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# **National Program of Cancer Registries Cancer Surveillance System Rationale and Approach**

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National Center for Chronic Disease Prevention and Health Promotion  
Division of Cancer Prevention and Control  
National Program of Cancer Registries**

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## Executive Summary

The Centers for Disease Control and Prevention (CDC) funds state and territorial health agencies to collect data on cancer. This document outlines the rationale and approach for receiving, assessing, enhancing, aggregating, and disseminating these cancer data from the states and territories funded by the CDC National Program of Cancer Registries (NPCR).

Cancer is a devastating disease. In 1999, approximately 1.2 million new cancer cases will be diagnosed (excluding basal and squamous cell skin cancers) with an estimated 563,100 deaths of cancer. One of every four deaths in the United States is from cancer. CDC has the responsibility for public health surveillance and disease prevention in the United States. Cancer surveillance is an essential component of this responsibility. Timely dissemination of cancer surveillance data to public health agencies and scientists is key to designing and evaluating cancer prevention and control activities.

Cancer registration is the fundamental method in the United States by which information is systematically collected about the incidence and types of cancer, the anatomic location, the extent of disease at the time of diagnosis, the kinds of treatment received by cancer patients, and the outcomes of treatment and clinical management. Within the United States, there are multiple national programs and organizations that actively collect and report data for cancer incidence, morbidity, mortality and survival. These data collected by each organization differ according to the mandates of the supporting agency. These national programs include the NPCR; the Surveillance, Epidemiology, and End Results (SEER) program; the North American Association of Central Cancer Registries (NAACCR); National Cancer Data Base (NCDB); and Central Brain Tumor Registry of the United States (CBTRUS).

The CDC-funded NPCR is a population-based system of cancer registries established in 1992 by the Cancer Registries Amendment Act (Public Law 102-515). In Fiscal Year 1999, CDC supported 45 states, 3 territories, and the District of Columbia for central cancer registries through cooperative agreements—36 for enhancing established registries and 13 for developing and implementing registries where none had been organized previously. When fully implemented, programs funded by NPCR will collect data on cancer for 96% of the U.S. population. CDC/NPCR implements its Congressional mandate by providing technical assistance and training to states in the establishment and operation of statewide registries, and by establishing and monitoring compliance with program standards for data completeness, timeliness, and quality.

State-specific cancer registry data are reported and published by individual states, but are not currently reported to CDC. CDC is establishing an NPCR Cancer Surveillance System (NPCR–CSS) for receiving cancer incidence data annually from CDC-funded programs. NPCR will use this information to summarize and report cancer surveillance data that will be available to public health agencies, health advocacy groups and researchers. These enhanced data will allow CDC to generate state-specific data reports to the states for continuous quality improvement. The information from these assessments will identify areas (for the individual states and CDC) for education, targeted technical assistance and training.

CDC's processing and aggregating of state cancer data provide cost-effective opportunities to enhance state data through linkages with other databases such as the National Death Index (NDI), U.S. Bureau of the Census data, geographic information systems, and Health Care Financing Administration/Medicare medical claims databases. These enhanced data will improve the utility and quality of cancer surveillance data at the state level.

In addition, the NPCR–CSS will provide (1) greater access to cancer data for the public, scientists, and policymakers (national public use data files of cancer incidence); (2) more accurate and more stable estimates of cancer incidence for population groups, including racial and ethnic minorities, medically underserved groups, and other subpopulations; and (3) information for regional and national analyses to more accurately identify geographic variability in cancer treatment practices as a means to assess use of state-of-the-art cancer treatment. Examples of specific uses of the NPCR–CSS database may include:

- Identifying areas in the United States with high proportions of women diagnosed with later stage breast cancers or invasive cervical cancer
- Providing state-specific cancer prevention and control management reports
- Guiding decisions about program resources and early detection efforts so that resources can be better planned and targeted to areas of need
- Expanding efforts to assess the patterns and quality of cancer diagnosis and treatment provided to women participating in breast and cervical cancer screening programs
- Identifying regions or states with higher rates of malignant melanoma in order to better target communities for prevention messages and education campaigns
- Identifying areas in the United States with high proportions of men and women diagnosed with late-stage colorectal cancer, and
- Developing, implementing, and evaluating new models of comprehensive, integrated approaches to cancer prevention and control

The NPCR–CSS will provide appropriate review for protection of human subjects (e.g., Institutional Review Boards). CDC is seeking protection of NPCR–CSS data from Freedom of Information Act inquiries and court subpoenas. CDC uses state-of-the-art methods to protect data and data systems and to maintain the confidentiality of health information (no patient identified information will be reported to CDC). These protections underpin CDC's ability to assure confidentiality and protection of an individual's information.

Information from this system will be disseminated by the production of public use data files (queryable at national and state levels), special monographs, research and surveillance articles in peer reviewed scientific journals, *MMWR* surveillance summaries, National Public Health Surveillance System reports, and NPCR program evaluation progress reports.

Close, collaborative relationships between CDC/NPCR and the individual state central cancer registries and other critical partners are key to the success of NPCR–CSS. The intent of this surveillance system is to provide, at reasonable cost, appropriate data for use by multiple constituents including CDC, state health departments, and end users of cancer data/information, such as national organizations, researchers, and the public.

NPCR–CSS represents an important step in the evolution of cancer registration in the United States. The NPCR–CSS and database will provide new resources for use by states, public health agencies, cancer researchers, and national organizations. By creating an infrastructure for central processing, enhancement, and aggregation of high quality cancer incidence data in a timely manner, the NPCR–CSS will promote new efforts to prevent and control cancer. The NPCR–CSS will contribute significantly to the national understanding of cancer risks and the need for science-based cancer prevention and control intervention programs.

