Nevada Central Cancer Registry Summit

Cancer Surveillance: It’s All About the Data

Fran Babcock, CTR, MT, BS
Deputy Branch Chief
Cancer Surveillance Branch

May 8, 2014
Presentation Outline

- Overview Cancer Surveillance Branch
- National Program of Central Registries
- Comparative Effectiveness Research (CER)
- Patient Centered Outcomes Research (PCOR)
CSB Mission

To lead, support, and enhance cancer surveillance systems and expand public health and research uses of cancer surveillance data.
**CSB Goals:**

- Provide leadership and direction for cancer surveillance in the U.S.
- Provide data on and conduct research with cancer incidence and mortality data to improve outcomes.
- Assess quality of cancer care and conduct patient centered outcomes research.
- Modernize cancer surveillance systems to improve accuracy, timeliness, and efficiency of registry systems.
- Expand the utility of cancer surveillance and surveillance data in areas including: cancer survivorship, cancer screening, evaluation of cancer interventions, and prevention.
National Program of Cancer Registries (NPCR)

- 1992 Cancer Registry Amendment Act, Public Law 102-515, authorized CDC to establish NPCR
  - Provided funds to CDC for funding states and territories to enhance or plan/implement registries
  - Work with states to develop model legislation and regulations
  - Provide training on Central Registry operations
  - Standardize a minimum set of data items
  - Set national standards for completeness, timeliness and quality
Scope of CDC Cancer Surveillance

- 48 funded programs
  - 45 states, DC, Puerto Rico, Pacific Islands Jurisdiction
- NPCR U.S. population coverage - 96% percent
  - In collaboration with NCI – 100% population coverage
- NPCR Cancer Surveillance System
  - Approximately 1.2 million new invasive cancer cases are submitted to CDC electronically each year
  - Data base includes approximately 18.4 million invasive cancer cases from 1995–2010
  - CDC does not receive identifiers (name, address, SSN)
NPCR: Data Flow

- Hospitals
NPCR: Data Flow

- Hospitals
- Radiation therapy centers
NPCR: Data Flow

- Hospitals
- Radiation therapy centers
- Medical oncology facilities
NPCR: Data Flow

- Hospitals
- Radiation therapy centers
- Medical oncology facilities
- Outpatient centers
NPCR: Data Flow

- Hospitals
- Radiation therapy centers
- Medical oncology facilities
- Outpatient centers
- Laboratories
NPCR: Data Flow

- Hospitals
- Radiation therapy centers
- Medical oncology facilities
- Outpatient centers
- Laboratories
- Physicians
NPCR: Data Flow

- Hospitals
- Radiation therapy centers
- Medical oncology facilities
- Outpatient centers
- Laboratories

State Central Cancer Registry Consolidation
NPCR: Data Flow

- Hospitals
- Radiation therapy centers
- Medical oncology facilities
- Outpatient centers
- Laboratories
- Physicians

State Central Cancer Registry Consolidation

Missing data consolidation
NPCR: Data Flow

- Hospitals
- Radiation therapy centers
- Medical oncology facilities
- Outpatient centers
- Laboratories
- Physicians

State Central Cancer Registry Consolidation

Final data

Missing data consolidation
NPCR Data Items

1ICD-O codes – conversion in data set to manage changes over time
NPCR Data Items

Record Identification
- Registry identification
- Patient ID number

\(^1\)ICD-O codes – conversion in data set to manage changes over time
NPCR Data Items

Record Identification
- Registry identification
- Patient ID number

Demographic
- Race
- Age
- Sex
- State
- County
- Zip code
- Census tract

\(^1\)ICD-O codes – conversion in data set to manage changes over time
## NPCR Data Items

<table>
<thead>
<tr>
<th>Record Identification</th>
<th>Cancer Identification ¹</th>
</tr>
</thead>
<tbody>
<tr>
<td>– Registry identification</td>
<td>– Date of diagnosis</td>
</tr>
<tr>
<td>– Patient ID number</td>
<td>– Primary site</td>
</tr>
<tr>
<td></td>
<td>– Histology</td>
</tr>
</tbody>
</table>

