

Surveillance Research Program

# STRATEGIC PLAN

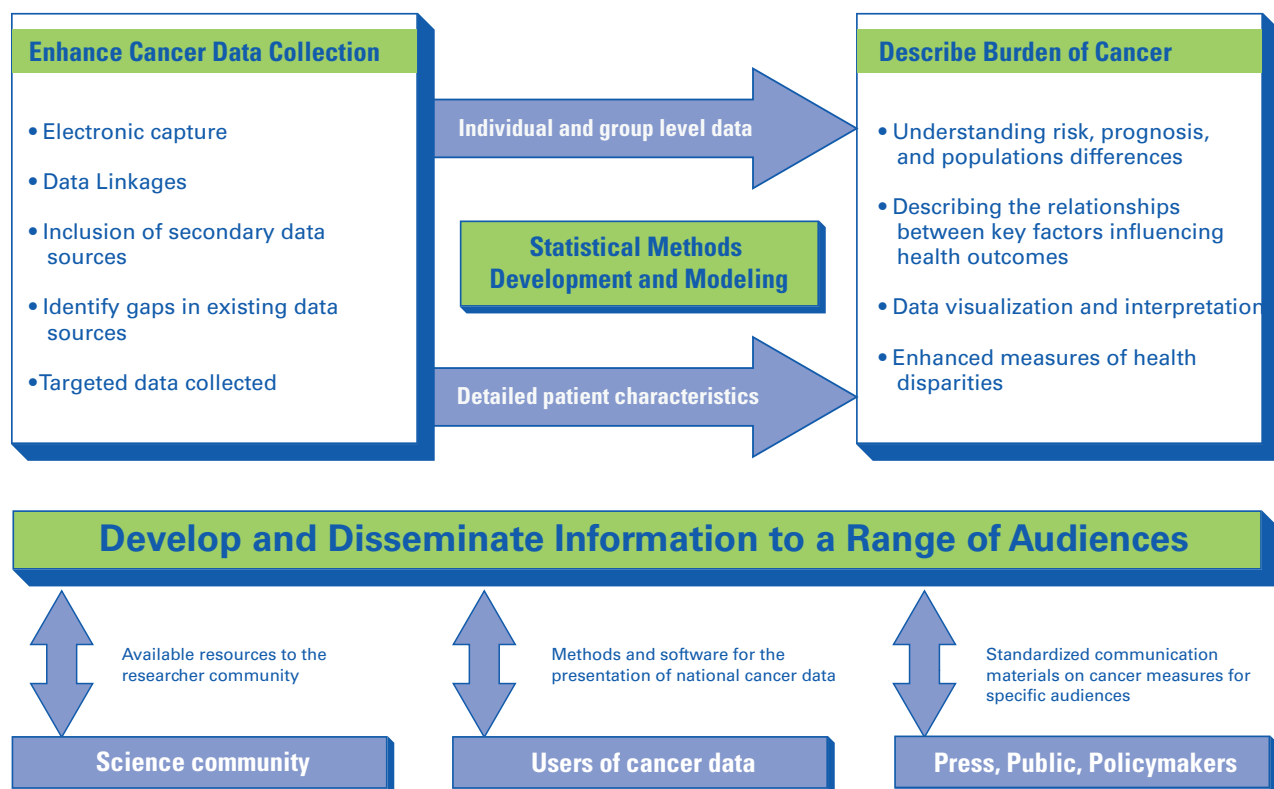
2010

U.S. DEPARTMENT  
OF HEALTH AND  
HUMAN SERVICES

National Institutes  
of Health

Division of Cancer Control and Population Sciences

## Leading the Science of Cancer Surveillance





## EXECUTIVE SUMMARY

Cancer accounts for nearly one-fourth of all deaths in the United States and ranks high among causes of mortality. Monitoring cancer trends and related factors is critical to reducing the burden of cancer. The National Cancer Institute (NCI) supports cancer surveillance research to study these trends and quantitatively measure cancer incidence, morbidity, survival, and mortality for persons with cancer in the United States. Cancer surveillance also assesses genetic predisposition, environmental and behavioral risk factors, screening practices, and the quality of care from prevention through palliation. In short, cancer surveillance measures progress made toward reducing the burden of cancer and provides a basis for advancing research and interventions across the cancer control continuum in prevention, early detection, diagnosis, treatment, and outcome. Appropriate decisions in science and public health depend on reliable data about the impact of efforts to control cancer, and cancer surveillance research provides a basis for the public to assess the efficacy of National efforts to detect and treat cancer in the general population.