## **I. Purpose**

The purpose of this document is to outline the Centers for Disease Control and Prevention's (CDC) rationale and planned approach for receiving, assessing, enhancing, aggregating, and disseminating cancer data from the states funded by the National Program of Cancer Registries (NPCR).

## **II. Disease Burden**

The American Cancer Society estimates that 8.2 million Americans have a history of cancer. In 1999, approximately 1.2 million new cancer cases will be diagnosed (excluding basal and squamous cell skin cancers). In 1999, an estimated 563,100 Americans will die of cancer—more than 1,500 people a day. One of every four deaths in the United States is from cancer.

### III. Overview

#### Agency Mission

The mission of CDC is to promote health and quality of life by preventing and controlling disease, injury, and disability. This mission is accomplished by engaging in a number of activities, including monitoring the health of the population, detecting and investigating health problems, developing sound public health policies, and implementing prevention strategies. In carrying out these activities, CDC works closely with state and local health departments and other partners (*CDC Fact Book FY 1998*). CDC has the responsibility for public health surveillance and disease prevention in the United States and is recognized for its scientific integrity and excellence.

CDC is committed to achieving the health promotion and disease prevention objectives of the Department of Health and Human Services' *Healthy People 2000*, a national activity to reduce morbidity and mortality and to improve the quality of life. CDC's Office on Smoking and Health and the Division of Cancer Prevention and Control (DCPC) address objectives related to the priority areas of Cancer and of Surveillance and Data Systems (TAB 1). In a subsequent planning document, *Healthy People 2010 Objectives: Draft for Public Comment*, one of the national goals will be to reduce the burden of cancer on the U.S. population by decreasing cancer incidence, morbidity, and mortality. A major new priority area, Community Access to Health Information and Surveillance Data, is proposed (TAB 1). This focus on data access will be a cornerstone of CDC's surveillance activities for the next decade and will include (but not be limited to) activities such as:

- Increasing the capacity to track national health objectives of special populations such as racial and ethnic minorities, medically underserved groups, and groups at high risk for selected cancers that may not be identifiable in statewide databases because of small numbers or other special circumstances;
- Tracking national health objectives across decades;
- Increasing the use of geographical information systems to promote capacity to target strategies to areas most in need; and
- Ensuring data collected at the national, state, and local levels are available and electronically aggregated and accessible by interested community individuals and organizations.

Within CDC, the Division of Cancer Prevention and Control (DCPC) plans, directs, and supports cancer prevention and control efforts through collaborations with prevention partners in state health agencies, federal agencies, academic institutions, and national, voluntary and private sector organizations. DCPC is responsible for directing, monitoring, and reporting on activities associated with the implementation of the Breast and Cervical Cancer Mortality Prevention Act of 1990 (Public Law 101-354) and the Cancer Registries Amendment Act (Public Law 102-515). The division plans and conducts epidemiologic studies and evaluations to identify the feasibility and effectiveness of cancer prevention and control strategies. DCPC provides technical consultation, assistance, and training to state and local public health agencies, and other health care provider organizations related to improved education, training, and skills in the prevention, detection, and control of selected cancers, including breast, cervical, colorectal, prostate, and skin cancers. In addition, DCPC seeks to identify problems, needs, and opportunities related to modifiable behavioral and other risk factors, and recommend priorities for health promotion, health education, and cancer risk reduction activities both for professionals and for the public. The division pursues the building of local coalitions and community networks, and the implementation of grass-roots activities to reach the target populations of persons at increased risk for developing cancer.

Within DCPC, the mission of the Cancer Surveillance Branch (CSB) includes:

- Plan, design, and conduct epidemiologic and clinical research using cancer surveillance data that contribute to scientific knowledge regarding cancer prevention and control;

- Monitor trends in cancer risk factors, incidence, mortality, and survival for cancer prevention and control;
- Provide leadership, technical assistance, and support to states for the planning, implementation, and evaluation of population-based, statewide central cancer registries which serve as the foundation for comprehensive, integrated cancer control programs;
- Collaborate with other federal, state, private, and international organizations to improve national and worldwide cancer surveillance; improve accessibility and utilization of population-based, cancer surveillance data; develop and disseminate standards for cancer data completeness, timeliness, and quality; and
- Contribute to the enhancement, design, and analysis of information systems for the surveillance, collection, and analysis of cancer data.

### **Cancer Surveillance and Cancer Registration**

Cancer surveillance is essential to a unified, scientific and public health approach to cancer prevention and control. Cancer surveillance is the ongoing, timely, and systematic collection and analysis of information on cancer risk factors (such as lifestyle factors, behavioral influences, genetic predispositions, or environmental exposures), screening and early detection, new cancer cases, cancer deaths, extent of disease at diagnosis, treatment, clinical management, and survival. Key to the success of cancer prevention and control is the timely dissemination of cancer data to the public health agencies and scientists responsible for designing, implementing, and evaluating cancer prevention and control activities (*At-A-Glance, 1999*). The role of surveillance in providing critical feedback to public health programs has been well recognized "...An ongoing system of data collection and collation is [also] not sufficient to constitute public health surveillance, because to be useful the data must be integrated into the conduct and evaluation of specific public health programs, which may include epidemiologic research leading to prevention...." (Thacker, 1988).

