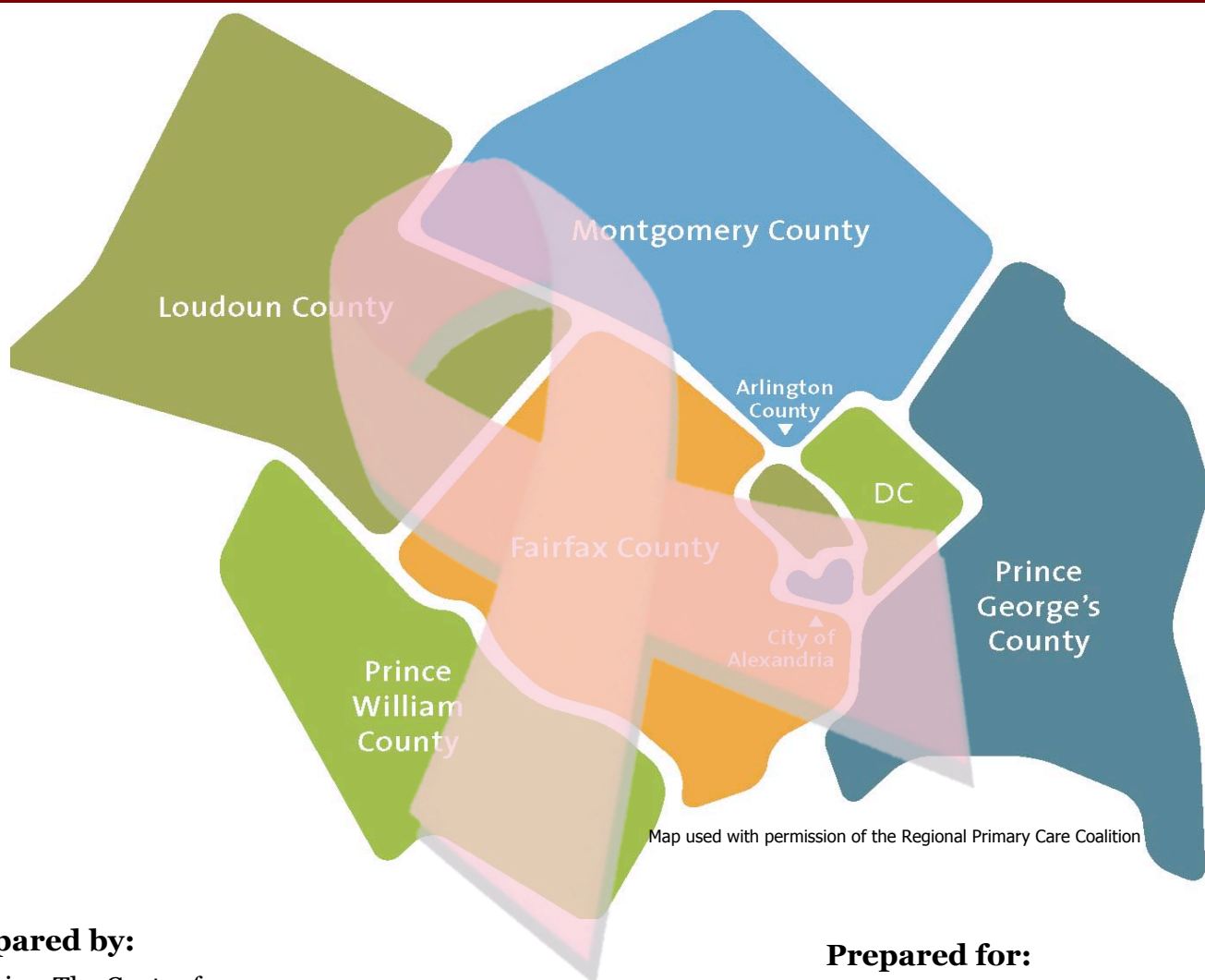


State of the Region Breast Health Care Assessment

Executive Summary

Prepared for the National Capital Area Regional
Breast Health Care Improvement Initiative
January 2011



Prepared by:

Mosaica: The Center for
Nonprofit Development and Pluralism
With the assistance of
The Regional Primary Care Coalition

Prepared for:

