

# **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](mailto:fahmed@cdc.gov))**



Department of Health and Human Services



# **Federal Cancer Registry Programs, USA**

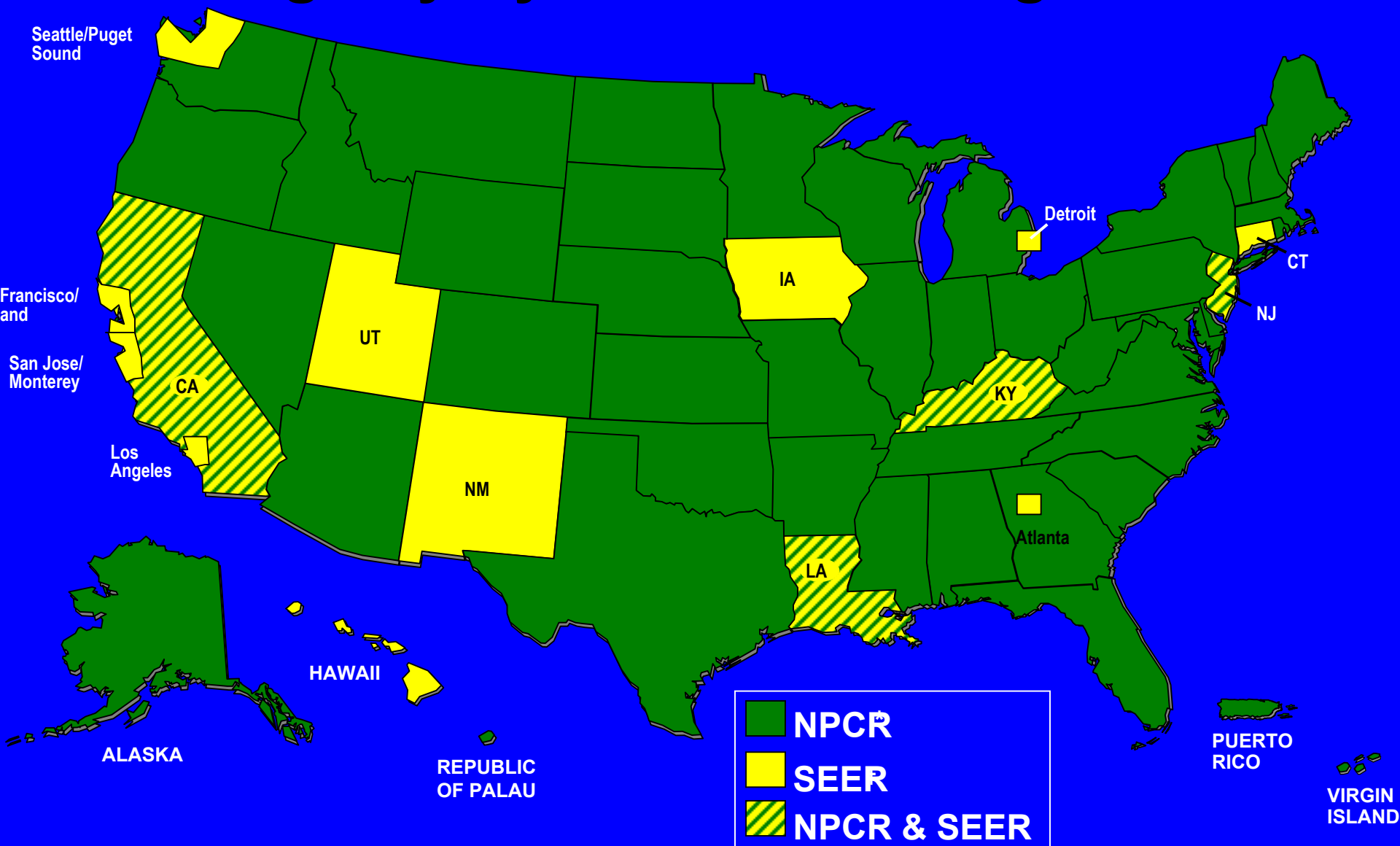
## **NCI's Surveillance, Epidemiology, and End Results (SEER) Program**

- National Cancer Act, 1971**

## **CDC's National Program of Cancer Registries (NPCR)**

- Cancer Registries Amendment Act, 1992**

# Cancer Registry By Federal Funding Source 2000



National Program of Cancer Registries (CDC)  
Surveillance, Epidemiology, and End Results Program (NCI)

# **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?

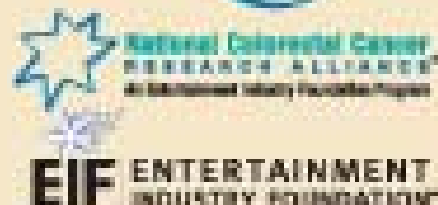
“You might look and  
feel fine, but you need  
to get the inside story.  
Colorectal cancer often  
has no symptoms, so  
please get tested. I did.”

