



CHAPTER 2

CANCER SURVEILLANCE

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CANCER SURVEILLANCE

A key to improving cancer control in Maryland is cancer surveillance. Public health surveillance is the ongoing, systematic collection, analysis, and interpretation of health data essential to the planning, implementation, and evaluation of public health practice. It involves the tracking of data and is closely integrated with the timely dissemination of these data to those who need it.¹ Additionally, surveillance can provide data to raise awareness of public health problems and support the development of policies.

Cancer surveillance utilizes data such as the occurrence of cancer (incidence), cancer deaths (mortality), risk factors for the development of cancer (e.g., smoking, overweight, fruit and vegetable intake), cancer screening behaviors (e.g., the use of mammography, colonoscopy, Pap tests), and diagnostic and treatment services in the population. In a well-functioning cancer surveillance system complete, timely, and high quality data are transformed into information that is easily accessible to those who use it to prevent and control cancer. Figure 2.1 illustrates the key elements of cancer surveillance.²

Cancer data and information have many uses including planning, policy-making activities such as resource allocation, evaluation of cancer prevention and control efforts, and applied research into the reasons behind the numbers.

This chapter utilizes case studies to illustrate real examples and situations where cancer surveillance information has contributed to public health action: the monitoring and evaluation of programs, policy making (including resource allocation), and applied research.

For example, data from the Maryland Department of Health & Mental Hygiene (DHMH), the Maryland Cancer Registry, and Maryland Vital Statistics have provided information that allows better understanding of the scope of the breast cancer problem in Maryland and expanded breast cancer screening services (Table 2.1).

In the past, cancer surveillance data were used in the development of the *Report of the Governor's Task Force to Conquer Cancer in Maryland* and the *Report of the Task Force to End Smoking in Maryland*.^{4,5} These reports provided policy direction for the allocation of funds and priorities under the tobacco settlement for the Cigarette Restitution Fund Program (CRF) in Maryland (Table 2.2).

Tracking cancer incidence and mortality rates over time to determine emerging trends is another aspect of cancer surveillance. One example of an important use of cancer surveillance data is to combine what is known about trends in cancer incidence (from the Maryland Cancer Registry) and mortality (from Vital Statistics) with trends in the aging of the population to

Table 2.1

**Cancer Surveillance Case Study:
Cancer Surveillance Leads to
Breast Cancer Screening Programs
(Planning)**

Cancer Surveillance Information:

- Maryland was among the top ten states in the nation with high breast cancer mortality rates in 1991. (Source: Maryland Vital Statistics, NCHS)
- Breast cancer incidence rates in Maryland were higher than those in the nation. (Source: Maryland Cancer Registry, SEER)
- Research indicated that breast cancer mortality could be reduced by approximately 30% with early detection and treatment.

State, Local, or Community Action:

The Health Services Cost Review Commission's (HSCRC) Illness Prevention Program was expanded in 1989 to include breast cancer screening proposals from Maryland hospitals. The Maryland Department of Health & Mental Hygiene provided technical assistance to hospitals applying for these dollars.

Results:

By 1992, 28 Maryland hospitals had applied for and received grant funding from the HSCRC to conduct local breast cancer screening programs for underserved women. Between 1989 and 1995, 34,000 women were screened, 45,000 mammograms were performed, and 366 women were diagnosed with breast cancer.

project the future burden of cancer in Maryland. This is an especially important issue because the baby boomer generation is entering the ages of greatest cancer incidence. Projecting the number of persons likely to be diagnosed with cancer in the future can help Maryland to plan for cancer prevention, education, and early detection programs as well as cancer diagnostic and treatment services (e.g., hospital beds, physician and nursing staffing, outpatient surgery and chemotherapy services, and rehabilitative, home health, and hospice care) and to foster cancer research.

Cancer surveillance data can be used to evaluate cancer prevention and control programs by monitoring trends in cancer incidence, stage, and mortality over time. For

Table 2.2

**Cancer Surveillance Case Study:
Cancer Surveillance and the
Maryland Tobacco Settlement
(Resource Allocation)**

Cancer Surveillance Information:

- Maryland ranked among the top states in cancer mortality in 1998. (Source: Maryland Division of Health Statistics, National Center for Health Statistics)
- More than \$3 billion is spent on the direct and indirect costs of smoking in Maryland per year.⁶
- Tobacco use is the leading cause of preventable deaths, including those due to cancer.⁷

State, Local, or Community Action:

In 1998, Maryland joined other states in a lawsuit against tobacco manufacturers to recover Medicaid costs associated with the treatment of smoking-related illness.

Results:

The state of Maryland is a signatory party to the master tobacco settlement agreement reached via multi-state litigation against the tobacco manufacturers. The Maryland Cigarette Restitution Fund Program was established in 2000 and is used to fund:

- tobacco-use prevention and cessation programs
- cancer prevention, education, screening, and treatment programs
- cancer research programs
- a tobacco crop conversion program.

example, cancer mortality rates in Maryland have been decreasing at a faster rate than that of the nation. For the time period 1986–1990, Maryland had the third highest cancer mortality rate in the nation; for the time period 1991–1995, Maryland ranked sixth highest; and for the time period 1996–2000, Maryland's rank dropped to the 11th highest cancer mortality rate in the nation.⁸

Cancer surveillance can support population-based research studies aimed at better understanding the cancer problem in Maryland. For example, data from the Maryland Cancer Registry was used for one research study to understand the geographic pattern of prostate cancer in the state (Table 2.3).

