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CANCER SURVEILLANCE



ancer surveillance is key to improving cancer control in Maryland. Public health surveillance—the ongoing, systematic collection, analysis, and interpretation of health data—is essential to the planning, implementation, and evaluation of public health practice.

DID YOU KNOW?

Cancer surveillance information contributes to public health action in Maryland and nationwide. This chapter presents real examples of how Maryland surveillance information is being used.

SURVEILLANCE INVOLVES THE COLLECTION OF DATA AND MONITORING OF TRENDS, and is closely tied to the timely dissemination of data to those who need it.¹ In addition, surveillance can provide data and information to raise awareness of public health problems and to inform public policies.

Cancer surveillance includes the collection of data on the occurrence of cancer (incidence), cancer deaths (mortality), risk factors for the development of cancer (for example, smoking, overweight, and fruit and vegetable intake), cancer screening behaviors (for example, the use of mammography, colonoscopy, and Pap tests), and diagnostic and treatment services. Factors affecting post-treatment quality of life and palliative care are increasingly important to cancer surveillance, as the scope of surveillance expands to include all phases of the disease.² A well-functioning cancer surveillance system transforms complete, timely, and high quality data into information that is easily accessible to those who use it to prevent and control the disease.

In Maryland, surveillance for cancer occurrences is conducted primarily through reporting of cancer diagnoses (incidence) and cancer deaths (mortality). Within six months after diagnosis of invasive and in situ cancer (excluding basal and squamous skin cancer of non-genital sites), information about the individual and the cancer must be reported, by legal mandate, to the Department of Health and Mental Hygiene’s (DHMH) Maryland Cancer Registry (MCR) by the state’s hospitals, radiation therapy centers, ambulatory care centers, laboratories, and physicians. Cases among Maryland residents diagnosed out of state are reported to the MCR through interstate data exchange agreements (with 12 states and the District of Columbia). Mortality from cancer is reported to, and analyzed by, the Vital Statistics Administra-

Cancer Surveillance and Maryland's Colorectal Cancer Successes

THE CHALLENGE

When the Maryland DHMH conducted surveillance of colorectal cancer (CRC) incidence and mortality in 2000, it found that Maryland rates were significantly above the national average. Racial disparities in CRC were also evident in Maryland, with statistically significantly higher incidence and mortality rates among blacks or African Americans compared to whites. In 2000, blacks or African Americans in Maryland had an age-adjusted CRC mortality rate 1.4 times that of whites (31.1 per 100,000 versus 22.1, respectively).⁴ Although CRC is largely preventable through screening, screening was underutilized.

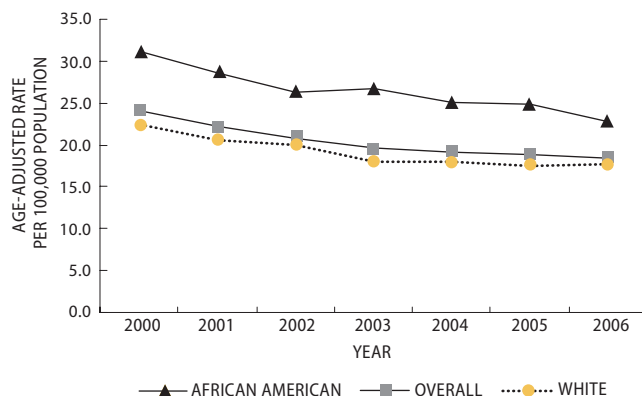
THE INTERVENTION

CRC was one of seven cancers “targeted” by the Maryland Cancer Prevention, Education, Screening, and Treatment Program, which was established under the Cigarette Restitution Fund (CRF) Program. In 2000, public health programs in Maryland began promoting screening for CRC. In 2001, Medicare started paying for screening colonoscopies. Using CRF funding, local health departments established outreach and screening programs targeted to individuals who had low-income, were uninsured, or were of minority race or ethnicity. In 2006, the CDC allocated additional funds to Maryland to establish a CRC Screening Demonstration Program in Baltimore City. In 2009, the CDC funded Maryland as part of the new national CRC Control Program for CRC education, outreach, screening, and promotion of insurance benefits.

