Facing the Challenge

DC Cancer Control Plan 2005-2010

Organizations in the DC Cancer Coalition

American Cancer Society

Archdiocesan Health Care Network

Breast Cancer Resource Committee, Inc.

Cancer Information Service (NCI)

Capital Hospice

Children's National Medical Center

Colorectal Cancer Network

DC Department of Health

DC Department of Health/Project WISH

DC Cancer Consortium

DC Hospital Association

DC Medical Society

DC Office of Cable TV

DC Primary Care Association

Delmarva Foundation

Dimensional Media Partners

FACES Project

For This Cause

Georgetown University Hospital

Georgetown University - Lombardi Cancer Center

George Washington University Cancer Institute

George Washington University School of Public Health and Health Sciences

Greater Southeast Community Hospital

Greater Washington Coalition for Cancer Survivors

Greater Washington Partnership

Howard University Cancer Center

Howard University Hospital

Johns Hopkins University School of Public Health

Men's Health Network

Merck and Company, Inc.

Metroplex Health & Nutrition Services Inc.

National Breast Cancer Coalition

National Cancer Institute, Center to Reduce Health Disparities

National Cancer Institute, Community Cancer Clinic at Cardozo

National Prostate Cancer Coalition

National Quality Forum

National Rehabilitation Hospital

Ovarian Cancer Coalition of Greater Washington

Petworth Assembly

Pfizer, Inc.

Planned Parenthood of Metropolitan Washington

Providence Hospital

Sibley Memorial Hospital

Smith Farm Center for Healing Arts

Spanish Catholic Center

The Mautner Project

Tumor Registrars Society of Metropolitan Washington

Unity Health Care

University of the District of Columbia, Cooperative Extension

US Too

Washington Home & Community Hospice

Washington Hospital Center - Cancer Institute

Washington Hospital Center

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Statement of Support for the DC Cancer Plan

As the directors of the District of Columbia's major cancer research and treatment centers, we see the consequences of cancer in our community every day.

As much as the cancer centers and cancer-related organizations in the District work to reduce the number of people being diagnosed with, suffering from, and dying from cancer, we realize that much more is needed. The Cancer Plan before you provides a blueprint for the next steps to be taken if we are to make meaningful progress toward reducing suffering and death from cancer.

We must work together if we are to reduce the burden of cancer in our city. To that end, the DC Cancer Coalition, a broad partnership of public and private institutions, organizations, and advocates has developed a comprehensive, coordinated plan with specific strategies to have a greater impact on cancer in the District. Our institutions are committed to work collaboratively together and with the cancer community in implementing the Plan, and we invite all other concerned citizens and organizations to join us.

Please become familiar with the Plan. Talk with your colleagues. Then identify how your institution, agency, or organization can use the Plan as a guide for your own activities and consider what role you can play in implementing strategies for the greater good of the citizens of the District of Columbia. In the days ahead, leaders of the Cancer Plan will reach out to you and seek your ideas, insight, and assistance. We hope you will respond. The lives of many citizens in our community depend on the efforts of all of us.

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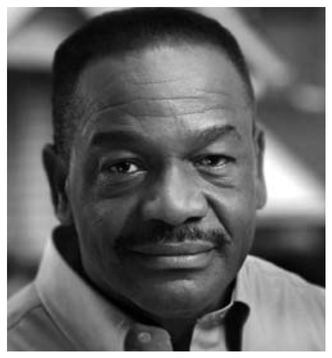
Georgetown University

Executive Summary: The Face of Cancer in the District of Columbia

Creating the District's First Cancer Plan



In 2001, because the District of Columbia has the highest cancer mortality rate in the United States, the DC Department of Health (DOH) created the DC Cancer Control Coalition to serve as a partner in addressing comprehensive cancer control and prevention. In 2003, the Department of Health received initial funding from the Centers for Disease Control and Prevention to begin this process.

The Coalition is a partnership of medical centers, nonprofit organizations, academic and research institutions, community groups, advocates, professional organizations, and others. We have worked together for four years to produce the District's first Cancer Plan—an analysis of the present environment, a blueprint to reduce the number of new cases of cancer and the number of cancer-caused deaths and to improve the quality of life for cancer survivors in the nation's capital.

As you will see, the need is urgent.

Cancer in the District: Portrait of Inequity

Our city of 560,178 residents—the nation's capital—has the highest cancer mortality rate per population in the United States. In 2005, according to American Cancer Society projections, about 2,820 individuals will be diagnosed with cancer in the District, and 1,170 will die of the disease. Cancer is the leading cause of death in DC among those 85 years and younger.

These high rates exist despite having four cancer centers, a total of 11 hospitals, and an abundance of excellent cancer care services. But many of these services are neither accessible nor affordable for many of DC's citizens—the poor and medically underserved (uninsured and underinsured), most of whom are Black or Hispanic. Inequitable distribution of cancer care plays a major role in the city's high mortality rates, and in every aspect of cancer control: screening, early detection, treatment, survivorship, palliative and end-of-life care.

About 58% of the District's population is Black, 27% is White and 3% Asian. About 10% of the population is of Hispanic origin (some self-identifying as White, and some as Black). Another 2% describe themselves as "two or more races or other." [Thomson Medstat ©2004] The Hispanic population is the city's fastest-growing and includes many of the poorest residents. Hispanic residents are the least likely to have health insurance of any kind.

Key factors influencing the high rates of cancer incidence and mortality include

- ***Lack of medical homes.*** Many of the District's residents—about 300,000—live in a "Health Professional Shortage Area (HPSA)." This includes many of the working poor. These residents lack what is called a "medical home," a primary care provider who knows their health history and is a reliable source of routine medical care. The single largest determining factor in the use of cancer services, from prevention through treatment and follow-up, is having a primary care physician who makes recommendations and provides assistance in navigating the health care system. The DC Primary Care Association (DCPCA) links this lack of adequate primary care to poorer health outcomes, higher health care costs, and overused, overcrowded emergency rooms. “Because people can’t find a doctor,” explains DCPCA, “they delay care, escalating the severity of illness to crisis and contributing to high disability rates.”

- ***Screening difficulties.*** Deaths from breast, cervical, colorectal, and prostate cancer can be avoided or decreased through screening procedures. However, facilities for cancer screening are few and far between in the District’s poorer neighborhoods. Most screening resources are located north of the Anacostia River, and many of the District’s poorest neighborhoods, where many of the cancer deaths occur, are southeast of the river. Remote locations for screening present a formidable barrier to participation.
- Additionally, the District underfunds screening programs for breast and cervical cancer. Project WISH, a CDC-funded screening program for breast and cervical cancers, has been hampered by problems related to management, reimbursement of providers, tracking, and patient follow-up. At this time, there is also no District funding allocated, and there are no systemic programs for, prostate and colorectal cancer screening.
- ***The health care labyrinth.*** In addition to its many hospitals and medical centers, the District prides itself on having many public and private health care clinics. However, the clinics are only loosely linked to each other and to other parts of the health care system. It can take people with symptoms a long time to get a clinic appointment, and a patient who does manage to get screened and receives a screening result indicating possible cancer may not get appropriate follow-up care, medications, counseling, rehabilitation and services like transportation.
- It can be very difficult for any patient—rich or poor, highly educated or uneducated—to navigate through the health care labyrinth in the District. When a diagnosis of cancer is compounded by factors such as limited English proficiency, poverty, cultural or cognitive barriers, lack of reliable transportation, and considerable distances to travel for care, it is not difficult to understand that people become overwhelmed and may elect to drop out of all or part of the health care system that exists, and not complete cancer treatments.
- ***Information deficit.*** The DC Cancer Registry has had difficulty collecting sufficient data on cancer in the Hispanic community, despite the fact that this segment is the City’s fastest-growing population. This data is needed to design effective measures for cancer control in the Hispanic community.
- ***Fragmented health insurance system.*** The DC HealthCare Alliance, in partnership with the DC Department of Health, private and nonprofit health clinics, offers low-income residents access to an array of health care services. Because the Alliance is extremely underfunded, it has never enrolled all eligible people. Specialists often avoid participating in its network because the Alliance reimburses physicians and hospitals very slowly and far below the actual cost of care (15 cents on the dollar). Hospitals and physicians who serve Alliance or Medicaid patients in the emergency room are not reimbursed at all. The District’s hospitals annually must absorb millions of dollars of uncompensated care—so much that some hospitals now are refusing to treat Alliance patients. This is clearly a broken system that fails to serve DC’s neediest patients with an array of illnesses—not only cancer—and meaningful reform is urgently needed.

- The Department of Health reports that a number of steps have been taken to further integrate and improve the Alliance and Medicaid, including appointment of a single Medical Director, adoption of HEDIS (Health Plan Employer Data and Information Set) measure reporting, implementation of new waivers, use of managed care organizations, and dual use of Income Management Administration. The DOH further notes that the department is in the midst of a major reform of the DC Alliance that will take effect in 2006.
- It should be noted that, unlike most states, the District of Columbia fails to spend any tobacco settlement funds received on health care and cancer services. This has left the city with almost no infrastructure with which to build an effective cancer control and prevention program.

The bottom line is that many of the District's neediest residents cannot or do not take advantage of available cancer care in the District. They struggle to navigate the convoluted health care system, the programs designed to provide care often fail to do so, there is no substantive public health structure—and as a result people are dying of cancer at high rates, despite living near highly sophisticated cancer care facilities.

Plan preparation and components

The DC Cancer Coalition workgroups (including physicians, public health experts, community leaders and others) have developed specific research-based chapters of the Plan. In each chapter, we assess the cancer burden, address current resources, identify gaps in care, and set forth prioritized recommendations that we believe will set the District and the health care community on course to correct the problems presented.

In the chapters that follow, we present separate discussions, goals, objectives and strategies for the following areas: Access to Care, Cancer Prevention, Smoking-Related Cancers, Head and Neck Cancers, Breast Cancer, Gynecologic Cancers, Colorectal Cancer, Prostate Cancer, Pediatric Cancers, Palliative Care, Cancer Survivorship, and Cancer Rehabilitation. In a separate document, we will also publish a resource guide for the region, *The Community Resource Directory for Cancer Survivors and Caregivers.*

What Must Be Done: Implementation

The next step in addressing cancer control and prevention is to use the Cancer Plan to move the District forward. We understand that bringing the Cancer Plan to life is the work of years, and that with individual and collaborative actions must come ongoing evaluation and mid-course corrections as needed to respond to the changing environment around us. At every step of the way, it will remain important to seek input from stakeholders throughout the city on progress and problems.

Some of the work ahead will require examining public policy that affects cancer in DC. Other priorities demand new avenues of collaboration among the city's health care providers, and securing the funding necessary to make collaboration possible and effective. These tasks are formidable, but the Coalition's members are committed to doing everything in our power to relieve DC's heavy burden of cancer incidence and mortality. Behind the statistics is great human suffering, and that suffering must be alleviated.

Almost every part of cancer care as it relates to the medically underserved majority of residents in the District of Columbia is broken and a clear path for change must be taken if lives are to be saved.

Goals and Objectives

OVERARCHING GOAL AND PRIORITIES OF THE DC CANCER COALITION

OVERALL GOAL: Reduce cancer incidence and mortality, reduce racial and ethnic disparities in cancer treatment, and improve the quality of life of cancer survivors by

Improving access to care

- Merge the DC Health Care Alliance and Medicaid
- Secure sufficient funding for the combined Alliance and Medicaid programs
- Ensure every resident has a "medical home" for primary care
- Provide patient navigation for cancer screening and treatment
- Coordinate cancer services by linking clinics and hospitals
- Improve cancer-related transportation services
- Improve cancer patients' access to clinical trials

Increasing rates of screening, particularly for breast, cervical, prostate and colorectal cancers, and providing all necessary follow-up cancer care

Increasing public awareness of healthy behaviors that prevent cancer

- Reduce tobacco use
- Reduce obesity
- Increase regular physical activity
- Eat healthy food and avoid overeating

Advocating with the City government on issues and funding relating to cancer

Educating health care providers about

- Early detection of cancers
- Pediatric cancers
- Rehabilitation
- Palliative and end-of-life care

Improving the collection and use of DC data about cancer

- Improve quantity and quality of data collected about the Hispanic population

Educating survivors and caregivers about resources and follow-up care

Increasing awareness of and availability of palliative care and end-of-life care

CHAPTER GOALS AND OBJECTIVES

ACCESS TO CARE

GOAL: To improve access to primary and cancer care for DC residents.

Objectives:

1) Create a coordinated patient navigation system by 2008.
2) Establish affiliation agreements between the community health centers, hospitals, and health care providers for diagnostic follow-up and treatment by 2007.
3) Improve access to public transportation for cancer patients by 2010.
4) Increase the participation of eligible minority residents in cancer-related clinical trials by 15% by 2010.
5) Educate consumers about access to cancer screening, care, and other services by 2010.

PREVENTION

GOAL: Reverse the trend toward obesity and overweight by increasing physical activity and the consumption of fruits and vegetables and by reducing caloric intake among DC residents.

Objectives:

1) Reduce the prevalence rate of obesity among DC adults to 15% by 2010.
2) Reduce the prevalence of overweight adults to 40% by 2010.
3) Reduce the prevalence rate of overweight and obese children to 5% by 2010.
4) Increase to 60% the prevalence rate of adults who engage in regular, moderate physical activity for at least 30 minutes a day at least five days a week by 2010.
5) Increase to 40% the prevalence rate of high school students who engage in moderate physical activity 30 minutes or more, five or more days a week by 2010.

SMOKING-RELATED CANCERS

GOAL: Reduce mortality from smoking-related cancers in the District of Columbia.

Objectives:

1) Reduce the level of smoking among high school students from 13% to 10% by the year 2010.
2) Reduce the level of smoking in current Black and Hispanic smokers and those with low levels of education by 25% by the year 2010.
3) Reduce general exposure to secondhand smoke by creating a smoke-free environment in all public places by 2006.
4) Reduce racial disparities in smoking prevalence by 2010.

HEAD AND NECK CANCERS

GOAL 1: Reduce the mortality rate in DC from cancers of the head and neck by 10%.

GOAL 2: Reduce the incidence of invasive cancers of the head and neck in DC by 10%.

Objective:

Increase to 50% the proportion of head and neck cancers detected at the local stage for both men and women by 2010.

BREAST CANCER

GOAL: Reduce mortality rates from breast cancer in the District by 10%, especially among Black women.

Objectives:

1) Reduce the incidence of invasive disease in DC by 10% by 2010.
2) Increase the number of women aged 50 through 64 who are screened annually by 10% by 2010.
3) Reduce the proportion of unstaged cases to less than 5% by 2010.

GYNECOLOGIC CANCERS

GOAL 1: Identify a greater proportion of cervical cancer cases before the cancer has spread beyond the local stage.

Objectives:

1) Increase the proportion of women diagnosed at the local stage to 90% by 2010.
2) Increase the rate of Pap screening to 90% (recent screens) and 97% (ever-screened) in all subgroups by 2010.

GOAL 2: Make 50% of women aware that postmenstrual bleeding is a possible symptom of endometrial cancer by 2010.

GOAL 3: Increase public awareness of ovarian cancer symptoms.

Objectives:

1) Reduce the incidence of late-stage diagnosis by 2010.
2) Improve the amount of accurate staging of ovarian cancer and reduce the proportion of cases classified as “stage unknown” to less than 5% by 2010.

GOAL 4: Improve the quality of care for underinsured and uninsured women in the District who have gynecologic cancer.

Objective:

1) Increase information and support to DC clinics and providers treating the target population by 2010.

COLORECTAL CANCER

GOAL 1: Reduce the mortality rate in DC from colorectal cancer by 10%.

GOAL 2: Reduce the incidence of invasive disease in DC by 10%.

Objectives:

1) Increase to 50% the proportion of colorectal cancer detected at the local stage for both men and women by 2010.
2) Increase to 50% the proportion of the adult population that reports having had a fecal occult blood test in the previous 2 years by 2010.
3) Increase to 60% the percentage of the population age 50 or older screened by sigmoidoscopy or colonoscopy by 2010.

PROSTATE CANCER

GOAL: To reduce the mortality rate from prostate cancer in DC by 10%.

Objectives:

1) By the year 2010, increase to 65% the percentage of Black men 45 years or older who are annually screened for prostate cancer.
2) By the year 2010, reduce the proportion of unstaged prostate cancer cases to less than 5%.

PEDIATRIC CANCERS

GOAL: To ensure that all District of Columbia children and adolescents with cancer, and their families, have access to the most beneficial medical care and supportive services.

Objectives:

1) Develop a system for coordinating research and the dissemination of information about diagnosis, clinical trials, treatment, follow-up care and supportive services to health care providers in DC by 2010.
2) Ensure that all DC childhood cancer patients and their families have access to culturally relevant information and services, from diagnosis through survivorship or end-of-life and bereavement services by 2010.
3) Establish a system to ensure that accurate data on incidence, survival, and mortality rates for pediatric cancers are collected and are available for health care providers, researchers, and the public by 2010.

PALLIATIVE CARE

GOAL 1: Integrate palliative care into the District's health care system and increase public understanding of palliative care and its role in cancer care.

Objectives:

1) Provide education about palliative care for health care providers and the public by 2010.
2) Promote the development of palliative care programs in health care facilities and community-based settings throughout the District by 2010.
3) Develop innovations and changes in the health care delivery system that promote palliative care services by 2010.

GOAL 2: Improve the availability of, and access to, palliative care services for the underserved and culturally diverse population of the District of Columbia by 2010.

Objectives:

1) Strengthen the health care delivery system, including palliative care for underserved and diverse populations in the District of Columbia by 2010.
2) Target public service messages about palliative care to specific underserved populations by 2010.

CANCER SURVIVORSHIP

GOAL: Improve the quality of life for DC cancer survivors.

Objectives:

1) Implement a coordinated patient navigation system by 2008.
2) Increase demand-responsive public transportation for low-income cancer survivors by 2007.
3) Assess current resources for survivors and caregivers by 2006.
4) Promulgate clinical practice guidelines for each stage of cancer survivorship, from diagnosis through long-term treatment and end-of-life care by 2007.
5) Establish a database on cancer survivorship by 2008.
6) Educate corporate, academic, and community policymakers and decision-makers about key health care issues for cancer survivors by 2008.
7) Develop a community awareness program for cancer survivors by 2007.

CANCER REHABILITATION

GOAL: Increase awareness of cancer rehabilitation services in the District of Columbia.

Objectives:

1) Create a repository of information on cancer rehabilitation services in the District of Columbia by 2007.
2) Increase awareness and knowledge of fellows in training, oncology physicians, and oncology nurses about cancer rehabilitation and services by 2008.
3) Increase public awareness of cancer rehabilitation and services available by 2009.
4) Develop liaisons among area hospitals and community organizations to conduct research on effective cancer rehabilitation assessment and treatment by 2010.

Introduction:

Developing a Cancer Control Plan for the District of Columbia

To address the problem of very high rates of cancer in the District of Columbia, in 2001 the DC Department of Health (DOH) created the DC Cancer Coalition. The Coalition was born when the DOH and other stakeholders attended a leadership institute sponsored by the Centers for Disease Control and Prevention, the American Cancer Society, the National Cancer Institute, and the American College of Surgeons. There we learned more about how to develop and implement comprehensive cancer control programs that integrated partnerships, communication, and collaboration. In 2003 the Department of Health received an initial grant for cancer planning from the CDC—and the Coalition began its work.

Committed to addressing the District's very high cancer rates—the highest cancer death rates in the nation—the Coalition is a broad-based partnership, including medical centers, nonprofit organizations, academic and research institutions, community groups, advocates, professional organizations, and others. All have an interest in cancer prevention and control. Our objective has been to develop a comprehensive cancer control plan that could serve as a blueprint for reducing the number of new cancer cases in the District and the number of deaths from cancer. We have followed the CDC's model of creating "an integrated coordinated approach to reducing cancer incidence, morbidity, and mortality through prevention (primary prevention), early detection (secondary prevention), treatment, rehabilitation, and palliative care." The Plan is designed to

- Identify the strengths and weaknesses of current cancer prevention and control efforts in DC
- Identify barriers that hinder prevention and control efforts and offer strategic options for surmounting them
- Provide a set of goals and objectives for cancer control based on a review of DC data
- Identify strategies for meeting those objectives.

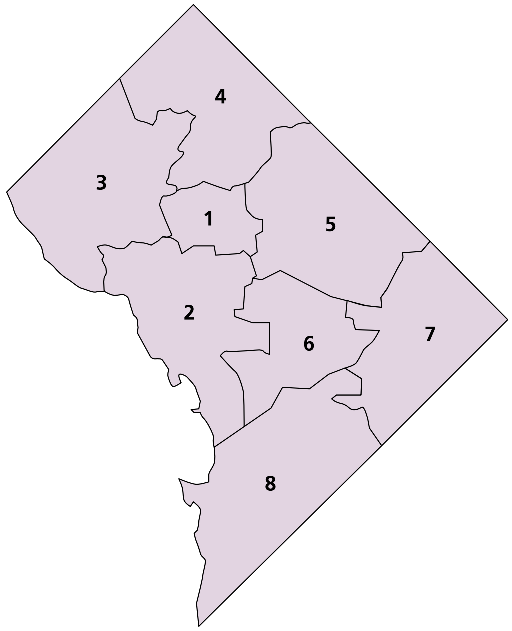
Disparities in cancer care in DC: Demographics and access

The District is home to an abundance of medical care facilities and providers, but equal access to cancer care services is significantly undermined by the physical location of those providers. Access to cancer screening, treatment, and follow-up care is, in some measure, influenced by where a District resident lives.

Geographically, the District is divided into four quadrants: northwest, northeast, southwest, and southeast. Politically, it is divided into eight wards (see Figure 1). Wards 1, 3, and 4 are in the northwest quadrant; Ward 2 straddles northwest and southwest; Ward 5 is mainly in the northeast (and a bit of northwest): Ward 6 is in northeast, southwest, and southeast; Ward 7 is in both northeast and southeast; and Ward 8 is in the southwest and southeast quadrants.

Many cancer-related health care facilities are located in northwest Washington (in Wards 1, 2, 3, 4, and parts of Ward 5). There is just one

Figure 1. Map of Washington, DC, by ward



full-service hospital located beyond the Anacostia River (Wards 7 and 8), serving 20% of the District's population. For those dependent on public transportation, especially those weakened by cancer, it can be difficult and exhausting to reach a hospital in another part of the city. One District hospital, Providence, is in the northeast quadrant. Another, Greater Southeast Community Hospital, is in southeast. The other nine—Children's National Medical Center, George Washington University Hospital, Georgetown University Medical Center, Howard University Hospital, National Rehabilitation Hospital, Sibley Memorial Hospital, Veterans' Affairs Medical Center, Walter Reed Army Medical Center, and the Washington Hospital Center—are all in the northwest. All four cancer centers—Georgetown, George Washington, Howard and Washington Hospital Center—are located in the northwest.

The inequitable distribution of infrastructure for cancer care in the District is reflected in the city's cancer incidence and mortality rates. Disparities in access to care and in the quality of care are seen in every aspect of cancer control: screening, early detection, incidence, treatment, quality of care, and survival. Disparity issues are considered in nearly every chapter of the Cancer Plan. We expect implementation of the Plan to facilitate the creation of an effective local infrastructure for reducing these disparities, for reducing high cancer incidence and mortality rates in the District, and for improving the quality of life of cancer survivors—wherever in the city they may live.

Ethnicity. As of 2004, DC's population was 58% Black, 27% White, and 3% Asian. Another 2% describes themselves as "two races or other." About 10% of the population is Hispanic (some self-identifying as White, some as Black). The Hispanic population, which is the fastest growing segment in the city, is located mainly in Wards 1 and 4.

Income. Although the city's population is distributed roughly equally among the eight wards, income distribution is unequal. A significant number (roughly 147,000 or 26%) of residents have household incomes below $20,000 a year. The high cost of living in Washington places households earning less than $20,000, especially those with earnings below $10,000, in extreme poverty. Average per capita income is highest in Ward 3 ($68,477) and lowest in Ward 8 ($14,137). Similarly, average household income is highest in Ward 3 ($134,506) and lowest in Ward 8 ($38,754).

Education. Almost 300,000 Washingtonians—22% of those older than 25—do not have a high school diploma. The highest number of people with college degrees is reported in Ward 3 (79%), and the lowest in Ward 8 (8%).

Developing the Cancer Plan

To develop the Plan, the Coalition created multidisciplinary workgroups (physicians, public health experts, community leaders, survivors, representatives of advocacy groups, nurses, social workers). Each workgroup developed a chapter of the Plan, reporting its findings to the full Coalition. The Coalition developed a list of objectives for cancer control based on a review of research data and identified strategies for achieving those objectives. We carefully evaluated the cancer burden in the District, analyzed tumor registry data on incidence and mortality, reviewed national data on cancer, catalogued existing resources for screening and early detection, considered the impact of disparities on health care, and sought out community leaders for advice and direction. We looked at modifiable and nonmodifiable risk factors for specific cancers, discussed control strategies based on evidence, examined approaches to health communications, categorized clinical services, compared survival rates, and built partnerships.

Primary focal points. The Plan's primary focus was on strategies known to reduce the number of cases of cancer and to reduce deaths from the disease. Recommendations for cancer screening were based mainly on those of the American Cancer Society, although recommendations from the Preventive Services Task Force and other professional organizations were also reviewed. A secondary focus was to identify resources to assist people with cancer, including support groups, educational programming, and other community opportunities. These resources are presented in a separate publication, the Community Resource Directory for Cancer Survivors and Caregivers.

Based on data about the burden of cancer and available health care resources in the District, we established cancer site priorities for DC's Cancer Plan of breast, cervical, colorectal, smoking-related cancers, head and neck cancers, and prostate cancer.

Priorities were based on scores of four factors:

- The extent of a particular cancer burden
- Whether intervention was important
- Whether intervention was feasible
- Whether intervention would have a measurable impact (that is, reduce incidence and/or mortality rates).

The burden of deaths from smoking-related cancers, for example, is sizable. Effective intervention is feasible, and its impact would be large and measurable. Similarly, the burden of prostate cancer is the District is both heavy and inequitable, and effective intervention is solidly feasible and measurable. Breast cancer interventions are a priority because the cancer burden is heavy, mammography is a fairly effective screening tool, screening reduces mortality, and effectiveness is measurable. Interventions to deal with colorectal cancer, a major problem in the District, are more difficult. The best way to intervene is through a citywide colonoscopy program. This would be very expensive and is therefore more difficult to implement—although efforts to educate physicians and patients about the value and importance of screening can have a positive effect.

For each type (or anatomical site) of cancer, we looked at risk factors, gaps in and barriers to cancer control, and the best-known prevention and control measures, before we identified goals, objectives, and strategies for that type of cancer. We also addressed access to care, what to do about smoking-related cancers, how to support and improve the quality of life for cancer survivors, how to improve palliative and end-of-life care, and how to integrate cancer rehabilitation services into overall cancer care.

The chapters were reviewed for accuracy and completeness by physicians and other health care professionals not associated with the Coalition, as well as by lay consumers. The Coalition is deeply indebted to these reviewers for time-consuming efforts that, they surely know, will benefit many. As part of its mission, the Coalition will review the Plan regularly and modify priorities to reflect new data, new scientific knowledge, and the availability of more or different resources. We have included an evaluation component, so we can measure progress.