Table 2.3**Cancer Surveillance Case Study:
Prostate Cancer (Research)****Cancer Surveillance Information:**

Prostate cancer is the most frequently reported cancer among Maryland men. Nationally, the mortality rate for prostate cancer is twice as high among black males than white males.

(Source: Maryland Cancer Registry, National Center for Health Statistics)

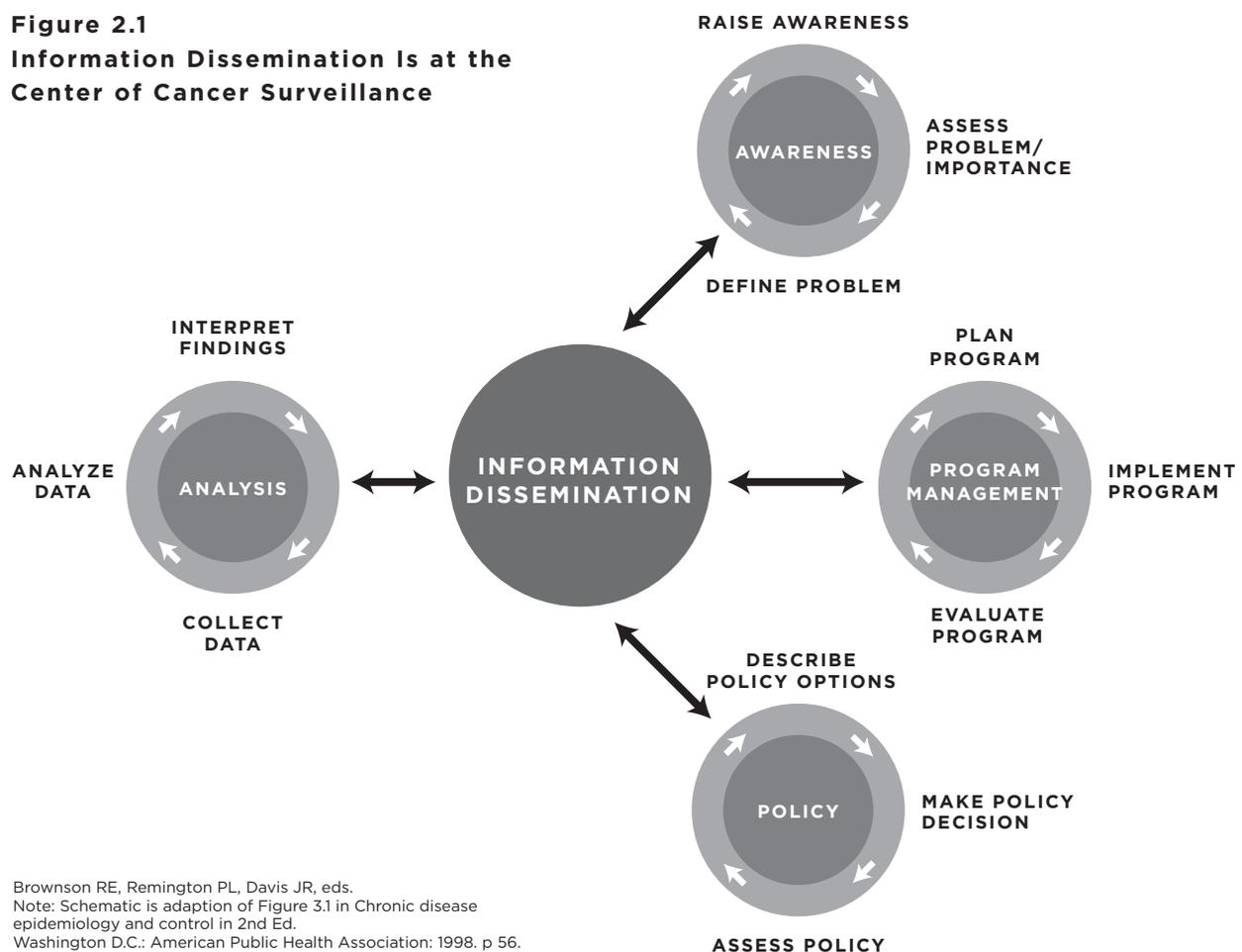
State, Local, or Community Action:

- The Johns Hopkins Bloomberg School of Public Health received a grant from the Centers for Disease Control and Prevention to investigate racial and geographic variations of prostate cancer incidence in Maryland.
- The Johns Hopkins investigators obtained and geo-coded prostate cancer data from the

Maryland Cancer Registry. Geo-coding data is a process that involves associating address information with a geographic location, which enables placement of a cancer case within a state, a county, and a zip code.

Results:

- While the analysis is still underway, preliminary results have highlighted areas of increased prostate cancer incidence.
- In addition, the analysis also identified a need to develop a mechanism for geo-coding post office box addresses. The investigators are collaborating with the Maryland Cancer Registry to obtain additional funding to develop methodology and software that central cancer registries can use to improve the effectiveness of geo-coding cancer registry data.

