

# **NPCR 2019 Program Review Meeting**

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**Division of Cancer Prevention and Control**

**RELIABLE | TRUSTED | SCIENTIFIC**



# 2018 Implementation



# Impact

- Delays software, edits, training, delay data collection
- Lack of coordination among cancer surveillance community
- Concern about quality data
- Workforce concerns
- Insufficient resources
- Ever increasing expectations

# Response

- **NO** changes in data collection until 2021
- Call for data
- Completeness measure
- Strengthening partnerships
- We want to hear from you!



# Recover

- One Voice Against Cancer – focus is on registry - \$70 M
- Alliance for Childhood Cancer
  - STAR - \$2 million
- AJCC executive meeting
  - CDC, NCI met with leadership
- NCHS –modernizing death reporting system
  - Pilot on cancer
- Association of Public Health Lab
  - Informatics messaging service
- Microsoft Headquarters
  - Seattle – invited use case



# Vision – Cancer Surveillance Branch

To provide **informative** and **innovative** data and **support** for the benefit of cancer prevention and control

**NPCR**  
NATIONAL PROGRAM  
of CANCER REGISTRIES

Measuring progress. Targeting action.

Cancer Registries' Value for You  
Learn [how registries work](#) and how they answer important questions about cancer.

United States Cancer Statistics  
**USCS**  
U.S. Cancer Statistics  
The Official Federal Cancer Statistics  
Use the [Data Visualizations Tool](#) or the [Public Use Database](#) to access United States Cancer Statistics.

Understanding Cancer Data  
Find out about NPCR's [high-quality](#) population-based cancer data.

Registry Tools and Software  
Learn about software and tools available for [collecting and processing, editing, and securing](#) registry data.



- Registry Operations

- DP 17-1701 – Component 1 and 2
- 50 Success stories, 4 Town Hall calls, 4 Newsletters
- Education – internal and external

- Data Collection and Reporting

- 36% Registries of Excellence, 44% Registry of Distinction – ALL registries included in USCS
- 45 states perform NDI linkage
- 43 states survival analytic database, 93% population coverage
- eMaRC, MU, RPUG calls and webinars, helpdesk
- IHS Linkages

- Dissemination

- USCS – new branding, more products
- Booths at national meetings
- New partners – MOU w/ ACS
- Publication and presentations
  - 30+ papers
  - 5 data briefs
  - 3 blogs
  - 20+ presentations

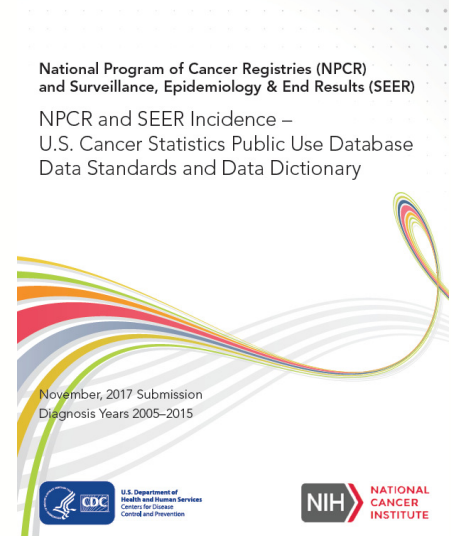




# Public Use Databases – 2018 Metrics

## U.S. Cancer Statistics

- **190** requests for access
  - ~50% academic or medical researcher
  - 23% cancer or public health partner
  - 22% pharma or private sector
  - 60% of users are new – no access to last year's file
  - 39 academic and 14 medical institutions represented
- **12** publications from extramural researchers
- Nearly **40k** page views of website




[www.cdc.gov/cancer/public-use](http://www.cdc.gov/cancer/public-use)


# Estimates by Congressional District

## U.S. Cancer Statistics

### Estimated Death Rates



Centers for Disease Control and Prevention  
CDC 24/7: Saving Lives. Protecting People™



**United States Cancer Statistics: Data Visualizations**

The official federal statistics on cancer incidence and deaths, produced by the Centers for Disease Control and Prevention (CDC) and the National Cancer Institute (NCI).