THE OUTCOME

From 2000 through 2008, more than 17,000 underserved Marylanders were screened for CRC through local public health programs. The percentage of Marylanders age 50 and older who ever received a sigmoidoscopy or colonoscopy increased from 50% in 1999 to 75% in 2008,⁶ and Maryland's age-adjusted CRC mortality rate dropped faster than the national rate. Maryland's national ranking in CRC mortality rates declined from 3rd highest (based on a five-year average mortality rate, 1996-2000) to 14th highest (2002-2006).⁷ As shown in the chart, Maryland also made significant progress in closing the racial disparity gap in CRC mortality.

Trends in Colorectal Cancer Age-Adjusted Mortality Rates in Maryland, by Race, 2000-2006



Source: NCHS Compressed Mortality File in CDC WONDER.

tion (VSA), using the underlying cause of death on the death certificate. Deaths among Maryland residents who died out of state are reported to the VSA under interstate data exchange agreements.

Surveillance entails diagnosing the tumor, determining whether a case should be reported, and reporting case information that is timely, complete, and accurate to the MCR. MCR staff “consolidate” the information on each tumor, which may be reported from multiple sources, and develops the final tumor record retained in the MCR database. MCR data are then reported to the North American Association of Central Cancer Registries (NAACCR) and to the Centers for Disease Control and Prevention (CDC) National Program of Central Cancer Registries (NPCR). MCR reports are also posted to appropriate Web sites (see Table 2.1). These national agencies “grade” the Maryland reports on their quality. Within 24 to 35 months after diagnosis, data on cancer cases are finalized and ready for analysis. The MCR attempts to identify all reportable cases in Maryland residents, but cases can be missed if the tumor is not identified or not reported on time.

Cancer case and death data are routinely age-adjusted and standardized to the US population for comparison, and are analyzed by gender, race, and county of residence. If sufficient information is available, cases with onset after 1999 are geocoded

DID YOU KNOW?

The Maryland Cancer Registry (MCR) collects and maintains confidential data on all reportable cancers diagnosed in people in Maryland. The MCR reports on the trends in cancer over time, which helps to identify program needs.

by latitude and longitude, county of residence, and ZIP code. In addition, census tracts are verified, corrected, or added.

As part of its mission to serve Marylanders, DHMH also conducts active surveillance on cancer screening and risk behaviors through several population-based statewide surveys. For example:

- The Behavioral Risk Factor Surveillance System (BRFSS) is an ongoing survey of adults 18 and older designed to collect data on risk behaviors and other factors that affect chronic disease, including cancer.
- The Maryland Cancer Survey (MCS), a biennial statewide survey conducted from 2002–2008 among adults age 40 years and older, focused on cancer screening, knowledge, and risk behaviors in this older population most at risk for developing cancer.
- The Maryland Adult and Youth Tobacco Surveys (MATS and MYTS), conducted in 2000, 2002, and 2006, focused on current and past tobacco use, secondhand smoke exposure, and smoking cessation among Maryland adults and youth.

Cancer surveillance data and information have many uses: planning, policymaking (including resource allocation and evaluation of cancer prevention and control efforts), and applied research. Applied research may examine areas of cancer control, such as risk factors, cancer prevention, and disparities in incidence and mortality.

By monitoring trends in cancer incidence, stage, and mortality over time, cancer surveillance data can be used to evaluate cancer prevention and control programs. For example, cancer mortality rates in Maryland have been decreasing at a faster rate than national rates. For the time period 1986–1990, Maryland had the third-highest cancer mortality rate in the nation; for the time period 2002–2006 Maryland’s rank dropped to the 20th highest cancer mortality rate nationwide.³

This chapter includes real examples of how

Research Uses of Cancer Surveillance Data

Maryland Researchers Examine Cancer Risk Factors

The CLUE community-based cohorts, CLUE I and CLUE II, were established in Washington County, Maryland in 1974 and 1989, respectively, to study cancer and heart disease. These studies take their name from the campaign slogan “Give Us a Clue to Cancer and Heart Disease.” In both studies, participants completed a brief questionnaire and donated a blood specimen. CLUE II participants were also asked to complete a questionnaire about their diet in 1989, and to complete questionnaires every two to three years beginning in 1996. More than 23,000 adults took part in CLUE I and more than 32,000 participated in CLUE II. Participants are monitored for the development of cancer using the Washington County Cancer Registry and the Maryland Cancer Registry. Information collected in 1974 and 1989, including the blood samples, has been used to determine possible protective factors or risk factors for cancer.