Figure 2.1
Information Dissemination Is at the Center of Cancer Surveillance

Brownson RE, Remington PL, Davis JR, eds.
Note: Schematic is adaption of Figure 3.1 in Chronic disease epidemiology and control in 2nd Ed.
Washington D.C.: American Public Health Association: 1998. p 56.

Databases Used for Cancer Surveillance in Maryland

In Maryland, cancer surveillance is supported by data from a variety of sources, including the Maryland Cancer Registry, the Maryland Vital Statistics Administration, the Maryland Behavioral Risk Factor Surveillance System, the Maryland Cancer Survey, and other databases, surveys, and research. Table 2.4 is a compilation of Maryland and federal databases that can be used for cancer and cancer-related surveillance. The table includes information on purpose, availability, and limitations of each database. These databases collectively represent the spectrum of cancer and cancer-related events occurring in Maryland. The Maryland Cancer Registry is a population-based database that collects information on all new cases of cancer in Maryland. The Maryland Vital Statistics Administration collects information from death certificates on all deaths in Maryland, including cancer deaths. The Maryland Hospital Discharge database, which is administered by the Health Services Cost Review Commission, collects medical information about individuals discharged from hospitals in Maryland. The Maryland Medical Care database, which is administered by the Maryland Health Care Commission, collects data on physicians' services provided to Maryland residents who have private health insurance. The Maryland Behavioral Risk Factor Surveillance System (BRFSS), which is administered by the DHMH, is a statewide telephone survey that collects information on knowledge and behavior of Maryland adults aged 18 and older related to major health conditions, such as screening for various types of cancer. The Maryland Cancer Survey (MCS), which is administered by the DHMH, is a statewide telephone survey that collects information on cancer risk factors and screening practices of Maryland adults aged 40 and older. The Maryland Adult Tobacco Survey (MATS) and Maryland Youth Tobacco Survey (MYTS) collect information on the use of tobacco products by Maryland adults and youth, respectively. The Maryland Oral Cancer Survey is a telephone survey that collects information on oral cancer risk factors and screening practices of Maryland adults aged 18 and older. The Maryland Statewide Health Network Baseline Survey of Maryland Counties (MSHN) is a telephone survey that collects information on cancer attitudes, knowledge, and practices of Maryland adults aged 18 and older in three regions of the state (Western Maryland, Baltimore City, and the Eastern Shore). The Maryland Medicaid Management Information System (MMIS) collects medical information on Maryland Medicaid recipients.

Some of these databases collect information for the entire population in Maryland (e.g. the Maryland Cancer Registry, the Maryland Vital Statistics Administration); other databases use a representative sample to collect information on Marylanders (e.g., BRFSS, MCS, MATS, MYTS). The remaining databases have information on certain segments of the Maryland population (e.g., the Maryland Medical Care database, MSHN, MMIS) such as the population served through Medicaid.

In addition, there are several federal databases that are used in cancer surveillance (also listed in Table 2.4). The National Cancer Institute (NCI) Surveillance, Epidemiology, and End Results Program (SEER) collects information on cancer incidence, stage, and survival from 11 cancer registries throughout the United States that are estimated to represent 14% of the U.S. population. (The NCI State Cancer Profiles is a tool for visualizing data through tables and graphs for the nation or by state.) The Centers for Disease Control and Prevention (CDC) National Program of Cancer Registries (NPCR) collects information from all states that have state cancer registries. The NPCR published its first report of cancer incidence in the nation, in coordination with SEER, in 2002. The National Center for Health Statistics has several databases. The NCHS National Vital Statistics System collects information on cancer mortality from each of the states in the nation. The NCHS National Health Interview Survey (NHIS) is a continuous in-person interview survey conducted on a random sample of households in the country that collects information on illness and disability (including cancer) in the nation. The NCHS's National Health and Nutrition Examination Survey (NHANES) collects information on the health and nutritional status of adults and children in the United States. The Environmental Protection Agency has numerous databases that can be consulted for cancer-related information. The U.S. databases are useful for comparison when statewide data is available and can inform users of national trends when state-specific information is not available.

Surveillance systems are designed to answer basic questions, generally about the entire population. Questions having more detail, greater depth, or broader scope require special research studies and are frequently initiated by scientists. Table 2.5 lists examples of questions that can be answered by the various databases used for cancer surveillance.

Table 2.4
Maryland Cancer-Related Database Summary: Databases That Can Be Used for Cancer Surveillance

