL incidence rates. Most of the published findings on HL incidence have been from white, black, and other race groups, which have not been further defined.

Estimating Complete Prevalence by State and or County. Angela Mariotto.

Complete prevalence represents the number or percent of people alive on a certain date in a population that previously had a diagnosis of the disease. It includes new cases as well as long-term survivors. Information on prevalence is important for health planning, resource allocation, and as an estimate of cancer survivorship. Because these activities are usually performed at local level, several organizations would like to have prevalence estimates at more regional levels such as county and/or state.

Incidence and Trend of Soft Tissue Sarcoma in Adolescent and Young Adult. Mei-Chin Hsieh.

This study proposes to examine the cancer incidence pattern of soft tissue sarcoma using a large aggregated cancer incidence data.

- Incidence rates, distributions of histological types, tumor characteristics and prognosis of soft tissue sarcomas (STS) in adolescents and young adults (AYAs), aged 15 to 29 years old, differ from those in children and older adults.

- AYAs with STS have lower participation in clinical trials than pediatric and adults and it is directly correlated with lower 5-year survival rate than their counterparts.
- There are a few publications describing the histology-specific STS incidence among AYAs; most are based on data from the Surveillance, Epidemiology, and End Results (SEER) Program area, which covers up to 26% of the U.S. population, and some are based on hospital-level data.

Collaborative Research Publications

Swan J, Wingo P, Clive R, West D, Miller D, Hutchison C, Sondik EJ, Edwards BK. **Cancer surveillance in the U.S.: can we have a national system?** *Cancer*. 1998 Oct 1;83(7):1282-91. PMID 9762927.

Cancer-related services are consuming ever-increasing health resources; along with this trend, health care costs are rising. As health care planners, researchers, and policymakers formulate strategies to meet this challenge, they are looking to cancer registries and the health information system built around them as collectors of the most extensive information regarding cancer treatment in the United States. Currently, there are multiple programs collecting and reporting data regarding cancer incidence, morbidity, mortality, and survival. This report profiles cancer surveillance efforts in the United States and describes the National Coordinating Council for Cancer Surveillance, which was organized in 1995 to facilitate a collaborative approach among the organizations involved.

Ries LAG, Wingo PA, Miller DS, Howe HL, Weir HK, Rosenberg HM, Vernon SW, Cronin K, Edwards BK. **The annual report to the nation on the status of cancer, 1973-1997, with a special section on colorectal cancer.** *Cancer*. 2000 May 15;88(10):2398-424. PMID 10820364.

This annual report to the nation addresses progress in cancer prevention and control in the U.S. with a special section on colorectal cancer. This report is the joint effort of the American Cancer Society, the National Cancer Institute (NCI), the North American Association of Central Cancer Registries (NAACCR), and the Centers for Disease Control and Prevention (CDC), including the National Center for Health Statistics (NCHS). Age-adjusted rates were based on cancer incidence data from the NCI and NAACCR and underlying cause of death as compiled by NCHS. Joinpoint analysis was based on NCI Surveillance, Epidemiology, and End Results (SEER) Program incidence rates and NCHS death rates for 1973-1997. The prevalence of screening examinations for colorectal cancer was obtained from the CDC's Behavioral Risk Factor Surveillance System and the NCHS's National Health Interview Survey. Between 1990-1997, overall cancer incidence and death rates declined. Joinpoint

analyses of cancer incidence and death rates confirmed the declines described in earlier reports. The incidence trends for colorectal cancer have shown recent steep declines for whites in contrast to a leveling off of the rates for blacks. State-to-state variations occurred in colorectal cancer screening prevalence as well as incidence and death rates. The continuing declines in overall cancer incidence and death rates are encouraging. However, a few of the top ten incidence or mortality cancer sites continued to increase or remained level. For many cancer sites, whites had lower incidence and mortality rates than blacks but higher rates than Hispanics, Asian and Pacific Islanders, and American Indians/Alaska Natives. The variations in colorectal cancer incidence and death rates by race/ethnicity, gender, age, and geographic area may be related to differences in risk factors, demographic characteristics, screening, and medical practice. New efforts currently are underway to increase awareness of screening benefits and treatment for colorectal cancer.