THE FOLLOWING EXAMPLES OF TOPICS INVESTIGATED as part of the CLUE I and CLUE II studies were made possible by the ability to link to cancer registries:

- Risk of developing subsequent cancer among people diagnosed with nonmelanoma skin cancer.⁸
- The association between C-reactive protein, a blood serum marker of chronic inflammation, and other hormones, and the risk of ovarian cancer.^{9,10}
- The potential role of serum biological markers, such as CA-125, for the early detection of ovarian cancer, and nonsteroidal anti-inflammatory medication in reducing risk of invasive breast cancer.^{11,12}
- Possible association between high levels of serum cholesterol and the aggressiveness of prostate cancer.¹³
- Meat and dairy consumption and the risk of developing prostate cancer.¹⁴

cancer surveillance has contributed to public health knowledge, policymaking, program evaluation, and research that translates into public health action.

The text box on page 2, Cancer Surveillance and Maryland’s Colorectal Cancer Success, shows that surveillance of colorectal cancer incidence by the Maryland DHMH led to a program to increase colorectal cancer screening statewide.

Cancer surveillance in Maryland also supports research aimed at better understanding cancer risk factors. The text box above, Research Uses of Cancer Surveillance Data, provides examples of research studies that use Maryland cancer surveillance data to examine the roles of cancer risk factors and protective factors in the development of cancer. Studies such as these make important contributions to cancer prevention and control efforts in Maryland and nationwide.

Types of Cancer Statistics

INCIDENCE

The rate of newly diagnosed cases during a specific time period.

MORTALITY

The rate of deaths during a specific time period.

PREVALENCE

The total number of cases in the population during a specific time period.

STAGE

The extent of a cancer in the body. Staging is usually based on the size of the tumor, whether lymph nodes contain cancer, and whether the cancer has spread from the original site to other parts of the body.

Data and Information for Cancer Surveillance in Maryland

Cancer surveillance in Maryland is supported by many types of data and information, including:

- Cancer incidence, mortality, and staging data.
- Prevalence of cancer screening and cancer-related risk behaviors.
- Cancer-related medical services and expenditures.
- Vital statistics data.

Table 2.1 (pages 6-7) summarizes key data and information resources relevant to cancer surveillance in Maryland. (A more detailed version of this table and a summary of data fields in key databases are available on the Cancer Surveillance page of the Maryland Cancer Plan Web site: www.marylandcancerplan.org). For each resource listed, the table identifies the administering agency or organization, briefly describes the types of information provided, and lists a Web link to that source. Departments, agencies, and commissions in the state of Maryland (e.g., DHMH, Health Services Cost Review Commission, Maryland Health Care Commission), various federal agencies (e.g., National Cancer Institute, Centers for Disease Control and Prevention, National Center for Health Statistics), as well as nongovernmental organizations (e.g., American Cancer Society), provide open access to a wide range of databases, data portals, and surveys via the Web. Key data sources used for cancer surveillance activities in Maryland include the MCR, Maryland BRFSS, MCS, and Vital Statistics Administration. Some of these data sources collect information on the entire Maryland population (e.g., MCR, VSA), while others collect information only on certain segments (e.g., Maryland Medical Care Data Base, Maryland Hospital Data) or use representative survey samples (e.g., BRFSS, MCS). The US sources described in Table 2.3 include state-specific cancer data (including Maryland data), national cancer incidence and mortality data, and data on prevalence of health risk behaviors.

Gaps and Solutions in Cancer Surveillance in Maryland

The following are gaps and possible solutions to enhance overall cancer surveillance in Maryland. Other chapters in this plan identify additional surveillance needs and recommendations specific to their area of concern.

Gaps in Data Collection

- Need for timely and accurate MCR data that include all reportable cancers diagnosed among Marylanders. Although the MCR complies with national requirements for data elements, information in those elements can be incomplete. For example: 1) stage of disease may be unknown, especially for cases reported only from laboratories; 2) survival, and thus prevalence data, cannot be obtained for Maryland cancer cases because the MCR is an “incidence” registry and is not funded for long-term follow-up of individuals diagnosed with cancer; 3) information is incomplete for risk factors such as current or prior occupation, tobacco use, length of residency at address at time of diagnosis or prior addresses before diagnosis, and cancer screening; and 4) MCR does not collect quality of care and quality of life information.