Cancer registration is an important component of cancer surveillance. Cancer registration is the fundamental method in the United States by which information is systematically collected about the occurrence of cancer (incidence), about the types of cancer that occur (histology, morphology, and behavior), the anatomic location (topography), the extent of disease at the time of diagnosis (stage), the kinds of treatment received by cancer patients, and the outcomes of treatment and clinical management (mortality and survival).

### **IV. Summary of Current Cancer Registration Efforts**

Within the United States, there are multiple national organizations and programs actively collecting and reporting data regarding cancer incidence, morbidity, mortality, and survival. These include CDC's NPCR, the National Cancer Institute's (NCI) Surveillance, Epidemiology and End Results (SEER) program, the Commission on Cancer of the American College of Surgeons' National Cancer Database (NCDB), and CDC's National Center for Health Statistics' (CDC/NCHS) Vital Statistics Monthly Reports and data tapes. In addition, the American Cancer Society (ACS) and two professional organizations, the National Cancer Registrars Association (NCRA) and the North American Association of Central Cancer Registries (NAACCR), disseminate cancer-related information to the public and to professional communities. The roles and relationships of national cancer registration organizations have been summarized elsewhere (Swan, 1998; TAB 2).

Over the past decade, the state central cancer registries and the national cancer registration organizations have worked diligently and successfully under the auspices of NAACCR to arrive at consensus on data formats, definitions, and standards for cancer registries in North America (*NAACCR Standards for Cancer Registries, Volumes I–IV*). The number of data variables collected, the data characteristics, the reporting requirements, and the criteria for completeness, timeliness and quality of cancer incidence data collected by the various organizations differ according to the mandates of their

supporting agencies (TAB 2). The current *NAACCR Case Record Layout Version 8* provides organization-specific recommended and required data items and sources of standards (TAB 3).

The following is a brief description of the major national organizations collecting and publishing cancer data:

The CDC-funded **National Program of Cancer Registries (NPCR)** is a population-based system of cancer registries established in 1992 by the Cancer Registries Amendment Act (Public Law 102-515). When fully implemented, states funded by NPCR will collect data on cancer for 96% of the U.S. population (TAB 4). CDC/NPCR implements its Congressional mandate by:

- Providing grants to states and territories (or their designees) to support the establishment and operation of population-based, statewide cancer registries;
- Providing technical assistance and training to states in the establishment and operation of statewide registries, including consultation in developing model legislation for statewide cancer registries, and establishing a computerized reporting and data processing system; and
- Establishing and monitoring compliance with national program standards for data completeness, timeliness, and quality (TAB 5).

In Fiscal Year 1999, CDC supported 45 states, 3 territories, and the District of Columbia for central cancer registries through cooperative agreements: 36 for enhancing established registries and 13 for developing and implementing registries where none had been organized previously (TAB 4). Data from individual state central registries participating in the NPCR are available 12 to 30 months after the close of the year in which the cancer is diagnosed (12 months is the goal). States are encouraged to establish agreements with neighboring states to exchange data about cancer cases diagnosed for residents outside their home states. CDC, in collaboration with its partners, has developed software such as EDITS to enhance the quality of cancer registry data and has established a list of CDC/NPCR recommended and required data elements for NPCR grantees (TAB 6) which evolve and change over time.

State-specific cancer registry data are not currently reported to CDC. Information is collected, maintained, and used primarily within individual states. States participating in NPCR use their data in a variety of ways such as to monitor and identify statewide trends, to describe cancer patterns among various state populations, and to evaluate state-specific screening and prevention measures.

The **Surveillance, Epidemiology, and End Results (SEER)** program is a population-based system of registries funded by NCI. It is an outgrowth of the National Cancer Act of 1971, which included a mandate to collect, analyze, and disseminate data that would aid in the prevention, diagnosis, and treatment of cancer. SEER was established to provide continuous cancer registration coverage in certain U.S. regions. SEER routinely generates national estimates of cancer incidence for most cancer sites from a nonrandom, national sample for all races combined, blacks and whites and by gender (with special monographs for other ethnic/ racial groups) (SEER, 1999). These activities are accomplished through a contractual arrangement with nonprofit organizations to collect and transmit data for all new cases in their geographic locations.

The SEER Program is comprised of 11 registries in 5 states (Connecticut, Hawaii, Iowa, New Mexico, and Utah) and 6 metropolitan areas (Atlanta, Detroit, Los Angeles, San Francisco/Oakland, San Jose/Monterrey, and Seattle/Puget Sound) covering about 14% of the U.S. population. The six metropolitan areas of SEER are also covered by NPCR-funded states. The SEER program includes high standards for data completeness and quality that provide the basis for in-depth supplementary research. Cases are followed annually to determine survival. NCI processes, aggregates, and analyzes data from these 11 registries, along with cancer-related death records from CDC's National Center for Health Statistics (NCHS). An annual publication of cancer data and public use data sets from the SEER program are available approximately 28 months after the close of the year in which the cancers are diagnosed. SEER provides public domain software (e.g., SEER\*Stat) with the public use data sets for improved usability (SEER, 1999).

The **North American Association of Central Cancer Registries (NAACCR)** plays a leadership role to support and coordinate the development, enhancement, and application of cancer registration techniques in population-based groups, so that quality data may be used for cancer control, epidemiologic research, public health programs, and patient care to reduce the burden of cancer in North America. NAACCR's objectives include providing standards and models for collecting, coding, editing, and exchanging cancer and patient information; coordinating changes and assuring continuity in data to be collected and exchanged; providing educational resources to registry operations and data utilization; providing technical assistance to NAACCR member organizations; improving, monitoring, and reporting the completeness and quality of data throughout North America; enhancing the completeness of casefinding and data collection; and, maximizing the dissemination, interpretation, and use of registry data. NAACCR provides forums through its committees for discussion and consensus development on registry methods, operations, education, and proposed coding changes.