### Demographic
- Race
- Age
- Sex
- State
- County
- Zip code
- Census tract

¹ICD-O codes – conversion in data set to manage changes over time
## NPCR Data Items

<table>
<thead>
<tr>
<th>Record Identification</th>
<th>Cancer Identification&lt;sup&gt;1&lt;/sup&gt;</th>
<th>Reporting Source</th>
</tr>
</thead>
<tbody>
<tr>
<td>Registry identification</td>
<td>Date of diagnosis</td>
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</tr>
<tr>
<td>Patient ID number</td>
<td>Primary site</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Histology</td>
<td></td>
</tr>
<tr>
<td>Demographic</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Race</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sex</td>
<td></td>
<td></td>
</tr>
<tr>
<td>State</td>
<td></td>
<td></td>
</tr>
<tr>
<td>County</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Zip code</td>
<td></td>
<td></td>
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<tr>
<td>Census tract</td>
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</tbody>
</table>

<sup>1</sup>ICD-O codes – conversion in data set to manage changes over time
# NPCR Data Items

<table>
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<tr>
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<th>Cancer Identification¹</th>
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</thead>
<tbody>
<tr>
<td>– Registry identification</td>
<td>– Date of diagnosis</td>
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<tr>
<td>– Patient ID number</td>
<td>– Primary site</td>
</tr>
<tr>
<td></td>
<td>– Histology</td>
</tr>
</tbody>
</table>

**Demographic**

- Race
- Age
- Sex
- State
- County
- Zip code
- Census tract

**Cancer Identification¹**

- Date of diagnosis
- Primary site
- Histology

**Reporting Source**

**Stage/Prognostic Factors**

- Summary stage
- Biomarkers (HER2, PR, ER)

¹ICD-O codes – conversion in data set to manage changes over time
# NPCR Data Items

<table>
<thead>
<tr>
<th>Record Identification</th>
<th>Cancer Identification¹</th>
<th>Follow-up/Death</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Registry identification</td>
<td>- Date of diagnosis</td>
<td>- Date of last contact/death</td>
</tr>
<tr>
<td>- Patient ID number</td>
<td>- Primary site</td>
<td>- Vital status</td>
</tr>
</tbody>
</table>

## Demographic
- Race
- Age
- Sex
- State
- County
- Zip code
- Census tract

## Reporting Source

### Stage/Prognostic Factors
- Summary stage
- Biomarkers (HER2, PR, ER)

¹ICD-O codes – conversion in data set to manage changes over time
<table>
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<tr>
<th>NPCR Data Items</th>
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<td><strong>Record Identification</strong></td>
</tr>
<tr>
<td>– Registry identification</td>
</tr>
<tr>
<td>– Patient ID number</td>
</tr>
<tr>
<td><strong>Demographic</strong></td>
</tr>
<tr>
<td>– Race</td>
</tr>
<tr>
<td>– Age</td>
</tr>
<tr>
<td>– Sex</td>
</tr>
<tr>
<td>– State</td>
</tr>
</tbody>
</table>
Standard Collection of Treatment Data within NPCR

- **Type of surgery**
  - Typically hospital based
  - Generally complete and accurate

- **Radiotherapy**
  - Radiation Oncologists tend to report to central cancer registry
  - Likely not as complete as surgery data

- **Chemotherapy**
  - Often not in hospital setting
  - Very difficult to collect
Cancer Data & Tools
Hosted by DCPC

- **United States Cancer Statistics**
  - Web-based report contains official federal government cancer statistics for new cancer cases and deaths.

