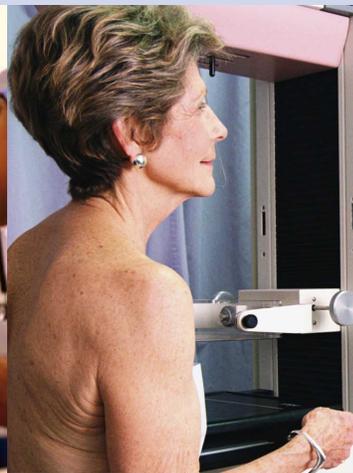


IMPROVING CANCER TRACKING  
TODAY SAVES LIVES TOMORROW:

# Do States Make The Grade?



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.

**ACKNOWLEDGEMENTS:**

*This report is supported by grants from The Robert Wood Johnson Foundation and The Pew Charitable Trusts and from individual champions for improved public health, including Joy A. Horwitz.*

*The opinions expressed in this report are those of Trust for America's Health and do not necessarily reflect the views of the funders.*

**SEPTEMBER 2003**

# Introduction

**M**ore than 30 years after the launch of the national War on Cancer, the disease remains the top health concern facing Americans today.<sup>1</sup> The American Cancer Society (ACS) estimates that more than half a million people will die of cancer in the U.S. this year.<sup>2</sup> Cancer costs our nation more than \$180 billion in health care spending and lost productivity from illness and death.<sup>3</sup> Millions of Americans are living with the disease every day. The statistics are alarming:

- In 2003, about 1.3 million new cancer cases are expected to be diagnosed.<sup>4</sup>
- Approximately 9,000 new cases of childhood cancer are expected among children from birth to age 14 in 2003. While childhood cancer is rare, it is the chief cause of death from disease in children between ages 1 and 14.<sup>5</sup>
- An estimated 211,300 new cases of invasive breast cancer will occur among women in 2003. Breast cancer is the most frequently diagnosed non-skin cancer in women.
- Approximately 220,900 new prostate cancer cases are expected during 2003.<sup>6</sup> Prostate cancer incidence rates for African-American men are 66 percent higher than for white men.<sup>7</sup>
- Other cancer disparities exist: The average age-adjusted cervical cancer mortality rate for white women from 1996-2000 was 2.7 per 100,000. For African-American women, the rate was more than double at 5.9 per 100,000.<sup>8</sup>

Despite advances in diagnosis and treatment, cancer is still responsible for one of every four deaths in the U.S. ACS estimates, however, that one-third of cancer deaths could be prevented.<sup>9</sup>

Trust for America's Health undertook this report to help create a vision for the next

generation of cancer tracking, control and prevention programs. The report specifically examines the efforts of health agencies in the states to track information about cancer and their use of this information to prevent and control the disease. First, it describes the importance of cancer tracking and some of the successes in the fight against cancer that tracking has helped to achieve. Second, it evaluates how well states are doing in their efforts to track, control and prevent cancer, and awards grades on a state-by-state basis. The report concludes with recommendations for how cancer tracking programs should be modernized. Increased efforts made to improve and expand prevention programs could help significantly reduce the burden of cancer on families, communities and the nation.

## Tracking: A Key To Winning The War On Cancer

State health agencies have all developed programs to track, control and prevent cancer. Cancer registries are the cornerstone of efforts to track the disease. They collect valuable information about cancer trends that is crucial to informing treatment and control efforts. Cancer registries compile cancer data for several purposes: to advance cancer research, to develop public health programs to reduce cancer rates and to improve treatment for cancer patients.

The battle against cancer involves many people: health care providers, physicians, researchers, epidemiologists, public health officials, legislators and communities. All of these individuals rely on registry data to develop and evaluate prevention and treatment strategies.<sup>10</sup>

Cancer registries in 40 states and the District of Columbia are housed in public health departments. In the other 10 states, cancer registries are housed in academic institutions. Both the federal and most state governments provide funding for cancer registries.

“Health tracking” is the monitoring of disease rates. The information compiled is essential for understanding and identifying potentially preventable causes for diseases, learning who is at risk and developing prevention strategies. Currently, there is no nationwide system in place to track cases of most chronic diseases, like diabetes, asthma or Parkinson’s. However, the cancer

research community has been a national pioneer in recognizing the importance of disease tracking. Today, all 50 states and the District of Columbia have cancer registry programs.

Many of America’s cancer registries trace their origins to the Connecticut Tumor Registry, which was established in 1935. Other states, as well as some cities and counties, gradually followed course, with many funding their registries through state or local public health departments. Rather than functioning in concert with public health programs, cancer registries historically collaborated more closely with surgeons and other physicians who treat cancer patients. As a result, cancer registries traditionally have focused on a clinical approach to battling cancer, which is based on treatment of patients once they have been diagnosed.

In 1972, the National Cancer Institute (NCI) launched the Surveillance,

## **HEALTH TRACKING: U.S. NEEDS A NATIONWIDE SYSTEM NOW**

*Through “health tracking,” cancer control experts collect and analyze information about cancer cases, including whom the disease strikes, the type of cancer and severity at the time of diagnosis. This information is vital to fighting the disease with prevention programs, early detection such as screenings and treatment. While cancer tracking in this country can be improved, it has helped save lives and reduce health care treatment costs.*

*Unfortunately there is no nationwide health tracking network in place for other chronic diseases, such as diabetes and heart disease. Yet the national cost of chronic disease is staggering: four out of five deaths each year and cost \$750 billion in annual health care spending and lost productivity. While the U.S. health care system excels at treating disease, we lack an understanding of chronic diseases that a national tracking system could*

*provide. This is crippling our ability to reduce and prevent chronic disease and help Americans live longer, healthier lives.*

### **The U.S. needs a Nationwide Health Tracking Network to improve our ability to:**

- Guide intervention and prevention strategies, including lifestyle improvements,
- Identify, reduce and prevent harmful risks,
- Improve public health policymaking, and
- Track progress toward achieving a healthier nation.

*The Nationwide Health Tracking Network would be administered by Centers for Disease Control and Prevention (CDC). Congress appropriated \$17.5 million in FY 2002 and \$28 million in FY 2003 to begin such a network.*

Epidemiology and End Results (SEER) program under the National Cancer Act. This law mandated the collection, analysis and dissemination of data useful for the prevention, diagnosis and treatment of cancer. The SEER program currently comprises nine statewide and six regional cancer registries. For three decades, SEER has served as a valuable source for national cancer incidence and survival trends and an important resource for researching the causes and most effective treatments for cancer.<sup>11</sup>

To further expand the scope of the registries, including adding an increased focus on prevention activities, Congress passed the Cancer Registries Amendment Act in 1992. The law was later reauthorized in 1998 and is expected to be reauthorized again in 2003. It provided significant federal funds to the CDC's National Program of Cancer Registries (NPCR) to support existing state cancer registries and to help establish registries in states without them. NPCR also required standardized data elements and reporting guidelines that registries were required to follow in order to receive federal funds. Funding for the program has

grown from \$16.8 million in 1994 to \$45.6 million in 2003.

According to CDC, "cancer registries collect information about the occurrence (incidence) of cancer, the types of cancers that occur and their locations within the body, the extent of cancer at the time of diagnosis (disease stage), and the kinds of treatment that patients receive."<sup>12</sup> CDC also states that the registries they fund should be designed to:

- Monitor cancer trends over time,
- Determine cancer patterns in various populations,
- Guide planning and evaluation of cancer control programs (e.g., determine whether prevention, screening and treatment efforts are making a difference),
- Help set priorities for allocating health resources,
- Advance clinical, epidemiologic, and health services research, and
- Provide information for a national database of cancer incidence.