Howe HL, Wingo PA, Thun MJ, Ries LA, Rosenberg HM, Feigal EG, Edwards BK. **Annual report to the nation on the status of cancer, 1973-1998, featuring cancers with recent increasing trends.** *J Natl Cancer Inst.* 2001 Jun 6; 93(11):824-42. PMID 11390532.

The American Cancer Society, the National Cancer Institute (NCI), the North American Association of Central Cancer Registries, and the Centers for Disease Control and Prevention, including the National Center for Health Statistics (NCHS), collaborate to provide an annual update on cancer occurrence and trends in the United States. This 2001 report contains a special feature that focuses on cancers with recent increasing trends. From 1992 through 1998, age-adjusted rates and annual percent changes are calculated for cancer incidence and underlying cause of death with the use of NCI incidence and NCHS mortality data. Joinpoint analysis, a model of joined line segments, is used to examine long-term trends for the four most common cancers and for those cancers with recent increasing trends in incidence or mortality. Statistically significant findings are based on a *P* value of .05 by use of a two-sided test. State-specific incidence and death rates for 1994 through 1998 are reported for major cancers. From 1992 through 1998, total cancer death rates declined in males and females, while cancer incidence rates declined only in males. Incidence rates in females increased slightly, largely because of breast cancer increases that occurred in some older age groups, possibly as a result of increased early detection. Female lung cancer mortality, a major cause of death in women, continued to increase but more slowly than in earlier years. In addition, the incidence or mortality rate increased in

10 other sites, accounting for about 13% of total cancer incidence and mortality in the United States. Overall cancer incidence and death rates continued to decline in the United States. Future progress will require sustained improvements in cancer prevention, screening, and treatment.

Edwards BK, Howe HL, Ries LA, Thun MJ, Rosenberg HM, Yancik R, Wingo PA, Jemal A, Feigel EG. **Annual report to the nation on the status of cancer, 1973-1999, featuring implications of age and aging on U.S. cancer burden.** *Cancer*. 2002 May 15;94(10):2766-92. PMID 12173348.

The American Cancer Society, the National Cancer Institute, the North American Association of Central Cancer Registries (NAACCR), the National Institute on Aging (NIA), and the Centers for Disease Control and Prevention, including the National Center for Health Statistics (NCHS) and the National Center for Chronic Disease Prevention and Health Promotion, collaborated to provide an annual update on cancer occurrence and trends in the United States. This year's report contained a special feature focusing on implications of age and aging on the U.S. cancer burden. For 1995 through 1999, age-specific rates and age-adjusted rates were calculated for the major cancers using incidence data from the Surveillance, Epidemiology, and End Results Program, the National Program of Cancer Registries, and NAACCR, as well as mortality data from NCHS. Joinpoint analysis, a model of joined line segments, was used to examine 1973-1999 trends in incidence and death rates by age for the four most common cancers. Deaths were classified using the eighth, ninth, and tenth revisions of the International Classification of Diseases. Age-adjusted incidence and death rates were standardized to the year 2000 population, which places more emphasis on older persons, in whom cancer rates are higher. Across all ages, overall cancer death rates decreased in men and women from 1993 through 1999, while cancer incidence rates stabilized from 1995 through 1999. Age-specific trends varied by site, sex, and race. For example, breast cancer incidence rates increased in women aged 50-64 years, whereas breast cancer death rates decreased in each age group. However, a major determinant of the future cancer burden is the demographic phenomenon of the aging and increasing size of the U.S. population. The total number of cancer cases can be expected to double by 2050 if current incidence rates remain stable. Despite the continuing decrease in cancer death rates and stabilization of cancer incidence rates, the overall growth and aging of the U.S. population can be expected to increase the burden of cancer in our nation.

Weir HK, Thun MJ, Hankey BF, Ries LA, Howe HL, Wingo PA, Jemal A, Ward E, Anderson RN, Edwards BK. **Annual report to the nation on the status of cancer, 1975-2000, featuring the uses of surveillance data for cancer prevention and control.** *Natl Cancer Inst.* 2003 Sep 3;95(17):1276-99. PMID 12953083.