- **Interactive Cancer Atlas (InCA)**
  - Web-based, interactive geographical information system (GIS) application that generates customized maps using data from the United States Cancer Statistics (USCS) series.
    - [http://apps.nccd.cdc.gov/DCPC_INCA/DCPC_INCA.aspx](http://apps.nccd.cdc.gov/DCPC_INCA/DCPC_INCA.aspx)

- **State Cancer Facts**
  - Provides state-specific data on primary sites, including number of new cancer cases, cancer deaths, and the age-adjusted incidence and mortality rates by race.
USCS Graphs

National Program of Cancer Registries (NPCR)

United States Cancer Statistics (USCS)

2009 Top Ten Cancers

Age-Adjusted Invasive Cancer Incidence Rates for the 10 Primary Sites with the Highest Rates within Race-and Ethnic-Specific Categories (Table 4.1.M1)

- Rates are per 100,000 persons and are age-adjusted to the 2000 U.S. standard population (19 age groups - Census P25-1130).
- Select Race: White, Black, Hispanic, Asian/Pacific Islander, American Indian/Alaska Native, Other.
- Incidence Rates
- Mortality Rates

Top 10 Cancer Sites: 2009, Male, United States—All Races

- Prostate
- Lung and Bronchi
- Colon and Rectum
- Urinary Bladder
- Melanomas of the Skin
- Non-Hodgkin Lymphoma
- Kidney and Renal Pelvis
- Oral Cavity and Pharynx
- Leukemias
- Pancreas
## United States Cancer Statistics (USCS)

### 2009 Cancer Types Grouped by Race and Ethnicity

#### All Cancer Sites Combined

**Display by Race & Ethnicity (Age-adjusted)**

For combined data, select 2005-2009 from Year.

#### Cancer Sites

<table>
<thead>
<tr>
<th>Cancer Sites</th>
<th>All Races</th>
<th>White</th>
<th>Black</th>
<th>Asian/Pacific Islander</th>
<th>American Indian/Alaska Native</th>
<th>Hispanic</th>
</tr>
</thead>
<tbody>
<tr>
<td>All Cancer Sites Combined</td>
<td>535.3</td>
<td>535.3</td>
<td>535.7</td>
<td>393.6</td>
<td>294.0</td>
<td>395.2</td>
</tr>
<tr>
<td>All Cancer Sites Combined (comparable to ICD-O-2)</td>
<td>515.3</td>
<td>504.7</td>
<td>587.6</td>
<td>303.3</td>
<td>201.8</td>
<td>388.8</td>
</tr>
<tr>
<td>Oral Cavity and Pharynx Data By Age</td>
<td>10.5</td>
<td>16.7</td>
<td>15.1</td>
<td>10.3</td>
<td>0.5</td>
<td>10.6</td>
</tr>
<tr>
<td>Lip</td>
<td>1.0</td>
<td>1.1</td>
<td>0.1</td>
<td>0.3</td>
<td>0.3</td>
<td>0.4</td>
</tr>
<tr>
<td>Tongue</td>
<td>4.6</td>
<td>5.1</td>
<td>3.4</td>
<td>2.4</td>
<td>2.2</td>
<td>2.7</td>
</tr>
<tr>
<td>Salivary Gland</td>
<td>1.6</td>
<td>1.7</td>
<td>1.2</td>
<td>0.5</td>
<td>1.1</td>
<td>1.1</td>
</tr>
<tr>
<td>Floor of Mouth</td>
<td>0.9</td>
<td>0.9</td>
<td>1.1</td>
<td>1.1</td>
<td>0.6</td>
<td>0.6</td>
</tr>
<tr>
<td>Gum and Other Mouth</td>
<td>1.8</td>
<td>1.8</td>
<td>1.7</td>
<td>1.7</td>
<td>1.3</td>
<td>1.3</td>
</tr>
<tr>
<td>Nasopharynx</td>
<td>0.8</td>
<td>0.6</td>
<td>1.1</td>
<td>3.1</td>
<td>0.5</td>
<td>0.5</td>
</tr>
<tr>
<td>Tongue</td>
<td>2.4</td>
<td>3.5</td>
<td>3.0</td>
<td>1.9</td>
<td>1.6</td>
<td>2.1</td>
</tr>
<tr>
<td>Osopharynx</td>
<td>0.7</td>
<td>0.7</td>
<td>0.7</td>
<td>0.7</td>
<td>0.6</td>
<td>0.6</td>
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<tr>
<td>Hypopharynx</td>
<td>1.5</td>
<td>1.1</td>
<td>0.0</td>
<td>0.6</td>
<td>1.1</td>
<td>1.1</td>
</tr>
<tr>
<td>Other Oral Cavity and Pharynx</td>
<td>0.4</td>
<td>0.4</td>
<td>0.5</td>
<td>0.4</td>
<td>0.5</td>
<td>0.5</td>
</tr>
<tr>
<td>Digestive System</td>
<td>99.1</td>
<td>95.6</td>
<td>127.6</td>
<td>92.5</td>
<td>73.5</td>
<td>97.9</td>
</tr>
<tr>
<td>Esophagus Data By Age</td>
<td>0.5</td>
<td>0.7</td>
<td>0.2</td>
<td>3.3</td>
<td>5.2</td>
<td>5.0</td>
</tr>
<tr>
<td>Stomach Data By Age</td>
<td>9.1</td>
<td>8.1</td>
<td>15.4</td>
<td>14.8</td>
<td>7.1</td>
<td>18.2</td>
</tr>
<tr>
<td>Small Intestine</td>
<td>2.4</td>
<td>2.4</td>
<td>3.6</td>
<td>1.3</td>
<td>1.2</td>
<td>1.7</td>
</tr>
</tbody>
</table>
USCS State Cancer Facts