Technical Notes Download Data Archive Cancer Data and Statistics Tools About USCS Questions and Answers Glossary

Overview Demographics Trends State/Country Congressional Districts Survival Prevalence Special Topics Related Data

**Area:** California | **District:** District 1 | **Estimated New Cases (Incidence) or Deaths (Mortality):** Estimated Death Rate

**Sex:**  Female  Male  Male and Female | **Races and Ethnicities:** All Races/Ethnicities | **Cancer Type:** All Types of Cancer

### Congressional District Estimates, 2011-2015

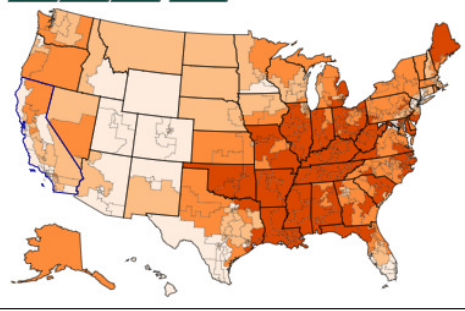
**California, District 1**  
**All Types of Cancer, All Races/Ethnicities, Male and Female**

**Attention users:** Incidence and death counts and rates presented in this tab are estimates derived from county-level data. These point estimates are provided to describe the cancer burden in the selected congressional district and are not meant for comparisons across congressional districts.

A congressional district is an electoral division that elects a single member of Congress. There are 438 congressional districts in the United States. The congressional district is based on the size of the population, which is measured by the decennial Census. The borders of congressional districts are set by states. Some congressional districts cover the entire state, some follow county borders, and some cover multiple counties or parts of counties.

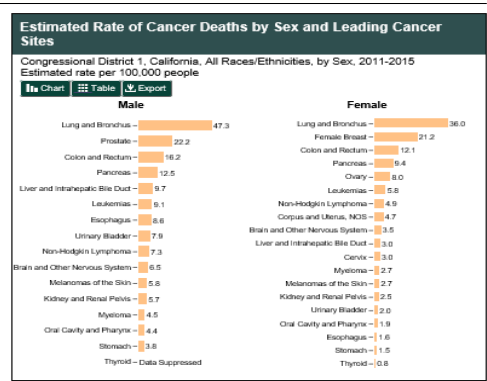
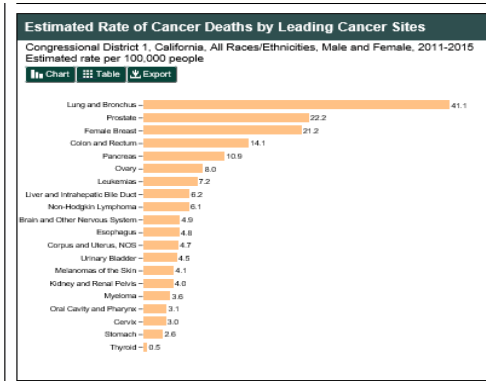
### Estimated Rate of Cancer Deaths in the United States, by Congressional District, 2011-2015

All Types of Cancer, All Races/Ethnicities, Male and Female  
Estimated rate per 100,000 people



In Congressional District 1, California, from 2011-2015, there were an estimated 21,713 new cases of cancer. For every 100,000 people, 457 new cancer cases were estimated.

Over those years, there were an estimated 8,235 people who died of cancer. For every 100,000 people in Congressional District 1, California, an estimated 168 died of cancer.



**Footnotes**

Rates and counts are estimates based on death data are from the CDC's National Center for Health Statistics National Vital Statistics System and cover 100% of U.S. population.

Rates and counts are not presented for people of unknown or other race. Black race categories are not mutually exclusive from Hispanic origin. See [Technical Notes](#).

- Rates and counts are suppressed if fewer than 16 cases (or deaths) were estimated in a specific category, such as cancer type, race, and ethnicity.

# Coming soon...

**United States Cancer Statistics: Data Visualizations**  
 The official federal statistics on cancer incidence and deaths, produced by the Centers for Disease Control and Prevention (CDC) and the National Cancer Institute (NCI).

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Special Topics

Choose Dataset: All/AN restricted to PRCDA only | Choose IHS Region: Pacific Coast | Sex:  Female  Male  Male and Female | Cancer Type: All Cancer Sites Combined

## Rate of New Cancers in American Indian/Alaska Native\*

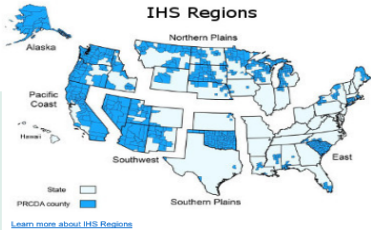
### Pacific Coast, United States, 2011-2015

#### All Cancer Sites Combined, Male

\*Data are restricted to non-Hispanic American Indian/Alaska Native living in IHS Purchase/Referred Care Delivery Area (PRCDA) counties.