NCI's Surveillance Research Program (SRP), housed within the Division of Cancer Control and Population Sciences (DCCPS), directs the collection and dissemination of information on cancer incidence, prevalence, mortality, and

survival in the United States. SRP collaborates with other DCCPS Programs in these efforts, particularly with the Applied Research Program (ARP), which addresses risk factors, health behaviors, health care services, economics, and outcomes, including patient-reported outcomes. In addition, the Behavioral Research Program (BRP) complements SRP and ARP efforts in cancer surveillance research through a portfolio of behavioral interventions, such as tobacco use, screening, dietary behavior, and sun protection. The programs, priority areas, and action plans described in this Strategic Plan are focused on activities managed by SRP.

SRP also works with other entities within NCI, the National Institutes of Health (NIH), and the Centers for Disease Control and Prevention (CDC), and with other federal agencies, and has developed strong partnerships with cancer registry and surveillance organizations. SRP's rigorous quality standards have made it a model for cancer surveillance activities throughout the world.

One of SRP's premier projects is the Surveillance, Epidemiology, and End Results (SEER) Program, which collects and manages high-quality data from cancer registries in specific geographic areas that represent 34.6 percent of the U.S. population. These data are used increasingly to

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answer questions about cancer etiology, prevention, treatment, and control. SEER collaborates with other agencies and programs to link with additional datasets and enhance cancer care and outcomes data. These include Medicare, Medical Health Outcomes Survey (MHOS), Consumer Assessment in Healthcare Providers and Systems (CAHPS), and the National Longitudinal Mortality Study (NLMS). The SEER Residual Tissue Repository (RTR) Program also plays an important role in data collection and management.

During the past decade, SRP has fostered standardization practices across the cancer surveillance field. The standardization of cancer registry data elements has allowed investigators to compare cases, treatments, and outcomes to support cancer research activities and promote public health. In addition, SRP has promoted the adoption and use of a standardized vocabulary across the surveillance arena. NCI is an active participant in the American Joint Committee on Cancer's (AJCC) collaborative staging efforts, works with numerous partners to standardize data items across the cancer registry community, and works to develop infrastructure and quantitative methodologies.

During the past 10 years, SRP also has built a substantial collection of methodologies for statistical analysis software, applications, and modeling, including the Cancer Intervention and Surveillance Modeling Network (CISNET), SEER\*Stat, Joinpoint, and DevCan. These data and tools are used to distill cancer trends in populations, and to track health disparities among subpopulations. SRP's grant portfolio for biostatistical cancer research is available online through the StatFund resource.

Integrating SRP activities with other NCI and NIH efforts helps to advance the battle against cancer. For example, the SEER Data Management System (SEER\*DMS), used by cancer registries across the United States, complies with the philosophy and guidelines of the cancer Biomedical Informatics Grid (caBIG®), which provides an information network that allows members of the cancer community to

share data and knowledge openly, in a standardized manner, using a common vocabulary. In addition, NCI's Center for Bioinformatics and SRP collaborate on electronic data capture activities, including by co-sponsoring the Tools for Electronic Data request for proposals (RFP).

SRP communicates cancer statistics to a variety of data users through online tools and annual and biennial reports. Cancer Control P.L.A.N.E.T. (Plan, Link, Act, Network with Evidence-based Tools), State Cancer Profiles, *Cancer Statistics Review* (CSR), and FastStats are among the Web-based resources instituted by SRP during the past decade. The *Annual Report to the Nation* describes cancer trends in the United States, and the *Cancer Trends Progress Report* highlights progress made against cancer in relation to Healthy People 2010 initiative targets.

Ten years following the *Cancer Surveillance Research Implementation Plan of 1999*, SRP convened extramural scientists and NCI staff with expertise in cancer surveillance to develop a vision for the next 5 to 7 years. In 2008, staff from SRP, DCCPS' Applied Research Program (ARP), and SEER-supported registries began a process to determine the future direction for SEER through a series of meetings entitled "SEER: Visioning the Future." The consensus was that the SEER Program should assess its impact on the field of population surveillance, especially in terms of the quality and depth of its data, accessibility and usability of data, leadership in defining data elements, innovation in data collection, and development of analytical methods applied to surveillance data.

SRP also held a more comprehensive strategic planning workshop in October 2009 to address scientific opportunities, challenges, and gaps in the cancer surveillance arena, with an emphasis on incidence, prevalence, mortality, and survival. Extramural participants and NCI staff considered the scope and content of cancer surveillance, analytic methods and models, integrated health informatics, populations with regard to differences in risk and prognosis, and health communication.