Primary Care Coalition of
Montgomery County

Executive Summary

Statement of Health Problem



Cancer is the second leading cause of death among U.S. women, and breast cancer is the most common non-skin cancer among women and the second leading cause of cancer deaths after lung cancer. Over 200,000 women in the U.S. are diagnosed with breast cancer each year, and about 40,000 die from breast cancer annually. About one in 35 U.S. women dies from breast cancer. Breast cancer incidence rates are highest among White non-Hispanic women, but death rates are highest among African American women.¹

Nationally, breast cancer rates decreased about 2% between 1998 and 2007, reflecting a reduction in cases among women over 50. Deaths have also decreased since 1990, probably as a result of both early detection and improvements in treatment.²

Early detection and prompt and effective treatment are essential to positive health outcomes, but many women – especially women who are low-income and uninsured – face considerable challenges in getting timely screening, diagnosis, and treatment. For many low-income women who lack private health insurance, safety-net clinics are the main source of health care, providing services regardless of the patient’s ability to pay and frequently coordinating preventive, acute, and chronic medical care. These clinics often play a critically important role in breast health care, referring patients for regular mammograms, arranging for necessary diagnostics, helping them obtain federal support for diagnosis and treatment when they are eligible and other financial assistance or charity care when they are not, and providing ongoing coordination and support, often through patient navigators. In the National Capital Region, safety-net clinics have a particularly important role to play in breast health care, since the region lacks a coordinated, integrated breast health care system, either within or across jurisdictions. Community-based nonprofits provide valuable outreach and often ongoing support to women with breast cancer. The National Breast and Cervical Cancer Early Detection Program (NBCCEDP) is an important source of screening and diagnostics and can help eligible women obtain Medicaid coverage for treatment. Hospitals provide screening and charity care. But safety net clinics can be the glue that coordinates every aspect of breast health care for low-income women, especially those without health insurance.

Background/Overview of Project



This report presents findings from a State of the Region Assessment of breast health care in the National Capital Region, conducted for the Primary Care Coalition of Montgomery County (PCC) by Mosaica: The Center for Nonprofit Development and Pluralism. The State Assessment is the first phase of the National Capital Area Regional Breast Health Care Improvement

¹ National Cancer Institute, Breast Cancer Home Page, www.cancer.gov, and Imaginis, “Breast Cancer: Statistics on Incidence, Survival, and Screening,” www.imaginis.com.

² American Cancer Society, “Breast Cancer Facts and Figures 2009-2010,” available at <http://www.cancer.org/acs/groups/content/@nho/documents/document/f861009final90809pdf.pdf>.

Initiative. Funded by Susan G. Komen for the Cure, the clinic-centered Initiative is designed to improve the efficiency and effectiveness of breast cancer screening, referral, and follow-up for low-income women in the region. Its long-term goal is to position clinics throughout the region to provide 100% of the low-income women aged 40 and over served by their clinics with access to high-quality, timely breast health care, and to contribute to the development of comprehensive, coordinated, patient-centered systems of community-based primary care that make excellent, affordable, linguistically and culturally appropriate health services available all across the region.

The Initiative is a regional expansion of PCC’s successful Breast Health Care Process Improvement Project, which uses a process improvement model anchored in community-based primary care clinics that serve as medical homes for low-income residents of Montgomery County.

PCC is collaborating with the Regional Primary Care Coalition (RPCC), a learning collaborative committed to helping to build coordinated patient-centered systems of community-based primary health care throughout the metropolitan Washington, DC region that provide high quality health care and advance health equity. It includes existing or emerging state, county, and regional primary care coalitions, funders, and resource organizations. RPCC has primary responsibility for managing a regional learning and action community for the Initiative.

The State of the Region Assessment



The State of the Region Assessment, carried out by Mosaica: The Center for Nonprofit Development and Pluralism, provides an in-depth analysis of the state of breast health care for low-income women in the National Capital Region. It helps to establish a knowledge base for the regional replication and expansion of the PCC model from Montgomery County, where it has demonstrated success, to other jurisdictions in the region. The assessment presents population and breast cancer screening and incidence rates and analyzes existing breast health care services and systems for low-income, uninsured women and reports safety-net clinic interest in and readiness for participation in replication efforts and the planned regional learning community.



