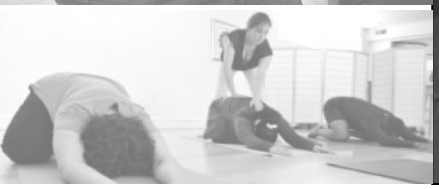
District of Columbia Cancer Control Plan

2013–2018



DC Cancer CONSORTIUM

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Executive Summary

The First Plan

In 2001, the District of Columbia Department of Health (DC DOH) created the DC Cancer Control Coalition, a partnership of organizations, institutions, advocates, and local residents dedicated to addressing the District's cancer burden. The creation of the Coalition formalized the efforts of a group of volunteers who formed in 1990 to advocate for a comprehensive cancer control program in the District.

The need was—and remains—unmistakable.

In terms of both incidence and mortality, cancer preys particularly heavily on African Americans—and approximately 51 percent of the District's 2010 population was of African descent.[1] Cancer mortality in the City is highest in Wards 5, 7 and 8—those with the highest concentration of African Americans and low-income residents.[2]

In 2010, roughly nine percent of District residents were Hispanic, and cancer mortality in Ward 1—with the District's highest concentration of Hispanics—is nearly as high as in Wards 5, 7 and 8.[3] Traditionally, Hispanic residents are the District residents least likely to have health insurance of any kind.[4] Moreover, barriers to preventive care and treatment for cancer have existed historically for both Hispanics and African Americans in the District.

These barriers include the lack of medical homes (primary care settings that provide routine health care), inequitable distribution of screening facilities, inadequate or absent insurance coverage, and the lack of culturally appropriate care.[5]

The result of these circumstances: cancers that have been diagnosed in late stages, or that could have been prevented entirely, are leading to increased mortality for some and a suboptimal quality of life for many survivors.

The response in 2001 was energetic.

In an effort funded by the Centers for Disease Control and Prevention (CDC), DC DOH and the Coalition worked for four years. Along the road, the Coalition incorporated to create the District of Columbia Cancer Consortium (DC Cancer Consortium or DCCC), a nonprofit 501(c)(3) organization comprised of approximately 70 organizations and individuals.

In 2005, the collaboration produced the District's first Cancer Control Plan—a comprehensive five-year array of strategies designed to reduce the number of new cases of cancer, decrease the number of deaths due to cancer, and improve the quality of life for cancer survivors in the nation's capital.[6]

In 2006, with the passage of the Community Access to Healthcare Act, the Consortium was awarded $20 million from the Master Settlement Agreement (the "tobacco settlement") to implement the Plan; the work was to be done in partnership with DC DOH, with which the Consortium shares responsibility for a coordinated approach to cancer control.[7] That amount was not received until 2007 and in December 2010 was reduced to $16.5 million, with the remaining $3.5 million shifted to balance the District's budget.

For the five-year implementation period, the team prioritized the Plan's objectives. Among top priorities: increasing access to care, improving the early detection of cancer, reducing tobacco-related mortality, increasing the quality of DC Cancer Registry data, improving awareness of the availability of palliative and end-of-life care, and enhancing systems of support for cancer survivors.

Working the Plan

To move toward achieving the Plan's objectives, myriad initiatives and programs were established through grant making and collaboration—particularly with the DC DOH. They include, for example:

- The City-wide Patient Navigation Network, a collaborative effort that increases all District residents' access to screening, treatment, and survivorship planning services through personalized patient support.

- The DC Screen for Life Program, a partnership providing screening and treatment services for colorectal cancer in communities with low income and high cancer risk.

- The breast and cervical cancer screening program, which provides grants to health institutions to increase services for District women who are uninsured or underinsured and ineligible for public screening or health insurance programs.

- A partnership with the DC DOH to maintain the District of Columbia Quitline, a toll-free telephone service for English- and Spanish-speaking residents who smoke but desire to quit, so they can obtain free nicotine replacement therapy products and smoking cessation counseling.

- A series of capacity-building training seminars has been offered through a partnership with the Graduate School USA in areas including grant writing, budgeting, social media, evaluation, and strategic planning. The purpose of the training is to support and strengthen Consortium members and community-based organizations with similar missions as they work to achieve the objectives of the Cancer Control Plan in the DC metropolitan area.

- A student internship program, in collaboration with the Graduate School USA, the DC Department of Health Bureau of Cancer and Chronic Disease, Cancer Control, and Screening Program, and the University of the District of Columbia's Public Health Education Program, offers students the opportunity to gain valuable skills and workforce experience through unpaid internships with Consortium partners. Selected students who participate in the program obtain insight into what local organizations are doing to combat cancer mortality rates and increase cancer awareness and access to care for District residents.

In parallel over the past five years, the District's residents have benefited from strategic and systemic improvements. Those include, for example:

- The transformation of the DC Health Care Alliance into a Medicaid managed care entity, effectively merging the local and federal public insurance programs administratively within a new cabinet-level agency (the Department of Health Care Finance), and including a streamlined, unified enrollment process.[8]

- The expansion of Medicaid under the federal Patient Protection and Affordable Care Act (PPAC), increasing the availability of insurance to more uninsured District resident adults.

- The progress of the public-private Medical Homes DC initiative (managed by the DC Primary Care Association) in expanding primary care capacity and quality, particularly in Wards 7 and 8.[9]

Have the efforts produced results? Yes. American Cancer Society projections of cancer mortality in 2011 forecast a 36.5 percent improvement in mortality from 2005, the year the initial Cancer Control Plan was crafted.[10] The greatest mortality decreases came in colorectal and prostate cancers, two of the cancers targeted in the Plan.[11]

That is excellent news, but there is still much to be done. Unfortunately, the District of Columbia continues to have

one of the country's highest cancer mortality rates,[12] lower than only four of this country's poorest states.[13] According to the American Cancer Society, 2,950 District residents were diagnosed with, and 1,010 died from cancer in 2012.[14] Despite progress, cancer persists as the leading cause of premature (before age 70) death in the District, and as the second most common cause of death overall, regardless of gender or race.[15]

Leveraging Wins: A New Five-Year Plan

To maintain the positive momentum of the first eight years, and to properly guide resources and programs for the next five, the Consortium initiated a revision process for the DC Cancer Control Plan.

In order to remain inclusive and relevant, the Consortium convened stakeholder groups for specific cancers and life stages along the cancer continuum. The groups were organized to maximize the depth and breadth of viewpoints and included, among others, cancer survivors, advocacy groups, physicians, public health experts, and community-based service providers.

Over 16 months, beginning in 2011, the groups met for a series of conversations in which they assessed the District's cancer epidemiology and overall burden, discussed needs and real-world challenges, and evaluated progress vis-à-vis the first Plan.

Utilizing expert opinion and existing data, the stakeholders developed five-year goals with measurable objectives designed to ensure movement toward the goals. Action steps and timeframes were devised, incorporating evidence-based interventions as much as practical, and including the anecdotal experiences of survivors and providers as appropriate.

The issue that overshadowed all stakeholder discussions was the **disparity** in cancer burden experienced by racial and other specific populations.

In the District, African Americans had either the highest incidence or highest mortality rate for each of the identified cancers. African Americans also were most affected by such issues as lack of access, diagnosis at later stage, inadequate palliative care, and low participation in clinical trials. According to a recent Rand report, black residents in the District were 90% more likely to die from cancer in 2008 than white District residents.[16]

The stakeholders resolved to tackle this issue directly. Each cancer-specific section of the Plan contains objectives and implementing activities aimed at addressing the disparity experienced by African Americans and other special populations residing in the District. The Plan also contains a special section on Health Equity.

The 2013-2018 DC Cancer Control Plan presents discussions, goals, objectives and action steps for five priority cancers: Breast, Cervical, Colorectal, Oral, and Prostate. In addition, the Plan addresses overarching issues affecting all cancers: Clinical Trials, Health Equity, Obesity Prevention, Palliative Care, Patient Navigation, Cancer Survivorship, and Tobacco-related Cancers.

While the chapters speak to current and projected conditions in the District, circumstances—political, economic, social, and medical—evolve over time, requiring flexibility in planning and openness in modifying strategies. This is why the Consortium intends the revised Cancer Control Plan to be a living document. During its five-year implementation, the Plan will be evaluated annually in order to examine data, assess progress and potential impact, and determine any need for refinement in objectives, activities or timeframes.

Implementation: What Is Needed to Produce Change

The stakeholders set out bold strategies and timeframes for driving down the District's cancer incidence, impact, and mortality over the next five years. But, for goals to be achieved, three elements are absolutely necessary. They are:

A true sense of **ownership** of the Plan—not only by the members of the Consortium, but also by the leadership structure of the City—is critical. Each member organization, individual stakeholder, executive branch agency, and legislative representative must be—and feel like—a necessary part of a systemic change process, working not only within an individual entity but as an integral and inseparable part of a coalition that is making an enormous difference in the local cancer burden.

Assets are a "must" for successful implementation. Private and public funding sources will need to be engaged to support the educational, service, and other initiatives outlined in the Plan. However, dollars are only one of the necessary resources. Others include innovations in collaborating, and coalition-building among new partners—all with an eye toward breaking out of parochial "silos" and working toward common public health goals. That is not always easy—but it has to happen. And stakeholder organizations must self-inventory internal resources—physical, human, organizational—that can contribute to achieving the Plan's goals. As yet unknown, the potential assets provided by the PPAC must be factored into the portfolio of assets that may become available to implement the Plan.

The last element is **data** for measurement and process improvement. This may seem a simple requirement, but it involves challenges, such as the sharing of

potentially proprietary information, the improvement of legacy information systems, and the expansion of traditional data elements. In addition, more substantial and comprehensive data collection is required to better target resources and efforts.

The work of the next five years is formidable—but its importance is immeasurable: this is truly a matter of life and death. For many cancers, the District of Columbia has among the highest incidence or mortality rates in the nation; in most cases, the rates in the District are higher than the national rates.

The DC Cancer Consortium and its member organizations are committed to serving as a unified voice for the District's medically underserved men, women, and children. Through collaboration, community engagement, and—most of all—wholehearted commitment from everyone who believes in the value of the work, we can together make great progress in lightening the heavy burden of cancer.

Now, after countless hours of work by scores of dedicated professionals and stakeholders, including those directly affected by cancer, the 2013-2018 DC Cancer Control Plan is complete. It provides the most current information on status, incidence, and mortality of specific cancers, along with an array of strategies to reduce the disproportionately high rates of cancer deaths and diagnoses in the District of Columbia.

The challenges, while considerable, are not insurmountable; they are simply factors that must be taken into account. The new Plan builds on the achievements of the original and recognizes new opportunities for collaboration with members and partners united in the urgency of the mission.

Two criteria were used to identify the cancers to be addressed in the 2013-2018 Plan: They include cancers that are the most preventable and most easily detected by testing; and cancers for which the District has among the highest incidence or mortality rates compared with national figures.

The primary audience for the new Plan is not the general public, but rather those individuals and organizations already involved in cancer prevention, treatment, patient education, and navigation. The Plan charges these individuals and groups with the responsibility for sharing information about cancer with their constituents, other health professionals, and community residents.

Goals and Objectives of the

2013-2018 DC Cancer Control Plan

OVERARCHING GOAL AND PRIORITIES

OVERALL GOAL: Reduce overall cancer incidence and mortality, reduce racial and other disparities in cancer incidence and outcomes, and improve the quality of care for and the lives of cancer survivors. Priorities for achieving the goal include the following:

Improving access to cancer care

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

Encouraging District-based research on its cancer burden, including gaps and challenges in cancer prevention, surveillance, and quality of care

Increasing public awareness of healthy behaviors that may prevent cancer

Advocating with the District government and other funding organizations on issues and funding relating to cancer

Educating health care providers

Improving the collection and use of DC data about cancer

Educating survivors and caregivers about resources and follow-up care, and assuring the quality of those supporting services

Increasing the awareness, availability, and quality of palliative care and end-of-life care

Chapter Goals and Objectives

Breast Cancer
Goal and Objectives

GOAL: Reduce the District's mortality due to breast cancer.

Objective 1: Increase from 81.6% to 90% the number of women aged 40 years and older who have received a mammogram within the past two years.

Objective 2: Increase early detection and prevention by improving the role of health care providers in ensuring access to appropriate women's health care, including risk reduction and clinical breast examination.

Objective 3: Decrease to no more than thirty days the time from abnormal breast cancer screening to definitive cancer diagnosis for all racial and income groups. (The current screening-to-diagnosis time is generally acknowledged to average 45 days.)

Objective 4: Decrease to no more than thirty days the time from diagnosis of breast cancer to treatment for all racial and income groups. (The current diagnosis-to-treatment time is generally acknowledged to average 45 days.)

Cervical Cancer
Goal and Objectives

GOAL: Reduce the District's mortality rate due to cervical cancer.

Objective 1: Increase cervical cancer screening rates for African American, Hispanic/Latina, and Asian women aged 21 to 70 years 10% above 2010 Behavioral Risk Factor Surveillance System (BRFSS) City-wide baseline of 87.1%.

Objective 2: Decrease incidence of invasive cervical cancer below 2008 baseline of 9.4 per 100,000 for all races.

Objective 3: Increase knowledge about and the availability of HPV vaccination above established baseline.

Objective 4: Increase the proportion of women with abnormal cervical cancer screening results who are diagnosed within sixty days after abnormal screening and who begin treatment within sixty days after diagnosis.

Cancer Clinical Trials
Goal and Objectives

GOAL: Increase by 15% the participation of the District's minority populations in clinical trials.

Objective 1: Implement a process for tracking patients participating in clinical trials in the District of Columbia.

Objective 2: Monitor, review, and provide annual feedback on the minority recruitment efforts of the District's cancer centers.

Objective 3: Develop a strategic plan to address the economic barriers to clinical trial participation faced by minority patients.

Colorectal Cancer
Goals and Objectives

GOAL 1: Reduce the incidence of colorectal cancer in the District.

Objective 1: Decrease the prevalence of lifestyle and dietary risk factors for colorectal cancer, including overweight and obesity, low intake of fruits and vegetables, lack of physical activity, and tobacco use.

Objective 2: Reduce by 50% the gap in the 2008 colorectal cancer incidence rate between Black residents (49.3) and White residents (33.9).

Objective 3: Identify and develop strategies to address colorectal cancer incidence disparities in high-risk populations.

GOAL 2: Reduce morbidity and mortality due to colorectal cancer in the District.

Objective 1: Increase by 20% colorectal cancer screening activity (fecal occult blood test and colonoscopy) for average-risk residents 50 years and older. This would increase the percentage of residents who are up-to-date with any screening in the past two years to 28.4% from the 2010 BRFSS baseline of 23.7%.

Objective 2: Decrease by 50% the 2008 gap in mortality rates between African American residents (21.0) and White residents (13.6).

Objective 3: Identify and develop strategies to address colorectal cancer mortality disparities in other high-risk populations.

Health Equity
Goal and Objectives

GOAL: Reduce/eliminate cancer burden disparities attributable to race/ethnicity, gender, culture, socio-economic status, language, and other social determinants.

Objective 1: Increase awareness among the public and health providers about social determinants and their influence on cancer rates.

Objective 2: Increase health equity criteria as part of all cancer program funding.

Objective 3: Expand existing database and tracking systems to include health equity factors (e.g., income, geographic area, etc.).

Obesity Prevention
Goal and Objectives

GOAL: Reduce the incidence of cancer in the District by improving the nutrition and physical activity of its residents in order to achieve and maintain a healthy weight.

Objective 1: Ensure the promotion and enactment of policies that create access to healthy foods and opportunities for physical activities in all District wards.

Objective 2: Advocate for and support an educational program utilizing effective behavior change messages to make District residents aware of linkages of unhealthy body weight to cancer, their weight status, and actions to achieve healthy weight.

Oral Cancer
Goal and Objectives

GOAL: Decrease the age-adjusted mortality due to oral cancer by 15%.

Objective 1: Develop a system of data collection to include measurements for screening and to ensure that best practices are being followed.

Objective 2: Initiate District-wide professional education program on appropriate oral cancer screening activity.

Objective 3: Increase by 10% the proportion of African American males over the age of 40 who have had an oral cancer examination in the past year.

Palliative Care
Goals and Objectives

GOAL 1: Improve the quality of education about palliative care and related services in the District.

Objective 1: Assess and develop recommendations to ensure that current pediatric and adult palliative care practices are based on national quality standards.

Objective 2: Develop initiatives, including outpatient options, to meet the needs of the palliative care population in the District.

GOAL 2: Promote the adoption of patient-centered continuity of care (including advance care planning) for patients, and support family caregivers.

Objective 1: Review current pediatric and adult programs that highlight a shared decision-making and patient-centered continuum of care, including those that focus on advance care planning and advance directives, and make recommendations for improved outcomes in the District.

Objective 2: Develop and implement strategic plan for assuring patient-centered care and shared decision-making in the District.

GOAL 3: Improve the policy and regulatory environment affecting access to pediatric and adult palliative care services in the District.

Objective 1: Develop an active policy team to advocate for enhanced reimbursement of government support and actively participate in District/national policy initiatives.

Access to Care and Patient Navigation Goals and Objectives

GOAL 1: Sustain District-wide longitudinal navigation services for District residents with cancer.

Objective 1: Maintain system of navigators as a safety net for individuals across the cancer continuum through the provision of patient navigation that includes community organizations, primary care and screening sites, and cancer centers.

Objective 2: Develop and implement a data collection plan that shows the value of patient navigation.

GOAL 2: Increase the quality of care received by District residents.

Objective 1: Remove barriers to care experienced by patients and increase self-efficacy of patients in navigating the health care system.

GOAL 3: Advocate for patient navigation as a reimbursable cost.

Objective 1: Develop an active policy team to raise awareness of the efficacy and efficiency of navigation and to advocate for reimbursement of patient navigation.

Prostate Cancer Goal and Objectives

GOAL 1: Reduce morbidity and mortality due to prostate cancer in the District.

Objective 1: Through the provision of professional and public education, improve the appropriateness of prostate cancer screening for District residents.

Objective 2: Establish a standard for community prostate screening process, including education and informed decision-making.

Objective 3: Increase the early detection and appropriate management of clinically relevant prostate cancer—cases with a high probability of rapid tumor growth—to mitigate adverse impact on chances of survival and quality of life.

Objective 4: Reduce the proportion of unstaged prostate cancer cases for all races from the 2004-2008 Surveillance Epidemiology and End-Year Results (SEER) baseline rate of 11.7 to less than 3.

Survivorship
Goal and Objectives

GOAL: Increase access to follow-up care, reduce recurrence, and improve the overall quality of life for the District's cancer survivors.

Objective 1: Analyze and report on the current state of survivorship needs, including medical, psychosocial, financial, nutrition, transportation, and rehabilitation needs for District resident survivors.

Objective 2: Utilizing national standards, establish District-wide comprehensive standards of care for survivorship programs, and educate providers on these standards.

Objective 3: Educate survivors, families, and caregivers on survivorship issues and appropriate standards for follow-up care.

Objective 4: Develop a strategic plan to address survivorship needs.

Tobacco-Related
Goal and Objectives

GOAL: Reduce disparities in tobacco use and tobacco-related cancer in the District.

Objective 1: Reduce the proportion of African American and Hispanic residents who are either adult smokers or middle and high school youth lifetime users by 10% of 2010 Behavioral Risk Factor Surveillance Survey (BRFSS) and Youth Risk Behavior Survey (YRBS) baselines.

Objective 2: Increase venues covered by tobacco-use restrictions or bans above 2010 baseline, which includes restaurants, bars, retail locations, and indoor places of employment.

Objective 3: Increase District policies addressing tobacco product promotion and marketing above 2010 baseline, which includes advertising near schools, couponing, samples, and point-of-purchase ads.

Objective 4: Increase District funding to CDC-recommended levels for local public and/or non-profit tobacco-control programs.

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The 2013-2018 DC Cancer Control Plan is the product of many individuals and organizations. First, and foremost, the DC Cancer Consortium wishes to acknowledge the expertise, commitment, and dedication of the more than 120 stakeholders who came together over a 16-month period to struggle with the critical questions and issues that had to be addressed by the Plan. Next, the Steering Committee and Consortium Board provided unwavering support for the process and critical feedback in developing the final product. Finally, the Consortium wishes to acknowledge the contributions of the following individuals:

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These individuals, along with Consortium staff and supporters, helped ensure that the 2013-2018 DC Cancer Control Plan moved from a concept to become a realistic roadmap that can be used to guide cancer control activities in the District of Columbia

Introduction

Background

In 2005, the Consortium produced the District's first Cancer Control Plan—a comprehensive five-year array of strategies designed to reduce the number of new cases of cancer, decrease the number of deaths due to cancer, and improve the quality of life for cancer survivors in the nation's capital.

The Consortium moved quickly into implementation of the Plan. It received initial funding from the Tobacco Master Settlement Fund in 2007 and awarded its first grants the following year. Since then, it has awarded more than $13 million in strategic grants in support of cancer awareness, patient navigation, screening, early detection, and treatment. DCCC also supports programs to help community- and faith-based organizations build capacity to serve residents' cancer care needs. These life-saving programs have the potential to be replicated elsewhere, offering a road map for effective cancer prevention and treatment in other urban areas.

The Consortium's collaborative efforts have produced significant results: the American Cancer Society (ACS) projects a 30 percent improvement in mortality since the release of the first Plan. The greatest mortality decreases are seen in colorectal and prostate cancers, two of the cancers targeted in the Plan.

But the progress, while significant, is only a beginning: in the District, there are still far too many men, women, and children coping with cancer. DC continues to have one of the country's highest cancer mortality rates, better than only four of the poorest states. And cancer persists as the leading cause of premature (before age 70) death in the District; it is the second most common cause of death overall, regardless of gender or race.

Challenges in the development of the new Cancer Control Plan

Demographic disparities

The Washington metropolitan area includes six of the ten wealthiest counties in the nation and a number of the country's top medical and cancer care centers. However, the region also has a significant population living below the poverty level—nearly 20 percent of DC residents and more than 30 percent of its children—and cancer incidence and mortality rates that are among the highest in the nation. More detail about these disparities is found throughout this report.

Data-related barriers

Accurate data is critical to the development of any Cancer Control Plan—and to creating effective strategies to help those at risk and those otherwise affected by cancer. Unfortunately, shortcomings in the available data make it difficult to gain more than a cursory insight into cancer disparities and their causes in the District.

For example, DCCC has encountered limits with respect to understanding cancer among some populations. The DC Cancer Registry does not have historical data on Hispanics/Latinos, a growing part of the District population. This is of special concern, given national data that indicates Latinas to be at particular risk for cervical cancer.

Gaps in data affect the ability to develop incisive objectives and action steps. In particular, specific data is needed to confirm or rebut clinician observations that some cancers present at an earlier age for some populations—meaning that screening would need to begin sooner.

A further issue is the age of available data: in many cases the most current is four years old.

A final data-related concern is the identification of minority populations. The DC Cancer Registry organizes information under "Black" and "White." DCCC assumes Black to mean African American, but it could also include anyone of African ancestry. Other data sources use "African American" as well as "Black." This report preserves the designation used by the data source, so some tables in the chapters refer to African Americans while others refer to Blacks.

Groundwork for the new Plan

The challenges, while considerable, are not insurmountable; they are simply factors that must be taken into account. And in 2011, the DCCC began working on its second five-year Cancer Control Plan. In that year, the Consortium initiated an assessment and planning process to determine the impact of the 2005-2010 Cancer Control Plan, identify changes in the state of cancer in the District, and engage a diverse group of over 120 stakeholders in the development of the new 2013-2018 Cancer Control Plan.

The new Plan builds on the achievements of the original, and recognizes new opportunities for collaboration with members and partners united in the urgency of the mission.

- The cancers included in the 2013-2018 Plan are those that are the most preventable and most easily detected by testing. They are also those for which the District bears the highest burden when compared with national incidence and mortality rates. The cancers addressed in the new Plan are:

- Breast
- Cervical
- Colorectal
- Oral
- Prostate

Additional chapters address overarching issues affecting all cancers:

- Clinical Trials
- Health Equity
- Palliative Care
- Patient Navigation
- Obesity Prevention
- Survivorship
- Tobacco Use

The 2013-2018 Plan was designed to provide a tool that could be used by stakeholders for outreach, education, and advocacy with their respective communities.

Creating the Plan

In examining the original Plan and its effectiveness, planning the updated document and crafting its details, a dedicated group of lay and professional stakeholders invested time and attention.

Overall leadership was provided by a Steering Committee comprised of subject matter experts, researchers, clinicians, and DCCC Board and administrative leadership (Please see Appendix 6).

In planning the process, DCCC decided not to rely on a small group of experts, but to bring together diverse panels of stakeholders with expertise and experience in each cancer or issue, and to support them from beginning to end. In all, 10 stakeholder panels were organized. (Please see Appendix 6.)

The stakeholder panels were diverse by race, gender, and discipline. They were organized to maximize the depth and breadth of viewpoints, and their members included, among others, cancer survivors, advocacy groups, physicians, public health experts, and community-based service providers. (Although each chapter in the new Plan contains extensive citations of reference materials, the Plan also includes occasional statements of opinion, or statements of fact, with no attribution provided. In all such cases, the statements are based on the experience and expertise of the stakeholders.)

Over 16 months, the groups met in a work process that included a series of sessions in which they reviewed data, assessed the District's cancer epidemiology and overall burden, discussed needs and real-world challenges, and evaluated progress vis-à-vis the first Plan. A special effort was made to address needs of underserved residents—not only Blacks but also Latinos, the LGTBQ population, and others who are not traditionally served.

Based on expert input, the stakeholders developed five-year goals with measurable objectives designed to ensure movement

toward the goals. Action steps and timeframes were devised, incorporating evidence-based interventions as much as practical. For most objectives, the stakeholder panels recommended the formation of specialized taskforces, adding new expertise as necessary, to carry out the implementation steps.

Once consensus was reached, DCCC developed **individual Plan chapters around the goals and objectives**. The stakeholders reviewed and provided input on the resulting drafts.

The Steering Committee's **final review and recommendations** for establishing action priorities were presented to the DC Cancer Consortium Board of Directors.