### FISCAL PRESSURE ON STATES: WILL IT COST LIVES?

*Most states are facing the worst fiscal crises in decades, with a collective shortfall of up to \$85 billion. Cancer registries have been impacted by these budget woes and often do not have the resources required to do their jobs in the most effective way possible. When states make spending decisions, the importance of registries for controlling and preventing cancer is often overlooked.*

*In the state of Texas, for example, the cancer registry narrowly escaped being "zeroed-out" in the state budget for 2004-2005, as the legislature struggled to reduce its \$10 billion deficit. Fortunately, the cancer registry was preserved.*

*However, it did suffer nearly a 10 percent budget cut for 2004-2005. This cut is further straining the state's ability to track cancer and its effort to obtain a nationally certified cancer registry. For instance, Texas has a current backlog of 25,000 cancer case records that must be processed. The budget cut will make it even harder to reduce the backlog. In addition, with less funding, plans to enhance data collection from outpatient facilities and physician offices will be severely impeded. The Texas registry needs additional staff and resources to address the backlog and continue its efforts to enhance data collection.*

In February 2000, CDC and NCI signed a Memorandum of Understanding (MOU) to establish formal collaboration between NCI's surveillance research programs and CDC's NPCR. The MOU seeks to better coordinate national cancer surveillance efforts by improving the availability of high-quality data, and advancing the capacity for surveillance research. For the first time ever in 2002, CDC and NCI published a national report, *United States Cancer Statistics: 1999 Incidence*. The

report contains federal government cancer statistics for more than one million invasive cancer cases diagnosed during 1999 among residents of 37 states, six metropolitan areas and the District of Columbia.<sup>13</sup>

The information collected by cancer registries can be used by a range of offices within state health agencies and by other researchers to develop public health initiatives to reduce cancer rates.

### SOME SUCCESSES

*The cancer trends revealed by tracking the disease have resulted in numerous advancements in treatment and prevention, such as cancer detection and screening programs. Finding the disease at the earliest stages provides more opportunities for effective treatment options and increases patients' chances for survival. Some examples of how registries have made a difference include:*

- ▲ *The Connecticut Tumor Registry identified an epidemic of lung cancer in women in 1977.<sup>14</sup> 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.*
- ▲ *In Canada registry data informed the development of more effective cervical cancer screening guidelines, including improved recommendations about the age and frequency at which women should be screened. These updated screening guidelines help doctors detect cervical cancer earlier, when it can be more successfully treated. As a result, death rates due to cervical cancer have decreased steadily.<sup>15</sup>*

▲ *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.<sup>16</sup>*

▲ *Cancer registries provide subjects for research studies that lead to primary prevention efforts. State cancer registries in Maine, New Hampshire, Massachusetts and Wisconsin participated in a study published in 1995 that found increased risk of breast cancer with increasing lifetime consumption of alcohol.<sup>17</sup> This and similar studies revealed that reducing excessive alcohol consumption is an important factor in reducing a woman's risk of developing breast cancer.*

# How Well Are States Tracking Cancer?

State cancer tracking efforts traditionally have been evaluated by the North American Association of Central Cancer Registries (NAACCR). NAACCR, established in 1987, is a collaborative umbrella organization for cancer registries, governmental agencies, professional associations and private groups in North America interested in enhancing the quality and use of cancer registry data. The organization annually reviews member registries for their ability to produce complete, accurate and timely data. The registry certification program then recognizes those registries meeting the highest standards of data quality with “gold” or “silver” award certificates for each data year.

Good data is critical, but ensuring the data is well used will save lives. In this report, Trust for America’s Health (TFAH) focused on examining not just states’ performance in compiling quality data, but also on how well the states use and apply this data to improve their cancer prevention and control programs. This added a new dimension to existing quality standards by analyzing if and how the information compiled helps inform prevention strategies and initiatives.

TFAH developed a grading system to determine how well states performed on criteria in four categories. NAACCR’s and NPCR’s data-quality criteria were used in conjunction with additional criteria to evaluate how the data is being used and applied to better understand risk factors and possible causes of cancer. The categories include:

- 1. Data Quality**– the accuracy, completeness and timeliness of data cancer registries collect on individuals diagnosed with cancer.
- 2. Data Linkage and Data Availability**– whether states are using the data from cancer registries to link to other available health information sources. The criteria also measure states’ performance in mak-

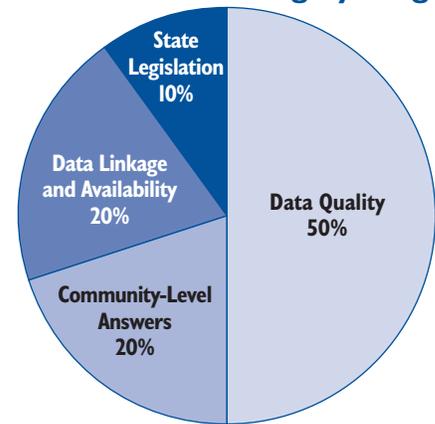
ing data available for research to determine whether specific behavioral and lifestyle factors, such as diet and exercise habits, or environmental factors such as second-hand smoke, certain viruses and pollutants, affect people’s risk of developing specific cancers.

- 3. Community-Level Answers**– how well the state provides data at the neighborhood level to answer community questions about cancer rates, while protecting the confidentiality of cancer patients.
- 4. State Legislation**– the state legislative and regulatory efforts to create and maintain effective cancer registries.

This survey of state health agencies was conducted from November 2002 through February 2003. The cancer registries were the point of contact for the states’ response. The survey asked states to report their proficiency on 36 standards.<sup>18</sup> These standards were grouped into the four categories described above. Designed to measure state performance, the standards drew on three sources: 1) NAACCR, 2) NPCR and 3) TFAH. (For a description of grading criteria, see Appendix A).

States were awarded points based on their performance on the 36 standards. The total points a state received in each category were weighted, and then overall grades were calculated. *Data Quality*, including accuracy, completeness, and timeliness comprised 50% of the total grade. This was weighted most heavily because it is critical to ensure that information is accurate *before* it is disseminated and used as the basis for public health initiatives. The *Data Linkage and Data Availability* and *Community-Level Answers* categories were each weighted as 20% of the grade. *State Legislation*, was weighted the lowest at 10% since adequate regulations and laws already exist in most states

### STATE GRADES: Category Weights



Percentage scores were translated into letter grades as follows: 90-100% = A; 80-89% = B; 70-79% = C; 60-69% = D; and below 60% = F.

### CASE STUDY

**NEW JERSEY:** Cancer registry data can help determine whether a community has elevated rates of cancer and suggest the reasons for this increase. In 1995, the New Jersey Department of Health and Senior Services (NJDHSS) responded to citizens' concerns that there was an elevated rate of childhood cancer in Dover Township, located in Ocean County, NJ. Using data from the New Jersey cancer registry, health officials discovered that the incidence of childhood cancer in Dover Township was significantly higher than would normally be expected when compared with the rest of the state. Leukemia and brain and central nervous system cancer rates were particularly elevated and the excess seemed to cluster in a particular section of Dover Township called Toms River. This prompted the NJDHSS and the U.S. Agency for Toxic Substances and Disease Registry

(ATSDR) to begin an epidemiological study in 1997 to examine the potential exposures associated with the elevated childhood cancer rates.