*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](http://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**

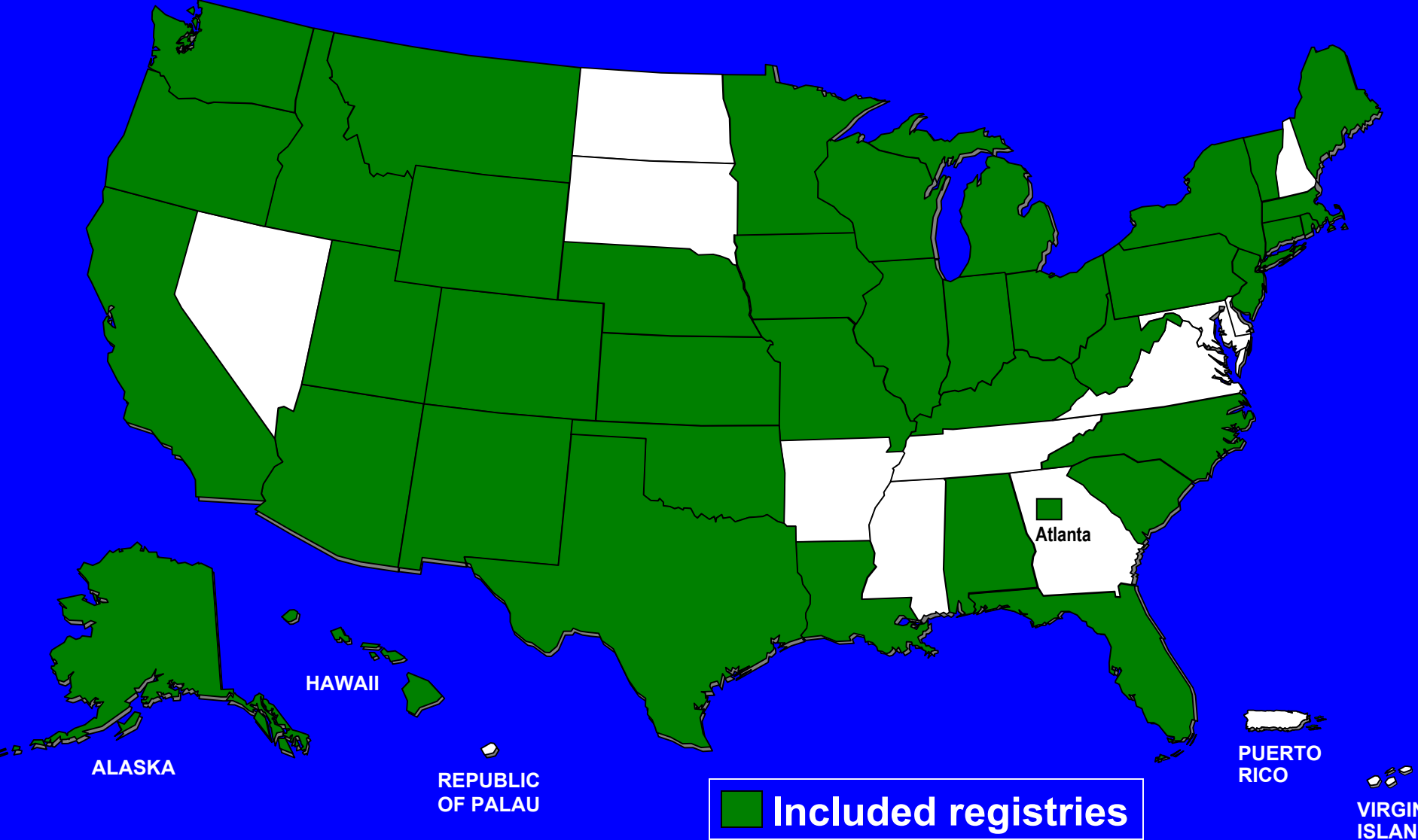
- **NPCR and SEER: Cancer incidence data\***
- **NCHS: Cancer mortality data\***
- **BRFSS: Behavioral data**

