

DATA, SURVEILLANCE, AND EVALUATION

VISION

A coordinated system for reviewing data collection activities and evaluating progress

Connecticut has a well-established system of cancer surveillance. The *Connecticut General Statutes* require that all new cancer cases, inpatient hospitalizations for cancer, and deaths due to cancer are reported to the Connecticut Tumor Registry, Connecticut Office of Health Care Access, or the Connecticut Department of Public Health. The Tumor Registry is the oldest registry of reported cancers in the United States, with records dating back to 1935. It is a part of the National Cancer Institute's Surveillance, Epidemiology and Ends Results (SEER) Program, and, together with other SEER registries, collects data used to set priorities for preventing and treating cancer in the United States. Data are contributed to the Registry's data base by Connecticut hospitals and private pathology laboratories, and through reciprocal agreements with all surrounding states and several other states.

Data on cancer hospitalizations are maintained in the Hospital Discharge and Billing Data Base, which includes data beginning with 1991. Death data have been maintained in the Connecticut Death Registry, part of the DPH Vital Records section, since 1848. Information on risk factors for cancer are collected through the Behavioral Risk Factor Surveillance System, Youth Risk Behavior Surveillance survey, and the Connecticut Youth Tobacco Survey. Other types of cancer-related data are collected through specialized studies and programs such as the Connecticut Breast and Cervical Cancer Early Detection Program at DPH.

The Data, Surveillance, and Evaluation Committee of the Connecticut Cancer Partnership has been instrumental in guiding the Plan's development, by reviewing all objectives to ensure that as many as possible are SMART (specific, measurable, attainable, realistic, and time-phased). Following the model of *Healthy People 2010*, those objectives in the plan without adequate baseline data have been labeled 'developmental,' and strategies include developing methods of obtaining suitable data. Strategies involving data, surveillance and evaluation from the major priority areas of the Plan are summarized in Table 9. The Committee's objectives and strategies are discussed below.

GOAL

To ensure the continued availability of high quality cancer-related data, and support the collection and synthesis of data described in the Connecticut Comprehensive Cancer Plan that are not currently available

DATA, SURVEILLANCE, & EVALUATION OBJECTIVE 1

Increase the use and timely dissemination of available information to increase knowledge about cancer incidence, prevalence, stage at diagnosis, treatment, hospitalizations, deaths, and related behavioral and environmental risk factors in Connecticut (Developmental)

Strategies

1. Promote the Connecticut Tumor Registry (CTR) and the use of CTR data to professionals by holding workshops or/and presentations about the CTR
2. Disseminate information about the CTR to the public, including information on reporting requirements for cancer
3. Explore use of the DPH and Partnership web sites to publicize cancer incidence, prevalence, stage at diagnosis, hospitalization, and death data
4. Continue support for the following existing data bases and collection mechanisms:
 - Connecticut Tumor Registry (CTR)
 - Connecticut Death Registry
 - Hospital Discharge and Billing Data Base
 - Behavioral Risk Factor Surveillance System (BRFSS)
 - Youth Risk Behavior Surveillance (YRBS)
 - Connecticut Youth Tobacco Survey (CYTS)
 - Breast and Cervical Cancer Early Detection Program
5. Support the publication of data on the incidence, prevalence, stage at diagnosis, treatment, hospitalizations, deaths, and trends for cancer and related risk factors in Connecticut

DATA, SURVEILLANCE, & EVALUATION OBJECTIVE 2

Create a mechanism for the Data, Surveillance, and Evaluation Committee to assist other committees in developing data collection tools, implementing data collection, and analyzing data required for setting baselines and targets and for measuring progress on objectives

Strategies

1. Meet routinely with members of all Partnership committees
2. Design methods of setting baselines and targets
3. Develop methods for measuring progress on objectives

DATA, SURVEILLANCE, & EVALUATION OBJECTIVE 3

Evaluate the implementation of the Connecticut Cancer Plan

Strategies

1. Enhance the mechanism for evaluating the implementation of the Connecticut Cancer Plan
2. Conduct annual evaluations
3. Disseminate evaluation results to the Partnership

TABLE 9
Connecticut Comprehensive Cancer Control Plan
Strategies from Each Priority Area Regarding Data, Surveillance, & Evaluation

Prevention

- ✓ Establish baseline for physical activity for high school students
- ✓ Establish baseline for cancer-related environmental exposures and protective measures