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 update cancer rates and trends in the United States. This report updates statistics on lung, female breast, prostate, and colorectal cancers and highlights the uses of selected surveillance data to assist development of state-based cancer control plans. Age-adjusted incidence rates from 1996 through 2000 are from state and metropolitan area cancer registries that met NAACCR criteria for highest quality. Death rates are based on underlying cause-of-death data. Long-term trends and rates for major racial and ethnic populations are based on NCI and CDC data. Incidence trends from 1975 through 2000 were adjusted for reporting delays. State-specific screening and risk factor survey data are from the CDC and other federal and private organizations. Cancer incidence rates for all cancer sites combined increased from the mid-1970s through 1992 and then decreased from 1992 through 1995. Observed incidence rates for all cancers combined were essentially stable from 1995 through 2000, whereas the delay-adjusted trend showed an increase that had borderline statistical significance ($P=.05$). Increases in the incidence rates of breast cancer in women and prostate cancer in men offset a long-term decrease in lung cancer in men. Death rates for all cancer sites combined decreased beginning in 1994 and stabilized from 1998 through 2000, resulting in part from recent revisions in cause-of-death codes. Death rates among men continued to decline throughout the 1990s, whereas trends in death rates among women were essentially unchanged from 1998 through 2000. Analysis of state data for the leading cancers revealed mixed progress in achieving national objectives for improving cancer screening, risk factor reduction, and decreases in mortality. Overall cancer incidence and death rates began to stabilize in the mid- to late 1990s. The recent increase in the delay-adjusted trend will require monitoring with additional years of data. Further reduction in the burden of cancer is possible but will require the continuation of strong federal, state, local, and private partnerships to increase dissemination of evidence-based cancer control programs to all segments of the population.

Jemal A, Clegg LX, Ward E, Ries LA, Wu XC, Jamison PM, Wingo PA, Howe HL, Anderson RN, Edwards BK. **Annual report to the nation on the status of cancer, 1975-2001, with a special feature regarding survival.** *Cancer*. 2004 Jul 1;101(1):3-27. PMID 15221985.

The American Cancer Society (ACS), 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 regarding cancer occurrence and trends in the United States. This 2004 report features a special section on cancer survival. Information concerning cancer cases was obtained from the NCI, CDC, and NAACCR and information concerning recorded cancer deaths was obtained from the CDC. The authors evaluated trends in age-adjusted cancer incidence and death rates by regression models and described and compared survival rates over time and across racial/ethnic populations. Incidence rates for all cancers combined decreased from 1991 through 2001, but stabilized from 1995 through 2001 when adjusted for delay in reporting. The incidence rates for female lung cancer decreased (although not statistically significant for delay adjusted) and mortality leveled off for the first time after increasing for many decades. Colorectal cancer incidence rates also decreased. Death rates decreased for all cancers combined (1.1% per year since 1993) and for many of the top 15 cancers occurring in men and women. The 5-year relative survival rates improved for all cancers combined and for most, but not all, cancers over 2 diagnostic periods (1975-1979 and 1995-2000). However, cancer-specific survival rates were lower and the risk of dying from cancer, once diagnosed, was higher in most minority populations compared with the white population. The relative risk of death from all cancers combined in each racial and ethnic population compared with non-Hispanic white men and women ranged from 1.16 in Hispanic white men to 1.69 in American Indian/Alaska Native men, with the exception of Asian/Pacific Islander women, whose risk of 1.01 was similar to that of non-Hispanic white women. The continued measurable declines for overall cancer death rates and for many of the top 15 cancers, along with improved survival rates, reflect progress in the prevention, early detection, and treatment of cancer. However, racial and ethnic disparities in survival and the risk of death from cancer, and geographic variation in stage distributions suggest that not all segments of the U.S. population have benefited equally from such advances.

Wingo PA, Howe HL, Thun MJ, Ballard-Barbash R, Ward E, Brown ML, Sylvester J, Friedell GH, Alley L, Rowland JH, Edwards BK. **A national framework for cancer surveillance in the United States.** *Cancer Causes Control.* 2005 Mar;16(2):151-70. PMID 15868456.