**\*Linked county-based SES data from Census 2000**

# Steering Committee Recommendations

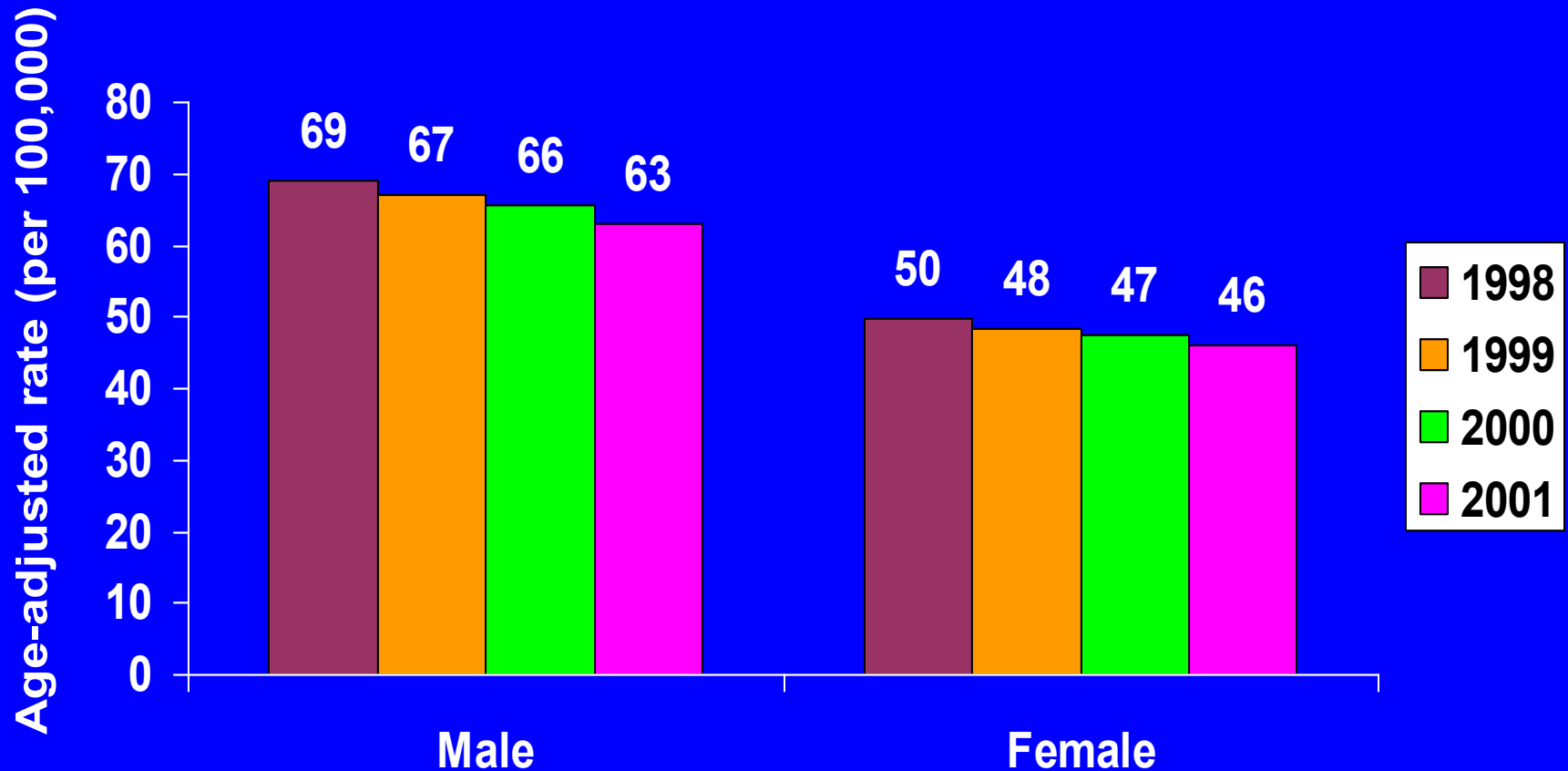
- Data for calendar years 1998-2001
  - Exceptions: Trends, multiple primaries
- NPCR and SEER registries meeting *U.S. Cancer Statistics* data quality criteria for all four years