The investigation found that girls from birth to age 19 were five times more likely to have leukemia if they were exposed in utero to well water which had been contaminated with the solvent trichloroethylene and other chemicals leaking from a nearby hazardous waste site. Children who drank well water from contaminated groundwater areas or who lived near a waste pipe from Ciba-Geigy Corporation's now closed Toms River manufacturing plant were far more likely to develop leukemia. This is a strong example of how registry data can be used to address public concerns about the health of a community.<sup>34</sup>

# State-By-State Grades

**T**hirty-four states and the District of Columbia participated in TFAH's survey, representing 71 percent of the U.S. population. Sixteen states either declined to participate or provided insufficient information to be evaluated. Of the participants, 12 received an A, 16 earned a B, and three received a C. Three states earned a D and one state received an F. (See Map, State-by-State Grades).

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

The report found that, while most states are performing well, particularly in maintaining high-quality cancer data, there is generally room for improvement when it comes to using the information to improve prevention efforts in two specific areas:

■ First, many states do not conduct adequate linkages to other sources of available information, such as occupational and behavioral studies. This information

would help public health officials identify and develop initiatives focusing on risk factors and possible causes of cancer.

■ Second, state performance in providing information about cancer rates at the neighborhood level is mixed. Providing this information to communities is important when it comes to answering the public's questions about possible disparities in cancer rates among different localities and ethnic groups.

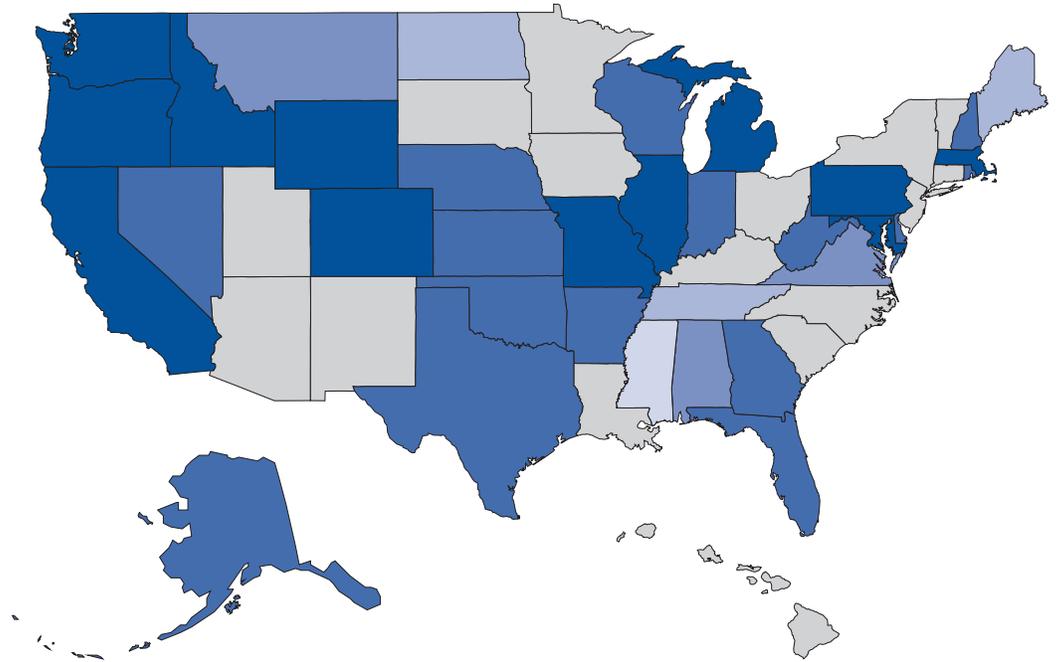
These two areas will be addressed further in the next section of the report.

## CASE STUDY

**NEW YORK:** As part of New York's Cancer Surveillance Improvement Initiative (CSII), the New York State Cancer Registry is improving the way information about cancer is conveyed and disseminated to the public. Using cancer registry data along with state-of-the-art mapping techniques, the New York State Cancer Registry's Web site maps cancer rates by zip code

throughout the state. The CSII also is planning to use maps to display the distribution of cancer risk factors by zip code throughout the state. These tools allow the public to begin to answer questions and concerns about cancer in their communities using readily available online information from the cancer registry.<sup>31</sup>

## STATE CANCER TRACKING GRADES



A	B	C	D	F	N/A
California	Alaska	Alabama	Maine	Mississippi	Arizona
Colorado	Arkansas	Montana	North Dakota		Connecticut
Idaho	Delaware	Virginia	Tennessee <sup>19</sup>		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 <sup>20</sup>
	West Virginia				Utah
	Wisconsin				Vermont

### Life-Saving Links Not Maximized

Of the 34 states and the District of Columbia that responded to TFAH's survey, 30 have at some time linked cancer registry data with other sources of information to better understand risk factors associated with cancer rates within a specific population. 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 data:

health-related behavioral/lifestyle, occupational and environmental.

When cancer registries conduct “data linkages” – combining cancer data with other databases – the combination identifies opportunities for cancer risk reduction. Twenty-seven cancer registries surveyed report that institutional constraints, including inadequate funding and staffing levels, limit their ability to perform data linkages on a routine basis. There are a number of basic data linkage stud-

ies that could be conducted more routinely to help enhance cancer tracking. Improved linkage efforts could positively impact:

■ **Enhancing Data Quality and Treatment Options.** According to the CDC, linking registry information to other sources can help to enhance the data collected. For example, most registries do not routinely collect information about other health issues a patient might have, such as heart disease, which can affect treatment options, or details about a treatment course, such as type of chemotherapy. Linkages with Medicare and health insurance claims databases can provide this important information.

■ **Identifying Risk Factors.** Conducting data linkages also can help identify opportunities for cancer-risk reduction. Linking registry data with information on lifestyle behaviors like diet, or environmental fac-

tors such as certain viral agents, or pollutants, can help better target cancer prevention efforts. For instance, environmental factors, including second-hand smoke, some pollutants, and viral agents such as certain types of human papillomavirus (HPV), have been linked to cancer.

■ **Development of Prevention Initiatives.** For example, several states have linked information about low rates of mammography screening with later-stage cancer diagnosis rates. Through such a study, Kentucky was able to target mammography screening outreach efforts and reduce the rates of late-stage breast cancer.<sup>21</sup>

■ **Reducing Health Disparities.** Linkages allow for the development of strategies to help target and reduce health disparities, such as differences in cancer rates within communities, socio-economic status, occupations, age ranges and ethnic groups.

## PROTECTING PATIENT CONFIDENTIALITY

*Medical information is among the most sensitive and personal information collected. Privacy is also central to the doctor-patient relationship. To protect medical privacy, the U.S. Department of Health and Human Services (HHS) issued regulations known as the "Privacy Rule." Congress gave HHS the authority to issue the rule in the Health Insurance Portability and Accountability Act of 1996 (HIPAA). The Privacy Rule defines administrative policies and procedures to safeguard patients' personal, private health information. It went into effect for most health organizations in April 2003.*

*The Privacy Rule aims to empower patients by guaranteeing them access to their medical records, giving them more control over the use and disclosure of their health information, and providing recourse if their medical privacy is compromised. A central feature of the rule is the informed consent provision, which specifies that a health organization cannot disclose private health information without the written, informed consent of the patient.*

*At the same time, the rule also recognizes the importance of public health surveillance, including cancer tracking conducted by cancer registries. Consequently, the Privacy Rule generally exempts cancer registries from the informed consent requirement. Health organizations covered under the rule must, however, maintain a log of private health information disclosures to cancer registries. This requirement preserves the patient's right to review an accounting of the disclosures of their private health information over a period of time, generally six years.<sup>27</sup>*

*All states have enacted laws requiring the confidentiality of cancer registry operations. The laws protect the identity of cancer patients and the sources reporting to the registries. CDC's National Program of Cancer Registries (NPCR) also requires the protection of patient confidentiality. Together, state laws, NPCR requirements and the federal Privacy Rule strive to achieve a balance between safeguarding patient confidentiality and enabling cancer tracking to prevent and control disease.*

- **Identifying At-Risk Communities.** For instance, linking water-quality data to cancer rates in neighborhoods may yield insights about the potential for water contamination to be associated with elevated cancer rates and the possible value of reducing exposures in future generations.
- **Informing Policy Priorities for Treatment and Control Efforts.** Systematically linking cancer data with Medicare and Medicaid could provide important information for establishing priorities for cancer treatment and control policies and resource allocation.