In the summer 2005, the DC Cancer Coalition held a series of five town hall meetings in neighborhoods around DC to introduce the Plan, to listen to residents' thoughts and reactions to the Plan and to encourage residents to get involved in fighting cancer in the District. The Department of Health also held a series of Health Disparities Town Halls at which they announced the Plan and invited residents to become involved in implementing the Plan.

The Coalition is pleased to present this Plan to the citizens, community leaders, and city authorities of the District of Columbia. We look forward to constructive comments and approval of the Plan's objectives and strategies, and to creating innovative, speedy, and effective actions for the next phase of our work—implementing the Plan. The District now joins 27 states that have developed cancer control plans.

Access to Care

Great therapeutic developments over the past few decades have led to more effective and less disfiguring cancer treatments. But not every American has benefited from this progress, as evidenced by higher cancer incidence rates and lower survival rates in certain populations. Poor people lack access to health care and are more likely than others to die of cancer, reported the American Cancer Society in its 1989 report, *Cancer in the Poor*. Moreover, poor people are less likely to be covered by health insurance and often do not seek care if they are unable to pay for it.

In 2004, the number of insured nationally rose to 45.8 million, compared to 45.0 million in 2003 and 39.8 million in 2000. A continuing decline in employer-sponsored plans is a major cause. The percent of working adults (18 to 64) who were uninsured climbed from 18.6% in 2003 to 19.0 percent in 2004, an increase of more than 750,000 people. Nationwide, African Americans (20%) and Hispanics (33%) were much more likely to be uninsured than White, non-Hispanic people (11%).

Reducing cancer incidence and mortality rates in the District of Columbia will require eliminating barriers to primary and cancer care for all DC residents, but especially the medically underserved—the poor, the uninsured, and the culturally isolated. Only with accessible, affordable personal health care services can DC residents hope for the best possible health outcomes.

Barriers to care in the District

Demographics—insurance coverage, poverty, education, race, language, age, and gender—explain many DC residents' failure to get adequate health care. Lack of knowledge and information about sound health practices may also keep many residents from getting the care they need.

Lack of health insurance. Whether DC residents have access to good health care often depends largely on whether they have health insurance coverage. *Lack of insurance or underinsurance (lack of full coverage or limited access to health care) is the most significant factor contributing to disparities in cancer care.*

In 2004, the number of insured nationally rose to 45.8 million, compared to 45.0 million in 2003 and 39.8 million in 2000. A continuing decline in employer-sponsored plans is a major cause. The percent of working adults (18 to 64) who were uninsured climbed from 18.6% in 2003 to 19.0% in 2004, an increase of more than 750,000 people. Nationwide, African Americans (20%) and Hispanics (33%) were much more likely to be uninsured than White, non-Hispanic people (11%).

Proportionately, more DC citizens are covered by employer-sponsored insurance than the national average because of the concentration of federal agencies and offices in the District. Of DC's non-elderly adults, 70% have employer-sponsored or self-paid insurance, 11% have Medicaid, 13% have no insurance and 5% fall into an "other" category. The number of uninsured non-elderly adults in DC (74,200) can swell by thousands throughout the year, as some residents temporarily lose their health insurance during a hiatus in employment.

Of those with no health insurance, 4% are enrolled in the DC HealthCare Alliance, a public-private partnership established after DC

General Hospital closed, to improve access to care for the uninsured. The Alliance suffers from insufficient funding and an inability to contract with specialists, such as oncologists, because of very low rates of reimbursement and very long delays in providing reimbursement.

Who are the uninsured?

- In 1999, 60% of DC adults may have qualified for Medicaid or DC HealthCare Alliance coverage, based on income. (Adults with children are eligible for Medicaid if their income falls below 200% of the federal poverty level.) DC Medicaid also provides some coverage for low-income, non-parent adults.
- In 1999, 36% of DC adults over age 65 had income that fell below 200% of the federal poverty level, possibly qualifying them for Medicaid.
- The number of Medicaid enrollees in DC represented 81% of the eligible population in 2001, according to the Centers for Medicare and Medicaid Services.
- Many of the "working poor" are uninsured: 72% of uninsured DC residents are part of family households in which at least one household member works part- or full-time, and 48% of the uninsured have family members who work full-time, year-round.
- The largest group of uninsured adults (29,500) is 30-to-49-year-olds, but another age group, the 19-to-29-year-olds, has the greatest percentage of uninsured. The two groups with the most uninsured members are Hispanic residents (about 13,800 residents, or 33.4% of the local Hispanic population) and non-Hispanic Blacks (with 50,200 residents, or 16.7% of non-Hispanic Blacks), as Table 1 shows.
- Undocumented aliens have no health insurance. Although they can receive free or low-cost health care at a community health center, the center will ask them to apply for Medicaid so it can recover some of its costs. Undocumented residents are reluctant to apply for a public program because it might mean having to divulge reportable information. If an undocumented alien visits the emergency room, he will be served. If he has to be admitted to the hospital, the admitting physician will have to follow the patient at no charge.
- In the year 2000, 13% of DC residents worked for small-business employers, who were less likely to offer insurance because of the high cost of premiums. About 63% of DC residents worked in service and retail positions that did not offer health insurance benefits.
- Some low-wage earners have to forfeit health insurance benefits because they cannot afford the employee's share of the premium.
- About one-third of DC's non-elderly adults went without health insurance for all or part of the two-year period from 2002 to 2003. Adults with no insurance and those with Medicaid are more likely than adults with private health insurance to report that they are in poor to fair health (18%, 29%, and 7%, respectively).
- Residents with some health insurance may not have coverage for pharmaceuticals, durable medical equipment, nutritional supplements, sub-acute care, long-term care, or mental health services. Medicare is the largest health insurance program with only partial coverage.
- Some adults don't seek treatment or care because they can't afford the cost of co-payments or out-of-pocket expenses for items that are not covered.

Table 1. Relative poverty and health insurance status in DC wards, 2000

	Less than 100% of federal poverty level (FPL)		Less than 100–150% of FPL		Less than 150–200% of FPL		Total Less than 200% FPL		Uninsured	
	Pop.	%	Pop.	%	Pop.	%	Pop.	%	Pop.	%
Ward										
1	15,329	21.7	7,901	11.2	5,870	8.3	29,100	41.2	11,209	22.2
2	10,813	19.4	3,929	7.0	3,513	6.3	18,255	32.8	5,367	10.6
3	5,228	7.6	2,228	3.2	1,745	2.5	9,201	13.4	2,536	5.0
4	9,023	12.2	4,765	6.4	6,111	8.2	19,899	26.8	5,160	10.2
5	13,475	19.9	6,056	9.0	5,764	8.5	25,295	37.4	7,067	14.0
6	13,199	20.9	5,692	9.0	3,631	5.8	22,522	35.7	5,054	10.0
7	17,449	24.8	6,880	9.8	5,720	8.1	30,049	42.7	5,330	10.5
8	24,754	36.1	7,934	11.6	7,018	10.2	39,706	57.9	8,873	17.5
Total	**109,270**	**20.3**	**45,385**	**8.4**	**39,372**	**7.3**	**194,027**	**36.0**	**50,596**	**12.5**

Source: Lurie 2002

Poverty, race, and socioeconomic status. Race and ethnicity themselves are not barriers to primary and cancer care, but minority status associated with poverty or with negative perceptions of the health care system may affect outcomes. As Mandelblatt and colleagues observe, some Hispanic and Black populations are either fatalistic about cancer or are too preoccupied with day-to-day survival to seek early detection or treatment.

Levels of education and literacy, especially health literacy, are important aspects of social status that affect health outcomes. The *Annals of Internal Medicine* reported that literacy skills predict an individual's health status more strongly than age, income, employment status, race, or ethnicity. Poor literacy impedes people's ability to learn about disease prevention, understand disease-related information, follow physicians' instructions, take medications properly, and self-manage health care.

Socioeconomic status is also a factor. Regardless of other factors, people in lower socioeconomic groups report less use of cancer screenings and are diagnosed with cancer at later stages than those in higher socioeconomic groups—even in Canada and Finland, countries with universal health care coverage.

Socioeconomic status also appears to affect the quality of care. People from lower socioeconomic groups also have poorer survival rates, possibly because of such factors as inadequate staging evaluation and delays in treatment. Regardless of treatment, cancer patients from lower socioeconomic groups with advanced cancer report less symptom control and less use of palliative and supportive care services (especially hospice) than patients from higher socioeconomic groups.

The percentage of uninsured in DC (13%) is lower than the national average (19%), but the percentage of residents who live in poverty (20.3%) is higher than the national average

Table 2. Distribution of District residents by age (2000, by ward)

Ward[1]	Total	Age							
		0-4	5-17	18-24	25-34	35-44	45-54	55-64	65+
City	572,059	32,536	82,456	72,637	101,762	87,677	75,310	49,783	69,898
	100%	5.7%	14.4%	12.7%	17.8%	15.3%	13.2%	8.7%	12.2%
1	73,364	4,105	8,997	11,386	17,959	12,007	8,326	4,900	5,684
	100%	5.6%	12.3%	15.5%	24.5%	16.4%	11.3%	6.7%	7.7%
2	68,869	1,803	3,710	17,786	16,720	9,788	7,599	5,191	6,272
	100%	2.6%	5.4%	25.8%	24.3%	14.2%	11.0%	7.5%	9.1%
3	73,718	2,857	5,960	9,864	15,519	10,863	10,864	7,653	10,138
	100%	3.9%	8.1%	13.4%	21.1%	14.7%	14.7%	10.4%	13.8%
4	74,092	4,196	11,495	5,723	9,438	11,629	11,478	7,441	12,692
	100%	5.7%	15.5%	7.7%	12.7%	15.7%	15.5%	10.0%	17.1%
5	72,527	4,001	11,327	8,030	8,764	10,734	10,077	6,670	12,924
	100%	5.5%	15.6%	11.1%	12.1%	14.8%	13.9%	9.2%	17.8%
6	68,035	3,342	8,315	6,417	14,016	11,934	9,939	6,287	7,785
	100%	4.9%	12.2%	9.4%	20.6%	17.5%	14.6%	9.2%	11.4%
7	70,540	4,963	14,457	5,721	8,808	10,634	9,382	6,726	9,849
	100%	7.0%	20.5%	8.1%	12.5%	15.1%	13.3%	9.5%	14.0%
8	70,914	7,269	18,195	7,710	10,538	10,088	7,645	4,915	4,554
	100%	10.3%	25.7%	10.9%	14.9%	14.2%	10.8%	6.9%	6.4%

[1] Wards effective January 1, 2002. Prepared by DC Office of Planning/State Data Center.
Source: US Census Bureau

(12.4%). Although the city's population is distributed roughly equally among eight wards, income and relative insurance status are distributed unequally (see Table 2).

Unfortunately, the poverty gap—the gap between the wealthy and poor—is as wide in DC as in any other major U.S. city, and the gap is widening. The average income of DC's wealthy families grew 38% in the 1990s; the income of poor families grew only 3%.

The adult populations in DC most likely to be uninsured are poor, male, and Hispanic or Black. The Hispanic population is particularly vulnerable, having the highest uninsured rate, being poorer than non-Hispanic Blacks or Whites, and having worse health indicators than both groups.

Language. Residents of the District of Columbia, many of whom are recent immigrants or temporary residents, come from more than 150 countries. This enriches the culture but creates linguistic challenges. A health care center, despite federal requirements to provide qualified interpreters, often cannot provide interpreters for every language. Even if an interpreter is available, the interpreter may know a word but not in a medical context, and the health care provider may not appreciate the cultural nuances of each phrase or topic. What's more, people from some countries may consider the direct and candid U.S. style of communication too forward or impolite. There is, therefore, sometimes a reduced chance of clear communication.

Age. Although 77% of all cancers are diagnosed in people 55 and older, older people may not realize their risk of cancer, may ignore symptoms, and may suffer from cognitive impairment and other medical conditions. And proportionately more of the elderly are poor and underinsured. Any of these factors may limit older people's pursuit of early detection or cancer treatment. And as the senior population grows, age will become a more significant barrier to good primary and cancer care. Heavy concentrations of adults 55 and older live in Wards 3, 4, 5, and 7 (see Table 3).

Gender. Evidence shows that men seek routine preventive medical care less often than women, but research has shown practitioner bias in screening men for cancer more often than women.

Culture. People immigrating to the District from other countries bring with them a host of customs, attitudes, and health care practices that can affect their health care here. Poor immigrants, especially when confronted with a complex health care system managed in a language different from their own, may simply avoid or minimize contact with it except in emergencies, and rely on practices they know from their own cultures. Similarly, the pressure of urgent daily priorities such as food, employment, transportation, education, housing, and safety may mean that cancer screening for early detection becomes a relatively low priority.

Transportation. Barriers to screening or cancer care can be as basic as not having transportation to an appointment with a physician or to purchase essential medications. Many patients do not have their own private means of transportation and their family members may work or may also not have a means of transportation. Public transportation is widely available in the District, but it often requires a far greater commitment of time—time away from work and from family—than arriving by private automobile would, for example. When the requirements of time are combined with the exhausting side effects of cancer treatment, transportation becomes a significant barrier. Moreover, demand-responsive transportation for cancer patients and disabled persons is limited in the District, and some volunteer drivers of agency transportation programs and taxicabs will not travel into neighborhoods they perceive as dangerous.

Barriers to care from primary care and cancer care providers

Problems among primary care providers and oncologists may limit some patients' access to good health care.

Physician competence, knowledge, attitudes, and beliefs. The greatest predictor of patient compliance with cancer screening is a physician's recommending a cancer screening test. But whether a primary care provider recommends such a test may be affected by:

- The provider's biases and beliefs about screening and treatment effectiveness
- Insufficient knowledge, training, or skill (performing a clinical breast exam, for example)
- A dearth of culturally sensitive resources
- Forgetfulness and lack of time
- Concern about the patient's other acute illnesses
- Conflicting screening guidelines from professional and health organizations
- Concerns about patient acceptance
- No chance of reimbursement
- Logistical or organizational barriers

Table 3: Relative access to health resources in District wards

Ward	Number of hospitals	No. of clinics and health centers
1	1 – Howard	12
2	2 – Georgetown, George Washington	17
3	1 – Sibley	1
4	1 – Walter Reed	2
5	5 – Children's, National Rehabilitation, Providence, Veterans, Washington Hospital Center	6
6	0	5
7	0	9
8	1 – Greater Southeast	6

Source: Washington Physicians Directory, 2004

- Prejudices based on age, race, gender, or sexual orientation
- Inadequate communication skills.

Too few health care professionals and services in low-income neighborhoods. As of 2001, DC had the highest physician-to-population ratio of any state, but most of those physicians do not work in low-income neighborhoods (see Table 4 for location of clinics by ward). According to the Bureau of Primary Care of the U.S. Department of Health and Human Services, 300,825 DC residents (52% of the total population) live in federally designated primary care Health Professional Shortage Areas (HPSAs) and 173,228 (30%) live in federally designated Medically Underserved Areas (MUAs). Areas designated HPSA and MUA tend to include many poor households and homes of racial and ethnic minorities.

A lack of "medical homes." Many of the 300,000 District residents identified as living in a Health Professional Shortage Area do not have a "medical home"— a primary care provider who knows a patient's health history and is a reliable source of non-emergency medical care. The DC Primary Care Association (DCPCA) has linked the lack of adequate primary care in DC to poorer health outcomes, higher health care costs, and overused and crowded emergency rooms. "Because people can't find a doctor," explains the DCPCA, "they delay care, escalating the severity of the illness to crisis and contributing to high disability rates."

Too few specialists serving poor neighborhoods. The DC HealthCare Alliance has difficulty enrolling and maintaining oncologists and other specialists, who feel the insurer's reimbursement rates are too low and slow.

Problems intrinsic to the local health care system

When DC General Hospital closed in 2000, its patients were transferred to DC's remaining hospitals. All the hospitals in DC accept Medicaid and DC HealthCare Alliance patients. When hospitals serve these populations, they are required to serve them in the emergency room as well. Seven percent (7%) of DC residents identify the emergency room as their primary source of medical care. A greater proportion of uninsured DC residents use the emergency room as their regular source of medical care than do insured residents.

Access to Care

DC prides itself on its many private and public community health centers that provide excellent primary care. The weakness of the community health centers is that they are only loosely linked to each other and to other parts of the health care system for services such as diagnostic follow-up, cancer treatment, behavioral health, transportation, counseling, pharmacy or hospital services. As a default, patients may use hospital emergency services that are more expensive and more traumatizing to the patients.

Timing and follow-up are also issues in health care centers, where it often takes too much time to arrange for diagnostic follow-up, treatment, and post treatment care. For lack of equipment and expertise to handle billing adequately, community health centers have at times had difficulty submitting timely program and financial information to contractors and health plans. Project WISH, the DC Breast and Cervical Cancer Early Detection Program, lost funding temporarily because it did not receive timely reports from community health centers that are Project WISH provider sites.

On the other hand, community health centers often have difficulty retrieving reports from specialists, especially those in hospitals, on Alliance and Medicaid patients they serve. There is controversy about who owns the information, suspicion about how the information will be used, and little cooperation among some health care providers. There is a strong sense in general that the community health centers want to strengthen their links to hospitals, the DC HealthCare Alliance, specialty providers, and the DC Department of Health.

Even an educated person, astute about health care, can have trouble navigating the labyrinth of health care resources, regulations, and procedures in the U.S. health care system, as well as complying with instructions from multiple physicians. Sometimes a family member or friend has the time and ability to help a patient maneuver through the health care labyrinth and even to serve as the patient's advocate. But add a complex medical condition and/or language, cultural, and financial barriers and the patient, overwhelmed, may drop out of part or all of the health care system.

Professional or lay "patient navigators" can help a patient through the system if a competent family member or friend cannot. Especially with medically underserved and vulnerable populations, patient navigation has been effective in improving access to good care. A few community health centers and DC's Project WISH successfully use patient navigators. But the need for patient navigation far outweighs current resources.

> ***Even an educated person, astute about health care, can have trouble navigating the labyrinth of health care resources, regulations, and procedures in the U.S. health care system, as well as complying with instructions from multiple physicians.***

Reimbursement and funding problems. After DC General Hospital closed, a program called the DC HealthCare Alliance was created to offer health care to uninsured DC residents whose income is 200% of the federal poverty level or less and who are not eligible for Medicaid or Medicare. In the DC HealthCare Alliance, through a partnership with the DC Department of Health, private and nonprofit community health centers offer access to inpatient hospital care, outpatient medical care (including preventive services), emergency services, prescription drugs, rehabilitative services, home health care, dental services, specialty care, and wellness programs (including pre- and post-natal care). But the Alliance faces certain challenges:

- Because the city chronically underfunds the Alliance, it has never been able to enroll all eligible persons.
- It added no additional community health centers or physicians to DC's medical infrastructure to serve the eligible population.
- It has had difficulty enrolling specialists in its network of physicians because of low and slow reimbursements.
- It does not reimburse physicians who serve DC HealthCare Alliance or Medicaid patients in the emergency room.
- It reimburses hospitals and physicians slowly and at far below the actual cost of care (15 cents on the dollar), so hospitals have to absorb millions of dollars in uncompensated care each year. Providers have little incentive to provide additional services to patient groups that do not generate revenue.

Another support service for District residents is the Archdiocesan Health Care Network, whose mission is to connect uninsured patients seen in their clinics with appropriate specialists and tests. This network has several hundred physician-specialist volunteers who will see patients from the clinics for workups and in some instances will provide surgery and follow-up care.

Regional resources and clinical trials. DC is fortunate in having eleven hospitals that provide cancer care. Lombardi Cancer Center (at Georgetown) has been designated a comprehensive cancer center by the National Cancer Institute. Other cancer centers include George Washington University Cancer Center, Howard University Hospital Cancer Center, and the Washington Hospital Center Cancer Institute. Three hospitals have medical schools and four are teaching hospitals. The cancer programs of eight hospitals are approved by the Commission on Cancer of the American College of Surgeons. Because of the quality and quantity of hospitals in DC, numerous cancer-related clinical trials offer state-of-the art cancer care, potentially improving access to quality care for the medically underserved and reducing disparities in cancer care among racial and ethnic groups. Historically, however, minorities and females are severely underrepresented in clinical trials, for various reasons. The literature has identified the barriers to minority participation in clinical trials and strategies for overcoming these barriers. There is no legislative mandate for insurers in DC to cover the routine costs of patient participation in clinical trials.

Community health centers. Half of the community health centers in DC offer early morning hours, 38% offer evening hours, and one-third offer Saturday hours. Ward 1 has the most community health centers; Ward 4 has none. In the District, there are

- Three federally qualified health centers (FQHCs) with 28 sites
- Three hospital-sponsored health centers with 14 sites
- Eleven private, nonprofit centers with 12 sites
- Twelve uncategorized clinics.

In the fall of 2003 the DC Primary Care Association reported that 52% of the FQHCs, 80% of the hospital community health centers, and all of the private nonprofit community health centers could not meet current needs with existing resources.

Limited screening programs and facilities in poor neighborhoods. Despite the District's very high cancer incidence and mortality rates, the DC Department of Health underfunds screening programs for breast, cervical, and prostate cancers and provides no funding for screening for colorectal cancer. Most screening resources are located north of the Anacostia River. Many of the poorest DC neighborhoods are southeast of the river. In Southeast DC, there is only one mammography facility: the Capital Breast Care Center. The remote location of most screening sites is a barrier to increasing cancer screening rates, especially for women who have difficulty taking time off from work or arranging for transportation and child care.

Problems filling prescriptions. Two organizations in DC (Rx4DC.org and DC Pharmaceutical Resource Center) help uninsured residents identify and apply to pharmaceutical companies that provide free medications to residents who are low income, are uninsured, or receive Medicaid. One problem is that pharmacies in some low-income neighborhoods do not stock prescription pain medications for fear of burglary related to substance abuse. This means that cancer patients who need these medications face additional hurdles obtaining relief.

Progress

The Department of Health reports that a number of steps have been taken to further integrate and improve the Alliance and Medicaid, including appointment of a single Medical Director, adoption of HEDIS measure reporting, implementation of new waivers, use of managed care organizations, and dual use of Income Management Administration. The DOH further notes that the Department is in the midst of a major reform of the DC Alliance that will take effect in 2006.

Meanwhile, the DC Primary Care Association, with significant support from the DC Department of Health, has launched a Medical Homes Initiative to strengthen the infrastructure of the community health centers network. The citizens who developed the DC Cancer Plan wholly support these efforts, including the DC Primary Care Association's plans to establish a coordinated, citywide database to track patient information.

Goals, Objectives, and Strategies

GOAL: To improve access to primary and cancer care for DC residents.

Objectives and strategies:

1) Create a coordinated patient navigation system by 2008.

- Seek funding for coordinated patient navigation in hospitals and community health centers.
- Develop a coordinated patient navigation system.

2) Establish affiliation agreements between the community health centers, hospitals, and health care providers for diagnostic follow-up and treatment by 2007.

- Facilitate negotiation of these affiliation agreements.

3) Improve access to public transportation for cancer patients by 2010.

- Work with the Washington Metropolitan Area Transit Authority (WMATA) to expand its demand-responsive system.

4) Increase the participation of eligible minority residents in cancer-related clinical trials by 15% by 2010.

- Advocate for legislation requiring insurers to cover routine patient costs for clinical trials.
- Update health care providers on clinical trials and encourage patient referrals.
- Launch an awareness and recruitment campaign focused on racial and ethnic populations, particularly Blacks and Hispanics.

5) Educate consumers about access to cancer screening, care, and other services by 2010.

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Cancer Prevention

Facts in brief

There is a growing body of epidemiological evidence suggesting that factors contributing to the development of cancer (as well as undermining overall health) include:

- Smoking and overconsumption of alcohol (especially combined)
- Overexposure to ultraviolet light (through sunlight or tanning salons)
- Overconsumption of red meat, especially when charred
- Overconsumption of fat and sugar
- Consumption of food cooked with harmful fats.
- Insufficient consumption of fruits, vegetables, and whole grains—rich in vitamins, antioxidants, and minerals that may help slow or prevent the development of cancers.
- Too little physical activity.

Cancer has now surpassed heart disease as the nation's number one killer for persons age 85 or younger. Coronary heart disease declined significantly after 1973, largely through changes in people's behavior—and it is not unreasonable to think that a similar decline in cancer incidence could occur if individuals changed to behaviors that appear to help prevent the disease: sound nutrition, no smoking, maintaining reasonable weight, minimal or no alcohol consumption, adequate, regular physical activity, and limited exposure to the sun. By some estimates, poor nutrition, physical inactivity, and obesity together account for roughly a third of all cancer deaths, and the use of tobacco another third. Prevention eliminates many problems and costs down the line, but it must be started early. The best way to prevent lung cancer, for example, is never to smoke. An ounce of prevention truly is worth a pound of cure—reducing illness, prolonging a healthy life, and maintaining a satisfactory quality of life.

American health has declined as Americans have shifted increasingly to a diet of foods high in fat, sugar, and refined grains—the staples of fast food restaurants that serve oversize portions to vast numbers of Americans. Almost a third of all children and teenagers consume fast food on a typical day.

Current dietary recommendations include minimal fats and red meat and plenty of fruits, vegetables, and whole grains. Fruits and vegetables are probably protective because of their fiber content, micronutrients, and colorful phytochemical compounds, such as the lycopene in tomatoes, the folates in leafy green vegetables, and the flavonoids in citrus. Not all valuable dietary factors have been isolated, so vitamin supplements may not be as valuable as whole foods.

The type of fat consumed matters to general health, as well. Authorities recommend that foods be prepared with such fats as olive oil, canola oil, and safflower oil.

Diets high in fruits, vegetables, and whole grains reduce the risk of cancer—especially cancers of the colon, esophagus, lung, and oral cavity. According to the National Cancer Institute's "Eat 5 to 9 a Day for Better Health" Program, to reduce risk people should consume at least five to nine servings a day of vegetables and fresh fruits, such as citrus, yellow and green leafy vegetables, soy products, and whole grain wheat products. A serving is approximately that amount that fits in the palm of the hand.

In the District of Columbia in 2003, 52.4% of adults were identified as overweight or obese, up from 50.5% in 1998

Surveys show that only 23% of adults and 21% of the young consume the minimum five daily servings of fruits and vegetables recommended by the National Cancer Institute. In Washington DC, only 29.5% of adults and 21.3% of the young (in 2003) consumed at least five servings of fruits and vegetables daily. Most people consume only two or three servings, and some none at all (USDA, 1998).

Overweight as a risk factor

Lifelong eating behaviors develop early in childhood. According to surveys conducted by the Centers for Disease Control, many DC teens aged 12 to 17 are at risk or already overweight. Rates are especially high among Hispanic and Black teens. Improving the nutrition and physical activity practices of children and adolescents is important for promoting their long-term health.

Concern is growing about obesity's effect on cancer, heart disease, and stroke. Obesity rates among adults increased 75% between 1991 and 2001. In the last 20 years, the rates have doubled in children and tripled in teens. The prevalence of obesity in men is the same among all racial/ethnic groups, but in women the prevalence is highest among Blacks. More than half of Black women over 40 are obese and 80% are overweight. The American Cancer Society estimates that obesity accounts for 14% of all cancers in men and 20% of those in women in the United States.