To improve accuracy of American Indian/Alaska Native (AI/AN) cancer statistics, analyses are restricted to areas with health care services provided by Indian Health Service (IHS). IHS Purchase/Referred Care Delivery Areas (PRCDA) consist of counties which include all or part of an AI/AN reservation and any county or counties which have a common boundary with a reservation. These cancer incidence data are restricted to populations residing in PRCDA counties (defined in the April 7, 2016 Federal Register) and are grouped at the IHS Region level.

Non-Hispanic whites living in PRCDA counties are presented for comparison.

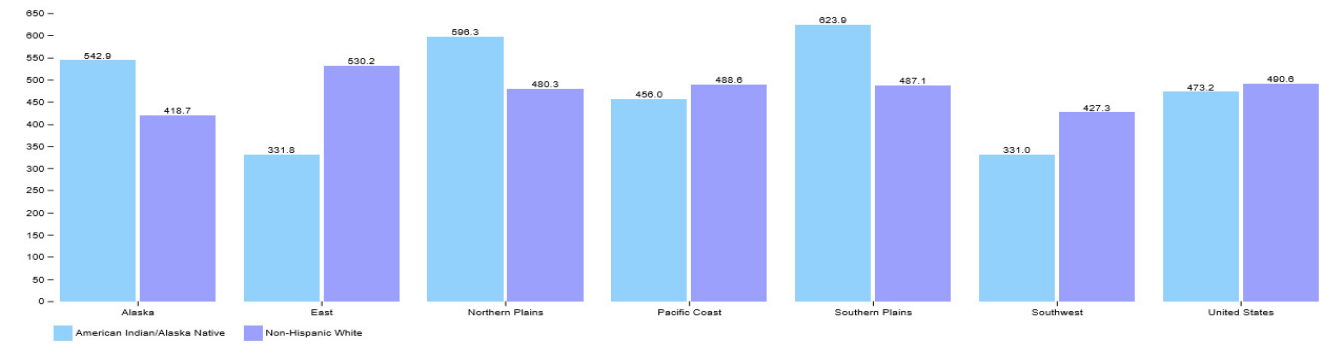


IHS Regions  
 State:   
 PRCDA county:   
[Learn more about IHS Regions](#)

### American Indian/Alaska Natives, Non-Hispanic, United States, 2011-2015

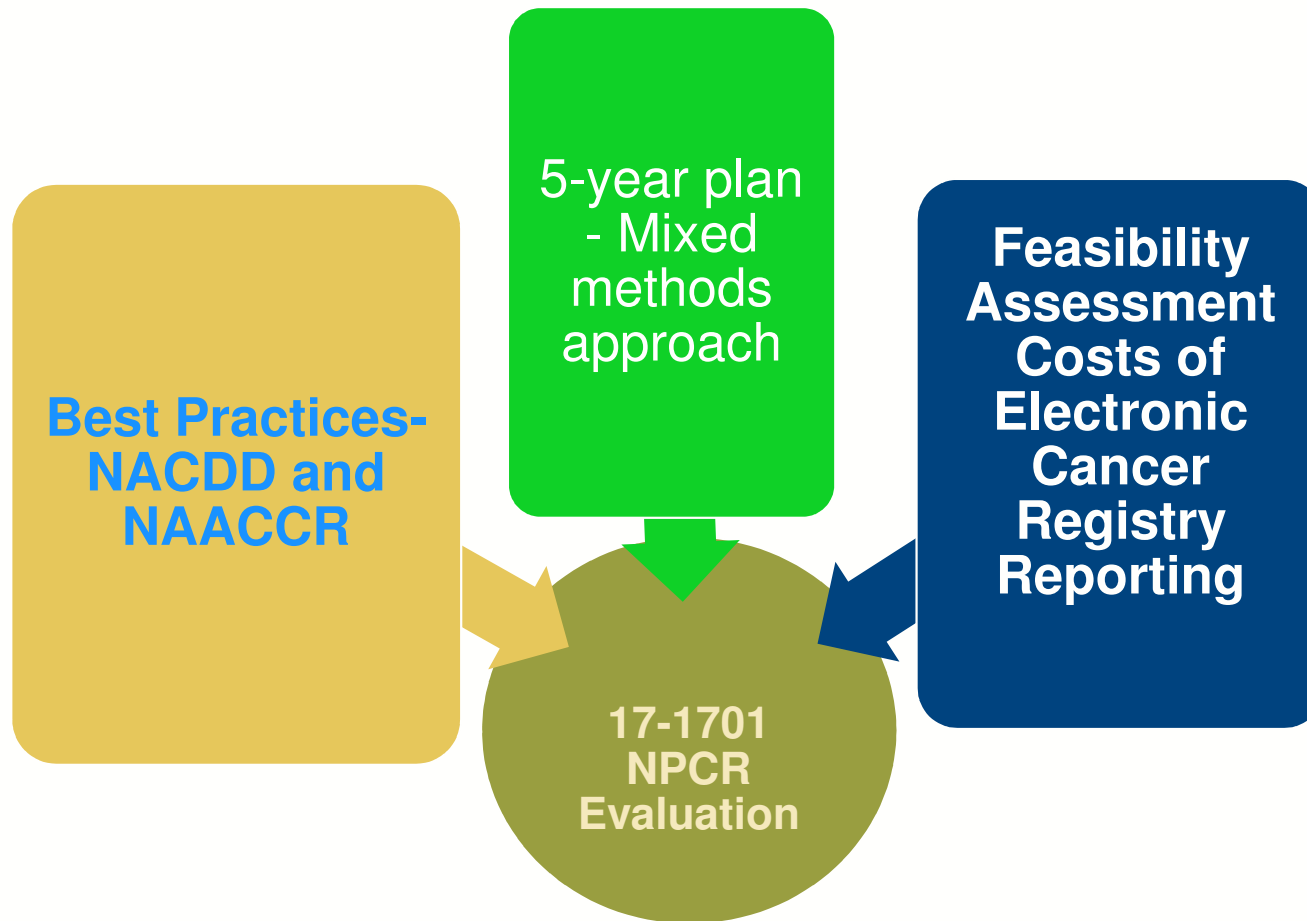
Rate of New Cancers by IHS Region and Sex  
 All Cancer Sites Combined, Male  
 Rate per 100,000 men