According to the TFAH survey, a number of states have shown how data linkages can be used to break new ground to better understand the obstacles to cancer reduction and treatment:

- Illinois linked cancer data to hospital discharge data to explore whether or not insurance status is associated with stage of cancer at time of diagnosis.

- Nevada linked cancer registry data to emergency room data to help determine the cost of cancer treatment and to evaluate the financial burden of cancer in Nevada.
- Oregon linked cancer registry data to Medicaid data to study cancer in the disabled Medicaid population, including the degree to which inadequate cancer control services among people with disabilities results in higher risk for preventable cancers and for diagnosis at later stages.
- Colorado linked cancer registry data with Medicare data to evaluate quality of care received by the elderly with breast and/or colorectal cancer.
- Seventeen states, including Maryland, New Hampshire, Pennsylvania and Wyoming, have linked cancer registry data with the Behavioral Risk Factor Surveillance Survey (BRFSS) to understand issues such as how the use of screening services varied by different types of cancer.<sup>22</sup>

## THE KEY TO LOWERING DISPARITIES

*Some ethnic minority groups and individuals living in poverty are more likely to become ill and die from cancer at rates that are higher than the rest of the population. For example:*

- ▲ *The number of new cases of invasive cancer per year from 1996-2000 was 521.7 for African-Americans and 479.8 for whites per 100,000 people.*
- ▲ *African-American men experience the highest incidence rates of lung and bronchial cancer, 120.4 per year per 100,000 males versus 79.4 for whites.*
- ▲ *Asian/Pacific Islanders have a liver cancer rate that is nearly three times as high as whites and a stomach cancer rate that is more than double that of whites.*
- ▲ *Hispanic/Latina females experience the highest incidence rates for cervical cancer, 16.8 per year per 100,000 females compared to 9.2 for whites.<sup>28</sup>*

*According to the Institute of Medicine, individuals living in poverty often lack health insurance or access to high-quality cancer care and typically experience high cancer incidence and mortality rates and low rates of survival.<sup>29</sup>*

*Cancer registry data can help public health officials create targeted programs that seek to reduce the number of cancer cases and cancer deaths. For example, analysis of cancer registry data can increase understanding of the factors that contribute to breast cancer severity among African-American women at the time of detection, which can lead to improved survival rates. Understanding these factors can help public health officials design outreach programs for African-American women that encourage them to seek mammography screening earlier, when treatment options may be more effective.*

- Twenty-one states, including Idaho, Massachusetts, Texas, Florida, and Georgia, have linked registry data with environmental databases to explore associations between cancer cases and air pollution, water contamination and potential exposure to hazardous waste sites.
- Sixteen cancer registries, including Arkansas, Illinois, Michigan, Oklahoma and West Virginia, have linked cancer data with occupational rosters to help

highlight possible exposures to cancer-causing agents in the work environment.

Data linkage studies can involve a wide range of potential analyses with varying amounts of personnel and computer time to conduct them. Currently, NPCR and state governments do not provide adequate resources for many state health agencies and registries to conduct the data linkages they would like to undertake. Registries use

## REAL-TIME AND RAPID REPORTING

*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. For example, prenatal X-ray exposure has been shown to increase the risk of childhood leukemia within a few years of birth. In some communities, such as Woburn, MA, and Tom's River, NJ, there was an excess of childhood leukemia in children whose mothers were exposed to contaminated well water while pregnant. For these reasons, it is desirable to examine childhood cancer patterns as rapidly as possible to see if unusual numbers are occurring in communities that may warrant further investigation and preventive action.*

*Real-time reporting of childhood cancer has been proposed by a citizen group in Tom's River, NJ, where a significant excess of childhood leukemia and brain cancer was first noted by the group and confirmed by the state cancer registry. In states with large populations, the hospital where a child is first diagnosed could transmit information electronically, with adequate privacy protection, to the state cancer registries. This would mean almost "real-time" reporting of the case. The hospital subsequently would report additional information to supplement the initial data it sent. Real-time reporting requires modernizing to take advantage of the latest available technology in electronic reporting systems. NPCR has called for electronic reporting for several years. NAACCR also has recognized the importance of moving toward electronic, real-time case reporting.<sup>30</sup>*

*With initial diagnostic information and minimal information, such as age at diagnosis and residential address, state cancer prevention staff could "screen" the data periodically to look for emerging patterns. This would require cooperation from the pediatric hospitals where a patient is first diagnosed and some additional state cancer registry personnel time, depending on the size of the state, but would include less than 10 percent of the statewide cancer cases (the approximate percentage of cancer cases that occur in children). Such a system would allow for rapid review of these cases to see if unusual new patterns emerge. Later, the full data on each childhood case, including first course of treatment and related clinical data could be added to enhance data completeness. **Real-time reporting of childhood cancer would provide the potential for early evaluation and intervention to prevent exposures and would respond to citizens' special concerns about childhood cancer.***

*In addition, real-time reporting for children could serve as a model for rapid reporting of adult cancer cases. With the use of new technologies, rapid reporting has become common in other public health initiatives. The CDC and some local communities have demonstrated this type of reporting in their tracking of West Nile Virus and severe acute respiratory syndrome (SARS). Though cancer is not an acute infectious disease, a modern registry system could and should develop additional procedures to compile useful data rapidly for immediate reporting once a case of cancer is accurately diagnosed.*

their resources to focus first on collecting and compiling high-quality data – linkages are a lower priority. Often there is too little funding to hire enough staff to create data linkages, which can be labor-intensive. Increased funding for data linkages should become a top priority for NPCR and the states, even though state and federal governments are facing significant deficits. Given that the nation spends more than \$180 billion on treatment and lost productivity due to cancer, investment in data linkages could help prevent new cases of cancer in the future, decrease the number of deaths from cancer and potentially save health care dollars.

At a meeting hosted by CDC/NPCR, cancer registry experts recognized the need to increase the value and utility of registry databases for cancer prevention and control by improving the linkages to other databases, such as geographic information systems (GIS) and census data.<sup>23</sup> By incorporating data linkages into routine cancer registry operations, public health programs can better target limited resources to:

- Modify policies and programs to improve preventive measures,
- Target populations for interventions,
- Provide information about risk factors, and
- Evaluate current activities.

## Many Community-Level Questions Go Unanswered

TFAH's study examined the performance of states in providing community-level data that can answer the public's and researchers' questions about disparities in cancer rates among different neighborhoods and ethnic groups. Of the 34 states and the District of Columbia that responded to TFAH's survey, only 14 reported that they provide data at the neighborhood level. More than half the states participating in TFAH's survey do not provide information at the community level, typically due to limited funding and resources.