In the District of Columbia in 2003, 52.4% of adults were identified as overweight or obese, up from 50.5% in 1998—mirroring nationwide trends that cut across both genders, all ages, and racial and ethnic groups.

Obesity trends among children will influence future rates among adults. Chances are that individuals who are overweight as children or young adults will be overweight as adults. In 2003, 11.5% of DC high school students were overweight and another 17.3% were at risk of becoming overweight. Rates are especially high among Latino and Black teens.

Smoking and alcohol

In hundreds of studies, smoking has been implicated as a cause of cancers of the lung and upper respiratory tract and is also associated with cancers of the large intestine, bladder, and pancreas. Investigators estimate that 30% of all U.S. cancer deaths are attributable to smoking.

Alcohol is known to interact with tobacco smoke in causing cancers in the oral cavity, upper respiratory tract, throat, and gastrointestinal tract. Alcohol and smoking have also been associated with second cancers arising in the mouth and throat after a first mouth or throat cancer has been treated. The most effective way to prevent cancers of the mouth and throat is to avoid tobacco and drink minimal amounts of alcohol. Alcohol has also been associated with cancers arising in the large intestine and pancreas, although the evidence is not as strong as with cancers arising in the head and neck. There is also evidence that alcohol may increase the risk of breast cancer in postmenopausal women.

Physical activity

Regular physical activity is an important factor in maintaining healthy weight and body composition. DC residents are not presently achieving recommended levels of regular physical activity. Survey data show that in 2003 half of DC adults engaged in moderate-intensity physical activity for 30 minutes or more at least 5 days of the week. The association between physical inactivity and cancer is weak, but physical activity has been shown to help prevent obesity, which is strongly associated with cancer. Over half of DC residents are not participating in enough physical activity to reap significant benefits.

There is a clear relationship between physical activity and risk of colon cancer: the more physical activity, the lower the risk of colon cancer.

Physical activity is also important in cancer treatment and rehabilitation, helping to improve mood, functional ability, quality of life and reducing fatigue, body weight, and the severity of some side effects.

The *2001 Shape of the Nation Report* issued by the National Association for Sport and Physical Education strongly recommended physical education for grades K through 6. Although 95% of the lower grades have physical education programs, they provide only about 40 to 50 minutes of exercise a week. Middle and high school levels require a physical education program, but the high school requirement extends only through grade 10, providing for 60 fifty-minute classes for ninth grade and 120 fifty-minute classes for tenth grade. Physical education grades are included in the grade point average. No other activity substitutions are allowed.

Avoiding overexposure to the sun

The most common carcinogen to which people are exposed is sunlight (especially ultraviolet light). Overexposure to sun has been associated with all forms of skin cancer, the most common cancer in humans. Most skin cancers can be treated; only one, melanoma, is difficult to treat and, when advanced, carries a high death rate. Since 1973 the rate of melanoma has been increasing in adults, young adults, and teenagers—especially among Whites. Presumably, the rising rate is the result of increased exposure to ultraviolet light either through sunbathing, overuse of tanning salons, and partial loss of the ozone layer. Frequent sunburns during childhood may increase the risk of melanoma or other skin cancers that occur years later. The routine use of sun block, which blocks ultraviolet light, is strongly recommended. The best prevention, however, is avoiding too much sun (especially in childhood) and not frequenting tanning salons.

Chemoprevention

Agents designed to prevent cancer or to inhibit growth of precancerous lesions are under extensive investigation. The National Cancer Institute, for example, is conducting a clinical study to determine whether selenium and vitamin E can prevent prostate cancer. Laboratory and clinical observations support the use of ordinary aspirin for the prevention of colon cancer, breast cancer, and lung cancer. Aspirin use must be balanced against potential complications such as internal bleeding and allergic reactions, but daily use of a single tablet of aspirin for life may reduce the risk of both cancer and heart attacks.

Why well-known preventive measures aren’t common practice

Why don’t more people eat healthy diets, get enough exercise, refrain from smoking and drinking too much alcohol, and generally follow practices that would reduce the likelihood of cancer and other chronic illnesses? There are several reasons. First, physicians fail to convey information about preventive care to their patients, for many reasons: they may not be trained or know enough to do so, they don’t have time, they aren’t reimbursed adequately for time spent urging preventive care, and after hearing conflicting professional recommendations may be skeptical about whether they work. Second, many people don’t know about preventive measures or how to implement them personally. This lack of understanding means people feel little incentive to temper their eating habits or alter their behavior.

In some communities, including many parts of DC, the nutrients recommended by the National Cancer Institute and other organizations may not be readily available as affordable staples in local food markets. And heavily outweighing public messages about healthy eating is the saturation advertising and pervasive marketing (especially to the young) of heavily processed foods and beverages low in nutritional value and high in fats, sugars, and calories—as well as tobacco companies’ continued subtle advertising to the young. Working parents, short on time, may find it difficult to cook fresh meals for their families, and instead rely on fast food and processed foods. Finally, the elimination of some physical education classes in many grades and schools has reduced emphasis on physical activity.

Goals, Objectives, and Strategies

GOAL: Reverse the trend toward obesity and overweight by increasing physical activity and the consumption of fruits and vegetables and by reducing caloric intake among DC residents.

Objectives:

1) Reduce the prevalence rate of obesity among DC adults to 15% by 2010.

2) Reduce the prevalence of overweight adults to 40% by 2010.

3) Reduce the prevalence rate of overweight and obese children to 5% by 2010.

4) Increase to 60% the prevalence rate of adults who engage in regular, moderate physical activity for at least 30 minutes a day at least five days a week by 2010.

5) Increase to 40% the prevalence rate of high school students who engage in moderate physical activity 30 minutes or more, five or more days a week by 2010.

Strategies:

- By January 2008, develop and maintain an intervention clearinghouse that encourages collaboration among partners; provides resources to program planners and resources to the public about nutrition, physical activity, and reduced cancer risk; and provides sample ordinances, organizational initiatives, and strategies.

- Develop a community-based volunteer cadre to counsel families on health education and preventive measures for cancer and other diseases.

- Develop culturally appropriate materials and promote prevention activities through community educational forums, the media, the DC government, employers and other vehicles.

- Include prevention information in all DC forums that address cancer issues.

- Join or supplement the efforts of other local organizations interested in controlling obesity, such as the American Heart Association and American Diabetes Association.

- Through the Mayor’s Council on Physical Fitness, implement school and work-based programs for interventions designed to improve healthy eating habits and physical activity, especially among children, teenagers, and young adults.

- Encourage employers to adopt programs that promote physical activity, such as onsite exercise facilities and subsidies for gym or athletic club memberships.

- Support Board of Education efforts to provide healthy, well-balanced meals to students in grades K-12, and to encourage good life-long eating behaviors.

- Decrease the availability and marketing of foods and beverages of low nutritional value in schools and increase the availability of nutritious food products.

- Through professional organizations, conduct educational programs so that physicians can promote the benefits of prevention practices to their patients.

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Smoking-Related Cancers

Facts in brief

- *When states are ranked for mortality rates, DC ranks highest for deaths from all smoking-related cancers—for both men and women* (see Table 1). The high mortality rates for these cancers may help explain DC's high overall death rate from cancer.
- Of the roughly 650 cases of smoking-related cancers a year in the District, about 400 are lung cancer. Most lung cancers (80 to 90% of cases) are attributable to smoking. As many as 75% of oral cavity cancers are probably attributable to smoking. Cancers of the lung, larynx, oral cavity and pharynx, esophagus, stomach, pancreas, bladder, and urinary tract occur more often in smokers than in nonsmokers.
- The lung cancer mortality rate for Black males in DC is similar to the Black rate nationally, but the rate for White males in DC is only 64% of the national rate for White males. In fact, for both White men and women, DC has the lowest lung cancer mortality rate of all states. This fact explains why the lung cancer ranking for the combined races in DC is closer to the average for the United States. However, the very high mortality for all other smoking-related cancers in DC overwhelms the lower rate for the more frequent lung cancer and results in DC leading the nation in mortality for all combined smoking-related cancer sites.
- DC's Black males carry the heaviest burden of combined smoking-related cancers. The 5-year incidence rates for these cancers is about 50% higher in DC's Black males than in the same race/gender group nationally. The rate in DC's Black women is only slightly higher than rates for Black women nationally. The incidence rates of the other smoking-related cancers in White men and women in DC are slightly lower than the national rates.
- In comparison with national Surveillance, Epidemiology and End Results (SEER) data, the incidence rates for smoking-related cancers in DC Black males show a greater excess than do the mortality rates according to data from the North American Association of Central Cancer Registries (NAACCR), suggesting that the high mortality ranking for DC is due to the cancers' more frequent occurrence rather than poorer survival rates after onset of cancer. The same conclusion can be reached for White males and females but not for Black women.
- The incidence rates for these smoking-related cancers comparing Black and White males within DC show even greater differences than comparisons with national rates. Rates for DC Blacks are 2-2.6 times higher than for DC Whites. Black women living in DC also have incidence rates that are 1.8 times higher than those for White women living in DC. The disparity by race in the risk of these cancers for both sexes is greater in DC than in the nation.
- Excesses in risk for smoking-related cancers in DC's Black males compared with other race/gender groups in DC begin as early as ages 35-44. Thereafter, these differences rise rapidly.

- The risk for various cancer sites in DC Black males is 2 to 8 times higher than for other groups by ages 55-64, according to NAACCR data.
- The higher incidence of smoking-related cancers in DC's Black population is not attributable to DC's urban characteristics. DC rates are higher than rates in Atlanta, a comparable East Coast city with a large Black population and minimal heavy industry.
- Mortality rates for the combined smoking-related cancers for Blacks in DC are among the highest in the country, whereas the same rates for Whites are among the lowest—which means there is a huge disparity in rates by race in DC.
- Since Black males in DC are at higher risk than other racial/ethnic groups for smoking-related cancers, the goal of any smoking control program in DC should be to reduce the proportionate number of Black smokers to a level similar to that for Whites.
- The rates of smoking-related cancers are almost twice as high in some wards compared to others. These differences in risks by ward might suggest some specific areas of DC where interventions are needed.

Smoking-related cancers in DC

Inequality is the most striking feature of incidence and mortality rates for smoking-related cancers in the District. Mortality rates from lung cancer are close to the U.S. average for all DC residents compared with U.S. residents generally. However, for the combined smoking-related cancers occurring in the aerodigestive system (lung, larynx, oral cavity, esophagus and stomach), as seen in table 1, DC ranks first or second in the nation in mortality rates for both men and women. *Mortality rates can reflect not only differences in what causes the disease but also differences in access to health care and possibly differences in responses to treatment.* The fact that the differences in incidence are much greater than the differences in mortality in comparing rates for Blacks and Whites suggests that the major reason for the higher excess mortality in DC in Blacks is the greater frequency of disease in this group. The goal of a smoking-related program for cancer control in DC should aim at reducing this racial disparity.

The incidence rates of lung cancer and other smoking cancers by ward or geographic area and gender in DC show major differences (see Table 2). For example, lung cancer rates in males are higher in Wards 1, 4, 5, 6, 7, and 8 than for males in Wards 2 and 3. Lung cancer and other smoking cancer rates are not always highest in the same wards, however, nor do

Table 1. DC's high ranking in mortality rates from smoking-related cancers, compared with other states (by gender)

Rank, among states, for deaths of	All	Lung	Larynx	Oral	Esophagus	Stomach
Males	1	19	1	1	1	2
Females	1	22	1	1	1	2

Source: Centers for Disease Control and Prevention, National Center for Health Statistics

Table 2. Age-adjusted incidence rates for selected smoking-related cancers in DC (by ward, 1997–2001)

Ward	Lung	Esophagus	Stomach
1	82.86	12.93	11.41
2	57.38	7.04	10.61
3	50.50	3.63	6.88
4	83.63	7.31	13.36
5	68.78	8.21	10.42
6	86.80	11.60	12.55
7	65.87	8.44	11.33
8	74.77	13.58	15.19

Note: Rates are per 100,000 persons and are age-adjusted to the 2000 U.S. standard population.
Source: DC Cancer Registry

the highest wards necessarily demonstrate the same excesses for men and women. Ward 3 has the lowest rates for almost all cancers for both men and women. No single ward has the highest rate for all of the cancers, despite the fact that these cancers all have smoking as a unifying risk factor. (All data represent an analysis for a five-year period to stabilize the rates by ward).

Survival

Survival rates from smoking-related cancers are generally very poor. The 5-year survival rates from these cancers (except for larynx and oral cavity cancers) range from 9% to 22%. Even oral cavity and pharyngeal cancers, with survival rates as high as 60% in the White population, require extensive surgery, which is often disfiguring, thereby limiting social interactions and reducing quality of life. The U.S. data indicate that survival following these cancers is generally poorer for men than it is for women and poorer for Blacks than for Whites. Survival is particularly poor for Black males. Although options for screening are limited for many of these cancers, head and neck cancers, the commonest of smoking cancers other than lung, are amenable to screening (see separate chapter on the subject).

The health burden from smoking

The health burden from smoking is not confined to cancer. Where there are high rates of smoking, excesses in mortality and hospitalizations for cardiovascular disease, stroke, and chronic obstructive respiratory disease are expected. The respiratory problems in smokers will also result in lost work time and poor quality of life, because of restricted activity. In women, the burden of smoking is often seen in poor reproductive performance, including infants born prematurely or small for their gestational age.

The burden from smoking is also borne by individuals who live or work with smokers and are passively exposed to smoke. This environmental contamination increases the risk of lung cancer, heart disease, and other conditions. Reducing smoking rates brings about a fairly immediate reduction in the health and cost burden from some major diseases, whereas the effect on cancer rates may be delayed for 10 to 20 years. Any program that reduces smoking rates will reduce health costs from several diseases, many of which occur with high frequency and high cost.

Risk factors for lung cancer

Several kinds of occupational and environmental exposure have been associated with the risk of lung cancer, but the factor that explains 80 to 90% of cases is cigarette smoking. The risk of lung cancer is reported to be 10 to 20 times higher in smokers than nonsmokers, depending on how long they smoked and how many cigarettes a day they consumed. Black men have higher incidence and mortality rates from lung cancer, are younger at age at diagnosis, and have worse chances for survival than White men.

While direct exposure to tobacco smoke is the most important risk consideration, any exposure to tobacco smoke carries a risk. Passive exposure to secondhand smoke has been estimated to increase the risk of lung cancer by about 25%. The more cigarettes smoked, the greater the risk to nonsmokers exposed to the smoke. Exposure to environmental tobacco smoke (ETS) is suspected to increase women's risk of heart disease and children's risk of respiratory conditions such as asthma attacks, especially in children under the age of 10. In a population with smokers, nonsmokers' health may be damaged the same way indirectly as smokers' health is damaged directly. Reducing the number of smokers in DC will reduce not only the direct effects of tobacco on smokers but also will reduce exposure of non-smokers to environmental tobacco smoke.

Other factors that have been associated with a risk of lung cancer are radon in homes, other environmental radiation, and several industrial chemicals, such as coke oven gas and metals from chromium refining. None of these factors should play a major role in lung cancer risk in DC.

Risk factors for other smoking-related cancers

For the other smoking-related cancers, smoking represents an important risk factor but not the only one. Tobacco is a major and independent risk factor for cancers of the larynx, oral cavity and pharynx, stomach, and esophagus. For all these cancers, British doctors have demonstrated a sevenfold increased risk for smokers over nonsmokers; heavy smokers had 15 times the risk of nonsmokers. Several studies have shown smokers to be at 3 to 13 times higher risk of oral cavity and pharyngeal cancers than nonsmokers.

Current smoking levels in DC

Historically, Blacks as a race reportedly start smoking later than Whites and smoke fewer cigarettes, but this pattern may be changing. According to the Behavioral Risk Factor Surveillance System (BRFSS) (see Table 3), smoking rates in 2003 are higher for Blacks in DC and in the United States than for Whites. However, since DC has a population of African immigrants who smoke, the increase in smoking reported by Blacks may be attributed to the African immigrant and/or African American population.

The reported rate of smoking among Hispanics in DC is higher than the U.S. rate for Hispanics.

The rate for smokers in DC with low education levels is 43% higher than the overall DC smoking rate and 11% higher than the U.S. rate for smokers with low education. The high rate for smokers with little education suggests that the DC smoking rate may be associated with low-income residents, which could explain some of the disparity in lung cancer rates by race.

Preventing smoking-related cancers

Smoking cessation has been the main focus in reducing tobacco-related cancers, but the ideal primary prevention strategy is to keep people of all ages from starting to smoke in the first place—because tobacco is one of the most addictive drugs. Of course, to stop smoking at any age will in the long run reduce the risk of smoking-related cancers. The benefits from smoking cessation not only reduce cancer risks but also may be felt more immediately and more dramatically in terms of reduced risks of cardiovascular disease and reproductive problems.

Secondary prevention through screening or early detection is important only for oral cavity

Table 3. Current cigarette smoking rates in DC compared with national norm

	Adults[1]		High School[2]		Middle School[3]	
	DC (%)	U.S. median (%)	DC (%)	U.S. median (%)	DC (%)	U.S. median (%)
Male	26.2	25.1	14.6	14.2	8.7	11.7
Female	18.2	19.8	12.0	12.4	10.1	10.2
White only, non-Hispanic	21.9	22.7	N/A	N/A	N/A	N/A
Black only, non-Hispanic	22.9	23.8	N/A	N/A	N/A	N/A
Hispanic	21.8	18.5	N/A	N/A	N/A	N/A
Low education[4]	31.9	28.7	N/A	N/A	N/A	N/A
Total	**22.3**	**22.4**	**13.2**	**13.4**	**9.4**	**11.0**

Note: Current cigarette smoking in adults defined as "ever smoked 100 cigarettes in lifetime and are current smokers (regular and irregular)." For youth, current cigarette smoking defined as "smoked on 1 or more days prior to the survey."

[1] Source: Behavioral Risk Factor Surveillance System, 2003

[2] Source: Youth Risk Behavior Surveillance System, 2003. Note: Only public high schools were surveyed.

[3] Youth Tobacco Survey, 2000

[4] Adults 25 years old and older with less than a high school education

cancers. For the other smoking-related cancers, no practical screening programs have been developed. .

Aims of a DC smoking program for cancer control

Any anti-smoking program in DC should aim to do four things:

- Prevent the initiation of smoking.
- Reduce the number of current smokers
- Decrease exposures to secondhand smoke
- Reduce the racial disparity in smoking-related cancers by providing effective smoking-cessation programs for all races.

Each of these aims will demand programs with slightly different emphasis but the programs should overlap as part of an integrated community-based plan that includes all five objectives below. Each objective must be considered separately but the programs for all five objectives should be integrated.

Funding for tobacco control in DC

To date, the District of Columbia has spent none of the $57.4 million tobacco-generated revenue it has received from the tobacco settlement payments and tobacco excise taxes for tobacco control and prevention. The District opted to securitize part of its settlement payments in exchange for a lump-sum payment to repay existing long-term debt. The Centers for Disease Control and Prevention has set minimum expected levels for states to spend on tobacco control and prevention. For DC, the minimum expectation is $7.5 million annually. *The District ranks worst of all states in the amount and percent of tobacco settlement funds it has spent on tobacco control and smoking prevention.*

To DC's credit, the tobacco excise tax is $1.00 per pack. California, Massachusetts, and Canada have proven that there is a direct relationship between increasing the tobacco excise tax and reducing tobacco use. Sadly, though, the revenue from the tax has not been appropriated for programs to prevent or reduce tobacco use.

Goals, Objectives, and Strategies

GOAL: Reduce mortality from smoking-related cancers in the District of Columbia.

Objectives and strategies:

1) Reduce the level of smoking among high school students from 13% to 10% by the year 2010.

- Initiate anti-smoking programs and smoking cessation programs in all high schools. Use programs similar to current DC programs and adapt programs used successfully elsewhere. Programs for smoking cessation must be racially and culturally appropriate and should involve both schools and other points of contact (such as youth centers, family planning clinics, pregnancy clinics, and maternal and child health clinics that see youths under 20).
- Consider new approaches to reaching young smokers, possibly using a "cluster" approach that engages youths' parents and peers.
- Consider an increase in the cigarette excise tax in 2007.

2) Reduce the level of smoking in current Black and Hispanic smokers and those with low levels of education by 25% by the year 2010.

- Establish a smoking cessation quit line for DC youth and adults that will address the needs of a multilingual and culturally diverse population. Include counseling and pharmacotherapy components.
- Target promotion of the cessation quit line to specific racial, ethnic, and geographic populations.
- Launch a targeted media blitz against smoking.
- Educate professionals about their importance and effectiveness in persuading smokers to stop.

3) Reduce general exposure to secondhand smoke by creating a smoke-free environment in all public places by the year 2006.

- Advocate for legislation that bans smoking in all public places.

4) Reduce racial disparities in smoking prevalence.

- The minimum objective for DC—a thread running through the previous three objectives—should be to ensure that DC meets tobacco goals for Healthy People 2010 (Reduce adult smoking to 18.5%) and meets CDC's recommended level of funding for anti-smoking activities ($7.5 million annually).

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Head and Neck Cancers

Facts in brief

- Oral cavity and pharynx cancers occur 1.7 times more frequently in Black males in DC than in Black males countrywide. (Local and national incidence rates in White males and in women of both races are similar.) Black males in the District are 2.4 times more likely than White males to be diagnosed with these cancers.
- Black males with oral cancers have only half the chance White males have of surviving for 5 years. The poorer survival rates of Black males are partly due to their cancers being diagnosed at a more advanced stage than those of White males.
- Incidence rates of cancer at each site in the oral cavity are low but the combined rates represent about 40% of all other smoking-related cancers, except lung cancer, in Black males. The higher rates of cancer in Black males appear to be concentrated in lesions of the tongue, the floor of the mouth, the oropharynx, and the hypopharynx. Lesions at many of these sites would be visible on direct examination of the oral cavity.
- The age-specific rates of oral cavity cancers are higher in Black males beginning at ages 35–44, and the rates for Black males increase more rapidly than for other race and gender groups. The rates peak at ages 55–64, when oral cavity cancers are 2.5 times more likely for Black males in DC than for White. For Black males in DC, the rate of oral cavity cancer declines after age 64, differing from other smoking-related cancers (including lung and stomach cancers), which generally show a gradual increase in risk extending past the age of 75. This may suggest other risk factors for these cancers besides smoking or other population differences.
- Ward 3 has the lowest rate for oral cavity cancers in males. The range of rates by ward differs 4.6-fold. Some of the variation is due to differences in racial distribution by ward.
- Patients with oral cavity cancers have a better survival rate than patients with smoking-related cancers at other sites, such as the lung, esophagus, and stomach. However, the treatment for this cancer may disfigure the patient, leading to a diminished quality of life.
- Patients with a first cancer of the oral cavity or pharynx have a 15 to 20 % chance of having a second new cancer in the same area or in the larynx, lung, or esophagus.

Cancers of the head and neck, including tumors arising in the oral cavity and pharynx, are associated with smoking.

Risk factors

Smokers have a 3- to 13-fold higher risk of oral cavity and pharynx cancers than non-smokers. Other factors, such as the use of smokeless tobacco products, also play a role in oral cavity cancers. Data are not available on adult use of smokeless tobacco in DC. According to national data for 2003, 5% of high school students in DC use smokeless tobacco.

Risks for oral cavity cancers double in heavy drinkers, compared with those who abstain from alcohol or are light drinkers. Moreover, studies suggest that combined exposures to smoking and heavy drinking in the population may increase the risk of oral cancer to higher levels than the added risks from each substance alone. Exposure to both heavy drinking and smoking increases the risk almost 80-fold while the risk from heavy smoking alone may be only 17-fold and the risk from heavy drinking alone only two-fold. Because the two exposures often occur together, most of the cancers will be related to both risks.

Differences in diet are thought to influence the risk of oral cancers. In fact, Chinese people from certain areas of China who eat salted fish have an especially high risk of nasopharyngeal cancers. Exposure to selected chemicals, such as formaldehyde and methyl ethyl ether, may increase the risk of selected sites of pharynx, nasopharyngeal and hypopharynx cancers.

Preventing oral cancers

Because oral cavity cancers are related both to cigarette smoking and smokeless tobacco products, campaigns encouraging people never to use the products and programs helping people stop using them could both be effective.

Oral cancer patients have a 15% risk of developing a second cancer of the head and neck or in the lungs—a much higher risk of second cancers than for other cancer sites. Many deaths from head and neck cancers are the result of second cancers. Many of these second lesions occur in the oral cavity or pharynx but may also occur in the larynx, lung, or esophagus. The risk of developing some second cancers might be prevented or the effects modified by changing patients' smoking or drinking habits and by early detection through screening.

Two factors—the high probability of second cancers and a risk for combined exposures that is greater than additive—strengthen the impact of reducing smoking. Where there is a synergistic effect between two common exposures and especially if the behaviors frequently occur together, reducing the exposure to either factor will greatly reduce the risk of the cancer. Early detection of a second cancer, or even of premalignant lesions, may improve the patient's chances for survival. Secondary prevention programs could be successful in reducing both advanced oral cancer lesions and deaths. They would focus on detection of both precancerous lesions and early-stage disease. Except for pharynx cancers, common sites should be visible on clinical examination.

Early detection is particularly important in oral cancer prevention because survival is significantly improved if the lesions are small at diagnosis and the extent of surgery may be less. Since surgery for advanced head and neck cancers is extremely deforming, the patient's quality of life could be improved with less radical surgery. Although cancer organizations may not suggest screening programs for all head and neck cancers because the cancer is relatively rare, *it is important to add oral cavity screening to routine clinical examinations, especially by both dental and medical practitioners, and to focus screening programs on high-risk groups.*

Secondary prevention would include a program to teach both physicians and dentists to look for early lesions in the oral cavity and to provide appropriate care for leukoplakia and erythroplakia. The professionals could train their patients to perform self-examination for these lesions. The white or reddish raised plaques found on oral mucosa are often a precancerous condition. Dentists may perform oral cavity screening routinely but older populations often do not use routine dental services so it is important to train physicians to perform the screening—especially for the elderly, who often see medical doctors for chronic health problems. Physicians may also need to be reminded of the high risk of second primaries of the oral cavity or pharynx in patients with an original primary cancer of the aerodigestive tract. Freestanding oral cancer screening programs are often underused. Primary prevention programs for smoking cessation can be added to these screening programs to enhance their effectiveness. Screening programs might be targeted at high-risk populations such as men in jails and halfway houses and other sites with many high-risk occupants who have had little contact with medical or dental services before living in such group facilities.

Signs and symptoms of head and neck cancer

The most common symptoms of head and neck cancer are listed below. Usually, only one sign or symptom is present.

- An ulcer or sore area in the head or neck that does not heal within a few weeks
- Difficulty in swallowing, or pain when chewing or swallowing
- Trouble with breathing or speaking, such as persistent noisy breathing, slurred speech or a hoarse voice
- A swelling or lump in the mouth or neck
- Pain in the face or upper jaw.

Goals, Objectives, and Strategies

GOAL 1: Reduce the mortality rate in DC from cancers of the head and neck by 10%.

GOAL 2: Reduce the incidence of invasive cancers of the head and neck in DC by 10%.

Objective: **Increase to 50% the proportion of head and neck cancers detected at the local stage for both men and women by 2010.**

Strategies:

- Educate dentists, physicians, and other health care providers about screening all patients, especially those who smoke, for early signs of head and neck cancer.

