



TRUST FOR AMERICA'S HEALTH IS A NON-PROFIT, NON-PARTISAN ORGANIZATION DEDICATED TO SAVING LIVES BY PROTECTING THE HEALTH OF EVERY COMMUNITY AND WORKING TO MAKE DISEASE PREVENTION A NATIONAL PRIORITY.

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IMPROVING CANCER TRACKING TODAY SAVES LIVES TOMORROW: Do States Make The Grade?

EXECUTIVE SUMMARY

More than 30 years after the launch of the War on Cancer, the disease remains the top health concern of Americans. Despite advances in diagnosis and treatment, cancer is still responsible for one of every four deaths in the U.S. Cancer illness and deaths annually cost the nation more than \$180 billion in health care spending and lost productivity.¹ The American Cancer Society (ACS) estimates, however, that one-third of cancer deaths could be prevented.ⁱⁱ

Information is the most vital tool for finding ways to more effectively treat and prevent the disease. Health agencies in each state are responsible for compiling information about the rates of cancer to study patterns and trends. These "cancer tracking" efforts are essential to help find cures, improve treatments and develop strong public health initiatives aimed at reducing cancer rates.

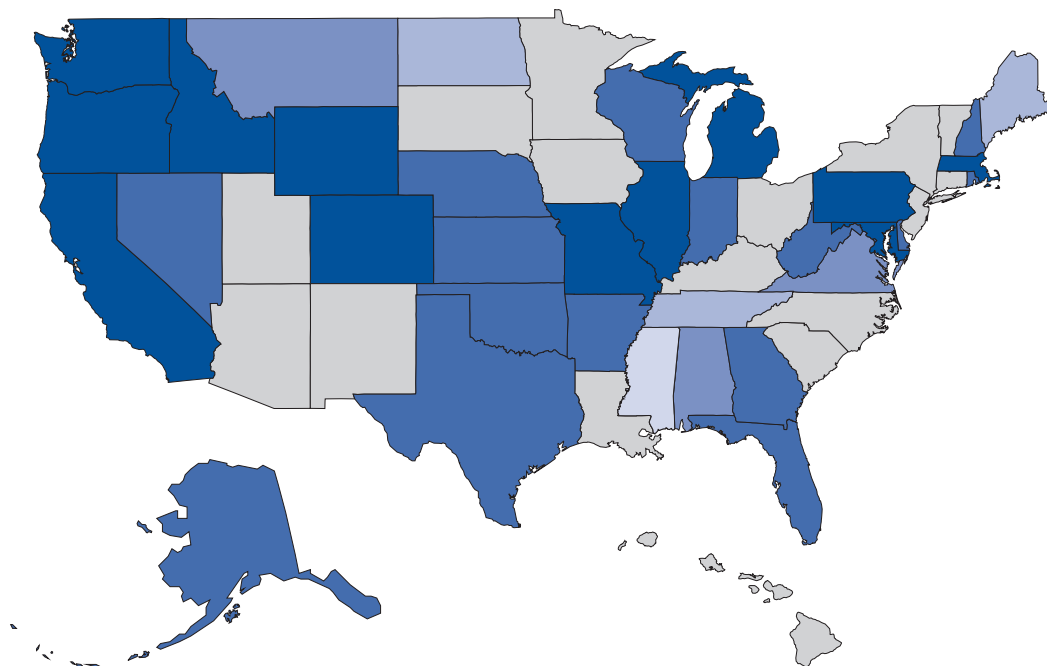
This report examines how well state health agencies are doing in their efforts to track, control and prevent cancer, and awards grades on a state-by-state basis. It concludes that states are missing key, important opportunities to reduce cancer rates.

According to the report findings, most states perform very well at maintaining high

quality data about cancer rates. However, findings also revealed cancer control and prevention could be greatly enhanced if increased efforts were made to connect cancer tracking information and other sources of health information on a routine and systematized basis. Additionally, the survey revealed a gap in the ability of states to answer the public's questions about disparities in cancer rates among different ethnic groups and communities.

Trust for America's Health (TFAH) offers specific recommendations for how cancer tracking could be improved to increase prevention efforts and reduce the burden of cancer on families, communities and the nation.

How Well Are States Tracking Cancer?



A	B	C	D	F	N/A
California	Alaska	Alabama	Maine	Mississippi	Arizona
Colorado	Arkansas	Montana	North Dakota		Connecticut
Idaho	Delaware	Virginia	Tennessee ⁱⁱⁱ		Hawaii
Illinois	District of Columbia				Iowa
Maryland	Florida				Kentucky
Massachusetts	Georgia				Louisiana
Michigan	Indiana				Minnesota
Missouri	Kansas				New Jersey
Oregon	Nebraska				New Mexico
Pennsylvania	Nevada				New York
Washington	New Hampshire				North Carolina
Wyoming	Oklahoma				Ohio
	Rhode Island				South Carolina
	Texas				South Dakota ^v
	West Virginia				Utah
	Wisconsin				Vermont

Thirty-four states and the District of Columbia participated in the TFAH survey, representing 71 percent of the U.S. population. Sixteen states either declined to participate or provided insufficient information to be evaluated.