2009* State Cancer Facts

State Cancer Facts show information for new cancer cases and deaths by state for the most common cancers.

Select a state on the map, or select from the list and click "Go."

Date last revised: November 21, 2012
*The most recent year for which statistics are currently available.
Content source: Division of Cancer Prevention and Control, National Center for Chronic Disease Prevention and Health Promotion
State Cancer Facts

Georgia

In 2009, according to the United States Cancer Statistics:

- 1,476,504 new cancer cases were diagnosed in the United States, including 42,432 in Georgia.
- 557,614 cancer deaths occurred in the United States, including 15,139 in Georgia.

New Cancer Case (Incidence) Rates

<table>
<thead>
<tr>
<th>Area</th>
<th>Rate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Georgia</td>
<td>401.4</td>
</tr>
<tr>
<td>United States</td>
<td>459.0</td>
</tr>
</tbody>
</table>

For every 100,000 men and women in Georgia, on average, approximately 401 were diagnosed with cancer and approximately 173 died from it.

For more information about top 10 cancers in Georgia:
- New cancer cases by gender
- Cancer deaths by gender

Note: Cancer data by race and ethnicity are available also from the links above.

* Case counts, incidence rates cover approximately 90% of the U.S. population; death counts and death rates cover approximately 100% of the U.S. population.
* Rates are per 100,000 persons and are age-adjusted to the 2000 U.S. standard population (19 age groups — Census P25-1100). See USCS for 95% confidence intervals for rates.

Cancer Facts "At a Glance"

Georgia Cancer Facts (PDF - Approximately 55K)

This 2-page PDF document provides key data on new cancer cases and cancer deaths for Georgia.

Georgia Cancer Registry Program

CDC funding for the state cancer registry began in 1994. The first diagnosis year for which cancer cases were reportable to CDC was 1995.

Georgia Comprehensive Cancer Registry
Division of Public Health
Georgia Department of Human Resources
2 Peachtree Street, NE
14th Floor
Atlanta, GA 30303-3181
(404) 639-1943
FAX: (404) 637-7517
Cancer Data & Tools

Hosted by CDC

- CDC WONDER
  - An online query system that produces age-adjusted and crude rates in tabular, map, and chart formats. [http://wonder.cdc.gov/cancer.html](http://wonder.cdc.gov/cancer.html)

- Environmental Public Health Tracking Network
  - A system of integrated health, exposure, and hazard information and data from a variety of national, state, and city sources. [http://ephtracing.cdc.gov/showHome.action](http://ephtracing.cdc.gov/showHome.action)

- Chronic Disease Indicators
  - A *cross-cutting* set of 97 indicators developed by *consensus* allowing states and territories and large metropolitan areas to *uniformly* define, collect, and report chronic disease data that are important to public health practice. [http://apps.nccd.cdc.gov/cdi/](http://apps.nccd.cdc.gov/cdi/)
Cancer Data & Tools

Hosted by others (outside of CDC)