# Registries Meeting Quality Criteria, 1998-2001\*



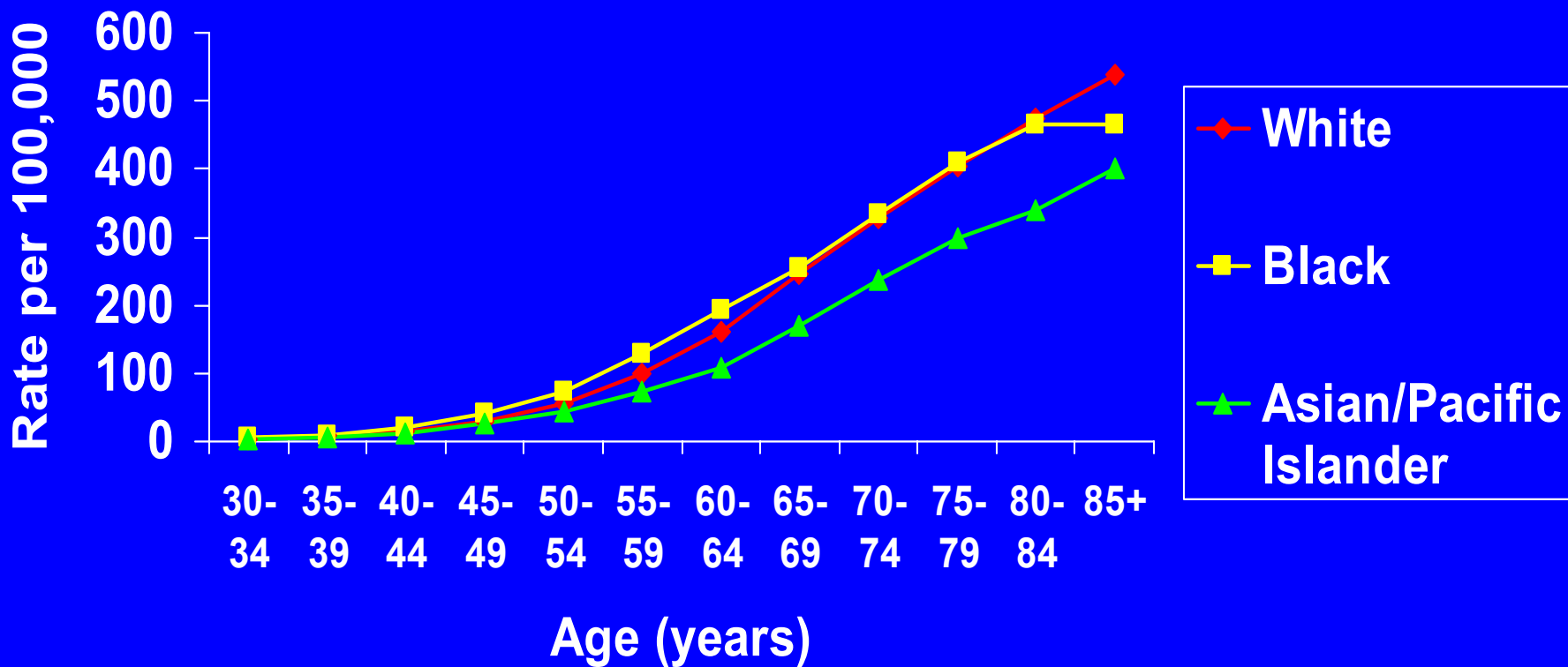
\*89% U.S. population coverage

# CRC Incidence is Declining, 1998-2001\*

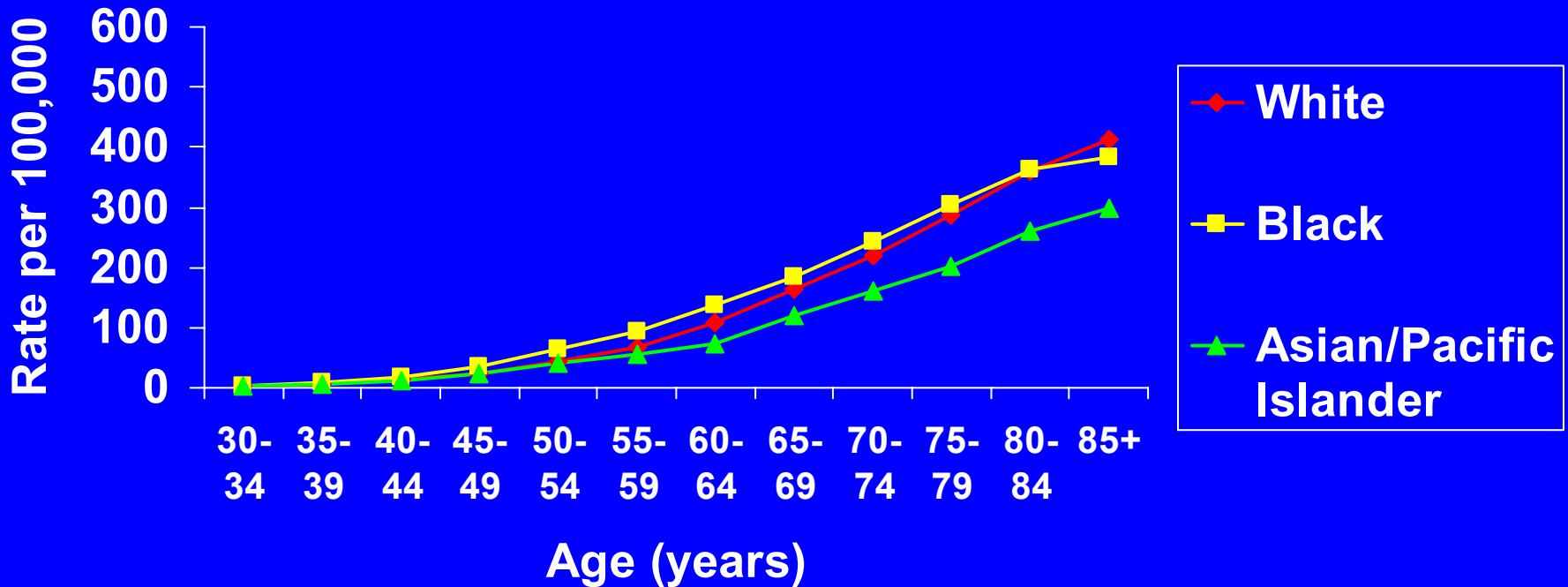


\*542,149 CRC cases (89% U.S. population coverage)