Now, after countless hours of work by scores of dedicated professionals, the 2013-2018 DC Cancer Control Plan is complete. It provides the most current information on status, incidence, and mortality of specific cancers, along with an array of strategies to reduce the disproportionately high rates of cancer deaths and diagnoses, in the District of Columbia.

Implementing the new Plan

The stakeholders set out bold strategies and timeframes for driving down the District's cancer incidence, impact, and mortality over the next five years. But for the goals to be achieved, four elements are absolutely necessary:

- A true **sense of ownership** of the Plan by all stakeholders, including policy makers, advocates, clinicians, and community leaders.

- Improved **data**—needed to measure progress and outcomes. The need to address obstacles such as proprietary information and the limitations of traditional data gathering is critical to gaining a clear understanding of how cancer affects certain populations and identifying new and emerging issues.

  It is also clear that there are significant data gaps that must be addressed in order to provide a comprehensive picture of cancer in the District of Columbia. Remedying these deficits may require modification of the DC Cancer Registry and other data sources or the development of new data collection instruments.

- Policy changes—in some cases, the stakeholder groups expect that the taskforces implementing the Plan's goals and objectives will also advocate for policy, program, and regulatory changes. Among examples cited in the Plan: (1) for obesity prevention, revised policies to create access to healthy foods and opportunities for physical activities in all District wards, (2) changes in reimbursement to allow greater access to palliative care, (3) for prostate cancer, mandating professional education hours on

chronic disease and cancer plus changes in health care financing, and (4) an increase in the tax on cigarettes, and tax treatment for other tobacco products that equals the treatment for cigarettes.

- Appropriate resources—the costs to implement the initiatives identified as priorities in the new five-year Plan total about $9 million a year, or $45 million over the duration of the Plan. These figures are based on 2010 estimates and will need to be adjusted to accommodate changes in the environment as well as new information about need.

Dollars are only one of the necessary resources. The Plan offers a roadmap for creating a unified vision for commitment that extends to surrounding jurisdictions.

DCCC recognizes that governments at all levels are likely to continue to experience enormous pressures on their budgets as demand for funding exceeds available revenues. So while there is a compelling rationale for government support, there is an equally strong case for private investment. When combined, these funding sources will ensure program stability and longer-term operational sustainability. Therefore, while the DCCC continues to press its case for public support, it also is reaching out more aggressively to the private sector—foundations, corporations, and individuals—for help. DCCC also recognizes that health issues, including cancer, are not just District problems but a matter of regional concern, with neighboring jurisdictions confronting many of the same issues as the District. Just as transportation and other issues are being dealt with on a regional basis, DCCC will also seek to increase its work with agencies and organizations in suburban Maryland and Northern Virginia. In addition to bringing new partners to the table, this effort could greatly expand resource opportunities.

Of the billions of dollars in tobacco taxes, fees, and Master Settlement Funds that states and localities collect each year, the Centers for Disease Control (CDC) estimates that only about three percent is actually spent on tobacco control and cancer programs. DC's one-time infusion of $16.5 million in Tobacco Master Settlement Funds was the first—and only—time the city committed significant monies toward tobacco control or cancer programs.

Among the Consortium's priorities over the next five years is identification of a dedicated funding source from the approximately $70 million in tobacco-related taxes and fees that DC takes in each year. The American Lung Association and CDC suggest that states and localities devote between 10 and 20 percent of their tobacco-related revenues to tobacco control and cancer programs—in DC, that's between $7 and $14 million.

Monitoring, oversight, and reporting

The stakeholder panels provide an infrastructure for implementing the Plan, and they have agreed to remain together to help carry out the identified action steps. DCCC will continue working with the stakeholder panels and the taskforces they create, and will help to identify appropriate resources. In addition, DCCC is responsible for continued monitoring, oversight, and periodic reporting on the Plan.

The 2013-2018 Cancer Control Plan is designed to be a living document with built-in flexibility. The Consortium has already established mechanisms for Plan monitoring and oversight. An annual evaluation of the Plan will be conducted to identify areas for modification.

Current plans call for quarterly meetings and/or semi-annual updates that DCCC will publish as supplemental reports about the Plan and its progress.

Cost of Implementing the 2013-2018 DC Cancer Control Plan

The goal of the 2013-2018 Cancer Control Plan is to reduce overall cancer incidence and mortality, *reduce racial and other disparities in cancer incidence and outcomes, and improve the quality of care for, and the life of cancer survivors.* The Plan targets cancers that are a priority – i.e., those in which District residents have among the highest incidence or mortality rates in the nation. The Plan also addresses critical overarching issues, such as patient navigation, clinical trials, and palliative care, among others. In sum, the Plan is designed to make a real-life immediate and long-term difference in the lives of District residents. Specific goals, evidence-based objectives, and strategic implementing actions are integrated into the Plan. The results are a plan that aims high but is nonetheless achievable. But the results anticipated by the Plan can be realized only if the Plan can be fully implemented. The DC Cancer Consortium has met the first requirement of implementation – ownership. More than 120 stakeholders from all sectors have worked over a year in consensus-building and the creation of the Plan. The second requirement of implementation, garnering investments, must be met in order for the Plan to become a reality.

Cost of Cancer

The American Cancer Society estimates that more than 1,600 people a day are expected to die from cancer.[1] Each of these deaths exacts a cost in medical care, family disruption, and productivity. The National Institutes of Health (NIH) estimated the 2007 overall annual costs of cancer at $226.8 billion.[2] Of this amount 45.8 percent ($103.8b) were incurred as direct medical costs; while, 54.2 percent ($123b) were indirect mortality costs related to lost productivity due to premature death. As the U.S. population ages, the financial amount spent on cancer care can be expected to increase as cancer-related medical care constitutes a substantial portion of overall

U.S. medical care costs.[3] The District of Columbia is expected to experience a 34 percent increase in cancer medical costs between 2010 and 2020 (from $259 million in 2010 to $347 million in 2020).[4] These figures are not adequate to describe the toll taken on families and communities from the loss of parents, partners, leaders, and neighborhood residents. Much of this loss could be averted if concrete measures are taken to ensure access to prevention, screening and early intervention, appropriate care, survivorship support, and navigation. The 2013-2018 Cancer Control Plan is designed to address the financial, productivity, and human costs associated with cancer in the District.

The goals and priorities defined by the Plan, include:

- Convening and facilitating collaborative cancer control efforts: Disease-specific screening and education programs remain a priority. For example, the Consortium is working with two major supporters of breast cancer control initiatives – the Avon Foundation and Susan G. Komen for the Cure – to help minimize any duplication of effort and make optimal use of the $13.5 million invested each year in the Washington metropolitan area.
- Strategic grant-making that focuses on increasing equity in access to care: A first-of-its kind survey of the residents of DC public housing will seek input on their perceptions of barriers in their lives and communities. Results from this survey will inform collaborative initiatives in the future.
- Translation and dissemination of evidence-based findings through training, education, funding, publications and other forms of communication.
- Providing technical assistance and capacity-building to strengthen community groups delivering relevant services: For example, by offering training to community groups in areas like grant writing, budgeting and strategic planning, these organizations will be able to secure sources of support on their own.
- Advocacy for systemic changes (reimbursements, research) that impact access to care: The Consortium is committed to raising and maintaining awareness among elected officials, other decision makers and members of the public about health equity issues, screening and treatment approvals relative to insurance coverage, improved insurance reimbursements, allowable expense coverage under insurance, enforcement of laws on sale of tobacco products, Department of Health priorities, etc.
- Ensuring the Consortium's strength as an organization: DCCC intends to increase its visibility within the

region, reinforcing not only the urgency of the mission, but also its unique ability to fulfill it. At the same time, it must continue to develop the internal structures that support financial stability and independence.

Building a Base and Garnering New Investments

In 2007, the D.C. City Council awarded $20 million in tobacco settlement funds to the Consortium to implement the DC Cancer Control Plan. That amount was later reduced to $16.5 million, with the remaining $3.5 million shifted to balance the District's budget. The Consortium awarded its first grants the following year. Since then, it has awarded more than $13 million in strategic grants in support of cancer awareness, patient navigation, screening, early detection and treatment. It also supported programs to help community- and faith-based organizations build capacity to serve residents' cancer care needs.

Among the key grants that received Consortium support were:

The Citywide Patient Navigation Network – This collaboration increases District residents' access to screening, treatment and survivorship planning services. The program created a comprehensive system of patient navigators, trained to overcome real and perceived barriers to cancer care and to communicate throughout the health care network. Program partners – which include health care providers, community service organizations, and even a cab company – identified a number of barriers and resolutions for each. To date, the program has helped more than 4,600 residents access and navigate health services and provided education and services to another 15,800.

DC Cancer Answers – This cancer telephone hotline is a collaboration of the American Cancer Society and The George Washington Cancer Institute and is supported by American Cancer Society specialists and the Citywide Patient Navigation Network. The helpline, which has been up and running since April 2011, also has been supported by awareness and outreach programs sponsored by Pfizer Medical Education, the local ABC affiliate WJLA-TV, and DCCC-sponsored special events. Bi-lingual transportation and resource guides and DCCC's revamped website, www.dccanceranswers.org, also enhance awareness.

DC Screen for Life – This partnership between the Howard University Cancer Center and The Georgetown University Lombardi Comprehensive Cancer Center provides colorectal cancer education, screening and treatment services in communities with historically low incomes and high cancer risk. Among the 413 residents screened to date, six cases of cancer were found and are being treated, and 118 cases of precancerous lesions were identified and extracted. The average screening cost of $1,200 per person is far less than the $64,000 or more associated with surgery, radiation and chemotherapy if precancerous lesions are not identified and addressed early.

Current estimates of the costs to implement the initiatives identified as priorities in the new five-year Plan total about $9 million a year, amounting to $45 million over the duration of the Plan. The budget for these funds has been earmarked to support grants and initiatives that directly affect District residents' access to prevention, treatment, and support services. Of the annual and five-year totals, about 42.5 percent is devoted to initiatives that support the overall plan, about 46.5 percent goes for disease and program-specific projects, and approximately 11 percent is for DCCC operations.

Investment in the Plan and in this innovative public-private partnership will save lives and in many cases lower health care costs and save taxpayers money. Program initiatives also will improve the quality of life for residents of the DC metropolitan area. With replication, the Plan can, potentially, do the same for residents of other urban regions in the country.

Cancer Plan Budget Breakdown

Program	Annual Cost
Access to care programs/Network Navigation	$2.5 million
Provider education and technical assistance	$500,000
Data and Surveillance/Reporting	$100,000
Membership technical assistance and capacity building	$75,000
Communications and Outreach	$500,000
Public Policy Education	$125,000
Tobacco control (cessation and remediation activities	$1.5 million
Colorectal cancer	$1 million
Obesity prevention	$800,000
Adult and Pediatric Palliative care	$250,000
Breast and Cervical cancer	$200,000
Prostate cancer	$150,000
Oral cancer	$75,000
Clinical trials	$90,000
Survivorship	$75,000
Pediatric cancer	$30,000
Total	$7,970,000

This preliminary budget is based on 2010 figures and will have to be adjusted to accommodate new costs and changes in need.

Breast Cancer

- The American Cancer Society estimated that in 2011, 230,480 new cases of invasive breast cancer would be diagnosed among women nationally, as well as an estimated 57,650 additional cases of in situ breast cancer (Breast Cancer Facts & Figures 2011-2012)
- The District of Columbia has the seventh highest incidence rate and the highest death rate from breast cancer in the United States (Breast Cancer Facts & Figures 2011-2102)
- Based on 2004-2008 Surveillance Epidemiology and End Results data, African American women had a death rate from breast cancer of 32.0 per 100,000 compared to 22.8 for White women, and 15.1 for Hispanic/Latina women. (SEER Stat Fact Sheets: Breast)

Breast cancer is the nation's second leading cause of cancer-related death among women, exceeded only by lung cancer. (In this chapter, unless otherwise noted, all data refers to female breast cancer.) It accounts for nearly one in three cancers diagnosed in women.[1] Most breast cancers are invasive, meaning they started in the ducts of the breast but have broken through the duct or glandular walls to invade the surrounding breast tissue; early, non-invasive cancers are also referred to as "in situ" cancers.

National trend data by race tell a compelling story about breast cancer.[2] African American women have higher incidence rates before 40 years of age and are more likely to die from breast cancer at every age than White women.[3]

Breast cancer incidence rates among White women increased rapidly—by 4.1percent per year—during the 1980s (coinciding with the introduction of mammography screening), then stabilized from 1987-1994. The rates increased again starting in 1995, peaking in 1999—but starting in 2002 and 2003, the incidence rates dropped sharply and then stabilized. Among African American women, the incidence rate also increased during the 1980s; however, the rate has remained stable since 1992, not following the decline trend experienced by White women.

Incidence rate data became available for women of other races in 1992. As a result of this expanded tracking, breast cancer was found to be the most common cancer among Latinas. From 2004 to 2008, incidence rates were 127.3 for Caucasian women, 119.9 for African American women, and 92.1 for Latinas. (Rates are per 100,000 population).[4] Analysis of cancer registry

data and private studies found that breast cancer presented at a younger age in both African Americans and Latinas.[5]

Deaths as a result of breast cancer have been consistently in decline over the years. Nationally, from 1998 through 2007, breast cancer death rates declined annually by 1.9 percent in Hispanics, 1.8 percent in Whites, 1.6 percent in African Americans, and 0.8 percent in Asian/Pacific Islander women.[6] Despite these declines, breast cancer mortality was higher for African American women than for White women; the rate for Latinas was lower. For 2004-2008, the mortality rate for breast cancer by race was 22.8 for Caucasian women, 32 for African American women, and 15.1 for Latinas.

Although the five-year relative survival rate for breast cancer has increased for all groups, there remains a significant racial gap between African American and Caucasian women. For the

2001-2007 period, the five-year relative survival rate was 77 percent for African American women and 90 percent among White women. The American Cancer Society attributes this disparity to both later stage at detection and poorer stage-specific survival among African American women. According to American Cancer Society statistics, African American women are more likely to be diagnosed with larger tumors than White women.

Each year in all racial groups, the percentage of women who participate in mammogram screening increases; however, there are still large numbers of low-income women who do not get mammograms. Research is well settled that the predominant barriers to mammogram screening among low-income women relate to access to care and having a regular health care provider.[7] However, even when these barriers are addressed, there is still a significant number of women not receiving mammograms. In a study of low-income African American and White women enrolled in a state-based managed care organization, 42 percent of eligible women had never had a mammogram. These women were insured, had a usual source of care, and had a regular health care provider. The study findings indicated that the level of knowledge about breast cancer, the importance of early detection, and information about the mammogram process were pivotal in determining whether the subjects chose to have mammograms.[8]

Breast Cancer in the District of Columbia

The District of Columbia has the seventh-highest incidence rate of breast cancer in the US, based on 2008 data from the National Cancer Institute. Data for 2004-2008 show that DC's rate of breast cancer at 134.2 per 100,000 is higher than the national rate of 121.2.[9]

Data from the Centers for Disease Control and Prevention shows that, nationally, African American women age 40 and older get mammogram screenings at a higher rate than any other racial group. Based on 2008 data (the latest available at this writing), 68 percent of African American women reported having had a mammogram in the last two years, compared to 67.9 percent of White women, 66.1 percent of Asian/Pacific Islander women, and 61.2 percent of Hispanic women.[10] Locally, the 2010 estimates from the Behavioral Risk Factor Surveillance System (BRFSS) show that 81.6 percent of all District women aged 40 and over had a mammogram within the past two years.[11]

According to the DC Cancer Registry, between 2004 and 2008 there were 2,111 cases of breast cancer in the District. Of these, 63 percent were in African American women. For all races, the incidence of breast cancer in the District exceeds the national rate. (Rates for Tables 1, 2, and 3 are per 100,000 persons and age-adjusted to the 2000 US standard population.)

Table 1. US and DC Female Breast Cancer Incidence Rates by Race, 2004-2008[12]

	US	DC
All Races	121.2	134.2
White	125.4	159.6
African American	116.1	126.6
Latina Hispanic	91.0	Not available

Table 2. Female Breast Cancer by Stage of Diagnosis, 2004-2008. Percent of Total Cases by Site and Race, DC Residents[13]

Race	Site				
	In Situ	Local	Regional	Distant	Unknown or Unstaged
All Races	19.3	41.0	28.2	5.8	5.7
White	21.2	44.6	25.8	3.9	4.6
African American	18.2	39.6	29.5	7.3	5.4

The District of Columbia has the nation's highest annual death rate from breast cancer: 27.6 per 100,000 in 2008 compared to 23.5 nationally.[14] Although the incidence rate of breast cancer is higher for White women, African American women are overrepresented among those dying from the disease.

Table 3. Age-Adjusted Mortality Rates by Ward for Female Breast Cancer Deaths Occurred in 2008, DC Residents[16]

Ward 1	21.0
Ward 2	24.5
Ward 3	19.8
Ward 4	22.1
Ward 5	40.5
Ward 6	28.5
Ward 7	29.9
Ward 8	39.0

Age-adjusted mortality rates for 2008 for DC show a rate of 28.2 for all races, but 17.7 for White women compared to 35.2 for African American women.[15] As Table 2 illustrates, more African American women than White women have their cancers diagnosed at the regional and distant stages (i.e. later, when the cancer has spread).

Mortality rates also have a geographic dimension, falling unequally across wards of the city, as illustrated by Table 3.

In the District, Wards 5, 6, 7 and 8 have higher poverty rates and lower educational attainment, and are home to a higher proportion of minorities.

District Programs and Services

Although a great majority of District women 40 and older are participating in regular breast cancer screening, significant numbers still are not. In addition, given the early onset of breast cancer among younger African American women, little is known about their participation in regular screening activities. Many factors affect screening practices, including lack of awareness and understanding of the need for and recommended frequency of screening, financial barriers, and lack of access to screening facilities. The District has implemented a number of strategies to support increased early detection. Included in these efforts are programs that link low-income, uninsured, and underinsured women with screening and diagnostic

services. As a part of the National Breast and Cervical Cancer Early Detection Program (NBCCEDP), the DC Department of Health provides free breast cancer screening and diagnostic follow-up for eligible women who are between the ages of 40-64 and uninsured or underinsured through Project Women Into Staying Healthy (Project WISH). Project WISH also provides patient navigation, transportation assistance, and cancer education to all women enrolled in the project. In addition, the District has allowed payment to be reimbursed through Medicaid for treatment services for uninsured women who are diagnosed with breast cancer.

Currently, the Department of Health, the DC Cancer Consortium, and breast cancer stakeholders have come together to establish the Mammography Surveillance System that will provide better population-based data. Such a system will be critical in identifying gaps in services, capturing data that may lead to a better understanding of health behaviors, and identifying factors that can lead to prioritizing and streamlining programs and services.

Breast Cancer

Goal and Objectives

GOAL: Reduce the District's mortality due to breast cancer.

Objective 1: Increase from 81.6% to 90% the number of women aged 40 years and older who have received a mammogram within the past two years.

Steps to achieve objective:

1. Develop and implement a data collection plan, building on existing research and information to assess knowledge and attitudes about breast cancer-specific information. To be included: risk factors, family history, screening and diagnostic modalities (and their risks and benefits), treatment options, etc., barriers to screening and factors that could promote health-seeking behavior (influencers, behavior promoters, etc.).
2. Utilize existing information to design and implement an education initiative about breast cancer, including risks, natural history and screening.
3. Leverage and secure resources to support data collection program and education initiative.
4. Evaluate education initiative and report findings to DCCC membership.
5. Utilize the collected data to construct and identify resources for a strategic plan to address through policy and resource development any identified economic barriers to screening, including threats to the sustainability and/or expansion of public and non-profit breast cancer screening and referral programs that focus on the underserved.

Measurements:

1. BRFSS data
2. National Breast and Cervical Cancer Early Detection Program (NBCCEDP) via DC Department of Health's Project WISH. and other nonprofit programmatic data
3. Payer utilization data
4. Process measures and milestones to be determined by taskforce, possibly to include pre- and post-testing for knowledge change
5. Mammography Surveillance System

Timeframe: 5 years

Objective 2: Increase early detection and prevention by improving the role of health care providers in ensuring access to appropriate women's health care, including risk reduction and clinical breast examination.

Steps to achieve objective:

1. Support providers in breast health initiatives, which can include using established best practices – e.g., patient reminder systems.
2. Develop and implement a data collection plan, building on existing data, to assess knowledge and attitudes of primary health care providers about women's preventive health care. To be included: chronic disease and women's cancer-specific information, including risk factors and high-risk populations, family history, screening and diagnostic modalities (and their risks and benefits),

treatment options, appropriate referrals, and follow-up care.
3. Identify and secure resources to support data collection plan.
4. Examine existing information; then design, and secure resources to implement, professional education initiatives about chronic disease and women's cancers (with evaluation) for various provider audiences.
5. Evaluate existing preventive health tools and best clinical practices, develop consensus, and develop an education and distribution plan for medical history, educational, and patient and provider screening reminder tools. Objective: to assist providers in providing appropriate clinical assessment (including history-taking and risk assessment) and patient education for women's health issues.
6. Develop a data collection and evaluation scheme for medical practice related to women's preventive health care.
7. Leverage DCCC membership to advocate with District licensing agency and professional boards for the inclusion of mandatory continuing educational requirements for chronic disease and cancer assessment and prevention.
8. Evaluate the impact of interventions for reporting to DCCC membership and for quality improvement.

Measurements:

1. BRFSS data (with additional question on clinical breast examination in even-number years)
2. Process measures and milestones to be determined by taskforce, possibly to include pre-/post-testing and survey data for knowledge and practice change

Timeframe: 5 years

Objective 3: Decrease to no more than 30 days the time from abnormal breast cancer screening to definitive cancer diagnosis for all racial and income groups. (The current screening-to-diagnosis time is generally acknowledged to average 45 days.)

Steps to achieve objective:

1. Convene taskforce to develop work plan.
2. Leverage DCCC membership to advocate for the inclusion of "time from screening to diagnosis" in publicly reported center quality measures.
3. Evaluate the current monitoring and assessment systems for breast cancer screening and follow-up activity, with benchmarking against identified regional and/or national models.
4. Utilizing information from the evaluation, monitor and collaborate with the DC Department of Health in its development of an active surveillance system and, as necessary, assist in the design of, and implementation plans for, such a scheme.
5. Examine potential public and private funding sources, and develop and implement a plan to assure resources for the availability of District-wide patient navigation services.
6. Evaluate the barriers to the establishment of routine patient navigation or case management for all patients within the District's cancer centers, and develop recommendations

to address regulatory and resource needs.
7. Report recommendations to DCCC membership for organizational advocacy.

Measurements:
1. Data from the Mammography Surveillance System
2. Process measures and milestones to be determined by taskforce

Timeframe: 5 years

Objective 4: Decrease to no more than thirty days the time from diagnosis of breast cancer to treatment for all racial and income groups. (The current diagnosis-to-treatment time is generally acknowledged to average 45 days.)

Steps to achieve objective:
1. Convene a taskforce to develop work plan.
2. Examine potential public and private funding sources, and develop and implement a plan to assure resources for the availability of District-wide patient navigation services.
3. Evaluate the barriers to the establishment of routine patient navigation or case management for all patients within the District's cancer centers, and develop recommendations to address regulatory and resource needs.
4. Examine administrative and regulatory barriers to timely care (payer authorization challenges, center capacity issues, etc.), and devise strategies to address them.

Cervical Cancer

The American Cancer Society predicts there will be 12,170 new cases of cervical cancer diagnosed in 2012, and 4,220 deaths from the disease. (*Cancer Facts & Figures 2012*)

Nationally, Hispanic/Latina women have the highest incidence rate of cervical cancer (11.5) while Black women have the highest death rate (4.3). (*Cervical Cancer Rates by Race and Ethnicity*, Centers for Disease Control and Prevention)

The District of Columbia has both a higher incidence rate (11.4) and mortality rate (3.4) than the US (8.1 and 2.4, respectively). (*Incidence Rate Report for District of Columbia, All Races, 2005-2009; Death Rate Report for District of Columbia, All Races, 2005-2009*, State Cancer Profiles, Centers for Disease Control and Prevention)

In 2009 (the most recent year for which numbers are available), 12,357 women in the US were diagnosed with cervical cancer--and 4,008 women died from the disease.[1] Racially, Hispanic/Latina women had the highest incidence rate, but African American women had the highest death rate, as illustrated in Table 1.

Table 1. Cervical Cancer Incidence and Death Rates by Race US 2004-2008

Race	Incidence Rate	Death Rate
White	7.7	2.2
African American	10.6	4.3
Hispanic	12.2	3.1
Asian/Pacific Islander	7.4	2.1
American Indian/Alaska Native	9.8	3.4

Rates are per 100,000 persons and are age-adjusted to the 2000 US standard population.
Source: Centers for Disease Control and Prevention. [2]

Incidence and mortality rates for cervical cancer have declined over the past decades in both White and African American women. Since 2004, incidence rates have decreased by 2.1 percent per year in women younger than 50 years of age and by 3.1 percent per year in women 50 and older. From 2004-2008, mortality rates decreased by 2.6 percent per year in African American women and remained stable in White women. However, Latino women suffer a disproportionate burden of cervical

cancer, with incidence and mortality rates nearly twice that of White women.

The main cause of cervical cancer is infection with the human papillomavirus (HPV). It is estimated that about 5.5 million people acquire a genital HPV infection each year. At any one time, over 20 million Americans have the virus.[3] Despite the widespread occurrence, few of those infected will develop cervical cancer. Health departments are increasingly recommending vaccination against the virus for those ages 9 through 26.

One- and five-year relative survival rates for women with cervical cancer are 87 percent and 69 percent, respectively. For those diagnosed with localized cancers, the five-year survival rate is 91 percent. Time of diagnosis is related to both race and age. Cervical cancer is diagnosed at an early stage more often in White women (49 percent) than in either Latinas or African American women (42 percent). It is diagnosed more often in women younger than 50 years of age (60 percent) than in those who are 50 and older (34 percent).[4] The American Cancer Society (ACS) estimates that 12,170 new cases of cervical cancer will be diagnosed and there would be 4,220 deaths from cervical cancer in 2012.