Solutions may include participating in development of data systems such as the Maryland Health Information Exchange to enhance collection of registry data; enhancing registry functioning and funding to improve access to current and complete data; assuring that clinical information is obtained on cases reported only by laboratories; and performing special studies to obtain additional information.

- Need for more complete information on ethnicity. The MCR currently uses the NAACCR algorithm to derive Hispanic or Latino ethnicity based on last and maiden names when ethnicity is non-Hispanic/non-Latino or missing. Solutions include encouraging consistent collection and reporting of ethnicity from hospitals and other reporting facilities.
- Need to have Certified Tumor Registrars (CTRs) report cancer data from hospitals in Maryland and need for CTRs to know the latest standards. Although Maryland has made great progress in this area—with more hospitals having CTRs and more being accredited by the Commission on Cancer of the American College of Surgeons—some gaps still exist. Solutions include increasing the number of CTRs in Maryland that perform cancer registration, increasing the training of tumor registrars, and increasing the number of hospitals in Maryland accredited by the American College of Surgeons.
- Need for additional surveillance for cancer risk factors and enhanced quality assurance for data collected. As of 2010, funding for the MCS has been reduced. If these surveillance activities are to be restored, additional funding is needed. In addition, risk factor surveillance data are self-reported, without independent verification of data such as frequency of cancer screening, body mass index, smoking patterns, and exercise frequency.
- Need for better mortality data collection systems, more training on reporting death certificate information, and more evaluation of the quality of mortality data. Need for funding to support these activities.
- Need for additional data on environmental and occupational exposures, either through additional surveys, additional information collected from people with cancer, or additional environmental monitoring.

- Need for complete and accurate first course of treatment data on cancers reported to the MCR. Treatment data are missing for cases that are reported only by laboratories.
- Need for follow-back to the physicians to collect treatment and staging information for cases reported only by laboratories.

Gaps in Access to Cancer Data

- Need for greater public awareness and access to cancer surveillance data on incidence, mortality, and behavioral risk factors. Solutions include creation of public-use data files (such as the MCS public-use dataset) and interactive access (e.g., Web-based, user-defined utility reports). The Maryland BRFSS has developed a public-use data application for analysis of BRFSS data and MCS data. Blending datasets is possible through tools such as the Maryland Environmental Public Health Tracking (EPHT) program (see Table 2.1, pages 6-7).
- Need for consistent agreements with other states for data exchange and data rerelease policies. Such agreements would enable out-of-state deaths and cancer diagnoses of Maryland residents to be rereleased 1) from Vital Records to the MCR and to EPHT, 2) from the MCR to EPHT, and 3) from the MCR, Vital Records, or the EPHT to researchers who meet Maryland standards for data release.

Gaps in Data Analysis

- Need for expansion of proactive or reactive analysis of cancer surveillance data and need for statistical methods for analysis of cancer in small areas or rare cancers. Solutions may include:
 - Using small area analyses that determine the number of health (or other) events occurring in small geographic areas (such as ZIP codes, block groups, or census tracts) and comparing health events occurring in one area to those occurring in a similar geographic area or a larger, standard population.
 - Using analytic tools for geographic area analysis and geographic information systems.
 - Developing data resources and analyzing leading cancer indicators along with potential existing or new sources from which related data can be obtained. Indicators could include incidence, mortality, treatment, risk behaviors,

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TABLE 2.1 Cancer Surveillance Systems