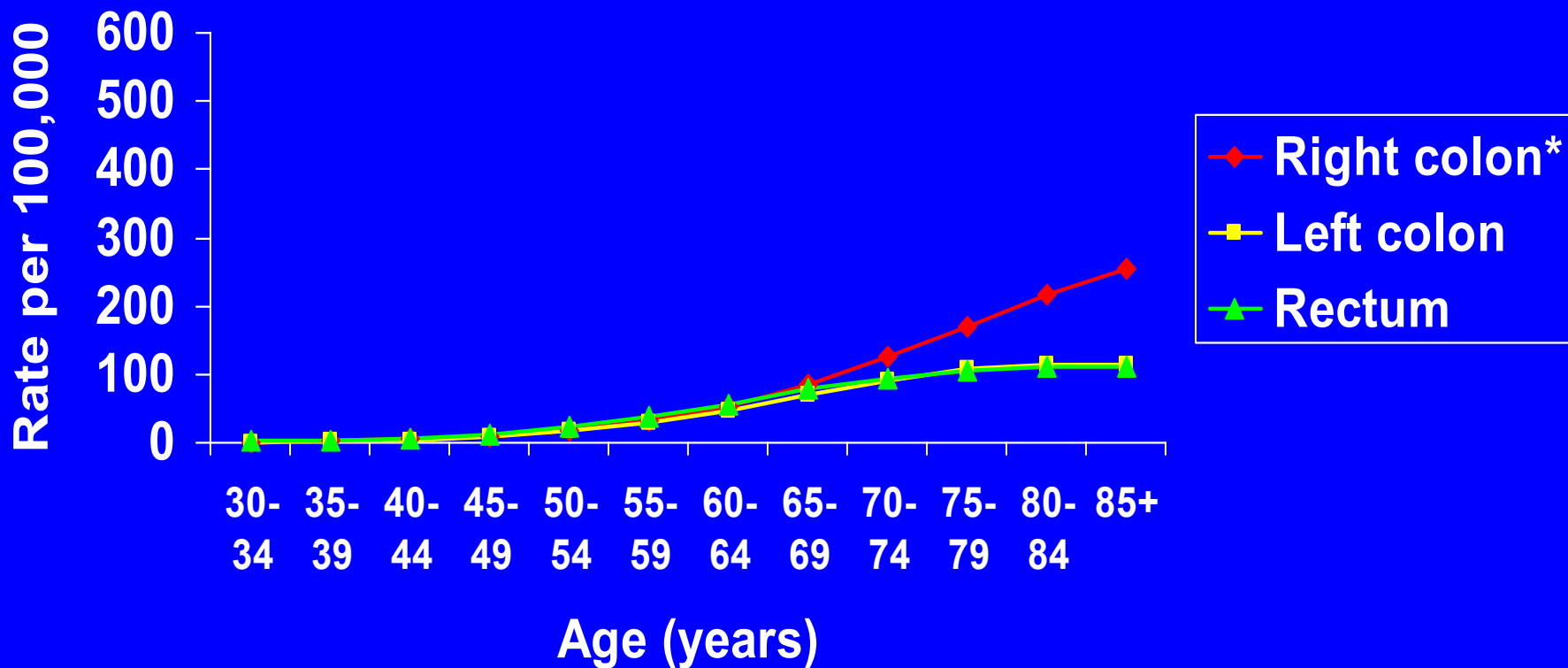
# CRC Incidence By Race, 1998-2001 Men



# CRC Incidence By Race, 1998-2001 Women



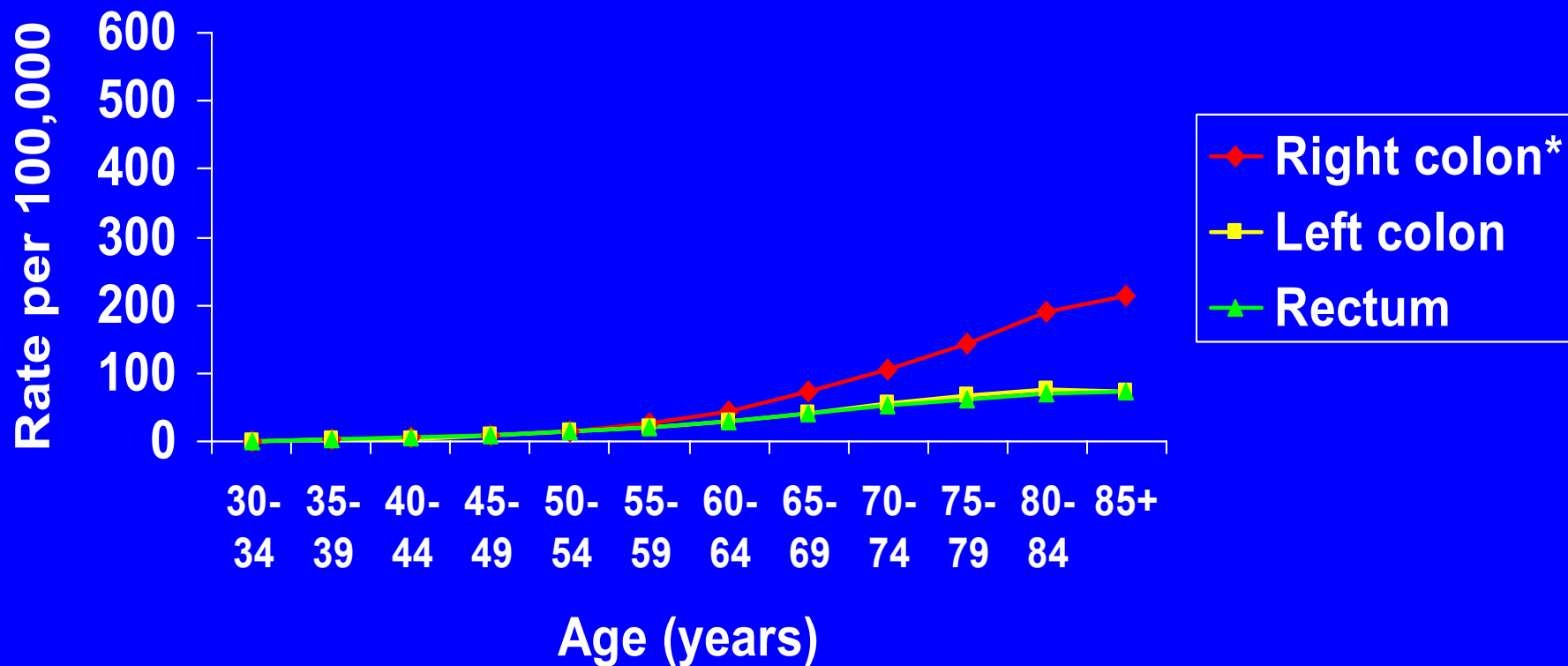
# Incidence of Right Colon Cancer Increases With Age, Men, 1998-2001



