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TECHNICAL REPORT

# Monitoring Cancer Outcomes Across the Continuum

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Data Synthesis and Analysis for the  
District of Columbia

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Sponsored by the DC Cancer Consortium

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## Summary

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To help inform future priority-setting by the DC Cancer Consortium (DCCC) and other entities concerned with the burden of cancer in the District of Columbia, as well as local government policymaking around cancer more broadly, this report synthesizes available data (including information in published reports, as well as the results of new data analyses) regarding cancer-related outcomes among District residents. A comprehensive understanding of cancer in the District requires information across the continuum of cancer prevention, treatment, and outcomes, and, moreover, an understanding of the variability in these outcomes for different subgroups of District residents, such as those defined by age, race, gender, location of residence within the District, or type of cancer. Monitoring and tracking of outcomes across the continuum of cancer prevention and treatment and by population subgroup over time is likewise essential to establishing an adequate evidence base for informed decisionmaking.

This report provides information on as wide a range of outcomes as permitted by available data across the continuum of cancer prevention and treatment, by population subgroup and over time. Data sources used in this report include the Behavioral Risk Factor Surveillance System (BRFSS), the National Cancer Database, the Centers for Disease Control and Prevention (CDC) and National Cancer Institute Wide-Ranging Online Data for Epidemiologic Research database, and the American Community Survey. The report provides background information on basic sociodemographic characteristics of District residents; describes behaviors related to cancer prevention, including tobacco use and physical activity, and use of services, such as human papillomavirus vaccination and screening tests for breast, cervical, colorectal, and prostate cancers; describes cancer incidence and mortality; profiles use of first courses of cancer treatment services received among those diagnosed with cancer; and summarizes information about the capacity of the local health care delivery system in the District to provide cancer prevention and treatment services to those who are publicly insured.

Key findings include the following:

### *General Access to Care*

- In 2010, 6.5 percent of adult District residents reported that they lacked health insurance coverage, compared with 15.1 percent of adults across the United States.
- Although District adults reported significantly fewer barriers to health care access than adults nationwide, access to health care providers or services remains a challenge for many District residents.
  - 13.6 percent of District adults reported not having a personal health care provider in 2010, 19.9 percent reported not having a routine checkup in the past year, and 8.9 percent reported missing care in the last 12 months because of cost.
- Black and Hispanic adults in the District were more likely to report being uninsured compared with white District residents in 2010, and both groups were more likely to report missing care because of cost. Blacks were more likely to have had a routine checkup in the last year compared with whites, however.

### *Primary Prevention*

- Overall, compared with adults nationally, District adults are less likely to report smoking, binge drinking, or heavy drinking and slightly more likely to report exercising.
- The rate of smoking is significantly higher, and the rate of exercise is significantly lower, among black District residents than among white residents.

- Self-reported smoking, alcohol use, and exercise rates among District residents appear stable from 2003 to 2010.

### ***Secondary Prevention***

- Overall, self-reported rates of cancer screening among District residents are higher than those among adults nationwide. For example, 90 percent of women ages 21 to 64 report receiving a Pap test within the last three years, compared with 84 percent of women nationwide, and 86.5 percent of District women ages 50–74 report having had a mammogram within the last two years, compared with 80 percent nationally.
- Although rates of breast and cervical cancer screening are similar across racial and ethnic groups in the District, black residents are less likely to report being screened for colorectal cancer than white residents.
- Women are less likely to report screening for colorectal cancer, and younger men in the recommended age range are less likely to report prostate and colorectal screening compared with older men.
- Cervical, colorectal, and prostate screening rates are significantly lower among uninsured residents.
- Self-reported cancer screening rates among District residents appear stable from 2003 through 2010.
- Additional data, not based on individual self-report, would provide a useful counterpoint to available BRFSS estimates.