NAACCR is a collaborative umbrella organization for cancer registries, governmental agencies, professional associations, and private groups in North America interested in improving the quality and use of cancer registry data. Currently, NAACCR has 125 members, including registries from all 50 U.S. states and 3 territories, 11 Canadian provinces and territories, and other major cancer organizations involved in standard-setting and cancer registration activities. CDC contracts with NAACCR to provide technical assistance and data quality assurance activities for NPCR-funded state central cancer registries, including case completeness and reabstraction audits, training workshops, and educational modules. NAACCR extensively draws from its membership to provide CDC with contractual technical assistance and educational activities.

Through a standing committee, NAACCR annually calls for cancer data from its member organizations and publishes *Cancer in North America* (CINA). The publication reports average annual, state-specific incidence rates for the most recent 5-year period by cancer site as well as by sex and by race (all races combined, whites, and blacks). Similar incidence rates are reported for an aggregation of data from states that meet specific criteria for data quality. For example, in the most recent CINA publication representing 1991–1995 diagnosis years, data were pooled from 19 states (Chen, 1999; TAB 8). The data also serve as a resource for special analyses by volunteers from the NAACCR membership. The submission of data for CINA is voluntary and participation has increased over time.

In 1997, NAACCR began offering to population-based registries a certification process to provide an objective assessment of the most recent cancer data available, according to 10 criteria established by NAACCR including completeness of case ascertainment; completeness of information recorded on critical variables (race, age, sex, county); percent of total cases that were identified only by death certificates (DCO%); proportion of duplicate case reports; the proportion of records that pass standardized edits without errors; and timeliness (data available at 23 months after the close of the diagnosis year). Confidential reports of state-specific results from the certification process are returned to the states who submit their data. Thirty-seven states participated in the most recent assessment of data from the diagnosis year 1996.

The **National Cancer Data Base (NCDB)** is comprised of cancer data from approximately 1,800 hospital-based registries and selected ambulatory care centers approved by the Commission on Cancer (CoC), administered by the American College of Surgeons (ACoS). NCDB contains about one-half of the cancer cases diagnosed in the United States each year. It is jointly sponsored and supported by the ACoS and the American Cancer Society (ACS) for the purpose of assessing and improving the quality of cancer care. Not all hospitals that diagnose or treat cancer in the United States participate in the COC program or report data to the NCDB. Therefore, it is not population-based, with variability in the completeness of central case reporting by state and by region of the United States.

Commission on Cancer-approved cancer programs are required to submit standardized data. This "Call for Data" collects data items required by the COC Approvals Program as specified in the Registry Operations and Data Standards (ROADS) manual (TAB 9). The NCDB prepares a cancer report describing the reporting facilities and cancer activities of contributing institutions in the *NCDB Annual Review of Patient Care* (National Cancer Database, 1998). In addition, NCDB provides an institution-

specific report back to contributing hospitals that compares the cancer treatment and survival data of the respective hospital with composite data from all facilities contributing to NCDB.

As a nationwide community-based, voluntary health organization, the **American Cancer Society (ACS)** plays a major role in interpreting and disseminating cancer data and information. ACS has used SEER incidence data, NCHS mortality data, and U.S. Census population statistics to annually forecast the number of new cancer cases and deaths expected to occur in the nation. ACS publishes *Cancer Facts and Figures* annually, a significant source of information regarding cancer for the public as well as for health professionals.

The **Central Brain Tumor Registry of the United States (CBTRUS)** is a not-for-profit corporation committed to providing a resource for gathering and disseminating current epidemiologic data on all primary benign and malignant brain tumors for purposes of accurately describing their incidence and survival patterns, evaluating diagnosis and treatment, facilitating etiologic studies, establishing awareness of the disease, and ultimately for the prevention of all brain tumors. CBTRUS receives data files from 13 states funded by SEER or by NPCR that collect incidence data on benign and malignant brain tumors. The data are used for descriptive studies and analyses.

The **National Cancer Registrars Association (NCRA)** is a non-profit professional organization whose purposes are to establish standards of education for cancer registrars, inform its members of the latest methods of cancer diagnosis, treatment, and current trends in incidence and survival, and to make cancer patient data readily available for clinical and epidemiologic research.

## V. Cancer Surveillance Data Needs

To meet national cancer prevention and control objectives, fulfill agency responsibilities for public health surveillance, meet CDC and DCPC missions, comply with Congressional mandates, and assist state health departments to reduce the cancer burden in their respective states, additional data and information about cancer is needed by CDC. Data from NPCR-funded state central cancer registries could contribute significantly to meeting CDC's and states' cancer surveillance information needs.

### CDC Program Planning and Evaluation

CDC sponsors and supports a wide variety of public health programs in the United States designed to monitor and reduce morbidity and mortality from cancer such as (but not limited to) the National Tobacco Control Program, the National Breast and Cervical Cancer Early Detection Program (NBCCEDP), the National Program of Cancer Registries, the National Colorectal Cancer Roundtable, prostate cancer control initiatives, and the Skin Cancer Primary Prevention and Education Initiative. Increasingly, there is departmental, Congressional, and public demand for federal agency documentation of measurable program objectives and achievement of program and outcomes (e.g., the Government Performance and Results Act of 1993).