\*Right colon: cecum to splenic flexure

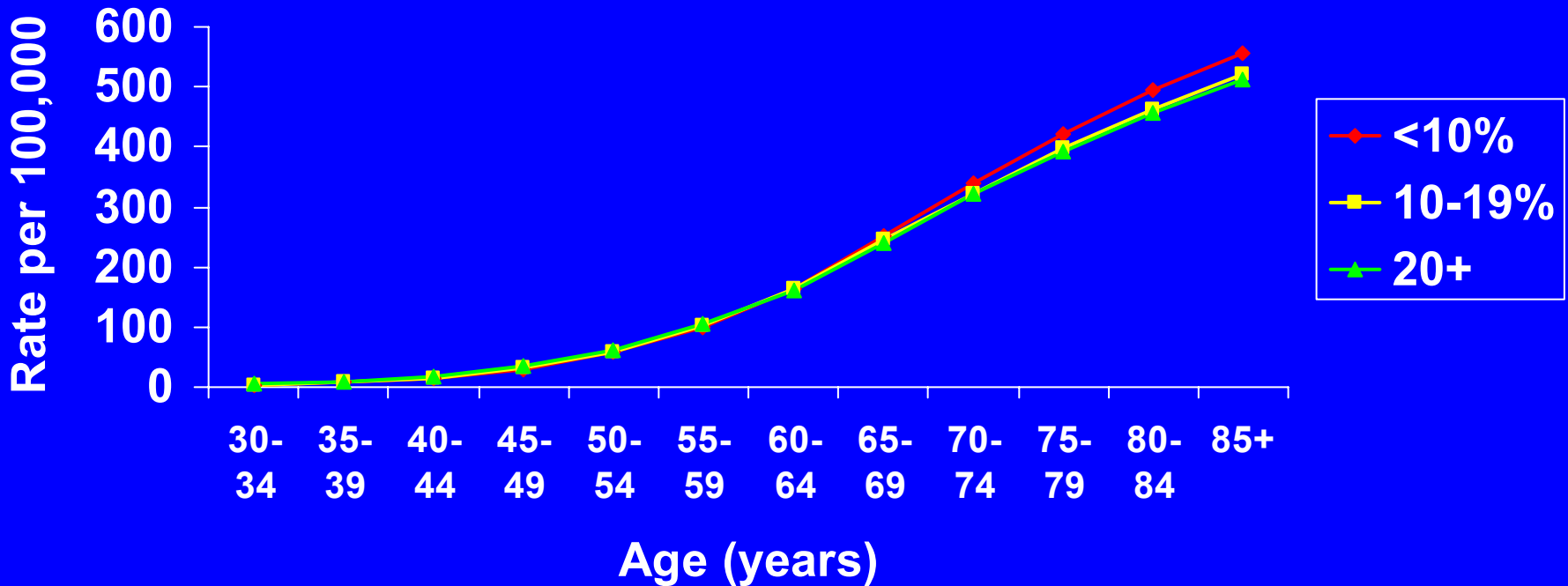


# Incidence of Right Colon Cancer Increases With Age, Women, 1998-2001



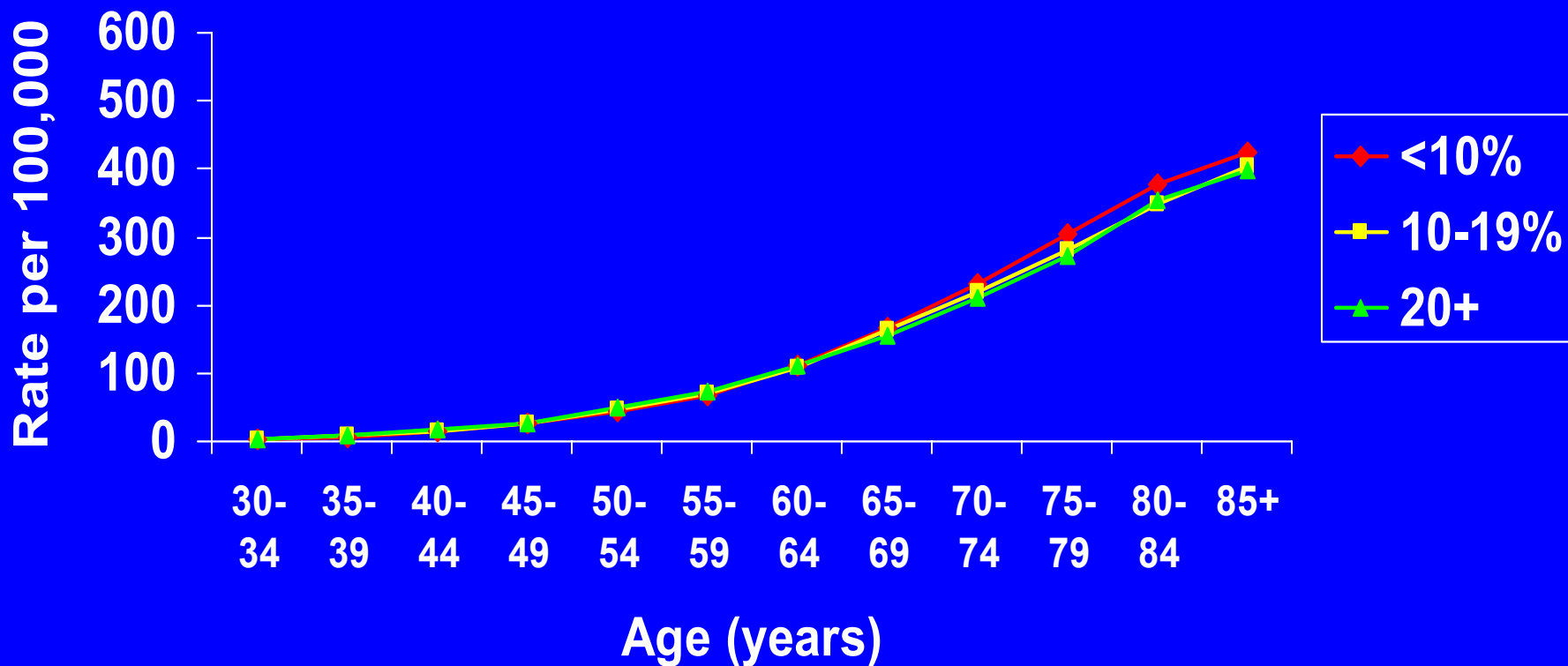
\*Right colon: cecum to splenic flexure