95% Confidence Interval:  Hide  Show  
 Comparison rate among White, non-Hispanic:  Hide  Show

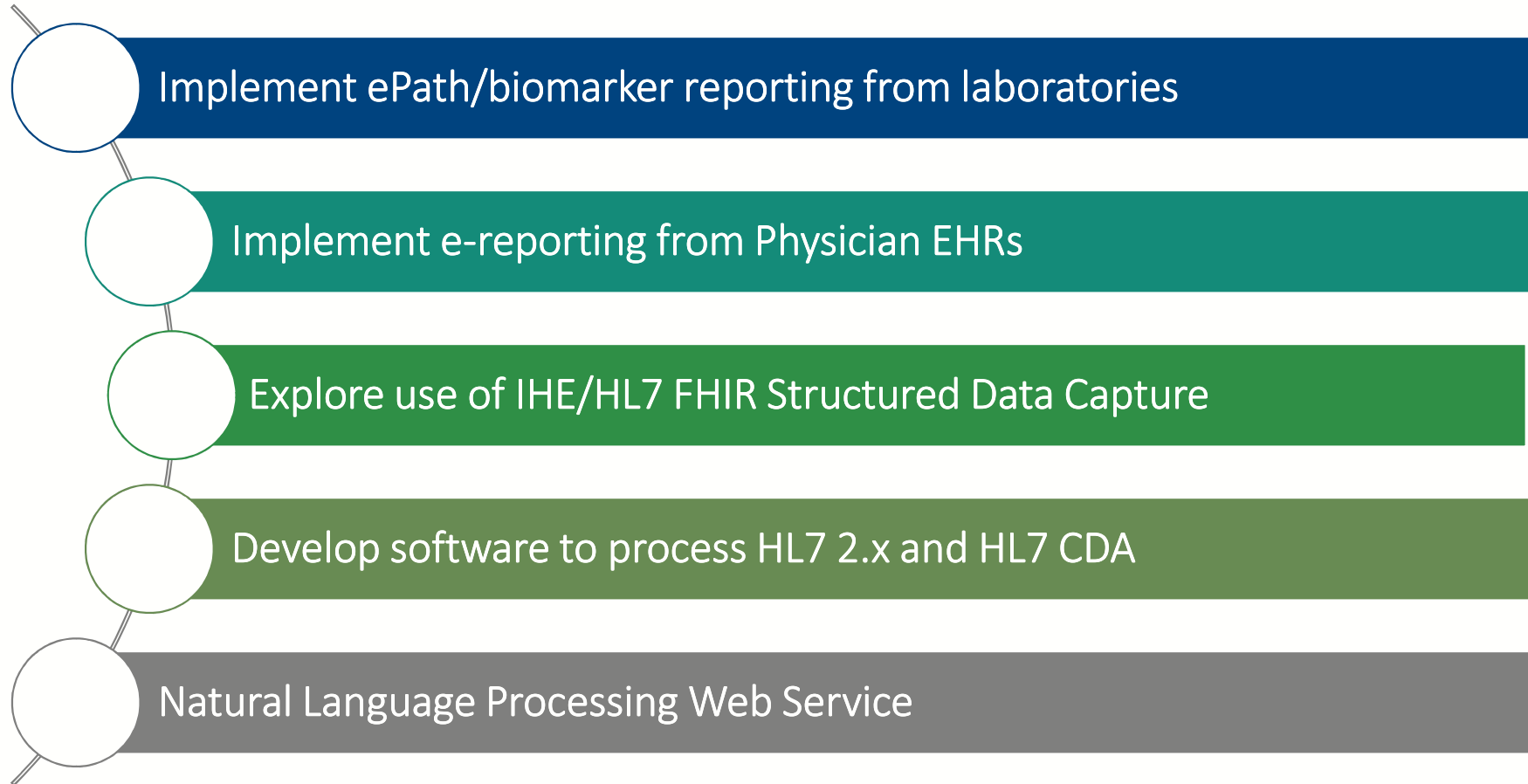


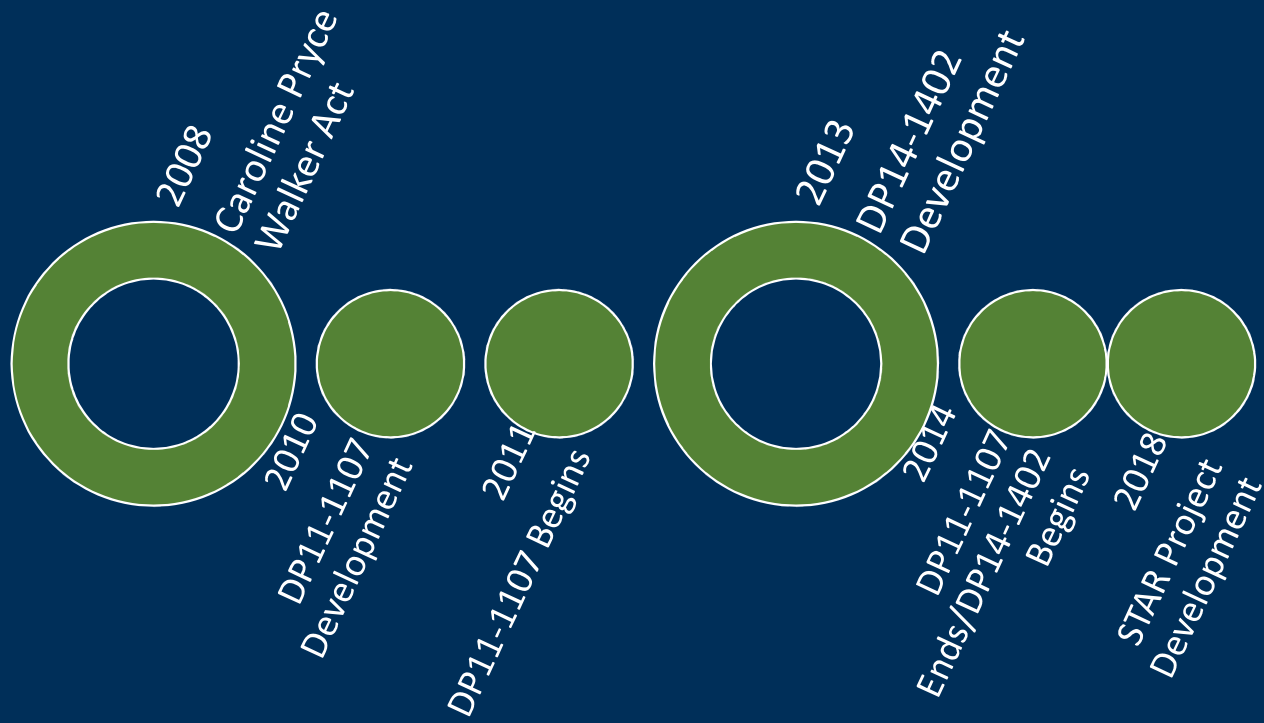
IHS Region	American Indian/Alaska Native (Rate per 100,000 men)	Non-Hispanic White (Rate per 100,000 men)
Alaska	542.9	418.7
East	331.8	530.2
Northern Plains	598.3	480.3
Pacific Coast	458.0	488.8
Southern Plains	623.9	487.1
Southwest	331.0	427.3
United States	473.2	480.8

# NPCR Evaluation Projects at a Glance



# CDC's Strategies to Improve Cancer Data and Reporting





## Example of real-time reporting

# Surveillance: We are all in this together

## Surveillance Systems

Collecting stage  
And MANY other data items



## Clinicians

Staging patients  
Planning care

## AJCC Cancer Staging

TNM Staging  
Prognostic Factors

# Many Thanks!