Cancer information collected under NPCR is needed to evaluate the success and remaining challenges in meeting CDC program goals and objectives, as well as to identify areas for education and training, technical assistance, and resource allocation. For example, Public Law 101-354, authorizing NBCCEDP, requires annual reporting to Congress on CDC's progress toward reducing morbidity and mortality due to breast and cervical cancer (*CDC Fact Book, 1998*). State registry data for DCPC program evaluation could be used (but not limited to):

- Identify areas in the United States with high proportions of women diagnosed with later stage breast cancers or invasive cervical cancer using a data pooled from the NPCR-funded states. The information will help guide CDC decisions about program resources and early detection efforts so that resources can be better planned and targeted to areas of need;
- Assist CDC in the expansion of efforts to assess the patterns and quality of cancer diagnosis and treatment provided to women participating in NBCCEDP;

- Assist CDC in identifying regions or states with higher rates of malignant melanoma in order to better target communities for prevention messages and education campaigns;
- Identify areas in the United States with high proportions of men and women diagnosed with later stage colorectal cancer to help guide CDC decisions about program resources for public and medical provider education about the value of screening and early detection; and
- Develop, implement, and evaluate new models of comprehensive, integrated approaches to cancer prevention and control.

Annually, NPCR must assess and report on states' compliance with assurances prescribed by the Cancer Registries Amendment Act and with program standards for completeness, timeliness, and quality of their data. State registry data could be used to specifically evaluate NPCR through (but not limited to):

- Direct measurement of completeness, timeliness, and quality of state data as well as development, testing, and assessment of new parameters of data quality for variables such as race/ethnicity, stage at diagnosis, treatment, occupation/industry, geographic location, etc.;
- Provision of continuous, cumulative, and longitudinal assessment annually of the completeness and quality of registry data for all years of data collected since January 1, 1995. To maintain important feedback and documentation of the continuous improvement in states' data completeness, timeliness, and quality, state-specific reports could be generated and transmitted back to states comparing them to states' performances on a regional or national basis; and
- Assessment of needs for training workshops and educational modules for cancer registrars, epidemiologists, public health officials, and other professional groups to improve the quality and completeness of cancer staging data.

#### **Enhancement of Cancer Incidence Data**

In 1998, CDC/NPCR hosted an ad hoc meeting of cancer registry experts including representatives from NPCR-funded states to provide guidance on future potential new directions for NPCR. Priority needs were identified to increase the value and utility of the cancer registry databases for cancer prevention and control by improving the linkages of state cancer registry databases with other databases such as (but not limited to):

- The National Death Index (NDI) to increase the completeness and accuracy of information about vital status of cancer patients who move to another state;
- Census data to add important measures of socioeconomic status;
- Geographic information systems (GIS) to obtain geocoding at sub-county levels that could assist in the analysis and interpretation of data related to potential environmental exposures and reports of possible cancer clusters; and
- Medical claims databases such as Health Care Financing Administration/Medicare to enhance the ability of CDC and of states to describe and interpret the costs of providing medical services for the diagnosis and treatment of cancer.

#### **Increased Use of Cancer Incidence Data**

A critical component of CDC's surveillance efforts is enhancement of states' capacity to apply cancer incidence data for cancer prevention and control. During NPCR's second project period, which begins on July 1, 2000, a primary goal will be to further expand and emphasize enhancement of states' capabilities in data use. During the next 5-year project period, NPCR will work with state health departments toward achievement of standards for data completeness, timeliness, quality, and use. According to NPCR's formal program objectives for the next project period, states will be strongly encouraged to carry out the

following activities: make public use datasets (at an appropriate level of detail) available within the state; provide data for researchers in a manner which is timely and ensures data security and confidentiality; and, demonstrate use of registry data by the state health department for planning and evaluation of cancer control interventions.

States will be asked to report annually to CDC on the progress of these activities. NPCR will then summarize and report on this progress as part of evaluation activities for the national program.

Registry data from the states could contribute significantly to the national understanding of cancer risks and the need for scientific and cancer prevention and control intervention programs. Cancer control and prevention strategies can be guided by determining the burden of cancer at the state, regional, and national levels (Armstrong, 1992). Analysis of aggregated data from NPCR-funded states on a regional or national basis states could assist in the planning and implementation of new cancer prevention and control initiatives by:

- Deriving more accurate and more stable estimates of cancer incidence for population groups including racial and ethnic minorities, medically underserved groups, and other subpopulations. The SEER program covers only 14% of the U.S. population and underrepresents specific population subgroups such as American Indians, Hispanic subgroups, and rural residents (Nattinger, 1997). There are relatively small numbers of cancer cases available in the SEER database for these important populations, as well as for African Americans and Hispanics for particular types of cancer. Therefore, estimates of cancer rates, especially for specific types of cancers, vary widely from year to year with wide "margins of error." New CDC and federal programs could be developed to better meet the challenges of cancer incidence, morbidity, and mortality in these special populations. This effort is consistent with President Clinton's priorities on narrowing the health disparities for racial and ethnic minorities ([DHHS Office of Minority Health Web site](#));
- Conducting regional and national analyses to more accurately identify geographic variability in cancer treatment practices as a means to assess use of state-of-the-art cancer treatment, as well as to identify deviations from standards of cancer care (e.g., post lumpectomy radiation in breast cancer, adjuvant chemotherapy for Stage III colon cancer, lumpectomy vs. modified radical mastectomy for breast cancer). Regional analyses of utilization of cancer treatment services and quality of cancer care would better reflect medical practice and referral patterns. Given the rapid changes in the health care delivery system in the United States, many Americans are traveling across state lines to be diagnosed or receive treatment for cancer. These efforts are consistent with the recommendations of the Institute of Medicine "that a cancer data system is needed that can provide quality benchmarks for use by systems of care" (IOM Report, *Future of Public Health*, 1988; IOM, *Unequal Burden of Cancer*, 1999); and
- Promoting greater access to cancer data for public, scientists, and policymakers. In 1997, through a CDC Conference Support Grant, NAACCR convened a workshop to further explore cancer surveillance information needs (Broadmoor, CO, conference). Participants at this workshop included representatives from key national organizations and state central cancer registries. Participants agreed that there is a need for national public use data files of cancer incidence. A matrix of data aggregation issues related to the types of public use data files was identified during this workshop (TAB 10). Development of query able public use databases (state-specific, regional, national) to be mounted on the Internet could make cancer data and information more accessible to the public, scientists, and policymakers.