Database/System Contact Phone No. Website for Reports and/or Data	Main Purpose	Demographic and Geographic Coverage	Years of Available Data	Data Availability	Examples of Data Collected	Comparability with U.S. and Other State Reports on Cancer Outcomes	Notes/ Limitations
MD Cancer Registry DHMH, Family Health Administration, Center for Cancer Surveillance and Control 410-767-5521 www.fha.state.md.us	To register cancer incidence among Maryland residents	All Maryland residents; age, race/ethnicity, date of diagnosis, county of residence	1992–2001	Aggregate data available; release of county or case-based data requires approval by the DHMH Institutional Review Board	Cancer site, stage; patient's age at diagnosis, race, sex, county of residence	NAACCR contribu- tors, other states, Canada, Mexico, SEER on basic cancer measures	No information on survival status; limited detail on stage of cancer, occupation, and other risk factors (smoking, screening)
MD Behavioral Risk Factor Surveillance System (BRFSS) DHMH, Family Health Administration, Center for Prevention Health Services 410-767-5159 www.marylandbrfss.org ; www.cdc.gov/brfss	To collect popula- tion-based behavioral health data about chronic diseases, injuries, and preven- tive health services that contribute to premature morbidity or mortality	4,400 telephone surveys from MD, English-speaking adults aged 18 and over; stratified sample based on urban or rural telephone prefix/ exchange; age, race, ethnicity, sex, marital status, education, employment, income, county of residence	1988–2001	User-generated reports available on MD DHMH website for estimates where the sample is >50 surveys; user-generat- ed reports available on CDC website, statewide only; CD-ROM data available for 1990– 2001 from CDC	MD residents aged 40 and over who have had a colonoscopy within the past 2 years; mammography, exercise, nutrition, and overweight	National and other state BRFSS studies, Maryland Cancer Survey, Oral Cancer Survey, and Maryland Statewide Health Network Survey	Annual data not available for some counties; no data on non-English speaking residents; self-reported data and refusals to answer the survey or parts of it; non-coverage due to households without phones; estimates based on sample sizes <50 should be interpreted with caution
MD Cancer Survey (MCS) DHMH, Family Health Administration, Center for Cancer Surveillance and Control 410-767-0791 Website: www.fha.state.md.us/ cancer/pdf/MCS_Report _2002-V3.pdf	To collect popula- tion-based behavioral and health data related to cancer surveillance and screening practices	5,000 telephone surveys from MD, English-speaking adults aged 40 and over; stratified sample based on urban or rural telephone prefix/ exchanges; same demographics as BRFSS	2002	Report available at website; data use policy being developed	MD residents aged 40 and over who have undergone cancer screening; similar to BRFSS	National and state BRFSS, Oral Cancer Survey, and MD Statewide Health Network Survey	Persons <40 years old not captured; no data on non-English speaking residents; self-reported data and refusals to answer the survey or parts of it; non- coverage due to house- holds without phones; estimates based on sample sizes <50 should be interpreted with caution

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MD Vital Statistics Administration 410-767-5950 www.mdpublichealth.org/vsa	To administer birth/death certification and summarize mortality statistics for administrative and public health use	All births/deaths among Maryland residents; year of death, place, data and age at death, place of birth, race, ethnicity, sex, cause(s) of death	Data files: 1970 to present; vital statistics reports: 1960 to present	Aggregate and county level data available upon request; release of single-record data requires DHMH Institutional Review Board approval; public-use data available through CDC	Age, race, Hispanic origin, sex, marital status, education, occupation, residence, place of death, cause of death, manner of death	National Vital Statistics System (NVSS) collected by the National Center for Health Statistics (NCHS); standards set by NCHS	Verification of cause of death information is not possible; lack of automated death registration delays public health analysis
MD Adult Tobacco Survey (MATS) and MD Youth Tobacco Survey (MYTS) DHMH, Family Health Administration/ Office of Health Promotion, Education and Tobacco-Use Prevention 410-767-1362 www.fha.state.md.us/crfp/html/stats.cfm	To collect behavioral, lifestyle, and other data supporting CRF's Tobacco-Use Prevention and Cessation Program	MATS: 16,596 telephone surveys from MD, English-speaking adults aged 18 and over; sample stratified by jurisdiction MYTS: 55,967 middle and high school-based surveys; 2-stage cluster sample generated for each jurisdiction	MATS: 2000 MYTS: 2000 and 2002	September 1st of each year for prior year; Data Use Policy is in development; county level data are available	Prevalence of tobacco use (all tobacco products); tobacco cessation; attitudes, knowledge about tobacco use, social context, and exposure to second-hand smoke	MATS: BRFSS MYTS: National Youth Tobacco Survey (NYTS) and youth tobacco surveys in other states	Some minority populations may be under-represented; MATS: No data on non-English speaking residents; self-reported data and refusals to answer the survey or parts of it; non-cover-age due to households without phones MYTS: Excludes school dropouts, students whose parents refused to let them participate, and those who were absent during survey
MD Hospital Discharge Database DHMH, MD Health Care Commission, HSCRC 410-764-2605 www.hscrc.state.md.us	To provide a standard set of data about each hospital discharge or ambulatory care visit; hospital rate setting	Patients served by Maryland's 66 general hospitals, not including specialty hospitals (e.g., chronic care)	Data files: 1980 to present Electronic files: 1996 to present	Confidential and unidentified formats available; hospital and patient's jurisdiction are captured; out-of-state patients are normally excluded from analysis	Discharges include ICD-9* codes for primary, secondary diagnosis and CPT** codes of procedures or procedures due to cancers listed as the primary diagnosis, by jurisdiction of residence or hospital	National Hospital Discharge Survey (NHDS) collected by the National Center for Health Statistics (NCHS) and other states' hospital discharge databases	Does not assure that cancer is captured if cancer is not listed as one of discharged diagnoses