Enhancements to cancer surveillance systems are needed for meeting increased demands for data and for developing effective program planning, evaluation, and research on cancer prevention and control. Representatives from the American Cancer Society, Centers for Disease Control and Prevention, National Cancer Institute, National Cancer Registrars Association, and North American Association of Central Cancer Registries have worked together on the National Coordinating Council for Cancer Surveillance to develop a national framework for cancer surveillance in the United States. The framework addresses a continuum of disease progression from a healthy state to the end of life and includes primary prevention (factors that increase or decrease cancer occurrence in healthy populations), secondary prevention (screening and diagnosis), and tertiary prevention (factors that affect treatment, survival, quality of life, and palliative care). The framework also addresses cross-cutting information needs, including better data to monitor disparities by socioeconomic status, to assess economic costs and benefits of specific interventions for individuals and for society, and to study the relationship between disease and individual biologic factors, social policies, and the environment. Implementation of the framework will require long-term, extensive coordination and cooperation among these major cancer surveillance organizations.

Edwards BK, Brown ML, Wingo PA, Howe HL, Ward E, Ries LA, Schrag D, Jamison PM, Jemal A, Wu XC, Friedman C, Harlan L, Warren J, Anderson RN, Pickle LW. **Annual report to the nation on the status of cancer, 1975-2002, featuring population-based trends in cancer treatment.** *J Natl Cancer Inst.* 2005 Oct 5;97(19):1407-27. PMID 16204691.

This 2005 report updates statistics on the 15 most common cancers in the five major racial/ethnic populations in the United States for 1992-2002 and features population-based trends in cancer treatment. Reported incidence and death rates were age-adjusted to the 2000 U.S. standard population, annual percent change in rates for fixed intervals was estimated by linear regression, and annual percent change in trends was estimated with joinpoint regression analysis. Population-based treatment data were derived from the Surveillance, Epidemiology, and End Results (SEER) Program registries, SEER-Medicare linked databases, and the National Cancer Incidence (NCI) Patterns of Care/Quality of Care studies. Among men, the incidence rates for all cancer sites combined were stable from 1995 through 2002. Among women, the incidence rates

increased by 0.3% annually from 1987 through 2002. Death rates in men and women combined decreased by 1.1% annually from 1993 through 2002 for all cancer sites combined and also for many of the 15 most common cancers. Among women, lung cancer death rates increased from 1995 through 2002, but lung cancer incidence rates stabilized from 1998 through 2002. Although results of cancer treatment studies suggest that much of contemporary cancer treatment for selected cancers is consistent with evidence-based guidelines, they also point to geographic, racial, economic, and age-related disparities in cancer treatment. Cancer death rates for all cancer sites combined and for many common cancers have declined at the same time as the dissemination of guideline-based treatment into the community has increased, although this progress is not shared equally across all racial and ethnic populations. Data from population-based cancer registries, supplemented by linkage with administrative databases, are an important resource for monitoring the quality of cancer treatment. Use of this cancer surveillance system, along with new developments in medical informatics and electronic medical records, may facilitate monitoring of the translation of basic science and clinical advances to cancer prevention, detection, and uniformly high quality of care in all areas and populations of the United States.

Howe HL, Wu X, Ries LA, Cokkinides V, Ahmed F, Jemal A, Miller B, Williams M, Ward E, Wingo PA, Ramirez A, Edwards BK. **Annual report to the nation on the status of cancer, 1975-2003, featuring cancer among U.S. Hispanic/Latino populations.** *Cancer*. 2006 Oct 15;107(8):1711-42. PMID 16958083.

The American Cancer Society, Centers for Disease Control and Prevention, National Cancer Institute, and North American Association of Central Cancer Registries collaborate annually to provide U.S. cancer information, this year featuring the first comprehensive compilation of cancer information for U.S. Latinos. Cancer incidence was obtained from 90% of the Hispanic/Latino and 82% of the U.S. population. Cancer deaths were obtained for the entire U.S. population. Cancer screening, risk factor, incidence, and mortality data were compiled for Latino and non-Latino adults and children (incidence only). Long-term (1975-2003) and fixed-interval (1995-2003) trends and comparative analyses by disease stage, urbanicity, and area poverty were evaluated. The long-term trend in overall cancer death rates, declining since the early 1990s, continued through 2003 for all races and both sexes combined. However, female lung cancer incidence rates increased from 1975 to 2003, decelerating since 1991 and breast cancer incidence rates stabilized from 2001 to 2003. Latinos had lower incidence rates in 1999-2003 for most cancers, but higher rates for stomach, liver, cervix, and myeloma (females) than did non-Latino white populations. Latino children have higher incidence