### **Additional Epidemiologic, Surveillance, and Health Services Research**

Aggregation of data by CDC from NPCR-funded registries would permit new etiologic, prevention, and control research that previously would not have been possible in the racial and ethnic populations, medically under served groups, and other subpopulations such as studies of cancer treatment and quality of care. This effort is consistent with President Clinton's priorities on narrowing the health disparities for racial and ethnic minorities ([DHHS Office of Minority Health Web site](#)).

Compilation of cancer registry data by CDC from NPCR states would provide additional regional and national data and make possible additional etiologic, prevention, and control research related to less common cancers such as brain tumors and childhood cancers. Such research is currently limited by the small numbers of such cancers that are identified in the SEER database. Improving information on incidence, mortality, and trends of childhood cancer is a specific priority of the White House Children's Environmental Health and Safety Task Force.

Pooling of cancer data by CDC from individual state cancer registries into a NPCR–CSS database would permit regional analyses of cancer incidence and regionalized studies of cancer etiology, prevention, and control knowing that possible risk factors or environmental exposures that may be important to cancer prevention and control do not honor geopolitical boundaries.

Data from the NPCR–CSS database could be used to increase health services research and evaluation, such as (but not limited to) assessing the potential role of screening for prostate cancer with prostate-specific antigen in the diagnosis, treatment, and survival from prostate cancer among black and Hispanic men; evaluating the long-term impact of anti-retroviral therapies on infants of women infected with the human immunodeficiency virus; and, investigating the relationship of behavioral risk factors to cancer incidence and outcomes.

## **VI. The NPCR–Cancer Surveillance System (NPCR–CSS)**

To meet national cancer prevention and control objectives, fulfill agency responsibilities for public health surveillance and meet CDC missions, comply with Congressional mandates, and better meet the needs of state public health departments, CDC proposes to establish the NPCR–Cancer Surveillance System by receiving, assessing, enhancing, aggregating, and disseminating cancer incidence data from the states funded by NPCR.

A schematic for the NPCR–CSS data collection and processing is shown in Figure 1. The technical and resource needs for this system have been identified and are in the process of being implemented (TAB 11).

NPCR-funded states would annually submit to CDC a cumulative data set containing all de-duplicated cancer incidence case records diagnosed beginning January 1 of the state-specific, NPCR reference year (i.e., 1995 for 37 states, 1996 for 8 states, 1997 for 1 state, 1998 for 3 states/territories). Data will be submitted in a standardized format—currently the NAACCR record layout. Reporting formats and requirements could change as national standards change. The case records will include (but may not be limited to) selected NPCR-required and recommended data elements including (but not limited to) demographic information, tumor information, stage at diagnosis, and treatment (TAB 7). Data will be submitted via computer diskettes or the Internet if security and confidentiality can be assured by the state and by CDC.

An objective evaluation of states' data compared to program data standards will be conducted by CDC. The data evaluation will include (but not be limited to) case completeness, the percent of death certificate-only reports, the quality and completeness of selected required data elements, and the timeliness of reporting. For example, CDC will perform edit checks, perform SEER recodes, prepare management reports, and return reports to states (for verification and follow-up) and to the respective CDC project officer. State data will be evaluated on cases reported at 12 months, 24 months, and 36 months after the close of the diagnosis year. States will review and reconcile errors and inconsistencies and resubmit the data to the CDC contractor. This process of data validation may occur multiple times until contemporary data meet specified minimal standards for completeness and quality. In addition, CDC will develop, test, and measure new parameters for data timeliness and quality for variables such as (but not limited to) stage at diagnosis, treatment, occupation/industry.

Through arrangements made by CDC, states will have the opportunity to enhance their state data with information from external databases. With the availability of additional funds to NPCR, CDC could fund centralized or regional contractors to serve as direct resources for the state registries so that states would have the opportunity to link their state-specific cancer databases with other databases. Such databases

may include (but not be limited to) the National Death Index (NDI), GIS databases, census data, and the Health Care Financing Administration/Medicare database. Currently, few state registries have sufficient financial resources to link with these important databases. Centralization or regionalization of the linkages with CDC support would permit optimization of cost-effectiveness through economies of scale and potentially result in operational savings for the states. A state's individually enhanced data then would be returned to the state for primary analysis. Linking state data would increase the value and utility of the databases for cancer prevention and control. In addition, states will have the opportunity to disseminate their state-specific cancer incidence and mortality statistics through an Internet-based interactive system (e.g., CANQUES) with technical support from a CDC contractor.