Papanicolaou (Pap) tests are used to diagnose cervical cancer. Income level, age, cultural issues, and sexual orientation are among the factors in whether Pap tests are a regular part of preventive health care. Latina women suffer the added burdens of limited English language proficiency, fear due to immigration status, and lack of understanding about cervical cancer and Pap tests.[5] The National Health Interview Survey (NHIS) in 2008 found that women age 18 and older with a family income of at least 200 percent of the poverty level were more likely to have had a Pap test in the preceding three years than those who were poor (income <100 percent of poverty) or near poor (income 100percent to <200percent of poverty).[6] The survey also found that women 65 or older were less likely to have had a Pap test in the preceding three years than were younger women, regardless of poverty level.

Cervical Cancer in the District of Columbia

Following the national trend, cervical cancer has been in decline in the District of Columbia overall. Incidence rates for cervical cancer have fallen from a high of 16.6 in 2003 to 12.7 in 2005, and finally to 9.4 in 2008.[7] This encouraging news, however, does not tell the full story of this disease in the District. Compared with national data, the District has higher rates of both incidence and mortality, as reported in Table 2. When race is considered, White women in the District have a higher incidence rate but a lower mortality rate compared to the US as a whole.

Table 2. Cervical Cancer Incidence and Mortality Rates, by Race, DC Residents Compared to US 2004-2008				
	All Races	White	Black	Hispanic/ Latina
Incidence Rate	11.4	9.0	11.5	
US Incidence Rate	*8.1*	*8.0*	*10.0*	*12.2*
Mortality Rate	3.4	1.9	4.3	
US Mortality Rate	*2.4*	*2.2*	*4.3*	*3.1*

Rates are per 100,000 persons age-adjusted to the 2000 US standard. Source: DC Cancer Registry; Surveillance Epidemiology and End Results (SEER).

According to the DC Cancer Registry, for cervical cancers diagnosed in 2008, White women in the District show a higher incidence rate than Black women (10.0 and 9.5, respectively) but a lower mortality rate (0.0 compared to 5.1 for Black women).[8] The Behavioral Risk Factor Surveillance Survey (2010) states that 87.1 percent of District women 18 years of age and older reported having had a Pap smear within the preceding three years.[9] For those women diagnosed with cervical cancer, there is a significant difference, by race, in the stage at which their cancer is diagnosed.

There is currently no available data that provides insight into the reasons for this disparity. In addition, there is no research that explores the types and extent of barriers that may be faced by those women who are not compliant with their Pap tests, particularly minority women and other s illustrated in Table 3, White women represent three-quarters of local stage diagnoses, while Black women represent the majority of diagnoses at the regional and distant stages.

Cervical Cancer Activities in the District of Columbia

In 2008, a great majority of District women reported having had Pap smears within the three preceding years, but no demographic information exists about these women and whether they are at a greater risk for breast cancer and taking advantage of this preventive health procedure. Some efforts to address this problem have been made in the District. As part of the National Breast and Cervical Cancer Early Detection Program, the DC Department of Health provides free cervical cancer screening and diagnostic follow-up for eligible women who are between the ages of 21-64 and uninsured or underinsured through Project WISH. This program also provides patient navigation, transportation assistance, and cancer education for all women enrolled.

Table 3. Cervical Cancer Stage at Diagnosis, Percent of Total Cases, by Race, DC Residents for Cancers Diagnosed in 2008			
Stage at Diagnosis	All Races	White	Black
Local	32.1	75.0	15.8
Regional	42.9	25.0	52.6
Distant	21.4	0.0	31.6

Rates are per 100,000 persons age-adjusted to the 2000 US standard. Source: DC Cancer Registry; Surveillance Epidemiology and End Results (SEER).

There is currently no available data that provides insight into the reasons for this disparity. In addition, there is no research that explores the types and extent of these barriers that may be faced by those women who are not compliant with their Pap tests, particularly minority women and other underserved populations. Further research may provide insight into the disparity.

Cervical Cancer Control Goals and Objectives

GOAL: Reduce the District's mortality due to cervical cancer

Objective 1: Increase cervical cancer screening rates for African American, Hispanic/Latina, and Asian women aged 21 to 70 years 10% above 2010 Behavioral Risk Factor Surveillance System (BRFSS) City-wide baseline of 87.1%.

Steps to achieve objective:

1. Convene taskforce of current stakeholders to organize, engage other proposed members, and devise work plan.
2. Develop, leverage necessary resources for, and implement a data collection plan to map providers performing screenings and the availability of support services (day care, language translation, etc.) within the community; determine cultural, financial, and language barriers to screening services.
3. Analyze existing and/or newly collected information and then design, identify necessary funding for, and implement a program to improve cultural competency and access by assuring linkages of providers and patients to existing public or private organizations identified as performing work targeting the identified racial and ethnic communities.
4. Work with the DC Department of Health and non-profit organizations to develop a process for monitoring and advocating for the optimal promotion, administration, and efficiency of public and non-profit cervical cancer screening programs that focus on the underserved.
5. Collect and analyze data to assess knowledge and attitudes of the identified racial, ethnic, lesbian, bisexual, and transgender communities about cervical cancer- specific information. Data collected will include risk factors, screening and diagnostic modalities, treatment options, and barriers to screening, with a goal of developing an outreach plan to increase knowledge about the need for cervical cancer screening and its availability.
6. Engage public health and medical/nursing association partners in assessing the present knowledge base of health care providers about cervical cancer screening in order to develop and implement an education or information dissemination plan for current evidence-based guidelines, screening techniques, the use of client and provider reminders, and follow-up.
7. Evaluate the impact of interventions for reporting to DCCC membership and quality improvement.

Measurements:
1. BRFSS data
2. National Breast and Cervical Cancer Early Detection Program (NBCCEDP) via DC Department of Health's Project WISH. and non-profit programmatic data
3. Payer utilization and Health Effectiveness Data and Information Set (HEDIS) data
4. Process measures and milestones to be determined by workgroup

Timeframe: 5 years

Objective 2: Decrease incidence of invasive cervical cancer below 2008 baseline of 9.4 per 100,000 for all races.

Steps to achieve objective:
1. Convene taskforce to organize, engage other proposed members, and devise work plan.
2. Provide periodic assessment and feedback on plans, initiatives, and programs developed by DCCC cancer workgroups.
3. Provide periodic assessment and feedback on plans, initiatives, and programs regarding access to appropriate women's health care developed by DCCC breast and cervical cancer taskforces.
4. In collaboration with DCCC leadership, achieve consensus on goals of partnership with organizations working on reducing risks related to co-factors of cervical cancer, in terms of any specificity of population (youth, child-bearing age, etc.), as well as policies and programs.
5. Accumulate and examine information on current District-wide initiatives, organizations, and coalitions addressing sexual health and sexually transmitted infection risk reduction for the specified populations.
6. After the examination of District-wide initiatives, develop any required communications plan for promoting the linkage of cancer to HPV and HIV groups working in those areas.
7. Utilize the communications plan to advocate with appropriate leadership (governmental, non-profit coalition officers, etc.) to identify common ground, avenues for mutual support, and concerns related to cervical cancer prevention, in addition to participating in decision-making with planning groups or coalitions.
8. Provide periodic updates to DCCC leadership and members for feedback and ongoing improvement efforts.

Measurements:
1. BRFSS and Youth Risk Behavior Survey (YRBS) data
2. DC Cancer Registry data
3. Payer utilization and HEDIS data
4. Process measures and milestones to be determined by workgroup

Timeframe: 5 years

Objective 3: Increase knowledge about and the availability of HPV vaccination above established baseline.

Steps to achieve objective:

1. Convene taskforce of current stakeholders to organize, engage other proposed members, and devise work plan.
2. Analyze the existing data and information systems that measure public knowledge about HPV vaccinations and monitor their usage.
3. Utilize the results of the analysis, develop recommendations for any necessary improvements or expansions to those systems in order to provide adequate information for the establishment of baseline data and follow progress; then leverage DCCC membership and resources for implementation.
4. Assess the District's implementation of the Human Papillomavirus Vaccination and Reporting Act of 2007 ward-level public information campaign requirements, and facilitate the collaboration of non-profit and governmental organizations in the campaign's use of evidence-based educational techniques, resourcing, implementation, and/or quality improvement.
5. Monitor the District's implementation of Human Papillomavirus Vaccination and Reporting Act of 2007 vaccination program requirements, and facilitate the collaboration of non-profit and governmental organizations in the program's focus, use of current evidence-based guidelines and research, monitoring of vaccine-related adverse events, resourcing, implementation, and/or quality improvement.
6. Work with the Departments of Health and Health Care Finance; assess financial barriers to the access and affordability of HPV vaccinations; produce recommendations as to policy, program, and regulatory changes that will address them; and prepare a report to DCCC membership in order to guide the organization's advocacy work.
7. Engage public health and medical/nursing association partners in assessing the present knowledge base of health care providers about HPV vaccinations in order to develop and implement an education or information dissemination plan for current evidence-based guidelines.
8. Evaluate the impacts of educational interventions that address knowledge and beliefs about, and attitudes toward, the HPV vaccine and vaccine utilization and report to DCCC membership to identify areas for quality improvement.

Measurements:

1. BRFSS data
2. DC DOH Vaccine Registry data
3. Payer utilization and HEDIS data
4. Process measures and milestones to be determined by taskforce

Timeframe: 2 years

Objective 4: Increase the proportion of women with abnormal cervical cancer screening results who are diagnosed within sixty days after abnormal screening and who begin treatment within sixty days after diagnosis.

Steps to achieve objective:

1. Convene taskforce of current stakeholders to organize, engage other proposed members, and devise work plan and reporting schedules.
2. Develop, leverage necessary resources for, and implement a data collection plan to assess gaps in providers and support services in the community and determine potential barriers to care.
3. Analyze existing and/or newly collected information; then design, identify necessary funding for, and implement a program to assure linkages of providers and patients to existing public or private organizations identified as performing work addressing the identified barriers.
4. Examine the existing data systems as to their capability and quality in monitoring diagnosis and treatment times and develop, as necessary, either an improvement plan or a tracking system for ongoing quality improvement.
5. Evaluate the availability of patient navigation services from the point of abnormal screening and provide recommendations and support for DCCC efforts to improve access to navigation.
6. Work with the DC DOH and non-profit organizations to develop a process for monitoring and advocating for the optimal promotion, administration, and efficiency of public and non-profit cervical cancer screening and referral programs that focus on the underserved.
7. Develop a policy and regulation advocacy plan to address any identified financial and specialist density challenges to cervical cancer diagnosis and treatment, to possibly include health insurance coverage changes, educational loan repayment, and tax relief for locating in underserved communities.
8. Evaluate the impacts of interventions and report to DCCC membership to develop recommendations for quality improvement.

Measurements:

1. BRFSS data
2. National Breast and Cervical Cancer Early Detection Program (NBCCEDP) via DC Department of Health's Project WISH and non-profit programmatic data
3. Payer utilization and HEDIS data
4. Process measures and milestones to be determined by taskforce

Timeframe: 5 years

Clinical Trials

The National Cancer Institute notes that adult participation in clinical trials is as low as two percent (2%), while pediatric cancer clinical trial participation is at 70 percent (70%). (*Boosting Clinical Trial Participation, 2011,* National Cancer Institute,)

Physicians who are recruiting for and aware of clinical trials have a higher likelihood of recommending a cancer patient for participation. (Cancer Clinical Trials: The Basic Workbook)

Minorities experience many barriers to participation in clinical trials. The barriers are both patient-generated and physician-centered. (Journal of Clinical Oncology, 2004; National Cancer Institute/Harris Interactive Report, 2001)

A three-pronged approach involving third-party community-based organizations, primary care physicians and oncologists holds promise for increasing cancer clinical trials among minority groups. (*Journal of Cancer Education,* 2011)

Cancer clinical trials (CCTs) have resulted in tremendous breakthroughs in prevention, diagnosis and treatment, uncovering, for example, the link between nutrition and cancer and the genetic markers that are predictive of certain cancers, such as female breast cancer. Clinical trials are credited with breakthroughs in establishing the effectiveness of lumpectomies for breast cancer, new chemotherapy drugs for colon cancer, and the combination of chemotherapy and radiation for advanced cervical cancer.[1]

Despite these benefits, only two to four percent of newly diagnosed adult cancer patients participate in cancer clinical treatment trials, according to the National Cancer Institute.[2] This is in dramatic contrast to the more than 70 percent of pediatric cancer patients who participate in CCTs. A recent Institute of Medicine committee report on cancer clinical trials has recommended that all participating physicians should "strive to make participation in clinical trials a key component of clinical practice and to achieve high accrual rates of 10 percent or more." The Institute of Medicine reports that "therapies offered through CCTs should ideally be considered the preferred treatment choice for physicians and patients." The National Comprehensive Cancer Network (NCCN) goes further, stating "the best management for any patient with cancer is in a clinical trial." There are many reasons the numbers of adult CCTs are so low. These reasons, or barriers to CCT participation, are experienced by accruing and non-accruing oncologists, referring health care providers and cancer patients.

Barriers Experienced by Referring Health Care Providers

The primary source of CCT participants is physician referrals. Barriers for health care professionals include:[5]

- Lack of awareness of appropriate and available clinical trials
- Unwillingness to "lose control" of a patient's care
- Belief that standard therapy is best
- Belief that referring to and/or participating in a clinical trial adds an administrative burden
- Concerns about the patient's care or how the patient will react to the suggestion of clinical trial participation

A 2000 Harris Interactive, Inc. survey of 425 primary care physicians and oncologists found that the respondents had very positive attitudes about clinical trials. In a second survey, by the American Society of Clinical Oncology (ASCO), in which the 3,550 physician respondents were active clinical trial recruiters, 80 percent of these physicians reported they had enrolled a patient in a clinical trial in the past three years. But that encouraging news wasn't reflected in actual patient enrollment: the oncologists stated that, although 20 percent of their patients were eligible for a clinical trial, they approached only half those patients about enrolling, and only half of those approached (5 percent) were actually enrolled.

According to the ASCO study, increased data collection and other administrative tasks were significant barriers to their recruitment of patients for clinical trials as well as expense. The ASCO study found that the cost to physicians for data management and other research expenses associated with enrolling a patient in a cancer clinical trial (Phase III) was about $2,000. Finally, some physicians noted that eligibility for clinical trials was too restrictive and expressed the desire for clinical trials to be open to patients at all stages of treatment.

It might be expected that oncology specialists would be in a better position than other health professionals to know about available clinical trials. A study of 1,533 specialty physicians associated with the National Cancer Institute who cared for colorectal and lung cancer patients (496 medical oncologists, 228 radiation oncologists, and 809 surgeons) confirmed this conclusion.[6] Of those surveyed, 87.8 percent of medical oncologists, 66.1 percent of radiation oncologists, and 35.0 percent of surgeons reported referring or enrolling one or more patients in clinical trials during the previous 12 months.

At least two studies have indicated that bias in the selection of CCT participants is at least a partial factor in the low participation of minorities and other underserved populations. One study found that African American patients were more likely to be considered ineligible for CCT participation compared to other races, and all patients perceived as *likely to be noncompliant* were African American.[7] Another study found that the oncologist's immediate and subjective assessment of patient suitability – unrelated to eligibility – directly affected whether or not that patient was invited to participate in a CCT.[8] These studies imply

that even at major cancer centers, patients from minority groups are less likely to be approached for CCT participation, regardless of eligibility.

Barriers Experienced by Cancer Patients

Patients diagnosed with cancer also face barriers to participation in clinical trials. A 2001 Harris Interactive, Inc. survey of 6,000 people with cancer looked at some of the reasons so few adults participated in clinical trials.[9] Highlights of the study included:

- 85 percent of people with cancer were either unaware or unsure that clinical trials were an option; but 75 percent of these people said they would have been willing to enroll had they known it was possible
- Of those who were aware of the clinical trial option, most declined participation because they believed:
    - The treatment they would receive would be less effective than standard care
    - They might be given a placebo
    - They would be treated like a "guinea pig"
    - Their insurance company would not cover costs
- Of those who did participate in a clinical trial:
    - 97 percent said they were treated with dignity and respect and rated their quality of care as "excellent" or "good"
    - 86 percent said their treatment was covered by insurance

It is well documented that minorities, individuals over 65, and other medically underserved populations are underrepresented in clinical trials. One study utilized community-based partnerships to increase minority participation in CCTs through a three-pronged strategy targeting community leaders/intermediaries, primary care physicians, and oncology staff. The study had positive outcomes in increasing knowledge and awareness among all groups (and ultimately among cancer patients), in improving clinical researchers' cultural competency skills relative to recruiting and retaining minority participants, and in fostering new processes and structures to facilitate CCT participation.[10]

What the Research Means for District Residents

Washington, DC is fortunate to have eight cancer treatment centers. These and other agencies offer a number of clinical trial opportunities for District residents diagnosed with cancer. To date, there is no data or tracking system in place that can give a complete picture of District residents' participation in clinical trials. Such information could greatly benefit outreach, recruitment, and enrollment efforts.

Increased participation by District residents will have a two-fold benefit. First, of course, is the opportunity for District cancer patients to receive breakthrough treatment. Second, given the demographic make-up of the District, increasing the numbers of District residents who participate in clinical trials offers a treasure trove of data that can greatly inform cancer research as a

whole. The critical tipping point appears to be the lack of information and knowledge about the availability of clinical trials as an option. Mechanisms to increase the knowledge of both health providers and patients, and to match patients with appropriate CCTs, are critical.

Cancer Clinical Trials Goal and Objectives

GOAL: Increase by 15% the participation of the District's minority populations in clinical trials.

Objective 1: Implement a process for tracking patients participating in clinical trials in the District of Columbia.

Steps to achieve objective:

1. Convene taskforce of representatives from each cancer center to organize, engage other proposed members, and devise work plan.
2. Assess current data collection systems, both local and benchmarks from other areas.
3. Design tracking system, based on assessment, to include such data as eligible patients and reasons for non-participation.
4. Develop implementation and quality assurance plan, with process measures.
5. Complete system implementation and assess periodically for quality improvement.

Measurement:

1. Milestones and process measures to be developed by workgroup

Timeframe: 5 years

Objective 2: Monitor, review, and provide annual feedback on the minority recruitment efforts of the District's cancer centers.

Steps to achieve objective:

1. Convene taskforce of stakeholders to organize an advisory board (to include a set of current stakeholders, representatives of the District's cancer centers, and possibly other proposed parties) and devise routine work and reporting schedules.
2. Assess barriers to minority involvement and accumulate best practices and evidence-based interventions (such as the Ohio State University model) to increase awareness, improve availability, and enhance clinical trial accrual for minorities.
3. Utilizing best practices and accumulated evidence-based interventions, examine and compare minority recruitment efforts of the District cancer centers to each other and to any accepted standards, with recommendations for improvement. Prepare and distribute periodic reports to cancer centers and to the DCCC for coordination and advocacy work.

Measurements:

1. Milestones and process measures to be developed by workgroup
2. Accrual rates (National Cancer Institute [NCI] Cooperative Group data, NCI Community Cancer Centers Program data)

Timeframe: 5 years

Objective 3: Develop a strategic plan to address the economic barriers to clinical trial participation faced by minority patients.

Steps to achieve objective:

1. Convene taskforce of stakeholders to organize, engage other proposed members, and devise work schedule.
2. Assess state of economic barriers and enablers in the District, including the impact of current national and local legislative efforts.
3. Benchmark strategies to address barriers.
4. Develop strategic plan with process measures.
5. Design plan to implement the strategy.

Measurement:

1. Milestones and process measures in plan development to be decided by workgroup

Timeframe: 5 years

Colorectal Cancer

Colorectal cancer is the third most common cancer in the US, responsible for 10% of all cancer deaths. ("Colorectal Cancer Statistics," Centers for Disease Control and Prevention.)

One in 20 men and women will be diagnosed with cancer of the colon or rectum during their lifetime. (Surveillance Epidemiology and End Results Stat Fact Sheets, Colon and Rectum Cancer.)

Most invasive colorectal cancers begin as polyps; it takes an average of 5 to 15 years before polyps become malignant and form invasive cancers. (Colorectal Cancer Facts & Figures 2011-2013, American Cancer Society. Cancer Facts & Figures 2012, American Cancer Society.)

For all stages of colorectal cancer, the five-year survival rate is 63% for Whites and 53% for Blacks. By race and gender the numbers are: 65.4 for White males; 64.6 for White females; 55.9 for Black males; and 57.6 for Black females. (SEER StatFactSheets: Colon and Rectum.)

Since 1998, the incidence of colorectal cancer has declined 3.0% per year in men and 2.3% in women. (Colorectal Cancer Facts & Figures 2011-2013. American Cancer Society.)

Colorectal (colon) cancer affects men and women of all racial groups and is more prevalent as a person ages. Obesity has been identified as a risk factor for colorectal cancer.[1] It is estimated that 143,460 men and women (73,420 men and 70,040 women) will be diagnosed with colorectal cancer and 51,690 men and women will die of the disease in 2012.[2] Over 90 percent of new cases and 94 percent of deaths occur in people aged 50 or older.

From 2005-2009, the median age at diagnosis for cancer of the colon and rectum was 69.[3] The Centers for Disease Control and Prevention (CDC) guidelines call for regular screening of both men and women starting at age 50.[4] However, the American College of Gastroenterology recommends that African Americans begin colorectal cancer screening at age 45 due to the high incidence rate.[5]

Screening can be divided into two functions: prevention and detection. Prevention screening consists of flexible sigmoidoscopy or colonoscopy, and removal of precancerous polyps. Detection screening is done to determine the presence of blood in the stool through Fecal Occult Blood Testing (FOBT). According to CDC's Morbidity and Mortality Weekly Report (MMWR), titled "Cancer Screening—United States 2010," overall 58.6 percent of adults reported being up-to-date with colorectal cancer screening—lower than the

Healthy People 2020 target of 70.5 percent. Respondents aged 65-75 were more likely to be up-to-date than those aged 50-64.[6] Overall, in terms of both incidence and mortality rates, men rank 35 to 40 percent higher than women. Tables 1 and 2 show age-adjusted incidence and mortality rates by race and gender from 2005-2009. [7] From 2005-2009, the median age at death

Table 1. Colorectal Cancer Incidence Rates by Race and Gender, SEER 2005-2009

Race	Male	Female
All Races	54.0	40.2
White	53.1	39.2
Black	66.9	50.3
Hispanic	45.2	31.5

All rates are per 100,000 US 2000 Standard count. Source: DC Cancer Registry; Surveillance Epidemiology and End Results (SEER)

estimated that 76-90 percent of colorectal cancer cases can be prevented with the removal of polyps through colonoscopy.[9]

The 2002-2008 five-year relative survival rate by race and sex is 65.4 percent for White men, 64.6 percent for White women, 55.9 percent for Black men, and 57.6 percent for Black women.[10] (Relative survival rate measures the survival of the cancer patients in comparison to the general population.) Early diagnosis greatly increases survival. Table 3 describes the relative survival rate based on stage at diagnosis.[3]

Table 2. Colorectal Cancer Mortality Rates by Race and Gender, SEER 2005-2009

Race	Male	Female
All Races	20.2	14.1
White	19.5	13.6
Black	29.8	19.8
Hispanic	15.3	10.2

Table 3. Five-Year Relative Survival by Stage at Diagnosis, Colorectal Cancer, All Races, Both Sexes, 2002-2008

Stage at Diagnosis	5-Year Relative Survival Rate (%)
Localized (confined to primary site)	89.9
Regional (spread to regional lymph nodes)	69.6
Distant (cancer has metastasized)	11.9
Unknown (unstaged)	33.9

Colorectal Cancer in the District of Columbia

The District of Columbia has the highest mortality rate from colorectal cancer in the nation. In the District, Blacks bear the highest burden for both incidence and mortality from colorectal cancer. Tables 4 and 5 illustrate this fact.[11]

Table 4. Incidence Rate, Colorectal Cancer, by Race and Sex, SEER 2005-2009, DC Residents

Race	Male	Female
All Races	53.0	42.2
White	NA	NA
Black (includes Hispanic)	63.3	46.9

Table 5. Mortality Rate, Colorectal Cancer, by Race and Sex, SEER 2005-2009, DC Residents

Race	Male	Female
All Races	23.1	17.7
White	12.8	11.8
Black (includes Hispanic)	30.7	21.4

Against a national 25-year downward trend in colorectal cancer mortality rates among African Americans, the past five years have seen an increase in colorectal mortality rates for Blacks in the District. This is perhaps because, in the District, African Americans lag behind Whites at each stage of cancer diagnosis. Table 6 presents the latest data comparing stage of diagnosis by site and race.[12]

Table 6. District of Columbia SEER Stage at Diagnosis of Colorectal Cancer, 2008 Percent of Total Cases by Site and Race

Race	Local	Regional	Distant
All Races	37.3	24.6	22.7
White	41.4	27.6	24.1
Black	35.9	23.4	22.4

Since the risk of colorectal cancer increases with age, one would expect to see greater incidence rates in those areas of the city that are home to large numbers of residents 50 and older. Based on 2010 Census data, 169,950 District residents are 50 and older. Refer to the well-being table in Appendix I to see a breakdown of the percentage of these older adults in each ward.[13]

Similarly, mortality rates should align with population distribution and incidence rates. As Table 7 illustrates, this is not the case for some wards[14]. An explanation of the discrepancies has not yet been developed. One reason for the high mortality rates in some wards may be the low rate of screening and detection activities, which may correspond to availability of financial and other resources. Data is not yet available to gain a picture of the level of screening activities by race or ward. Research indicates that factors that influence screening include: income, education level, whether or not there is a consistent or identified health provider, and whether screening services are covered by

insurance.[15] As a result, it can be expected that the screening rate would be lower in those wards that reflect lower socioeconomic conditions. The well-being indicators table (Appendix 1) provides some insight into wards in which there are low screening rates.

Table 7. Age-Adjusted Mortality Rates by Sex and Ward for Colorectal Cancer Occurred in 2008, DC Residents

Ward	Male & Female	Male	Female
1	14.6	27.0	8.6
2	5.4	0.0	9.2
3	15.3	14.7	15.8
4	17.2	24.4	12.0
5	19.0	14.3	21.9
6	19.9	18.5	18.7
7	21.3	21.5	20.9
8	28.6	29.8	26.3

District Programs and Activities

Increasing the rates of screening among men and women aged 50 and older is a key strategy for affecting colorectal cancer control. This is particularly the case with regard to populations that bear a disproportionate burden from the disease. National organizations and local providers have been working to increase awareness about colorectal cancer and the need to make regular screening part of the individual's health maintenance. Efforts to increase screening have been partially successful, but there is still a need for higher screening rates.