of leukemia, retinoblastoma, osteosarcoma, and germ-cell tumors than do non-Latino white children. For several common cancers, Latinos were less likely than non-Latinos to be diagnosed at localized stages. The lower cancer rates observed in Latino immigrants could be sustained by maintenance of healthy behaviors. Some infection-related cancers in Latinos could be controlled by evidenced-based interventions. Affordable, culturally-sensitive, linguistically appropriate, and timely access to cancer information, prevention, screening, and treatment are important in Latino outreach and community networks.

Pickle LW, Hao Y, Jemal A, Zou Z, Tiwari RC, Ward E, Hachey M, Howe HL, Feuer EJ. **A new method of estimating United States and state-level cancer incidence counts for the current calendar year.** *CA Cancer J Clin.* 2007 Jan-Feb;57(1):30-42. PMID 17237034.

The American Cancer Society (ACS) has published the estimated number of new cancer cases and deaths in the current year for the United States that are commonly used by cancer control planners and the media. The methods used to produce these estimates have changed over the years as data (incidence) and statistical models improved. In this paper the authors present a new method that uses statistical models of cancer incidence that incorporate potential predictors of spatial and temporal variation of cancer occurrence and that account for delay in case reporting and then projects these estimated numbers of cases ahead 4 years using a piecewise linear (joinpoint) regression method. Based on evidence presented here that the new method produces more accurate estimates of the number of new cancer cases for years and areas for which data are available for comparison, the ACS has elected to use it to estimate the number of new cancer cases in *Cancer Facts & Figures 2007* and in *Cancer Statistics, 2007*.

Espey DK, Wu XC, Swan J, Wiggins C, Jim MA, Ward E, Wingo PA, Howe HL, Ries LA, Miller BA, Jemal A, Ahmed F, Cobb N, Kaur JS, Edwards BK. **Annual report to the nation on the status of cancer, 1975-2004, featuring cancer in American Indians and Alaska Natives.** *Cancer.* 2007 Nov 15;110(10):2119-52. PMID 17939129.

The American Cancer Society, the Centers for Disease Control and Prevention, the National Cancer Institute, and the North American Association of Central Cancer Registries collaborate annually to provide updated information on cancer occurrence and trends in the U.S. The 2007 report features a comprehensive compilation of cancer information for American Indians and Alaska Natives (AI/AN). Cancer incidence data were available for up to 82% of the U.S. population. Cancer deaths

were available for the entire U.S. population. Long-term (1975 through 2004) and fixed-interval (1995 through 2004) incidence and mortality trends were evaluated by annual percent change using regression analyses (2-sided $P < .05$). Cancer screening, risk factors, socioeconomic characteristics, incidence data, and stage were compiled for non-Hispanic whites (NHW) and AI/AN across six regions of the United States. Overall cancer death rates decreased by 2.1% per year from 2002 through 2004, nearly twice the annual decrease of 1.1% per year from 1993 through 2002. Among men and women, death rates declined for most cancers. Among women, lung cancer incidence rates no longer were increasing and death rates, although they still were increasing slightly, were increasing at a much slower rate than in the past. Breast cancer incidence rates in women decreased 3.5% per year from 2001 to 2004, the first decrease observed in 20 years. Colorectal cancer incidence and death rates and prostate cancer death rates declined, with colorectal cancer death rates dropping more sharply from 2002 through 2004. Overall, rates for AI/AN were lower than for NHW from 1999 through 2004 for most cancers, but they were higher for cancers of the stomach, liver, cervix, kidney, and gallbladder. Regional analyses, however, revealed high rates for AI/AN in the Northern and Southern Plains and Alaska. For cancers of the breast, colon and rectum, prostate, and cervix, AI/AN were less likely than NHW to be diagnosed at localized stages. For all races/ethnicities combined in the United States, favorable trends in incidence and mortality were noted for lung and colorectal cancer in men and women and for breast cancer in women. For the AI/AN population, lower overall cancer incidence and death rates obscured important variations by geographic regions and less favorable healthcare access and socioeconomic status. Enhanced tobacco control and cancer screening, especially in the Northern and Southern Plains and Alaska, emerged as clear priorities.

