



# The Value of Cancer Registries to the Public's Health

Cancer registries provide high quality cancer data to inform policy at the local, state, and national levels

In 2019, more than 1.7 million Americans will be diagnosed with cancer and nearly 607,000 are expected to die of the disease. Without cancer registries, such data would not be available to the public, policy makers, or researchers.

The National Program of Cancer Registries (NPCR) at the Centers for Disease Control and Prevention (CDC) provides technical, operational, and financial support to almost all state cancer registries to help ensure data collected are representative of the U.S. population. **Registries provide a road map in the fight against cancer.**

The NPCR collects cancer case and death rate data from cancer registries in **46** states, the District of Columbia, and three territories, encompassing **97%** of the U.S. population.

Health care providers, public health officials, and researchers use registry data to:

## Monitor

Cancer incidence and mortality trends over time.

## Evaluate

Cancer patterns in populations and to identify high-risk groups.

## Guide

Planning and evaluation of cancer control programs.

## Inform

Priorities for allocating health resources.

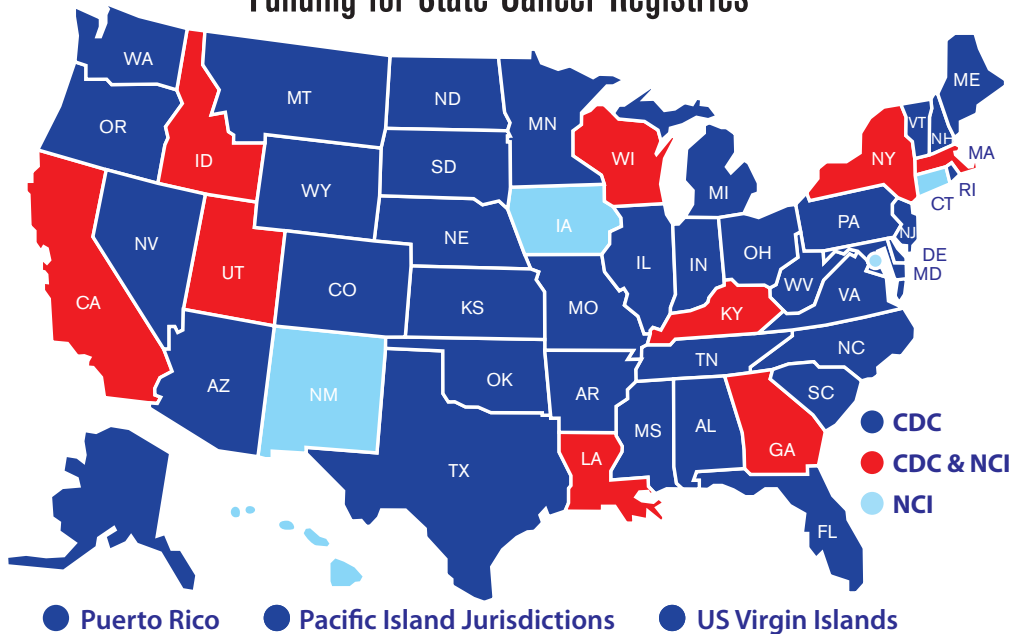
## Research

Cancer causes and prevention strategies to see which work well.

## More About NPCR's Work

- NPCR helps collect national and state-specific cancer incidence data to help identify trends or shifts in the burden of cancer so policymakers can take steps to reverse negative trends.
- State registry data are the foundation of a state's Comprehensive Cancer Control Program and provide the information needed to inform planning efforts, to allocate resources, and to evaluate progress.
- NPCR registry data are critical to CDC's cancer prevention programs, including the National Breast and Cervical Cancer Program and the Colorectal Cancer Control Program, to help states focus on populations most in need of prevention and screening efforts.

## Funding for State Cancer Registries



Note that the color of the states represents the registry's funding source(s): CDC's NPCR, the National Cancer Institute's Surveillance, Epidemiology, and End Results (SEER) program, or both. The map does not include regional registries such as the Seattle-Puget Sound Registry or the Cherokee Nation Registry.

The Centers for Disease Control and Prevention (CDC) compiles data from the cancer registries and issues a number of reports such as "Geographic Variation in Pediatric Cancer Incidence—United States, 2003–2014" published in a 2018 *Morbidity and Mortality Weekly Report (MMWR)*. This report gave state-level estimates on nationwide pediatric cancer incidence, not just differences by the U.S. census regions of Northeast, Midwest, South, and West. CDC researchers found that between 2003 and 2014, pediatric cancer incidence was highest in **New Hampshire, the District of Columbia, and New Jersey**. Researchers also calculated that the highest rate of leukemia was in the West. These findings can help to advance health care providers' awareness of pediatric cancer, enhance treatment capacity and survivorship care where needed, and foster cancer surveillance.