The State Assessment complements the Susan G. Komen for the Cure National Capital Region 2010 Community Profile Report and benefited from its Health Systems Analysis and from access to provider interview summaries. The Community Profile focused on several specific geographic areas: Wards 7 and 8 in the District of Columbia, Prince George’s County in Suburban Maryland, and Arlington and Prince William Counties in Northern Virginia. One of its special features was the women’s perspective provided through use of focus groups.

PCC’s State of the Region Assessment is designed to look at breast health care in the region as a whole and in each of the “state” jurisdictions – the District of Columbia, Northern Virginia, and Suburban Maryland. Because the PCC model is clinic-based, the assessment focuses heavily on the role of safety-net clinics in breast health care, including the services they provide and their

interactions with other breast health care providers, from culturally-focused outreach groups to mammography and treatment providers.

Carried out over a 10-month period in 2010, the assessment used a community-based collaborative research methodology that combined online surveys with safety-net clinics, interviews, key informant sessions, and extensive secondary research. Providers of breast health care participated in key informant sessions and interviews, provided feedback on resulting matrices showing not just who provides what breast health care services, but also the relationships, referral process, strengths, and barriers to care in each jurisdiction and regionally. Though it focused on safety-net clinics serving as medical homes in potential expansion areas – the District of Columbia, the five health districts of Northern Virginia, and Prince George’s County, Maryland – the assessment also provides comparative population, breast cancer screening, and breast cancer incidence rates and a review of breast health care systems and services in Montgomery County, where PCC’s model has already been implemented.

Summary of Findings



Following are some of the State Assessment’s key findings:

- The Washington, DC region has 31 safety-net clinics that serve as medical homes to women 40 and over, spread almost equally among Washington, DC (10), Northern Virginia (11), and Suburban Maryland (10). Together they operate 92 facilities providing primary health care to people who might otherwise be unable to obtain it. Two clinics located in DC have facilities in Montgomery County. About 55% of clinics provide services to people who live in other jurisdictions.
- Together, these clinics provided care to an estimated 59,800 women 40 and over in 2009, about 55,650 of them low-income and 34,000 low-income and uninsured.
- Of the 22 clinics surveyed in DC, Northern Virginia, and Prince George’s County, all provide or arrange breast health care, but only 45% have specific funding to support breast health care activities (Clinics headquartered in Montgomery County were not surveyed because the Regional Initiative is already operating there).
- Breast cancer incidence rates are highest in DC, Montgomery County, and Fairfax County, while breast cancer mortality is highest in DC, Prince George’s County, and Prince William County. Annual screening rates in DC, Suburban Maryland, and Northern Virginia are between 62% and 64%, all slightly above the national average of 59.7%.
- Among the greatest challenges faced by clinics is arranging breast health care services for women who are undocumented or are recent refugees or immigrants and do not qualify for federally supported treatment, and for immigrant women with limited English proficiency.
- Among the greatest challenges to timely and high quality breast health care for low-income women 40 and over throughout the region, as identified by clinics, hospitals, community-based outreach groups, and other providers, are the following:
 - Lack of service coordination
 - Limitations in scope or funding of NBCCEDP Program that limits access to screening, diagnostics, and/or treatment for some low-income, uninsured women

- Administrative complexities in helping patients obtain charity care, apply for state-supported diagnostic or treatment services, or get timely approval for diagnosis or treatment for women served through Medicaid MCOs
 - Lack of access to specialty care, especially oncology and surgery
 - Lack of affordable care for women with incomes just above 200% of the federal poverty level
- Financial issues are less important in DC than systemic challenges, since about 95% of DC women 40-64 have health insurance, and DC has already made the health reform-authorized transition to non-categorical Medicaid for individuals with incomes up to 200% of the federal poverty level. Maryland provides diagnostic and treatment services through its general funds for women who do not qualify for Medicaid, though the eligibility process is extremely demanding. No similar program exists in Virginia, where the principal source of treatment funding for low-income uninsured women is charity care.
 - In all jurisdictions, it can be especially difficult to obtain mammograms for women under 40, even if there is a family history of breast cancer, and for women 65 and over who are not eligible for Medicare. Women 40-49 have lower priority under NBCCEDP than women 50-64, which can mean delays in screening with program funds, especially near the end of the fiscal year.