- Through community, church-based, and work-based programs inform people about the risk factors and the early signs and symptoms of head and neck cancer and the need for screening, especially in a smoker or heavy drinker of alcohol.

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Breast Cancer

Facts in brief

- Among women, breast cancer is the second leading cause of cancer-related deaths nationally, after lung cancer. Nationally, it is the most commonly diagnosed non-skin cancer among women, accounting for nearly one-third of all cancers diagnosed. Over her lifetime, a woman has a one-in-seven chance of developing breast cancer.
- Almost 80% of breast cancers are diagnosed in women aged 50 and older. More than half of breast cancers are diagnosed in women aged 65 and older. Women 65 and older have a significantly higher mortality rate (148.9) than women 64 and younger (19.8).
- Roughly 80% of women diagnosed with breast cancer have no known risk factors.
- Nationally, White women have the highest incidence rate (140.8. cases per 100,000 women), followed by Black women (121.7), Asian/Pacific Islander women (97.2), and Hispanic women (89.8).
- However, Black women have the highest mortality rate nationally (35.9 deaths per 100,000 women), followed by White women (27.2), Hispanic women (17.9), and Asian/Pacific Islander women (12.5).
- Between 1992 and 2000 the incidence rate for Black women remained the same. However, Black women were more likely than White women to be diagnosed with large tumors (larger than 5.0cm).
- White women have a higher incidence of breast cancer after age 42; Black women have a slightly higher incidence rate before age 42.
- Incidence rates have remained relatively stable, increasing only 0.4% from 1987 to 2000. Mortality rates declined 2.6% annually from 1992 to 2000—but the decline was twice as great for White women as for Black women.
- About 10% of women who are carriers of the BRCA1 or BRCA2 gene develop breast cancer.
- The District has the highest breast cancer mortality rate in the country (at 37.3 per 100,000 women).
- In 2005 an estimated 520 women in the District will be diagnosed with breast cancer and 100 will die of the disease.
- The incidence rate in DC (143.3), the fifth highest among all states, is considerably higher than the national average (132.2).
- Men can get breast cancer, but male breast cancer is rare (1,300 cases per year).

Table 1. Incidence of breast cancer in women in the District (1998-2002, by ward)

	Number of cases	Rate
District of Columbia	2,224	145.3
Ward 1	177	131.2
Ward 2	329	224.3
Ward 3	414	173.0
Ward 4	348	138.3
Ward 5	292	132.3
Ward 6	248	130.3
Ward 7	242	123.2
Ward 8	152	103.9
Address unknown	22	~

Note: Data exclude in situ cancers. Rates are per 100,000 women and are age-adjusted to the 2000 U.S. standard population.
~ Number of cases too small (25 or less) to calculate reliable rate.
Source: DC Cancer Registry.

Table 2. Women's deaths from breast cancer in the District (1998-2002, by ward)

	Number of deaths	Rate
District of Columbia	545	35.8
Ward 1	44	34.6
Ward 2	68	48.8
Ward 3	79	33.2
Ward 4	90	35.6
Ward 5	94	41.7
Ward 6	53	29.0
Ward 7	74	36.6
Ward 8	43	29.2

Note: Rates are per 100,000 women and are age-adjusted to the 2000 U.S. standard population.
Source: DC Cancer Registry.

Breast cancer is the most frequently diagnosed cancer among District women and the second most frequently diagnosed cancer among all District residents. The incidence rate is highest in Ward 2 (224.3 per 100,000 women), followed by Ward 3 (173.0), as Table 1 shows.

The mortality rate from breast cancer is the third highest cancer mortality rate in the District. Ward 2 has the highest breast cancer mortality rate (48.8), followed by Ward 5 (41.7), as Table 2 shows.

Research has documented treatment differences between Black and White women. Many researchers attribute the delayed diagnosis of breast cancer in many Black women to a lack of health insurance or limited access to mammography, although there is some indication that cultural beliefs about health care and socioeconomic factors, such as income and education, may explain some of this disparity. But Black women, especially those younger than 45, also develop more aggressive tumors than White women. Those aggressive tumors are difficult to treat and often present at a late stage. Mutations in the p53 tumor suppressor gene, which are associated with poorer outcomes, are more likely to occur in Black women and might make chemotherapy treatment less effective.

Risk factors

Modifiable risks

Alcohol. Studies have shown the risk of breast cancer to increase slightly with increased alcohol consumption.

Diet and obesity. Many cohort studies have found that obesity increases the risk of post-menopausal women developing breast cancer.

Hormonal therapy. Studies suggest that reproductive hormones promote the growth of some cancers. Recent use of hormone (estrogen) replacement therapy (HRT) has been shown to increase the risk of breast cancer (the longer the period of HRT, the greater the risk).

Nonmodifiable risks

Age. The risk of developing breast cancer increases with age, for both men and women. Most breast cancers occur in women over the age of 50; the risk is especially high for women over the age of 60.

Breast cancer is the most frequently diagnosed cancer among District women and the second most frequently diagnosed cancer among all District residents.

Family history of breast cancer. Only 10% of women who develop breast cancer are genetically predisposed to developing the disease. Mutations in two genes (BRCA1 and BRCA 2) account for nearly half of these inherited forms of breast cancer. In addition, women who have two or more first-degree relatives (mother, sister, aunt) with breast cancer diagnosed at an early age are at increased risk for developing the disease.

Hormonal history. Women with an early onset of menstruation (before age 12) are at higher risk of developing breast cancer. In general, breast cancer risk declines 10% to 20% for each year menarche was delayed. Epidemiological studies have consistently demonstrated that late onset of menopause (age 55 and over) is associated with greater risk of breast cancer.

Childbirth history. Women who experience more pregnancies are at decreased risk, and women who bore their first child when they were 20 years old or younger have about half the risk of women who completed their first full-term pregnancy at age 30 and over. Women who never have children or have their first child after age 30 are at slightly increased risk.

Sexual orientation. When cultural comparisons are made, lesbian women appear to be at higher risk of breast (and cervical) cancer because of delayed screenings and higher rates of alcohol consumption, tobacco use, obesity, and never having given birth to a viable infant.

Ways to reduce the incidence of breast cancer

Certain actions may lower (but not eliminate) women's risk of developing breast cancer. Lifestyle changes that may help reduce women's risk of developing breast cancer include limiting alcohol consumption, eating a low-fat diet, breastfeeding their infants, and increasing physical activity. In the District of Columbia:

- Nearly 30% of women 18 and older report engaging in no physical activity.
- More than half of adult women in the District, and 68% of Black women, are considered overweight (with a body mass index greater than 25.0). Rates of obesity continue to increase.
- DC residents with only a high school education have overweight rates over 70%.

Research has shown that tamoxifen and other agents can reduce the risk of breast cancer in women who are at high risk for developing the disease, and the risk of recurrence in women who have already had breast cancer. These agents do have side effects.

Prophylactic mastectomy is an option available to women with moderate to high

Table 3. Stage at which women in the District were diagnosed with breast cancer (1998-2002, percentage by ward)

	Localized (%)	Regional (%)	Distant (%)	Unstaged (%)
District of Columbia	58.0	27.1	5.3	9.7
Ward 1	58.6	29.3	5.0	7.2
Ward 2	55.4	27.7	5.7	11.3
Ward 3	65.9	26.4	3.3	4.4
Ward 4	54.8	27.0	6.3	11.9
Ward 5	60.9	22.8	5.4	10.9
Ward 6	58.4	26.8	5.6	9.2
Ward 7	58.0	25.6	5.2	11.2
Ward 8	44.2	35.3	7.1	13.5

Source: DC Cancer Registry.

risk of developing breast cancer in their lifetime. The procedure can reduce the risk by 90% in women who are at moderate to high risk. However, this is a drastic procedure and should be considered very carefully. It is often regarded as an important option for women who carry the BRCA1 or BRCA2 genes or who are at very high risk for breast cancer because of a strong family history of the disease.

Ways to reduce deaths from breast cancer

Screening and early detection. There has been a modest decline in deaths from breast cancer, which has been attributed to successful screening programs and improvements in treatment. Mammography, an X-ray of the breast, detects about 90% of breast cancers in women without symptoms. Often these cancers are too small for health care providers to feel during clinical breast examination. Mammography screening may identify women who have cancer or precancerous lesions in the breast that require further evaluation, including a biopsy. Results from post-mammography biopsies are non-cancerous in 70 to 80% of women. Mammography testing is more accurate in postmenopausal than in premenopausal women. The breast tissue in younger women is denser than that in post-menopausal women, making it more difficult for mammography to detect breast cancer.

Women diagnosed with breast cancer at an early stage, when the tumor is confined to the breast (localized), have a 97% chance of surviving 5 years; when the cancer has spread to the region around the breast, 78%; and when the cancer has spread to other organs, 23%. Table 3 shows data on stage of cancer at diagnosis in District wards.

Although some recent studies have cast doubt on the value of mammography screenings, both the National Cancer Institute and the American Cancer Society firmly support the value of mammography as a means of detecting breast cancer at an early stage. The American Cancer Society recommends that:

- Women get yearly mammograms starting at age 40.

Table 4. Percentage of women 40 and older who got a recent mammogram* District of Columbia and U.S., 2002

	DC (%)	U.S. (%)
40 years old and older	68.7	61.5
40-64 years old	68.8	60.5
65 years old and older	68.5	63.8
White only, non-Hispanic	61.9	62.4
Black only, non-Hispanic	71.9	62.8
Low education**	64.0	52.3

** Mammogram within the past year.*

*** Women 40 years old and older with less than a high school education*

Source: Behavioral Risk Factor Surveillance System

- Clinical breast exam (CBE) be part of a periodic health exam about every three years for women in their twenties and thirties, and every year for women 40 and older.
- Women know how their breasts normally feel and report any breast change promptly to their health care provider.
- Women at increased risk (through family history, genetic tendency, or past breast cancer) talk with their doctors about the benefits and limitations of starting mammography screening earlier, having additional tests (such as breast ultrasound and MRI), or having more frequent exams.

According to the Behavioral Risk Factor Surveillance System (BRFSS), although proportionately more women in DC are getting recommended mammograms than do so nationally, 30% of women in the District are still not being screened regularly for breast cancer (see table 4). Only 69% of women in the District 65 years old and older reported having had a mammogram in the past year, although the incidence of breast cancer increases the most among women in their sixties. More Black women (72%) are receiving mammograms than White women (62%) in DC, but only 64% of women with less than a high school education are receiving mammograms.

In 2004, the Delmarva Foundation, a quality improvement organization, reported that only 51% of Black women on Medicare (age 65+ and/or disabled) are being screened for breast cancer, compared with 61% nationwide.

Diagnosis. If a palpable mass is present or a mammogram reveals a suspicious lesion, a biopsy is needed to determine the nature of the lesion, or mass. Three types of biopsy procedure are available: fine needle aspiration, core biopsy, or excisional biopsy. Each has advantages and disadvantages. The type of biopsy required often depends on the mass's location, size, and visibility on the mammogram.

Treatment. Breast cancer is commonly treated by a combination of surgery, radiation therapy, chemotherapy, and hormone therapy. Surgery is still the first line of treatment, but researchers have found that less extensive, more conservative surgery is just as effective as radical surgery. Now surgeons may remove only the tumor or only a small part of the breast, especially if the cancer is small. One reason for regular mammograms is to find the small tumors so that extensive surgery is not needed. For large tumors, a simple or more extensive mastectomy may be necessary, but reconstruction of the breast is often possible. In some cases, radiation or hormonal therapy or chemotherapy may be required in addition to surgery. The additional treatment is designed to remove any residual tumor that may have not been visible at surgery.

Selection of therapy is influenced by age, menopausal status, stage of disease, the tumor's histologic and nuclear grade, and status in terms of estrogen and progesterone, among other factors. The earlier the breast cancer is diagnosed, the more treatment options women have.

Barriers to reducing the breast cancer burden

Women's knowledge, attitudes, and beliefs. Some women avoid mammograms out of a belief that screening is unnecessary if the woman is asymptomatic or has no family history of cancer. Others fear a diagnosis of cancer. One study found that Blacks knew less about cancer and were more fatalistic about it than Whites.

Socioeconomic barriers. Age, poverty, and isolation make it difficult for many women in the District to get either primary care or cancer care. In a city with a high cost of living, 36% of residents are at 200% of the federal poverty level or below. For 30% to 40% of minorities, cost is the reason women report failing to follow up on their physicians' recommendations. Women also have trouble getting time off from work and finding adequate transportation and child care. English is not the primary language for about 17% of DC residents, and access to language interpreters is limited. Poor literacy, including poor health literacy, makes it difficult for many patients to understand and follow instructions from the doctor or the pharmacy.

Cultural issues between patients and health care providers. Minority and immigrant residents report they do not sense an understanding or respect from physicians who do not share their racial and ethnic heritage.

Lack of access to health care providers and screening. The waiting time for a mammogram in DC is now five weeks. For women who have trouble getting time off from work, finding help with child care, and making their way on public transportation to screening services and clinical breast exams, having to wait a long time to be seen is discouraging. They often lose their motivation and fail to show up for appointments.

There are too few mammography facilities, especially in areas that serve the poor. D.C. General Hospital closed all inpatient services in spring 2001 and some outpatient services, including breast cancer screening. Hadley Hospital and Columbia Hospital for Women, primary providers of mammography and other breast health services, also went out of business.

There are insufficient public screening and treatment resources for the medically underserved through Project WISH, the District's Breast and Cervical Cancer Early Detection Program.

It is unknown what percentage of women eligible for Project WISH in DC are served. Nationwide Breast and Cervical Early Detection Programs serve only 10% to 20% of the eligible population. The District government does not supplement federal funding, so Project WISH must designate most of its funds to serving women aged 50 to 64. There are few other resources in the District to screen women between the ages of 40 and 49.

Fragmented health care system. In DC, community health centers have difficulty finding specialists who will take cases of medically underserved women who need follow-up and/or treatment after a suspicious mammogram.

Difficulty navigating the health care system. Sometimes understanding and maneuvering through the health care system (making an appointment, following pre-appointment instructions, getting to the appointment, understanding the findings and instructions from the health care provider and following through on the instructions) can be overwhelming to a person. Especially if a woman faces any of the additional barriers mentioned above, she may not pursue the screening or medical appointment.

Lack of access to rehabilitation and support services. Not all women are referred appropriately to rehabilitation services, support programs, or other cancer care resources.

Goals, Objectives, and Strategies

GOAL: Reduce mortality rates from breast cancer in the District by 10%, especially among Black women.

Objectives:

1) Reduce the incidence of invasive disease in DC by 10% by 2010.

2) Increase the number of women aged 50 through 64 who are screened annually by 10% by 2010.

3) Reduce the proportion of unstaged cases to less than 5% by 2010.

Strategies targeted to women:

- Partner with community organizations and local breast cancer organizations to bring tailored messages about breast cancer screening to all medically underserved Black women and to women 50 years old and older. Encourage such groups to enlist the help of influential public figures from whom such messages might be more persuasive. Tailored messages should address myths, fears, and negative attitudes about breast cancer and screening.
- Partner with local Centers for Medicare and Medicaid (CMS), AARP, senior service organizations, and the Department of Motor Vehicles to educate Medicare and Medicaid beneficiaries about the benefits and coverage for breast cancer screening.
- Make information about resources for breast cancer screening, treatment, and support readily available to women.

Strategies involving system-wide change or activities:

- Advocate for sufficient city funding for Project WISH to supplement federal funding, so that the program can reach at least 50% of the women eligible for the program.
- Subcontract additional components of Project WISH if management and budgeting for the program are inadequate or unstable.
- Develop a system that coordinates and connects community health centers with hospitals to ensure continuity of care regardless of patients' insurance or payor status.
- Implement a patient navigation system in DC to help women connect with appropriate diagnostic services, treatment facilities, medical appointments, second opinions, and follow-up examinations.
- Expand the mobile mammography screening program, especially for Black women. Such a program could also screen for hypertension, cholesterol, and other diseases.

Strategies targeting health care providers:

- Ensure that all appropriate health care providers know about breast cancer screening guidelines, local resources for screening and treatment of medically underserved women, and community resources that support screening, treatment, and referral.
- Ensure that all appropriate health care providers are trained to provide clinical breast examinations for women at the appropriate age.
- Make a family history of breast cancer a required part of every woman's medical record.
- Encourage physicians to set up effective reminder systems for annual screening of female patients.
- Make screening a part of annual physical examinations for all women 50 years old and older.

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Gynecologic Cancers

Facts in brief:

- Gynecologic cancers account for 6% of cancers diagnosed in the District of Columbia each year. Close to 200 cases a year are diagnosed, including about 50 cases of invasive cervical cancers, more than 40 of ovarian cancer, 70 to 90 of endometrial (uterine) cancer, and an unknown number of pre-invasive cervical cancers.
- Death from one gynecologic cancer—cervical cancer—is avoidable. Since the introduction of Papanicolaou (Pap) smear screening programs in this country in the 1950s, cervical cancer mortality rates have declined by about 75%. Despite high rates of disease, cervical cancer mortality has declined in DC as well.
- DC has the highest rate of cervical cancer in the United States, and the proportion of cervical cancer cases diagnosed in advanced and unknown stages is greater in DC than in the rest of the country (see Figure 1). Nearly all cases (92%) of invasive cervical cancer are diagnosed among minority women. Only Black women in DC have higher than U.S. average death rates from cervical cancer. Yet invasive cervical cancer is a preventable disease. The main reason women are diagnosed after cervical cancer has spread and the main reason they die—is that they have not received a Pap smear. Evidence shows that women are most likely to get a Pap smear if a doctor recommends it.
- Endometrial (uterine) cancer is often a curable disease. In 95% of cases there is vaginal bleeding. Women should be alerted to recognize bleeding after menopause as an early warning sign that could lead to earlier diagnosis and the greater likelihood of a cure.
- Late diagnosis is also the main reason for the high mortality rate from ovarian cancer, and there are only subtle early symptoms and warning signs that women and health care providers can watch for. In the absence of a screening test, awareness of the disease's symptoms may help women seek medical care earlier in this cancer's progress.

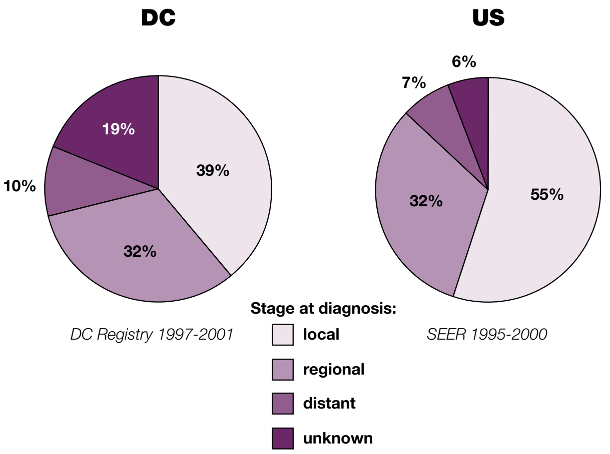
A single intervention could reduce deaths from cervical cancer. Unfortunately, fewer interventions exist for the other gynecologic cancers, although new screening tests may be on the horizon. In this chapter we provide information about, and suggestions for controlling, cervical cancer, endometrial (uterine) cancer, and ovarian cancer in the District of Columbia.

CERVICAL CANCER

In the diagnosis and treatment of cervical cancer, regular use of Pap smear screening is critical because precancerous changes can be detected and readily treated. Pap smear screening rates have increased dramatically in the past two decades; well over 80% of women surveyed nationally reported having had a recent Pap test.

Screening rates in the District are on a par with the rest of the country, with 89.4% of DC women reporting having had a Pap smear in

Figure 1. High-rate of late-stage diagnosis of cervical cancer in DC (compared with U.S. rates)



Source: DC Cancer Registry, SEER

the past 3 years and 94% reporting they ever had a Pap smear. Despite these high rates, there has been a worrisome decline in the proportion of women reporting a recent Pap smear (see Figure 2). There is some indication that this trend reflects an influx of Latinas, many of whom are emigrating from countries with very high rates of cervical cancer and poor access to screening.

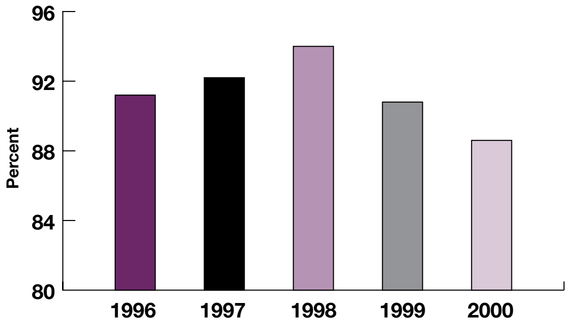
Almost all women with cervical cancer are infected with human papillomavirus (HPV), which is the main cause of this cancer. (Note, however, that although infection with HPV is apparently necessary for cervical cancer to develop, most women infected with HPV clear the infection spontaneously and do not develop cervical cancer.) Retrospective reviews of new cases of cervical cancer, or follow-back studies, consistently report that the majority (45% to 65%) of new cases occur in women who have never been screened or among those whose last test was three or more years before their diagnosis. Among cases with recent screening, up to one-third of cases have been interpreted as failure to detect existing precancerous or cancerous lesions, and between 4% and 30% of cases failed to receive timely, or any, diagnostic evaluation.

Risk factors for cervical cancer

Studies show that several factors increase the risk of cervical cancer. Risky behaviors exert their influence through their effects on the risk of acquiring or maintaining specific strains of infection with human papillomavirus (HPV). Women who are sexually active at an early age, or have multiple sexual partners, are at greater risk of infection. Women who acquire HPV are at greater risk of having that infection persist to cause cancer if they are older, smoke, are pregnant, are infected with HIV or are otherwise immune suppressed, have severely limited diets (poor in folic acid, vitamin C, and other micronutrients), or use oral contraceptive pills. Women who are poor and have no health insurance or regular source of health care are at greater risk of dying from advanced cervical cancer because, in that population group, rates of screening, follow-up on abnormal tests, and definitive cancer treatment are much lower. Women who undergo a complete hysterectomy for conditions other than cancer are no longer at risk of developing abnormal cervical tissue because all cervical tissue has been removed.

In a study characterizing HPV infection among DC women, Hildesheim and colleagues found a 34% prevalence of HPV infection among 400 low-income women with normal Pap smears who were receiving care at publicly funded clinics in the late 1980s. We do not have any more recent data using newer, more sensitive HPV tests, so the rates are probably higher at present. Many of the women among DC's growing Latino population have recently emigrated from countries in Central and South America that have some of the world's highest prevalence rates for HPV infection and cervical cancer. Cervical cancer is the

Figure 2. Rising and falling trends in Pap smear screening in DC*



**Women 18 and older who have not had a hysterectomy and report having had a Pap smear in the past 3 years.*

Source: DC Behavioral Risk Factor Surveillance System

fourth leading cause of death from cancer in Latinas in the United States. According to SEER 2000 data, Latinas have the highest rates of cervical cancer rates of all U.S. population groups.

Screening for cervical cancer

Screening for cervical cancer is recommended starting within the first three to five years after the onset of sexual activity or by age 21. After two or three negative annual Pap smears, screening is recommended every two or three years. The American Cancer Society and the American College of Obstetricians and Gynecologists recommend the FDA-approved HPV DNA test as a reasonable approach to screening women 30 or older, as an alternative to examination alone. If a woman has had more than five to seven normal Pap smears, including a normal Pap smear within the past three years, screening can probably cease after age 65 or 70. Screening is also unnecessary for women who have had a hysterectomy for noncancerous conditions or for women with medical conditions limiting life expectancy to less than five years.

The most important reason that women present with cervical cancer that has already spread or die from this disease is failure to obtain a regular Pap smear. Roughly half of the cervical cancers detected nationally are in women who have never been screened and 10% are in women who haven't been screened within the last five years. For Pap smear screening to lead to early detection of precursors of cervical cancer or invasive disease, women must receive regular Pap smear screening, the quality of the smears and their interpretation must be adequate, and when findings are abnormal, follow-up and resolution must be prompt.

Nationally, the main reasons women don't get Pap smears include the following: Their doctor fails to recommend it; they don't have a regular health care provider, live in an area with few primary care providers, or haven't had a recent visit; they don't know where screenings are available or why screening is important; they fear a cancer diagnosis or believe cancer cannot be cured; they want to avoid the inconvenience, discomfort, or embarrassment of the Pap smear; or they don't have time. If they don't have health insurance, cost is probably also a factor. And cultural beliefs held by new immigrants or other minority groups may also affect whether they seek screening. Similar problems with knowledge, attitudes, and beliefs have been reported as barriers to follow-up on abnormal screening tests or symptoms of cervical cancer.

The risk of dying from cervical cancer is greater in the District's medically underserved communities, including southeast DC. Where there are fewer primary and cancer care physicians there will be less patient education about risk factors, fewer recommendations for screening, and less access to treatment. The most common reason for failure to obtain a Pap smear is the health care provider's failure to recommend it.

Variations in sensitivity of Pap tests

Recent analyses suggest that Pap smears in general practice vary widely in ability to detect changes in tissue. Sensitivity may vary because of poor exfoliation of cells from the cervix, inadequate sampling by the provider, and/or inaccurate laboratory interpretation. Physicians also vary in their understanding of what makes a smear unsatisfactory. With so much variability in test performance, some women could be classified either false positive or false negative. There appears to be no data summarizing screening quality in the DC area. Adding HPV testing improves detection of true disease.

Follow-up after screening

Black women self-reported comparable or higher rates of Pap smear use than Whites starting in the 1980s, but rates of incomplete diagnostic follow-up and initial diagnosis at the stage of invasive and late-stage disease have been consistently higher among Black, Latinas, and other minority women. Problems with language, acculturation, and access, as well as fewer years spent in the United States account for low screening rates and late diagnosis among minority immigrant women.

Death from one gynecologic cancer—cervical cancer—is avoidable. Since the introduction of Papanicolaou (Pap) smear screening programs in this country in the 1950s, cervical cancer mortality rates have declined by about 75%. Despite high rates of disease, cervical cancer mortality has declined in DC as well.

Treatment for cervical cancer

Women diagnosed before cervical cancer spreads have a dramatically better chance of survival. Two other factors can influence stage-specific survival: the histological (cell) type of cancer and the treatment prescribed. In general, there are two main types of cervical cancer: squamous cell and glandular (adenocarcinoma). In the few studies conducted, there appears to be no difference in histological type in cancers in the DC (compared with the United States) that would lead to lower survival rates in DC. But studies show that about 10% of all women diagnosed with invasive cervical cancer receive no cancer-directed therapy or receive inappropriate care. Minority women, older women, and women with distant or unstaged disease are less likely to receive cancer treatment. We found no studies of cervical cancer treatment patterns in the District.

Reaching women and preventing deaths

Invasive cervical cancer is a preventable disease. Even the highest cervical cancer rates in the country translate into relatively few women affected (compared with other cancers), but all cases of invasive cervical cancer—especially those arising from lack of screening or adequate follow-up—signal the public health system's failure to detect and treat this disease at its early, pre-invasive stage. All cases of invasive cervical cancer should therefore trigger a careful review of missed opportunities for controlling the disease.