Jemal A, Thun MJ, Ries LA, Howe HL, Weir HK, Center MM, Ward E, Wu XC, Ehemann C, Anderson R, Ajani UA, Kohler B, Edwards BK. **Annual report to the nation on the status of cancer, 1975-2005, featuring trends in lung cancer, tobacco use, and tobacco control.** *J Natl Cancer Inst.* 2008 Dec 3;100(23):1672-94. Epub 2008 Nov 25. PMID 19033571.

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 2008 report includes trends in lung cancer incidence and death rates, tobacco use, and tobacco control by state of residence. Information on invasive cancers was obtained from the NCI, CDC, and NAACCR; information on mortality was obtained

from the CDC's National Center for Health Statistics. Annual percentage changes in the age-standardized incidence and death rates (2000 U.S. 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. 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/or 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. 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.

Edwards BK, Ward E, Kohler BA, Ehemann C, Zauber AG, Anderson RN, Jemal A, Schymura MJ, Lansdorp-Vogelaar I, Seeff LC, van Ballegooijen M, Goede SL, Ries LA. **Annual report to the nation on the status of cancer, 1975-2006, featuring colorectal cancer trends and impact of interventions (risk factors, screening, and treatment) to reduce future rates.** *Cancer*. 2010 Feb 1;116(3):544-73. PMID 19998273.

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 regarding cancer occurrence and trends in the United States. The 2010 report includes trends in colorectal cancer (CRC) incidence and death rates and highlights the use of microsimulation modeling as a tool for interpreting past trends and projecting future trends to assist in cancer control planning and policy decisions. Information regarding invasive cancers was obtained from the NCI, CDC, and NAACCR; information on deaths was obtained from the CDC's National Center for Health Statistics. Annual percentage changes in the age-standardized incidence and death rates (based on the year 2000 U.S. population standard) for all cancers combined and for the top 15

cancers were estimated by joinpoint analysis of long-term trends (1975-2006) and for short-term fixed-interval trends (1997-2006). All statistical tests were two-sided. Both incidence and death rates from all cancers combined significantly declined ($P < .05$) in the most recent time period for men and women overall and for 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 (i.e., lung and prostate cancers and CRC) and for two of the three leading cancers in women (ie, breast cancer and CRC). The long-term trends for lung cancer mortality in women had smaller and smaller increases until 2003, when there was a change to a nonsignificant decline. Microsimulation modeling demonstrates that declines in CRC death rates are consistent with a relatively large contribution from screening and with a smaller but demonstrable impact of risk factor reductions and improved treatments. These declines are projected to continue if risk factor modification, screening, and treatment remain at current rates, but they could be accelerated further with favorable trends in risk factors and higher utilization of screening and optimal treatment. Although the decrease in overall cancer incidence and death rates is encouraging, rising incidence and mortality for some cancers are of concern.

Kohler BA, Ward E, McCarthy BJ, Schymura MJ, Ries LA, Ehemann C, Jemal A, Anderson RN, Ajani UA, Edwards BK. **Annual report to the nation on the status of cancer, 1975-2007, featuring tumors of the brain and other nervous system.** *J Natl Cancer Inst.* 2011 May 4;103(9):714-36. Epub 2011 Mar 31. PMID 21454908.