Findings



Populations of Low-income Uninsured Women

The primary focus of the assessment is breast health care for women 40 and over who are both low-income and uninsured. Because a very high percentage of low-income women in the District of Columbia are insured but still face major challenges in obtaining breast health care, the assessment also explored the needs of low-income women who have public insurance through Medicaid or the DC Alliance (The Alliance provides care to otherwise uninsured DC individuals and families whose household income is below 200% of the federal poverty threshold).

Regional Overview: The table below provides U.S. and regional Census estimates of the population of women 40-64, including the number who are low-income and the number who are low-income and uninsured. It also provides estimates of the patient population aged 40 and over in the region's safety-net clinics, including the total number, number who are low-income, and number who are low-income and uninsured.

As the table indicates, the U.S. and regional data are not fully comparable to the clinic data, for several reasons:

- **The clinic data include a wider age group:** The clinic data cover women 40 and over, while the Census data include only women 40-64. Census estimates of the number of low-income uninsured women – the Small Area Health Insurance Estimates (SAHIE) – are not provided for women 65+. Because of Medicare, it is likely that a relatively small proportion of women 65 and over in the overall population are uninsured. However, patients 65 and over served by safety-net clinics in the National Capital Area are sometimes not eligible for Medicare because of their immigration status.
- **The data are from different years:** Clinic patient data are for 2009, while the most recent SAHIE estimates are for 2007.

- **Some clinics do not have precise figures on the number or percent of women patients 40 and over who are low-income and uninsured.** For example, less precise data on the income and insurance status of patients is available from some safety-net clinics that are not CHCs/FQHCs and do limited or no third party billing, and from clinics that have either no electronic medical records or system limitations on the reports they can generate.
- **Clinic populations do not necessarily live in the jurisdiction where they receive services.** CHCs/FQHCs are required to serve people regardless of their place of residence, and mobility within the region means that individuals who want continuity in their health care may live in one state and receive medical care in another.

Safety-Net Clinic and Regional Populations of Women and Women Patients	U.S. Population 2007: Census Bureau Estimates (Women 40-64)	Regional Population, 2007: Census Bureau Estimates (Women 40-64)	Safety Net Clinics: Estimated Patient Population, 2009 (Women 40+)
Number of Reporting Clinics			31
Number of Facilities			92
Reported Number of Women 40-64 or 40+	50,098,031	800,313	59,800
Estimated Number of Low-Income Women 40-64 or 40+	14,894,179	120,397	55,650
Estimated Number of Low-Income Uninsured Women 40-64 or 40+	4,410,509	46,763	34,000

Sources: DC, Northern Virginia, and Prince George’s County clinic data from surveys and follow-up communications, supplemented by data from clinic websites and annual reports and Bureau of Primary Health Care summary data for DC community health centers; Montgomery County clinic data from Primary Care Coalition of Montgomery County; primarily 2009 data. Regional population estimates from Census Bureau, including Small Area Health Insurance Estimates (SAHIE), 2007.

The table below provides more detailed population data for the U.S. and for each of the major jurisdictions in the Washington, DC region.

Estimated Population of Low-Income Uninsured Women 40-64 in the U.S. and the Region, 2007					
Population Group	U.S.*	Region	NoVA	Suburban MD	DC
Population of Women 40-64	50,098,031	800,313	379,822	323,998	96,493
Number of Low-Income* Women 40-64	14,894,179	120,397	32,747	55,925	31,725
Percent of Women 40-64 who are Low-Income	29.7%	15.0%	8.6%	17.3%	32.9%
Number of Low-Income Uninsured Women 40-64	4,410,509	46,763	17,554	23,784	5,425
Percent of Low-Income Women 40-64 who are Uninsured	29.6%	38.8%	53.6%	42.5%	17.1%
Percent of Women 40-64 who are Low-Income Uninsured	8.8%	5.8%	4.6%	7.3%	5.6%

* U.S. data count women as low-income if they are below 250% of the federal poverty level (FPL); other poverty data are for women below 200% of FPL.

Sources: Census Bureau estimates as of July 1, 2007. Insurance data from Census Bureau Small Area Health

Insurance Estimates (SAHIE) for 2007.

As the table indicates, the poverty rates for women 40-64 in the region and in jurisdictions other than the District of Columbia are below the national rate. Poverty rates are lowest in Northern Virginia, where 8.6% of women 40-64 are low-income, according to 2007 Census estimates, compared to 32.9% of women in the District of Columbia, 29.7% nationwide, and 17.3% in Suburban Maryland.