Research indicates that efforts to reduce HPV prevalence, increase screening rates or Pap test sensitivity, or improve compliance with follow-up will all yield significant reductions in cervical cancer incidence and mortality. So will improved treatment. Interventions to increase Pap smear screenings vary tremendously in effectiveness. Because the levels of HPV prevalence, screening frequency and quality, and treatment are largely unmeasured in the District, it is difficult to select a single “best” cancer control strategy. Interventions that have proven effective elsewhere include mailed or telephone reminders to get a Pap smear (which increased Pap smear use by up to 18.8%), using a culturally appropriate lay health worker (which increased use by 18.0%), and offering same-day screening using a nurse-practitioner (which increased screening by 32.7%). Various interventions should be tested and evaluated for effectiveness with different District populations.

Newer interventions in development may have future applications in DC. For instance, vaccines to prevent infection in women with HPV 16 and 18 are expected to become available in the near future. Immunization would need to occur before the onset of sexual activity. Data on the efficacy of HPV vaccines in males are not yet available. The first clinical trials have shown 100% effectiveness, so this technology is promising.

ENDOMETRIAL (UTERINE) CANCER

Endometrial cancer, which develops from the endometrium, the inner lining of the uterus, is the fourth most common cancer in women, after lung, breast, and colon cancer. In 2005 about 40,000 women nationwide will be diagnosed with endometrial cancer; about 7,300 are expected to die of the disease. About 70% of all cases of endometrial cancer occurs in women aged 45 to 74; only 8% occur in younger women. The chance of any woman being diagnosed with endometrial cancer is about 1 in 40, according to the National Cancer Institute.

After increasing from 1988 to 1998, incidence rates of endometrial cancer leveled off through 2001. The 5-year relative survival rate is 85%, and when this cancer is diagnosed at an early stage—as is the case for most women—the 5-year survival rate increases to 96%. Although this cancer is 40% more common in White women, Black women are nearly twice as likely to die from it. Survival rates for Whites exceed those for Blacks by at least 10 percentage points at every stage of diagnosis.

Burden of endometrial cancer in Washington, DC

In 2002, 84 women were diagnosed with endometrial cancer, and 31 died of the disease, as reported in the latest information available from the DC Cancer Registry.

Endometrial cancer mortality rates in DC increased slightly from 1978-2002 but have remained stable in the period 1998-2002. Mortality rates in the District for Black women are higher than those for White women, and higher than those for Black women nationwide.

Risk factors for endometrial cancer

According to a recent publication for physicians from the American College of Obstetricians and Gynecologists (ACOG) and the Society of Gynecologic Oncologists, the most common cause of endometrial cancer is an excess of estrogen, a female hormone, often found in women who take estrogen therapy alone after menopause. However, women who take combination birth control pills (estrogen plus progestin) appear to have a lower risk. Other risk factors include

- Not ovulating regularly and often missing menstrual periods
- Beginning menstruation before age 12
- A history of infertility or never having given birth
- Experiencing menopause late in life

- Use of tamoxifen, an anti-estrogen drug used to treat women with breast cancer
- Obesity and/or diabetes
- A high-fat diet
- Family history, especially for women with the inherited tendency to develop a type of colon cancer called hereditary nonpolyposis colon cancer (HNPCC)
- Endometrial hyperplasia (abnormal thickening of the endometrium)
- Breast or ovarian cancer
- Prior pelvic radiation therapy.

It's important to understand that only a small percentage of women who have only one of these risk factors will develop endometrial cancer.

Interventions to decrease the burden of endometrial cancer

Prevention. Most cases of endometrial cancer cannot be prevented. However, these steps can help lower risk:

- Use of oral contraceptives. Taking these for a long time appears to offer protection for at least 10 years after a woman stops taking them.
- Controlling obesity and diabetes
- Eating a diet high in fruits, vegetables and whole grains
- Regular exercise.

Screening and early detection. At present there is no early detection test or examination recommended for women without symptoms who are at average risk for this disease. The American Cancer Society recommends that at the time of menopause, women should be made aware about the signs and symptoms of this cancer, especially the importance of seeking immediate treatment for any vaginal bleeding. About 90% of women with endometrial cancer develop vaginal bleeding or discharge that generally leads to early diagnosis. The Pap test for cervical cancer does not detect gynecologic cancers other than cervical cancer.

Treatment. Treatment for endometrial cancer depends on the type and stage of the cancer when it is diagnosed and each woman's overall health. It is important that women with this cancer have their cancers thoroughly and systematically staged to help determine the best course of treatment. Surgery is the most common treatment for endometrial cancer, and in some cases radiation treatment may be recommended. Chemotherapy may sometimes be used, and hormone therapy is also an option for some forms of endometrial cancer.

Follow-up. After treatment for endometrial cancer is complete, monitoring for recurrence should include pelvic examinations every three to four months for two or three years, and then twice a year thereafter. About 75% of recurrences are found within the first three years of followup; thereafter, recurrence is less likely.

Barriers to care for endometrial cancer

Barriers include:

- The absence of a screening test
- Unawareness of the fact that vaginal bleeding or discharge is an early and important warning sign for this cancer—thereby delaying diagnosis and treatment
- Limited access to specialists, which may mean that initial surgery for this cancer may not produce the careful staging of the disease needed to determine optimal treatment

- Delays in treatment, inadequate monitoring of the disease during and after treatment, and inadequate support for side effects from treatment because patients are uninsured or underinsured (a recurrent theme).

OVARIAN CANCER

Ovarian cancer is the deadliest of gynecologic cancers, accounting for more deaths than any other cancer of the female reproductive system. This cancer, for which there is presently no screening test for the general population, is the fifth most commonly diagnosed cancer among women, ranking second among gynecologic cancers. Ovarian cancer represents about 3% of all cancers diagnosed in women. Nationally about 22,220 women are expected to contract the disease in 2005, and 16,210 women will die from it.

During 1995-2001, the incidence of ovarian cancer declined at a rate of 0.8% a year, with rates declining fastest in women 65 or older. The incidence of ovarian cancer is 18.1 for Whites (per 100,000 women, age-adjusted to the 2000 U.S. population standard) and 12.0 for Blacks. The mortality rate for Whites is 9.3; for Blacks, 7.6.

In 1995-2000, about 78% of women with ovarian cancer survived one year after diagnosis and, according to the American Cancer Society, the overall 5-year survival rate is 44%. For women diagnosed and treated before the cancer has spread outside the ovary, the 5-year survival rate is 90 to 95%. But only 21% of ovarian cancers are found at this early, localized stage.

Burden of ovarian cancer in Washington, DC

In 2002, the latest data available from the DC Cancer Registry reported that 41 women in the District developed ovarian cancer (see Table 1), and 32 died of the disease.

The disease has a very high rate of recurrence, especially for the great majority of women who are diagnosed with cancer that has spread beyond the ovary. Women in recurrence often undergo years of treatment before a majority succumb to the disease.

Impact of disease stage. Statistics for 1997-2001 show that 58% of Black women diagnosed with ovarian cancer in DC have advanced disease (regional or distant metastases), compared with 45% of White women. Early-stage diagnosis is a strong predictor of treatment success for all women with ovarian cancer.

It is worth noting is that in the District, 24% of Black women and 28% of White women are reported as having “unknown” staging. This suggests either pervasive reporting problems or a relatively high percentage of surgery on ovarian cancer patients that may not be performed by gynecologic oncologists, the physicians who specialize in treating women with gynecologic cancers.

Table 1. Incidence for ovarian cancer in DC (by race, 1997–2002)

	1997	1998	1999	2000	2001	2002	Total Count
White non-Hispanic	8	11	15	17	7	14	72
Black non-Hispanic	23	23	19	32	26	27	150
All races	36	40	38	52	36	41	244

Source: DC Cancer Registry

Risk factors for ovarian cancer

Age. The risk of ovarian cancer increases with age, especially at or after menopause. About 50% of all ovarian cancers are found in women over 63.

A family history of ovarian cancer. Women with a family history of ovarian cancer have a higher risk of developing it. Women with a personal or family history of breast and/or colorectal cancers are also at increased risk. Risk may be inherited from either side of the family. However, only about 10% of ovarian cancers result from an inherited tendency to develop the disease. Mutations of the BRCA 1 and BRCA2 genes produce a very high risk of ovarian cancer. Also, hereditary nonpolyposis colon cancer (HNPCC), a syndrome caused by gene mutations, puts people at high risk for colorectal cancer and endometrial (uterine) cancer. While the risk level for ovarian cancer is much smaller with HNPCC than with the BRCA1 and BRCA2 mutation, this genetic mutation does cause 1% of all ovarian cancers.

Infertility or history of no childbearing. Some research shows that prolonged use of the fertility drug clomiphene citrate, especially without achieving pregnancy, may increase risk for developing ovarian cancer. Also, women who have had no children or who had their first child after age 30 or experienced menopause after age 50 may have an increased risk of ovarian cancer, as there appears to be some correlation between the number of menstrual cycles in a lifetime and the risk of ovarian cancer.

Use of estrogen replacement therapy and hormone replacement therapy. Recent information suggests that using estrogen replacement therapy (ERT) increases the risk of developing ovarian cancer, and that the risk increases with continued use. The risk among women who used ERT longer than 10 years was almost double that of women who had never used it, and the risk tripled among those who used it for 20 years or more.

Interventions to decrease the burden of ovarian cancer

Prevention. There is no proven way to prevent the development of ovarian cancer, but steps can be taken to reduce risk. Women with a family history of ovarian cancer and/or breast cancer may consider genetic testing, surgical removal of ovaries and fallopian tubes, and other steps that may help decrease risk. Decisions about risk reduction should be made in consultation with family members and health care professionals who can help assess risk and available options.

Increased awareness of symptoms. Conventional medical wisdom used to be that there were no symptoms of ovarian cancer, but recent research has documented a clear cluster of symptoms. It is important to teach women to be aware that a cluster of symptoms—including back pain, fatigue, bloating, constipation, abdominal pain, and urinary urgency—may be warning signs when they occur frequently and increase in severity over time.

Screening. There is no reliable screening method for ovarian cancer at present. Available methods now include a CA-125 blood test and a transvaginal ultrasound for women who have symptoms suggesting ovarian cancer or who are at high risk for the disease. Only about half of women with early-stage ovarian cancer have elevated levels of CA-125, and the test sometimes produces false-positive results. Neither of these tests is intended for general screening and neither is accurate enough to justify use in routine care for women, but a clinical trial is presently under way to determine the effectiveness of this combination of tests for women at high risk.

Development of better screening tests.

At present numerous approaches are being tested to develop a screening test, including studies based on proteomics (the study of cell proteins). It is thought that changes in an organ caused by the presence of a disease such as cancer may produce detectable changes in the patterns of blood proteins, enabling testers to detect the difference between cancer and noncancer. Several specific patterns for ovarian cancer have been identified, involving different analysis techniques, but tests need to be validated in clinical trials involving large groups of women before it can be determined if a reliable screening test is possible using this approach.

Treatment. Treatment for ovarian cancer is generally predicated on the stage of the disease but almost always involves surgery and chemotherapy. The kind of surgery depends on how far the cancer has spread. Evidence shows that these complex surgeries should be performed by a gynecologic oncologist, a cancer specialist expert in this surgery. These specialists will stage the cancer appropriately and will remove as much of the cancer as possible. Chemotherapy is almost always given to women with ovarian cancer, especially those whose cancer has spread beyond the ovary. In some instances, radiation therapy or other treatments may also be recommended.

Support

Access to support during and after treatment is important to women with ovarian cancer, as many cancers recur and women may need support, information, and assistance for years beyond initial diagnosis. Some DC area cancer centers—notably Georgetown University Lombardi Cancer Center and George Washington University Cancer Institute, both in Ward 2—have ongoing moderated support groups specifically for women with gynecologic cancers.

Initial ovarian cancer treatment, including surgery and chemotherapy, often lasts for almost a year, and many women achieving remission will require months beyond the end of treatment to achieve their former energy levels and the abatement of chemotherapy's side effects. Moreover, recurrence rates are high, and women facing recurrence also face difficult chemotherapy regimens and perhaps additional surgery. Women who are well supported by family, friends, and compassionate employers face a less challenging time than those who are not.

Most ovarian cancer chemotherapy can be given at physicians' offices, at cancer centers and other hospitals, and, in rare instances, at clinics. Many of the hospitals treating gynecologic cancers are located in Wards 1, 2, 3, and 4 (Howard, George Washington, Georgetown, Sibley, and Walter Reed); Wards 6, 7, and 8 are distant from the area's cancer centers. Women who rely on public transportation to reach treatment face an additional burden.

Barriers to care for ovarian cancer

There are several barriers to adequate care of ovarian cancer patients, apart from the fact that there is no reliable screening tool for ovarian cancer. Barriers include:

Not recognizing warning signs and symptoms. Lack of awareness of the subtle warning signs of ovarian cancer by physicians and patients can produce a late diagnosis. Moreover, some women erroneously believe that the Pap test also screens for ovarian cancer.

Delayed diagnosis. Some medical professionals may be unaware that ovarian cancer has symptoms and may misdiagnose women in their care, especially since many of the symptoms of the disease can be confused with other conditions. Not infrequently women diagnosed with ovarian cancer complain of long waits and of needing to see multiple physicians to get a correct diagnosis.

Limited access to specialists. Surgery is sometimes performed on women with ovarian cancer by doctors with no specialized training in gynecologic oncology. This results in less-than-optimal surgery and inadequate screening, which may yield inadequate treatment throughout the course of the disease.

Inadequate treatment. For women who are uninsured or underinsured, the District's clinics and Medicaid may offer the only avenue for getting treatment for ovarian cancer. There is no research documenting these problems in the District, but anecdotal evidence suggests that in this environment women may experience delayed treatments, missed treatments, insufficient monitoring for disease progression and recurrence, no appropriate treatment for side effects, and insufficient social support. Patients who rely on the District's Healthcare Alliance system suffer because very few physicians and other health care professionals are willing to treat them because of the Alliance's reputation for late and below-cost reimbursement for services and for medications for managing the disease and side effects.

Goals, Objectives, and Strategies

GOAL 1: Identify a greater proportion of cervical cancer cases before the cancer has spread beyond the local stage.

Objectives and strategies:

1) Increase the proportion of women diagnosed at the local stage to 90% by 2010.

- Conduct a retrospective review of invasive cases to identify missed opportunities or problems with the quality of care.
- Focus resources on identifying and screening women 30+ who have never had Pap smears.

2) Increase the rate of Pap screening to 90% (recent screens) and 97% (ever-screened) in all subgroups by 2010.

- Survey women to assess knowledge, attitudes, and behaviors and to address barriers to regular screening. Use a multilingual survey and a large enough sample to analyze subgroups.
- Target outreach to Latinas and Asian women, based on survey data.
- Target outreach to oldest women and women who have never been screened.

GOAL 2: Make 50% of women aware that postmenstrual bleeding is a possible symptom of endometrial cancer by 2010.

- Evaluate the feasibility of public education about (and ascertain level of knowledge about) endometrial cancer symptoms.
- Develop a public education campaign.

GOAL 3: Increase public awareness of ovarian cancer symptoms.

1) Reduce the incidence of late-stage diagnosis by 2010.

- Conduct a public education campaign in the District, especially targeted to high-risk women.
    - Develop culturally appropriate information, materials, and training for health care clinics.
    - Develop information, materials, and training for senior citizen centers.
    - Develop information for distribution to health care providers.

2) Improve the amount of accurate staging of ovarian cancer and reduce the proportion of cases classified as “stage unknown” to less than 5% by 2010.

- Develop physician awareness programs to make community-based primary care physicians, gynecologists, and surgeons aware of the need for appropriate use of gynecologic oncologists.

GOAL 4: Improve the quality of care for underinsured and uninsured women in the District who have gynecologic cancer.

1) Increase information and support to DC clinics and providers treating the target population by 2010.

- Implement a patient navigation system in clinics for women with gynecologic cancers.
- Implement a targeted information campaign to make women eligible for Medicaid benefits aware of and use community services and resources.
- Provide continuing professional education for providers operating in District health care clinics.
- Encourage gynecologic cancer advocacy groups in the community to provide education and program support in District clinics and cancer centers.

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Colorectal Cancer

Facts in brief:

- Colorectal cancer, the third most common cancer in the country, is responsible for 10% of all cancer deaths. There were an estimated 146,940 new cases nationally in 2004 and 56,730 deaths. Among men and women, DC has the highest mortality rate from colorectal cancer, higher than the national norm.
- The lifetime risk of developing colorectal cancer for both men and women is 6%. Americans who die from colorectal cancer lose on average 13.4 years of life.
- Since 1985, the incidence of and mortality rate for colorectal cancer has been declining about 2% a year, although the decline has been more prominent among Whites. The decline is attributed largely to increased screening and surveillance and improvements in treatment.
- Early detection reduces mortality. Most invasive colorectal cancers begin as polyps, and it takes an average 5 to 15 years before polyps become malignant and form invasive cancers.
- The cancer is detected at an early stage, when survival rates are better, among only 27% of White men, 25% of White women, 24% of Black men, and 23% of Black women. For all stages combined, the relative 5-year survival rate is 63% for Whites and 53% for Blacks.
- Everyone age 50 or over is at risk and should be screened.
- If there is to be only one colonoscopy screening in a lifetime, the most effective age to screen is at 60. Data suggest that screening at this age can reduce mortality from colorectal cancer by 70%. It is better to screen once than not at all.

The burden of colorectal cancer in Washington, DC

Among U.S. men and women, Washington DC has the highest mortality rate from colorectal cancer, higher (at 25.0 deaths per 100,000 people) than the average U.S. rate (21.2 cases/100,000) (see Table 1). Against a 25-year trend downward in colorectal mortality rates among Blacks in the U.S., the past 5 years have seen an increase in colorectal mortality rates in Blacks in DC..

The annual incidence rate for DC (59.8 cases/100,000) is higher than the national incidence (53.1 cases/100,000). And the rates of colorectal cancer are higher for Blacks than for Whites in all age groups. In DC, the incidence of colorectal cancer is highest in Wards 2 and 5 and lowest in Ward 3 (see Table 2). Ward 8, despite its high level of poverty, has a relatively low number of cases, perhaps because young people comprise a significant proportion of the ward. *For 2005, the estimated number of new cases of colorectal cancer in Washington DC (340) is greater than the estimated number of lung cancer cases (310)—and the number of expected deaths from colorectal cancer in DC is 130.*

Table 1. Deaths from colorectal cancer in the District (1998-2002, by gender and ward)

	Men and women		Men		Women	
	Deaths	Rate	Deaths	Rate	Deaths	Rate
District of Columbia	695	25.0	311	24.7	384	25.2
Ward 1	66	26.7	30	23.7	36	29.8
Ward 2	80	31.4	35	29.3	45	33.2
Ward 3	90	22.2	40	23.8	50	21.1
Ward 4	114	23.7	49	23.5	65	23.8
Ward 5	119	25.5	55	25.0	64	26.1
Ward 6	88	27.7	41	28.7	47	26.8
Ward 7	92	24.0	39	22.0	53	25.7
Ward 8	45	20.8	22	25.0	23	18.0
Unknown[1]	^	~			^	~

Note: Rates are per 100,000 persons and are age-adjusted to the 2000 U.S. standard population.

[1] Address for cancer death unknown

^ Number of deaths 5 or less not reported because of confidentiality issues

~ Number of deaths too small (25 or less) to calculate reliable rate.

Source: DC Cancer Registry

Table 2. Incidence of colorectal cancer in the District (1998-2002, by ward)

	Men and women		Men		Women	
	Cases	Rate	Cases	Rate	Cases	Rate
District of Columbia	1,666	59.8	745	59.3	921	60.2
Ward 1	155	62.0	65	51.0	90	72.8
Ward 2	184	69.6	83	67.6	101	71.3
Ward 3	194	47.4	71	42.5	123	50.9
Ward 4	259	55.2	112	56.3	147	54.4
Ward 5	318	68.1	149	66.1	169	70.0
Ward 6	197	60.8	93	63.4	104	58.6
Ward 7	213	56.0	107	60.9	106	51.7
Ward 8	134	61.2	59	65.2	75	58.5
Unknown	12	~	6	~	6	~

Note: Rates are per 100,000 persons and are age-adjusted to the 2000 U.S. standard population.
~ Number of deaths too small (25 or less) to calculate reliable rate
Source: DC Cancer Registry

Risk factors

Nonmodifiable Risk Factors

Advancing age. Age is the most common risk factor for colorectal cancer. The incidence of the disease increases with age, especially after 60. Thus, screening becomes more effective with age.

Family history of the disease. Most colorectal cancer is found in people who are not at high risk. But specific mutations have been found in two types of colorectal cancer sometimes inherited in families (see Genetic testing).

Modifiable risk factors

Colonic or rectal polyps. Nearly all colorectal cancer evolves from adenomas, benign tumors that often grow as a polyp. Polyps are common; when large, they may progress to invasive cancer. But polyps can be both identified and removed through colonoscopy screening. Colonoscopy is required to remove the polyps before they become cancerous. Post-mortem studies show that 25% to 50% of the populationwill have single or multiple adenomas in the colon by age 70.

Inflammatory bowel disease. Inflammatory bowel disease is associated with a risk for colorectal cancer. Ulcerative colitis that persists for many years may lead to an usually high risk. Crohn's disease (sometimes called regional ileitis) is also, but infrequently, associated with the cancer.

Inappropriate diet. Studies suggest that obesity is a risk factor for colorectal cancer. Other factors have been implicated, including low consumption of fiber and high consumption of red meat and fat, but these findings have not been substantiated.

Reducing deaths from colorectal cancer

The main interventions to reduce deaths from colorectal cancer include prevention, genetic testing (when appropriate), screening and early detection of precancerous lesions and cancer.

Primary prevention

Encourage changes in what and how much people eat. Dietary interventions are designed to promote and increase the consumption of foods and nutrients known to reduce the risk of cancer. This means less meat and more fruits, vegetables, and fiber. It also means reducing obesity, a recognized risk factor for colorectal cancer and many other diseases.

Encourage more physical activity. There is evidence that regular physical activity may help prevent the onset of many forms of cancer.

Genetic testing

Encourage genetic testing, when appropriate. Individuals with a family history of colorectal cancer can have their DNA tested to determine whether they have inherited the HNPCC syndrome (hereditary nonpolyposis colorectal cancer) or the FAP (familial adenomatosis polyposis) syndrome, two mutations known to predispose families to colorectal cancer. The HNPCC syndrome often occurs in patients younger than 50, so early testing is advised whenever there is a family history of colectal cancer.

Screening and early detection

Screening improves the chances of early detection and the removal of benign adenomatous polyps (precancerous lesions) and the detection of small, localized cancers that are surgically curable. Unfortunately in DC, two-thirds of colorectal cancers are diagnosed beyond these pre-cancerous or early (localized) stage (see Table 3). The National Cancer Institute estimates that wide use of screening could save more than 20,000 lives a year.

Four screening tests are in common use: *the fecal occult blood test, sigmoidoscopy, colonoscopy, and radiological visualization with double-contrast barium enema.* Only the fecal occult blood test can be considered a true screening test because of its reliability, low cost, simplicity, and availability.

Fecal occult blood test (FOBT). The most common screening test for colorectal cancer, FOBT detects small quantities of blood present in the stool. The test, which can be performed at home, is simple, inexpensive, and available from drug stores. To reduce the risk of cancer, the test should be performed annually for at least 10 years, under a physician's guidance. Because FOBT is a screening test and not a diagnostic test, a positive result should be followed by a colonoscopy. Unfortunately, a high rate of false-positive results greatly increases the number of unnecessary colonoscopies performed. Physicians should inform patients in advance about substances in the diet (such as vitamin C) that can produce misleading test results.

> ***Early detection reduces mortality. Most invasive colorectal cancers begin as polyps, and it takes an average 5 to 15 years before polyps become malignant and form invasive cancers.***

Sigmoidoscopy. A standard procedure that examines only the distal or left colon and rectum, the sigmoidoscopy is only moderately expensive and takes only a short time. Although sigmoidoscopy is considered effective in reducing deaths from colorectal cancer, many physicians do not recommend it because it examines only the left side of the colon. If cancer or precancerous lesions are found, colonoscopy must follow.

Colonoscopy. Fiberoptic colonoscopy is the gold standard in screening, permitting visualization of the inside of the entire colon. Colonoscopy has substantial drawbacks as a screening test. It requires highly trained personnel and is expensive and time-consuming. An intravenous catheter is used to administer sedatives, recovery time is one hour, and a second person must accompany the patient home. But colonoscopy is the only procedure that can identify and remove precancerous polyps and detect early cancer. Colonoscopy should be required of everyone in whom cancer is suspected, who has had previous colorectal cancer, or who is at very high risk. Colonoscopy is most effective in preventing cancer if performed between the ages of 56 and 66, when precancerous polyps are most likely to be present.

Double contrast barium enema. Often used for surveillance by radiologists, this may be useful in some cases for identifying polyps that are difficult to recognize by colonoscopy. Most often, patients are referred by their physician for this procedure.

Follow-up for high-risk patients

Repeated screening at specified intervals is recommended for individuals who are at high risk because of previous polyps, a family history of the disease, inflammatory bowel disease, or curative-intent resection (surgery) for colorectal cancer. The idea is to detect cancers early so they can be treated before they are able to metastasize. Patients with a history of polyps or surgery for colorectal cancer should undergo regular surveillance, because new polyps or additional primary cancers often arise in the colon years later.

Barriers to reducing the cancer burden

Screening rates for colorectal cancer remain lower than those for other cancers. Less than

Table 3. Stage of colorectal cancer at diagnosis in DC men (1998-2002, percentage by ward)

	Localized (%)	Regional (%)	Distant (%)	Unstaged (%)
District of Columbia	33.3	34.6	20.0	12.2
Ward 1	31.0	35.5	20.6	12.9
Ward 2	33.2	32.1	18.5	16.3
Ward 3	42.3	34.5	13.4	9.8
Ward 4	33.2	39.4	17.4	10.0
Ward 5	33.0	34.6	22.3	10.1
Ward 6	33.5	31.5	21.8	13.2
Ward 7	29.6	31.5	23.0	16.0
Ward 8	27.6	38.8	23.9	9.7

**Includes in situ and local stages*
Source: DC Cancer Registry

half of the U.S. population age 50 and older takes advantage of colorectal cancer tests within the recommended time intervals, according to a National Health Interview Survey. A successful prevention and control program requires recognizing the barriers to screening for cancer and finding the resources to overcome them—whether they are associated with patients, health care providers, or the health care system itself. In the final analysis, the most commonly reported barriers to screening are a lack of awareness about testing and the physician's failure to recommend testing.

Common barriers as patients see them

The public appears not to have been well informed about the risk of, or the risk factors associated with, colorectal cancer. Despite widespread publicity about colon cancer, increased reimbursement for screening, and data from national health surveys, the screening rates for colorectal cancer are significantly lower than those recorded for breast or cervical cancer. Common reasons for not undergoing screening include

- Practical issues, such as inconvenience (an entire day is required for a colonoscopy)
- Conflicts with work or family
- Lack of insurance or medical coverage
- Lack of interest
- The tests' unpleasantness
- Anxiety about the results
- Lack of access
- Lack of awareness about testing
- Fear of cancer
- The idea that cancer cannot be cured
- Age (young patients are less compliant than older patients)
- The physician's failure to recommend the test.