State data meeting existing minimum NPCR data standards (and potential additional standards) will be included in an aggregate NPCR–CSS database. From this aggregated database, products such as summary statistics, special monographs, and annual reports will be generated. Multiple levels of public-use data sets developed from the aggregated database will be available through data release agreements to public health practitioners and cancer researchers. CDC will coordinate and provide oversight of scientific review, human subjects review, and protection from research risks for any CDC-sponsored reports, publications, analyses, or studies resulting from using the NPCR–CSS database.

## **VII. Data Security and Confidentiality**

Cancer registry data from the NPCR-funded states will be highly sensitive. CDC/NPCR and its contractors, designees, or others serving as an agent of CDC shall adhere to all safeguard requirements associated with data sensitivity and application criticality levels required by the DHHS Automated Information Systems Security Program Handbook 2.0, Chapters II and III (DHHS, 1997). The NPCR–CSS database and all data received from the states are designated "Highly Critical" requiring "High Security." Access to data and data files would be strictly regulated and monitored. For example, public use data sets would be compiled in a fashion to minimize risk of disclosure of personal identities. Any analysis of data from public use data sets for the intended purpose of determining the personal identity of a person represented in the databases would be strictly prohibited. CDC/NPCR and its contractors, designees, or others serving as an agent of CDC shall comply with all new data confidentiality and privacy regulations and laws that may be enacted in the future resulting from the Health Insurance Portability and Accountability Act (HIPAA).

CDC recognizes the importance of individual privacy and data confidentiality and has successfully protected information in the past. No known breaches in confidentiality have occurred at CDC. CDC uses state-of-the-art methods to protect data and data systems to maintain the confidentiality of health information. These protections are essential to CDC's public health functions and underpin CDC's continuing access to health information. Therefore, CDC/NPCR will seek a "Certificate/Assurances of Confidentiality"—a special federal designation that would acknowledge achievement of critical data security and confidentiality requirements and that seeks protection of any data submitted by the states to CDC or its contractors from disclosure as a result of Freedom of Information Act inquiries or court subpoena. In addition, CDC will investigate and assess new data security technologies such as (but not limited to) advanced data encryption for possible application to the NPCR–CSS.

## **VIII. Key Collaborations**

Close, collaborative working relationships between CDC/NPCR and the individual state central cancer registries are key to the success of NPCR–CSS. The NPCR–CSS has been designed based on input and feedback from states, from other federal agencies, and from national, not-for-profit organizations. The intent has been to design a component of a public health program-based cancer surveillance system to meet the needs of multiple parties including CDC, the state health departments, and end users of cancer data/information such as national organizations, researchers, and the public at a reasonable cost.

To ensure that the NPCR–CSS continues to meet the ever-changing needs of multiple interested parties, CDC will establish a Scientific Oversight Committee (SOC) made up of representatives from CDC's state, academic, clinical, and national partners. The SOC will provide guidance and advice to CDC regarding

critical scientific issues such as (but not limited to): NPCR program standards; cancer registry data content; appropriate uses of data derived from NPCR–CSS; data security and confidentiality; protection from research risks; and, priorities for special projects or supplementary research. In addition, the SOC and appropriate Institutional Review Boards will review requests for use of data from the NPCR–CSS databases requiring the highest levels of protection of confidentiality and scientific standards.

To ensure that the NPCR–CSS becomes and remains as efficient as possible, CDC will establish a Logistics Working Group (LWG) made up of representatives from NPCR-funded state central cancer registries and CDC. The LWG and potential subcommittees will provide guidance and advice to CDC regarding critical logistical issues such as (but not limited to): NPCR program standards; cancer registry data content; preparation of data for submission/transmission, data processing and enhancement in NPCR–CSS; data flow; and technical and training needs of the states.

As a collaborative umbrella organization for cancer registries, governmental agencies, professional associations, and private groups in North America, NAACCR is interested in improving standardization, quality, and use of cancer registry data. CDC/NPCR and NAACCR will continue to work closely to identify areas for collaboration and coordination in order to forge a successful alliance to meet mutual goals and objectives. Such collaboration and coordination could include special initiatives such as (but not limited to): joint calls for data; nonhospital reporting; epidemiologic, surveillance, or health services data analyses; and design of educational modules or activities to improve the quality and use of cancer incidence data.

The National Institutes of Health is a leading federal agency supporting research to improve the health of all Americans. The NCI is the principal unit of NIH charged with conducting cancer surveillance, research, and information services. The SEER program, as described previously, provides estimates of the burden of cancer in 11 areas of the United States, and provides the basis for special studies and clinical research. As federal partners, CDC and NCI will continue to identify areas for collaboration and coordination between the SEER and NPCR programs to forge a successful alliance to achieve complete and comprehensive cancer surveillance in the United States. Such collaboration and coordination could include jointly funded special initiatives such as (but not limited to): nonhospital reporting; epidemiologic or health services research; and mapping of standardized staging between cancer classification systems.

The American College of Surgeons is a leading authority and standard setter in cancer registry operations and maintains a large hospital-derived database on cancer care. CDC is committed to identifying new approaches to more fully develop collaborations with ACoS in cancer staging classification and in health services research related to the patterns and quality of cancer care in the United States.

CDC is committed to providing critical information derived from NPCR–CSS to NCRA and its members about cancer data completeness, timeliness, and quality and to collaborating in the development of innovative educational strategies to better meet the training needs of cancer registrars. In addition, the availability of an aggregated cancer incidence database from NPCR states could be quite useful to the ACS to meet the information needs of cancer patients, their families, and the public.