Table 1. Cancer Surveillance Priority Areas and Action Plan, 2010

PRIORITY AREAS AND ACTION PLAN 2010	
PRIORITY AREA 1	Provide a more complete depiction of the burden of cancer in the United States, past, present, and future.
Action Plan	1. Link with other data sources.
	2. Develop processes to obtain and use other types of variables and data.
	3. Collect more detailed individual data from a limited number of registries.
PRIORITY AREA 2	Collect better quality data on the burden of cancer in the United States more efficiently through effective utilization of electronic tools.
Action Plan	4. Identify and evaluate relevant data sources.
	5. Automate the capture of information.
	6. Expand interoperability and standardization of surveillance data.
	7. Use data-capture techniques and statistical modeling to improve the timeliness of cancer statistics reporting.
PRIORITY AREA 3	Improve understanding of the differences and disparities in the burden of cancer in the United States.
Action Plan	8. Enhance measurements of health disparities.
	9. Expand data visualization and interpretation.
PRIORITY AREA 4	Better understand the continuum in the burden of cancer in the United States from risk to prognosis.
Action Plan	10. Evaluate the potential impact of prevention, early detection, and treatment on cancer statistics to inform cancer research and policy development.
	11. Identify and track a cohort of cancer patients to obtain data and monitor impacts at the population level.
PRIORITY AREA 5	Communicate cancer statistics more effectively to researchers and users and make the data more accessible and understandable to all.
Action Plan	12. Conduct needs assessment to identify data needs and audiences and develop a plan to communicate cancer statistics and interpret data for audiences.
	13. Produce standardized communication materials.
	14. Disseminate information on existing resources to researchers and evaluate their effectiveness.
	15. Develop and disseminate methods and software for the analysis and presentation of National cancer statistics.

Results from the SEER Visioning and SRP strategic planning efforts resulted in this Strategic Plan for the future direction of NCI-supported cancer surveillance research. This Executive Summary presents an overview of the Strategic Plan's four priority areas and 15 research opportunities in these areas (Table 1). The full report provides more detailed information about NCI-supported cancer surveillance research efforts and future directions.

## PRIORITY AREA 1

**Provide a more complete depiction of the burden of cancer in the United States, past, present, and future.**

**Action Plan 1: Link with other data sources.** New technologies such as geographic information systems (GIS) and the electronic health record (EHR) provide an opportunity to increase data collection in a cost-effective manner. Expansion should be accomplished by establishing linkages between SEER, the NCI Cancer Human Biobank (caHUB®) and caBIG®, and the National Cancer Data Base (NCDB), as well as deeper data mining of Centers for Medicare and Medicaid Services' (CMS) Medicare data. Other data linkages might be established with larger insurance systems and professional societies. The relationship between reporting sources and the contents of the registries' summary records should be explored to maximize the benefits achieved from linked data.

**Action Plan 2: Develop processes to obtain and use other types of variables and data.** As understanding of risk, prognosis, and population differences advances, more individual data should be collected to support this progression. Processes that are developed to collect and use these data should be sensitive to privacy, patient consent, and legal issues, and be designed with the flexibility to accommodate changes in scientific advances. Better ways to support an expanded collection of patients' treatment

history, disease status, and followup, as well as genomic data, should be established to facilitate access to multilevel data from multiple sources while maintaining patient data confidentiality. A process for using U.S. Census information to link surveillance data to other data types, such as biomarker data, should be developed.

**Action Plan 3: Collect more detailed individual data from a limited number of registries.** The collection of quality data should be expanded by capturing more detailed individual data and specimens on a limited basis. A select number of registries should focus on acquiring and maintaining a high-quality collection in a specific area for several years, with relevant information about the process applied when planning future collection efforts. Partnerships also could be established with other successful collection efforts.

## PRIORITY AREA 2

**Collect better quality data on the burden of cancer in the United States more efficiently through effective utilization of electronic tools.**

**Action Plan 4: Identify and evaluate relevant data sources.** Data sources are needed that expand the current boundaries of the SEER dataset and support the emphasis on population-based cancer surveillance. Relevant sources should be examined for the availability of electronic data that can be linked. Ongoing collaborations, such as those with CMS for the SEER-Medicare dataset, should be evaluated for the potential to obtain further information, including treatment data.

**Action Plan 5: Automate the capture of information.** The nationwide movement toward adopting EHRs provides a prime occasion to further automate the capture of cancer-related information. In addition, use of natural language processing (NLP) should be explored to ensure greater accuracy in the extraction of information from hospital reports.