- 12 states received As
- 15 states and the District of Columbia received Bs
- 3 states received Cs
- 3 states received Ds
- 1 state received an F.

The top five performing states were California, Colorado, Massachusetts, Washington and Wyoming.

Principal Findings: Missed Opportunities To Reduce Cancer Rates

1. Most states Do a Good Job Collecting and Maintaining High-Quality Data.

2. Life-Saving Links are Not Maximized. Most states do not adequately connect cancer tracking data with other sources of health information, such as occupational, environmental and behavioral studies. This information would help public officials identify and develop initiatives focusing on risk factors and possible causes of cancer.

■ Thirty states have at some time linked cancer data with other sources of health information to better understand risk factors associated with cancer rates within specific populations. However, only eleven states – Arkansas, California, Colorado, Illinois, Massachusetts, Oklahoma, Texas, Washington, West Virginia, Wisconsin and Wyoming – have ever linked their cancer data with all of the following types of information: health-related behavioral lifestyle, occupational and environmental.

■ Twenty-seven states reported that institutional constraints, including inadequate funding and staffing levels, limit

their ability to perform data linkages on a routine basis.

■ Incorporating data linkages into routine cancer tracking efforts would help public health programs to:

- Modify policies and programs to improve cancer prevention,
- Target populations where intervention would be beneficial,
- Provide improved information about risk factors, and
- Evaluate how well current prevention and treatment initiatives are working.

3. Many Community-Level Questions Go Unanswered. Many states do not adequately answer questions from researchers and the public about possible disparities in cancer rates among different localities and ethnic groups.

■ Each year, there are more than 1,000 inquiries from members of the public who want answers about cancer rates in their communities. Often, groups suspect they are experiencing a “cancer cluster” – a higher-than-expected number of cases within a region, time-period and number of people. Clusters tend to be controversial due to challenges facing investigations – politics, perceptions, statistical chance and limitations of sci-

ence. Rarely do these investigations result in the identification of true clusters.^v However, these questions can be properly addressed, and in most cases put to rest, only by providing information at a neighborhood level.

■ Only 14 states reported that they were able to provide data at the neighborhood level. This is typically due to limited funding and resources.

EXAMPLES OF SUCCESS

A tradition of complete and accurate data has allowed California data to be used in hundreds of research investigations. For example, from 1988 through 1999, the California Cancer Registry studied the incidence of cancer among members of the United Farmworkers of America (UFW), a largely Hispanic farm worker labor union. Results showed that the risk of leukemia, stomach, cervical and uterine cancers was elevated in California farm workers. UFW members also experienced later stages of disease at diagnosis than other California Hispanics for most major cancer sites. Additional research into the potential causes of this increased risk for certain cancers is planned, including a study of farm workers' exposure to pesticides.^{viii}

CONCLUSION: A Vision For 21st-Century Cancer Tracking

EXAMPLES OF SUCCESS

The **Kentucky** registry was able to help save lives and millions of dollars in cancer treatment costs. In the early 1990s, 35 percent of women diagnosed with breast cancer in that state were in the late-stage of the disease, for which the survival rate is low. Registry data was used to identify areas of the state that had high rates of late-stage and low rates of early-stage breast cancer. With additional funding from the CDC, the state expanded mammography outreach activities in these communities. In 1996, the percentage of women in the state diagnosed with late-stage breast cancer had declined to 30 percent. In addition to the potential lives saved, detecting these cancers earlier also saved an estimated \$4.7 million in treatment expenditures.^{vi}

Most states should enhance their cancer tracking efforts to help reduce cases of cancer that could be prevented altogether. While budget pressures loom, relatively small increased investments at state and federal levels could result in reducing the number of new cancer cases in this country. Better routine use of cancer tracking information would result in improved cancer prevention and control programs.

Modernizing cancer tracking efforts will require:

- Routine and systemized linkages of cancer case information with other sources of health information;
- Community- and researcher-friendly policies and practices to answer questions at neighborhood levels, while maintaining patient confidentiality;
- Real-time reporting for childhood cancers and rapid reporting for adult cancers to expedite time-sensitive research and treatments; and
- Continued high standards for maintaining quality data.

RECOMMENDATIONS FOR ACTION

The results of TFAH's survey suggest a series of actions for policymakers to consider to help fight, and ultimately win, the War on Cancer.