Barriers among health care providers

The key factor in promoting cancer screening is a physician-patient relationship of trust. Patients are most likely to comply with screening if their physician recommends it. One important barrier to screening is the health care providers' failure to take a careful family history of cancer and to refer family members for testing if there is evidence of a familial pattern. Other barriers include little or no access to screening facilities, lack of trained personnel, lack of information about screening centers, and practice- or capacity-related problems.

Barriers in the health care system

Economics and limited access are barriers to screening. Reimbursement seems to have a positive effect on screening rates. The relative odds of Medicare beneficiaries with incomes below $25,000 a year getting a sigmoidoscopy increased between 1997 and 1999. All groups should be made aware that Medicare provides reimbursement for colonoscopic screening performed every 10 years for patients at average risk.

Rules about reimbursement coverage need to be clarified because lack of knowledge or widespread variation in reimbursement rules and application serve only to discourage screening. Screening should be included in health plans offered by both private and government sources, and reimbursement should not be so low as to discourage screening. Insurers should be made aware that routine screening is cost-effective because it prevents costly treatment and hospitalization.

Goals, Objectives, and Strategies

GOAL 1: Reduce the mortality rate in DC from colorectal cancer by 10%.

GOAL 2: Reduce the incidence of invasive disease in DC by 10%.

Objectives:

1) Increase to 50% the proportion of colorectal cancer detected at the local stage for both men and women by 2010.

2) Increase to 50% the proportion of the adult population that reports having had a fecal occult blood test in the previous 2 years by 2010.

3) Increase to 60% the percentage of the population age 50 or older screened by sigmoidoscopy or colonoscopy by 2010.

Strategies

- Encourage professional organizations to promote screening among their members. Collaborate with DC's medical societies to promote colorectal cancer prevention and control and to overcome barriers to screening. Seek representation on the Public Health and Communications Council of the Medical Society in Washington. Invite professional medical organizations, especially for primary care, to become active members of the DC Cancer Coalition.

- Develop the infrastructure to provide screening for all DC residents, whatever their cultural or ethnic background. Do this through collaboration among primary care physicians, internists, surgeons, and gastroenterologists. Create an enduring collaboration that includes public enterprises, research communities, and professional organizations with an interest in the causes, prevention, and consequences of colorectal cancer.

- Develop community education and outreach campaigns about common risk factors and early symptoms, the benefits of screening and lifestyle modification, centers for screening for all cancers, treatment facilities and support services, and the availability of financial assistance.

- Reduce cultural, ethnic, and financial barriers to screening by targeting education programs to the medically underserved and high-risk populations—taking into account language barriers and low rates of literacy.

- Encourage athletes, television personalities, politicians, teachers, and other role models to serve as advocates for routine screening (whatever the test).

- Increase the number of physicians who recommend screening to patients and who routinely take a family history of cancer. Train physicians to inquire about every patient's family history of cancer, whatever the purpose of their medical visit, and invite family members to undergo screening or genetic testing if a familial risk pattern exists.

- Encourage physicians to use reminder or other systems for recalling patients for screening.
- Make health care professionals aware of centers in DC for colorectal cancer screening and surveillance, of genetic testing and genetic counseling services, of treatment facilities, and of cancer rehabilitation centers.
- Through professional associations, arrange for scientific presentations, newsletter items, and postgraduate education about colorectal cancer prevention and control, including the benefits of early detection.
- Encourage at least once-in-a-lifetime colonoscopy screening at about 60 as a “rite of passage.” At least one colonoscopy is better than none, and colonoscopy is most effective at the age of 60.
- Promote better insurance coverage and other forms of assistance for colorectal screening.

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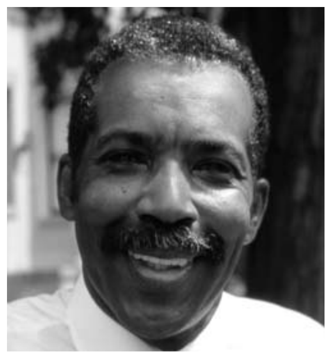
Prostate Cancer

Facts in brief:



- Prostate cancer is the second leading cause of cancer deaths among men in the U.S.—second only to lung cancer. One in three new cancer cases in men arises in the prostate gland.
- The projected number of new cases nationally in 2005 is 230,090—with an estimated 30,350 men dying from the disease. This is the most commonly diagnosed non-skin male cancer in most Western countries.
- Estimates are that 610 men in the District will be diagnosed with prostate cancer and 80 men will die from the disease in 2005.
- The lifetime risk of being diagnosed with invasive prostate cancer is 1 in 6. The risk increases from the age of 50 on. Men at higher risk (because they have fathers or blood-related uncles who had prostate cancer at an early age) should begin testing at age 45.
- DC has the highest mortality rate from prostate cancer in the nation. The rate is twice as high in Black men as in White. Incidence rates for Black men in DC are among the highest in the nation. The incidence and death rates for Black men are highest the world over, according to the International Agency for Cancer Research. The risk is lowest in men of Asian descent.
- Nationally, the median age for diagnosis is 66 for Black men and 69 for White men. The median age of death from prostate cancer is 77 for Black men and 79 for White.
- On average, 9 years of life are lost to prostate cancer.
- The causes of prostate cancer are largely unknown.
- Prostate cancer eventually affects nearly all men but is clinically unimportant in most men.

An uneven burden

Prostate cancer does not affect everyone equally. Its impact on Black men is especially hard. As far back as the 1930s, investigators documented racial differences in survival and mortality. The explanations offered today are the same as those offered years ago—including inadequate medical care, environmental factors, cultural differences, diet, hereditary factors, and social habits.

From 1998 through 2002, there were 2,671 new cases of prostate cancer in the District of Columbia (see Table 1).

Incidence and mortality rates (Tables 1 and 2) are highest in Wards 2 and 4. The incidence of prostate cancer in White men began to decline nationally in 1993 and for Black men in 1994. Differences in incidence, clinical stage, and histological (cell) grade are still found in every age group among White and Black men.

Prevention

Currently, there is no known way to prevent prostate cancer, although the National Cancer Institute is conducting research on prevention. Men are usually advised to avoid or minimize risk factors, but this is not always possible.

Table 1. Incidence of prostate cancer in DC (1998–2002, by ward)

	Cases	Rate
District of Columbia	2,671	213.7
Ward 1	225	187.0
Ward 2	319	262.1
Ward 3	301	178.2
Ward 4	519	253.0
Ward 5	428	191.2
Ward 6	291	198.9
Ward 7	375	211.9
Ward 8	190	215.2
Unknown	23	~

Note: Rates are per 100,000 men and are age-adjusted to the 2000 U.S. standard population.

~ Number of cases too small (25 or less) to calculate reliable rate.

Source: DC Cancer Registry

Risk factors for prostate cancer

Common risk factors include age, race, family history of the disease, diet, and serum androgen levels. Nearly all risk factors have been found through studies of White men, so additional risk factors specific to Black men are unknown. Most investigators have assumed that risk factors operate similarly across racial groups.

Age. Age is the strongest risk factor. Prostate cancer is largely a disease of older men; it is rare below the age of 50. The risk increases steadily with age and more than half of all men will have some cancerous growth by the time they are 80, although in most cases it goes unnoticed. Half of all cases are registered in men over 75 and 90% of prostate cancer deaths occur in men 65 and over.

Race. Prostate cancer's devastating effects on Black men are reflected in national data. For the years 1998–2002 in DC, the incidence rate of prostate cancer in White men was 160.8 for all ages and 252.1 for Black men. The mortality rate per 100,000 men was 23.4 for White men and 66.4 for Black.

The onset of invasive prostate cancer comes at a younger age in Black men, and Black men also register premalignant changes earlier. HGPIN (high-grade prostatic intraepithelial neoplasia), a premalignant lesion that progresses to invasive cancer, is more prevalent in Black men than in White. HGPIN was found at autopsy in 18% of Black men in their forties (compared with 14% of White men the same age); in 31% of Black men in their fifties (21% of White men); in 69% of Black men in their sixties (38% of White men); in 78% of Black men in their seventies (50% of White men); and in 86% of Black men in their eighties (68% of White men). More extensive HGPIN developed earlier in Black men younger than 60 than in White men the same age. The higher prevalence of HGPIN in Black men may explain the higher incidence of prostate cancer in this population, but questions remain as to what causes the higher incidence of HGPIN at a relatively young age in Black men.

Within a clinical setting, Black men are more likely to present with advanced-stage disease and less differentiated tumors than White men. The reason is unknown.

Differences between Black and White men are evident in many studies. In a military population in which all men have equal access to care, for example, Black men had tumors averaging two and a half times greater in volume at diagnosis, had higher mean (geometric) pretreatment PSA levels, and were 3 years younger on average than White men. The military setting may eliminate limitations on access but not necessarily socioeconomic factors or environmental differences that affect prostate cancer.

Table 2. Deaths from prostate cancer in DC (1998–2002, by ward)

	Deaths	Rate
District of Columbia	421	33.4
Ward 1	33	29.4
Ward 2	47	40.3
Ward 3	32	19.0
Ward 4	96	44.2
Ward 5	92	38.2
Ward 6	44	32.9
Ward 7	55	30.2
Ward 8	22	27.9

Note: Rates are per 100,000 men and are age-adjusted to the 2000 U.S. standard population.
Source: DC Cancer Registry

For years the Gleason score, an accepted prognostic factor based on histologic evaluation, has been known to correlate with outcome in prostate cancer. The score, which is evaluated at the time of surgical resection, reflects events that occurred in the tumor before discovery and treatment. Black men are diagnosed with higher Gleason scores than White men.

Finally, we know that screening and early detection are significant for survival. An important but unresolved issue is whether studies have documented that disparities in survival rates are eliminated by early diagnosis and by treatment before metastasis.

In sum, studies have shown that a racial/ethnic disparity exists in age of diagnosis and in incidence and mortality rates from prostate cancer. Studies also show that basic biological and clinical differences exist between prostate cancers in Black and White men. Some differences related to delays in diagnosis or inadequate treatment may be avoidable and clearly impose a heavier burden of disease on Black men. This burden will continue to affect the control and treatment of prostate cancer in a setting of disparity.

Family history of the disease. The relative risk of prostate cancer doubles if a man has one first-degree relative diagnosed at age 70 or under. Risk quadruples with two relatives, if one of them is diagnosed under the age of 65.

Diet. Increased risk has been associated with high consumption of fat, and decreased risk has been associated with consumption of isoflavones, vitamin E, selenium, vitamin D, and lycopene. But these associations have not been rigorously substantiated.

There are no consistent published data to support an association between body-mass index (BMI) and incidence of prostate cancer. But obesity has been associated with higher-grade cancer and higher recurrence rates after radical prostatectomy. Black men have higher recurrence rates and a greater BMI than White men, which suggests that obesity may be associated with the progression of latent to clinically evident prostate cancer.

Heavy consumption of red meat and fat from animal sources have been associated with an increased risk of prostate cancer in Black men. Circulating androgen levels are related to dietary fat intake and higher levels of androgen, especially dihydrotestosterone, may account for the higher prostate cancer risk in Black men. It has been suggested that reducing animal fat intake would reduce prostate cancer, especially the aggressive form, in Black men. The anti-oxidant lycopene has been thought to protect against the development of prostate cancer. In a multi-center, population-based case control study of 437 men, serum lycopene levels were lower in Black men than in White, raising the possibility that differences in lycopene exposure may contribute to the racial disparity. If dietary factors are involved in the disparity, as is often proposed, they must account for most if not all differences in the disease between Black and White men.

Epidemiological studies also support diet's role in the cause of prostate cancer. The disease is not as common in parts of the world where the diet is primarily plant-based and low fat.

Early detection and follow-up testing

Screening for early prostate cancer has had an impact, though largely in White men. As a result of screening, diagnosis is now made some 5 to 6 years earlier than it was in 1985, the proportion of cases diagnosed at an advanced stage has declined, the proportion of patients diagnosed at a "good-risk" stage has increased, and mortality rates have declined. Screening becomes more effective and more important for detecting cases in older men because the disease is more common as men age.

> ***DC has the highest mortality rate from prostate cancer in the nation. The rate is twice as high in Black men as in White men.***

There are limitations to the early detection of prostate cancer. Only two methods for screening are available: a blood test for prostate-specific antigen (PSA) and a digital rectal examination. Neither test is diagnostic but can only suggest a suspicion of cancer. The PSA blood test is more common but is not 100% predictive of cancer. If any result is positive, a biopsy must follow.

Screening for prostate-specific antigen (PSA). Our approach to prostate cancer underwent a revolution with the introduction of PSA screening in 1988. Screening remains controversial within medical communities, largely because it has not been proven in clinical trials to reduce mortality rates. The U.S. Preventive Services Task Force found insufficient evidence to recommend for or against routine screening using PSA, but it did find evidence that screening detects earlier-stage disease. The populations most likely to benefit from screening are men aged 50 to 70 and men 45 or older who are at increased risk—including Black men and men with a family history of the disease (especially in a father or blood-related uncle).

It should be emphasized that the most common cause of an elevated PSA test is benign prostatic hypertrophy, which is common in older men. Large prostates have more PSA, so a rise in PSA means that the gland is enlarging rapidly, which can be a sign of cancer, infection, or physiological enlargement with age. PSA levels can be raised for several hours just by having the prostate checked by digital rectal examination, so PSA blood tests should be drawn before the doctor examines the prostate. Having an ejaculation raises PSA for up to 48 hours. Active infections increase PSA levels and there is no way to differentiate between a PSA raised by cancer or by infection.

Digital rectal examination (DRE). Physicians often recommend a digital rectal examination, a simple procedure. It is painless and takes only a few minutes. The test is used as an adjunct to the PSA blood test, which is not always reliable. About 15% of men with an abnormal rectal examination will have prostate cancer.

Surveillance. Black men are at significantly greater risk for receiving less post-treatment PSA surveillance than White men. Black men are half as likely to receive annual post-treatment testing. The impact of reduced surveillance on care is important, since variations in testing may reflect a lack of access to good follow-up. Lack of access to health care is often cited as an explanation for the higher mortality rate among Black men. Lack of adequate surveillance may also have implications for subsequent medical conditions and costs. Moreover, Black men may need post-treatment surveillance more than White men because they more likely to have unfavorable prognostic factors. It has not been proven that adequate post-treatment testing improves survival or reduces morbidity. But if testing works, being tested less often may contribute to the higher mortality rate observed in Black men.

Treatment

Advances in PSA screening have led to a dilemma. Most cases of prostate cancer are now found through PSA screening, but autopsy studies show that many men die with prostate cancer but no clinical evidence of disease. So although prostate cancer is a common disease that may affect all men, especially those 70 and older, most prostate cancers do not progress or progress so slowly that the disease never surfaces during life. Medical ethics dictates that patients with cancer should be offered treatment. And because of the cancer's sinister reputation, many patients enter into treatment for a disease that may never progress or cause death. But for many men, the resulting over-treatment may have serious consequences. We assume that the more advanced or aggressive disease found in Black men will preclude more conservative therapy in many cases. This is likely to result in higher rates of complications because of the more extensive treatment required.

The issue here is not simply screening, which occurs less often with Black men, but apparently a more aggressive form of disease. In Black men the disease has an earlier age of onset than in White men, is usually found at a higher stage and grade, and is more likely to cause death. In DC, at least 20% of patients with prostate cancer are not assigned a stage by the physician. Staging is important for guiding appropriate therapy and estimating survival. It is also necessary for evaluating the results of treatment. Finally, staging is used an indicator of the quality of care.

Treatment options include:

- Surgical removal of the prostate. Newer treatment methods include laparoscopic surgery and robotic surgery, which reduce pain and post-operative time in the hospital.
- Radiation, either external or through seeds implanted in the prostate (brachytherapy).
- Cryosurgery (surgical procedure that destroys abnormal tissue by freezing).
- Chemotherapy.

All of these treatments may lead to urinary incontinence, sterility, and erectile dysfunction (impotence), although modern techniques can reduce these complications.

The reason for screening is that the patient is more likely to be cured if the cancer is diagnosed at an early stage, while still confined to the prostate, and then treated. It is important to identify and treat the patients most likely to succumb to prostate cancer.

There is disparity in treatment. Of 112,445 prostate cancer patients diagnosed in 1992–96, 46% of Black men (compared with 40% of White men) were not aggressively treated. Specifically, 33% of Black men did not receive cancer-directed surgery or radiation (compared with 28% of White men); and 13% of Black men (12% of White men) underwent a transurethral resection of the prostate only. Reasons for this difference were not fully evaluated despite the adjustment of a number of prognostic indicators. Nonaggressive management may have been influenced by many factors.

Barriers to reducing deaths from prostate cancer

The PSA test is the only blood test available for prostate cancer screening, and it is recommended by most professional organizations. But because of controversy about PSA testing, some physicians do not promote informed decision-making—do not fully help patients understand the seriousness of prostate cancer or the risks and benefits of screening and alternatives to it, do not help them decide what to do, and do not help them make decisions about screening that are consistent with the patients' preferences. Men should be able to discuss the advantages and disadvantages of prostate cancer testing with their physicians so they can make their own decision about screening.

The most important factor affecting whether a man goes for screening is whether his physician recommends or performs it. All physicians should automatically discuss the possibility of PSA testing for early prostate cancer with every male patient 50 and Black males 45 and over, as part of general medical care. Physicians who do not routinely advise testing or discuss prostate cancer with their male patients are contributing to the problem. So are health maintenance organizations that do not have an active prostate cancer screening and detection program or who do not make both their male and female participants aware of the program.

Goals, Objectives, and Strategies

GOAL: To reduce the mortality rate from prostate cancer in DC by 10%.

Objectives:

1) By the year 2010, increase to 65% the percentage of Black men who are screened annually for prostate cancer.

2) By the year 2010, reduce the proportion of unstaged cases to less than 5%.

Strategies targeted to patients:

- Insure that men receive clear and balanced information about the advantages and disadvantages of the PSA test and the location of diagnostic and treatment facilities.
- Inform men and their spouses or partners about the importance of an annual PSA test and the location of screening centers.
- Conduct large-scale screening campaigns sponsored by local community organizations through events likely to attract many men.
- Support activities of local community groups, church organizations, and others aimed at informing men about risk factors, the benefits of early detection, early symptoms, and the need for early treatment. Encourage such groups to enlist the help of sports figures and other role models from whom such messages might be more persuasive.
- Find ways to overcome negative cultural attitudes to testing and treatment through education, open discussion, and other ways of disseminating information.
- Inform elderly men about Medicare reimbursement for screening.

Strategies involving system-wide change or activities:

- Develop a system that connects and integrates information about screening, diagnostic services, treatment, insurers, and follow-up for all DC men, regardless of cultural background—so they know where and when to go for screening, diagnosis, treatment, follow-up, and personal support.
- Implement navigator and similar programs in which paid individuals or volunteers help patients with abnormal PSA tests find their way to appropriate diagnostic services, treatment facilities, medical appointments, second opinions, and follow-up exams.
- Arrange for area hospitals to offer free PSA screening on the same five consecutive days in September (National Prostate Cancer Awareness Month) for under- and uninsured men. Costs could be covered by the Department of Health, donations, and private industry. Ask physicians to donate time and ask the Ad Council to donate time for developing a marketing campaign.

- Expand the mobile screening program, especially for Black men. Such a program could also screen for hypertension, cholesterol, and other diseases.
- Encourage third party insurers and managed care organizations to conduct educational and screening campaigns with men 50 and over (45 and over, for Black men) in the same way they encourage mammograms for women.

Strategies targeting health care providers:

- Encourage all physicians to take a family history of prostate cancer in men of all ages. Make a family history of prostate cancer a required part of every male's medical record.
- Through local chapters of professional medical societies, encourage physicians to refer men for screening.
- Encourage physicians to set up effective reminder systems for annual screening for their patients.
- Make screening an expected part of every man's annual physical examination.
- Encourage full surveillance according to established guidelines for those who have been treated or who have elevated PSA levels.

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Pediatric Cancers

Facts in brief

- Each year about 12,400 children and adolescents in this country are diagnosed with cancer.
- Annual incidence rates for leukemia, the most common childhood cancer, increased about 20% from 1975 to 1998 and have since remained fairly stable.
- Nationally, childhood leukemia is diagnosed more often among Whites than among other racial and ethnic groups, but Black and Hispanic children have poorer survival rates.
- The annual incidence of invasive cancers in people under age 20 increased from 11.4 cases per 100,000 children in 1975 to 15.2 per 100,000 in 1998. This increase has slowed in recent years.
- Pediatric cancers are relatively uncommon but are the leading cause nationally of disease-related death among children from infancy through 14.
- In 1997-2001, 101 new cases of cancer were reported among children (from infancy through age 19) in the District of Columbia (see Figure 1).
- In the same period, 80 children and adolescents died from cancer in DC.

Although pediatric cancer represents only 1% of all cancers in the United States, it imposes a substantial burden on children, their families, and friends, and on the systems that provide services for them, both in the short and long term. As treatment becomes more effective, adolescents and adults who survive childhood cancer are living longer. With the blessing of longer lives come medical and psychosocial challenges that society and health care providers must understand and address.

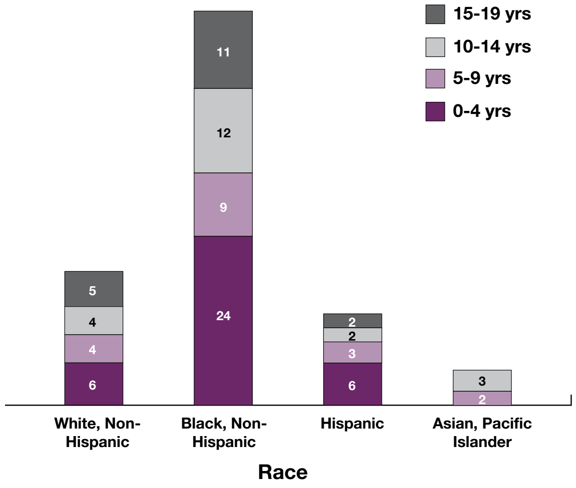
In the District of Columbia, cancer's ranking as cause of death varies by age group. It is the second most frequent cause of death among children 4 and under, behind birth defects. For children 5 to 9 years old it is the fourth most frequent cause of death, for those 10 to 14 it ranks fifth, and for those 15 to 24 it ranks sixth.

Great progress has been made in treating many childhood cancers and the mortality rate has declined significantly. In fact, among all cancers in the country, treatment of childhood cancers has been among the most successful. Between 1975-1979 and 1995-2000, survival rates for all childhood cancers rose from 57.6% to 77.1% for boys and from 68.3% to 81% for girls. However, the improvement in survival rates for adolescents (15 to 19) with invasive cancers has been nearly half that for other age groups.

Psychological impact on a child of diagnosis and treatment

Children's reactions to diagnosis and treatment have been the most studied aspect of pediatric oncology. Decades of research indicate that most children and families experience acute distress during the most

Figure 1. Number of cancer cases among DC youth, 1997-2001 (by race and age group, through age 19)



Note: Eight cases of cancer (in which race is unknown) are not included in this exhibit: four cases in children 4 and under, one in 5-to-9-year-olds, one in 10-to-14-year-olds, and two in 15-to-19-year-olds.

Source: DC Cancer Registry

intense treatment phases but that with time this distress subsides. Over the past three decades, numerous steps have been taken to reduce procedural distress and to improve communications with young patients about their disease and treatment. Still, many children with pediatric cancers continue to experience a range of distress symptoms and have difficulty accomplishing developmental tasks.

Older adolescents (15-to-19-year-olds) represent a unique subset of childhood cancer patients, distinguished by poorer outcomes, longer delays in diagnosis, much lower rates of participation in clinical trials than younger patients, and special kinds of psychosocial issues. Nationally, fewer than 35% of older adolescents are enrolled at institutions that offer NCI-sponsored clinical trials, whereas over 90% of younger children receive care at such institutions.

Impact on the family

Parents of a child diagnosed with cancer must juggle several critical responsibilities: maintaining a household, caring for the child and siblings, and providing financially for the family. Most families must jump right from diagnosis into treatment with little time to resolve feelings or to plan how best to manage treatment and minimize family disruptions.

Advances in treatment and changes in insurance coverage have led to shorter inpatient hospital stays and more frequent trips to the hospital for outpatient care. Parents must negotiate with their employers for time off from work to bring their child to the hospital for scheduled and emergency care. Anxiety about being able to continue working is compounded when the child's insurance is tied to their employment. The hidden and out-of-pocket financial costs associated with cancer treatment can be a source of extreme difficulty.

Patients' siblings need attention and support, from the time of diagnosis through the complexities of treatment. In some families, brothers and sisters of childhood cancer survivors experienced symptoms of post-traumatic stress when evaluated 5 years after their sibling's treatment ended.

Lingering and long-delayed effects

Through multidisciplinary treatment, nearly 80% of children with cancer are cured of their disease. With increasing long-term survival has come increasing concern about the survivors' quality of life. Two out of three childhood cancer survivors have at least one ongoing physical or psychological problem (called "late effect") as a result of the cancer therapy they receive. One third of them face moderate to severe late effects, including neurocognitive,psychological, cardiopulmonary, endocrinologic, and musculoskeletal effects and secondary malignancies. Some late effects may be minor, but childhood cancer survivors are 10.8 times more likely to die than people the same age and sex in the general population. Some late effects are detected shortly after therapy is discontinued; others, years after therapy has ended. Late effects can develop into chronic health problems that require life-long medical follow-up.

Many pediatric cancer survivors are at increased risk for heart or lung disease and secondary cancers, making it important to provide ample patient education and counseling about healthy lifestyle choices. Research suggests that comprehensive behavioral counseling programs can influence survivors' decisions about reducing overexposure to sun, getting regular exercise, eating a well-balanced diet, and not smoking or drinking alcohol. Such counseling programs are strongly recommended for survivors of pediatric cancers.

Great progress has been made in treating many childhood cancers and the mortality rate has declined significantly.

Unfortunately, like the population as a whole, pediatric cancer survivors are inconsistent about making good lifestyle decisions and often have less than ideal health habits. For example, they often use tobacco and alcohol just as often as their peers who have not been treated for cancer. Young adult cancer survivors also report sedentary lifestyle rates similar to those in the general population. Well-designed studies of ways to promote healthy behaviors within this vulnerable population are needed.

The Childhood Cancer Survivor Study revealed that about 95% of childhood cancer survivors were employed, but were less likely than their siblings to be employed. Survivors of childhood cancer have a hard time getting health insurance coverage because many companies refuse to cover treatment for pre-existing illness. In a large cohort of childhood cancer survivors, 30% had not had a physical examination in the last two years and only 19% had been seen in an oncology clinic.

End-of-life concerns

Pain management can be effectively provided using the World Health Organization recommendations. Continued and escalating pain management may be needed for months. The literature reveals many resources for pain management in children but relatively few for the management of such symptoms as anxiety and depression.

Evaluating child and family satisfaction with end-of-life care has been challenging for many reasons. Research in this field has lagged behind research in end-of-life care for adults and there are many ways the end of a child's or adolescent's life differs from that of an adult. Most children do not die in a short time, often exceeding the norms used by third party payers for adult patients at the end of life. Nurses who provide hospice care to children need specialized training and support.

What causes childhood cancers?