**Action Plan 6:** *Expand the interoperability and standardization of surveillance data.* Standards for the collection and coding of health data from a variety of sources are needed to ensure the consistent quality and interoperability of data. Cancer surveillance organizations, researchers, and clinicians should form mutually beneficial collaborations to impose a structure for data collected at the point of care. Standardization should help to simplify the process of recording medical information by clinicians.

**Action Plan 7:** *Use data-capture techniques and statistical modeling to improve the timeliness of cancer statistics reporting.* Methods should be developed to reduce the current 3-year time period between diagnosis, notification of the registry about a case, and reporting of incidence rates by the registry. New data-capture techniques and statistical modeling could provide a means to expedite the reporting of cancer statistics, such as through a delay-adjustment model. In addition, a data-alert system should be designed to inform registrars about new information added to a case chart and lessen the need to review data that were evaluated previously.

## PRIORITY AREA 3

**Improve understanding of the differences and disparities in the burden of cancer in the United States.**

**Action Plan 8:** *Enhance measurement of health disparities.* Methods for measuring health disparities and encouraging the use of tools such as the health disparities calculator (HD\*Calc) should be improved. Census tract data on area socioeconomic status and other disparities indicators should be evaluated for their potential to link to cancer surveillance data and use in analyzing cancer disparities.

**Action Plan 9:** *Expand data visualization and interpretation.* To better identify and quantify cancer risk and prognosis, data about subpopulations should be identified geographically and analyzed. Methods of data visualization and interpretation should be more fully explored, including geocoding techniques, spatial data, and spatial-temporal data, to determine relevant factors influencing risk or prognosis.

## PRIORITY AREA 4

**Better understand the continuum in the burden of cancer in the United States, from risk to prognosis.**

**Action Plan 10:** *Evaluate the potential impact of prevention, early detection, and treatment on cancer statistics to inform cancer research and policy development.* Through the understanding of risk factor trends, use of early detection and treatment, and information on risks and efficacy from clinical trials, models can predict the impact on cancer incidence and mortality trends, as well as provide estimates of potential impact if interventions were more widely implemented in the population.

**Action Plan 11:** *Identify and track a cohort of cancer patients to obtain data and monitor impacts at the population level.* Tracking a cohort of cancer patients through the registry system will provide a comprehensive approach to population studies that is unavailable through multiple independent cancer registries and individual investigator-initiated studies. Guidance is needed for developing collaborative cohorts in the registry system, with access to cohort data available to investigators who are not participating in the cohort. The registry system would provide nationally representative samples to supplement data from more localized groups, allowing the opportunity to examine socioeconomic factors and other health disparities variables.

## PRIORITY AREA 5

**Communicate cancer statistics more effectively to researchers and users and make the data more accessible and understandable to all.**

**Action Plan 12:** *Conduct a needs assessment to identify data needs and audiences, and develop a plan to communicate cancer statistics and interpret data for audiences.* A strategy should be developed to communicate cancer statistics and help researchers and other audiences interpret and report data with accuracy. The needs of various audiences, ranging from scientists to policymakers to the general public, should be evaluated and a plan to communicate cancer statistics should be developed that distinguishes approaches for these audiences. The needs assessment should identify existing products, ascertain the need for new materials, and recommend refinements to existing resources to encourage more effective use. The plan should outline steps to promote existing resources as well as advise on the translation of data and preparation of other communication materials for lay audiences.

**Action Plan 13:** *Produce standardized communications materials.* To present a coherent message about cancer rates and help reduce the misinterpretation of statistical data, standardized communication materials are needed. Standards should be adopted by leading organizations regarding a clear and unified message about understanding

and using surveillance statistics. Consensus about common data elements and the creation of standardized templates that present data to different audiences should be initial steps toward this goal. Explanation of data limitations and cross-links between the SEER Web site and other credible Web resources should be provided to help researchers use data more effectively.

**Action Plan 14:** *Disseminate information on existing resources to researchers and evaluate their effectiveness.* Better methods to promote existing resources to researchers are needed. A systematic, heuristic review of existing resources and how they are promoted and accessed should be conducted to provide a structured approach that promotes these resources to the wider research community. SEER-Medicare has been used widely by the research community and provides a model of how research resources can be used to address a range of research questions. NCI also could facilitate access to local cancer surveillance data and make data from SEER and other registries more readily available.

**Action Plan 15:** *Develop and disseminate methods and software for the analysis and presentation of national cancer statistics.* Development of new methods and software to analyze and present national cancer statistics will help invigorate the field and inform research conducted on earlier stages of the cancer control continuum to increase the impact of research on cancer mortality in the United States. One such tool is a cancer survival query system that could help researchers and other audiences obtain easier access to surveillance survival data.