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<p>MD Medical Care Database DHMH, MD Health Care Commission, Data Systems & Analysis 410-764-3570 www.mhcc.state.md.us/ database/_database.htm</p>	<p>To support policy decision making; health options, health market, and cost and utilization patterns</p>	<p>Practitioner fee-for- service encounters and prescription drug cov- erage among MD resi- dents privately insured or insured through HMOs</p>	<p>1996–2001</p>	<p>Detailed data avail- able down to zip code and county level; patient ID is encrypt- ed; data available 1 year after collected</p>	<p>Coverage type, claim-related conditions, diagnosis code, procedure code, reimbursement amount</p>	<p>Medical care items are often compared with SEER data; this system does not encompass entire Maryland population</p>	<p>Excludes services provided for self-pay, Medicaid, and unin- sured populations; excludes MD residents who work out of state, are self-insured, or insured through self- funded employers; does not include insti- tutional bills; data for HMOs excludes pri- mary encounters; rates not available due to lack of population denominators</p>
<p>MD Oral Cancer Survey DHMH, Family Health Administration, Office of Oral Health 410-767-5736</p>	<p>To collect knowledge and behavioral data relating to oral cancer risk factors, signs, symptoms, and dental health screening exams</p>	<p>1,127 telephone surveys from MD, English-speaking adults aged 18 and over; over sampling of African-American men; age, race, ethnicity, sex, status, education</p>	<p>First survey: September 2002</p>	<p>Data available approximately 6 months from end of collection; data-use policy is pending; county-level data is not available</p>	<p>MD residents aged 18 and over who have undergone oral cancer exams in the past year</p>	<p>Some comparability to BRFS and MCS</p>	<p>No data on non- English speaking resi- dents; self-reported data and refusals to answer the survey or parts of it; non-cover- age due to households without phones; estimates based on samples <50 should be interpreted with caution; county- and region-specific data not available</p>

Database/System Contact Phone No. Website for Reports and/or Data	Main Purpose	Demographic and Geographic Coverage	Years of Available Data	Data Availability	Examples of Data Collected	Comparability with U.S. and Other State Reports on Cancer Outcomes	Notes/ Limitations
MD Statewide Health Network (MSHN) Baseline Survey University of Maryland, School of Medicine, Office of Policy and Planning 410-706-1742	To examine health attitudes, knowledge, and practices of MD residents in three regions (Baltimore City, Western MD, and the Eastern Shore)	Approximately 500 interviews per county among English-speak- ing MD adults aged 18 and over; general demographic information	First survey; ongoing as of July 2003	Data-use policy in development; internal data use with strict discretion; lag time from collection to dissemination TBD	Knowledge, attitudes, and practices relating to health behaviors; insurance, preventive services for lung, skin, breast, colon, prostate, cervical, and oral cancers; other tobacco-related diseases, CVD, (hypertension, stroke)	Some comparability to BRFSS and the Commonwealth Fund	Only includes data from selected jurisdictions in the state
Maryland Medicaid Management Information Systems II DHMH, Medical Care Programs, Medicaid Operations, Data Management & Analysis, Office of Planning & Finance 410-767-5683	To collect medical, administrative, and billing information to monitor financial transactions for Medicaid recipients	Maryland Medicaid recipients	1995-2002 (earlier years available)	Aggregate data avail- able on request; release of identifiable data requires DHMH Institutional Review Board approval; county level data is available	Demographics, disease prevalence (ICD-9*); treatment (e.g., inpatient, outpatient, hospital, physician) by procedure code	Compares with national and state Medicaid administrative databases	Does not specify whether the diagnoses listed are suspected and being ruled out or are confirmed

*ICD-9 refers to the American Medical Association's *International Classification of Diseases*
**CPT refers to the American Medical Association's *Current Procedural Terminology*

National Cancer-Related Surveillance Systems

Database/System	Website	Focus
National Cancer Institute		
■ Surveillance, Epidemiology, and End Results (SEER)	www.seer.cancer.gov/publications	Incidence, mortality, cancer prevalence, and reports
■ Wonder	http://wonder.cdc.gov	
■ State Cancer Profiles	www.statecancerprofiles.cancer.gov	
Centers for Disease Control and Prevention		
■ National Program of Cancer Registries	www.cdc.gov/cancer/npcr	Incidence; incidence and mortality
■ State/Territory Cancer Data	www.cdc.gov/cancer/dbdata.htm	
National Center for Health Statistics (NCHS)		
■ National Health Interview Survey (NHIS)	www.cdc.gov/nchs/nhis.htm	41,000 household interviews annually on health behaviors, chronic conditions, health care coverage and use, and health status and limitations; periodic modules include: cancer, HP2010, diabetes
■ National Health and Nutrition Examination Survey (NHANES)	www.cdc.gov/nchs/nhanes.htm	Health and nutritional status of adults and children in the U.S.; examples of data include: disease or condition prevalence, risk factors, nutrition monitoring, growth and development, disease monitoring
■ National Viral Statistics System (NVSS)	www.cdc.gov/nchs/nvss.htm	Death rates
■ CDC WONDER	http://wonder.cdc.gov	Death rates
Other		
■ American Cancer Society (ACS)	www.cancer.org/docroot/home/index.asp	Incidence and mortality, cancer facts and figures, reports from 1997-2002 by state; various environmental databases
■ Environmental Protection Agency	www.epa.gov (search for databases)	