Early Detection

- ✓ Establish baseline for patients who do not receive timely and appropriate follow-up after receiving abnormal breast cancer screening results
- ✓ Establish baseline for patients who do not receive timely and appropriate follow-up after receiving abnormal Pap test results
- ✓ Establish baseline for patients who receive timely and appropriate follow-up after receiving abnormal colon screening results
- ✓ Establish baseline for public awareness of risk factors and early signs of skin cancer
- ✓ Establish baseline for screening utilization among racial and ethnic communities

Treatment

- ✓ Complete surveys of available non-web-based resources for public (e.g., telephone lines, written information), taking into account needs of diverse populations
- ✓ List all open Connecticut clinical trials in Connecticut hospitals, cancer centers, and oncology offices and provide link to NCI's PDQ information
- ✓ Create inventory of private practice oncologists and clinicians with an oncology subspecialty who presently participate in clinical trials; assess number and location of non-participating physicians interested in forming a linkage to data collection and analysis resources
- ✓ Conduct survey to determine number of private practice oncologists presently participating in clinical trials; assess number and location of non-participating physicians interested in forming a linkage to data collection and analysis resources
- ✓ Conduct literature search on barriers and gaps to treatment; conduct focus groups to determine if Connecticut barriers and gaps differ
- ✓ Conduct literature search, focus groups and surveys of patients, families and health professionals regarding barriers that hinder patients in accessing pain and symptom management during treatment
- ✓ Develop mechanisms to identify barriers and benefits to Connecticut hospitals for ACoS accreditation

Survivorship

- ✓ Establish baseline for number of survivors and providers who access and utilize survivor support services
- ✓ Identify criteria for deciding how to assess the quality of the service organization before including it in the centralized information database
- ✓ Survey survivors to determine the baseline number of survivors aware of guidelines for survivorship care
- ✓ Conduct a survey of health care providers to determine the baseline number of providers aware of available guidelines for survivorship care.

Palliative and Hospice Care

- ✓ Assess geographic distribution of CT physicians and nurses certified in palliative and hospice care
 - ✓ Identify organizations that offer palliative or hospice care education programs and facilitate collaboration to increase end-of-life-educational opportunities in Connecticut.
 - ✓ Assess current coverage for pain and palliative/hospice services offered by Medicare, Medicaid and private insurance companies; establish baseline
 - ✓ Assess current status of palliative care services in long-term care facilities; establish baseline
 - ✓ Assess current status of hospital and long term care contracts with Medicare-certified hospice programs; establish baseline
 - ✓ Obtain statewide and local annual survey data from NHPCO to determine baseline; develop strategies to increase survey participation by Medicare-certified hospice programs in Connecticut
 - ✓ Assess end-of-life needs, in partnership with Veteran's Home administrators and staff
 - ✓ Monitor patient/family satisfaction with pain and symptom management through yearly surveys by CT Council for Hospice and Palliative Care
 - ✓ Survey cancer survivors' pain experience through ACS Navigation program
 - ✓ Review and disseminate data on compliance with JCAHO pain standards in CT health care institutions
 - ✓ Obtain baseline data on annual number of referrals to hospice, including analysis by demographic criteria
 - ✓ Conduct needs assessment to identify barriers to access to hospice and palliative care for all Connecticut residents, particularly minority/underserved populations
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REFERENCES

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- ¹³ Mandelblatt and Yabroff, *op. cit.*
- ¹⁴ Mandelblatt and Yabroff, *op. cit.*
- ¹⁵ Von Eschenbach A. 2005. *The Director's Corner: Welcome to the National Cancer Institute*. <http://www.nci.nih.gov/directorscorner/welcome/print?page=&keyword>
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DATA, SURVEILLANCE, AND EVALUATION TIMETABLE

Goal	Objective	Strategy	2005	2006	2007	2008	On-going	
Ensure the continued availability of high quality cancer-related data and support the collection and synthesis of data described in the Connecticut Comprehensive Cancer Plan that are not currently available	1. Increase use and timely dissemination of information about cancer and its risk factors	1. Promote the Connecticut Tumor Registry (CTR), hold workshops and presentations						
		2. Disseminate information about the CTR						
		3. Explore use of DPH and partnership web site for publicizing cancer information						
		4. Continue support for existing data bases and collection mechanisms						
		5. Support publication of data on cancer and its risk factors						
	2. Create a mechanism for the Data, Surveillance, and Evaluation Committee to assist other committees	1. Meet routinely with members of other Partnership committees						
		2. Design methods of setting baselines and targets						
		3. Develop methods for measuring progress						
	3. Evaluate the implementation of the Connecticut Comprehensive Cancer Plan	1. Enhance the mechanism for evaluating the Plan						
		2. Conduct annual evaluation						
		3. Disseminate evaluation results to the Partnership						