## Cancer Facts and Figures

Data on new cases collected by NPCR and published in American Cancer Society, *Cancer Facts and Figures: 2019*. Atlanta: American Cancer Society, 2019.

State	New Cases of Cancer	Deaths Caused by Cancer	State	New Cases of Cancer	Deaths Caused by Cancer	State	New Cases of Cancer	Deaths Caused by Cancer
Alabama	28,950	10,630	Louisiana	26,800	9,260	Oklahoma	20,540	8,420
Alaska	3,090	1,120	Maine	8,920	3,310	Oregon	23,320	8,270
Arizona	37,490	12,470	Maryland	33,140	10,780	Pennsylvania	79,890	28,170
Arkansas	16,580	6,800	Massachusetts	40,020	12,420	Rhode Island	6,540	2,140
California	186,920	60,590	Michigan	58,360	21,150	South Carolina	29,830	10,720
Colorado	26,800	8,120	Minnesota	30,560	10,020	South Dakota	4,770	1,680
Connecticut	21,950	6,470	Mississippi	17,050	6,720	Tennessee	37,350	14,840
Delaware	5,870	2,140	Missouri	35,480	13,080	Texas	124,890	41,300
District of Columbia	3,190	1,020	Montana	5,920	2,100	Utah	11,620	3,310
Florida	131,470	45,000	Nebraska	9,780	3,520	Vermont	3,920	1,440
Georgia	50,450	17,880	Nevada	14,810	5,390	Virginia	45,440	15,200
Hawaii	7,120	2,560	New Hampshire	8,610	2,820	Washington	39,160	13,010
Idaho	8,390	3,040	New Jersey	53,400	15,860	West Virginia	12,440	4,820
Illinois	68,560	24,410	New Mexico	9,460	3,720	Wisconsin	34,220	11,730
Indiana	35,280	13,690	New York	111,870	35,010	Wyoming	2,930	980
Iowa	17,810	6,480	North Carolina	58,690	20,410	United States	1,762,450	606,880
Kansas	15,340	5,550	North Dakota	3,940	1,280			
Kentucky	26,400	10,580	Ohio	67,150	25,440			

## Examples of How States Use NPCR Data to Improve Cancer Outcomes

Data in the **Louisiana** cancer registry (called the Louisiana Tumor Registry) showed that new cases of anal canal squamous cell carcinoma were increasing among Louisiana residents with a low socioeconomic status who were typically treated in public hospitals. In public hospitals, patients waited an average of almost five months from the first time they saw a doctor about their symptoms until receiving the specific diagnosis. A delay of twelve additional weeks on average to begin treatment followed, yet such an interval can make the cancer harder to treat. The Louisiana Tumor Registry provided data on demographics, census-tract socioeconomic status, tumor characteristics, stage, and date of treatment for patients treated for this kind of anal cancer in one public hospital. Hospital staff linked wait times

with demographic data, HIV status, and cancer stage. As a result of this review, doctors at the hospital were inspired to find ways to diagnose and to treat patients with anal cancer more quickly. These patients now begin treatment approximately thirty days after diagnosis.

**N**ebbraska, like other states, uses its data to produce a number of fact sheets with statistics on cancer incidence, mortality, staging, and screening so that residents, policymakers, health care professionals, and researchers can understand the impact cancer has on the state. Fact sheets include *All Cancers in Nebraska*, *Colorectal Cancer in Nebraska*, *Cancer in Minorities in Nebraska*, and *Pediatric Cancer in Nebraska*.

The **Washington** State Cancer Registry (WSCR), along with the Cancer Surveillance System (CSS), provided data to the Puget Sound affiliate of the Susan G.

Komen Foundation (PS Komen) for its Community Profile Report. In compiling the report, PS Komen discovered that a greater proportion of late-stage breast cancer occurs in Lewis and Pacific counties. Further, African-American, Hispanic, and American-Indian/Alaska-Native women have the highest rates of breast cancer among racial and ethnic groups. PS Komen found that low-income women experienced a greater proportion of late-stage breast cancer, possibly because they lacked access to timely breast cancer screening and information. This statistical information led PS Komen to distribute funds to support breast cancer education, screening, and patient-navigation services for these high-risk populations in order to reduce the number of late-stage breast cancer cases in priority communities. As a result, there appears to be a noticeable, and perhaps statistically significant, reduction in late-stage breast cancer, as well as improvements in survival rates among these women with breast cancer.