Table 2.5
Examples of Questions that Surveillance Systems Can Answer in Maryland

Sample Questions About Cancer in Maryland	Cancer Surveillance Source	Answer
How many men had lung cancer in Maryland in 1999?	Maryland Cancer Registry	In 1999, 1,904 cases of lung cancer were reported among men in Maryland.
How many women died of breast cancer in Cecil County in 2000?	Maryland DHMH Vital Statistics	In 1999, 10 breast cancer deaths were reported among women in Cecil County, Maryland.
How does Maryland's rate of colorectal cancer compare with the United States'?	Maryland Cancer Registry; SEER (U.S.)	Compared to the U.S. (53.3 per 100,000 population), the Maryland 1999 incidence rate is not statistically significantly different (54.3 per 100,000 population).
Does the Eastern Shore have a higher rate of breast cancer mortality than Western Maryland?	Maryland Cancer Registry	The Eastern Shore has 30.9 breast cancer deaths per 100,000 population compared to 27.2 breast cancer deaths per 100,000 population in Western Maryland (1995–1999 data). The rate is not statistically significantly different.
Do black men have a higher rate of prostate cancer than white men of the same age in Baltimore City?	Maryland Cancer Registry	In 1999, black men in Baltimore City had a higher prostate cancer incidence rate (236.7 per 100,000 population) than white men (168.8 per 100,000 population). This rate is statistically significantly higher.
What percent of melanoma cases in Maryland were diagnosed at an early stage in 1999?	Maryland Cancer Registry	In 1999, 43.6% of melanoma cases were diagnosed at an early stage in Maryland.
What percentage of Maryland adults and youth smoke or use tobacco products?	Maryland Adult Tobacco Survey Maryland Youth Tobacco Survey	In 2002, 19.8% of Maryland adults reported being current smokers. In 2002, 18.4% of youth in grades 9–12 reported being current smokers.
What percentage of Marylanders eat 5 or more vegetables and fruits each day?	Behavioral Risk Factor Surveillance System (BRFSS)	In 2000, 27.4% of Marylanders reported eating 5 or more fruits and vegetables a day.

Improvements in Cancer Surveillance in Maryland

Since publication of the 1996 Maryland Cancer Control Plan, there have been notable improvements in several of the cancer surveillance databases in Maryland. In addition, several new databases have been implemented since the 1996 cancer plan. The following improvements have expanded Maryland's ability to measure, track, and report changes in cancer control:

- The Maryland Cancer Registry has received the gold standard from the National Program of Cancer Registries for the quality and completeness of its data in 2001, 2002, and 2003. This means that complete, timely, and accurate data have been assembled to represent Maryland's cancer incidence. The Maryland Cancer Registry utilizes data from the Maryland Vital Statistics Administration to produce an annual report on cancer mortality in Maryland.
- The Maryland Vital Statistics Administration is using a computerized algorithm that is applied to determine the underlying cause of death when multiple causes of death are specified on Maryland death certificates. The Maryland Vital Statistics Administration Annual Report has become timelier and all reports since 1996 are available on the Internet.⁹
- The Maryland Behavioral Risk Factor Surveillance System (BRFSS) has increased its sample size from 3,600 interviews in 1996 to 4,800 interviews in 2002. The BRFSS regularly over-samples the rural areas of the state, enabling annual regional measurement of most risk factors and preventive services.¹⁰
- New surveys have been implemented, such as the Maryland Youth Tobacco Survey (2000 and 2002) and the Maryland Adult Tobacco Survey (2000),¹¹ the Maryland Medical Care database (1996-present), the Maryland Oral Cancer Survey (2002), and the Maryland Cancer Survey (2002), which give a clearer picture of cancer risk factors and screening in Maryland.
- Maryland's "Annual Cancer Report" has been published since the baseline report in 2000 under the Cigarette Restitution Fund Program, detail-

ing cancer outcomes in the state's priority areas.¹²

- The Maryland Cancer Registry Advisory Committee meets several times a year to advise the Maryland Cancer Registry on issues related to data quality, data use, and data dissemination.

Despite these important advances, there is more that can be done in cancer surveillance to accelerate analysis and promote cancer awareness, policy development, and program planning for cancer prevention and control in Maryland. Cancer surveillance in Maryland must move from "data rich" to "data smart."

Gaps in Cancer Surveillance in Maryland

The Cancer Surveillance Committee identified the following gaps in cancer surveillance. These gaps are listed in relationship to the steps in the cancer surveillance model depicted in Figure 2.1.

Gaps in Data Collection

- **Lack of all the data elements needed for cancer surveillance.** For example, stage of disease for various cancer sites reported to the Maryland Cancer Registry is incomplete. Survival status of all individuals diagnosed with cancer in Maryland is not available. (Survival rates refer to the proportion of individuals diagnosed with cancer who are alive at varying years after their diagnosis. Five-year relative survival rates are often used to monitor improvements in cancer treatment.) Other data elements are not completely reported to the Maryland Cancer Registry, such as occupational status, tobacco use, length of residency, etc. In addition, there may be a need for new analyses and qualitative studies, which may require additional data collection (e.g., quality of care data).
- **Lack of complete information on race, ethnicity, and place of residence for all new cases of cancer.** Ethnicity is under-reported to the Maryland Cancer Registry. The Maryland Cancer Registry is currently developing an algorithm to better estimate Hispanic ethnicity.
- **Need to improve the quality of data elements submitted to the Maryland Cancer Registry among selected facilities.** This could be accomplished by: increasing training of

tumor registrars; increasing the number of certified tumor registrars in Maryland who perform cancer registration; and increasing the number of American College of Surgeon-approved hospitals in Maryland.