Securing adequate resources to make screening and follow-up care available to low-income men and women and those who are under- or uninsured continues to be a challenge. Efforts aimed at increasing the awareness of the importance of colon health education among the immigrant community as well as younger men and women have also been an area of activity.

Colorectal Cancer Goals and Objectives

GOAL 1: Reduce the incidence of colorectal cancer in the District.

Objective 1: Decrease the prevalence of lifestyle and dietary risk factors for colorectal cancer, including overweight and obesity, low intake of fruits and vegetables, lack of physical activity, and tobacco use.

Steps to achieve objective:

1. Convene taskforce to organize activities, engage other proposed members, and devise work and reporting schedules.
2. Provide periodic assessment and feedback on plans, initiatives, and programs developed by DCCC obesity prevention and tobacco-related cancer taskforces.

Measurements:

1. Behavioral Risk Factor Surveillance System (BRFSS) data
2. Youth Risk Behavior Survey (YRBS), a school-based survey that collects data on six types of health behaviors contributing to death or disability among adolescents and adults
3. Process measures and milestones to be determined by taskforce

Timeframe: 5 years

Objective 2: Reduce by 50% the gap in the 2008 colorectal cancer incidence rate between Black residents (49.3) and White residents (33.9).

Steps to achieve objective:

1. Convene taskforce to organize activities, engage other proposed members, and devise work and reporting schedules.
2. Examine previously collected data to identify (a) providers performing screening endoscopy in wards with high proportions of residents of African descent; (b) referral patterns; and (c) the availability of support services (day care, language translation, etc.) within those communities. Determine cultural, financial, and language barriers to the use of screening services for residents of African descent.
3. Analyze existing and/or newly collected information and (a) design, (b) identify necessary funding for, and (c) implement a program to improve cultural competency and access to screening and follow-up services. This is to be done by assuring linkages of the identified providers and patients to existing public or private organizations identified as performing work targeting the identified communities.
4. As part of the partnership with safety-net clinics and providers (specified in Goal 2, Objective 2), examine endoscopy referral and follow-up processes, then provide and implement recommendations for improvement.
5. As part of the work with the Departments of Health and Health Care Finance, (a) assess financial barriers to the availability of community-based screening endoscopy, (b) produce recommendations as to policy, program,

and regulatory changes that will address them, and (c) include the recommendations in the report to DCCC membership in order to guide the organization's advocacy work.
6. Examine possible public and private funding sources, and develop and implement a plan to assure resources for the sustainability and expansion of District-wide colorectal cancer screening and treatment programs that focus on the underserved.
7. As part of the engagement with public health and medical/nursing association partners, assess the knowledge base of primary health care providers on colorectal cancer (risk factors, etc.), then develop and implement an education, training and/or information dissemination plan. The plan will support or improve medical history taking, risk assessment, and anticipatory guidance, including the support of any recommended tools to increase the efficiency of current practice and patient management (such as provider reminders and recall systems).
8. Evaluate the impacts of interventions for reporting to DCCC membership, to ensure the methods used are best practices, widely acceptable, and generalizable to larger populations.

Measurements:
1. DC Cancer Registry
2. Payer utilization and Health Effectiveness Data and Information Set (HEDIS) data
3. Process measures and milestones to be determined by taskforce

Timeframe: 5 years

Objective 3: Identify and develop strategies to address colorectal cancer incidence disparities in high-risk populations.

Steps to achieve objective:
1. Convene taskforce to organize activities, engage other proposed members, and devise work and reporting schedules.
2. In concert with morbidity and mortality reduction efforts described in Goal 2, examine existing data sources to (a) identify District populations with disproportionately high incidence rates due to colorectal cancer, (b) make recommendations to address any data element or collection deficiencies, and (c) report recommendations to DCCC membership for advocacy work.
3. Develop, leverage resources for, and implement a data collection plan to create a comprehensive map of screening services and support services in wards with high proportions of the identified populations.
4. Identify barriers to access to screening services for high-risk populations in target communities.
5. Analyze existing and/or newly collected information, then design, identify necessary funding for, and implement a program to improve cultural competency and access. This is to be done by assuring linkages of providers and patients to existing public or private organizations identified as performing work targeting the identified racial and ethnic communities.
6. Utilize the previous analysis to develop and implement a targeted, culturally competent outreach and educational program for the identified groups, to

increase knowledge about the need for colorectal cancer screening and its availability, possibly including community health workers and small group education.
7. Develop research questions regarding colorectal screening and treatment within the identified populations, and promote their investigation to guide District policy and programming.
8. Evaluate the impacts of interventions for reporting to DCCC membership, to ensure the methods used are best practices, widely acceptable, and generalizable to larger populations.

Measurements:
1. DC Cancer Registry
2. Payer utilization and HEDIS data
3. Process measures and milestones to be determined by taskforce

Timeframe: 5 years

GOAL 2: Reduce morbidity and mortality due to colorectal cancer in the District.

Objective 1: Increase by 20% colorectal cancer screening activity (fecal occult blood test and colonoscopy) for average-risk residents 50 years and older. This would increase the percentage of residents who are up-to-date with any screening in the past two years to 28.4%, from the 2010 BRFSS baseline of 23.7%.

Steps to achieve objective:
1. Convene taskforce to organize activities, engage other proposed members, and devise work and reporting schedules.
2. Develop and implement a data collection plan building on existing District-specific research about colorectal cancer that will provide more comprehensive information about risk factors, screening, treatment, and health behaviors.
3. Examine existing and/or newly collected information and (a) design, (b) identify funding for, and (c) implement an education initiative (with evaluation) about colorectal cancer. Subjects would include risks, natural history, and screening, and the initiative could incorporate community health workers, internet-based media, and small media (e.g., videos and printed materials).
4. Sustain and expand existing resources and secure new resources to support the data collection program and health education/promotion strategies.
5. Engage public health and medical/nursing association partners in assessing the present knowledge base of health care providers about colorectal cancer screening in order to develop and implement an education, training, and/or information dissemination plan. The plan would focus on current evidence-based guidelines, screening techniques, the use of provider reminders and recall systems for promoting screening activity, and post-screening follow-up.
6. Work with the Departments of Health and Health Care Finance to (a) assess financial barriers to community-based screening activities, (b) produce recommendations as to policy, program, and regulatory changes that will decrease them, and (c) prepare a report to DCCC membership in order to guide the organization's advocacy work.
7. Evaluate the impacts of interventions for reporting to DCCC membership, and

to ensure the methods used are best practices, widely acceptable, and generalizable to larger populations.

Measurements:
1. BRFSS data
2. Payer utilization and HEDIS data
3. Process measures and milestones to be determined by taskforce

Timeframe: 5 years

Objective 2: Decrease by 50% the 2008 gap in mortality rates between African American residents (21.0) and White residents (13.6).

Steps to achieve objective:
1. Convene taskforce to organize activities, engage other proposed members, and devise work and reporting schedules.
2. Develop, leverage necessary resources for, and implement a data collection plan to map (a) providers performing screenings in wards with high proportions of African Americans; (b) referral patterns; and (c) the availability of support services (day care, language translation, etc.) within those communities. In addition, determine cultural, financial, and language barriers to the use of screening services for African American residents.
3. Analyze available information, then design, identify necessary funding for, and implement a program to improve cultural competency among providers and access by patients. This is to be accomplished by enabling linkages of providers and patients to existing public or private organizations identified as performing work targeting the identified communities.
4. In partnership with safety-net clinics and providers, examine referral and follow-up processes, providing and implementing recommendations for improvement.
5. Utilize the analysis from Step 3 to develop and implement a targeted, culturally competent outreach and educational program for the identified providers, to increase knowledge about the need for colorectal cancer screening and its availability, possibly including small media and small group education.
6. Working with the Departments of Health and Health Care Finance, (a) assess financial barriers to the availability of treatment, (b) produce recommendations as to policy, program, and regulatory changes that will address them, and (c) prepare a report to DCCC membership in order to guide the organization's advocacy work.
7. Examine possible public and private funding sources, and develop and implement a plan to assure resources for the sustainability and expansion of District-wide colorectal cancer screening and treatment programs that focus on the underserved.
8. Develop research questions regarding colorectal screening and treatment, including the health impacts of screening individuals of African descent before 50 years of age, and promote their investigation to guide District policy and programming.
9. In partnership with cancer centers and hospitals, identify recognized measures of quality in cancer treatment (including survival by stage and complication rates), and develop and implement a

system for data collection, assessment, and annual public reporting.
10. Evaluate the impact of intervention for reporting to DCCC membership and to ensure the methods used are effective for diverse populations.

Measurements:
1. DC Cancer Registry
2. Payer utilization and HEDIS data
3. Process measures and milestones to be determined by taskforce

Timeframe: 5 years

Objective 3: Identify and develop strategies to address colorectal cancer mortality disparities in other high-risk populations.

Steps to achieve objective:
1. Convene taskforce to organize activities, engage other proposed members, and devise work and reporting schedules.
2. Examine existing data sources to (a) identify District populations with disproportionately high mortality rates due to colorectal cancer, (b) make recommendations to address any data element or collection deficiencies, and (c) report recommendations to DCCC membership for advocacy work.
3. Develop, sustain, and expand necessary resources for, and implement a data collection plan to (a) map providers performing screenings in wards with high proportions of the identified populations; (b) describe the availability of support services (day care, language translation, etc.) within those communities; and (c) determine cultural, financial, and language barriers to the use of screening services for residents in those populations.
4. Analyze existing and/or newly collected information, then design, identify necessary funding for, and implement a program to improve cultural competency and access. This is to be accomplished by enabling linkages of providers and patients to existing public or private organizations identified as performing work targeting the identified racial and ethnic communities.
5. Utilize the previous analysis to develop and implement a targeted, culturally competent outreach and educational program for the identified groups, to increase knowledge about the need for colorectal cancer screening and its availability, possibly including community health workers and small group education.
6. Develop research questions regarding colorectal screening and treatment within the identified populations, and promote their investigation to guide District policy and programming.
7. Evaluate the impacts of interventions for reporting to DCCC membership, to ensure the methods used are best practices, widely acceptable, and generalizable to larger populations.

Measurements:
1. DC Cancer Registry
2. Payer utilization and HEDIS data
3. Process measures and milestones to be determined by taskforce

Timeframe: 5 years

Health Equity

- Persons with lower socioeconomic status (SES) have higher cancer mortality rates than those with higher SES regardless of race/ethnicity. American Cancer Society. *Cancer Facts and Figures 2012.*
- Uninsured persons are more likely to be diagnosed with cancer at later stages and less likely to receive standard treatment. American Cancer Society. *Cancer Facts and Figures 2012.*
- Racial and ethnic minorities tend to receive lower-quality health care even when income and insurance status are controlled. American Cancer Society. *Cancer Facts*

Since the inception of the DC Cancer Consortium, considerable progress has been made in reducing the incidence and mortality rates of cancer among District of Columbia residents. Examples include developing a more coordinated system of care, providing training and education to promote cultural sensitivity among medical providers, and expanding patient navigation services to shorten the time between diagnosis and treatment. Steps have also been taken to ensure that all residents, regardless of income, have access to a medical home. Although these achievements are a step forward, minorities and persons with low incomes continue to be disproportionately impacted.

Health disparities are defined as *measurable differences in health status among distinct segments of the population including differences that occur by gender, race or ethnicity, education or income, disability, or geographic locality.*[1]The incidence and prevalence of cancer, both locally and nationally, are among the best illustrations of the pervasiveness of health disparities; breast and colorectal cancer rates are prime examples. For instance, White women are more likely to develop breast cancer; however, mortality rates are highest among African American women.[2] And in the District of Columbia, the age-adjusted death rate from colon cancer in African Americans is more than two times that of Whites. [3]Some of these disparities may be caused by genetic predispositions, attitudes, or personal choices that increase cancer risks or result in late detection. Eradication of these differences will require a more comprehensive and unconventional approach that addresses the root causes of the problem.

Although the healthcare delivery system plays a major role in preventing disease and

healing the sick, it is very clear that health status is also linked to the conditions in which people live, work, eat, and play. Consideration of these social and environmental conditions is critical to any plan aimed at eliminating or reducing the presence of disease. Cancer is no exception, as these conditions influence prevention, early detection, and treatment outcomes. Forces that contribute to poor health include unequal access to community resources that promote healthy lifestyles, unsafe neighborhoods, unhealthy home environments, and limited access to affordable fresh fruits and vegetables.

Socioeconomic Status

Socioeconomic status is also a strong predictor of health status and cancer survival outcomes.[4] For example, the five-year survival rate for persons who develop cancer is more than ten percentage points higher for persons who live in affluent census tracts than for those who live in poorer census tracts. This is partially because social and environmental conditions that promote health are more accessible for those with wealth, power, or social prestige than for those who live in poverty or have low incomes. In policy development and community planning, the voices of marginalized populations are frequently unrecognized due to factors such as language, culture, disability, and lack of access to influential individuals or networks. Moreover, the chronic, day-to-day stressors encountered by these populations have a profound impact on health status.

Health equity is defined as *the absence of systemic disparities in health and its determinants among groups of people at different levels of social advantage.* In light of the District of Columbia's racial/ethnic composition, coupled with communities and neighborhoods that magnify an income gap, health equity is the cornerstone of the DC Cancer Control Plan. This is because more than 60 percent of the District's residents are racial/ethnic minorities, 13 percent are foreign born, and 14.6 percent do not speak English as a primary language.[5] Approximately 18.57 percent of DC's 601,723 residents live in poverty, with many concentrated in communities east of the Anacostia.[6]

These disenfranchised populations carry a disproportionate burden of cancer, and the reasons go beyond individual choices and the capacity of the healthcare delivery system. Contributing factors include discrimination based on race, social class or sexual orientation; poor or hazardous working conditions; underinsurance; and chronic levels of stress about meeting basic needs.

Social Justice

Social justice is defined as *equitable distribution of social, economic, and political resources, opportunities, and responsibilities and their consequences.*

Viewing cancer through a social justice lens is a philosophic underpinning of the DC Cancer Consortium's work. Efforts toward social justice will promote prevention and improve treatment and survival outcomes of persons living with cancer.[7,8] The vision can be attained only by the establishment of policies and practices that promote equitable access to a socially, economically, and politically just standard of living for all residents of the Nation's Capital. It will require a conscious and concerted effort to close the gap in health among populations that have different levels of wealth, power, and/or social prestige.

This transformation will rely on an increased level of awareness among policymakers, clinicians, community planners, employers, and other stakeholders. And most importantly, changes in practice and public policy that promote equitable access to institutional resources for all populations are necessary. The DC Cancer Consortium will continue to lead efforts and advocate for change on a micro and macro level to achieve these goals. The Consortium's efforts will be organized around three strategies: communication and education, funding, and data collection and tracking.

Health Equity Goals and Objectives

GOAL: Reduce/eliminate cancer burden disparities attributable to race/ethnicity, gender, culture, socio-economic status, language, and other social determinants.

Objective 1: Increase awareness among the public and health providers about social determinants and their influence on cancer rates.

Steps to achieve objective:

1. Create and widely distribute population-specific materials.
2. Develop and disseminate information to health providers on social determinants and their influence on screening, diagnosis, and treatment of cancers.

Measurement:

1. Milestones and process measures to be developed by taskforce.

Timeframe: 5 years

Objective 2: Incorporate health equity criteria as part of all cancer program funding.

Steps to achieve objective:

1. Establish health equity standards as part of all funding mechanisms and proposal evaluation processes.
2. Review existing programs and systems against criteria for health equity and make corrections as required.
3. Identify and secure funding to support partnerships between health providers and agencies that represent disparately affected populations.
4. Advance efforts to promote clinical trial participation among underrepresented populations, including minorities, older individuals, etc.

Measurement:

1. Milestones and process measures to be developed by taskforce

Timeframe: 5years

Objective 3: Expand existing data base and tracking systems to include health equity factors (e.g., income, geographic area, etc.).

Steps to achieve objective:

1. Define social determinants that affect cancer rates.
2. Track cancer morbidity and mortality rates based on income, race, ethnicity, primary language, geography, and other social characteristics.

Measurement:

1. Milestones and process measures to be developed by taskforce

Timeframe: 5years

Obesity Prevention

- Over one-third of adults (35.7%) in the US are obese. ("Adult Obesity Facts" Centers for Disease Control and Prevention.)
- In 2010, no state had a prevalence of obesity less than 20%. ("Adult Obesity Facts" Centers for Disease Control and Prevention.)
- In 2010, the obesity rate for the District of Columbia was 22.2%. ("Adult Obesity Facts" Centers for Disease Control and Prevention.)
- Being overweight or obese increases a person's risk of getting esophageal, endometrial (uterine), post-menopausal breast, and colorectal cancers. ("The Weight-Cancer Link" American Institute for Cancer Research (AICR).
- The American Institute for Cancer Research (AICR) estimates that one-third of the most common cancers can be prevented annually through healthy diet, regular physical activity and being lean. ("The Weight-Cancer Link" American Institute for Cancer Research (AICR).

The Centers for Disease Control and Prevention (CDC) have declared obesity an epidemic affecting the health of the nation's adults and children. For adults, overweight and obesity are determined by a height-weight calculation called the Body Mass Index (BMI). An adult who has a BMI of 25 to 29.9 is considered overweight. A BMI of 30 or higher is considered obese.

In "Obesity At-A-Glance 2011," the CDC reports that more than a third of the nation's adults (over 72 million people), and 17 percent of US children, are obese.[1] Obesity is a trend that has been growing at an alarming rate. A comparison of data from the National Health and Nutrition Examination Survey (NHANES) III (1988-1994) with NHANES 1999-2000 shows an increase of obesity in adults 20 and over from 56 percent in 1988-1994 to 64 percent in 1999-2000.[2] During 1980-2008, obesity rates doubled for adults and tripled for children. By 2010, no state had a prevalence of obesity less than 20 percent.[3] This epidemic affects all racial population groups, as well as lesbians; [4] however, there are substantial differences in obesity prevalence by race, and these differences vary by gender and age. Four large comparison studies suggest that lesbians are one-and-a-half to two times more likely than heterosexual women to be overweight or obese.[5] Obesity rates are higher among African American and Latina lesbians than White lesbians.[6]

According to the National Health and Nutrition Examination Survey, 51 percent of African American women aged 20 and older were obese, compared with 43 percent of Hispanics and 33 percent of Whites.[7]

The Link Between Obesity and Cancer

Overweight and obesity have been identified as risk factors for many cancers, particularly esophageal, uterine, post-menopausal breast, and colorectal cancers.[8] Researchers for the American Cancer Society have estimated that 14 percent of all cancer deaths in men, and 20 percent in women, could be blamed on excess weight.

Since the 1990s, much more has been learned about the causal relationship between obesity and cancer. According to the latest research, obesity influences the levels of a number of hormones and growth factors, such as insulin-like growth factor 1 (IGF-1), insulin, and leptin. These are all elevated in obese people and can promote the growth of cancer cells.[9] For example, increased circulating leptin levels in obese individuals are associated with a higher incidence of colorectal cancer, according to the World Cancer Research Fund/American Institute for Cancer Research.

Obesity is also associated with cancer mortality. For example, a study of 287,760 men, ages 50 to 71 years, enrolled in 1995-1996 in the National Institutes of Health-AARP (American Association of Retired Persons) Diet and Health Study found that higher weight gain increased the risk of dying from prostate cancer.[10] Nutrition, physical activity, and other efforts aimed at combating obesity should also be part of any cancer prevention strategy.

Table 1 shows the estimated percentages of selected cancers correlated with obesity:

Table 1. Estimated Percentage of Cancers Caused by Obesity, 2009 [11]

Type of Cancer	Estimated %
Endometrial	49
Esophageal	35
Kidney	24
Colon	9
Postmenopausal Breast	17
Pancreatic	28
Gall bladder	21

The American Institute for Cancer Research (AICR) estimates that Americans can prevent one-third of the most common cancers through "healthy diet, regular physical activity, and being lean."[12] A sample of the cancers that could be prevented annually is illustrated in Table 2.

Table 2. Cancers That Could Be Prevented Annually through Diet, Physical Activity, and Being Lean, 2009 [12]

Cancer	% Prevented
Postmenopausal Breast	38
Colorectal	45
Mouth, Pharyngeal and Laryngeal	63
Esophageal	69
Endometrial	70
Prostate	11

Obesity in the District of Columbia

According to "Obesity in the District of Columbia," the DC Department of Health's Final Obesity Report 2009, more than half of all adults living in the District (55 percent) are either overweight or obese.[13] Women in the District are tied with four other states – Alabama, Louisiana, Mississippi, and Texas – for the highest obesity rates (37 percent) in the nation.[14] According to the DC Department of Health, two out of every three African American residents (69 percent) and over half of all Hispanic residents (57 percent) are overweight or obese, compared to one out of three white residents (39 percent).[15]The Department noted that obesity increased with lower socioeconomic status. This correlation is demonstrated by the geographical and income differences displayed in Table 3.

Table 3. Obesity and Income, District of Columbia Residents by Ward[16]

	DC	W1	W2	W3	W4	W5	W6	W7	W8
% Obese	22.2	19	13	12	22	30	19	40	42
Average Household Income	$115,015	$98,485	$190,692	$257,385	$116,668	$78,559	$120,526	$54,677	$44,076

In addition to nutrition and lifestyle, environmental factors also affect overweight and obesity. These include limited availability of stores and farmers' markets selling fresh fruits and vegetables, high concentrations of convenience and carry-out stores, and unavailability of safe recreation and exercise venues. Wards 7 and 8 have the lowest incomes and the highest obesity rates and also lack access to stores selling fresh fruits and vegetables. Ward 3, with the city's highest average income, has the lowest obesity rate as well as the highest number of outlets from which to purchase nutritious food, including 14 large and small grocery stores and farmers' and organic markets. Other findings about DC residents reported in the DC Department of Health's Final Obesity Report 2009 include:

- Women were more likely than men to be obese (25 percent versus 19 percent), but men were more likely than women to be overweight (38 percent versus 29 percent).
- 93 percent of Caucasians reported participating in recreational exercise, compared to 70 percent of African Americans, and 67 percent of Hispanics.
- Participation in regular physical exercise increased with income, from 55.5

percent in the District for those earning less than $15,000 to 91.3 percent for those earning $75,000 and above.[16]

- Although District park and recreational facilities are spread throughout the city, many residents cite the high crime rates in their communities as a deterrent to using these resources.[17]

District Programs and Activities

In 2008, the District of Columbia Department of Health's Community Health Administration convened the District of Columbia Obesity Prevention and Reduction Work Group, consisting of stakeholders from across the city. The Department analyzed existing data to support the work group's activities. In January 2010, the Department released "Obesity in the District of Columbia: Final Obesity Report 2009." Shortly thereafter, in February 2010, the Department unveiled the city's Obesity Action Plan 2010-2015, containing the goals and objectives developed by the work group. While the Obesity Action Plan did not directly address the issue of obesity and cancer, it laid critical groundwork that can be built upon to expand and enhance cancer prevention activities.

The Obesity Action Plan addressed the issues of overweight and obesity among adults and children, analyzing environmental factors that affect the problem, such as availability of grocery stores carrying fresh fruits and vegetables, safety of and access to parks and recreation areas, overrepresentation of fast food restaurants in vulnerable neighborhoods, and agency policies. Other efforts have been made to include positive health outcomes as part of local initiatives and agency objectives. Wellness Fairs have been held to increase awareness of the dangers of overweight and obesity and of the benefits of adopting a healthy lifestyle.

There is a great need for the connection between obesity and cancer to become better known among health professionals and policymakers as well as among vulnerable and at-risk populations. Some community-based organizations—for example those serving low-income Latinos—have established nutrition education classes to assist clients in making better food choices and in re-tooling traditional dishes to make them more nutritious and to greatly decrease fat content. These and other efforts are particularly important for those individuals who work in jobs such as construction work that allow only a short time for lunch and where there are few choices for purchasing nutritious food.

Obesity Goal and Objectives

GOAL: Reduce the incidence of cancer in the District by improving the nutrition and physical activity of its residents in order to achieve and maintain a healthy weight.

Objective 1: Ensure the promotion and enactment of policies that create access to healthy foods and opportunities for physical activities in all District wards.

Steps to achieve objective:

1. Convene a taskforce to develop a work plan and schedule to achieve objective.
2. In partnership with DCCC leadership, achieve consensus on goals of partnership with organizations working on reducing obesity, in terms of policies and programs.
3. Develop a communications plan for explaining the linkage of cancer to the lack of healthy nutrition, physical activity, and healthy weight, as well as the need for coordinated efforts, to groups working in those areas.
4. Accumulate and examine information on District-wide initiatives (such as the District's Chronic Disease Initiative, Obesity Action Plan, and Live Well DC), organizations, and coalitions that are addressing nutrition, physical activity, and/or chronic disease control, looking for opportunities for collaboration.
5. Utilizing the communications plan, advocate with appropriate leadership (governmental, non-profit coalition officers, etc.) to gain input to or membership in planning groups or coalitions and ensure the representation of concerns related to cancer prevention.
6. Provide periodic updates on collaborative work to DCCC leadership and members, for feedback and ongoing improvement efforts.

Measurements:

1. Milestones and process measures to be developed by workgroup
2. Behavioral Risk Factor Surveillance Survey (BRFSS) data

Timeframe: 1 year to implement, 5 years of continual operation

Objective 2: Advocate for and support an educational program utilizing effective behavior change messages to make District residents aware of linkages of unhealthy body weight to cancer, their weight status, and actions to achieve healthy weight.

Steps to achieve objective:

1. Convene taskforce of stakeholders (including public health educators and researchers) to develop work plan and schedule to achieve objective.
2. Build on existing efforts to develop and implement a data collection plan to assess: residents' dietary quality; barriers to healthy food; physical activity; knowledge about the relationship among nutrition, body weight/BMI, and cancer; attitudes about dietary habits and their alteration; and what could promote dietary habit change.
3. Leverage resources to support data collection program.
4. Research best practices and evidence-based educational interventions regarding nutrition, physical activity, and linkages to cancer prevention.