- **State Cancer Profiles website (NCI)**
  - Interactive graphics and maps provide quick and easy access to cancer statistics at the national, state and county level. Statistics are displayed by geographic region, race/ethnicity, cancer site, age, and sex. [http://www.statecancerprofiles.cancer.gov/incidencerates/](http://www.statecancerprofiles.cancer.gov/incidencerates/)

- **Central Brain Tumor Registry of the US**
  - A not-for-profit corporation committed to providing a resource for gathering and disseminating current epidemiologic data on all primary brain tumors, benign and malignant. [http://www.cbtrus.org/](http://www.cbtrus.org/)

- **Office of Women’s Health**
  - Offers statistics and information on a variety of health topics important to women and their families. [http://www.womenshealth.gov/statistics/](http://www.womenshealth.gov/statistics/)
Research Data Center (RDC)

www.cdc.gov/rdc/B1DataType/Dt131.htm
Comparative Effectiveness Research (CER)
Background for Comparative Effectiveness Research (CER)

- Clinical trials – Gold Standard for assessing effectiveness of cancer treatment

- Significant skepticism about use of observational studies

- Medical claims data has been used in prior attempts to assess treatment on a large population scale

Institute of Medicine Report Brief, Initial National Priorities for Comparative Effectiveness Research, June 2009. For more information visit www.iom.edu/cerpriorities
Background

- 2009 Institute of Medicine (IOM) Report - “Initial National Priorities for Comparative Effectiveness Research (CER)”
  - 100 initial CER priorities; 7 priorities focus on cancer outcomes
  - The key elements of this definition are the direct comparison of effective interventions, the study of patients in **typical day-to-day clinical care**, and the aim of tailoring decisions to the needs of individual patients.

Institute of Medicine Report Brief, Initial National Priorities for Comparative Effectiveness Research, June 2009. For more information visit www.iom.edu/cerpriorities
Background

- U.S. Health and Human Services awarded funding for investing in data infrastructure in support of more population based CER

- Central cancer registries provide a unique “starting point” for assessing quality and effectiveness of care
  - Population based
  - Consolidate information from multiple sources
  - Legal authority to collect information

- However, significant resources are needed to ensure complete treatment data is collected
CER Project
An Opportunity for Cancer Registries to:

- Develop new sustainable methods for rapid data collection and the expansion of data items collected through linkages and electronic reporting.

- Develop new capacity for innovative public health applications of cancer registries.

- Develop datasets for researchers to address as many CER-related research questions as possible.
NPCR CER Project

- $20 Million U.S. dollars in 2010
- Established 10 Specialized Registries
- Project Length: May 2010 – Sept. 2013
- Created dataset for CER research
## Funded States

<table>
<thead>
<tr>
<th>Specialized Cancer Registry States</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alaska</td>
</tr>
<tr>
<td>California</td>
</tr>
<tr>
<td>Colorado</td>
</tr>
<tr>
<td>Florida</td>
</tr>
<tr>
<td>Idaho</td>
</tr>
<tr>
<td>Louisiana</td>
</tr>
<tr>
<td>New Hampshire</td>
</tr>
<tr>
<td>North Carolina</td>
</tr>
<tr>
<td>Rhode Island</td>
</tr>
<tr>
<td>Texas</td>
</tr>
</tbody>
</table>
CDC Specialized Registries

Blue: Specialized Registry (AK, CA, FL, ID, LA, NC, NH, TX, CO, RI)
Specialized Registries

Collect detailed treatment and other data on:

- 2011 cancer cases
  - Breast
  - Colon
  - Rectum
  - Chronic Myeloid Leukemia

- Florida – 5 county area*
  (Dade, Broward, Hillsborough, Orange, and Palm Beach)

- California – greater Sacramento area*
  (Region 3 - Alpine, Amador, Calaveras, El Dorado, Nevada, Placer, Sacramento, San Joaquin, Sierra, Solano, Sutter, Yolo, Yuba)
Additional Data Collection – Breast, Colon, Rectum, Chronic Myeloid Leukemia (CML) only

- **Biomarkers**
  - KRAS, HER2, ER and PR status, and BCR-ABL2

- **Treatment regimens**
  - focus on specific regimens for colorectal and breast cancer and chronic myeloid leukemia (CML)