# CRC Incidence Is Higher In Counties With Less Poverty\*, Men, 1998-2001



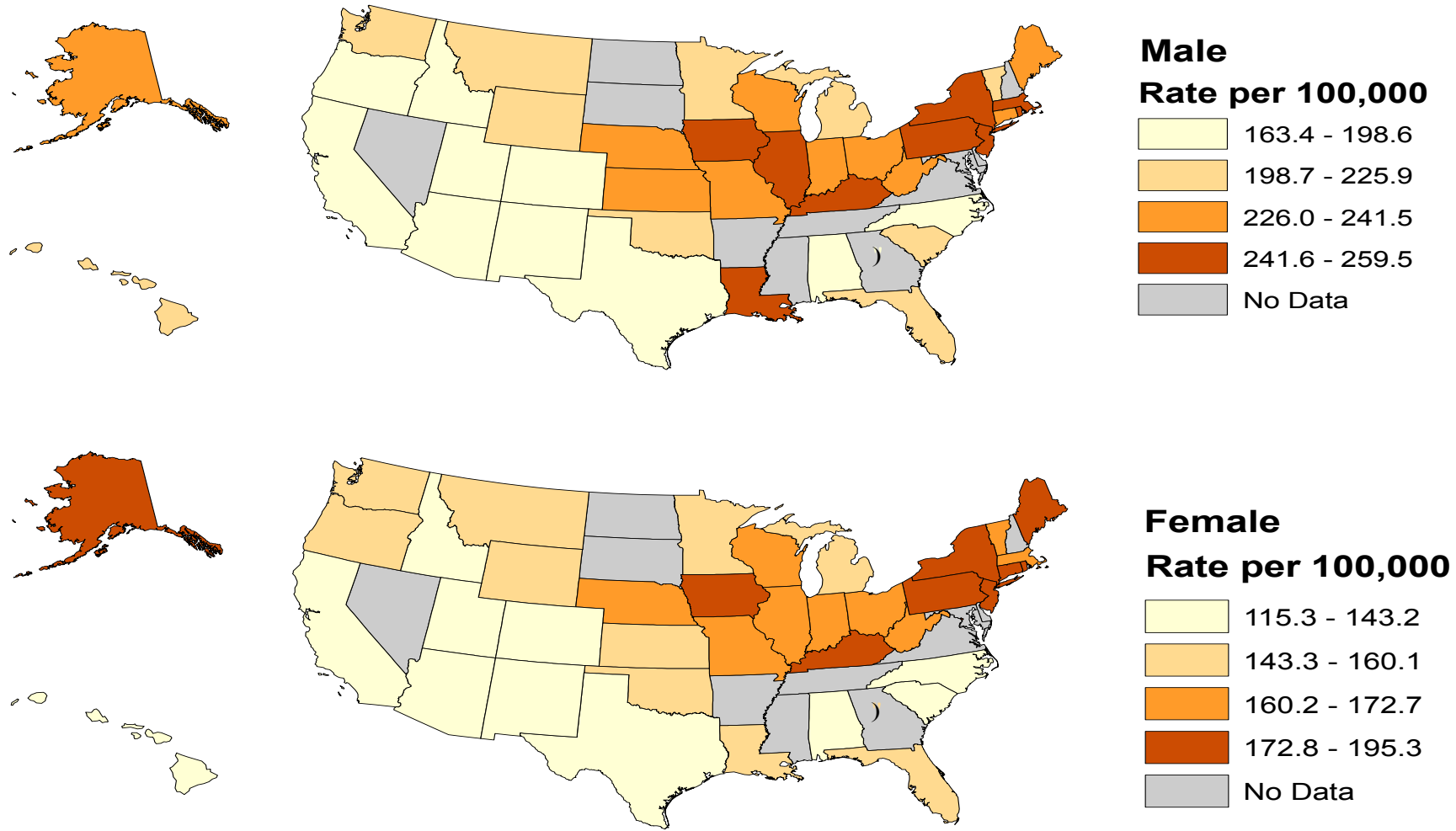
\*Percent of county population below federal poverty level (data not available for 4 states)