### ***Cancer Incidence and Mortality***

- Overall, age-adjusted cancer incidence in the District is similar to that for the United States as a whole, while mortality is higher. In keeping with the rest of the nation, cancers with highest incidence and mortality in the District are colorectal, lung and bronchus, prostate, and breast.
- Cancer incidence and mortality among black residents of the District are dramatically higher than for white residents of the District. Higher overall cancer incidence and mortality among black District residents is attributable to a higher incidence of colorectal, lung and bronchus, and prostate cancers, and higher rates of mortality for all common cancers, than among white residents.
- Cancer incidence and mortality among white District residents are lower than they are among whites nationally. In contrast, cancer incidence among black District residents is comparable with that for blacks nationally, while cancer mortality among black District residents is higher than it is for blacks nationally.
- Overall cancer incidence rates remained stable in the District from 2005 to 2009, as they did nationally.
- Although cancer mortality appears to have declined slightly faster in the District than it has nationally between 2005 and 2009, mortality rates in 2008 among District residents still exceeded those in the United States.

### ***Cancer Treatment***

- As many as 40 percent of the newly diagnosed cancers treated in the District may be among non-District residents.
- 9 percent of the District population is Hispanic, whereas 2 percent of patients seeking their first course of cancer treatment in 2009 were Hispanic. Data on the number of new cancer cases

among Hispanic residents of the District, as well as data on patterns of seeking cancer treatment outside the District, would be useful for better understanding potential issues around access to cancer treatment among Hispanics.

- From 2006 to 2009, the proportion of black newly diagnosed patients with colorectal, lung and bronchus, and prostate cancers seeking their first course of treatment increased, mirroring increases in the number of cases for these cancer sites among black District residents during that time period.
- Approximately 2 in 5 District residents who are diagnosed with cancer are age 65 and older. Correspondingly, approximately 40 percent of patients seeking their first course of cancer treatment are covered by Medicare.
- Although approximately 1 in 5 District residents is uninsured, is covered by Medicaid, or receives care from the DC Alliance, only 6 percent of cancer patients seeking their first course of treatment are uninsured or on Medicaid. Data on the number of new cases of cancer by insurance status (any coverage, type of coverage) are important for better understanding potential issues around access to cancer treatment among uninsured District residents and those enrolled in Medicaid.
- Black patients, and those who are uninsured or covered by Medicaid, appear to be more likely to present for first course of treatment with Stage IV cancers than white patients and those who are privately insured. Delayed diagnosis and first treatment are associated with poorer cancer survival rates.
- Available data are insufficient for assessing the quality of cancer treatment delivered to patients in the District overall or disparities in quality of care across patients of different races or other characteristics.

### ***Survivorship and End-of-Life Care***

- Additional study is needed to examine the capacity for comprehensive case management services for cancer survivors in the District, especially for residents covered by Medicaid and Alliance.
- Little data are available on quality of survivorship and end-of-life care for cancer patients in the District overall or by racial or ethnic subgroups.

### ***Health System Capacity***

- While available data suggest that capacity for screening is largely adequate for individuals with insurance coverage, capacity for diagnostic and treatment care is limited for the uninsured, those enrolled in DC Alliance, and those with Medicaid coverage.
- Actual availability of diagnostic and treatment services is likely to be considerably more limited than provider lists suggest. Once an individual has a positive screening result, patient navigators often must work extensively to find a clinical site that will take a patient with Medicaid managed care or Alliance coverage.
- Navigation services, such as those provided by the Citywide Patient Navigation Network, play a vital role in helping patients receive needed care across a fragmented system in which availability of care varies by insurance type and clinical sites.
- In most cases, providers try to enroll eligible individuals (who are uninsured or covered by Medicaid managed care organizations or Alliance) diagnosed with cancer in fee-for-service (FFS) Medicaid. However, enrollment may be challenging for patients whose initial screening tests are conducted outside of Project WISH (Women Into Staying Healthy—a program funded by the CDC to provide free cancer education, screening, and diagnostic services to women who are uninsured or underinsured or who have family incomes less than 250 percent of the federal poverty level).