- **Radiotherapy treatments**

- **Chemotherapy treatments**
  - Height & Weight at or near diagnosis
  - Dosage
  - Dates

- **Completion Status**

- **Subsequent Treatment (As available)**
Expanded Data Collection in Specialized Registries
All Cases

Capture additional or higher quality data:
- Race/ethnicity
- Place of birth
- Height and weight
- Occupation
- Vital status
- Co-morbid conditions
- Smoking history
- Jak2
- Census tract
- Cancer staging – AJCC TNM Stage
Specialized Registries

Main Goals: Applies to all cancer cases going forward

- Develop sustainable methods to enhance cancer registry data for CER through:
  - Data linkages
    - Hospital discharge data
    - Medicaid
  - Expanded data collection for all cases

- Additional supported activities to build registry infrastructure
  - Training cancer registrars (data collectors)
  - Expansion of electronic reporting from pathology and clinical labs
  - Expanding reporting from non-hospital sources
Specific CER Questions
Developed in Concert with Agency for Healthcare Quality and Research (AHRQ)

- Are colorectal cancer patients tested for KRAS and are the results used appropriately to determine treatment? What impact does KRAS testing have on 2-3 year survival among colorectal cancer patients?

- Are rectal cancer patients receiving radiotherapy and what is the timing of radiotherapy? Are disparities apparent in the appropriate neo-adjuvant use of radiotherapy among these patients?
Specific CER Questions
Developed in Concert with Agency for Healthcare Quality and Research (AHRQ)

- Are women with breast cancer being tested appropriately for HER2, progesterone receptor (PR2), and estrogen receptor (ER) status and treated appropriately?

- Are chronic myeloid leukemia patients being tested for the BCR-ABL2 gene and receiving appropriate treatment according to those results?
Long-term Outcomes for CER

- Linkage to National Vital Status death records
- Assess mortality differences between those receiving treatment A versus B
- Longer term follow-up required for meaningful mortality analyses
- Opportunity for intermediate outcomes
  - Progression, recurrence (more at the end)
Results

- Data submitted to CDC Sept. 2013
- Data now available to researchers through the National Center for Health Statistics (NCHS) Research Data Centers (RDC)
  - Restricted environment – data privacy carefully protected
  - Provides access for non-CDC researchers
- Future updates to RDC dataset expected – linkages to National Death Index for example
### 2011 Cancer Case Counts
#### 10 Specialized Registries, NPCR

<table>
<thead>
<tr>
<th>All Cancers</th>
<th>275,536</th>
</tr>
</thead>
<tbody>
<tr>
<td>Breast</td>
<td>46,572</td>
</tr>
<tr>
<td>Colorectal</td>
<td>23,963</td>
</tr>
<tr>
<td>CML</td>
<td>940</td>
</tr>
<tr>
<td>Total CER</td>
<td>71,475</td>
</tr>
</tbody>
</table>
Patient Centered Outcomes Research (PCOR)
Patient Centered Outcomes Research – CER with recognition of patient priorities

- Additional funding from HHS to extend follow-up of breast, colon, rectum cancer cases through 2014.
- Progression, recurrence, disease free status
- Five of the Specialized Registries
  - Louisiana
  - Idaho
  - Colorado
  - New Hampshire
  - Rhode Island
- Data collection beginning
### 2011 Cancer Case Counts
#### 5 Specialized Registries, NPCR PCOR funded Follow-up

<table>
<thead>
<tr>
<th></th>
<th>10 registries</th>
<th>5 registries</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Breast</strong></td>
<td>46,572</td>
<td>11,749</td>
</tr>
<tr>
<td><strong>Colorectal</strong></td>
<td>23,963</td>
<td>6,019</td>
</tr>
<tr>
<td><strong>CML</strong></td>
<td>940</td>
<td>0</td>
</tr>
<tr>
<td><strong>Total CER</strong></td>
<td>71,475</td>
<td>17,768</td>
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</tbody>
</table>
The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

Contact:
Fbabcock@CDC.GOV