# CRC Incidence Is Higher In Counties With Less Poverty\*, Women, 1998-2001



\*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

# 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**



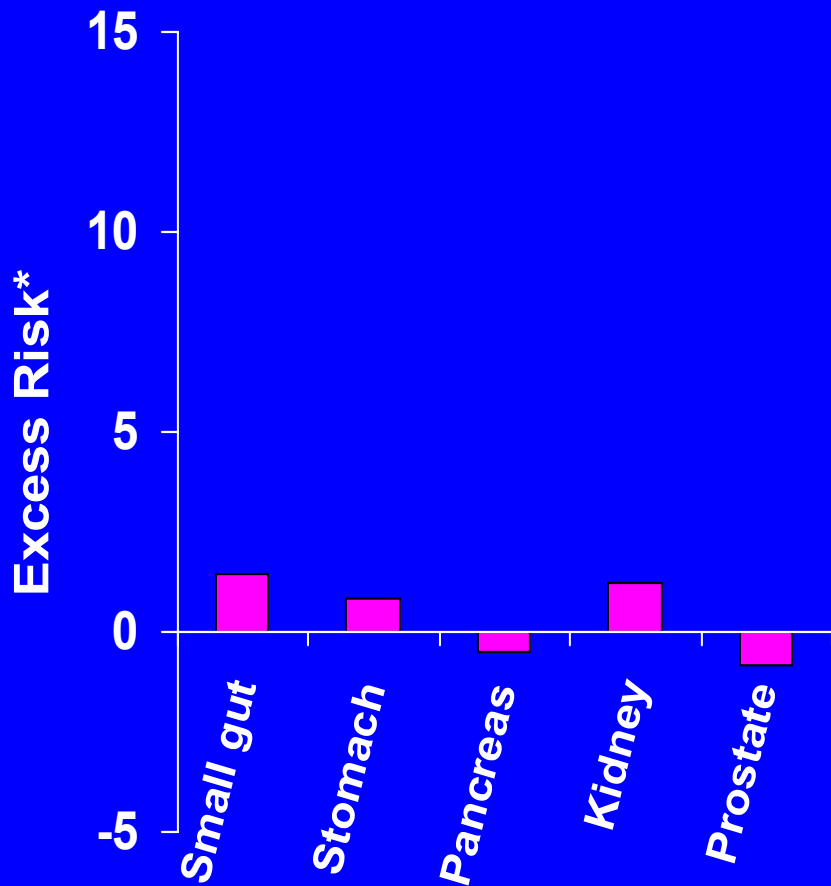
# Excess Risk of Primary Cancers in CRC Survivors: Definition

**Excess risk\* =**

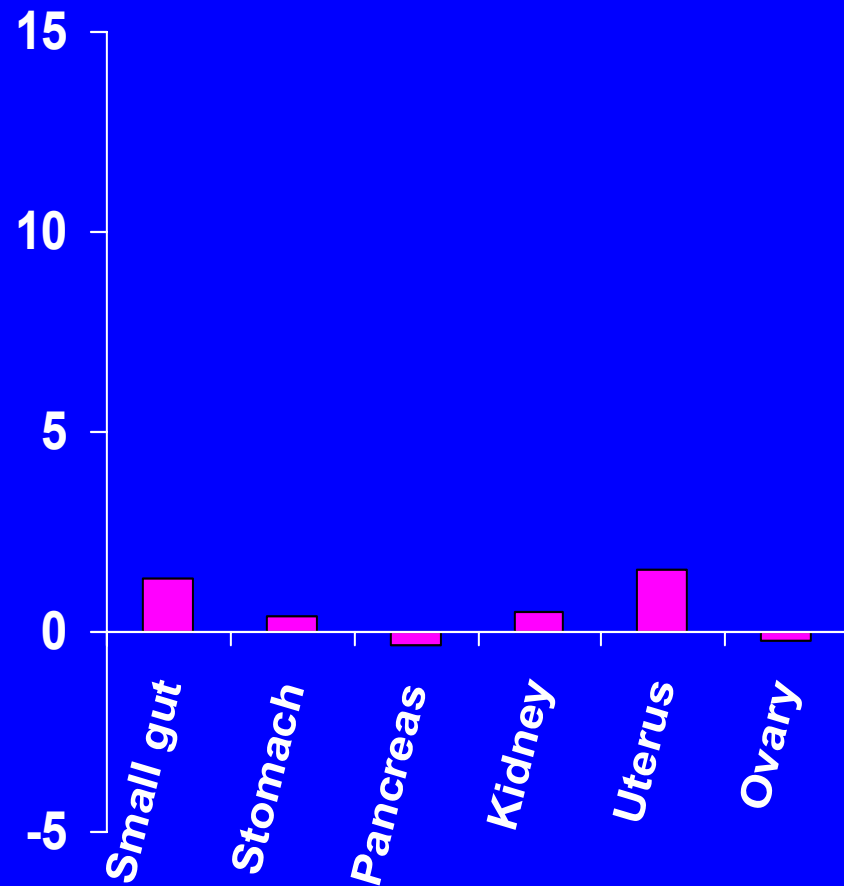
**(# of *observed* cancers in CRC survivors) –  
(# of *expected* cancers if CRC survivors had  
the same cancer rate as the general  
population)**

**\*Excess number of primary cancers per  
10,000 CRC survivors per year**

# Excess Risk of Primary Cancers in CRC Survivors is Low



**Male**



**Female**

\*Per 10,000 CRC survivors per yr

# Excess Risk of Primary Cancers in CRC Survivors is High in Certain Subgroups



\*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](http://www.cdc.gov/cancer)