5. Utilizing the data from the needs assessment, best practices, and evidence-based interventions, design, leverage resources for, and conduct research studies to test the effectiveness of various behavior change messages specific to District residents, using connections to cancer prevention, in improving a population's dietary habits and weight.
6. Report on findings to DCCC leadership.
7. Using the report, identify collaborative partners and work with them to develop cross-promotional efforts in any educational or communication plans.

Measurements:

1. Milestones and process measures to be developed by workgroup, including study findings
2. Behavioral Risk Factor Surveillance System (BRFSS) data

Timeframe: 5 years

Oral Cancer

- More than 30,000 new cases of oral and pharyngeal cancer are diagnosed annually and over 8,000 deaths due to oral cancer occur. ("Oral Cancer", Division of Oral Health, Centers for Disease Control and Prevention.)
- Men are twice as likely to be diagnosed with oral cancer as women. ("Oral Cancer" Division of Oral Health, Centers for Disease Control and Prevention.)
- Although White men have a higher incidence rate, Black men have a higher mortality rate. (SEER Stat Fact Sheets: Oral and Pharynx.)

The Centers for Disease Control and Prevention (CDC) estimate that more than 30,000 new cases of oral and pharyngeal cancer are diagnosed each year, and more than 8,000 deaths each year are due to oral cancer.[1](Unless specifically noted, in this Plan oral cancer refers to cancer of the oral cavity and pharynx.) When the definition of oral cancer is expanded to include not only the mouth and pharynx, but the tongue and other oral cavity sites, the numbers of cases and deaths increase dramatically. The American Cancer Society (ACS) estimates 80,500 new cases of cancers of the tongue, mouth, pharynx, and other oral cavity sites will be diagnosed and 15,700 deaths will occur in 2012.[2] ACS 2012 estimates for oral and pharyngeal cancer only also show an increase, as illustrated in Table 1.

Table 1. Estimated New Oral and Pharyngeal Cancer Cases and Deaths, by Sex, US and DC, 2012

	Both Sexes	Male	Female
Estimated New Cases-US	40,250	28,540	11,710
Estimated New Cases-DC	--	--	--
Estimated Deaths-US	7,850	5,440	2,410
Estimated Deaths-DC	--	--	--

Nationally, the age-adjusted incidence rate was 10.6 per 100,000 based on cases diagnosed in 2004-2008. The risk of oral and pharyngeal cancer increases with age. From 2004-2008, the median age at diagnosis for oral cancer was 62. Approximately 0.6 percent were diagnosed under age 20, 2.3 percent between 20 and 34, 6.3 percent between 35 and 44, 20.5 percent between 45 and 54, 27.5 percent between 55 and 64, 21.2 percent between 65 and 74, 15.6 percent between 75 and 84, and 6.0 percent at 85 and older.[3]

Table 2. Incidence Rates by Race and Sex, US 2004-2008[4]		
Race	**Male**	**Female**
All Races	15.7	6.2
White	16.1	6.2
Black	15.6	5.6
Hispanic	9.0	3.9
Asian/Pacific Islander	10.9	5.3

(Rates for Tables 2, 3, and 4 are per 100,000 based on a US 2000 count; given the racial makeup of the District of Columbia, American Indian/Alaska Native designations have been eliminated from the tables.)

Table 2 shows that Whites had a higher incidence rate than Blacks, followed by Asian/Pacific Islanders, American Indians/Alaska Natives and Hispanics. The national age-adjusted mortality rate, based on deaths 2004-2008, was 2.5 per 100,000 men and women. For that same period, the median age at death was 67. Approximately 0.1 percent died under age 20, 0.8 percent between 20 and 34, 3.2 percent between 35 and 44, 14.5 percent between 45 and 54, 24.2 percent between 55 and 64, 23.8 percent between 65 and 74, 21.8 percent between 75 and 84, and 11.5 percent among those 85 and older.

Table 3 shows that Blacks had the highest mortality rate, followed by Whites, Asians/Pacific Islanders, and Hispanics.

The overall relative 5-year survival rate, based on 2001-2007 Surveillance Epidemiology and End Results (SEER) data, was 60.8 percent. The rate increases dramatically when the cancer is diagnosed at its earliest stage, i.e., when it is localized. The 5-year relative survival rate for oral cancer diagnosed when it is localized is 82.5 percent; it drops to 55.5 percent when the stage at diagnosis is regional and 33.2 percent at the distant stage; and it is 50.4 percent when the stage is unknown.

Race and gender significantly affect the relative 5-year survival rate. Based on 2001-2007 SEER data, that rate was 62.0 percent for White men compared to 37.3 percent for Black men, and 63.2 percent for White women compared to 52.6 percent for Black women.

Table 3. Mortality Rates by Race and Sex, US 2004-2008[4]		
Race	**Male**	**Female**
All Races	3.9	1.4
White	3.7	1.4
Black	6.0	1.5
Hispanic	2.4	0.8
Asian/Pacific Islander	3.0	1.3

Table 4. Comparison of Age-Adjusted Oral Cancer Incidence and Death Rates, US and DC. 2004-2008[4]		
	US	**DC**
Incidence Rate	10.8	13.0
Death Rate	2.5	3.8

Oral Cancer in the District of Columbia

Based on 2004-2008 SEER data, the District of Columbia has higher rates of both incidence and death from oral cancer compared to the rest of the nation. The City's annual death rate of 3.8 per 100,000 residents translates into an average of 23 deaths per year over the 2004-2008 data period. A comparison of average annual deaths between White and Black men highlights a significant disparity. For the 2004-2008 period, for White males in the District the average deaths per year over that time period was 3 or fewer compared to 13 for Black males.[5]

When compared with other regions in the US, Black males in the District bear an even more disproportionate burden for oral cancer. For example, Black males in the District had an oral cancer incidence rate of 29 per 100,000 in 2009, compared to the incidence rate of 16 per 100,000 for the jurisdictions in the SEER 9 registries. (SEER 9 registry sites are Atlanta, Connecticut, Detroit, Hawaii, Iowa, New Mexico, San Francisco-Oakland, Seattle-Puget Sound, and Utah.) In addition, comparative survival rates were also dramatically lower for Black males in the District. According to DC Department of Health statistics, the two-year survival following a local stage diagnosis was 34 percent for Black men in the District, while the rate was 72 percent for other regions, such as those in the SEER 9 registry.

Both smoking and excessive alcohol use are risk behaviors associated with oral cancer. According to 2010 estimates from the Behavioral Risk Factor Surveillance System (BRFSS), 14.8 percent of District residents 18 and older self-identify as smokers. Another indicator that may be useful in trying to identify particular populations who are at risk is education level. Researchers studying the link between mortality rates for oral cancer (for 2005-2007 and trends for 1993-2007) by educational attainment found that decreases in mortality rates were greatest among men and women with 12th grade or more education.[6] According to the 2000 Census, 22 percent of District adults have not completed high school, but this figure varies, with some wards of the City having a greater or lesser proportion of high school graduates than others. The Centers for Disease Control and Prevention has also linked oral cancer with the *genital human papillomavirus* (HPV), a common sexually transmitted infection. HPV-associated oropharyngeal cancer rates in the District are among the highest in the nation for both men and women. For men, the rates are 6.55 to 8.18 per 100,000; for women the rates are 1.05 to 2.07 per 100,000.[7]

District Programs and Activities

Efforts have been mounted to increase oral cancer screening among African American males in the District. Strategies have included targeting areas such as public housing communities for outreach, education, and access to screening.

Oral Cancer Goal and Objectives

GOAL: Decrease the age-adjusted mortality due to oral cancer by 15%.

Objective 1: Develop a system of data collection to include measurements for screening and to ensure that best practices are being followed.

Steps to achieve objective:

1. Convene taskforce to organize, engage other proposed members, and develop a work plan and schedule.
2. Assess current data collection systems, both local and from other areas, to determine best practices.
3. Based on assessment, select data elements that accurately capture screening activity and quality, and potential feasible sources of data.
4. Design data collection system, with process and outcome measures to monitor progress.
5. Develop an implementation plan to include resource development and training, with process measures.

Measurement:

1. Milestones and process measures to be developed by taskforce.

Timeframe: 5 years

Objective 2: Initiate District-wide professional education program on appropriate oral cancer screening activity.

Steps to achieve objective:

1. Convene taskforce to organize, engage other proposed members (Board of Dentistry, dental educators, etc.), and devise work plan and schedule to achieve objective.
2. Examine existing guidelines on oral cancer screening for adoption as standards of care.
3. Determine the appropriate benchmarks and evidence-based methods for professional education.
4. Based on assessment of screening activity conducted under Objective 1, develop educational program for dental providers and other providers as the assessment indicates, with process and outcome measures.
5. Design implementation plan with process measures to ensure progress.
6. Implement program and study the impact for continual improvement.

Measurements:

1. Milestones and process measures to be developed by task force
2. Number of providers trained
3. Knowledge change measured by pre- and post-testing
4. Insurance utilization data
5. Behavioral Risk Factor Surveillance System (BRFSS) data

Timeframe: 5 years

Objective 3: Increase by 10% the proportion of African American males over the age of 40 who have had an oral cancer examination in the past year

Steps to achieve objective:

1. Convene task force of current stakeholders to organize, engage other proposed members, and devise work schedule.
2. Develop data collection and monitoring program, including adding oral cancer screening to the BRFSS, and establish local baseline reflecting incidence,

screening, treatment, and other clinical and demographic data.
3. Conduct assessment of state of economic and non-economic screening barriers and enablers in the District, including the impact of current national and local legislative efforts, policies, and administrative practices specific to African American males.
4. Based on the assessment in step two, develop strategic plan with process and outcome measures.
5. Benchmark strategies from other jurisdictions and examine evidence-based initiatives to address barriers and increase screening rates.
6. Design implementation plan with process and outcome measures to ensure progress.
7. Implement strategy and study the impact for continual improvement.

Measurements:
1. Milestones and process measures in plan development to be decided by workgroup
2. Insurance utilization data
3. BRFSS data

Timeframe: 5 years

Palliative Care

- Palliative care is receiving increased recognition as a specialty that offers opportunities to improve outcomes and control costs in a health care system facing reform. One example: in a study of patients with metastatic lung cancer, those who received early palliative interventions had improvement in quality of life and mood, received fewer life-prolonging therapies at the end of life, and yet had longer survival. (JAMA)
- Today, it is estimated that palliative care programs are offered by about 22percent of hospitals with fewer than 50 beds, 54 percent with 50-299 beds, and about 85 percent with more than 300 beds. (Center to Advance Palliative Care)
- The Commission on Cancer (CoC) uses standards that outline the key elements of quality cancer care to be provided to every person with cancer treated in a CoC-accredited facility throughout the diagnosis and treatment process. These elements include psychosocial support, care for cancer-related pain, palliative care, and hospice care. (The American College of Surgeons' Commission on Cancer)

There is an urgent need for both practitioners and the public to understand the nature and scope of palliative care, and how such care can help in the treatment of patients with serious illness, including cancer, from diagnosis forward.

Palliative care is specialized medical care for people with serious illnesses. It is focused on providing patients with relief from the symptoms, pain, and stress of a serious illness—whatever the diagnosis. The goal is to improve the quality of life for both the patient and the family. Palliative care is provided by a team of doctors, nurses, social workers, and others (such as chaplains) who work with a patient's other doctors to provide an extra layer of support. It is appropriate at any age and at any stage in a serious illness, and can be provided along with curative treatments.[1] Once informed, consumers are extremely positive about palliative care and want access to this type of care:

- 95 percent of consumers agree that it is important for patients with serious illness and their families to know about palliative care.
- 92 percent say it is important that palliative care services be made available at all hospitals for patients with serious illness and their families. [2]

Early access to palliative care specialists improves quality of care and quality of life for both patients and families. Several recent studies have also demonstrated that palliative care may be associated with a significant *prolonging* of life for some patient populations.[3] Researchers suggest that reasons for the prolonging may include

a reduction in depression (recognized as an independent predictor of mortality), fewer hospitalizations and high-risk medical interventions, reduction in overall symptom burden, and improved support for family caregivers. Confusing palliative care with hospice or "end-of-life" care remains a critical barrier to accessing needed services early in the course of a cancer diagnosis. Hospice services, which are a form of palliative care, are limited in the United States by Medicare statute to those individuals with a prognosis of six months or less. While health care reform has succeeded in creating an exception for children that allows concurrent hospice and curative care, for most individuals hospice still remains restricted to the terminal stages of disease. Palliative care, as noted above, may be accessed at any stage.

A Philosophy of Care, and a System for Delivering It

Palliative care is both a philosophy of care and an organized, highly structured system for delivering care. Its goals include enhancing quality of life for patient and family, optimizing function, 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.

Palliative care is provided by a trained interdisciplinary team of palliative specialists who work with a patient's other doctors and providers to give an extra layer of support. [4]

The National Consensus Project for Quality Palliative Care (NCP) describes the scope of palliative care as:

- Managing pain and other symptoms effectively while incorporating psychosocial and spiritual care according to patient and family needs, values, and beliefs.
- Focusing on the central role of the family unit in decision-making.
- Affirming life by supporting the patient's and family's goals for the future.
- Neither hastening nor postponing death.
- Providing a support system to help patients live as actively as possible.
- Providing a support system to help the family (including children) cope during the patient's illness and, if the illness is terminal, in their own bereavement.
- Using a team approach to address the needs of patients and families.

The NCP sought input from a broad range of palliative care professionals, health care organizations, consumers, and payers, and developed the *Clinical Practice Guidelines for Quality Palliative Care, Second Edition*. These guidelines serve as a foundation for the National Quality Forum Preferred Practices and have become a hallmark within the field. They guide policymakers, providers, practitioners, and consumers in understanding the principles of quality

palliative care and helped to shape the new Joint Commission's Advanced Certification for Palliative Care Programs.[5]

Pediatric Palliative Care

While palliative care for adults has improved over recent years, pediatric palliative care is still in its infancy, with only a few national centers—but there is growing interest in improving palliative care for children. Currently there is no structured home care program for pediatric palliative care, or any pediatric hospice, in the District of Columbia. The DC Cancer Consortium recognizes the unique needs of pediatric patients and their families and seeks to examine gaps in care and to recommend areas for improvement.

While closely related to adult palliative care, the care of children and their families must be considered separately. The World Health Organization describes pediatric palliative care this way: [6]

- Palliative care for children is the active total care of the child's body, mind, and spirit, and also involves giving support to the family.
- It begins when illness is diagnosed, and continues whether or not a child receives treatment directed at the disease.
- Health providers must evaluate and alleviate a child's physical, psychological, and social distress.
- Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited.
- Quality palliative care can be provided in tertiary care facilities, in community health centers, and even in children's homes.

Children are considered in four categories in *A Guide to the Development of Children's Palliative Care Services,* produced by the Association for Children with Life-threatening or Terminal Conditions and their Families (ACT):

Group 1 – Life-threatening conditions for which curative treatment may be feasible but can fail; access to palliative care services may be necessary alongside attempts at curative treatment and/or if treatment fails.

- Group 2 – Conditions for which premature death is inevitable, but there may be long periods of intensive treatment aimed at prolonging life and allowing participation in normal activities, such as with cystic fibrosis.
- Group 3 – Progressive conditions without curative treatment options, where treatment is exclusively palliative and may commonly extend over many years, for example, Batten disease and muscular dystrophy.
- Group 4 – Irreversible but non-progressive conditions with complex healthcare needs leading to complications and likelihood of premature death. Examples include

severe cerebral palsy and multiple disabilities following brain or spinal cord insult.

The Patient Protection and Affordable Care Act (PPAC), signed into law in March 2010, includes Section 2302, "Concurrent Care for Children" (CCC), which requires state Medicaid programs to pay for concurrent curative treatment and hospice services for children with life-limiting or life-threatening conditions who qualify for hospice services. Prior to this change in federal law, parents were faced with forgoing curative treatments for a child in order to receive hospice services. Although the CCC provision represents significant improvement in access to hospice for children, looming cuts threaten hospice care for both children and adults as the specifics of health care reform continue to emerge.

The District's Palliative Care Services

In 2011, the Center to Advance Palliative Care and the National Palliative Research Institute released state-by-state report cards. The reports examine variations in access to hospital palliative care in order to influence both the public and policy makers toward increasing the availability of palliative services.

Many states received high grades, but the authors of the report cards note that a high grade reflects only the existence of a service, not at which point or points in the course of an illness it is being accessed. They note that millions of Americans do not have access to palliative care services from the point of diagnosis and throughout the course of an illness.

The District of Columbia received an "A," noting that all hospitals list palliative services, though the make-up and variation of palliative care teams is not described. However, the inequitable geographical distribution of hospitals and other health care infrastructure in the District of Columbia, described elsewhere in this report, presents challenges for the effective, seamless delivery of palliative care.

For a listing of palliative care providers, refer to these websites:

- The DCCC Resource Locator www.dccanceranswers.org.
- The Get Palliative Care organization www.getpalliativecare.org/
- The Center to Advance Palliative Care www.capc.org/reportcard/home/DC/RC/District%20of%20Columbia

Background for the Palliative Care Goals

Delivering quality palliative care means recognizing the full range of challenges faced by patients and families at any point along the course of illness. A comprehensive cancer control plan should work toward improving the prevention of suffering by emphasizing continuous

attention to all dimensions of pain experienced by both patient and family. This can be accomplished by integrating palliative care in cancer programs in conjunction with efforts aimed at disease prevention (through education and policy), prevention of advanced disease (through early detection), and anticancer treatment. Key palliative care areas to be addressed in the DC Cancer Control Plan are improving education about palliative care and its scope, education regarding pain management, promoting patient-centered continuity of care, and improving the policy and regulatory environment as it pertains to palliative care.

The burden of cancer-related illness is high for both patients and their families, and distress from symptoms significantly contributes to this burden.[7] Symptoms vary according to the kind of cancer, organ involvement, and treatment given, as well as emotional responses to diagnosis and treatment. 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, depression, and delirium. Depression and delirium are often under-recognized and under-treated, although both respond to treatment.

Chronic pain leads symptoms in terms of prevalence and potential consequences. Pain in cancer survivors is poorly described in the literature; an effort to improve pain outcomes suggests the need for continued professional education on pain management. Integrating best practices for pain management will improve pain relief and contribute to humane, effective, and affordable cancer care.[8] Despite treatment guidelines to improve relief of pain for most patients, a review suggests that as many as 43 percent of cancer patients receive inappropriate care for pain.[9] Improved pain relief may allow patients to complete cancer treatments and experience overall improvement in quality of life.
Children are not small adults: strategies and dose-specific guidelines to manage children's pain are different. As they pass through developmental stages, children face physiologic changes that influence pain relief strategies. Even the most disabled children face dynamic and often rapid changes in their natural growth patterns. Without expert attention to their challenging and changing needs, children may suffer needlessly during the course of an illness. Should the child survive, tolerance for pain is lowered throughout the life span,[10] and a legacy of suffering follows. Palliative expertise in pain management is therefore an essential component of the care for this vulnerable population.

In pediatrics, it is important to understand the resiliency exhibited by children during an illness, and reflect that understanding in criteria for access to critically needed services such as hospice and palliative care.

Other educational initiatives concerning palliative care are critically needed, including an effort to better differentiate hospice and palliative care, to integrate palliative care earlier in the disease trajectory, and to more fully address the needs of the family.

For example, the role of family caregivers in chronic and terminal illness is increasing, largely caused by changing demographics and a shift of health care from the hospital into the home.

The new and often unfamiliar roles that family caregivers assume, and their ability to positively affect the patient's comfort, safety, and well-being, are not to be underestimated. Family caregivers assist in or completely take on the role of advocate, physical caregiver, medication administrator, financial manager, case manager, and a host of other responsibilities.[11] Early and ongoing palliative care interventions can help prevent family crisis and create cohesion by assessing family functioning and using interdisciplinary team members to meet the array of family needs.

It is not enough just to provide information. 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. Frequent reassessment is required, along with shared care planning that respects individual and family abilities, capacities, and values. This patient-centered care includes an emphasis on early advance care planning, starting with early, non-threatening conversations with the family.

Cancer remains the second leading cause of death in the United States, accounting for nearly one out of every four deaths.[12] The number of deaths underscores the need for early interventions to explore advanced care planning and the need to revisit patient and family goals frequently throughout cancer care.

The importance of focusing on earlier advance care planning is also highlighted by the growing costs of informal caregiving; those costs increased by 20 percent between 2007 and 2009, to $450 billion worth of services.[13] Palliative care can help families prepare for and deal with those costs.

The role of palliative care is even more important when the family is coping with a child's serious, potentially life-threatening illness. Pediatric palliative care affects the whole family, with the burden of care falling upon parents and siblings or grandparents.[14] This often leads to loss of work days for the caregiver, loss of

employment and consequently the potential loss of health insurance. Siblings may take part in caregiver activities and will require emotional and psychological support that is appropriate for their developmental stage.

The suffering and potential loss of a child can be overwhelming enough. The additional stress of lost wages and healthcare coverage can make the situation worse and affect parental well-being. Palliative supportive services are essential components of care, including the interdisciplinary approach to care, attention to anticipatory and current grief assessment, and links to community resources. The entire family system is coping with the disease as their lives become individually, collectively, and permanently altered.

Prior to the passage of PPACA, there were numerous barriers to accessing palliative and hospice services for all ages. As we move forward under this law we are faced with an inevitable restructuring of payment systems for these services.

Currently, hospice services for all age groups are paid for primarily through Medicare and Medicaid benefits. The recent passage of the PPAC has improved access to and payment for pediatric hospice services. Yet even with this new legislation, there remain gaps in coverage for individuals of all ages who would benefit from palliative care services—those who either are not eligible for hospice care (e.g. do not meet hospice criteria of a six-month or less prognosis), or do not choose hospice care. The passage and implementation of Section 2302 of the PPAC reveals an environment ripe for submission of child and adult palliative care Waivers or State Plan Amendments.

Despite the successful adoption of Medicaid's Concurrent Care in Children provision, PPAC requires the Department of Health and Human Services to review hospice payments, and there may be new alternatives for paying for such services in the future.

There are many other policy and regulatory issues that warrant tracking, increased attention, and participation in policy and legislative reform. The palliative care goals in this chapter include establishment of a policy team in the District to improve efforts to influence decisions regarding these invaluable palliative care services for patients, families, and providers.

Palliative Care

Goals and Objectives

GOAL 1: Improve the quality of education about palliative care and related services in the District.

Objective 1: Assess and develop recommendations to ensure that current pediatric and adult palliative care practices are based on national quality standards.

Steps to achieve objective:

1. Gather palliative care best practices and benchmarks from established palliative care authorities/sources (e.g. National Consensus Project, Center to Advance Palliative Care, National Hospice and Palliative Care Organization) to guide necessary competencies.
2. Conduct literature review and outline recognized specialty domains of pediatric and adult palliative care.
3. Using accumulated information, produce assessment plan that includes identification of target groups, development of data-gathering tools (surveys, focus groups, etc.), review of palliative care educational and marketing materials, and identification of resources.
4. Conduct assessment of current pediatric and adult palliative care practices.
5. Organize and analyze the data collected, comparing identified needs to the services, materials and supports currently provided by District programs, as well as to the identified best practices.
6. Develop recommendations to improve and assure the quality of services, educational programs, and supporting materials. Include recommendations on cultural issues for all age groups.
7. Prepare report for general DCCC membership and taskforce use for strategic planning.
8. After completion of assessment and recommendations, convene taskforce to organize, identify and incorporate strategic partners (drawing from organizations within and/or which serve minority populations), and devise work schedule.

Measurement:

1. Process measures and milestones to be determined by the taskforce

Timeframe: 3 years

Objective 2: Develop initiatives, including outpatient options, to meet the needs of the palliative care population in the District.

Steps to achieve objective:

1. Convene taskforce (with both pediatric and adult care focus) to organize efforts and devise work schedule.
2. Enact recommendations from Objective 1.
3. Based on results, develop strategic plan to improve and assure pain and symptom management, including professional education, measures for pain management improvement, and the identification of resources for all age groups.
4. Implement initiatives and assess impacts for continual improvement.

Measurements:

1. Process measures and milestones to be determined by the taskforce may include:

a. Survey completion
b. Strategic Plan completion
c. Pre-and post-testing of knowledge change
d. Institutional pain assessment data

Timeframe: 2 years (subsequent to Objective 1 – to be completed within five years) with assessment, planning, and implementation

GOAL 2: Promote the adoption of patient-centered continuity of care (including advance care planning) for patients, and support family caregivers.

Objective 1: Review current pediatric and adult programs that highlight a shared decision-making patient-centered continuum of care, including those that focus on advance care planning and advance directives, and make recommendations for improved outcomes in the District.

Steps to achieve objective:

1. Convene taskforce to organize, engage other partners, and devise work schedule.
2. Assess current practices in the District and other states, research federal initiatives, and accumulate best practices and evidence-based interventions. Potential sources: Coalition To Transform Advanced Care (C-TAC); La Crosse, WI Physician Orders for Life-Sustaining Treatment (POLST**);** Medical Orders for Life-Sustaining Treatment (MOLST) protocols; etc.
3. Based on assessment, recommend initiatives to improve patient outcomes (pediatric and adult populations) and develop District-specific outcome measures.
4. Produce report.

Measurements:

1. Process measures and milestones to be determined by the taskforce, but may include:
   a. Systematic review of institutional practices
   b. Literature review of other state practices
   c. Submission of report for public dissemination

Timeframe: 1 year

Objective 2: Develop and implement strategic plan for assuring patient-centered care and shared decision-making in the District.

Steps to achieve objective:

1. After completion of assessment and recommendations, convene taskforce to organize, identify, and incorporate strategic partners for pediatric and adult populations, and devise work schedule.
2. Utilizing assessment and recommendations report, determine consensus approach on strategies and timelines for implementing programs and/or initiatives, to include the identification of resources.
3. Implement initiatives with the engagement of identified strategic partners.
4. Study the impacts for continued improvement.

Measurement:

1. Process measures and milestones to be determined by the taskforce but may include:
   a. Development of implementation plan

Timeframe: 2 years for planning, 4 years, including implementation and review

GOAL 3: Improve the policy and regulatory environment affecting access to pediatric and adult palliative care services in the District.