### Cancer Registry Data at Work: Cancer Survivors by State

Initial data collected by NPCR and published in American Cancer Society *Cancer Treatment & Survivorship Facts & Figures 2019-2021*  
Atlanta: American Cancer Society, 2019

State	Number of Cancer Survivors
Alabama	244,320
Alaska	36,550
Arizona	392,530
Arkansas	143,320
California	1,888,480
Colorado	225,470
Connecticut	243,410
Delaware	55,460
District of Columbia	18,750
Florida	1,482,090
Georgia	446,900
Hawaii	84,960
Idaho	77,860
Illinois	651,810
Indiana	296,940
Iowa	185,720
Kansas	151,950
Kentucky	254,780
Louisiana	232,100
Maine	95,540
Maryland	275,420
Massachusetts	434,230
Michigan	570,760
Minnesota	300,980
Mississippi	135,260
Missouri	300,200
Montana	59,970
Nebraska	108,500
Nevada	132,950
New Hampshire	84,080
New Jersey	543,190
New Mexico	111,620
New York	1,105,550
North Carolina	470,120
North Dakota	38,430
Ohio	581,350
Oklahoma	207,260
Oregon	213,620
Pennsylvania	771,120
Rhode Island	67,900
South Carolina	280,890
South Dakota	42,810
Tennessee	326,530
Texas	1,140,170
Utah	115,840
Vermont	34,360
Virginia	408,060
Washington	386,540
West Virginia	117,070
Wisconsin	313,370
Wyoming	33,310
United States	16,920,370

In partnership with the Well Woman HealthCheck Program, the **Arizona** Cancer Registry (ACR) conducted an Association of State and Territorial Health Officials (ASTHO) Breast Cancer Learning Collaborative. Through the ASTHO, ACR performed detailed analysis of cancer registry data to uncover breast cancer disparities. ACR found that Arizona women of color (black, Hispanic, and American Indian) are diagnosed with breast cancer at a median age seven years younger than white non-Hispanics and are also diagnosed with more aggressive tumors than white non-Hispanics. The findings were discussed in both a report and stakeholder meetings across the state. The ACR determined that women of color should begin screening

for breast cancer earlier than the current federal guideline of age 50 and recommended to Arizona Health Plans and Federal Qualified Health Centers that women begin screening for breast cancer at 40 years of age. Today Well Woman HealthCheck Program material encourages mammograms for women 40 and older.

Data from the **West Virginia** Cancer Registry are included in the *WV Cancer Plan 2016-2020* written by the Mountains of Hope West Virginia Cancer Coalition (MOH). (Registry data are also the basis for the annual *West Virginia Cancer Burden Report*.) Dedicated to reducing the human and economic toll of cancer in the state, MOH includes in its coalition hundreds of health care providers, volunteers, cancer survivors, advocates affiliated with various community-based organizations, research and academic institutions, public and private agencies, patient advocacy associations, and other cancer-related organizations in the state. MOH coalition members use the data from the registry to determine bi-annually its priorities and to allocate resources accordingly; its most recent top priority is to “reduce the use of tobacco products and electronic nicotine delivery systems” among adults, youth, and young adults. This priority directly responds to lung cancer’s being the leading cause of cancer death in West Virginia. MOH distributes several mini-grants to support projects around the state that address the plan’s priorities, such as A Breath of Fresh Air which works to expand tobacco-cessation efforts at a nonprofit organization providing health care in the western edge of the state.

Using the county-specific data in **Kentucky’s** cancer registry, Kentucky’s Breast and Cervical Screening Program identified counties with low breast and cervical incidence but with high mortality rates. Key stakeholders used the information to leverage funding for clinical services, including more funding for screening services in order to diagnose these cancers earlier when treatment is more effective. Innovative tools such as mobile mammography were made available to reach underserved women and to increase screening rates.

## ACS CAN’s FY 2020 Funding Request

The more accessible and usable registry data are, the more impact they can have on the public’s health. Unfortunately, there now is a 24-month delay between when data are initially collected and when the system can report them. By providing at least \$70 million, Congress can ensure that the CDC is able to create a cloud-based system that would record data in real time and modernize its current system of data capturing. Funding to modernize the current system will allow larger studies monitoring the burden of disease, prevention strategies, and treatment efficacy to further improve cancer prevention, early detection, and care.