- **Lack of quality control and quality assurance methods in some of the databases used for cancer surveillance.** For example, there is no quality assurance assessment of causes of death; this could lead to the possibility of misclassification errors. One study has suggested that a high proportion of prostate cancer deaths may have been due to other primary causes.

Gaps in Access to Cancer Data

- **Need for greater access to cancer surveillance information.** This could be accomplished in a number of ways, including the creation of public-use data files and interactive access (e.g., Web-based, user-defined utility reports) to databases used for cancer surveillance in Maryland. Public-use data files and user-defined utility reports allow easy access to data and allow analysis of data in aggregate groups (e.g., geographic area, race, sex, etc.), while protecting the confidentiality of the individuals represented in the dataset. Public-use data files and utility reports have been created for a number of federal databases such as the NPCR,¹³ BRFSS,¹⁴ and NCI SEER Program.¹⁵ The Centers for Disease Control and Prevention and the National Cancer Institute have recently collaborated to create a public-use cancer data file on state cancer profiles using state-based cancer incidence and mortality data.¹⁶ The Maryland Cancer Registry is currently collaborating with the NCI to develop a public-use data file for cancer incidence data in Maryland. Similarly, the Maryland BRFSS has developed a public-use data file. Public-use data files widen accessibility to data, shorten the time frame for analysis, and increase the likelihood that the data will be used.

Gaps in Data Analysis

The ability to proactively or reactively analyze cancer surveillance data must be expanded. This expansion may be accomplished in the following ways by:

- Training in statistics, including small area analysis, an analytic method used to determine the number of health (or other) events which occur

in small geographic areas such as zip codes, block groups, or census tracts (the goal of the analysis is to compare health events occurring in one area to those occurring in a similar geographic area or a larger, standard population)^{17,18}; training in cancer epidemiology and biology, including cancer in children; training in risk and health communication; and adaptation of the CDC's *Guidelines for Investigating Clusters and Health Events*. In order to analyze changes in cancer incidence within communities (smaller than a jurisdiction), for less common cancers, and within racial and ethnic groups, there is a need for expertise in, and new approaches to, small area analysis.

- Using analytic tools for small area analysis, geographic area analysis, and geographic information systems.
- Developing a list of leading cancer indicators (e.g., incidence, mortality, treatment, risk behaviors), avoidable cancer events, and events that are sentinels of problems in the delivery of cancer prevention, education, screening, and treatment services that can be used to monitor or track changes in cancer control in Maryland.

- It is vital to provide technical assistance to local health departments in cancer surveillance and analysis. Assistance from state agencies and academic health centers in analyzing local data, compiling county-specific data (including trends over time), and directing further studies or collection of additional data would have an impact on planning, targeting, and monitoring cancer programs.

- In addition, there is a need for expanded research into risk factors, etiology, and outcomes and the knowledge, attitudes, and behaviors of both the public and providers. The quality of care provided to cancer patients for selected cancers must be evaluated and CRF-funded research on surveillance-related topics must be encouraged. Of course, additional funding for research must be sought to accomplish these goals.

Gaps in Information Dissemination

- **Sub-optimal dissemination of existing cancer surveillance data to those who are implementing programs and policies**

to improve cancer control. These professionals, along with the general public, need increased access to cancer reports and cancer statistics in order to optimize the efforts of cancer surveillance. The Internet has proven to be effective in reaching those who wish to know.

In addition, each of the other chapters in this plan describes site-specific cancer surveillance needs and recommendations. This chapter's recommendations address overall cancer surveillance needs.



Cancer Surveillance Goals, Objectives, and Strategies

Goal:

Fully implement cancer surveillance—the development, collection, analysis, and dissemination of cancer information—in Maryland.

Target for Change

By 2008, increase the capacity to conduct cancer surveillance in Maryland.

Objective 1:

Develop, maintain, and enhance data systems to ensure accurate, timely, and complete information needed for the prevention and control of cancer.

Strategies:

1. Continue to support the Maryland Cancer Registry Advisory Committee in its role as advisor to the Maryland Cancer Registry on issues related to data quality, data use, and data dissemination.
2. Encourage the development of quality assurance and quality control methods in all databases used for cancer surveillance in Maryland.
3. Re-establish a statewide Cancer Surveillance Advisory Group to meet regularly to further cancer surveillance in Maryland.
4. Develop a set of leading cancer indicators (e.g., incidence, stage, survival, mortality, treatment, risk behaviors), avoidable cancer events, and events that are sentinels of problems in the delivery of cancer prevention and control services that can be used to monitor or track changes in cancer control in Maryland.
5. Facilitate standardized measurement of race, ethnicity, and geographic area in databases that can be used for cancer surveillance in Maryland.
6. Provide training opportunities for cancer registrars and other collectors of cancer-related data.
7. Increase the number of Certified Tumor Registrars in Maryland who actively work in cancer registration.
8. Explore barriers as to why hospitals do not have an in-house tumor registry.