While the District of Columbia has the highest level of poverty among women 40-64, it has the lowest percent of low-income uninsured – an estimated 17.1% of low-income women, and 5.6% of all women 40-64, are uninsured. The vast majority of DC residents have either private or public health insurance – either Medicaid or the DC Healthcare Alliance. Despite lower poverty rates in the other jurisdictions, low-income women in Northern Virginia and Suburban Maryland are much more likely than DC residents to be uninsured. These states have less generous Medicaid programs and lack a state-level broad-coverage public medical care program like the DC Alliance.

Data Inconsistencies: It is challenging to fully understand the population of low-income and uninsured women in the region and in safety-net clinic patient populations and to make meaningful comparisons. Clinics often serve people who live in other jurisdictions and do not always have accurate information about the income and insurance status of their patients. There are also some important limitations in the SAHIE data. For example, it appears that the national estimate of the number of uninsured women 40-64 in the District of Columbia may be overstated. SAHIE figures are based on 2007 Current Population Survey (CPS) data, and that survey does not list DC Alliance as an insurance option. As a result, DC Alliance members sometimes are counted as insured, sometimes as uninsured. A 2009 District of Columbia Health Insurance Survey, conducted for the DC Department of Health Care Finance by the Urban Institute and Social Sciences Research Solutions, found that 6.2% of all residents and 7.9% of adults 19-64 are uninsured, and 10.6% of all residents were uninsured at some point in the past 12 months.³ The study also found that 55.6% of the uninsured have incomes below 200% of the federal poverty level (FPL). Using the DC figures, if it is assumed that 7.9% of all women 40-64 in DC are uninsured, and 55.6% of the uninsured are low-income, then 4.4%, not 5.6%, of all women residents aged 40-64 are low-income uninsured. This means there are about 4,238 low-income uninsured women in DC – 22% below the 5,425 SAHIE estimate.

Safety-Net Clinic Populations

The 31 safety-net clinics in DC, Northern Virginia, and Suburban Maryland together serve about 34,000 low-income uninsured women 40 and over each year and a total of about 55,650 low-income women in this age group. The safety-net clinics in the District are serving about 8,000 low-income uninsured women 40 and over, the Northern Virginia clinics about 16,050, Prince George's County facilities about 1,300, and Montgomery County clinics about 8,650. A very high proportion of safety-net clinic clients in DC, Northern Virginia, and Suburban Maryland – about 93% – are low-income. These estimates are approximations. Some clinics, particularly in the District, serve patients who live in other jurisdictions, and clinics do not always have

³ Urban Institute, "Uninsurance in the District of Columbia: A Profile of the Uninsured, 2009," April 29, 2010. Available online at <http://www.urban.org/publications/412084.html>.

complete and accurate information on their patients' income and insurance status. However, they show that the clinics are serving a significant proportion – in some jurisdictions a large majority – of low-income, uninsured women residents 40 and over.

Safety-Net Clinics that Serve as Medical Homes



Description of the Region's Safety-Net Clinics: Safety-net clinics – including federally funded Community Health Centers/Federally Qualified Health Centers (CHCs/FQHCs), free, public, hospital-based, and other nonprofit clinics – play a key role in providing and coordinating breast health care services in the Washington, DC region. Most function as medical homes, providing clinical breast exams, referring patients for mammograms based on established policies, helping to arrange diagnosis and treatment when needed, and providing follow-up, often through patient navigators. The State Assessment conducted online surveys that reached 22 safety-net clinics – 10 headquartered in Washington, DC, 11 in Northern Virginia, and 1 in Prince George's County. Descriptive and patient information was also obtained for 9 safety-net clinics headquartered in Montgomery County, where the Breast Health Care Initiative is already operating, and for two facilities of DC-based clinics that are located in that county. Nine of these 31 clinics are CHCs/FQHCs and 1 is an FQHC “look alike,” 5 describe themselves as free clinics, 3 are hospital associated, 2 are city/county associated, and 11 are other nonprofit clinics.

What is a “Medical Home”?