Objective 1: Develop an active policy team to advocate for enhanced reimbursement of government support and actively participate in District/national policy initiatives.

Steps to achieve objective:

1. After completion of assessment and recommendations, convene taskforce to organize a core policy team, identify and incorporate strategic partners, and devise work schedule.
2. Utilizing assessment and recommendation report, implementation plan, and assessments of the current political and regulatory environment, create team priorities, objectives, and strategies for local and national policy- and regulation-related activities.
3. Prepare report.
4. Work with strategic partners, including government and non-governmental organizations, to institute action steps.

Measurement:

1. Process measures, milestones, and outcomes to be determined by the taskforce but may include:
   a. Availability and implementation of 1915 (c) waiver and/or other federal vehicles

Timeframe: 4 years

Access to Care and Patient Navigation

- Pioneered in the 1990's by Harold Freeman, patient navigation is a culturally competent intervention that is increasingly used to address health disparities, access to care and quality care issues in the US. (www.hpfreemanpni.org).
- The National Cancer Institute Center to Reduce Cancer Health Disparities and the American Cancer Society funded the national Patient Navigation Research Program (PNRP), conducted over five years (2006-2010) at nine sites across the US, including Washington, DC. Results suggest that patient navigation is an effective intervention to improve timeliness of care. (National Cancer Institute Center to Reduce Cancer Health Disparities)
- The American College of Surgeons' Commission on Cancer (CoC) defines patient navigation as "individualized assistance offered to patients, families, and caregivers to help overcome health care systems barriers and facilitate timely access to quality medical and psychosocial care" and includes navigation as a new patient-centered standard of care for institutions seeking accreditation for their cancer program. (Commission on Cancer, 2012)
- Effective in 2012, the CoC now requires that accredited cancer care institutions establish a patient navigation process by 2015. (Commission on Cancer, 2012)

The Institute of Medicine's report, *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*[1], calls attention to disparities in quality care and delivery for racial and ethnic minorities and the uninsured that continue to plague the health care system in the United States. Patient navigation is a culturally competent intervention that is increasingly used to address health disparities, access to care and quality care issues in the US. Pioneered in the 1990's by Dr. Harold Freeman[2,3], patient navigation was designed to reduce cancer disparities among the poor in Harlem, New York specifically through screening, diagnosis and treatment of cancer. Positive results of the intervention have led to expansion across the entire cancer continuum with widespread replication across the country
and in various diseases such as diabetes, heart disease and HIV/AIDS.

In 2005, President Bush signed into law the Patient Navigator Outreach & Chronic Disease Prevention Program[4], which outlined six required responsibilities of non-medical patient navigators:

- Acting as liaisons by assisting in the coordination of health care services and provider referrals.
- Facilitating the involvement of community organizations in assisting individuals who are at risk for or who have cancer or other chronic diseases

to receive better access to high-quality health care services.

- Notifying individuals of clinical trials and, on request, facilitating enrollment of eligible individuals in these trials.
- Anticipating, identifying, and helping patients to overcome barriers within the health care system.
- Coordinating with the relevant health insurance ombudsman programs to provide information to individuals about health coverage.
- Conducting ongoing outreach to health disparity populations.

The National Cancer Institute Center to Reduce Cancer Health Disparities and the American Cancer Society funded the national Patient Navigation Research Program (PNRP)[5], conducted over five years (2006-2010) at nine sites across the U.S. Results suggest that patient navigation is an effective intervention to improve timeliness of care. DC data offers evidence that navigated women with a diagnosed breast cancer experienced a reduction in the time from screening result to diagnostic resolution as compared to non-navigated women (25.1 days versus 42.1 days from time of abnormal finding to time of diagnostic resolution).[6] This is particularly significant since African American women are more likely to have their cancer diagnosed at a later stage that their White counterparts.

The American College of Surgeons' Commission on Cancer (CoC) defines patient navigation as "individualized assistance offered to patients, families, and caregivers to help overcome health care systems barriers and facilitate timely access to quality medical and psychosocial care" and includes navigation as a new patient-centered standard of care for institutions seeking accreditation for their cancer program.[7] The CoC accredits institutions representing approximately 70 percent of the cancer care delivered in the United States. The new standard requires these institutions to establish a patient navigation process to address cancer health disparities and barriers to care, driven by and responsive to a community needs assessment. The new standard became effective in 2012 and should be phased in to be fully in place by 2015.

Longitudinal Network Navigation is an innovative model of navigation that has been pioneered in Washington, DC. As illustrated in Figure 1 below, Dr. Freeman's initial target was navigation from abnormal screening to treatment. The longitudinal network is more inclusive, encompassing navigation to screening services followed through post-treatment care, as depicted in Figure 2.

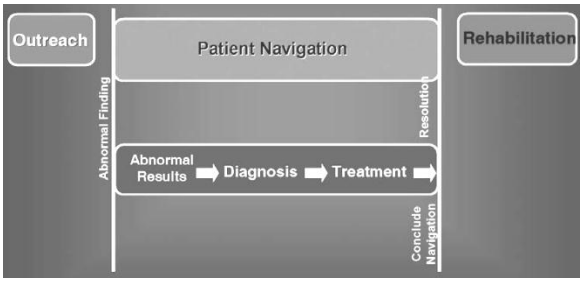


FIGURE 1. Patient navigation model. From Freeman HP, Muth BJ, Kerner JF. Expanding access to cancer screening and clinical follow-up among the medically underserved. Cancer Pract. 1995;3:19-30.

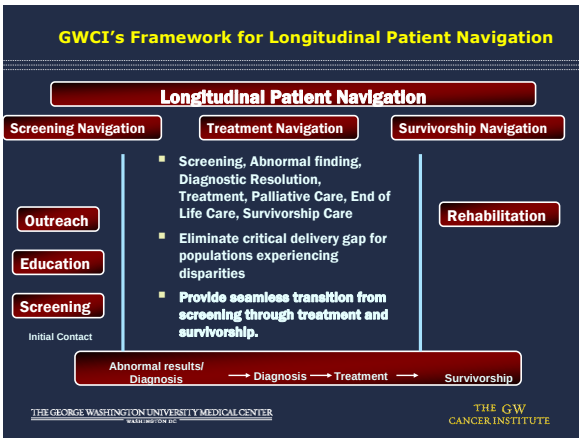


FIGURE 2. Longitudinal patient navigation model. From Steven R. Patierno, PhD; Nancy L. LaVerda, MPH; Lisa M. Alexander, EdD; Paul H. Levine, MD. Heather A. Young, PhD; and Heather J. Hoffman, PhD. Development of a city-wide integrative model to reduce breast cancer disparities in Washington, D.C. Oncology Issues March/April 2010; 28-35.

Thus, patients are able to access timely, coordinated, standard-of-care treatment and support services throughout the cancer continuum, particularly populations currently experiencing disparities in care.[8] Though nearly all patient navigation programs offer these services, programs often differ in terms of structure. Some use licensed professionals, such as social workers to provide navigation services, while others use highly-trained lay navigators. Some programs are more integrated with medical services than others. Still, the aim of all these services is to help patients find the best route through an often-confusing system to get the services they need.

Breaking down barriers across competing cancer centers and bridging relationships between community organizations, primary care settings, and screening and treatment centers are critical in a city with such dramatic cancer statistics and with clear structural barriers to care. The District of Columbia tops the nation in breast and prostate cancer incidence and death rates.[9] Cancer is the second leading cause of death among District residents with 22 percent[10] of deaths due to cancer and clear disparities between White and Black populations in the city.[11,12] A contributing factor of the major health care disparities in DC is the aggregation of cancer centers in the more affluent wards of the city and the lack of cancer providers in lower-income wards. Structural barriers to accessing care – including physical location of facilities and transportation to treatment – compound issues of cost and fear experienced by cancer patients with the fewest resources. Longitudinal Network Navigation mitigates some of these barriers by connecting patients to support and care regardless of where they live in the city. Top barriers identified by patients include insurance and financing barriers to care, fear, communication barriers with medical personnel, system problems with scheduling care, transportation barriers, language barriers, and social support concerns.[13] The DC Cancer Consortium City-Wide Patient Navigation Network has served more than 4,600 individuals in two years and removed nearly 17,000 barriers to care.

Cancer care, as practiced today, is a complex and mostly fragmented system requiring a patient to participate in different treatment regimens and interact with a number of specialists. Factoring in transportation, financial, and other barriers, even well-informed, medically-astute, and resourced patients can easily become lost. Hoffman, LaVerda, et al., found that the presence of health

insurance, alone, did not significantly eliminate the racial disparity associated with delays in the diagnosis of breast cancer in the District.[14] On the other hand, research suggests that patient navigation is an effective intervention that improves timeliness of care. Patient navigation may also result in cost savings as patients are more consistently compliant with treatment, obviating the need for frequent emergency room visits or hospitalizations.

According to Dr. Freeman, nine principles have evolved over the past 20 years that help define the standards and attributes for patient navigation programs:[15]

- Patient-centric healthcare service delivery model
- Integration of fragmented health care system for the individual patient
- Core function is to eliminate barriers to timely care across all segments of the healthcare continuum
- Scope of practice of navigation system is defined and distinct from that of all other providers
- Cost effective and commensurate with the training and skills necessary to carry out function
- Selection of navigator determined by level of skills required at a given phase of navigation
- Defined point at which navigation begins and ends
- Patients are navigated across disconnected systems of care, such as primary care sites and tertiary care sites
- Coordination required both within the navigation system and between the navigation system and other providers

Patient navigation is still evolving but it has already been shown to have a real and significant impact on access, treatment, and outcomes. Some examples are:

- Patient navigation confers a survival advantage mostly through earlier stage diagnosis. In Dr. Freeman's Harlem breast cancer experiment, there was a significant reduction in the number of patients presenting at advanced stages (3-4) and a corresponding increase in those presenting at Stages 0-I. During this period, the five-year survival rate increased 31 percentage points (from 39 percent before navigation services were instituted to 70 percent with navigation).[16]
- Significantly fewer hospitalizations among head and neck cancer patients have been reported for those who received patient navigation compared with a historical control group who did not receive navigation services.[17]
- Ell, et al. reported higher rates of treatment adherence to chemotherapy and radiation therapy regimens for breast and gynecologic cancer patients who received patient navigation.[18]
- The Boston Medical Center found patient navigation to be a viable strategy to increase minority accrual into clinical trials.[19]

- Patient navigation was found to contribute to increased colorectal cancer screening among low-income minorities 50 years of age and older in an urban health clinic. Within six months of physician recommendation, 15.8 percent of navigated patients complied with an endoscopic exam, compared with only 5 percent of non-navigated patients. The navigated group also demonstrated higher rates of fecal occult blood test completion than the non-navigated group (42.1 versus 25 percent).[20]
- Several studies found that patients receiving navigation services reported improved satisfaction with health care and decreased anxiety levels.

Access to Care and Patient Navigation Goals and Objectives

GOAL 1: Sustain District-wide longitudinal navigation services for District residents with cancer.

Objective 1: Maintain system of navigators as a safety net for individuals across the cancer continuum through the provision of patient navigation that includes community organizations, primary care and screening sites, and cancer centers.

Steps to achieve objective:

1. Define patient navigation scope of practice.
2. Determine structure for District-wide longitudinal navigation services.
3. Collect information to help inform the development of consensus-based navigation competencies; survey institutions nationally to draft consensus-based competencies in collaboration with other national stakeholders.
4. Identify, develop and implement core competencies for navigation to establish navigation as a distinct profession.
5. Create a certification process by differentiating roles across the navigation continuum from community health workers to nurse navigators.
6. Develop standardized training curricula.
7. Plan, coordinate and implement standardize trainings for District-wide navigators.
8. Examine potential public and private funding sources, and develop and implement a plan to assure resources for the availability of District-wide patient navigation services.
9. Continue collaborative working relationships and training for a District-wide longitudinal navigation program, which allows for navigators to build professional capacity, troubleshoot navigation cases, plan for sustainability and increase capacity to support survivors post-treatment.

Objective 2: Develop and implement a data collection plan that shows the value of patient navigation.

Steps to achieve objective:

1. Identify and secure resources to support data collection plan.
2. Pilot data collection tool.
3. Aggregate outcomes across all longitudinal navigation services in the District to inform cancer control activities.
4. Track, compile and report data.

Measurement:

1. Process measures and milestones to be developed by navigation network, which may include evaluation of data collection tool.

Timeframe: 3 years

GOAL 2: Increase quality of care received by District residents.

Objective 1: Remove barriers to care experienced by patients and increase self-efficacy of patients in navigating the health care system.

Steps to achieve objective:

1. Increase proportion of patients receiving navigation.

2. Increase number of patients receiving survivorship information and support.
3. Decrease number of patients lost to follow up after adverse finding.
4. Teach District navigators best practices in integrated health care and techniques to employ them to benefit patients most in need.
5. Develop a strategic plan to address top barriers to care as identified by existing Longitudinal Network Navigation programs.
6. Support providers with best practice initiatives such as patient reminder systems.

Measurement:

1. To be determined, but may include evaluation of the removal of barriers to indicate access to care and reduction in racial and ethnic disparities in health care.

Timeframe: Five years

GOAL 3: Advocate for patient navigation as a reimbursable cost.

Objective 1: Develop an active policy team to raise awareness of the efficacy and efficiency of navigation and to advocate for reimbursement of patient navigation.

Steps to achieve objective:

1. Advocate at the national level for health policy change that leads to the financial sustainability of patient navigation services.
2. Publicize policy white paper and utilize recommendations as a framework to institute action steps.
3. Report recommendations in policy white paper to DCCC membership for organizational advocacy.
4. Present recommendations in policy white paper to District officials and policy stakeholders.
5. Implement recommendation of policy white paper with the engagement of identified strategic partners.

Measurement:

1. Process measures and milestones to be determined by the taskforce, but may include development of implementation plan.

Timeframe: 5 years

Prostate Cancer

- Prostate cancer is the second leading cause of cancer deaths among men in the U.S. – second only to lung cancer. (Centers for Disease Control and Prevention)
- Prostate cancer is the most common non-skin cancer in America, affecting 1 in 6 men. (Prostate Cancer Foundation)
- For the year 2007, the Centers for Disease Control and Prevention reported that 223,307 men in the U.S. were diagnosed with prostate cancer and 29,093 men died from the disease. (Centers for Disease Control and Prevention)
- Nationally, Black men have the highest incidence rate for prostate cancer, followed by men who are White, Hispanic, Asian/Pacific Islander, and Native American. This ranking also holds true for death rates. (Centers for Disease Control and Prevention)
- The risk of prostate cancer increases with age. According to the CDC, six or seven out of every 100 men who are 60 years old today will get prostate cancer by the age of 70. (Centers for Disease Control and Prevention)

According to the Centers for Disease Control and Prevention (CDC), trend data has shown that, nationally, both the incidence and mortality rates of prostate cancer have been in decline. From 1998 to 2007 in the US, deaths from prostate cancer have:

- Decreased by 3.8 percent per year among White men
- Decreased by 4.2 percent per year among Black men
- Decreased by 3.8 percent per year among Hispanic men
- Decreased by 3.1 percent per year among Asian/Pacific Islander men

Despite this encouraging outlook, prostate cancer is still one of the most common cancers in men and the second leading cause of death in men.[1] The causes are largely unknown; however, all men are at risk. The American Cancer Society estimates there were 241,740 new cases of prostate cancer diagnosed in the US in 2012, and 28,170 deaths.[2] Prostate cancer is usually diagnosed through a screening known as the Prostate-Specific Antigen (PSA) test. The most common risk factor is age. More than 75 percent of men diagnosed with prostate cancer each year are over the age of 65.[3] Ethnicity is also a risk factor, with Black men at higher risk than Whites. In 2008, incidence rates among African Americans (241 per 100,000 men) were significantly higher than for Whites (149 per 100,000). Family history and genetics are also predictors of whether a man is likely to

develop prostate cancer. The risk is further increased if the cancer was diagnosed in a family member younger than age 55, or if it affected three or more family members. Some research also indicates that obesity increases the risk for aggressive prostate cancer.[4]

According to the American Cancer Society Guidelines for Early Detection of Cancer, men who are African American, or have a father or brother who had prostate cancer before age 65, should talk with their doctors and consider being screened starting at age 45.[5] Some studies have indicated that veterans exposed to Agent Orange have a higher risk of developing prostate cancer.[6] The American Urological Association recommends that higher-risk populations should get a baseline PSA along with a physical examination of the prostate (known as a digital rectal exam or DRE) at age 40.[7] Further, research published in the Journal of Clinical Oncology found that even small rises in the tPSA (total prostate-specific antigen) "markedly" increased the risk of prostate cancer as much as 25 years before actual diagnosis.[8]

Prostate Cancer in the District of Columbia

The incidence rate for prostate cancer in the District of Columbia for 2004-2008 is 187.9, higher than the national rate of 152.9. The District of Columbia has the highest mortality rate from prostate cancer in the nation – 41.7 versus 24.4 nationally.[9] Following the national statistics, among District residents, Black men have the highest incidence of prostate cancer: according to the DC Cancer Registry, the rate is 40.8, compared to 14.2 for White men, and 20.9 for all races.[10] The American Cancer Society estimated that, in 2012, 540 District men would be diagnosed with prostate cancer, and 60 would die from the disease.[11]

Most prostate cancers are diagnosed while they are localized (confined to the prostate gland), however, more Black men (4.3 percent) as compared to White men (2.7 percent) have their cancers diagnosed at the later distant stage, when the cancer has spread to the bladder, rectum, lymph nodes, or distant organs, such as the bones.[12]

The mortality rate for prostate cancer falls unevenly across wards, as illustrated by Table 1.[13]

Table 1. Age-Adjusted Mortality Rates by Ward for Prostate Cancer, 2008 (per 100,000 persons, age-adjusted to 2000 US standard)

Ward	Rate
Ward 1	25.8
Ward 2	25.5
Ward 3	13.1
Ward 4	27.6
Ward 5	24.1
Ward 6	47.0
Ward 7	30.0
Ward 8	98.9

The wards with the highest rates are also home to the highest proportion of African Americans and residents with the lowest household incomes.[14]

District Programs and Services

Local hospitals, health providers, community-based organizations, and advocates have worked together and separately to:

- Increase awareness of prostate cancer through outreach, health information, and education campaigns.
- Increase access to information in non-health settings, such as barbershops.
- Conduct outreach and education to increase awareness among younger men about their risk and to encourage them to add prostate cancer screening to their health regimen as they age.
- Heighten "risk perception" among men, especially African American men who are most prone to develop the disease.
- Provide accurate information about currently available tests and treatment options, including their limitations and possible side effects.
- Promote examinations of African American men beginning at 45 years of age.
- Encourage examinations of men who are 50 years or older, or who have a close family history of the disease and are considered at "high risk." High-risk men also include Vietnam veterans who have been exposed to Agent Orange.

Providing easy access to screening and treatment is an ongoing part of the District's efforts.

Prostate Cancer
Goal and Objectives

GOAL 1: Reduce morbidity and mortality due to prostate cancer in the District.

Objective 1: Through the provision of professional and public education, improve the appropriateness of prostate cancer screening for District residents.

Steps to achieve objective:

1. Convene task force to organize and engage other partners (including representatives of primary care providers, public health educators, health literacy experts, etc.) and devise work plan and schedule to achieve objective.
2. Assess state of best practices and evidence-based educational interventions to increase knowledge about the risks and benefits of prostate cancer screening, both in professional care providers and general populations.
3. Assess current research on public and professional knowledge and attitudes about informed decision-making and prostate cancer-specific information, including risk factors, personal history, screening and diagnosis modalities (and their risks and benefits), treatment options, etc.
4. Based on assessments, develop, leverage resources for, and implement any required data collection plan, possibly including surveys and focus groups, to obtain District-specific information on public and professional knowledge and attitudes, as well as information on messaging (influencers, etc.).
5. Utilizing available research, design, leverage resources for, and implement professional and public educational initiatives to increase knowledge about prostate cancer and the risks and benefits of screening, possibly including internet-based, print, and small-group instructional modalities.
6. Develop campaign that will target specially burdened populations such as African Americans to heighten their perception of risk and encourage earlier screening (at 45 years of age).
7. Develop a monitoring strategy, possibly including Behavioral Risk Factor Surveillance System (BRFSS) questions, surveys, health record reviews, and health payer and health system monitoring, to track informed decision-making and screening activity.
8. Continually study the impacts of intervention for improvement and make periodic reports to DCCC membership.

Measurements:

1. Process measures and milestones to be determined by taskforce
2. Data collected as part of system developed, possibly including State-added BRFSS data
3. Knowledge change, as measured by pre- and post-testing

Timeframe: 5 years

Objective 2: Establish a standard for community prostate screening process, including education and informed decision-making.

Steps to achieve objective:

1. Convene taskforce, including organizations performing community

screening, to develop work plan and schedule to achieve objective.
2. Using existing data sources, complete an inventory of current community screening programs, including populations served, educational materials and processes used, use of informed decision-making, and data collection methods used for measuring screening and follow-up activity.
3. Collect and assess best practices and evidence-based interventions for community screening and lay person-based client education.
4. Analyze the collected data and achieve consensus on standards for community screening programs.
5. Advocate with public and non-profit funders to build unified standards into requests for proposals and applications, and with organizational leaders to gain buy-in.
6. Develop a dissemination and educational plan for program staff and organizational leaders for the unified standards and any knowledge foundation required for implementation.
7. Develop a monitoring strategy, possibly including surveys, program reports, and record reviews, to track informed decision-making, screening activity, and follow-up.
8. Study the impacts of initiatives for continual improvement and reporting to DCCC membership.

Measurements:
1. Behavioral Risk Factor Surveillance Survey
2. Process measures and milestones to be determined by task force
3. Data collected as part of system developed

Timeframe: 5 years

Objective 3: Increase the early detection and appropriate management of clinically relevant prostate cancer, those cases with a reasonably high probability of disease, which adversely impacts chances of survival and quality of life.

Steps to achieve objective:
1. Convene taskforce to organize and engage other proposed members (including representatives of primary care providers, patient navigators, etc.) to develop work plan and schedule to accomplish objective.
2. Assess barriers (economic and non-economic) to, and enablers of, appropriate prostate cancer screening and management in the District, using existing data or through the development and implementation of a needs assessment plan.
3. Develop and implement policy plan for assuring appropriate early detection opportunities, possibly to include mandated professional education hours on chronic disease and cancer and changes in health care financing.
4. Leverage DCCC membership to advocate for the assurance of public and/or private resources for the availability of District-wide patient navigation services.
5. Examine current data collection and monitoring schemes for screening, referral, and treatment activity in the District; produce recommendations on system and quality improvement (including modification of Cancer

Registry criteria to capture active surveillance as a medical management tool, abnormal screening tracking, etc.); and report findings for further planning and advocacy.

Measurements:

1. DC Cancer Registry data (track numbers of men diagnosed and treated, proportion of cancers staged as distant upon diagnosis)
2. Process measures and milestones to be determined by task force

Timeframe: 5 years

Objective 4: Reduce the proportion of unstaged prostate cancer cases for all races from the 2004-2008 Surveillance Epidemiology and End-Year Results (SEER) baseline of 11.7 to <3.

Steps to achieve objective:

1. Determine the proportion of unstaged cases by race and the source of these unstaged cases.
2. Convene taskforce of stakeholders to organize, engage other proposed members (including representatives of the appropriate medical specialists, medical educators, etc.), and devise work and reporting schedules.
3. Examine barriers (education and training-related, etc.) to prostate cancer staging and its assurance in the District, using existing data or through the development and implementation of a needs assessment plan.
4. Design, develop funding for, and implement a professional educational program to improve prostate cancer staging.
5. Examine District cancer center accreditation and certification standards in order to develop any required policy and regulatory intervention plan to provide for assurance of timely and appropriate staging at the District's cancer centers.
6. Study the impacts of initiatives for continual improvement and reporting to DCCC membership.

Measurements:

1. DC Cancer Registry data
2. Process measures and milestones to be determined by task force

Timeframe: 2 years to implement, 5 years of ongoing activity

Survivorship

- A person is considered a cancer survivor from the moment he or she is diagnosed with cancer. There are nearly 14 million cancer survivors nationally and about 20,000 in DC. (American Cancer Society. Cancer Treatment and Survivorship Facts & Figures 2012-2013.)
- In 1971 there were three million cancer survivors (1.5 percent of the U.S. population). In 2001, there were 9.8 million (3.5 percent of the population)(National Cancer Institute. National Institute of Health, 2011) If current trends continue, one-third of American women and half of American men will eventually be diagnosed with cancer.
- A national health objective for 2020 is to increase to 72.8 percent the proportion of cancer patients living more than five years after diagnosis. This objective has already been achieved for children with cancer, but not yet for adults. (Healthy People 2020 U.S. Department of Health and Human Services.)

Little data exists about survivorship prevalence, treatment, and use of services in the District. Current treatment data includes a number of survivors who come from other states and nations, and many D.C. residents may get their treatment outside of the District. A diagnosis of cancer affects a person's well-being in multiple ways. The physical effects result from treatments (radiation, chemotherapy, and surgery), medicines, and coexisting conditions. Those effects:

- Can be both acute and chronic, and can occur during and after treatment.
- May include pain, fatigue, nausea, and hair loss, depending on the cancer's site and treatment, as well as changes in nutrition, diet, and exercise. Can be so debilitating that the patient needs bed rest. May require palliative care to manage pain and symptoms at any point on the continuum.
- May in the long term (because of the cancer itself or treatment for it) include decreased sexual function, loss of fertility, persistent edema (swelling), fatigue, chronic pain, and major disabilities such as loss of a limb or confinement to a wheelchair.

In addition, cancer often affects quality of life in these non-physical but significant ways:

- **Psychological** The diagnosis and treatment of cancer usually evoke a host of difficult emotions, including fear, stress, depression, anger, and anxiety—as well as feelings of hopelessness, helplessness, lack of control, and diminished self-esteem. Many survivors live with uncertainty and the fear that the cancer might return.
- **Economic** Cancer imposes costs that include the financial burdens of health care expenses, lack of insurance, and lost income because of 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.