DATABASE OR DATA SOURCE	LEAD AGENCY	DESCRIPTION
MARYLAND DATA SOURCES		
MD Cancer Registry (MCR) www.fha.state.md.us/cancer/mcr_home.cfm	DHMH	Collects, maintains, and reports on cancer incidence among Maryland residents, and serves as a resource for cancer prevention, control, and research efforts.
MD Behavioral Risk Factor Surveillance System (BRFSS) www.marylandbrfss.org	DHMH	Population-based surveys of Maryland adults age 18 years and older that collect information on health risk behaviors, preventive health practices, healthcare access, chronic disease (including cancer), and injuries.
MD Cancer Survey (MCS) www.fha.state.md.us/cancer/surv_data-reports.cfm	DHMH	Population-based surveys of Maryland adults age 40 years and older that collect information on cancer screening practices, cancer-related risk behaviors, and healthcare access.
MD Vital Statistics Administration (VSA) www.vsa.state.md.us	DHMH	Source of Maryland vital statistics data, analyses, and reports; cancer deaths reported by jurisdiction, age, gender, and race.
MD Adult Tobacco Survey (MATS) and MD Youth Tobacco Survey (MYTS) www.crf.state.md.us/html/stats.cfm	DHMH	Surveys to collect information on tobacco-use behaviors and prevalence, smoking cessation, and other information supporting CRF Tobacco-use Prevention and Cessation Program.
MD Hospital Data (Inpatient and Outpatient Data Sets) www.hscrc.state.md.us	HSCRC	Medical record abstract and billing data on hospital inpatient discharges and outpatient services; useful data for estimating costs of cancer treatment.
MD Medical Care Database www.mhcc.maryland.gov/health_care_expenditures/mcdb.html	MHCC	Data on ambulatory services and expenditures in Maryland, obtained from Maryland healthcare insurance carriers and EPOs.
MD Environmental Public Health Tracking (EPHT) http://eh.dhmh.md.gov/tracking	DHMH	Resource for data on Maryland environmental health topics (air quality, drinking water, lead, pesticides, children's environmental health) and health outcomes, including cancer.
FEDERAL DATA SOURCES		
Surveillance, Epidemiology, and End Results (SEER) Program www.seer.cancer.gov/publications	NCI	Data and statistics on cancer incidence, prevalence, and survival from specific geographic regions in the US, and national cancer mortality data.
State Cancer Profiles www.statecancerprofiles.cancer.gov	NCI, CDC	National, state, and county-level cancer data, including incidence and death rates, graphical trends analyses, interactive maps, and comparative data displays; focus is on cancer sites with evidence-based control interventions.
Cancer Control Plan, Link, Act, Network with Evidence-based Tools (Cancer Control P.L.A.N.E.T.) http://cancercontrolplanet.cancer.gov	NCI (with other sponsors)	Portal providing access to Web-based data and resources useful in design, implementation, and evaluation of evidence-based cancer control programs.
CDC Wide-ranging Online Data for Epidemiologic Research (CDC WONDER) http://wonder.cdc.gov	CDC	Query-based system for access to cancer incidence and mortality data, and other health-related data available from CDC.
National Program of Cancer Registries (NPCR) www.cdc.gov/cancer/npcr	CDC	Official federal statistics on cancer incidence and mortality, for US and individual states; aggregated county-level cancer incidence rates and counts for major cancers.
National Vital Statistics System (NVSS) www.cdc.gov/nchs/nvss.htm	NCHS	State and national vital statistics data, including cancer deaths and death rates.

TABLE 2.1 CONT. **Cancer Surveillance Systems**

DATABASE OR DATA SOURCE		LEAD AGENCY	DESCRIPTION
FEDERAL DATA SOURCES			
Youth Risk Behavior Survey (YRBS) www.cdc.gov/HealthyYouth/states/md.htm		CDC	Prevalence of health-risk behaviors, including tobacco and alcohol use, diet, physical activity, and sexual behaviors among Maryland students in grades 9-12; comparisons between state and national survey results also available.
Health Information National Trends Survey (HINTS) http://hints.cancer.gov		NCI	Survey to examine use of cancer-related information by American adults.
National Health Interview Survey (NHIS) www.cdc.gov/nchs/nhis.htm		NCHS	Annual national household survey on health behaviors, chronic conditions, healthcare coverage and use, and health status; supplemental modules have included topics such as cancer, immunization, and complementary and alternative medicine.
National Health and Nutrition Examination Survey (NHANES) www.cdc.gov/nchs/nhanes.htm		NCHS	Health and nutritional status of adults and children in the US. Examples of data include: disease or condition prevalence, risk factors, nutrition monitoring, growth and development, disease monitoring.
OTHER DATA SOURCES			
Cancer Facts and Figures www.cancer.org		ACS	Annual reports of cancer incidence and death data by state, probability of developing cancer by age, cancer survival rates, cancer disparities, and special topics in cancer.
DHMH	Maryland Department of Health and Mental Hygiene	NCI	National Cancer Institute (U.S. National Institutes of Health)
CRF	Cigarette Restitution Fund	CDC	Centers for Disease Control and Prevention
HSCRC	Maryland Health Services Cost Review Commission	NCHS	National Center for Health Statistics (Centers for Disease Control and Prevention)
MHCC	Maryland Health Care Commission		
EPO	Exclusive Provider Organization	ACS	American Cancer Society

and avoidable cancer events. In addition, such indicators could include events that are sentinels of problems in cancer prevention, education, screening, and treatment services that can be used to monitor or track changes in cancer control in Maryland.