A “medical home” is a health facility that provides or arranges patient-centered comprehensive health services – acute, chronic, and preventive – either providing needed services directly or arranging referrals. Usually the medical home provides primary care on-site. It is the first point of contact when a patient needs any health care other than emergency services – the starting point for obtaining preventive services, screening and diagnosis, and treatment. It maintains the patient's medical records.

A majority (55%) of the region's safety-net clinics (17 of 31) but a minority (36%) of the 22 non-CHC/FQHC clinics (8 of 22) accept patients from outside their target area. The 9 CHCs/FQHCs are *required* to serve patients regardless of residence. Clinics in the District of Columbia are more likely than clinics in Northern Virginia or Montgomery County to report serving patients outside their primary service area. They are particularly likely to report serving patients who live in Prince George's County. This access to care in another jurisdiction is important for Prince George's County residents, since that county has a single nonprofit safety-net clinic, an FQHC with five facilities in the county but (as has been pointed out in several studies) without the capacity to serve all those in need of low-cost or free medical care.

Involvement in Breast Health Care: The State Assessment obtained information about breast health care involvement from 22 of the clinics – those headquartered in DC, Northern Virginia, and Prince George's County – through an online survey, supplemented by interviews and key informant sessions. About three-fourths (73%) of these clinics indicated that they are they are *moderately* or *very* familiar with their state's NBCCEDP. However, half the clinics – 8 of 11 in Northern Virginia 3 of 10 in the District of Columbia – said they do not refer any of their patients for screening under the program. Only 10 of the 22 have specific funding to cover breast health care activities. Ensuring appropriate, timely care represents a challenge because they must

refer patients for most breast health services, from mammograms to biopsies, surgery, radiation, and chemotherapy. Nearly all the clinics report challenges in providing timely breast health care services. Generally, they find it easier to arrange mammograms than to obtain diagnostic services, especially biopsies requiring surgery, and treatment. They report the greatest challenges in arranging breast health care services for women who are undocumented or are recent immigrants or refugees and do not qualify for federally supported treatment, and for women who are not fluent English speakers. Surgical treatment, non-surgical treatment, and follow-up care represent particular challenges for these populations.

Breast Health Care Services

All the jurisdictions in the region have a wide variety of breast health care services and providers. Some clinics and NBCCEDP programs provide outreach, as do an array of mostly ethnic-focused nonprofit community-based organizations. Clinics and hospitals as well as some of the community-based organizations provide clinical breast exams. Mammography providers include hospitals, private mammography groups, and the Capital Breast Care Center, which is associated with Georgetown University’s Lombardi Cancer Center. Most of the mammography providers also offer diagnostic tests, with biopsies done mostly by hospital-based surgeons and physicians in private practice. Hospitals and individual physicians provide treatment services; charity care is available but often difficult and complex to access. Clinics, hospitals, and some community-based organizations provide patient navigation or other care coordination, and sometimes follow-up. Support groups are most often run out of hospitals or by community-based organizations. All jurisdictions have hospices that provide end-of-life services regardless of ability to pay. The individual services exist in each jurisdiction, with variations in capacity and in the extent to which they are accessible to low-income uninsured women 40 and over.

Breast Cancer Mortality and Incidence Rates

As the table below shows, the District of Columbia has the highest breast cancer incidence rate (number of new cases per 100,000 population) in the region, and Prince George’s County, the District, and Prince William Health District in Northern Virginia have the highest breast cancer mortality rates (deaths per 100,000 population). Data indicating stage of cancer at diagnosis indicate that women in Montgomery County are most likely among all residents of the region to be diagnosed while their cancer is still at the *Localized* stage (56%) and least likely to be diagnosed when it is at the *Distant* stage (4%). Women in Arlington County are most likely to be diagnosed when their cancer is in the *Regional* or *Distant* stage (46%), but have the lowest incidence rate (113.5).⁴

Breast Cancer Incidence & Mortality Rates	U.S.	DC	Northern VA					Suburban MD	
			Alex-Andria	Arlington	Fairfax	Lou-doun	Prince William	Mont-gomery	Prince George’s
Breast Cancer Incidence Rate (per 100,000)	120.6	144.7	93.9	113.5	126.7	121.3	116.2	129.6	116.7
Breast Cancer Mortality Rate (per 100,000)	24.0	28.5	17.1	24.7	23.4	26.2	28.1	20.2	30.3

⁴ Staging data charts and incidence and mortality data for DC wards are provided in the report.