Key national organizations and other parties interested in cancer data first met in 1995 to examine the current state of cancer surveillance and to coordinate their activities within the United States through communication and collaboration (TAB 2). The group members recognized that the purposes for which they were convened required continuous efforts resulting in the formation of the National Coordinating Council for Cancer Surveillance (NCCCS). Currently, NCCCS consists of members representing 12 organizations. Continued active participation by CDC/NPCR in the NCCCS will enhance opportunities to develop national strategies and identify problems and possible solutions in cancer registration and cancer surveillance. CDC is committed to supporting the NCCCS in its efforts and to providing leadership in public health surveillance.

In 1998, the Council of State and Territorial Epidemiologists (CSTE) established cancer as a reportable disease as part of the chronic disease indicators of the National Public Health Surveillance System (NPHSS) (TAB 12). The NPCR–CSS will contribute data to the NPHSS. The NPCR–CSS will work alongside other surveillance systems at CDC such as (but not limited to) the HIV/AIDS Surveillance

System; Birth Defects Monitoring Program; Pregnancy Risk Assessment Monitoring System; the Childhood Blood Lead Surveillance Program; and the National Immunization Registry Program for appropriate coordination, integration, and collaboration.

## **IX. Legislative Authority**

The CDC mission statements and the activities described in this document are derived from the general authority granted CDC (through the Secretary of Health and Human Services) under Section 301(a) of the Public Health Service Act (PHSA) [42 U.S.C. 241 (a)] which authorizes CDC to "...conduct in the Service, and encourage, cooperate with and render assistance to other appropriate public health authorities, scientific institutions and scientists, in the conduct of, and promote the coordination of research, investigations, experiments, demonstrations, and studies related to the causes, diagnosis, treatment, control and prevention of physical and mental diseases and impairment of man...." CDC is further authorized under Section 301 (a)(1) of PHSA [42 U.S.C.241(a)(1)] to "collect and make available through publications and other appropriate means information as to, the practical application of, such research and other activities." Specific authority to cooperate with and advise the States on matters relating to public health, and to encourage cooperation between the States and to advance the public health, is provided by section 311 of the PHSA (TAB 13).

Responding to the needs of states and their citizens, Congress established NPCR in 1992 by enacting the Cancer Registries Amendment Act (Public Law 102-515). This legislation authorizes CDC to make grants to states (or their designees) to support the operation of a population-based, statewide cancer registry; provide technical assistance to states in the establishment and operation of statewide registries, including assistance in developing model legislation for statewide cancer registries and assistance in establishing a computerized reporting and data processing system; and to set up standards for data completeness, timeliness, and quality. According to federal regulations (Code of Federal Regulations Title 45 subchapter A Part 92.42 subpart c) CDC has the authority to access all data and records related to grants and cooperative agreements to states and local governments (TAB 13).

## **X. Conclusion**

CDC is fully committed to fulfilling its cancer prevention and control objectives, public health responsibilities, agency missions, and Congressional mandates by creating new opportunities for receiving, assessing, enhancing, aggregating, and disseminating cancer data from the states funded by the National Program of Cancer Registries. NPCR–CSS represents an important step in the evolution of cancer registration in the United States. The NPCR–CSS and database will provide new resources for use by states, public health agencies, cancer researchers, and national organizations. By creating an infrastructure for central processing, enhancement, and aggregation of high quality cancer incidence data in a timely manner, the NPCR–CSS will enable new efforts to prevent and control cancer. Careful attention to data security and confidentiality will protect the privacy of cancer patients balanced appropriately with society's need to know and understand more about this deadly disease. This new cancer surveillance infrastructure will be an important tool in national efforts to reduce the morbidity and mortality from cancer and to improve the quality of life of cancer patients in the United States.

## List of TAB Content Titles

TAB 1

*Healthy People 2000 and Healthy People 2010: Draft for Public Comment Objectives*

TAB 2

Cancer Surveillance in the U.S.: Can we have a national system?

TAB 3

North American Association of Central Cancer Registries (NAACCR), Case Record Layout, Version 8

TAB 4

National Program of Cancer Registries (NPCR)

TAB 5

NPCR 5-Year Program Objectives Evaluation Criteria: Completeness, Timeliness, and Quality Standards

TAB 6

List of NPCR Required Data Elements

TAB 7

Surveillance, Epidemiology, and End Results (SEER), National Estimates of Cancer Incidence, Mortality, and Survival Rates (Sample)

TAB 8

Cancer Incidence in North America (CINA), 1991–1995 Volume One: Incidence (Sample)

TAB 9

National Cancer Data Base (NCDB) Annual Call for Data from Computerized Cancer Registries

TAB 10

Executive Summary of Recommendations for Public Use Files of National Cancer Data, Broadmoor Conference

TAB 11

Development of Databases of Cancer Incidence Data: Technical and Resource Needs

TAB 12

Council of State and Territorial Epidemiologists (CSTE) Position Statement #CD4 (Cancer)

TAB 13

Public Health Service Act, Section 301 and Cancer Registries Amendment Act (Public Law 102-515)  
Code of Federal Regulations (45CFRs92.42)

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## Additional Resources

[U.S. Cancer Statistics Incidence and Mortality Data](#)

[CANQUES and SEER\\*Stat information on Web sites](#)

Chen, VW, Wu XC, Andrews PA (eds). *Cancer in North America, 1991–1995, Volume Two: Mortality*. Sacramento, CA: North American Association of Central Cancer Registries, 1999.