Each year, more than a thousand communities or individuals raise concerns to their health departments about their neighborhoods' cancer rates.<sup>24</sup> Often these communities suspect they are experiencing a "cancer cluster." A higher-than-expected number of cancer cases in a certain geographic area over a defined period of time within a specific group of people is considered to be a cluster. Cancer clusters tend to be controversial because of the many challenges facing cluster investigations - politics, perceptions, statistical chance and limitations of science. Rarely do investigations result in the identification of true cancer clusters.<sup>25</sup>

These questions and concerns can only be properly addressed, and in most cases put

### CASE STUDY

**CALIFORNIA:** California is one of America's leaders in cancer tracking. Due to the size and diversity of California's population, more is known about the occurrence of cancer among diverse populations than in most other states. 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 stage 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.<sup>32</sup>

to rest, by providing information about cancer rates at a neighborhood level. The public should be able to obtain cancer registry data in two ways: by reviewing published annual reports or by asking states for it directly. In reality, neither approach guarantees that the public and researchers receive information specific enough to be able to adequately address their questions at a neighborhood level.

States' annual reports provide statewide cancer rates and sometimes publish rates at smaller geographic levels, such as by county, city or town. Typically, however, data specific to neighborhoods is only available when special requests are made by the public. These requests are often prompted by concerns that there may be a potential cancer cluster. The TFAH survey found that 21 of the 34 states and the District of Columbia surveyed do not make neighborhood-specific data available to citizens requesting it. In addition, of the 14 states that do provide neighborhood-level data to citizens, 12 states publish breakdowns of cancer cases by age, sex and race, but two do not. Many cancer-tracking experts point out that very high-quality control standards should be met before data is made available to the public, to ensure that communities are receiving and relying on information that is as accurate as possible.

All of the states have patient privacy laws that require them to limit the availability of data

at the neighborhood level. Accordingly, some states have developed policies allowing data to be released at any geographic level under certain conditions. For example, several states allow aggregate data to be released at a small geographic level, as long as it contains more than five cancer cases. The experience of cancer registries in other countries demonstrates that confidentiality can be protected while tracking cancer within specific communities and providing such data to citizens at a geographic level small enough to answer their questions.<sup>26</sup>

TFAH's survey found that all states but Rhode Island had written cancer cluster investigation protocols. These protocols are important to the public because they establish formal rules that describe if, when and how a state will act to investigate a possible cancer cluster. Cancer registries provide state health officials with a measure as to whether the observed incidence of cancer is elevated for a specific time period. In addition, they also can provide a statistical estimate as to whether 'chance' can be excluded as a competing explanation for the occurrence of the cancer cluster. If there are indications that there are a statistically significant greater number of cases, then the health department may initiate an investigation, depending on the written protocols.

## CASE STUDY

**OREGON:** Before the 1992 Cancer Registries Amendment Act, Oregon was one of the many states lacking a statewide cancer registry. With the help of national funds, Oregon has achieved the nation's highest standards in data quality and completeness in only a few years of operation. The registry is now producing comprehensive

summary data reports and using the data both internally and in collaboration with external researchers. For example, data is being used to document the degree to which inadequate cancer control services among people with disabilities results in higher risk for preventable cancers and for diagnosis at later stages.<sup>33</sup>

## CONCLUSION:

# A Vision for 21st-Century Cancer Tracking

State cancer tracking, prevention and control programs are critical to winning America's War on Cancer. They seek to reduce illness and death due to cancer, and have achieved some real success. States have used cancer tracking data to save lives by improving cancer screening guidelines and developing public health programs that have reduced people's risk of developing and dying from cancer.

Yet states can do more. Many states could enhance their data tracking efforts to help reduce cases of cancer that could have been prevented altogether. Many states need to work towards expanding their data linkages to other databases. This would accelerate the pace of valuable discoveries of the factors that contribute to cancer and identify groups who are at risk today. Most states also need to improve efforts to provide information that helps answer communities' questions about cancer rates in their neighborhoods. While budget pressures loom, cancer tracking and control must be funded adequately at the state and federal levels.

In order to modernize cancer tracking, prevention and control programs in the U.S., a new, concerted commitment is required to ensure that states are able to:

- 1) Conduct data linkages to combine registry data with other sources of information essential to cancer prevention, including lifestyle and behavior factors, and environmental data, such as certain viruses and pollutants;**
- 2) Develop community-friendly practices, which help answer the public's questions about cancer rates in their neighborhoods, while maintaining the confidentiality of individuals;**

- 3) Implement real-time reporting for childhood cancer and rapid reporting for adult cancer; and**

- 4) Continue high standards for data quality.**

State cancer tracking programs have been successful at providing information that improves "secondary prevention" — cancer screening and early detection. However, many states are falling short in efforts to use the information they collect to help reduce cases of cancer that could be prevented altogether. Identifying factors that place individuals or communities at risk for developing cancer and working to reduce those factors in order to lower that risk is called "primary prevention."

An example of primary prevention that states could undertake is to link data on patterns of environmental behavior, such as tobacco exposure, diet or exercise, to data on cancer rates. Given current resources, many states do not include such data linkages for primary prevention among their ongoing or regular cancer tracking activities. Yet such linkages have the potential to become an even more effective tool in the fight against cancer by expanding their focus to include more efforts to stop new, preventable cases of cancer from occurring.

Reducing preventable cases of cancer and increasing cancer screening rates could potentially reduce health care spending over time for health care consumers, including the federal and state governments, as well as employers. More important, advancements in understanding and improving cancer prevention can result in reduced illness and countless lives saved.

# Recommendations For Action

The results of TFAH's survey suggest a series of actions for policymakers to consider with respect to modernizing America's cancer tracking system 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 both primary and secondary 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 NPCR at \$65 million, an increase of approximately \$19 million, would help modernize cancer tracking. Spending money on tracking can save health care expenditures, and more important, save lives. Cancer tracking should also be integrated into a comprehensive Nationwide Health Tracking Network administered by the CDC designed to monitor chronic diseases.

**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 should also adopt policies that allow them to provide information at a neighborhood level that guard 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 preventive 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, 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 standards in these areas, Congress should mandate 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 programs, yet obstacles remain. The IOM should examine the respective SEER and NPCR programs and make recommendations that will guide development of a seamless cancer tracking system in the U.S.

# Appendix A:

## DESCRIPTION OF THE GRADING CRITERIA

### Data Quality

Nineteen criteria were used to assess data quality. All but one of the criteria have been used by CDC's National Program of Cancer Registries (NPCR) to evaluate the first five years of their program.<sup>35</sup> Nine of the 19 criteria are used by the North American Association of Central Cancer Registries (NAACCR) in their registry certification program.<sup>36</sup> Where NPCR and NAACCR criteria were the same, TFAH used NAACCR's criteria when assigning points. Criteria derived from NAACCR standards were scored using a 3-point system. A state scored 0 points if it performed below NAACCR's "silver" level, 2 points if it performed at NAACCR's "silver" level and 4 points if it performed at NAACCR's "gold" level. Criteria based on NPCR's standards were scored using a 2-point system. A state scored 0 points if it did not meet the NPCR criteria and 1 point if it did meet the criteria. Scores on each criterion were added together to create a category-specific grade.

The *Data Quality* scoring method assigned more weight (more points) to NAACCR criteria to account for the relative value and importance of the NAACCR registry program as an indicator of state cancer registries' performance with regard to data quality, completeness and timeliness. In addition, the scoring system translated NPCR's and NAACCR's non-numeric evaluation procedures into comparable numeric values. This study used NAACCR's list of silver- and gold-certified states for 2000 incidence data to validate the Data Quality grading system and to ensure accurate reporting by the states. The Data Quality grades will differ slightly from NAACCR's certification results due to the differences in scoring methods and the inclusion of additional criteria from NPCR.