- **Social** Pain and disability may diminish survivors' sense of social well-being by limiting the time they can spend with people important to their lives, despite the value of support from family, friends, the workplace, and social activities. Cancer's impact on survivors' self-image may also cause difficulty interacting with school peers, friends, or coworkers.
- **Functional** Survivors can experience limitations in their ability to work, resume physical activities, return to "normal" life, and undergo rehabilitation.
- **Spiritual** Concerns include connection with a higher power and issues of faith and trust, as well as existential questions.

Stages of the Cancer Experience

Fitzhugh Mullan, MD, a District cancer survivor, originally articulated the cancer experience as a process that spans diagnosis, treatment, and beyond. During the early stage of survivorship, patients often experience significant anxiety, pain, discomfort, and worry about dying. After treatment ends, uncertainty may persist, and the survivor may experience physical limitations, changes in body image, and problems with trust—resulting from both the illness and the treatment. Family members, friends, and caregivers are also affected by the diagnosis and by subsequent stages of survivorship.[1]

At all stages, cancer can deprive those diagnosed of their independence and can disrupt the lives of family members and other caregivers.

Despite the challenges of cancer, survivors have demonstrated resiliency in adapting back to life after diagnosis. For many survivors, the cancer experience may 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, and some survivors become more spiritual as a result of the experience.

Survivor Needs Vary from Stage to Stage

The greatest needs for survivors are high-quality, timely, and accessible screening programs, medical treatment, and primary care. Additional needs vary depending on where survivors are in the cancer experience.[2] [3]

Diagnosis

It is overwhelming to receive a cancer diagnosis. A survivor must adjust emotionally to the diagnosis, often handling the high levels of stress and anxiety that can come with having to understand medical terminology, make treatment decisions,

select a medical team, address employment issues, and plan for other lifestyle changes.

During Treatment

When treatment begins, needs may include reliable, consumer-friendly information; help making treatment decisions; guidance on how to talk with health care providers, partners, 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.

Transitioning Off Treatment

The transition off treatment can be bittersweet for many survivors. While the end of treatment can be a time of celebration or reflection, it is also a time of uncertainty and adjustment to a "new normal" that can be difficult for patients and caregivers. Without a formal transition process, survivors may feel abandoned by the health care providers with whom they have bonded over the weeks, months, or even years of treatment. Fear of recurrence is common for many survivors; that fear can increase feelings of uncertainty about their future. For some survivors, the end of treatment does not mean the end of many challenges that persist when treatment is over, such as employment or financial issues. As cancer survivors have become more celebrated and stigma has been reduced, survivors may have to deal with expectations from family and friends who do not understand that the cancer recovery process can take time.[4]

After Cancer Treatment

As the number of survivors has increased due to better screening and treatment options, the long-term and late effects of cancer and its treatment have become more apparent. When treatment has ended, survivors may have physical concerns related to energy levels, fatigue, cognitive issues, sexual functioning and fertility, neuropathy (nerve damage), and pain. Emotional concerns can arise because of fear of recurrence, sadness and depression, grief, identity issues, and risk to family members because of hereditary predisposition to cancer. Practical concerns can include school and employment issues, debt, and insurance. [5]

End-of-Life Planning

End-of-life issues can occur during any stage of the cancer experience. 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.[6]

While research on childhood cancer survivors has led to the development of evidence-based guidelines for post-treatment care, the data about survivors of adult-onset cancers is much less robust. Currently, for most survivors there is a lack of evidence for identifying, preventing, and treating late and long-term effects. Even without this data, however, it is clear that survivors need continued access to a great variety of resources.

In its landmark report, *Lost in Transition: from Cancer Patient to Cancer Survivor,* the Institute of Medicine (IOM) documented the need to focus on the post-treatment stage as a distinct part of the cancer trajectory. Many cancer survivors in this country face considerable challenges after completing active treatment, including ongoing issues from treatment and late effects that may occur at any point after treatment ends. Cancer survivors are often unaware of the need for continued monitoring, and there is confusion among oncologists and primary care providers about who should provide survivorship care and what that entails. These challenges may produce concerns and affect quality of life in some or all of the areas mentioned at the beginning of this chapter.[7]

Issues for Caregivers

As with survivors, the needs of caregivers change throughout the cancer trajectory. At diagnosis and during treatment, they may be stressed and overwhelmed and may have feelings of sadness, anger, grief, guilt, and loneliness. Caregivers may need additional support, including help in making sure they are taking care of themselves as well as of the survivor. Later, the transition off active treatment may be difficult for caregivers. They may feel a sense of loss, and struggle with the question, “What do I do now?” They may continue to play a key role post-treatment and share many of the concerns survivors do. Changes in family relationships and intimacy may also need to be addressed.[8]

Care for Survivors

To define survivorship care clearly, the Institute of Medicine identified four essential components:

- **Prevention** of recurrence, new cancers, and other late effects
- **Surveillance** for metastasis, recurrence, and second cancers, as well as medical and psychosocial late effects assessments
- **Interventions** for the consequences of cancer and its treatments

- **Coordination** between specialists and primary care providers to ensure that the survivors' needs are met

Recommended by the IOM and others in the cancer community, Survivorship Care Plans (SCPs) are tools for improving communication and care coordination in the treatment and post-treatment stages. The SCP should be developed and integrated early in the treatment stage. This presents the first opportunity for the oncology team and the survivor to communicate about survivorship concerns and needs, identify and plan for anticipated long-term/late-term effects, devise strategies for healthy behaviors, and discuss appropriate resources. After treatment, the SCP includes a treatment summary of all care received; it is prepared by the patient and physician, often with input from a caregiver. As a roadmap for post-treatment care, the SCP also indicates who is responsible for different aspects of care and when that care should be provided.[9]

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 traditional teachings from various cultures. Integrative cancer care modalities include acupuncture, biofeedback, yoga, meditation, and nutrition. Many of these practices have arisen from Eastern philosophies and from a different view of body mechanics and the genesis of illness and healing.

In complementary and integrative medicine, a holistic approach to cancer care treats the whole person rather than a collection of diseased body parts. With documented evidence of the mind-body effect and the value and role of complementary therapies in cancer care, the medical establishment has become more receptive to efforts to combine traditional medical care with practices that reduce stress and enhance the body's natural healing capacity.

Adopting some of the principles and practices of complementary and integrative medicine can be helpful to survivors as they progress in recovery—as 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, care plans are individually tailored to each patient's symptoms and complaints, looking at the underlying causes and aiming toward achieving the best possible level of physical, emotional, and spiritual wellness—all in concert with the traditional treatment the patient is undergoing.

Complementary and integrative medicine can offer benefits to patients and caregivers at any stage of the cancer continuum. Benefits can include, for example:

- Reducing stress, focusing on personal control and empowerment, and encouraging relaxation; this is helpful at any point, including during treatment and periods of watchful waiting, and, as appropriate, to allow a focus on end-of-life planning
- Rebuilding core strength, stamina, and flexibility
- Strengthening the immune system
- Focusing on a healthful diet
- Providing relief from anxiety or depression, or from symptoms such as pain, appetite loss, nausea, or sleeplessness
- Mobilizing the powers of the mind to maximize quality of life

Services and Programs in the District

The Greater Washington area is home to a wealth of local and national resources, including eight hospitals with cancer treatment programs accredited by the American College of Surgeons Commission on Cancer. One hospital (Georgetown University Lombardi Comprehensive Cancer Center) has been designated a comprehensive cancer center by the National Cancer Institute. But many DC survivors, caregivers, and health care providers are not aware of, or using, these resources. A comprehensive list, including programs that help survivors navigate the system, is available in the DCCC Resource Locator at www.dccanceranswers.org.

As physically close as medical and support services may be 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 service organization, also assist with transportation, but again the assistance is limited.

Support groups are a critical link for many survivors during and after treatment. Support group members share practical information such as what to expect during treatment, how to manage pain and 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. Even the most supportive family and friends cannot understand exactly how it feels to have cancer; support groups give survivors a chance to talk about their experiences with others living with cancer. The group experience may give them a sense of belonging that helps them feel less alone

and better understood. A variety of support groups and educational programs exist across the DC area at hospitals and in the community.[10]

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. A number of the city's working poor are uninsured (they have no insurance, and their income is between 250 percent and 350 percent of the Federal Poverty Level), or under-insured (they have insurance, but either their plan does not cover a particular service, or their deductible and/or copayment is high and unaffordable, making care inaccessible to them).

District residents with low income and no health insurance sometimes wait until a crisis arises to seek health care and then often seek help in hospital emergency rooms. Being diagnosed with cancer in the emergency room usually means that cancer is diagnosed at a later stage, when the chances of survival are slimmer and the treatment required is more extensive and expensive.

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 percent 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.

Mirroring the national landscape, a gap also exists in the availability of post-treatment survivorship programs that provide clinical care and address the four domains recommended by the IOM. While there are several options for follow-up care for pediatric cancer survivors in DC, few options exist for survivors of adult-onset cancers.

Survivorship Care Plans are not routinely provided to DC cancer survivors and their other healthcare providers. Patients and providers are often unaware of post-treatment survivorship needs. Those who do receive SCPs typically receive them at the end of treatment, potentially contributing to further gaps in service provision.

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.

Rehabilitation for Cancer Survivors

Many cancer survivors experience physical impairments and disabilities that affect their quality of life; for those people, cancer rehabilitation can play an integral role in

maximizing physical, psychological, and social well-being.[11]

The impairments and deficits that can arise in a patient's cancer experience depend on the organ involved, the impact and toxicities of cancer treatments, and pre-existing deficits.

Common physical impairments include muscle weakness, edema, reduced range of motion in the joints, swallowing difficulties, memory loss, aphasia (loss of the ability to speak or understand speech), and bone instability due to metastases. These impairments may bring pain, fatigue, weakness, loss of mobility, incontinence, peripheral neuropathy, fibrosis (thickening and scarring of connective tissue), and greater dependence on others.

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 in an effort to improve the quality of life.[12]

Depending on the patient's needs, one of four types of cancer rehabilitation may be appropriate:[13]

- **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 palliative therapy might also help keep joints from contracting and might prevent unnecessary deterioration from inactivity.[14]

Rehabilitation therapies are targeted to different types of cancer and are adapted to the specific needs of the individual, identifying and tailoring 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 and multiple myeloma 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. If a melanoma and head & neck cancer survivor has excessive scar tissue, a rehabilitation specialist may provide manual therapy techniques and scar massage to restore joint mobility and flexibility. If a gastrointestinal and ovarian cancer survivor's chief problems are fatigue and weak abdominals, a rehabilitation specialist may prescribe lumbar stabilization exercises for strengthening and endurance training.

Locally Available Rehabilitation

DC cancer patients can receive rehabilitation services in any of the 11 area hospitals that provide cancer care, but MedStar National Rehabilitation Hospital focuses exclusively on rehabilitation. That institution has a collaborative arrangement with MedStar's Washington Cancer Institute to improve rehabilitative care for cancer patients. Outpatients can also receive rehabilitation care and therapy closer to home through the MedStar National Rehabilitation Hospital and Networks.

Physicians and rehabilitation specialists work as a team to provide high-quality care throughout the continuum of care at the MedStar National Rehabilitation Hospital and Networks. In order to restore the patient's normal functions as much as possible, it is important to provide early rehabilitation targeted to the patient's needs. An assessment by the treating physicians—the medical, surgical, and radiation oncologist, physiatrist (a physician specializing in physical medicine and rehabilitation), and rehabilitation specialists—will determine the best treatment regimen for a patient.

The challenge for rehabilitation professionals is to spread awareness about the benefits of cancer rehabilitation. 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.[15] 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 to begin collecting data on where cancer rehabilitation services are available and how people can find them locally.

Survivorship
Goal and Objectives

GOAL: Increase access to follow-up care, reduce recurrence, and improve the overall quality of life for the District's cancer survivors.

Objective 1: Analyze and report on the current state of survivorship needs, including medical, psychosocial, financial, nutrition, transportation, and rehabilitation needs for District resident survivors.

Steps to achieve objective:

1. Convene stakeholder taskforce to organize, engage other proposed members (public health researchers, etc.), and devise work schedule.
2. Obtain useful information and lessons learned for future assessment efforts by examining previous District-specific findings (2010 DCCC survivor focus groups), and national survivorship data collection efforts such as:
    a. George Washington Cancer Institute (GWCI)/LIVE**STRONG** survey
    b. IOM report: *Lost in Transition: From Cancer Patient to Cancer Survivor*
    c. President's Cancer Panel report
    d. Centers for Disease Control (CDC)/Lance Armstrong Foundation (LAF) National Action Plan
    e. CDC/American Cancer Society (ACS)/GWCI National Cancer Survivorship Resource Center findings
3. Informed by previous assessments, design and implement needs assessment plan, possibly to include surveys and focus groups for stakeholders, if information gaps remain.
4. Collect information from District cancer centers on current services, as well as from nationally recognized centers for benchmarking.
5. Organize and analyze the data collected, comparing needs to the services and supports currently provided by District programs.
6. Produce report.

Measurement:

1. Milestones and process measures to be developed by taskforce

Timeframe: 2 years

Objective 2: Utilizing national standards, establish District-wide comprehensive standards of care for survivorship programs, and subsequently educate providers on these standards.

Steps to achieve objective:

1. After initiating the survivorship needs assessment, convene stakeholder taskforce to organize, engage other proposed members (oncology center team members, primary care providers, etc.), and devise work schedule.
2. Collect and assess existing care planning tools (local and national) for key elements.
3. Collect existing national standards (Commission on Cancer), guidelines (*National Comprehensive Cancer Network* [*NCCN]* etc.), and quality measures.

4. Analyze the collected data and agree on standards of care.
5. Develop dissemination plan and, with the assistance of health educators, an education plan for specific target audiences (oncology team staff, navigators, primary care providers, etc.), including identification of funding resources.
6. Implement plans and study the penetration of the standards and their impact for continual improvement.
7. Produce report on penetration and impact.

Measurements:

1. Milestones and process measures to be developed by taskforce, including pre- and post-knowledge assessments for educational initiatives

Timeframe: 2 years for implementation, 4 years with inclusion of follow-up assessments

Objective 3: Educate survivors, families, and caregivers on survivorship issues and appropriate standards for follow-up care.

Steps to achieve objective:

1. Upon completion of survivorship needs assessment, convene stakeholder taskforce to organize, engage other proposed members (public health educators, etc), and devise work schedule.
2. Utilizing state of survivorship report and comprehensive standards of care, identify target audiences and develop a culturally-aware educational plan, possibly to include a conference and small-group learning initiatives.
3. Organize an implementation plan with timeline and resource development.
4. Implement educational initiatives and assess impacts for continual improvement.

Measurements:

1. Milestones and process measures in plan development to be decided by taskforce, including pre-and post-knowledge assessments for educational initiatives

Timeframe: 2 years

Objective 4: Develop a strategic plan to address survivorship needs.

Steps to achieve objective:

1. Convene stakeholder taskforce to organize, engage other proposed members, and devise work schedule.
2. Examine the District's current regulatory and resource environment specific to survivorship issues.
3. Using state of survivorship report and standards of care, develop a strategic plan to address economic and non-economic barriers and challenges, including costs for implementation.
4. Report out strategic plan for DCCC membership and staff.

Measurements:

1. Milestones and process measures in plan development to be decided by taskforce

Timeframe: 2 years (after completion of Objective 2)

Tobacco-related Cancers

- Lung cancer is the leading cause of cancer death in the U.S. for both men and women. (American Cancer Society)
- In the US, tobacco use is responsible for nearly 1 in 5 deaths annually; this equals about 443,000 deaths each year. (American Cancer Society)
- In the District, Black males are at the highest risk for smoking-related cancers. (DC Cancer Registry)
- Reductions in the number of people who smoke or consume smokeless tobacco could prevent most of the estimated 30,200 new cases and 7,800 deaths from oral cavity and pharynx cancers in the U.S. (Centers for Disease Control and Prevention)

Tobacco use is responsible for nearly 1 in 5 deaths in the US, about 443,000 early deaths each year.[1] For both men and women, the overwhelming number of lung cancers is caused by cigarette smoking. However, several other forms of cancer can also be attributed to smoking, including cancer of the oral cavity, pharynx, larynx, esophagus, bladder, stomach, cervix, kidney, and pancreas, as well as acute myeloid leukemia.[2]

Most research on tobacco-related cancers has focused on cancers of the oral cavity and pharynx, esophagus, larynx, and lung and bronchus. Tobacco plus heavy alcohol consumption increases the chance of developing these cancers. Men have a higher incidence of these cancers than women. Tables 1 and 2 present the 2012 estimated new cancer cases and deaths by gender.[3]

Table 1. Estimated New Cases of Select Tobacco-Related Cancers by Gender, US 2012

Cancer Site	All Genders	Male	Female
Oral Cavity & Pharynx	80,500	57,080	23,420
Esophagus	17,460	13,950	3,510
Larynx	12,360	9,840	2,520
Lung & Bronchus	226,160	116,470	109,690

Table 2. Estimated Deaths from Select Tobacco-Related Cancers by Gender, US 2012			
Cancer Site	**All Genders**	**Male**	**Female**
Oral Cavity & Pharynx	15,700	10,880	4,820
Esophagus	15,070	12,040	3,030
Larynx	3,650	2,880	770
Lung & Bronchus	160,340	87,750	72,590

Smokeless tobacco, also known as chewing tobacco or snuff, has been found to cause oral cancer. [4] These products increase the risk of developing cancer of the mouth and throat, esophagus, and pancreas.

Each year, about 3,400 non-smoking adults die of lung cancer as a result of breathing secondhand smoke. Also annually, secondhand smoke causes about 46,000 deaths from heart disease in people who are not current smokers.[5]

Tobacco-related Cancers in the District

In the District of Columbia, 16.2 percent of adults[6]—over 77,000 individuals—are current cigarette smokers, compared to the national median of 18.4 percent. This figure places the District 10th among states for smoking; however, DC ranks highest for deaths from all smoking-related cancers, for both men and women. Among adult District residents who smoke, the following demographic characteristics have been documented:[7]

- More men than women smoke (19.2 percent compared to 13.7 percent, respectively).
- Education appears to be a factor, with 27.2 percent of smokers having less than a high school education compared to 12.5 percent of those with more than high school.
- Smoking appears to decrease with age, with 23.8 percent of those 18-24 reporting they are smokers, compared to 14.9 percent for 25-44 year olds, 19.8 percent for 45-64 year olds, and 10.6 percent for those 65 and older.
- More African Americans (23.3 percent) and Hispanics (13.4 percent) are smokers than Whites (9.1 percent).

Of the roughly 650 cases of smoking-related cancers a year in the District, about 400 are lung cancer. However, smoking-related cancers and the risk for these cancers are not shared equally by all District residents. Black males carry the heaviest burden for smoking-related cancers. They have more than twice the incidence rate, as well as

significantly higher mortality rates for lung cancer than their White male counterparts. By contrast, for both White men and women, DC has the lowest lung cancer mortality rate of all states. Tables 3 and 4 show the comparative incidence and mortality rates for lung cancer by gender and race for District residents.

Table 3. Age-adjusted incidence rates by sex and race for lung/bronchus cancer diagnosed in 2008, DC residents

Race	Male & Female	Male	Female
All races	61.4	81.0	47.5
White	36.8	42.0	32.8
Black	74.1	105.5	53.4

Table 4. Age-adjusted mortality rates by sex and race for lung/bronchus cancer diagnosed in 2008, DC residents

Race	Male & Female	Male	Female
All races	52.2	73.2	38.6
White	39.3	54.9	26.7
Black	61.9	87.7	46.4

In addition to race, the incidence of smoking-related cancers has a geographical dimension. Table 5 shows that the rate of smoking-related cancers in the District is almost twice as high in some wards as in others.

Table 5. 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	11.70	12.55
7	65.87	8.44	11.33
8	74.77	13.58	15.19

(Note: For Tables 3-5, rates are per 100,000 persons and are age-adjusted to the 2000 US standard population.)

District Programs and Activities

A number of efforts in the District focus on preventing and stopping tobacco use. Tobacco settlement payments and high tobacco excise taxes support these efforts.

Attention has been paid to addressing the impact of media and tobacco industry promotions on individuals' decisions to smoke. Cessation activities have included telephone and in-person counseling and support as well as medical intervention. Significant headway has been made in the creation of smoke-free workplace environments in an effort to reduce exposure to secondhand smoke. The ban on smoking covers government as well as private worksites, schools, child care facilities, restaurants, retail stores, and recreational facilities.

Tobacco-related

Goal and Objectives

GOAL: Reduce disparities in tobacco use and tobacco-related cancer in the District.

Objective 1: Reduce the proportion of African American and Hispanic residents who are either adult smokers or middle and high school youth lifetime users by 10% of 2010 Behavioral Risk Factor Surveillance Survey (BRFSS) and Youth Risk Behavior Survey (YRBS) baselines.

Steps to achieve objective:

1. Convene task force to organize, engage other proposed members, and devise work and reporting schedules.
2. Develop, leverage resources for, and implement a data collection plan, possibly to include information from previous District-specific research or planning efforts, surveys and focus groups. The purpose is to assess knowledge, perceptions, and attitudes of the identified racial and ethnic communities about: tobacco use; tobacco's health and cancer risk factors; and measures to decrease initiation of tobacco use, limit exposure to tobacco smoke, and restrict minors' access to tobacco products.
3. Analyze information to develop message content for a targeted, recurring educational mass media campaign for African American and Hispanic adults and youths, utilizing a combination of broadcast and print media, to discourage tobacco use initiation and to promote cessation. Leverage resources and implement the campaign.
4. Monitor DC Department of Education standards and DC schools' activities related to tobacco use and health risks, and evaluate for engagement opportunities in order to ensure and improve quality of those standards and activities.
5. Work with community coalitions and organizations to examine existing information to organize and implement a grassroots information campaign for community mobilization for desired policy change. Campaign to include select mass media events and presentations to neighborhood and ward-level groups and associations on topics such as tobacco retailer compliance with laws restricting youth sales.
6. Collaborate with community coalitions and organizations in the design and implementation of governmental engagement and policy plans to support and expand enforcement of minor-access laws, increase the tax on cigarettes, include small cigars in the definition of cigarettes, and equalize tax treatment for other tobacco products with cigarettes.
7. Prepare report for general DCCC membership and task force use for strategic planning.

Measurements:

1. BRFSS and YRBS data
2. Metropolitan Police Department (MPD) data
3. Process measures and milestones to be determined by workgroup

Timeframe: 3 years for cigarette tax increase, 5 years for equalizing tax treatment for other tobacco products

Objective 2: Increase venues covered by tobacco-use restrictions or bans above 2010 baseline, which includes restaurants, bars, retail locations, and indoor places of employment.

Steps to achieve objective:

1. Convene task force to devise work plan and reporting schedules.
2. Utilize analysis of available information to organize and implement a grassroots information campaign for community mobilization for desired policy change, including select mass media events and presentations to neighborhood and ward-level groups and associations on topics such as current local tobacco-use restrictions and their health impacts.
3. Design and implement governmental engagement and policy plans to apply tobacco-use restrictions to venues such as public housing, substance abuse treatment facilities, and universities.
4. Prepare report for general DCCC membership and task force use for strategic planning.

Measurements:

1. Process measures and milestones to be determined by workgroup, to include related local bills introduced, local bills successfully passed into law, and local regulatory changes

Timeframe: 2 years for regulatory changes, 4 years for those requiring legislative action

Objective 3: Increase District policies addressing tobacco product promotion and marketing above 2010 baseline, which includes advertising near schools, couponing, samples, and point-of-purchase ads.

Steps to achieve objective:

1. Convene task force to devise work plan and reporting schedules.
2. Examine other local jurisdictions and research related to local tobacco product promotion and marketing in order to devise a set of desired controlling policies and regulations that are in keeping with federal Constitutional protections.
3. Utilizing the previous information analysis, organize and implement a grassroots information campaign for community mobilization for desired policy change, including select mass media events and presentations to neighborhood and ward-level groups and associations on topics such as the audience for and impacts of current local tobacco product advertising and promotions.
4. Design and implement governmental engagement and policy plans to impact local tobacco product promotion and marketing.
5. Prepare report for general DCCC membership and task force use for strategic planning.

Measurement:

1. Process measures and milestones to be determined by workgroup, to include related local bills introduced, local bills successfully passed into law, and local regulatory changes

Timeframe: 2 years for regulatory changes, 4 years for those requiring legislative action

Objective 4: Increase District funding to CDC-recommended levels for local public and/or non-profit tobacco-control programs.

Steps to achieve objective:

1. Convene task force to devise work plan and reporting schedules.
2. Design and implement governmental engagement and policy plans to impact the allocation of local funds levels in order to achieve CDC recommendations for both total funding and intervention- and activity-level allocations.
3. Prepare report for general DCCC membership and task force use for strategic planning.

Measurement:

1. Process measures and milestones to be determined by task force

Timeframe: 5 years

Glossary

African American: Generally refers to descendants of the African diaspora or Africans brought to America to work as slaves. (Also, variably, the term "Black" is used to refer to this group.)

African descent: Persons whose ancestral homes or ancestors are African. May include African Americans, as well as persons who do not self-identify as African American, such as those from Senegal, Ghana, etc.

Barriers: Those factors or conditions, whether physical, emotional, attitudinal, or environmental, that diminish access to screening, diagnosis, treatment, and aftercare. Some examples are poverty, lack of a regular health care provider, lack of insurance, unavailability of screening and other services, among others.

Black: A term that may refer to African Americans as well as others of African descent. Became widely used beginning in the 1960s with the emergence of the US civil rights and other liberation movements.

BRFSS (Behavioral Risk Factor Surveillance System): A state-based system of health surveys that collects information on health risk behaviors, preventive health practices, and health care access; the BRFSS is primarily related to chronic disease and injury. [www.cdc.gov/brfss/about.htm]

Cancer: A term for diseases in which abnormal cells divide without control and can invade nearby tissues. Cancer cells can also spread to other parts of the body through the blood and lymph systems. There are several main types of cancer. Carcinoma is a cancer that begins in the skin or in tissues that line or cover internal organs. Sarcoma is a cancer that begins in bone, cartilage, fat, muscle, blood vessels, or other connective or supportive tissue. Leukemia is a cancer that starts in blood-forming tissue such as the bone marrow, and causes large numbers of abnormal blood cells to be produced and enter the blood stream. Lymphoma and multiple myeloma are cancers that begin in the cells of the immune system. Central nervous system cancers begin in the brain and spinal cord. Cancer is also referred to as malignancy. [www.cancer.gov/dictionary]

Cancer Control Plan Stakeholder Group: A diverse group of individuals representing the clinical, community, research, and special populations concerned with or invested in the development of the DC Cancer Control Plan. A stakeholder group was convened to address each specific cancer and overarching issue contained in the Plan. Each stakeholder group reviewed data related to specific cancers and developed the goals and objectives at the heart of the DC Cancer Control Plan.

