Promoting the Use of Cancer Registry Data for Colorectal Cancer Prevention and Control

Faruque Ahmed, MD, PhD, MPH
Cancer Surveillance Branch
Centers for Disease Control and Prevention
(E-mail: fahmed@cdc.gov)

Department of Health and Human Services
Federal Cancer Registry Programs, USA

- NCI’s Surveillance, Epidemiology, and End Results (SEER) Program
  - National Cancer Act, 1971
- CDC’s National Program of Cancer Registries (NPCR)
  - Cancer Registries Amendment Act, 1992
Colorectal Cancer Monograph Project

- Use registry data to provide information for colorectal cancer (CRC) prevention and control

- Publish monograph as a journal supplement

- First time that NPCR is coordinating a monograph

- Increased attention of public health community on colorectal cancer
Are You the Picture of Health?

“You might look and feel fine, but you need to get the inside story. Colorectal cancer often has no symptoms, so please get tested. I did.”

Katie Couric, Co-Founder
EIF’s National Colorectal Cancer Research Alliance

If you’re over 50, talk to your doctor and get screened.

www.cdc.gov/screenforlife
CRC Monograph Collaborators

- NPCR- and SEER-funded cancer registries
- National Cancer Institute
- Centers for Disease Control and Prevention
- American Cancer Society
- ORC Macro
Monograph Chapters

- Introductory article
- CRC incidence by age, sex, race, and ethnicity
- Incidence in children and young adults
- Incidence patterns by histology and grade
- Urban/rural differences in incidence
Monograph Chapters (Contd.)

- Effects of urban/rural and SES on stage
- Subsite-specific incidence and stage distributions by SES
- Secular changes in incidence by subsite, stage, and race/ethnicity
- Relationship between stage at diagnosis and proximity to endoscopy facilities
Monograph Chapters (Contd.)

- CRC mortality and YPLL by race and ethnicity
- Regional variations in incidence and mortality
- Factors associated with regional differences in incidence and mortality
- Extracolonic primary cancers in CRC survivors
- NPCR case completeness and data quality
CRC Monograph Data

- NPCR and SEER: Cancer incidence data*
- NCHS: Cancer mortality data*
- BRFSS: Behavioral data

*Linked county-based SES data from Census 2000
Steering Committee Recommendations

• Data for calendar years 1998-2001
  – Exceptions: Trends, multiple primaries

• NPCR and SEER registries meeting *U.S. Cancer Statistics* data quality criteria for all four years
Registries Meeting Quality Criteria, 1998-2001

*89% U.S. population coverage
CRC Incidence is Declining, 1998-2001

*542,149 CRC cases (89% U.S. population coverage)
CRC Incidence By Race, 1998-2001

Women

Age (years)

Rate per 100,000

30-34 35-39 40-44 45-49 50-54 55-59 60-64 65-69 70-74 75-79 80-84 85+

White
Black
Asian/Pacific Islander
Incidence of Right Colon Cancer Increases With Age, Men, 1998-2001

*Right colon: cecum to splenic flexure
Incidence of Right Colon Cancer Increases With Age, Women, 1998-2001

*Right colon: cecum to splenic flexure

*Percent of county population below federal poverty level (data not available for 4 states)

*Percent of county population below federal poverty level (data not available for 4 states)
CRC Incidence Among Persons Aged >50 Yrs*

*Age-adjusted to the 2000 U.S. standard population

---

**Male**
Rate per 100,000

- 163.4 - 198.6
- 198.7 - 225.9
- 226.0 - 241.5
- 241.6 - 259.5
- No Data

**Female**
Rate per 100,000

- 115.3 - 143.2
- 143.3 - 160.1
- 160.2 - 172.7
- 172.8 - 195.3
- No Data
Challenges

- Potential overlap between chapters
- NPCR data accessible only by CDC and ORC Macro staff*

*Public-use dataset in beta testing phase (CDC WONDER). Restricted-access dataset will be available for researchers.
Presentation of Selected Chapters

• NAACCR Conference, June 2005
  – Effect of urban/rural and SES on stage
  – Subsite-specific incidence and stage
  – Histologic patterns of CRC incidence
  – CRC monograph introductory chapter
  – NPCR case completeness and data quality
Presentation of Selected Chapters (Contd.)

• Society for Epidemiologic Research Conference, June 2005
  – Extracolonic primary cancers in CRC survivors
Extracolonic Primary Cancers in Colorectal Carcinoma Survivors: Results Using 1975-2001 SEER Data

Faruque Ahmed*, Marc Goodman†, Carol Kosary‡, Bernado Ruiz§, Xiao-Cheng Wu§, Vivien Chen§, and Catherine Correa§

*Centers for Disease Control and Prevention, Atlanta
†University of Hawaii, Honolulu
‡National Cancer Institute, Bethesda
§Louisiana State University, New Orleans
Excess Risk of Primary Cancers in CRC Survivors: Definition

Excess risk* =

(# of observed cancers in CRC survivors) –

(# of expected cancers if CRC survivors had the same cancer rate as the general population)

*Excess number of primary cancers per 10,000 CRC survivors per year
Excess Risk of Primary Cancers in CRC Survivors is Low

*Per 10,000 CRC survivors per yr
Excess Risk of Primary Cancers in CRC Survivors is High in Certain Subgroups

Excess Risk* Per 10,000 CRC survivors per yr

- Uterus, Females Aged <50 yrs
- Prostate, Black Males

*Per 10,000 CRC survivors per yr
Publication of Monograph

- Special supplement of the journal *CANCER*
- To be published in summer 2006
Acknowledgments

• Such a monograph possible because of substantial prior work over the years
  – NPCR and SEER cancer registries
  – NAACCR
  – NCI
  – CDC
• Contributions of the 60 monograph participants
CRC Monograph Participants

- Aaron Adade
- Faruque Ahmed
- Linda Alley
- Lyn Almon
- Janet Bates
- Vivien Chen
- Vilma Cokkinides
- Patricia Colsher
- Sharan Campleman
- Catherine Correa
- Carol Gotway Crawford
- Rosemary Cress
- Steven Coughlin
- John O. Davies-Cole

- Brenda Edwards
- Donatus Ekwueme
- Gary Ellison
- Temeika Fairley
- Carol Friedman
- Robert German
- Marc Goodman
- Benjamin Hankey
- Jovanka Harrison
- Missy Jamison
- Amy Kahn
- Ikuko Kato
- Janet Kelly
- Mynna Kightlinger
CRC Monograph Participants (Contd.)

- Jessica King
- Carol Kosary
- Sue-Min Lai
- Anne Lanier
- Denise Lewis
- Mary Lewis
- Jim Martin
- Genevieve Matanoski
- Frances Michaud
- Barry Miller
- Cyllene Morris
- Marion Nadel
- Janie Nichols
- Arti Parikh-Patel
- Loria Pollack
- Yuan Ren
- Thomas Richards
- Bernado Ruiz
- Laura Seeff
- Recinda Sherman-Seitz
- Sherri Stewart
- Grant Tao
- Kathleen Thoburn
- Jeannette Jackson-Thompson
- Trevor Thompson
- Bob Uhler
- Juliet VanEenwyk
- Jen Wike
- Melanie Williams
- Phyllis Wingo
- Xiao-Cheng Wu
- Kevin Zhang
www.cdc.gov/cancer