Little is known about the causes of pediatric cancers. Prenatal exposure to X-rays and specific genetic syndromes have been associated with higher risk of acute lymphoblastic leukemia (ALL), and a family history of Hodgkin's disease or retinoblastoma is associated with an elevated risk for these disorders in children. Immunodeficiency is associated with increased risk for non-Hodgkin's lymphoma. However, the currently known risk factors provide very little guidance to parents or public health agencies as to environmental or lifestyle changes that can reduce risk for pediatric cancers. This distinguishes childhood cancer from many cancers that appear in adulthood.

Many questions have been raised about the possible role of exposure to environmental toxins as triggers of cancer in children. More research is needed to determine what aspects of the environment may pose danger to children, perhaps in interaction with specific genetic factors.

Ways to reduce the national burden of pediatric cancer

Here's some of what we have learned from research about how to reduce the burden from childhood cancer:

Provide access to medical information, treatment, and care. The American Academy of Pediatrics (1997) provides guidelines for pediatric cancer centers that delineate the personnel, facilities, and capabilities deemed essential for caring for children with cancer. An adequate center will have specialized staff, including a board-certified pediatric hematologist/oncologist who coordinates care, pediatric oncology nurses, board-certified radiologists, pediatric social workers, psychologists, child life specialists, and pediatric nutrition experts, as well as a number of consulting specialists.

Parents, patients, and siblings generally benefit from assistance in several areas: information and education; emotional and practical support from their established network of family, friends, and community organizations; networking with others who are in a similar situation; activities to bring normalcy, distraction, or enjoyment to the family; and additional assistance to meet concrete needs. Information and education generally starts at the treatment center but needs to be supplemented by written materials offered at an appropriate reading level and in the family's language. For some families and many children, video materials are welcome.

Some families use the Internet to research diagnosis, treatment options, and resources and to find support, but not every family has access to the Internet or is comfortable navigating it. Families can get information (including brochures and materials) from disease-related organizations, including the Leukemia and Lymphoma Society, the Childhood Brain Tumor Foundation, Candlelighters, and CureSearch. Some organizations provide ways for parents to communicate with other parents in similar circumstances, including activity groups that provide a place for parents or patients to meet and to share information. SuperSibs, a national program, sends several packages filled with games, coupons, words of encouragement, and treats to each brother or sister in the patient's family, so that the sibling can receive mail and attention "just for him or her."

Provide access to psychosocial and educational support. Families who cannot meet their household expenses during their child's treatment can turn to the network of community agencies that exist to provide crisis intervention services: local departments of social service, the Salvation Army, and other faith-based organizations. These organizations have limited budgets, however, and may be able to help a family only once. It is important for pediatric oncology centers to help families find financial assistance.

Anne Kazak of the Children's Hospital of Philadelphia recommends psychosocial assessment of children and family early in the course of treatment, followed by tailored interventions. She notes that systemic programs with broad reach, such as procedural pain interventions in outpatient settings, could benefit many patients. Adolescents face both illness and distinctive developmental challenges: moving away from dependence on family, developing confidence in managing responsibility for decisions, planning for the future, and navigating relationships with peers who are increasingly crucial to each other for identity formation. Psychosocial support sensitive to their needs can strengthen their adherence to challenging medical guidelines.

Activity programs that provide fun or distraction for children with cancer help shift a family's focus for a while from illness back to childhood. There are small local and national programs with the same missions as the better-known Make-A-Wish Foundation and the Hole-in-the-Wall Gang Camps. Make-A-Wish, the biggest of the national wish-granting organizations, has moved from the original plan of granting a "last wish" to a dying child to supporting a wish for each child with a life-threatening illness. Most camps offer special programs for siblings as well as ongoing programs throughout the year that allow families to get together.

School is sometimes interrupted for children undergoing treatment for cancer. Family members and social workers can sometimes arrange for tutoring in the hospital and at home, and formal school re-entry programs have been found to improve children's level of comfort and success when they return to school after being absent for treatment of cancer.

Some kinds of cancer and treatment can affect a child's ability to concentrate and learn. For some patients, neuropsychological assessment is crucial for identifying difficulties and strengths that need to be addressed, and neuropsychological consultation with parents and school personnel can improve the child's chances for educational success.

Provide access to long-term care and ongoing contact with pediatric oncology care. Guidelines and models of care for adult survivors of pediatric cancer illustrate the complexity of needs to be addressed for good health and well-being. The Children's Oncology Group provides detailed indicators, including age of diagnosis and types of treatment, for specified screenings at specified intervals visit *www.survivorshipguidelines.org*. Counseling to address quality of life issues can also be beneficial.

Provide access to hospice care and bereavement counseling. Hospice care for children who are dying offers comfort and support for both patient and family.

Parents who lose a child may experience complicated grief reactions. Pediatric oncology centers and hospitals can inform parents about community-based support programs such as Compassionate Friends and can offer bereavement counseling, support groups, and memorial services after a child's death.

Gaps in infrastructure and capacity in Washington, DC

Early and best medical intervention. Three hospitals in the District of Columbia—Children's National Medical Center, Georgetown University Medical Center, and Howard University Hospital—provide oncologic treatment for children with cancer. At each of these sites families can receive diagnosis, education, and treatment, with additional services coordinated with NIH and Johns Hopkins University Medical Center when medical needs or insurance carrier requests so indicate. Each hospital provides both inpatient and outpatient services.

We do not know to what extent primary care providers and parents in the District of Columbia have access to current information about symptoms of childhood cancer, ways to access clinical trials, or services for caring for the patient and siblings during treatment and across the survivor's lifespan. There is anecdotal evidence from staff in local hospital-based pediatric oncology programs that parents and children sometimes receive multiple inaccurate diagnoses before they reach an oncology center that provides appropriate assessment. Systems for educating and updating those who provide primary care for children and adolescents in the District of Columbia could reduce the length of time between onset of symptoms, accurate diagnosis, and beginning of treatment for cancer. The three hospitals that provide pediatric oncology assessment and treatment in DC and the DC Department of Health could coordinate their efforts and facilitate making up-to-date information available for providers and residents of the District of Columbia.

The present provider network for pediatric oncology care is informal and unstructured, and at the time of diagnosis families and young people might not realize what medical services are readily available in DC. Staff in each hospital try to identify patient and family needs, but if parents had direct access to a centralized DC source of information, they could feel more control over this aspect of their lives.

There is evidence that adult survivors of childhood cancers receive suboptimal screening care. There is no centralized or systematic ongoing educational support for DC's primary care physicians whose patients include childhood cancer survivors. Those physicians may have trouble finding the most recent information about risks associated with pediatric cancer and cancer treatment and about evidence-based screening practices. Continuing education and Web-based information for physicians who see adult survivors could help improve the quality of care for these patients.

Access to adequate patient and family education and support. Psychosocial support staff at the three pediatric oncology hospitals offer help getting social services, sibling support activities, psychological and spiritual support for family members, and information about community organizations that offer information and support. Staff members exchange information informally, but have no formal or ongoing collaborative efforts to assess or address the unmet psychosocial needs of DC's pediatric cancer patients and survivors and their families.

The Ronald McDonald House serves all three pediatric treatment centers and offers "a home away from home" for families while their child is receiving treatment. The House offers low-cost (free, if necessary) housing to families, help with food for meals, and help with transportation to the treatment center. It also provides a supportive environment in which families with seriously ill children can meet and interact. The Believe in Tomorrow Foundation and the Casey Cares Foundation celebrate patients' birthdays or other important events and offer tickets to sporting events, live performances, and the circus. The Carol Jean Cancer Foundation, Special Love, and the American Cancer Society provide free camping experiences for children with cancer and their siblings in the Metro area.

There are often significant gaps between families' financial need and available resources during the course of a child's treatment and afterwards. Families whose children receive Medicaid and who have no access to a car are eligible to receive transportation benefits (taxi transportation or bus tokens) in our area, but if they have a car there is sometimes no help with gasoline or parking expenses. Families also struggle with financial concerns during their child's end of life care, and if the child dies may face the double burden of funeral expenses and coping with loss.

Access to educational and rehabilitative services. None of the inpatient treatment programs for children with cancer in the District of Columbia has District teachers onsite. While hospital staff members offer to help patients and staff in DC schools prepare children for school re-entry, this is sometimes a complex task that requires ongoing medical, social, educational, and psychological support. Simple procedures for activating a hospital- and home-based educational program to help children keep up with their peers would be extremely helpful to children in both the short and long term.

Social workers and other specialists in each treatment center aim to help patients stay in touch with their home school through tutoring by school personnel. But constraints within school districts can significantly delay or limit tutoring services. Staff at each pediatric cancer treatment center provide education and some support for school personnel in DC, but they have no formal relationship with the DC Board of Education to ensure that school personnel receive enough appropriate information about educating these children when they return to the classroom.

Access to neurological assessment is limited, mainly because many third-party payers will not allow for neuropsychological testing from providers familiar with the impact of treatment for childhood cancers. Each children's hospital in DC does provide this on a fee-for-service basis, but it is out of reach for some families. Establishing additional ways to pay for this important service would facilitate more accurate educational programming for children with learning disabilities associated with cancer and its treatment.

DC's three pediatric oncology centers as well as the National Rehabilitation Hospital provide rehabilitation services for children recovering from cancer treatment. The goals of pediatric rehabilitation include minimizing the impairment and maximizing function for age-appropriate life roles (school, play, and work) and minimizing the burden of disability for the parents and caregivers. The providers at the National Rehabilitation Hospital can help survivors make the transition back to home life and should be included when community-wide meetings are organized.

Access to hospice care. The trauma associated with knowing that there is no cure for the illness one's child is experiencing, and watching that child experience declining health, is compounded in DC by the inability to access pediatric hospice care. Such a service would allow parents to bring their child home or to a non-hospital environment. Hospice nurses are well trained in caring for adults at the end of life but often have little experience providing hospice care to children and adolescents. In DC, pediatric hospice care is extremely difficult to find and, when available, is provided by an adult program; there is no separate pediatric hospice program. Problems with reimbursement pose barriers to continuity of care, notes the non-profit organization Children's Cause for Cancer Advocacy *www.childrenscause.org*. Medicaid and private insurers do not currently cover costs associated with pediatric end-of-life care or physician time spent counseling families and overseeing the transition to hospice care.

DC pharmacies often do not carry the narcotic pain medications needed to alleviate end-of-life suffering. Some hospice nurses are reluctant to go into certain areas of DC carrying the narcotic pain medications their patients need, perhaps for fear of being targets of criminal activity. Families sometimes move to nearby states to live with extended family so their children can get hospice care and timely relief with narcotic pain medications. A concerted effort by various stakeholders is needed to establish accessible pediatric hospice care in the District.

It may be difficult for some families to get bereavement counseling because of financial limitations or difficulty matching a family's language or culture. In such instances it would be helpful if a chaplain or social worker at one hospital could give parents information about appropriate support groups available elsewhere, including other hospitals.

Access to long-term care and ongoing contact with pediatric oncology care. Each of the pediatric oncology centers in DC offers long-term care for survivors and help transitioning to adult health care providers. The risk factors associated with childhood cancer warrant specialized care for survivors, and there is no readily identifiable source of information for individuals who have no prior association with pediatric oncology in DC. The Institute of Medicine reports that only about 40 to 45% of survivors are receiving follow-up care in specialized institutions. There is no accurate count of how many survivors of childhood cancer reside in DC. None of the hospital-based programs that provide follow-up care currently offers any kind of outreach or public education for underserved survivors.

Goals, Objectives, and Strategies

GOAL: To ensure that all District of Columbia children and adolescents with cancer, and their families, have access to the most beneficial medical care and supportive services.

Objectives and Strategies:

1) **Develop a system for coordinating research and the dissemination of information about diagnosis, clinical trials, treatment, follow-up care and support services to health care providers in DC by 2010.**

- Organize a conference to bring together pediatric care providers and representatives from pediatric oncology centers in DC to identify common objectives and to develop processes for addressing them.
- Create and maintain a public listserv for sharing information about pediatric oncology diagnostic, treatment, and follow-up care services that are available at each institution.
- Develop a DC-wide approval mechanism for collaborative internal review board proposals so that all three hospitals serving children can work together more rapidly.

2) Ensure that all DC childhood cancer patients and their families have access to culturally relevant information and services, from diagnosis through survivorship or end-of-life and bereavement services by 2010.

- Establish a centralized resource center responsible for creating an up-to-date database for patients and parents (including information about websites, printed educational materials in various languages, and support and advocacy groups) and for identifying and advocating for ways to address gaps in resources.

- Organize a conference to bring together patients and family members, representatives of the DC school system, and experts in pediatric oncology to 1) identify objectives relevant to the educational needs of pediatric cancer patients and survivors, 2) identify barriers to getting basic educational instruction and essential individualized services, in the hospital, at home, and in the school system, as well as neuropsychological evaluations recommended by cancer care providers, and 3) develop strategies to address these barriers.

- Ensure that all health care providers who diagnose pediatric cancers have information to give parents at the time of diagnosis about how to get in touch with parent-to-parent support networks.

- Establish and publicize a support system for long-term care of survivors of childhood cancers, where adolescents can get help with the transition to adult care providers, and where adults can get education about and screening for secondary malignancies and other late effects.

- Develop an alliance between providers of therapeutic recreational activities and facilitators of support systems to help ensure that DC cancer patients, survivors, and their siblings and parents have access to therapeutic recreation.

- Create a viable coordinated system for providing hospice and bereavement care in DC for children with cancer and their families.

3) Establish a system to ensure that accurate data on incidence, survival, and mortality rates for pediatric cancers are collected and are available for health care providers, researchers, and the public by 2010.

- Organize a series of meetings of DC Cancer Coalition members, pediatric cancer center representatives, and DC Cancer Registry staff to identify and evaluate existing procedures, barriers to the routine collection of reliable data, and strategies for addressing these barriers.
- Develop a system for communicating with providers who diagnose pediatric cancers to ensure they understand the process for providing complete information to the DC Cancer Registry and to address questions or concerns they may have about the process.

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Palliative Care

Patients with cancer need, deserve, and are eligible for palliative care from the day they are diagnosed.

But sometimes health care practitioners delay referral to palliative care specialists, fearing that introducing the subject may cause alarm and lead patients to believe the end is near. This behavior underscores the urgent need for both practitioners and the public to understand the scope of palliative care and how it can help in cancer treatment from diagnosis forward.

What is palliative care?

Palliative care is medical care provided by an interdisciplinary team, including the professions of medicine, nursing, social work, chaplaincy, counseling, nursing assistants and other health care professions. It is focused on the relief of suffering and providing support for the best possible quality of life for patients facing serious life-threatening illness, and their families. It aims to identify and address the physical, psychological, spiritual and practical burdens of illness.

Palliative care is both a philosophy of care and an organized, highly structured system for delivering care, and it includes the goals of enhancing quality of life for patient and family, optimizing function, and helping with decision-making and providing opportunities for meeting other personal goals. It can be delivered concurrently with life-prolonging care, or as the main focus of care. (National Consensus Project, 2004)

Palliative care and hospice programs have grown rapidly in the past several years, in response to both a growing population living with chronic, debilitating and life-threatening illnesses and to health care providers' growing interest in knowing how to care for such patients.

Palliative care is designed to

- Manage pain and other symptoms effectively while incorporating psychosocial and spiritual care according to patient and family needs, values and beliefs
- Focus on the central role of the family unit in decision-making
- Affirm life by supporting the patient and family's goals for the future
- Neither hasten nor postpone death
- Provide a support system to help patients live as actively as possible
- Provide a support system to help the family cope during the patient's illness and in their own bereavement, including the needs of children
- Use a team approach to address the needs of patients and families.

Palliative care practice guidelines call for delivery of services in all settings in which cancer patients receive health care—in the hospital, hospital outpatient clinics, emergency facilities, and at home. Communication among varied health care settings can be difficult, but a core value of palliative care is to promote and facilitate continuity of care, to ensure that the patient's and family's choices and preferences are respected, and to prevent errors, needless suffering, and feelings of abandonment.

Addressing the full range of suffering

Delivering quality palliative care means recognizing the full range of burdens and challenges on both patients and families at any point along the course of illness. They must find ways to cope with the stress associated with the threat of serious illness while trying to manage changes in their daily lives.

By integrating palliative care in cancer programs early, along with efforts aimed at disease prevention (through education and policy), prevention of advanced disease (through early detection), and anticancer treatment, a comprehensive cancer control plan might work toward improving the prevention of suffering by emphasizing continuous attention to all dimensions experienced by both patient and family.

Symptoms. Distressing symptoms may be experienced by a patient at any time during the course of a cancer diagnosis. It is important for the public and health care professionals to learn how to prevent and manage pain and other symptoms while simultaneously promoting a broader sense of well-being that comes from meeting the patient's needs in all aspects of his or her life. Balancing the goals of cure and the goals of palliative care, improving symptom management, and providing emotional and practical support will help improve overall care and quality of life.

Palliative care specialists pay attention to both symptoms (subjective physical and psychological phenomena) and measurable signs (clinical observations that lead to the formulation of a diagnosis). Symptom relief can be jeopardized when reliance on measurable signs guides treatment rather than the comprehensive assessment and management of the experience of symptoms combined with signs and knowledge of the natural history of the disease.

Symptoms vary according to the kind of cancer, organ involvement, and treatment given and emotional responses to diagnosis and treatment. Physical symptoms have an impact on both patient and family beyond the physical domain, because they are interconnected with the disease process.

More than half of patients with advanced disease commonly report symptoms of fatigue, pain, anxiety, and loss of appetite. Patients fear pain the most, and patients and families may associate pain with advancing disease. Other common symptoms include weakness, nausea and vomiting, constipation, shortness of breath (dyspnea), depression, and delirium. Depression and delirium are often underrecognized and undertreated, although both respond to treatment.

Patients often worry about the burdens of caregiving on family and friends. Attention to caregiver issues and finding resources to help caregivers can help resolve this aspect of patients' concerns.

Although pain, other symptoms, anxiety, and depression may be common to cancer, they are sometimes overlooked by health care professionals accustomed to providing high-tech diagnostic and treatment-related services for acute, short-term medical problems. For this reason, it is important to

- Educate the public and health care providers about ways to prevent pain and other symptoms and to promote wellness, even in the face of disease
- Create change in the health care system, so that palliative care becomes a routine for all cancer patients and their families
- Ensure that palliative care be comprehensive and continuous, beginning immediately after diagnostic evaluation

- Balance the two goals of curing and caring for individuals with cancer
- Educate families and health care professionals alike about dealing with pain, symptoms, quality of life, and end-of-life issues.

Supporting family caregivers

Changing demographics and a shift of health care from the hospital into the home is significantly increasing the role of family caregivers in chronic and terminal illness. The responsibilities associated with caring for a loved one are expected to increase. Whether patients are receiving aggressive treatment aimed at a cure or have shifted toward maximizing comfort, they are likely to have many needs and concerns. As care shifts to the home, palliative care providers must help address family caregivers' needs as well as those of the patient.

Among primary family caregivers, 70% are spouses; about 20 % are children (mostly daughters or daughters-in-law), and about 10% are friends or more distant relatives. Family includes both biological relatives and people the patients have identified as playing a significant role in their lives, and being in frequent contact.

As family caregivers observe the suffering of a loved one with serious illness or facing death, they too struggle with their own losses and changing roles and concerns about caregiving. Families are profoundly influenced by a loved one's experience of living with cancer. Day-to-day family activities, roles and relationships, and the meaning of life become altered. Palliative care can help prevent family crisis and create cohesion by assessing family functioning and using interdisciplinary team members to meet the array of family needs.

Family caregiver responsibilities may include monitoring for changes in the patient's health status, symptom management, emotional support, coordination of medications, treatments and social services, and assistance with the activities of daily living. Other more external care needs include activities carried out on the patient's behalf, such as obtaining prescriptions, transportation, scheduling and coordination of appointments, and dealing with insurance, and other financial issues. Caregivers may not know, without instruction, how to provide care, what to expect as disease progresses, how to assess and manage symptoms, or when to summon health care professionals for assistance.

Responsibilities of caregiving include

- ***Financial costs.*** Caregivers are not generally paid for the care they provide, and many have out-of-pocket expenses for medicine, medical care, and durable medical equipment (hospital bed rental, wheelchairs, walkers, oxygen, etc.), as well experiencing lost income and benefits—especially if both the patient and the caregiver are unable to work. An estimated 20% of family caregivers have to make major adjustments to their work schedules or leave work altogether to care for a loved one. Financial problems can mount quickly. Minority caregivers, especially Black and Hispanic individuals, are more likely to experience financial hardship when compared to Whites.
- ***Time and logistics.*** Family caregivers may have to balance employment responsibilities and caregiving duties such as transportation and direct care, which varies from a few hours a week to the equivalent of a full-time job.
- ***Physical tasks.*** Family caregivers are assuming more of the physical care of the patient throughout the trajectory of illness, including advanced disease.

- ***Emotional burdens and mental health risks.*** While caring for a loved one, family caregivers also must adjust to a different role and cope with losses. Depression can occur, as can anxiety and fatigue associated with watching a loved one's health decline. Health care professionals should regularly assess the emotional status of the family caregiver in order to provide needed help and support.
- ***Health risks.*** It is not unusual for family caregivers to neglect their own health when caring for a loved one with cancer. Risk of exacerbating a pre-existing illness or developing a new disease may occur if the primary caregiver starts out in poor health, sleeps less and lives with daily anxiety about the patient's condition.

Providing information alone is not sufficient. Palliative care providers understand that family caregivers need both information and support as they assume round-the-clock care that was previously provided in inpatient settings. Additionally, if the patient dies, caregivers and other family members need support into the bereavement period.

How palliative care can decrease the cancer burden

The goal of community health is to promote health and prevent illness, and three levels of prevention activities in palliative care can help to accomplish this goal.

In primary prevention—activities that prevent the occurrence of health problems—palliative care reduces risk factors and prevents problems by anticipation, planning, and treatment. This is done by informing other health care professionals through educational activities, by using an interdisciplinary team to support patient and family, and by providing community education about how palliative care helps support patients and families.

Changes in the health care system are needed in the District of Columbia for palliative care to become a routine aspect of health care for all individuals with cancer and their families. Systemic changes are needed so the District provides

- Comprehensive, continuous care for people with cancer
- Interdisciplinary care that addresses all facets of health care
- Balanced healthcare goals of curing and caring for people with cancer
- Recognition of death as an inevitable part of life, for which advanced care planning can improve the quality of life
- Financing for the development of palliative care programs

It should be noted that, unlike most states, the District of Columbia fails to spend any tobacco settlement funds received on health care and cancer services. This has left the city with almost no infrastructure with which to build an effective cancer control and prevention program.

Secondary prevention focuses on early identification and treatment of existing health problems to prevent the situation from worsening. In palliative care, this means direct care, counseling and support groups, and related activities. Secondary prevention involves

- Identifying people who are likely to need palliative care services, including people with cancer and other chronic illness or disability
- Providing education for patients, families, and health care professionals on palliative care and how it works to help manage patient needs

- Strengthening caregiving systems in community-based settings
- Establishing long-term and acute care palliative services in community-based settings, including access to needed medications in area pharmacies, and the implementation of laws to protect the individual and family's personal preferences at the end of life (DC's Comfort Care Law).
- Developing funding sources for palliative care
- Encouraging palliative care research and quality improvement

The inequitable distribution of hospitals and other health care infrastructure in the District presents challenges for the effective, seamless delivery of palliative care.

Tertiary care correlates with rehabilitation for individuals with illness, focusing on restoring and maintaining the highest possible level of functioning, and preventing recurrence of problems. For people with cancer, palliative care services should focus on

- Direct services from the interdisciplinary palliative care team
- Access to rehabilitation services
- Hospice care
- Bereavement and counseling services

The District's palliative care services

The inequitable geographical distribution of hospitals and other health care infrastructure in the District presents challenges for the effective, seamless delivery of palliative care. To respond to some of those challenges, the DC Partnership to Improve End-of-Life Care was formed in 1998, as one of the Community State Partnership programs funded by the Robert Wood Johnson Foundation. The Partnership, now known as The Greater Washington Partnership, seeks participation from every segment of the community touched by life-threatening illness.

The resources section of the DC government website (http://dc.gov) provides links to the DC Department of Health and to organizations like the National Hospice and Palliative Care Organization (NHPCO). The "find a provider" service on NHPCO's website (www.nhpco.org) identifies two hospice organizations, both located in Northwest DC but serving patientsthroughout the City: Capital Hospice and Community Hospices. Both organizations provide hospice care in the home or in hospice-run inpatient facilities. Each also offers palliative care, grief counseling, and bereavement services.

Community Hospices is affiliated with The Washington Home, which provides long-term care and post-hospital rehabilitation services. Capital Hospice, serving patients in the District, Northern Virginia, and Prince George's County, provides hospice care and also offers professional education through its Institute for Education and Leadership. Both organizations are part of The Greater Washington Partnership.

Not listed with NPHCO's "find a provider" is another Northwest organization, Joseph's House, which provides end-of-life and hospice care for homeless men with late-stage AIDS. Joseph's House provides around-the-clock nursing care in a family-like setting for as many as 11 resident patients at a time, with priority given to men who are homeless or who have been incarcerated.

Palliative Care

Active palliative care programs in the District include the Providence Hospital Palliative Care Services, in Northeast DC. Providence addresses the needs of patients and loved ones at the end of life through an interdisciplinary team. DC residents are also served by the Lombardi Cancer Center Palliative Care program at Georgetown University Hospital in Northwest. Palliative care programs are underway at George Washington University Hospital and in development at the Washington Hospital Center Cancer Center.

Goals, Objectives, and Strategies

GOAL 1: Integrate palliative care into the District's health care system and increase public understanding of palliative care and its role in cancer care.

Objectives and Strategies:

1) Provide education about palliative care for health care providers and the public by 2010.

- Provide professional education and training in palliative care to increase the number of skilled palliative care providers in the region.
- Provide public education about palliative care so more cancer patients and their families will seek palliative care services as soon as cancer is diagnosed.

2) Promote the development of palliative care programs in health care facilities and community-based settings throughout the District.

- Publicize how palliative care can reduce human suffering and costs for cancer patients and their families and can also reduce public costs for cancer care.
- Promote policy and financing changes that support reimbursement for palliative care services in the home and in community and institutional settings.
- Support development of innovative program models to ensure the availability of good palliative care in home, community and institutional settings.
- Support improvement of palliative care and hospice service for adults and children.
- Conduct research that evaluates the impact of palliative care on patient suffering, health outcomes and cost-effectiveness in cancer care.

3) Develop innovations and changes in the health care delivery system that promote palliative care services by 2010.

- Promote patient-centered care that encourages advance care planning and the discussion of quality of life issues in all health care encounters.
- Promote innovations within and between health care providers and settings that improve continuity of care for cancer patients and their families.
- Encourage an interdisciplinary approach to health care that attends to the physical, psychological, social, and spiritual needs of cancer survivors and their families.
- Train skilled health care teams to discuss death and dying as a normal part of the human experience.
- Promote collaboration among palliative care providers and community service organizations to further the continuum of care important to excellent palliative care.

- Reduce cancer pain to pain relief that is satisfactory to patients and their families in 100% of cancer patients in the District within two years.

GOAL 2: Improve the availability of, and access to, palliative care services for the underserved and culturally diverse population of the District of Columbia

Objectives and Strategies:

1) Strengthen the health care delivery system, including palliative care for under served and diverse populations in the District of Columbia by 2010.