Centers for Disease Control and Prevention (CDC): The United States' national public health institute and a federal agency under the US Department of Health and Human Services. The CDC works to protect public health and safety by providing information to enhance health decisions, and it promotes health through partnerships with state health departments and other organizations. The CDC focuses national attention on developing and implementing disease prevention and control, environmental health, occupational safety and health, health promotion, injury prevention, and education activities designed to improve the health of the people of the United States.

Citywide Patient Navigation Network: Across the District, a network of local patient navigators who work collaboratively with other members of the health care community to provide support for cancer patients and their families throughout the cancer experience, from screening to end-of-life. The system particularly targets medically underserved populations, such as minorities and those without insurance or who receive publicly funded insurance coverage. The Network is a project of the DC Cancer Consortium; it is affiliated with The George Washington University Cancer Institute.

Clinical breast examination (CBE): A physical exam of the breast performed by a health care provider to check for lumps or other changes.

Clinical trial: A type of research study that tests how well new medical approaches work in people. These studies test new methods of screening, prevention, diagnosis, or treatment of a disease. Also called a clinical study.

Clinical Trial Phase: A part of the clinical research process that answers specific questions about whether treatments that are being studied are effective and safe. Phase I trials test the best way to give a new treatment and the best dose. Phase II trials test whether a new treatment has an effect on the disease. Phase III trials compare the results of people taking a new treatment with the results of people taking the standard treatment. Phase IV trials are done using thousands of people after a treatment has been approved and marketed, to check for side effects that were not seen in the Phase III trial.

Cultural competence: The ability to effectively interact with people who come from different cultures. Four skills areas make up cultural competence: awareness, attitude, knowledge, and cross-cultural skills (or ability to translate from one culture to another).

DC Cancer Answers: A cancer resource telephone line/service created by the DC Cancer Consortium, operated in partnership with the American Cancer Society (ACS), The George Washington University Cancer Institute, and the Citywide Patient Navigation Network. DC Cancer Answers may be reached at (202) 585-3210, or www.dccanceranswers.org

DC Cancer Consortium (DCCC): A consortium consisting of more than 75 organizations dedicated to reducing the disproportionately high rates of cancer deaths and diagnoses in the District.

Members include cancer centers, cancer control partner organizations, research institutions, advocates, and others. A grant-making 501(c)(3) public charity, the Consortium leverages its role as facilitator, convener, and steward of the DC Cancer Control Plan. The Consortium provides a comprehensive clearinghouse for information from public and private health care professionals about cancer services throughout the Washington region. Through professional and organizational development programs, the Consortium also works to build capacity for community-based organizations and partners. www.dccanceranswers.org

DC Cancer Control Plan: A plan developed in collaboration with stakeholders including cancer centers, community-based organizations, advocacy organizations, and cancer survivors. The Plan outlines the goals and objectives for the District and helps guide cancer control activities in the areas of prevention, improved treatment, survivorship support, health equity, and continued research. The Plan also provides a guideline for the allocation of resources. Copies of the Plan are available on the DC Cancer Consortium website: www.dccanceranswers.org

DC Cancer Registry: A mandated program that requires the reporting of cancer diagnoses and/or treatment to the Director of the DC Department of Health. The Registry provides the local data used in the development of the Cancer Control Plan, special outreach, and other efforts affecting cancer prevention, diagnosis, and treatment of District residents. Hospital records are the main source of data for the Registry. The Registry captures epidemiological data on cancer, conducts epidemiological research, and analyzes cancer data and trends. It is part of a national program of state-based cancer registries, and part of the Community Health Administration of the Department of Health.

DC Health Care Alliance (DCHCA or Alliance): A public program for low-income District residents who are uninsured and not eligible for other programs, such as Medicaid. Health benefits are provided by private doctors, clinics, and hospitals. DCHCA is administered by Chartered Health Plan, Inc. and United Healthcare. Health benefits include screening for breast cancer (women), HPV, prostate cancer, and colorectal cancer (members 50 and older) as well as smoking cessation counseling.

DC Department of Health: The lead public health agency charged with promoting and protecting the health, safety, and quality of life of residents, visitors, and those doing business in the District of Columbia. It is responsible for identifying health risks; educating the public; preventing and controlling diseases, injuries, and exposure to environmental hazards; promoting effective community collaborations; and optimizing equitable access to community resources.

End-of-life care: Care provided to those with a terminal illness or terminal condition that has become advanced, progressive, and incurable.

Family history: A clinical history of family illness and disease designed to determine a

patient's relative risk of specific cancers and to help determine the timing and frequency of screening.

FAP: Familial Adenomatous Polyposis, a rare, inherited condition that causes extra tissue (polyps) to form in the upper part of the large intestine (colon) and upper part of the small intestine (duodenum). Untreated, the polyps in the colon almost always become cancerous by age 40. [http://www.mayoclinic.org/familial-adenomatous-polyposis/]

Genetic pre-disposition: An inherited risk of developing a disease or condition. It does not mean that a person will develop the disease, but that the person's risk may be higher than that of the general population. For example, individuals with a family history of colorectal cancer may have a predisposition to developing the disease.

Hard-to-serve: Individuals or specific groups that face barriers that make it difficult for providers to meet their health needs. Barriers might include, for instance, limited English language proficiency, cultural or religious beliefs, lack of knowledge, etc.

Health care reform: A general rubric used for discussing primarily governmental policy changes that affect health care delivery. The phrase is often used to refer to the Patient Protection and Affordable Care Act, signed into law on March 23, 2010, and the Health Care and Education Reconciliation Act of 2010, signed on March 30. The laws generally seek to achieve universal coverage and expand preventive care, among other services.

Health disparities: Preventable differences in the burden of disease, injury, violence, or opportunities to achieve optimal health that are experienced by socially disadvantaged populations. Populations can be defined by factors such as race or ethnicity, gender, education, income, disability, geographic location, or sexual orientation. Health disparities result from multiple factors such as poverty, environmental threats, inadequate access, etc.

Health equity: The distribution of health resources in a way that reduces the disproportionate burden of disease on particular populations, such as minorities.

Healthy People 2020: A government-sponsored statement of national objectives in 28 focus areas, including cancer, designed to identify and reduce the most significant preventable health threats within the United States. The overall goals are to increase the quality and length of life and to eliminate health disparities.

HEDIS (Health Effectiveness Data and Information Set): A tool used by more than 90 percent of US health plans to measure performance on health care and service delivery. HEDIS consists of 76 measures across five domains of care.

High-risk populations: Populations with characteristics that make them predisposed to, or at greater risk for, an illness (such as cancer) than the general population. Characteristics can include race, gender, obesity, age, etc.

Hispanic: Originally referred to the Spanish-speaking people and culture of Spain and Portugal; now expanded to include people of Latin America, particularly those living in the US.

HPV (human papillomavirus): A type of virus that can cause abnormal tissue growth (for example, warts) and other changes to cells. Infection for a long time with certain types of HPV can cause cervical cancer. HPV may also play a role in some other types of cancer, such as anal, vaginal, vulvar, penile, oropharyngeal, and squamous cell skin cancers.

IBD (inflammatory bowel disease): A broad term that describes conditions with chronic or recurring immune response and inflammation of the gastrointestinal tract. The two most common inflammatory bowel diseases are ulcerative colitis and Crohn's disease.

Incidence rate: The number of new cases in a population in a specified time period. Usually counted as cases per 100,000 persons in a geographic area based on census population count.

Latino: A person of Latin American origin living in the US.

Minorities: A sociological category within a demographic. It is a category that is differentiated and defined by the social majority group. Categories may be characterized by ethnicity, race, income, or sexual orientation, among others.

Mortality rate: The number of deaths in a population in a specified time period. Usually counted as deaths per 100,000 persons in a geographic area based on census population count.

NHANES (National Health and Nutrition Examination Survey): A program of studies designed to assess the health and nutritional status of adults and children in the United States. The survey is unique in that it combines interviews and physical examinations.

Obesity: The state of being well above the ideal body weight for a person's age and height. Medically, people are considered obese if their weight is 20 percent or more above ideal weight. Obesity has been identified as a risk factor for a number of cancers, including postmenopausal breast, endometrial, esophageal, kidney, colon, and prostate, among others.

Obesity Action Plan: The Obesity Action Plan 2010-2015, a plan initiated by the DC Department of Health to address overweight and obesity among District residents.

Pain management: A branch of medicine that employs an interdisciplinary approach for easing the suffering and improving the quality of life of those living with pain. A pain management team may include medical practitioners, clinical psychologists, physiotherapists, and nurse practitioners, among others. Treatment approaches may include pharmacologic measures, interventional procedures, physical therapy, and psychological measures such as biofeedback and cognitive behavioral therapy.

Palliative care: Specialized medical care for people with serious illnesses. It is focused on providing patients with relief from the symptoms, pain, and stress of a serious illness – whatever the diagnosis. The goal is to improve quality of life for both the patient and the family. Care is provided by a team of doctors, nurses, and other specialists who work together with a patient's other doctors to provide an extra layer of support. Palliative care is appropriate at any age and stage in a serious illness and can be provided along with curative treatment. (Center to Advance Palliative Care www.capc.org)

Pap smear test (Papanicolaou Test): A procedure in which cells are scraped from the cervix for examination under a microscope. The "Pap test" is used to detect cancer and changes that may lead to cancer, as well as other conditions (e.g., infection or inflammation) that are not cancer.

Patient navigation/navigators: An organization or system that helps patients and their families make informed decisions and access health resources, such as diagnostic testing, treatment options, palliative care, and other medical and support services.

SEER (Surveillance, Epidemiology and End Results Program): A source for cancer statistics in the United States. SEER collects information on incidence, prevalence, and survival from population-based cancer registries covering approximately 28 percent of the US population, then compiles reports on all of these, plus cancer mortality for the entire country. SEER is a program of the National Cancer Institute (NCI). (www.seer.cancer.gov)

Secondhand smoke: Environmental tobacco smoke that is inhaled involuntarily or passively by someone who is not smoking. Secondhand smoke has been linked to lung cancer.

Specially-impacted populations: Populations and subgroups that experience differences in incidence and/or mortality from the majority population. May also refer to differences in impact of specific policies or clinical practices.

Stakeholder: A person or organization with an interest in the success of the DC Cancer Control Plan and who contributes knowledge, data, or other intellectual property to support Plan development or implementation.

Steering Committee: The DC Cancer Control Plan Steering Committee was developed to make higher-level decisions about the process to revise the 2013-2018 DC Cancer Control Plan. It was charged with making recommendations to the DCCC Board of Directors for final approval of goals and objectives and endorsing priorities. The Steering Committee was designed to be of moderate size in order to be manageable.

The Steering Committee has been consulted as a group and individually for information, analysis, suggestions, and editing throughout the process. Steering Committee members were encouraged to become as involved in the revision process as time and interest allowed. For example, some Steering Committee members have

also participated in a DCCC stakeholder group.

Specific roles of the Steering Committee:

A. Planning oversight
B. Consultation as content knowledge experts
C. Endorsement and prioritization of Stakeholder recommendations

Surveillance: An epidemiological practice by which the spread of disease is monitored in order to establish patterns of progress. The main role of surveillance is to predict, observe, and minimize harm, as well as increase knowledge about which factors contribute to such circumstances. For example, the Behavioral Risk Factor Surveillance System (BRFSS) collects information on risky behaviors that may result in disease, as well as preventive health measures.

Survivor: A person who has received a diagnosis of cancer, from the time of diagnosis through the balance of his or her life.

Survivorship Care Plan: A treatment plan and a plan for care after a survivor is no longer in treatment. The Survivorship Care Plan should be integrated early in the treatment stage. This presents the first opportunity for the oncology team and the survivor to communicate about survivorship concerns and needs, identify and plan for anticipated long-term/late-term effects, design strategies for healthy behaviors, and discuss appropriate resources.

Underserved: A subgroup that has received lower access to health services and resources as compared with the general population. Examples include minorities, elderly, geographically isolated, limited English speaking, etc.

Underinsured: People who have insurance, but a) whose plan does not cover a particular service, or b) whose deductible and/or copayment is high and unaffordable, making health care inaccessible.

Uninsured: People who do not have insurance and whose income is more than 200 percent of the Federal Poverty Level (FPL), and therefore are not eligible for Alliance or Medicaid.

Unstaged: Cancer for which there is not enough information to indicate a stage.

Waiver: A device authorized by the Social Security Act that allows states to waive government-mandated requirements pertaining to Medicaid. Waivers are used to test new approaches, expand services, etc.

YRBSS (Youth Risk Behavior Surveillance System): The YRBSS monitors six types of health-risk behaviors that contribute to the leading causes of death and disability among youth and adults, including: behaviors that contribute to unintentional injuries and violence; sexual behaviors that contribute to unintended pregnancy and sexually transmitted diseases, including HIV infection; alcohol and other drug use; tobacco use; unhealthy dietary behaviors; and inadequate physical activity. YRBSS also measures the prevalence of obesity and asthma among youth and young adults. YRBSS includes a national school-based survey conducted by the CDC, as well as state, territorial, tribal, and local surveys

conducted by state, territorial, and local education and health agencies and tribal governments.

Acronyms

ACS –American Cancer Society
DCCC – District of Columbia Cancer Consortium
FPL – Federal Poverty Level - http://aspe.hhs.gov/poverty/12poverty.shtml/#guidelines
GWCI – The George Washington University Cancer Institute
IBD – Inflammatory Bowel Disease
NCI – National Cancer Institute
NIH – National Institutes of Health
LAF – Lance Armstrong Foundation

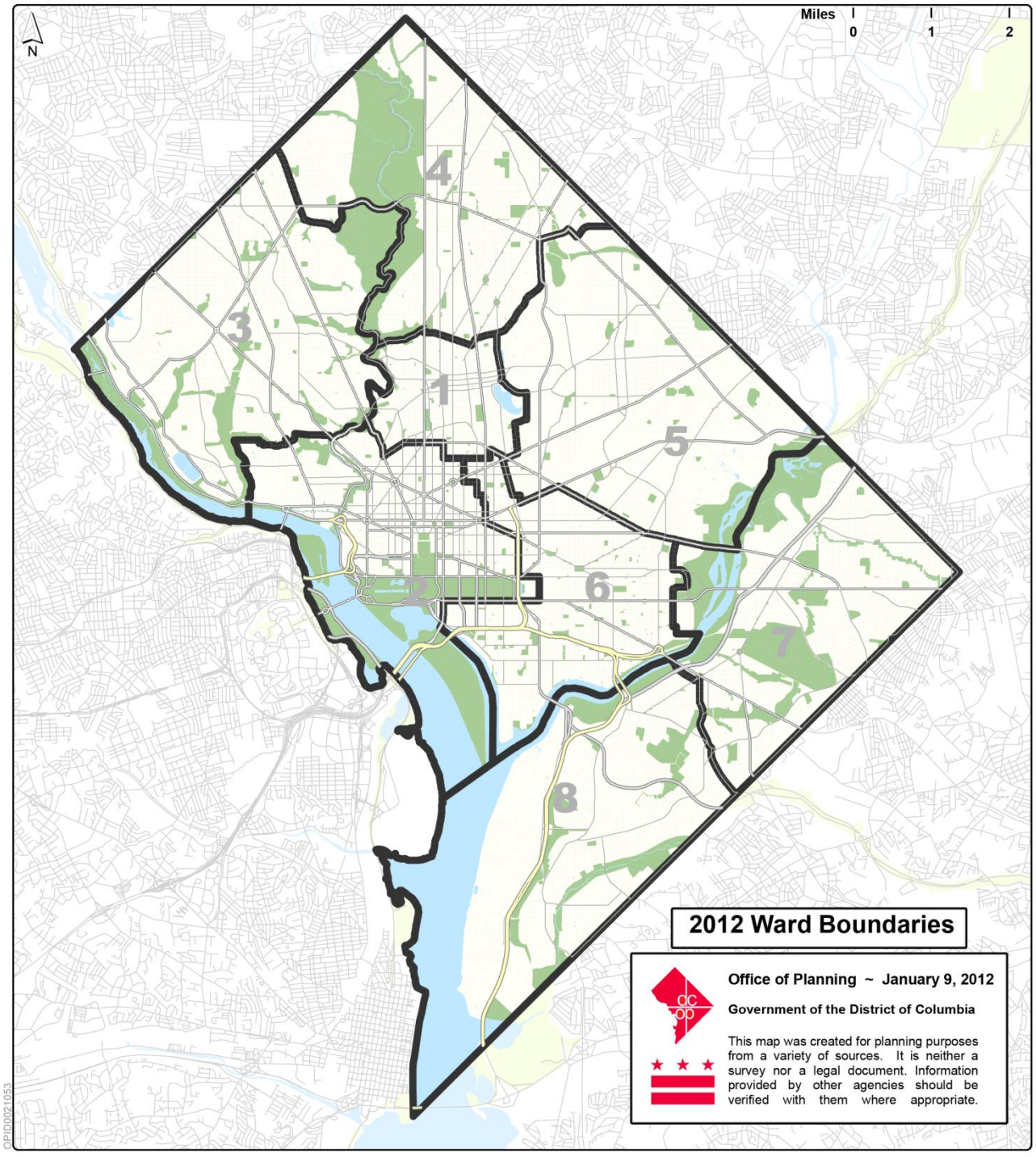
Appendices

Appendix 1 -Indicators of Well-Being, DC/Wards

Indicators of Well-Being, DC/Wards									
	All	**W1**	**W2**	**W3**	**W4**	**W5**	**W6**	**W7**	**W8**
Population: (2010)									
% African American	51	33	13	5.6	59	77	42	96	94
% Hispanic	9.1	21	9.5	7.5	19	6.3	4.8	2.3	1.8
% White	35	41	67	78	20	15	47	1.4	3.3
% of DC Residents > 50 Years of Age, by Ward		14,874 9%	16,700 10%	25,275 15%	27,006 16%	25,874 15%	20,038 12%	23,264 37%	16,919 9%
% Obese 2000		19	13	12	22	30	19	40	42
% Poverty rate 2005-2009	18	16	15	6.9	9.9	19	18	26	35
% <HS diploma 2005-2009	15	19	8.1	3.4	17	19	12	20	21
% Unemployment rate 2005-2009	9.2	7.2	4.0	3.4	7.6	13	8.4	19	17
Average Household Income	$115,016	$98,485	$190,692	$257,386	$116,668	$78,559	$120,526	$54,677	$44,076

Sources: 2010 US Population Count; NeighborhoodInfoDC.com – The Urban Institute

Appendix 2 - DC Ward Map



District of Columbia Ward Map

Appendix 3 - Hospitals with cancer programs

Accredited by the American College of Surgeons Commission on Cancer

George Washington University Hospital

900 23rd Street Northwest

Washington, DC 20037-2327

Phone: 202-715-4000

www.gwhospital.com

- Teaching Hospital Cancer Program
- 2010 Commission on Cancer Outstanding Achievement Award Recipient

Georgetown University Medical Center

Lombardi Comprehensive Cancer Center

3800 Reservoir Road Northwest

Washington, DC 20007-2113

Phone: 202-444-2000

www.georgetownuniversityhospital.org

- NCI-Designated Comprehensive Cancer Program

Howard University Hospital

Howard University Cancer Center

2041 Georgia Avenue Northwest

Washington, DC 20060-0002

Phone: 202-865-6100

http://huhealthcare.com/healthcare/hospital

- Teaching Hospital Cancer Program

Providence Hospital

1150 Varnum Street Northeast

Washington, DC 20017-2180

Phone: 202-269-7000

www.provhosp.org

- Teaching Hospital Cancer Program

Sibley Memorial Hospital

5255 Loughboro Road Northwest

Washington, DC 20016-2695

Phone: 202-537-4000

www.sibley.org

- Community Hospital Comprehensive Cancer Program
- 2009 Commission on Cancer Outstanding Achievement Award Recipient

Washington, DC Veterans Medical Center

50 Irving Street Northwest

Washington, DC 20422-0002

Phone: 202-745-8000

www.washingtondc.va.gov

- Veterans Affairs Cancer Program

MedStar Washington Hospital Center

Washington Cancer Institute

110 Irving Street Northwest

Washington, DC 20010-2975

Phone: 202-877-7000

www.whcenter.org

- Teaching Hospital Cancer Program

Walter Reed National Military Medical Center

8901 Wisconsin Avenue

Bethesda, MD 20889-5600

Phone: 301-295-4611

www.wrnmmc.capmed.mil

- Teaching Hospital Cancer Program

Other hospitals with cancer programs

United Medical Center

1310 Southern Avenue Southeast

Washington, DC 20032

Phone: (202) 574-6000

www.united-medicalcenter.com

Children's National Medical Center

111 Michigan Avenue Northwest

Washington, DC 20010

Phone: 202-476-5000

www.childrensnational.org

MedStar National Rehabilitation Hospital

102 Irving Street Northwest

Washington, DC 20010

Phone: 202.877.1000

www.nrhrehab.org

Appendix 4 -DC Cancer Consortium Board of Directors

John J. Lynch, MD, FACP, Chairman
Clinical Assistant Professor of Medicine, Georgetown University School of Medicine
Former Associate Medical Director, Washington Cancer Institute, MedStar Washington Hospital Center
Past President, District of Columbia Medical Society

Donald E. Henson, MD, Vice Chairman
Co-director of the Division of Cancer Control and Epidemiology
George Washington University Cancer institute

James "Jim" Butler, Treasurer
Consultant, Children's Health Services

Jack Sheahan, Secretary
President, Greater Washington Coalition for Cancer Survivors

James S. Cobey, MD, MPH, FACS
President, District of Columbia Medical Society

Elizabeth Carrott Minnigh
Attorney at Law, Buchanan Ingersoll & Rooney PC

Anne Marie O'Keefe, JD, PhD
Associate Professor, School of Community Health & Policy, Morgan State University

Joan T. Panke, MA, RN, AHCPN
Consultant, Palliative Care

B. P. Walker, MD, MBA
Dean, Health Sciences, Department Chair and Program Director, Health Sciences, Graduate School USA (GS)

Appendix 5 -DC Cancer Consortium Staff

Executive Staff

YaVonne Vaughan
Executive Director

David Castañeda
Deputy Director and Chief Operating Officer

Staff

Stuart Berlow
Policy Manager

Courtney Clyatt
Director, Program Monitoring and Evaluation

Michele Coleman
Director of Corporate and Strategic Partnerships

Lisa Bass Cooper
Communications Manager

Derrick Faison
Project Manager

Appendix 6 - Steering Committee and Stakeholders

Chiledum Ahaghotu, MD, Howard University Hospital

Kimberly Bell, Center for Strategic Health Alliances

Sherry Billings, DC Department of Health

Marc Boisvert, MD, Washington Cancer Institute

Stacy Bradner, MBA, PMP, Howard University Cancer Center

Ray Michael Bridgewater, Assembly of Petworth

Jacquetta Brooks, Mautner Project

Leslie Calman, PhD, Mautner Project

Cindi Carney, RN, Capital Hospice

Phil Carpenter, MDiv, Hospice Foundation of America

Dana Casciotti, PhD, Cancer Prevention and Treatment Fund

Danielle Chapman, RN, DC Public Schools

Toroitich Cherono, Smith Center for Healing and the Arts

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Tesha Coleman, Capital Breast Care Center

Aysha Corbett, MD, Unity Health Care

Tim Cox, Washington Home and Community Hospices of DC, MD, VA

John Davies-Cole, PhD, MPH, DC Department of Health

Charles Debnam, CTTS, Breathe DC

Brandel France de Bravo, MPH, Cancer Prevention Treatment Fund

Gretchen Derewicz, American Cancer Society

Rachelle Dixon, Mautner Project

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Yvonne Francis PT, MBA, CMLDT, National Rehabilitation Center

Wendy Gadson, VITAS Innovative Hospice Care of Greater Washington

Annette Galassi, RN, National Cancer Institute

Canary Girardeau, Summit Health Institute for Research and Education

Caroline Goncalves, Campaign for Tobacco Free Kids

Carol Gresenz, MD, RAND Health

Taryn Habberley, MA, DC Dental Society

Ron Hall, Howard University Hospital

Donald Henson, MD, DC Cancer Consortium (DCCC)

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Deborah Hughes, DDS, Prince George's County Department of Health

Jonathan Hwang, MD, Washington Cancer Institute

Elizabeth Ide, MA, Mautner Program

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Stephen Jefferson, DC Cancer Consortium Member

Mary Jane Joseph, RN, Primary Care Coalition

Heather R. Kapp, MPH, LICSW, Washington Cancer Institute

Adeyinka Layiemo, MD, MPH, Howard University Hospital

John Lazar, American Cancer Society

Jennifer Leonard, JD, MPH, The George Washington University School of Public Health and Health Services

Paul Levine, MD, The George Washington University School of Public Health and Health Services

Diane Lewis, ALTA Consulting Group, Inc.

John Lynch, MD, DC Cancer Consortium

Jeanne Mandelblatt, MD, MPH, Lombardi Cancer Center

Deirdre McGinley-Gieser, American Institute for Cancer Research

Margo Michaels, MPH, Education for Network to Advance Cancer Clinical Trials

Candice Mitchell, DDS, Howard University School of Dentistry

Tia Montgomery, Howard University Cancer Center

Iris Jeffries Morton, DDS, Howard University School of Dentistry

Theresa Morrow, Women Against Prostate Cancer

J. Cameron Muir, MD, Capital Hospice

LaQuandra Nesbitt, MD, MPH, DC Department of Health

Ify Nwabukwu, African Women's Cancer Awareness Association

Lavdena Orr, MD, Chartered Health Plan

Carole O'Toole, Smith Center for Healing and the Arts

Mary Grace Pagaduan, MPH, Susan G. Komen Race for the Cure

Joan Panke, RN, Anne Arundel Medical Center

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