Sources: U.S. rates from State Cancer Profiles, 2003-2007. Maryland, DC, and Virginia data from State Cancer Registries, 2003-2007. Rates for the Fairfax and Prince William Health Districts were calculated by Mosaica to include both county data and data from the small cities that are included in these two health districts; however, mortality data for Manassas Park were unavailable.

Breast Cancer Screening Rates

Available data indicate that more than 60% of women 40-64 in the District of Columbia, Maryland, and Virginia received a mammogram in 2006, which puts them all slightly above the national rate of 59.7%. Data also indicate that the screening rate is highest in the District of Columbia. DC also reports the highest percentage of women receiving a mammogram through the National Breast and Cervical Cancer Early Detection Program (NBCCEDP) over a two-year period from early 2006 to early 2008 (22.0%). Virginia reports the lowest percent (12.3%), with Maryland in the middle (16.8%), slightly above the national rate of about 15%. The District of Columbia screens many Maryland and Virginia women under its NBCCEDP program, and it is not clear whether the screening rates reported by any of the jurisdictions have been adjusted to count only residents of their state.

Percent of Women Receiving a Mammogram	U.S.	VA	MD	DC
Percent of all women 40+ who received a mammogram (2006)	61.2%	62.2%	63.9%	64.2%
Percent of all women 40-64 who received a mammogram (2006)	59.7%	60.6%	62.7%	63.0%
Percent of program-eligible women* 40-64 who received a mammogram through NBCCEDP in past 2 years (early 2006 to early 2008)	Approx. 15%	12.3%	16.8%	22.0%

* States set the income eligibility for their NBCCEDP programs within federal parameters. The income limit in most states, including DC and MD, is 250% of the federal poverty level (FPL); the limit in VA is 200% of FPL.

Sources: Overall screening data from American Cancer Society research, 2009; NBCCEDP data from the NBCCEDP program, obtained through a special request to the Government Accountability Office (GAO).

National Breast and Cervical Cancer Early Detection Programs



NBCCEDP is the primary source of federal funding for breast health care services, primarily screening and diagnosis, along with some outreach and education, for low-income uninsured women, primarily aged 40-64. A key element of the program is that states must provide special categorical eligibility to Medicaid for women with breast cancer who were screened under the program, if they are low income and otherwise eligible for Medicaid. State matching funds are required, and some states (including Maryland) provide general funds to cover diagnosis and treatment for women not eligible for Medicaid. States have flexibility with regard to eligibility, income guidelines, and procedures. NBCCEDP provides important screening and diagnosis and often outreach and education services for low-income, uninsured women, but serves only a small minority of eligible women – 15% nationally.

The table below summarizes income eligibility, age group priorities, and key issues for the state programs in DC, Maryland, and Virginia. As the figure shows, program coverage is especially limited in Virginia. In both Suburban Maryland and Northern Virginia, the number of funded slots for screening and diagnosis is insufficient, and funds sometimes run out before the end of the funding year. The DC program, on the other hand, has found it difficult to spend all funds because most DC women 40-64 have Medicaid or are covered by the DC Alliance – so it provides screening for DC women with incomes of 200-250% and then makes services available for women from the suburbs for at least part of the year.

National Breast and Cervical Cancer Early Detection Program Characteristics				
Jurisdiction	Project Name	Income Eligibility	Age Group	Key Issues
DC	Project WISH	200-250% FPL	Priority: 50+ (25% can be 40-49)	<ul style="list-style-type: none"> ▪ Focus on 200-250% FPL group – DC Alliance pays first ▪ Underutilized, so screens NoVA and Suburban MD residents ▪ Project on hiatus 10-1/12-31-10 – new contracts begin January 2011
MD	MD Breast & Cervical Cancer Program (BCCP)	<250% FPL	Serves women 40-64; priority: 50-64	<ul style="list-style-type: none"> ▪ Insufficient screening funds ▪ State general funds for diagnosis & treatment of non-Medicaid eligible women ▪ Expanded Services planned but delayed in “home rule” counties including Montgomery and Prince George’s
VA	Every Woman’s Life (EWL)	<200% FPL	40-64	<ul style="list-style-type: none"> ▪ Insufficient screening funds ▪ Must be screened or diagnosed with EWL funds to access Medicaid through program ▪ No state alternative for women not able to access Medicaid ▪ Must enroll through 4 state-contracted sites in NoVA