- 1. Expand data linkage activities.** Cancer tracking data can be linked with other sources of health information to provide important information and insights. The use and application of cancer data is critical to determining cancer excesses in specific populations and enhancing prevention efforts. As a condition of federal support, states should work in conjunction with the CDC and researchers to identify appropriate linkage studies.
- 2. Provide additional funding for cancer tracking.** Although federal and state budgets are under pressure, additional

funding from both of these levels of government is crucial. Funding the CDC's National Program of Cancer Registries (NPCR) at \$65 million, an increase of approximately \$19 million, would provide cancer tracking with much needed modernizations. Spending money on tracking now can save health care expenditures, and more important, save lives later.

- 3. Make data available to the public while protecting patient confidentiality.** States should actively work to make community-level cancer data easily accessible and available to the public and researchers. Health agencies in the states also should adopt policies that allow them to provide information at a neighborhood level while guarding patient confidentiality.

4. Improve reporting time. Within five years, all registries should set the goal of achieving real-time reporting for childhood cancers. Cancer is a chronic disease that may be initiated decades before the diagnosis is made, but that time lag does not exist in childhood cancers. State public health departments should examine childhood cancer patterns as rapidly as possible to see if unusual numbers are occurring in communities that may warrant further investigation and preventative actions. Moreover, real-time reporting could potentially contribute to time-sensitive cancer treatments and research activities. Real-time reporting for childhood cancer could serve as a model for eventually establishing rapid reporting for adult cancers.

5. Strengthen public accountability and enforce performance standards. Standards for data quality and timeliness are important first steps in improving cancer registry data and programs. However, nationally sanctioned standards do not exist to guide states' policies and practices regarding data linkages and response to public concerns. To establish such standards and methods for tracking progress on an ongoing basis, the North American Association of Central

Cancer Registries (NAACCR) and NPCR should work directly with researchers and community groups. NPCR has worked hard to assist registries, but it must exercise stronger leadership to motivate steady improvement. Should these organizations fail to prepare adequate performance and accountability standards, Congress should mandate that NPCR set standards on data linkages and response to public concerns for all registries receiving federal support.

6. Institute of Medicine (IOM) should conduct a study on the federal role in cancer registries. Congress should direct the IOM to conduct a review of the existing, bifurcated registry system in the U.S. The National Cancer Institute and the CDC separately fund cancer registries. Both programs serve important purposes, but maintain distinct goals and missions. Progress has been made toward coordinating these major registry programs, yet obstacles remain. The IOM should examine the respective Surveillance, Epidemiology and End Results (SEER) and NPCR programs and make recommendations that will guide development of a seamless cancer tracking system in the U.S.

EXAMPLES OF SUCCESS

*The **Connecticut** Tumor Registry identified an epidemic of lung cancer in women in 1977.^{vii} These findings provided important data about the connection between smoking and lung cancer. This resulted in increased efforts to raise awareness through public health programs about the health impacts of smoking.*

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THE FULL REPORT IS AVAILABLE ON THE TFAH WEB SITE: WWW.HEALTHYAMERICANS.ORG

Endnotes

- i "Cancer Registries: The Foundation for Cancer Prevention and Control." Centers for Disease Control and Prevention. http://www.cdc.gov/nccdphp/bb_cancer_reg/. 2001.
- ii "Cancer Facts & Figures 2003." American Cancer Society. Atlanta, Georgia. 2003.
- iii Tennessee and South Dakota are the only two states receiving 'capacity-building funds' from NPCR for the purpose of developing cancer registries where a limited or no statewide registry previously existed ("NPCR Funded States." Center for Disease Control and Prevention. www.cdc.gov/cancer/npcr/awards.html).
- iv South Dakota participated in TFAH's study. However, as the registry is presently in transition from a limited cancer data collection system to a statewide, population-based registry. Accordingly, the data provided were not sufficient for grading in comparison to other states.
- v Neutra, R. "Reviews and Commentary: Counterpoint from a Cluster Buster," *American Journal of Epidemiology*. July 1990: 132(1).
- vi "Cancer Registries: The Foundation for Cancer Prevention and Control AT-A-GLANCE 2001." Centers for Disease Control and Prevention. <http://www.cdc.gov/cancer/npcr/2001AAG-npcr.htm>. 2001.
- vii Weigs, JW. "Epidemic Lung Cancer in Women," *The Journal of the American Medical Association*. 1977: 238:10.
- viii "2002 Program Fact Sheet Cancer Registries: The Foundation for Cancer Prevention and Control." Centers for Disease Control and Prevention. <http://www.cdc.gov/cancer/npcr/register2002.htm>. 2002.