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. The 2011 report highlights brain and other nervous system (ONS) tumors, including nonmalignant brain tumors, which became reportable on a national level in 2004. Cancer incidence data were obtained from the NCI, CDC, and NAACCR, and information on deaths was obtained from the CDC's National Center for Health Statistics. The annual percentage changes in age-standardized incidence and death rates (2000 U.S. population standard) for all cancers combined and for the top 15 cancers for men and for women were estimated by joinpoint analysis of long-term (1992-2007 for incidence; 1975-2007 for mortality) trends and short-term fixed interval (1998-2007) trends. Analyses of malignant neuroepithelial brain and ONS tumors were based on data from 1980-2007; data on nonmalignant tumors were available for 2004-2007. All statistical tests were two-sided. Overall cancer incidence rates decreased by approximately 1% per year; the decrease was statistically

significant ($P < .05$) in women, but not in men, because of a recent increase in prostate cancer incidence. The death rates continued to decrease for both sexes. Childhood cancer incidence rates continued to increase, whereas death rates continued to decrease. Lung cancer death rates decreased in women for the first time during 2003-2007, more than a decade after decreasing in men. During 2004-2007, more than 213 500 primary brain and ONS tumors were diagnosed, and 35.8% were malignant. From 1987-2007, the incidence of neuroepithelial malignant brain and ONS tumors decreased by 0.4% per year in men and women combined. The decrease in cancer incidence and mortality reflects progress in cancer prevention, early detection, and treatment. However, major challenges remain, including increasing incidence rates and continued low survival for some cancers. Malignant and nonmalignant brain tumors demonstrate differing patterns of occurrence by sex, age, and race, and exhibit considerable biologic diversity. Inclusion of nonmalignant brain tumors in cancer registries provides a fuller assessment of disease burden and medical resource needs associated with these unique tumors.

Boscoe FP, Johnson CJ, Henry KA, Goldberg DW, Shahabi K, Elkin EB, Ballas LK, Cockburn M. **Geographic proximity to treatment for early stage breast cancer and likelihood of mastectomy.** *Breast.* 2011 Aug;20(4):324-8. Epub 2011 Mar 25. PMID 21440439.

Women with early stage breast cancer who live far from a radiation therapy facility may be more likely to opt for mastectomy over breast conserving surgery (BCS). The geographic dimensions of this relationship deserve further scrutiny. For more than 100,000 breast cancer patients in 10 states who received either mastectomy or BCS, a newly-developed software tool was used to calculate the shortest travel distance to the location of surgery and to the nearest radiation treatment center. The likelihood of receipt of mastectomy was modeled as a function of these distance measures and other demographic variables using multilevel logistic regression. Women traveling more than 75 km for treatment were about 1.4 times more likely to receive a mastectomy than those traveling under 15 km. Geographic barriers to optimal breast cancer treatment remain a valid concern, although most women traveling long distances to receive mastectomies are doing so after bypassing local options.

Henry KA, Boscoe FP, Johnson CJ, Goldberg DW, Sherman R, Cockburn M. **Breast cancer stage at diagnosis: is travel time important?** *J Community Health*. 2011 Dec;36(6):933-42. PMID 21461957.

Recent studies have produced inconsistent results in their examination of the potential association between proximity to health care or mammography facilities and breast cancer stage at diagnosis. Using a multistate dataset, the authors re-examine this issue by investigating whether travel time to a patient's diagnosing facility or nearest mammography facility impacts breast cancer stage at diagnosis. We studied 161,619 women 40 years and older diagnosed with invasive breast cancer from 10 state population-based cancer registries in the United States. For each woman, they calculated travel time to their diagnosing facility and nearest mammography facility. Logistic multilevel models of late versus early stage were fitted, and odds ratios were calculated for travel times, controlling for age, race/ethnicity, census tract poverty, rural/urban residence, health insurance, and state random effects. Seventy-six percent of women in the study lived less than 20 minutes from their diagnosing facility, and 93 percent lived less than 20 minutes from the nearest mammography facility. Late stage at diagnosis was not associated with increasing travel time to diagnosing facility or nearest mammography facility. Diagnosis age under 50, Hispanic and non-Hispanic Black race/ethnicity, high census tract poverty, and no health insurance were all significantly associated with late stage at diagnosis. Travel time to diagnosing facility or nearest mammography facility was not a determinant of late stage of breast cancer at diagnosis, and better geographic proximity did not assure more favorable stage distributions. Other factors beyond geographic proximity that can affect access should be evaluated more closely, including facility capacity, insurance acceptance, public transportation, and travel costs.

NAACCR, Inc.
2121 W. White Oaks Drive, Suite B
Springfield, IL 62704
217.698.0800
217.698.0188 fax
info@naaccr.org
www.naaccr.org