### Data Linkage and Availability

TFAH established four criteria to assess whether state cancer registries or other state health department programs:

- Link cancer data with other individual and/or population-level databases to provide enhanced health tracking;<sup>37</sup> and
- Implement an NPCR standard mandating that state cancer registries have procedures allowing public health researchers access to confidential case information. Note that some state laws prohibit access to confidential case information, and NPCR standards do not supercede state law. Some states choose to make their data available in public use databases, which can meet the needs for cancer control planning, but may not meet the needs for all types of research. This is not ideal from the cancer research and prevention standpoint.

Performance on each criterion in this category was scored using a 2-point scoring system. A state received 1 point if it had such procedures in place and 0 points if it did not. Scores on each criterion were added together to create a category-specific grade. To get an "A" in this category, states had to receive the maximum possible points on every standard.

### Community-Level Answers

TFAH established four criteria to evaluate how well states provide information about cancer rates at a neighborhood level to the public to help better understand possible disparities. Performance on each criterion was scored using a point system. States that provided citizens with the least informative data scored 1 point. States that provided citizens with moderately informative data scored 2 points. States that provided citizens with the most informative data scored 4 points.<sup>38</sup> The criterion regarding written cancer protocols was scored using a 2-point system. States with a written cancer cluster protocol in place scored 2 points, states without one scored 0 points. Scores on each criterion were added together to create a category-specific grade. To get an "A" in this category, states had to receive the maximum possible points on every standard.

## State Legislation

TFAH's *State Legislation* criteria were based on 9 NPCR program evaluation criteria. Performance on each criterion was scored using a 2-point system. States received 1

point for performing the criteria and 0 points it did not. Scores on each criterion were added together to create a category-specific grade. To get an "A" in this category, states had to receive the maximum possible points on every standard.

GRADING SYSTEM GRID						
Criteria	Point System				Final Weight	
	0	1	2	4		
DATA QUALITY	Collect and report all NPCR-required data items**	Missing 1 or more	No missing			50%
	Use NAACCR standardized record layout**	No	Yes			
	Employ at least 1 certified tumor registrar**	No	Yes			
	Written data quality policies & procedures**	No	Yes			
	Passing EDITS*/**	< 97%		± 97%	100%	
	Text information is included in computerized form as well as data codes**	No	Yes			
	Re-abstracting audits in reporting facilities performed within past year**	No	Yes			
	Independent audit of the registry performed within past 5 years**	No	Yes			
	Missing age at diagnosis*/**	> 3%		† 3%	† 2%	
	Missing race*/**	> 5%		† 5%	† 3%	
	Missing sex*/**	> 3%		† 3%	† 2%	
	Missing county/state*/**	> 3%		† 3%	† 2%	
	Duplicates*/**	> 2/1,000		† 2/1,000	† 1/1,000	
	Data ≥ 90% complete available within 23 months of the diagnosis year*	No			Yes	
	Current published annual reports available within 12 months of the diagnosis year (as of December 2002)**	> 24 months	† 24 months	† 12 months		
	Interstate data sharing agreements with all border & retirement states**	No	Yes			
Completeness*/**	< 90%		≥ 90%	± 95%		
Death clearance & follow-back*/**	No DCO or > 5%		† 5%	† 3%		
Case-finding audits in reporting facilities performed within past year**	No	Yes				
Data Linkage & Availability	Data linked to health data (access/quality of care) and/or lifestyle behavioral risk factor data by registry or in partner with other state programs or departments***	No	Yes			20%
	Data linked to environmental risk factor databases by registry or in partner with other state programs or departments***	No	Yes			
	Data linked to occupational risk factor databases by registry or in partner with other state programs or departments***	No	Yes			
	Raw data available to external public health researchers***	No	Yes			
Community-Level Answers	Informative geographic level***		County	City/Zip Code	Census Tracts/Block Groups	20%
	Informative demographic categories at lowest geographic level***		< 2 variables	2 variables	Gender, Race & Age	
	Informative tumor site data at lowest geographic level***		All sites combined	Site Specific or Appropriate aggregations	All Sites Combined and Site Specific	
	Written cancer cluster investigation protocols***	No		Yes		
State Legislation	Complete case reporting from all facilities diagnosing or treating cancer**	No	Yes			10%
	Complete case reporting from all practitioners diagnosing or treating cancer**	No	Yes			
	Access to medical records**	No	Yes			
	Uniform reporting format**	No	Yes			
	Protection of confidentiality**	No	Yes			
	Use of data for research**	No	Yes			
	Release of data for research**	No	Yes			
	Protection of individuals from liability**	No	Yes			
Cases reported to central registry within 6 months**	No	Yes				

\*NAACCR registry certification program criteria; \*\*NPCR program evaluation criteria; \*\*\*TFAH criteria

## DESCRIPTION OF THE GRADING SYSTEM GRID

### Data Quality (50% of overall grade)

- 1) Report all NPCR data items – Standardized data collection is key to a surveillance system that ensures useful data on every case of cancer is collected and allows cancer rates to be compared and aggregated across state registries.
- 2) Use NAACCR standardized record layout – Standardized record layouts ensure that data can be compiled from different registries.
- 3) Employ at least one certified tumor registrar – Certified tumor registrars receive specialized training and are essential for effective registry functioning.
- 4) Written policies and procedures – Written protocols available to registry staff with varied experience and tenure are necessary to help ensure that registry operations are consistent, and of high quality.
- 5) Passing EDITS – EDITS is a software logic program developed by CDC and maintained by NAACCR that registries use to test the validity and logic of individual cancer records.
- 6) Text information included in computerized form as well as data codes – Text information is vital for including more information than is conveyed with standardized coded data.
- 7) Re-abstracting audits in reporting facilities performed within the past year – Re-abstracting audits provide not only valuable information regarding errors reported in the original data file, but can prevent such errors in the future.
- 8) Independent audits of the registry performed within the past five years – Reviews of registry performance by independent experts or academic users of the data provide a fresh perspective on registry operations.
- 9) Missing age at diagnosis – No more than 3% of reported cases should be missing data on an individual's age.
- 10) Missing race – No more than 5% of reported cases should be missing data on an individual's race.
- 11) Missing sex – No more than 3% of reported cases should be missing data on an individual's sex.
- 12) Missing county/state – No more than 3% of reported cases should be missing data on the county or state in which an individual resides.
- 13) Duplicates – No more than 1 case per 2,000 should have duplicate records for each primary tumor.
- 14) Timely data – Complete, quality data need to be available within 23 months of the diagnosis.
- 15) Annual cancer reports – Annual cancer reports need to be made publicly available within 12 months of the close of the diagnosis year. An annual report contains at minimum, age-adjusted incidence rates and age-adjusted mortality rates for the diagnosis year by sex for selected cancer sites and, where appropriate, by sex, race and ethnicity for selected cancer sites.<sup>39</sup>
- 16) Interstate data sharing agreements with all border and retirement states – Data sharing agreements ensure that if a state resident is diagnosed outside of the state, the diagnosis is reported back to the state registry where the patient permanently resides.
- 17) Completeness – Registries should contain at least 90% of state residents diagnosed with cancer. Registries estimate the percent of expected, unduplicated cases to provide a measure of the completeness of ascertaining all cases of cancer diagnosed among state residents.

- 18) Death clearance and follow-back – No more than 5% of cases should be identified through death certificates. Registries calculate the percent of cases that are identified by death certificate only, meaning the case escaped the normal reporting process through hospital or clinic procedures and was identified only because the patient’s death certificate noted the type of cancer.
- 19) Case-finding audits in reporting facilities performed within the past year – Case-finding audits help to verify complete reporting of cancer by diagnosing facilities and practitioners.