- Need to provide technical assistance to local health departments in cancer surveillance and analysis. Assistance in analyzing local data, compiling county-specific data (including trends over time), and directing further studies or collecting additional data could help in program planning, and targeting or monitoring cancer programs.
- Need to expand research into cancer risk factors, etiology, outcomes, and knowledge, attitudes, and behaviors of the public and of providers.
- Need to evaluate the quality of care provided to

cancer patients.

- Need for ongoing or increased funding to meet these surveillance needs.

Gaps in Information Dissemination

- Need for enhanced dissemination of existing cancer surveillance data to the public and to those who are implementing programs and policies to improve cancer control. Solutions include increasing access to cancer reports and cancer statistics through the Internet.

GOALS - OBJECTIVES - STRATEGIES

GOAL 1

Collect, analyze, develop, and disseminate Maryland cancer information.

OBJECTIVE 1

Through 2015, implement solutions to address at least three of the gaps in cancer surveillance data collection identified in the Surveillance Chapter of the Maryland Cancer Plan.

STRATEGIES

- 1 **MEET NATIONAL STANDARDS** for accuracy, timeliness, and completeness of Maryland Cancer Registry (MCR) data needed for cancer prevention and control including:
 - National Program of Cancer Registries (NPCR) data standards for US cancer statistics and multi-year data for NPCR Web site.
 - North American Association of Central Cancer Registries (NAACCR) data standards for one-year incidence data.
 - Cancer in North America (CINA) plus data standards (NAACCR Web-based and research data file) for multi-year incidence data.
- 2 **PROVIDE ONGOING, ADEQUATE STAFFING, FUNDING, AND SYSTEMS** to obtain, maintain, and support high quality, timely, and accessible cancer incidence and surveillance data.
- 3 **MAINTAIN THE MARYLAND CANCER REGISTRY ADVISORY COMMITTEE** to provide ongoing multidisciplinary advice to the MCR on cancer incidence data quality, release, use, timeliness, and reporting.

OBJECTIVE 2

Through 2015, analyze cancer data and develop reports to assist with meeting the needs of the public and researchers.

STRATEGIES

- 1 **PERFORM ONGOING ANALYSES** of Maryland cancer data including small area analyses that address cancer cluster concerns and disparities among subgroups. Document results and findings in published reports.
- 2 **ESTABLISH METHODS** to measure the extent to which cancer data and information needs are being met.
- 3 **DEVELOP THE LEADING CANCER INDICATORS** (e.g., mortality, incidence, stage at diagnosis, treatment, risk behaviors, avoidable cancer events, and events

that are sentinels of problems in cancer prevention and control services) that are used to monitor cancer control in Maryland.

- 4 **COLLABORATE WITH OTHER ENTITIES** to standardize collection, analysis, and reporting of cancer-related data necessary for cancer surveillance. Explore opportunities for linking cancer databases with other cancer-related or non-cancer related databases to facilitate answering questions of interest.

OBJECTIVE 3

Through 2015, increase public availability and awareness of Maryland cancer mortality, incidence, and risk factor information.

STRATEGIES

- 1 **EXPAND PUBLIC ACCESS** to Maryland cancer data by inclusion on the Internet sites such as:
 - State Cancer Profiles
 - Cancer Control P.L.A.N.E.T.
 - NPCR
 - CINA Plus Cancer Inquiry System
 - CDC WONDER
 - Maryland BRFS
 - Maryland Environmental Public Health Tracking
- 2 **EXPAND DISSEMINATION** of Maryland cancer data to the public by
 - Producing Maryland incidence and mortality reports and posting to the DHMH Web site.
 - Preparing Maryland Cigarette Restitution Fund Program biennial cancer reports and posting to the DHMH Web site.
 - Publishing information of interest such as leading indicators and data to answer research questions.
- 3 **INCREASE PUBLIC AWARENESS** of Maryland cancer publications through various forms of communications (e.g., memos, letters, Internet postings, news media).

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