- Educate health care and palliative care service providers about the special needs of minority and underserved populations, including the public and private health care services currently available.
- Advocate for basic health care services where gaps exist in the current health care system, a prerequisite for all levels of palliative care.
- Work with community-based organizations currently used by DC's minority populations to incorporate palliative care into existing health care and other basic human services.

2) Target public service messages about palliative care to specific underserved populations by 2010.

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Cancer Survivorship

Facts in brief

- Nationwide, more and more patients diagnosed with cancer are surviving cancer 5 years and more. There are about 10 million cancer survivors nationally and about 20,000 in DC. A person is considered a cancer survivor from the moment he or she is diagnosed with cancer.
- In 1971 there were three million cancer survivors (1.5% of the U.S. population). In 2001 there were 9.8 million (3.5% of the population). If current trends continue, one-third of Americans will eventually be diagnosed with cancer.
- For every survivor, three other people close to the survivor are significantly affected by the diagnosis.
- A national health objective for 2010 is to increase to 70% the proportion of cancer patients living more than 5 years after diagnosis, an objective already achieved for children with cancer but not yet for adults.
- Little data exists about survivorship prevalence, treatment, and use of services in the District. Current treatment data include a number of survivors who come from other states and nations, and many D.C. residents may get their treatment outside of the District.

Stages of the cancer experience

Different concerns characterize the three stages of the cancer experience (survivorship), as first described by Fitzhugh Mullan, M.D., himself a District cancer survivor. In the acute stage (when patients are diagnosed and begin treatment), patients often experience significant anxiety, pain, and discomfort, and worry about dying. Family members, friends, and caregivers are also affected by the diagnosis and by later stages of survivorship.

In the extended stage, after therapy and during remission, uncertainty may persist, and the patient may experience physical limitations, changes in body image, and problems with trust—resulting from both the illness and the treatment. During this time of watchful waiting, the patient wonders if symptoms are signs of recurrence or just part of everyday life. When treatment ends, diminished contact with the health care team can cause great anxiety. Physical limitations may persist. Some survivors may learn to live with chronic side effects and anxiety.

In the permanent stage, cancer is not the first thing survivors think about in the morning. More and more cancer survivors are living in this stage, about which more research is needed.

Measuring quality of life after cancer generally involves assessing

- Physical state: effects of treatments (radiation, chemotherapy, surgery) and drugs, fatigue, nutrition, diet, exercise, pain, and coexisting conditions
- Psychological well-being: stress, pain management, self-image, and sexuality
- Economic concerns: insurance, finances, and ability to earn income and pay debts

- Social relationships: support from family, friends, workplace, and social activities
- Functional capacity: ability to work, resume physical activities, return to "normal" life, rehabilitation
- Spiritual: connection with a higher power, issues of faith, trust, existential questions.

End-of-life issues can occur during any stage. Good end-of-life care affirms life and regards dying as a normal process, neither hastening nor postponing death, but providing relief from distress and integrating psychological and spiritual aspects of care. End-of-life care aims for the best possible quality of life for cancer survivors by controlling pain and other symptoms and by addressing psychological and spiritual needs.

Cancer's effects

A diagnosis of cancer threatens a person's physical, psychological, social, spiritual, and economic well-being. At all stages, cancer can deprive those diagnosed of their independence and can disrupt the lives of family members and other caregivers. Cancer's physical symptoms

- Can be both acute and chronic
- Can occur during and after treatment
- May include pain, fatigue, nausea, and hair loss, depending on the cancer's site and treatment
- Can be so debilitating that the patient needs bed rest
- May require palliative care to manage pain and symptoms
- May in the long term (because of the cancer itself or treatment for it) include decreased sexual function, loss of fertility, persistent edema, fatigue, chronic pain, and major disabilities.

Adults who are long-term survivors of pediatric cancers are often at increased risk for reoccurrence of the original cancer or of opportunistic diseases. Both the survivors and their health care providers must be aware of symptoms and the need for regular check-ups and follow-up care.

Cancer imposes emotional and social costs on survivors and members of their personal support systems. The diagnosis and treatment of cancer usually evokes a host of difficult emotions, including fear, stress, depression, anger, and anxiety—as well as feelings of helplessness, lack of control, and diminished self-esteem. Survivors may have trouble coping with pain or disabilities caused by their disease or treatment. Many cancer survivors go on to lead active lives, and the cancer experience may ultimately help them find renewed meaning in their lives and build stronger connections with loved ones. They may also develop a commitment to "give back" to others going through similar experiences. But they almost always live with uncertainty and the fear that the cancer might return. Pain and disability may diminish their sense of social well-being by limiting the time they can spend with people important to their lives. And they may have trouble interacting with school friends or coworkers, because of cancer's impact on their self-image.

Cancer also imposes economic costs, including the financial burdens of health care costs and lost income from limited ability to work. Sometimes survivors lose a job because of their employers' preconceived notions about the impact cancer will have on their work capabilities. And the less income they have, the less able they are to get quality health care.

Complementary and integrative medicine

To deal effectively with cancer and its effects, some survivors pursue complementary or integrative medicine that combines the discipline of modern science with the teachings of ancient healing. A holistic approach to cancer care treats the whole person rather than a collection of diseased body parts. With increasing acceptance of the mind-body effect, the medical establishment has become more receptive to efforts to combine traditional medical care with practices that in soothing the spirit enhance the body's natural healing capacity. Many of these practices have arisen from Eastern philosophies and from a different view of body mechanics and the genesis of illness and healing.

Adopting some of the principles and practices of integrative and complementary medicine can be helpful to survivors as they progress in recovery—so long as they are medically safe, practiced under appropriate supervision, and not used as a substitute for traditional treatment. The professional's role is to evaluate the safety and effectiveness of various practices, study research on them, and recommend a combination of approaches appropriate to a specific survivor's case.

In the holistic view of patients practiced in complementary and integrative medicine, every care plan combines individually tailored patient-specific treatment of symptoms, complaints, and underlying causes with the aim of achieving the best possible level of wellness. Traditional medicine is combined with support for physical and emotional health and improved physiological functioning.

For patients newly diagnosed and awaiting treatment, the aim might be to:
- Reduce stress, focusing on personal control and empowerment
- Strengthen the immune system
- Provide relief from symptoms caused by anxiety or depression (such as appetite loss, nausea, or sleeplessness).

For patients undergoing aggressive curative treatment:
- Provide relief from treatment's side effects, such as nausea or pain
- Strengthen the immune system
- Reduce stress and encourage relaxation to help restore the mind and body between enervating treatments.

For patients in remission:
- Reduce stress during periods of watchful waiting
- Rebuild stamina and flexibility
- Resume a healthful diet, with an added emphasis on cancer prevention.

For patients who experience a relapse:
- The same services and objectives as in the pre-treatment and treatment phase, with even greater intensity.

For patients whose illness is not responsive to curative treatment:
- Control pain and symptoms as the illness progresses
- Mobilize the powers of the mind to maximize quality of life
- Reduce stress to allow for end-of-life planning.

As with other services for cancer survivors in the District, the distribution of practitioners of complementary and integrative medicine who work with cancer patients is uneven, clustering mostly in the more affluent wards.

Needs of Survivors and Caregivers

The greatest need for survivors is good, timely, accessible screening programs, medical treatment, and primary care. The survivors' needs vary depending on what stage they are in.

Related needs of survivors and caregivers in the acute stage may include reliable, consumer-friendly information; help making treatment decisions; guidance on how to talk with health care providers, partner, family, and children; help locating a treatment facility; insurance coverage for tests and treatment; help understanding and navigating the health care system; a health advocate or coaching in self-advocacy; transportation; child care; lodging; pain management; counseling; referrals to community resources; the ability to pay for cancer-related costs not covered by insurance; help working through treatment or coping without employment income; help dealing with the side effects of treatment, such as changes in appearance, energy level, sexuality, and nutrition; equipment and supplies; and help fulfilling spiritual needs.

Survivors and caregivers during the extended stage may have the same needs common in the acute stage and may also need information about essential cancer-related check-ups, help finding a physician who is knowledgeable about following survivors after cancer treatment; home care or respite care; help with legal and employment issues, education and other kinds of support.

Survivors' and caregivers' needs during the permanent stage may center on finding information about cancer's potential recurrence and the genetic component of cancer for relatives; on dealing with the long-term effects of treatment; and on finding appropriate hospice care and support for grief and bereavement.

Services and programs available in the District

The District is fortunate to have eight hospitals with cancer programs approved by the American College of Surgeons, one of which (Lombardi) has been designated a comprehensive cancer center by the National Cancer Institute. A wealth of local and national resources is available in the Greater Washington area, provided by the DC government, hospitals, health organizations, and community groups (see complete listing in the DC Community Resource Directory for Cancer Survivors and Caregivers). But many survivors, caregivers, and health care providers are not aware of, or using, these resources.

As physically close as these medical and support services are to DC residents, they are beyond reach if residents cannot pay for or travel to them. Many services are inaccessible for underserved populations that depend on public transportation. While the Washington Metropolitan Area Transit Authority (WMATA) does offer reduced fares for people with disabilities, and curb-to-curb service for people who cannot use the regular transit system, the service is limited and inadequate. Other organizations, such as the American Cancer Society and the United Planning Organization, a community services organization, also assist with transportation, but again the assistance is limited.

Support groups are a critical link for many survivors during treatment. Support group members share practical information such as what to expect during treatment, how to manage pain and treatment's side effects, and how to communicate with health care providers and family members. Exchanging information and advice may help bring survivors a sense of control and empowerment and reduce feelings of helplessness.

When treatment ends, so does the safety net of regular, frequent contact with the health care team. Many survivors miss this source of support, and adjusting to its loss can be difficult. In addition to depression, anxiety, or a sense of hopelessness, some survivors may also feel lonely and isolated, as even the

Table 1. Cancer support groups in the District of Columbia

SPONSOR	WARD	GENERAL	BREAST	CERVICAL & GYN.	COLOREC,	PEDIATRIC	PROSTATE	LUNG-TOBACCO	OTHER
Children's National Medical Center	5					✖			Caregiver
Georgetown, Lombardi Cancer Center	2		✖	✖				✖	Amputee, Head/Neck
George Washington Cancer Center	2	✖	✖	✖			✖	✖	Brain, Caregiver
Greater Southeast Community Hospital	8								
Howard University Cancer Center	1		✖					✖	
National Rehab. Hospital	5								Amputee
Providence Hospital	5	✖					✖	✖	Grief
Sibley Memorial Hospital	3	✖	✖				✖		Caregiver, Grief
Veterans Affairs Medical Center	5								
Walter Reed Army Medical Center	4	✖	✖				✖	✖	
Washington Hospital Center	5	✖	✖		✖			✖	Hematology
American Cancer Society	2	✖	✖				✖		
Colorectal Cancer Network	*				✖				
Mauntner Project for Lesbians/Caregivers	2	✖						✖	Caregiver, Grief
Nueva Vida	2		✖						
William Wendt Center	2								Grief

** The Colorectal Cancer Network is headquartered in Kensington, MD.*
Source: Greater Washington Coalition for Cancer Survivors

most supportive family and friends cannot understand exactly how it feels to have cancer. Support groups give them a chance to talk about their experiences with others living with cancer. They can share feelings and experiences that may seem too strange or difficult to share with family and friends. The group experience may give them a sense of belonging that helps them feel less alone and better understood.

Table 1 shows the type and location of support groups sponsored by hospitals and nonprofit organizations in the District of Columbia. One can see in it possible gaps in services, by type or at least by location. All the support groups are located in parts of the city not readily accessible to more than 20% of the city's residents. One of the primary criteria for participating in a support group is the convenience of the group sessions. Geographic access to other cancer-related services and mental health resources is also limited for many District residents. And the many outstanding mental health resources available at local hospitals and private clinics are beyond the financial reach of many Washingtonians—even if they could get to them.

All the support groups are located in parts of the city not readily accessible to more than 20% of the city's residents.

Gaps in services and access to services

Disparities in treatment and survival rates reflect the city's social geography, and economic inequality is mirrored in cancer death rates. The city's many working poor often lack health insurance and earn more than the threshold for many of the available financial assistance programs, such as the District of Columbia HealthCare Alliance for the uninsured. District residents with low income and no health insurance sometimes wait until a crisis to seek health care and then often seek help in hospital emergency rooms. Being diagnosed with cancer in the emergency room usually means a survivor's cancer is diagnosed at a later stage, when the chances of survival are slimmer and the treatment required is more extensive and expensive—to patients, survivors, and their families and to the system as a whole. Access to follow-up care may also be influenced by where patients and survivors live. Many cancer-related health care resources are located in Northwest Washington (Wards 1, 2, 3, 4 and parts of Ward 5). There is only one full-service hospital located beyond the Anacostia River (Wards 7 and 8), serving 20% of the population. For those dependent on public transportation, especially those weakened by cancer, it is often difficult to reach a hospital in another part of the city.

Goals, Objectives, and Strategies

GOAL: Improve the quality of life for DC cancer survivors.

The public health community can help increase understanding of cancer's physical, emotional, neural-cognitive, spiritual, and social effects. Drawing on current knowledge, it can also help realize potential interventions for improving survivors' quality of life.

Objectives and Strategies:

1) Implement a coordinated patient navigation system by 2008.

- Seek funding for coordinated patient navigation in hospitals and community health centers.
- Develop a coordinated patient navigation system.

2) Increase demand-responsive public transportation for low-income cancer survivors by 2007.

- Work with the Washington Metropolitan Area Transit Authority to seek solutions and funding to meet the transportation needs of low-income cancer survivors.

3) Assess current resources for survivors and caregivers by 2006.

- Using the American Cancer Society Community Assessment Interview Guide as a template, assess resources in DC for survivors and caregivers to establish a baseline against which to measure improvement in services.
- Identify gaps in needed programs, services, and facilities.
- Examine proven interventions and promising practices to determine programs and services that best address the needs of cancer patients and survivors, including palliative care services.
- Formulate recommendations to develop or expand resources for survivors and caregivers.

4) Promulgate clinical practice guidelines for each stage of cancer survivorship, from diagnosis through long-term treatment and end-of-life care by 2007.

- Educate primary care physicians, internists, oncologists, surgeons, and nurses about the clinical practice guidelines and the patient advocacy community.
- Conduct awareness and education campaigns for cancer survivors, so they know about the clinical practice guidelines.

5) Establish a database on cancer survivorship by 2008.

- Expand infrastructure in the DC Cancer Registry to collect, analyze, and report information on cancer for survivors.
- Expand reporting requirements for entities reporting to the DC Cancer Registry to include treatment information.

6) Educate corporate, academic, and community policymakers and decision-makers about key health care issues for cancer survivors, including the benefits of providing early rehabilitation services and the need for providing long term follow-up care by 2008.

  - Need to meet cancer survivors' needs for affordable transportation to health care services
  - Need to ensure cancer survivors' access to clinical trials and ancillary services

  - Problem of economic and insurance barriers to health care for cancer survivors
  - Quality-of-life and legal issues that cancer survivors face.
- Select target audiences and prepare presentation materials.
- Initiate educational meetings.

7) Develop a community awareness program for cancer survivors by 2007.

- Develop public education programs. Disseminate the information, empowering cancer survivors to make informed decisions.
- Teach survivors how to both find and evaluate available information (including information about nutrition, integrative medicine, the importance of regular check-ups, and the warning signs that cancer has recurred).
- Use innovative approaches to reach the target group of cancer survivors—for example, include information about services for survivors with monthly benefit payments from the District.
- Help survivors develop self-advocacy skills

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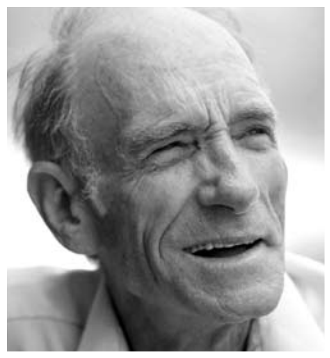
Cancer Rehabilitation



Medical advances in the diagnosis and management of cancer have markedly increased survival rates. For some patients the treatment may now result in a complete cure, with no perceived physical deficits, but an aggressive definitive treatment may leave other survivors with significant physical impairment or disability. To restore the patient's normal functions as much as possible, it is important to provide early rehabilitation targeted to the patient's needs. The challenge for rehabilitation professionals is to make both oncology professionals and the community more aware of the benefits of cancer rehabilitation.

An assessment by the treating physicians—the medical, surgical, and radiation oncologist and the primary care physician—will determine the best treatment regimen for a patient. Cancer rehabilitation services are interdisciplinary; they include but are not limited to nursing, physical therapy, occupational therapy, respiratory therapy, recreational therapy, speech-language pathology services, orthotics and prosthetics, vocational counseling, psychological counseling, and social services. Tailored to each patient's needs, these services are coordinated, integrated, and linked to other service systems, including acute care, nursing, and transportation. Rehabilitation tries to maximize the patient's functional ability and independence from the time of diagnosis through all stages of care.

Strengthening rehabilitation services in the District

Cancer programs and services in the District of Columbia have experienced exceptional growth in the 11 hospitals that provide cancer care. Cancer patients can receive rehabilitation services in any of these hospitals, but the National Rehabilitation Hospital focuses exclusively on rehabilitation. The National Rehabilitation Hospital has a collaborative arrangement with the Washington Cancer Institute to improve rehabilitative care for cancer patients. Outpatients can also receive rehabilitation care and therapy closer to home through the Regional Rehab Network Sites of the National Rehabilitation Hospital.

There is no consistent data collection and no repository of information about the number and type of cancer patients who receive inpatient and outpatient rehabilitation in the District of Columbia.

Many oncologists and other cancer care providers are unaware of the importance of rehabilitation in cancer care. Referrals for cancer rehabilitation are often made late or not at all. Patients may be referred for secondary diagnoses (such as lymphedema or tissue fibrosis) but are infrequently referred for other rehabilitation services. At the same time, many cancer patients know little or nothing about rehabilitation and thus sometimes resist it, viewing it as an unnecessary step in their treatment.

There is no consistent data collection and no repository of information about the number and type of cancer patients who receive inpatient and outpatient rehabilitation in the District of Columbia. It is important that we begin collecting data on where cancer rehabilitation services are available and how people can find them in the District of Columbia.

What type of cancer rehabilitation is appropriate?

Depending on the patient's needs, one of four types of cancer rehabilitation may be appropriate:

- *Preventive* rehabilitation therapy, which starts soon after diagnosis, aims to prevent functional loss by educating the patient, reducing the impact of expected disabilities, and identifying patient problems and concerns that may require professional intervention.
- *Restorative* techniques try to restore the patient to previous levels of physical, cognitive, and psychological functioning.
- *Supportive* rehabilitation therapy helps patients compensate for and minimize disabilities and provides emotional support while the patient adjusts to post-cancer lifestyle changes. Supportive therapy provides assistive devices to improve mobility and teaches simple self-care skills.
- *Palliative* techniques improve the patient's comfort level by minimizing or eliminating complications. Pain management and psychological support for patient and family are part of palliative services, but the therapy might also help keep joints from contracting and might prevent unnecessary deterioration from inactivity.

The impairments and deficits that arise in a patient's cancer experience depend on the organ involved, the impact and toxicities of cancer treatments, and pre-existing deficits. Common impairments include muscle weakness, edema (swelling), reduced range of motion in the joints, swallowing difficulties, memory loss, aphasia, and bone instability due to metastases. These impairments may bring pain, fatigue, weakness, loss of mobility, and greater dependence on others.

Rehabilitation therapies are targeted to different types of cancer and are adapted to the specific needs of the individual. The goal of rehabilitation is to identify and target rehabilitation to each patient's specific areas of deficit. For a breast cancer survivor with less range of motion in her arm after surgery, for example, rehabilitation would include range-of-motion exercises, strengthening exercises, and management of lymphedema (swelling in the arm). For a prostate cancer survivor, if the cancer has spread to the bones, rehabilitation might help the patient manage pain, at the same time providing such devices as walkers and canes to prevent falls and help with mobility. If a lung cancer survivor's chief problems are respiratory insufficiency and shoulder pain and stiffness, rehabilitation could help by providing deep breathing exercises, postural training, and range-of-motion exercises for the shoulders.

Goals, Objectives, and Strategies

GOAL: Increase awareness of cancer rehabilitation services in the District of Columbia.

Objectives and Strategies:

1) Create a repository of information on cancer rehabilitation services in the District of Columbia by 2007.

- Identify cancer rehabilitation services currently available in hospitals and other organizations.
- Develop a cancer rehabilitation questionnaire to disseminate to hospitals and organizations that provide rehabilitation services.
- Analyze the data and develop a directory of cancer rehabilitation services.
- Disseminate the information to health care providers, community organizations, and health care consumers.

2) Increase awareness and knowledge of fellows in training, oncology physicians, and oncology nurses about cancer rehabilitation and services as a separate and important discipline by 2008.

- Meet with key individuals in participating area hospitals that offer rehabilitation services to discuss the feasibility of cancer rehabilitation education.
- Develop a core curriculum in cancer rehabilitation.
- Launch teaching efforts in participating area hospitals.
- Evaluate results of the teaching curriculum with assistance from participating area hospitals.

3) Increase public awareness of cancer rehabilitation and services available by 2009.

- Create a list of organizations and hospitals engaged in community outreach and cancer rehabilitation activities to be disseminated to community organizations and hospitals.
- Publicize the availability of cancer rehabilitation through print, broadcast, and online media.
- Evaluate the impact of the media campaign by tracking referrals for cancer rehabilitation services.

4) Develop liaisons among area hospitals and community organizations to conduct research on effective cancer rehabilitation assessment and treatment by 2010.

- Meet with local research faculty interested in developing research activities in oncology rehabilitation.
- Promote research related to
    - Developing a multilingual tool to assess needs for cancer rehabilitation among minority populations and those with limited communication skills
    - Outcome studies on patients undergoing cancer rehabilitation
    - Establishing best practices and standard of care for cancer rehabilitation.

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Putting the Plan into Action

The DC Cancer Control Plan was developed by the community stakeholders and partners who form the DC Cancer Coalition. We have worked together for several years under a grant provided to the DC Department of Health from the Centers of Disease Control and Prevention. Because of the far-reaching goals for cancer control envisioned for the District, many individuals and organizations participated in the discussion, provided input, and collaborated at all levels of development to coordinate work and communications, reviewed the latest developments in cancer research, and determined the needs of a city known for the diversity of its communities and populations. In a real sense, this Plan will serve as a roadmap for the prevention and control of cancer in the District of Columbia until 2010.

Next, steps will be taken to put the Plan into action. Implementation will become the responsibility of all partners, including policymakers, health care providers, payers, community-based organizations, advocacy organizations, clinics, hospitals, other medical institutions and local government—all of the stakeholders committed to supporting interventions for cancer prevention, broader screening, earlier diagnosis, state-of-the-art cancer treatment, better quality of life for survivors, and more supportive end-of-life care.

A major and sustained citywide effort will be required to promote effective prevention and cancer control programs and practices. Everyone must understand that, because the District has the nation's highest mortality rates in many cancers, all of our citizens must engage in a personal and collective fight against cancer.

While this is a daunting effort, it is worth doing. Research shows that preventive measures can reduce the incidence of cancer and that screening for early cancer coupled with access to appropriate treatment can reduce the rates of death from various cancers. By implementing the District of Columbia's Cancer Control Plan we hope to measurably increase the number of cancers diagnosed at early, more treatable stages, and ensure that timely, high-quality treatments are available to all of our citizens. Implementation will be based on the principles of scientific reasoning, the application of scientific data, the appropriate use of behavioral sciences, and evidence-based guidelines promulgated by professional and government related organizations. Process and outcome evaluation will enable us to track our progress and impact.

American Cancer Society Screening Guidelines

Recommendations for the Early Detection of Cancer in Asymptomatic People

Breast cancer (female)

- Women should have yearly mammograms starting at age 40. The age at which screening should be stopped should be specific to the individual, depending on the potential risks and benefits of screening in the context of their overall health status and longevity.
- Clinical breast exams (CBE) should be part of a periodic health exam, about every 3 years for women in their 20s and 30s, every year for women 40 and over.
- Women should know how their breasts normally feel and promptly report any breast change to their health care providers.
- Breast self-exam (BSE) is an option for women starting in their 20s.
- Women at increased risk (for example, from family history, genetic tendency, past breast cancer) should talk with their doctors about the benefits and limitations of starting mammography screening earlier, having additional tests (such as breast ultrasound or MRI) or having more frequent exams.

Colorectal cancer

Beginning at age 50, men and women should begin screening with **ONE** of the examination schedules below:

- A fecal occult blood test (FOBT) or fecal immunochemical test (FIT) every year
- A flexible sigmoidoscopy (FSIG) every five years
- Annual FOBT or FIT as well as flexible sigmoidoscopy every five years *
- A double-contrast barium enema every 5 years
- A colonoscopy every 10 years
- Combined testing is preferred over either annual FOBT or FSIG every 5 years, alone. People who are at moderate or high risk of colorectal cancer should talk with a doctor about a different testing schedule.

Prostate cancer

The Prostate-Specific Antigen (PSA) blood test and the digital rectal examination (DRE) should be offered annually, beginning at age 50, to men who have a life expectancy of at least 10 years. Men at high risk (Black men and men with a strong family history of a first-degree relative diagnosed with prostate cancer at an early age) should begin testing at age 45. For men at average or high risk, information should be provided about what is known and what is uncertain about the benefits and limitations of early detection and treatment of prostate cancer, so that they can make informed decisions.

Cancers of the cervix

Screening should begin approximately 3 years after a woman begins having vaginal intercourse, but no later than 21 years of age. Screening should be done every year with regular Pap tests or every 2 years using liquid-based tests. At or after age 30, women who have had 3 normal test results in a row may get screened every 2-3 years. Alternatively, cervical cancer screening with HPV DNA testing and conventional or liquid-based cytology could be performed every 3 years. However, doctors may suggest a woman get screened more often if she has certain risk factors, such as HIV infection or a weak immune system.

Women 70 years old and older who have had three or more consecutive normal Pap tests in the last 10 years may choose to stop cervical cancer screening. Screening after a total hysterectomy (with removal of the cervix) is not necessary unless the surgery was done as a treatment for cervical cancer.

Cancer of the endometrium (uterus)

The American Cancer Society recommends that at the time of menopause all women should be informed about the risks and symptoms of endometrial cancer and strongly encouraged to report any unexpected bleeding or spotting to their physicians. Annual screening for endometrial cancer, with endometrial biopsy beginning at age 35, should be offered to women with or at risk for hereditary nonpolyposis colon cancer (HNPCC).

Cancer-related checkups

For individuals undergoing periodic health examinations, a cancer-related checkup should include health counseling and, depending on a person's age, might include examinations for cancers of the thyroid, oral cavity, skin, lymph nodes, testes, and ovaries, as well as for some nonmalignant diseases.

The American Cancer Society guidelines for early detection are assessed annually to identify whether there is scientific evidence to warrant a re-evaluation of current recommendations. If new evidence is sufficiently compelling to consider a change or clarification in a current guideline, or the development of a new guideline, a formal procedure is initiated. Guidelines are formally evaluated every 5 years, whether or not new evidence suggests a change in the existing recommendations.

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THE DC CANCER COALITION....

health care professionals, consumers and advocates working together to develop the DC Cancer Control Plan.

A few dozen coalition members gathered at Howard University in 2005.
Photo by Jeffrey Fearing, Ph.D., Howard University College of Medicine

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