### **Data Linkage & Availability** (20% of overall grade)

- 1) Data linked to health care intervention data and/or lifestyle behavioral risk factor databases by registry or in partner with other state programs or departments – Linking cancer registry data with health care intervention data and/or lifestyle behavioral risk factor data in order to help identify possible trends that warrant investigation or intervention.
- 2) Data linked to environmental risk factor databases by registry or in partner with other state programs or departments – Linking cancer registry data with hazardous exposure data (air emissions, toxic exposures from hazardous waste sites, water quality, etc.) ensures that states are using cancer registry data in order to identify possible health trends that warrant investigation or intervention.
- 3) Data linked to occupational risk factor databases by registry or in partner with other state programs or departments – Linking cancer registry data with occupational risk factor databases, such as occupational rosters, ensures that cancer data is being used to identify trends in specific occupations that warrant investigation or intervention.

- 4) Raw data available to researchers – States need to have provisions in place to ensure that confidential case data can be provided to external researchers for the purpose of public health research.

### **Community-Level Answers** (20% of overall grade)

- 1) Informative geographic level – Cancer data provided to citizens should be at an appropriate geographic resolution to answer community-level questions, while maintaining patient confidentiality. Data at too large a geographic level often dilutes the ability to observe trends in a localized area.
- 2) Informative demographic categories at lowest geographic level – Data provided to the public should be stratified by informative demographic variables, such as age, sex and race, in order to observe possible trends, while maintaining patient confidentiality.
- 3) Informative tumor site data at lowest geographic level – Data provided to the public should contain overall cancer rates, as well as site-specific and or appropriate aggregated data (e.g., leukemias), while maintaining patient confidentiality.
- 4) Written cluster investigation protocols – The existence of a written cluster investigation protocol helps to ensure that the state provides a thorough response to inquiries and concerns regarding a possible cancer cluster.

### **State Legislation** (10% of overall grade)

Cancer registries require support and authority through state legislation and/or regulations for effective operation and utility. All standards used are NPCR program evaluation standards. NPCR requires states that receive funds through their program to comply with standards 1-8 as delineated in the Cancer Registries Amendment Act.

- 1) Complete case reporting from all facilities diagnosing or treating cancer. State legislation/regulations should mandate the reporting of cancer cases to the registry by all hospitals, or other facilities providing screening, diagnostic or therapeutic services to patients with respect to cancer.
- 2) Complete case reporting from all practitioners diagnosing or treating cancer. State legislation/regulations should mandate that the reporting of cancer cases to the cancer registry by physicians, surgeons and all other health care practitioners diagnosing or providing treatment of cancer patients.
- 3) Access to medical records – State legislation/regulations should mandate that the registry is to have access to all medical records that identify cases of cancer or establish characteristics of the cancer, treatment of the cancer or medical status of the individual.
- 4) Uniform reporting format – State legislation/regulations should mandate that reporting facilities use standardized data formats when reporting data to the cancer registry.
- 5) Protection of confidentiality – State legislation/regulations should mandate the protection of confidentiality of all cancer case data reported to the cancer registry.
- 6) Use of data for research – State legislation/regulations should authorize the state cancer registry or other persons or organizations to conduct studies utilizing registry data, including studies of sources and causes of cancer, evaluations of the cost, quality, efficacy and appropriateness of diagnostic, therapeutic, rehabilitative and preventive services and programs relating to cancer, and any other clinical, epidemiological or cancer research.
- 7) Release of data for research – State legislation/regulations should contain provisions by which confidential case data may be disclosed to cancer researchers (in accordance with state law) for the purposes of cancer prevention, control and research.
- 8) Protect individuals from liability – State legislation/regulations should protect individuals who report information regarding cancer cases to the registry or who have access to cancer case information provided to the registry from liability in any civil action.
- 9) Cases reported to central registry within 6 months – State legislation/regulations should require that facilities and individuals report cases to the cancer registry within 6 months of the diagnosis.

# Appendix B:

## NAACCR CERTIFICATION LEVELS FOR 2000 INCIDENCE DATA<sup>40</sup>

NAACCR Certification Level	State		
<b>Gold</b>	Alaska	Michigan	
	California	Minnesota	
	Colorado	Missouri	
	Connecticut	Nebraska	
	District of Columbia	Nevada	
	Florida	New Hampshire	
	Georgia	New Jersey	
	Hawaii	New York	
	Idaho	North Carolina	
	Illinois	Oregon	
	Iowa	Pennsylvania	
	Kansas	Rhode Island	
	Kentucky	Washington	
	Louisiana	West Virginia	
	Maryland	Wisconsin	
	Massachusetts	Wyoming	
	<b>Silver</b>	Alabama	North Dakota
		Arizona	Ohio
		Indiana	South Carolina
Montana		Utah	
New Mexico			

### IMPROVING CANCER TRACKING TODAY SAVES LIVES TOMORROW: DO STATES MAKE THE GRADE?

#### AUTHORS

**Shelley A. Hearne, DrPH**

*Executive Director*

Trust for America's Health

**Susan L. Polan, PhD**

*Director of Government Relations*

Trust for America's Health

**Laura M. Segal, MA**

*Director of Communications*

Trust for America's Health

**Patti J. Unruh**

*Senior Communications Associate*

Trust for America's Health

#### CONTRIBUTING AUTHOR

**Richard W. Clapp, MPH, DSC**

#### TECHNICAL SUPPORT

Tellus Institute, Environmental Health

Program

#### PEER REVIEWERS

*The opinions expressed in this report do not necessarily reflect the views of these individuals or organizations.*