**Objective 2:**

Expand access to, and analysis of, the databases used for cancer surveillance in Maryland in order to better meet the information needs of program planners, policy makers, researchers, and the public.

Strategies:

1. Continue to pursue the creation of a public-use (non-confidential) data file for databases that are used for cancer surveillance in Maryland.
2. Expand the interactive access (e.g., Web-based, user-defined utility reports) to databases used for cancer surveillance in Maryland.
3. Develop a list of priority research questions about specific Maryland cancer problems; share these research questions with potential funding sources, the statewide academic health centers, researchers, health leaders, and others.
4. Develop a guide/report that reviews, aggregates, and summarizes methodologies that local and state health agencies and others could use to address small numbers issues and assessment of disparities, while maximizing information and maintaining privacy.
5. Increase the capacity of state agencies to perform small area analysis of cancer-related events in Maryland.
6. Investigate the feasibility of a prospective method for cancer monitoring.
7. Create a surveillance resource that would list existing population-based cancer data for assessment of local or state cancer concerns (e.g., watershed information, demographics available from the census, and others).

Objective 3:

Broadly disseminate cancer surveillance findings to promote cancer awareness, policy development, and implementation of cancer control programs

Strategies:

1. Develop and maintain a master distribution list of cancer reports.
2. Create a list of Internet websites for cancer-related surveillance reports and articles pertaining to Maryland cancer statistics and information.
3. Share major surveillance reports and findings with the media.
4. Establish feedback mechanisms by which users of cancer surveillance system information can provide suggestions, including their unmet needs for information, and other comments.
5. Maintain, periodically revise, and continue to create informational materials about cancer surveillance.
6. Continue to distribute cancer surveillance documents, including reports and articles, to the appropriate audiences.

References

- 1 Centers for Disease Control and Prevention, Guidelines Working Group. Updated guidelines for evaluating public health surveillance systems. *MMWR Recomm Rep* 2001 July 27; 50(RR13):1–35.
- 2 Brownson RE, Remington PL, Davis JR, editors. *Chronic disease epidemiology and control*. 2nd edition. Washington, D.C.: American Public Health Association, 1998:56.
- 3 PDQ Cancer information summary: breast cancer screening. Bethesda, MD: National Cancer Institute. (Accessed at <http://www.nci.nih.gov/cancerinfo/pdq/screening/breast/healthprofessional/>.)
- 4 Jacobs DL, Chair, and Benjamin GC, Vice Chair; the Task Force to Conquer Cancer in Maryland. Report of the governor's task force to conquer cancer in Maryland. December 9, 1999.
- 5 Wasserman MP, Chair and McFadden NJ, Vice Chair; the Task Force to End Smoking in Maryland. Making Maryland the tobacco free state: a report to the governor. December 9, 1999.
- 6 Centers for Disease Control and Prevention. Tobacco state control highlights 2002. (Accessed at http://www.cdc.gov/tobacco/statehi/statehi_2002.htm.)
- 7 McGinnis JM, Foege WH. Actual causes of death in the United States. *JAMA* 1993 Nov 10;270(18):2207–12.
- 8 Ries LAG, Eisner MP, Kosary CL, et al., editors. *SEER Cancer Statistics Review, 1973–1990; 1973–1995; 1975–2000*. Bethesda, MD: National Cancer Institute, 2003. (Accessed at http://seer.cancer.gov/csr/1975_2000.)
- 9 Maryland Department of Health & Mental Hygiene, Vital Statistics Administration. *Maryland Vital Statistics Annual Report 2000*. (Accessed at <http://mdpublichealth.org/vsa/doc/00annual.pdf>.)
- 10 Maryland Department of Health & Mental Hygiene, Maryland Behavioral Risk Factor Surveillance System (BRFSS). (Accessed at <http://www.fha.state.md.us/oipha/html/brfss.html>.)
- 11 Maryland Department of Health & Mental Hygiene, Cigarette Restitution Fund Program. Initial findings from the baseline tobacco study. February 8, 2001. (Accessed at <http://www.dhmh.state.md.us/esm/initialbaseline.pdf>.)
- 12 Maryland Department of Health & Mental Hygiene, Cigarette Restitution Fund Program. Annual cancer reports. (Accessed at <http://mdpublichealth.org/crfp/html/stats.cfm>.)
- 13 Centers for Disease Control and Prevention, Cancer Prevention and Control. National program of cancer registries. (Accessed at <http://www.cdc.gov/cancer/npcr>.)
- 14 Centers for Disease Control and Prevention. Behavioral Risk Factor Surveillance Survey (BRFSS). (Accessed at <http://www.cdc.gov/brfss>.)
- 15 National Cancer Institute. Surveillance, Epidemiology, and End Results Program. (Accessed at <http://www.seer.cancer.gov>.)
- 16 Centers for Disease Control and Prevention / National Cancer Institute. State cancer profiles. (Accessed at <http://statecancerprofiles.cancer.gov>.)
- 17 Wisconsin Department of Health & Family Services. Small area analysis in southeastern Wisconsin, 1992–1994. (Accessed at <http://www.dhfs.state.wi.us/healthcareinfo/excerpts/saawg.htm>.)
- 18 Elliot P, Wakefield JC, Best NG, Briggs DJ. *Spatial epidemiology: methods and applications*. London: Oxford University Press, 2000.