- Medicaid FFS enrollees have many more options for care than Medicaid managed care enrollees. However, transitioning from managed care to FFS Medicaid may result in disruptions in care, including changes in providers and drug formularies.
- Few providers and facilities offering cancer treatment, palliative care, and end-of-life care are located in Wards 7 and 8.

The findings above reveal disparities in cancer-related outcomes between black and white District residents across the continuum. First, black District residents are more likely than white residents to be uninsured. Lack of insurance is associated with lower rates of routine cancer screening among asymptomatic patients and may delay care for patients experiencing early symptoms of cancer. In addition, the rate of smoking is significantly higher, and the rate of exercise is significantly lower, among black District residents than among white residents, placing black residents at higher risk of the most common cancers. Further, black residents are less likely to report being screened for colorectal cancer than white residents. While rates of breast and cervical cancer screening are similar across racial and ethnic groups in the District, national studies of self-reported screening data suggest that black and Hispanic survey respondents may overreport screening behaviors more than whites do (Rauscher, Johnson, et al., 2008). Other evidence suggests that black District residents face barriers to cancer treatment other than insurance coverage: Insured black District residents with suspicious mammogram results experience substantially longer times to diagnostic resolution than insured whites (Hoffman, LaVerda, et al., 2011). Finally, black cancer patients in the District are more likely to present for their first course of cancer treatment at later stages than white patients, reducing their likelihood of survival. Limitations in general access to health care, in primary and secondary prevention, and in access to cancer-related treatment all likely contribute to observed differences in mortality from cancer between black and white District residents.

Perhaps as notable and important as the key findings summarized above are the gaps in available information regarding key elements of the cancer continuum. In what follows, we highlight important opportunities for data collection and analysis, noting the scarcity of information for describing outcomes for certain population subgroups, as well as current limitations of data for tracking historical and future trends in outcomes.

**(1) More needs to be known about cancer treatment patterns and quality in the District.**

More comprehensive data on treatment is needed to assess (a) the full range of treatment received by patients, (b) the degree to which treatment is in accordance with standards for quality of cancer care, and (c) variation in treatment patterns over time and across subgroups of interest.

**(2) Regular, continued monitoring and timely reporting of cancer-related outcomes among District residents are essential, as is assuring validity and comprehensiveness of cancer registry data in the District.**

Routine, consistent, and timely reporting of cancer-related outcomes in the District is essential to guide the efforts of government and nongovernmental entities working to reduce the burden of cancer in the District.

**(3) Supplementary data would provide a more robust understanding of potential barriers to cancer screening.**

Self-reports of cancer screening are subject to recall bias, as survey respondents, especially those who are black and Hispanic, tend to overreport screening (Rauscher, Johnson, et al., 2008). Therefore, it would be useful to supplement BRFSS data by exploring rates of screening developed from other data

sources, such as claims data, and gleaning information from patient navigators in the Citywide Patient Navigation Network to identify barriers to screening among vulnerable populations.

**(4) Opportunities exist to learn more about patient experiences across the continuum.**

Although measuring patients' experiences with cancer care is a critical component of overall quality assessment, to our knowledge, no systematically collected surveys are conducted with cancer patients in the District regarding their experiences with cancer care at any stage of the continuum. Administration of surveys of experiences with cancer treatment, survivorship, and end-of-life care could inform quality improvement or consumer choices between cancer treatment facilities.

**(5) More information is needed on awareness and knowledge of cancer prevention and control among District residents.**

Little empirical data are available regarding the degree to which District residents—overall, or by relevant geographic or sociodemographic subgroups—are aware of cancer risks, protective factors, or the benefits of early detection. The National Cancer Institute's Health Information National Trends Survey surveys a nationally representative sample of American adults biennially regarding cancer awareness and communication and may present opportunities for identification of gaps in awareness and knowledge in the District.

**(6) More attention needs to be given to understanding the regional burden of disease, patient flows across geographic borders, and regional capacity for cancer care.**

Many cancers treated in the District are among non-District residents, suggesting the need for exploration of the key drivers of care-seeking across District boundaries and an assessment of health care capacity that encompasses the District and surrounding counties.