#### Division of Cancer Prevention and Control

National Center for Chronic Disease

Prevention and Health Promotion

Centers for Disease Control and Prevention

#### Division of Cancer Control and Population Sciences

National Cancer Institute

National Institutes of Health

#### Elizabeth Ward, PhD

*Director, Surveillance Research*

Department of Epidemiology and

Surveillance Research

American Cancer Society

#### Daniel Wartenberg, PhD

*Professor*

University of Medicine and Dentistry

New Jersey – Robert Wood Johnson

Medical School

Department of Environmental and

Community Medicine, Environmental and

Occupational Health Sciences Institute

and Cancer Institute of New Jersey

# Endnotes

- 1 The Mellman Group, Inc. and Public Opinion Strategies. "National Survey on Public Perceptions of Risk from Bioterrorism and Other Health Threats," Trust for America's Health. <<http://healthyamericans.org/newsroom/surveymemo0515.pdf>> 15 May 2002.
- 2 "Cancer Facts & Figures 2003." American Cancer Society. Atlanta, Georgia. 2003.
- 3 "Cancer Registries: The Foundation for Cancer Prevention and Control." Centers for Disease Control and Prevention. <[http://www.cdc.gov/nccdphp/bb\\_cancer\\_reg/](http://www.cdc.gov/nccdphp/bb_cancer_reg/)> 2001.
- 4 "Cancer Facts & Figures 2003." American Cancer Society. Atlanta, Georgia. 2003. This estimate excludes noninvasive cancer of any site except urinary bladder, and does not include basal and squamous cell skin cancers.
- 5 "Cancer Facts & Figures 2003." American Cancer Society. Atlanta, Georgia. 2003.
- 6 Ibid.
- 7 TFAH calculation based on 1996-2000 prostate cancer incidence rates of 164.3 per 100,000 for white males and 272.1 per 100,000 for African-Americans. Source for prostate cancer incidence rates: "Cancer Health Disparities," National Cancer Institute. <<http://www.cancer.gov/newscenter/healthdisparities>> 23 April 2003.
- 8 "Cancer Health Disparities." National Cancer Institute. <<http://www.cancer.gov/newscenter/healthdisparities>> 23 April 2003.
- 9 "Cancer Facts & Figures 2003." American Cancer Society. Atlanta, Georgia. 2003.
- 10 "Importance of Cancer Registry." National Cancer Institute, <[http://training.seer.cancer.gov/module\\_cancer\\_registration/unit1\\_importance.html](http://training.seer.cancer.gov/module_cancer_registration/unit1_importance.html)> Accessed 4 August 2003.
- 11 Several states that participated in the Trust for America's Health evaluation have registries (either state-wide or regional) that currently participate in the SEER program. These states include Alaska (Alaska Native Tumor Registry), California, Georgia (the Atlanta and Rural Georgia Registries), Washington (Seattle-Puget Sound Registry) and Michigan (Detroit registry).
- 12 "2003 Program Fact Sheet, Cancer Registries: The Foundation for Cancer Prevention and Control." Centers for Disease Control and Prevention. <<http://www.cdc.gov/cancer/npcr/register.htm>> 19 August 2003.
- 13 United States Cancer Statistics: 1999 Incidence. Atlanta (GA): Department of Health and Human Services U.S. Cancer Statistics Working Group, Centers for Disease Control and Prevention and National Cancer Institute; 2002.
- 14 Weigs JW. "Epidemic Lung Cancer in Women," The Journal of the American Medical Association, 1977: 238:10.
- 15 Ries LAG, Eisner MP, Kosary CL, Hankey BF, Miller BA, Clegg L, Mariotto A, Fay MP, Feuer EJ, Edwards BK (eds). SEER Cancer Statistics Review, 1975-2000. National Cancer Institute, Bethesda, MD, <[http://www.seer.cancer.gov/csr/1975\\_2000/](http://www.seer.cancer.gov/csr/1975_2000/)> 2003.
- 16 "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.
- 17 Longnecker, et al. "Risk of Breast Cancer In Relation To Lifetime Alcohol Consumption." J Natl Cancer Institute, 1995; 87:923-929.
- 18 One limitation of TFAH's survey is that it does not take into account the fact that state cancer tracking programs are at varying stages of development and have varying levels of resources. Older programs may have had many opportunities for data linkages and community interactions than newer registries that have only recently received federal funding. Newer cancer tracking programs may therefore be focusing their attention and resources on establishing themselves and meeting minimum quality standards.
- 19 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.htm](http://www.cdc.gov/cancer/npcr/awards.htm)>). 26 August 2003.

- 20 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.
- 21 "Cancer Registries: The Foundation for Cancer Prevention and Control AT-GLANCE 2001." Centers for Disease Control and Prevention. <<http://www.cdc.gov/cancer/npcr/2001AAG-npcr.htm>.> 2001.
- 22 The Behavioral Risk Factor Surveillance System (BRFSS) is a telephone survey conducted by all state health departments, the District of Columbia, Puerto Rico, the Virgin Islands, and Guam with assistance from CDC. The BRFSS is the largest continuously conducted telephone health survey in the world. States use BRFSS data to track critical health problems and to develop and evaluate public health programs.
- 23 "Cancer Surveillance System (NPCR-CSS)." Centers for Disease Control and Prevention. <<http://www.cdc.gov/cancer/npcr/npcr-css.htm>.> July 1999
- 24 Trumbo, Craig W. "Public Requests for Cancer Cluster Investigations: A Survey of State Health Departments," American Journal of Public Health. August 2000: 90(8).
- 25 Neutra, R.. "Reviews and Commentary: Counterpoint from a Cluster Buster," American Journal of Epidemiology. July 1990: 132(1).
- 26 Sankila R, et al. "Informed Consent in Cancer Registries," Lancet (letter), 12 May 2001: 357: 1536.
- 27 Hodge, James G Jr. Letter to Holly L. Howe, Executive Director, North American Association Central Cancer Registries. <[http://www.naaccr.org/filesystem/pdf/Academic\\_Letter\\_Interpreting\\_HIPAA2.pdf](http://www.naaccr.org/filesystem/pdf/Academic_Letter_Interpreting_HIPAA2.pdf).> July 2001: 13.
- 28 "Cancer Health Disparities." National Cancer Institute. <<http://www.cancer.gov/newscenter/healthdisparities>.> 23 April 2003.
- 29 Haynes, Alfred M and Smedley, Brian D (eds). The Unequal Burden of Cancer: An Assessment of NIH Research and Programs for Ethnic Minorities and the Medically Underserved. Committee on Cancer Research Among Minorities and the Medically Underserved, Institute of Medicine. 1999.
- 30 "North American Association of Central Cancer Registries Overarching Goals and Tasks," NAACCR Leadership Retreat. <<http://www.naaccr.org/filesystem/pdf/Overarchinggoals2003-2005%2001-25-03.pdf>.> October 2002.
- 31 "The New York State Cancer Surveillance Improvement Initiative." New York State Health Department. <<http://www.health.state.ny.us/nysdoh/cancer/sublevel/csii.htm>.> December 2000.
- 32 "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.
- 33 "NPCR - The First 10 Years NPCR." Centers for Disease Control and Prevention. <<http://www.cdc.gov/cancer/npcr/npcr-pdfs/handout.pdf>.> 2002.
- 34 "Case-control Study of Childhood Cancers in Dover Township (Ocean County), New Jersey," Volume II: Final Technical Report. Division of Epidemiology, Environmental and Occupational Health, New Jersey Department of Health and Human Services in cooperation with the Agency for Toxic Substances and Disease Registry, U.S. Department of Health and Human Services. <[http://www.state.nj.us/health/eoh/hhazweb/case-control\\_pdf/Volume\\_II/vol\\_ii.pdf](http://www.state.nj.us/health/eoh/hhazweb/case-control_pdf/Volume_II/vol_ii.pdf).> January 2003.
- 35 Hutton, M, Simpson, L, Miller, D, et al. "Progress Toward Nationwide Cancer Surveillance: An Evaluation of the National Program of Cancer Registries: 1994-1999," Journal of Registry Management. 2001: 28:3: 113-120.

- 36 “Criteria and Standards for NAACCR Certification.” North American Association of Central Cancer Registries. <<http://www.naac-cr.org/filesystem/pdf/finalcriteriaforRegistrycertificationpage.pdf>> Accessed 2 September 2003.
- 37 Data linkages conducted by a registry for the purpose of case ascertainment or data quality were excluded.
- 38 ‘Most informative’ is defined as the data: were at the census tract/census block level (or relevant aggregations); did include specific demographic stratifications (race sex, age); and included cancer data for site specific cancer sites and all sites combined. Data availability was also categorized into two additional groups: ‘Least informative,’ defined as the data were: at the county level or higher; did not include all specific demographic stratifications (race, sex and age); and only included cancer data for all cancer sites combined, or ‘Moderately informative,’ defined as the data: were at the city/town zip-code level; did not include all specific demographic stratifications (race, sex, age); and only included cancer data for site specific cancer sites or appropriate aggregations. States received 4 points for the most informative data, 2 points for moderately informative data and 1 point for least informative data.
- 39 “Program Announcement 02060: National Cancer Prevention and Control Program Notice of Availability of Funds.” Centers for Disease Control and Prevention. <<http://www.cdc.gov/cancer/dccp/pdf/Program-Announcement-02060.pdf>> 2002: 45.
- 40 “2002 Certified Registries of 2000 Incidence Data.” North American Association of Central Cancer Registries. <[http://www.naac-cr.org/index.asp?Col\\_SectionKey=12&Col\\_ContentID=98](http://www.naac-cr.org/index.asp?Col_SectionKey=12&Col_ContentID=98)> 2002.





1707 H Street, NW, 7th Floor  
Washington, DC 20006  
(t) 202-223-9870  
(f) 202-223-9871