Regional Strengths

Safety-net clinics, hospitals, community-based organizations, state and county NBCCEDP programs, and other providers are actively engaged in arranging, providing, and paying for breast health care services in the region. Many aspects of breast health care services work well, especially the high level of commitment among providers to provide timely, comprehensive services to low-income women 40 and over, regardless of challenges or barriers. Other strengths include the high level of health insurance coverage in the District of Columbia, the general funds allocated for breast health care treatment in Maryland, the number of safety-net clinics engaged in breast health care, and the successful use of patient navigators to help women access services in all jurisdictions.

Service Barriers and Gaps

Clinics and other providers identify numerous service barriers and gaps that make it difficult – sometimes extremely difficult – to ensure comprehensive, timely, coordinated breast health care

services to low-income, often uninsured women. Many of these barriers exist throughout the region. In addition, each jurisdiction has some specific issues that are especially important in understanding and improving breast health care services, often associated with state health care systems. Regional and jurisdiction-specific barriers and gaps are summarized below:

- **The Region:** Financial issues are important in every jurisdiction – though in different ways. Patient issues are also important, from language and cultural barriers to limited knowledge about breast cancer or available services to transportation problems. Some of the most important and challenging barriers are systemic. They involve narrowly defined program eligibility, limited access points, extremely complex and sometimes irresolvable documentation requirements for program access, and varied and demanding administrative regulations and procedures for pre-service authorizations that can prevent timely diagnosis and treatment. While many entities work together effectively to provide timely, comprehensive services for their low-income and uninsured patients, none of the jurisdictions has a coordinated system of breast health care services. All jurisdictions struggle with arranging and coordinating charity care and especially with identifying specialists to serve low-income uninsured women with breast cancer.
- **District of Columbia:** Challenges in providing timely and appropriate breast health care services are not primarily financial, since the vast majority of DC residents are eligible for either Medicaid or DC Healthcare Alliance. Yet DC clinics report more difficulty than clinics in the other jurisdictions in ensuring timely diagnosis, surgical and non-surgical treatment, and follow-up services for low-income women. A particular problem involves the varied and time-consuming administrative requirements for obtaining authorization for diagnosis and treatment services from Medicaid Managed Care Organizations (MCOs) if a woman has an abnormal mammogram. Since DC is already implementing the Affordable Care Act's Medicaid expansion and is moving more than half of all DC Alliance patients to Medicaid, mostly to MCOs, this issue is likely to increase in importance.
- **Northern Virginia:** Financial barriers are especially important in Northern Virginia. Every Woman's Life, the Virginia NBCCEDP program, is less accessible than the programs in the other jurisdictions due to a lower income limit (200% rather than 250%), a smaller number of access points and funded providers (4, compared to 10 in each of the Maryland counties and a similar variety in DC), and the requirement that women must be screened or diagnosed through the program to be eligible for Medicaid as a result of their breast cancer. Unlike DC and Maryland, there is no alternative state-funded treatment program for women who do not qualify for Medicaid. Charity care is the primary treatment option, and some women are referred out of the region to hospitals in Richmond (Virginia Commonwealth University) or Charlottesville (University of Virginia) for treatment. This includes treatments requiring multiple trips, like radiation or chemotherapy. The Northern Virginia situation is complicated by a lack of coordination among service providers, too few bilingual system navigators, and the absence of an organized process for accessing charity care.
- **Maryland:** Maryland's BCCP is partially decentralized, and the two Suburban Maryland counties each contract with 9-10 providers of outreach and education, screening, and diagnosis. The program provides flexible access enabling women with breast cancer to qualify for treatment if screened or diagnosed by any of the funded providers, regardless of who paid for those services. For women who cannot qualify for Medicaid under the program, there is an alternative route to state-funded treatment. However, the administrative requirements for documenting identity, Maryland residence, and income eligibility are so

demanding that many women are unable to meet them, despite assistance from patient navigators. In addition:

- **In Prince George’s County**, the lack of an adequate primary care infrastructure is an added concern that was recently documented by a Rand Corporation study. Greater Baden Medical Services is the only community health center. It has five facilities in the county and has been expanding capacity, but cannot meet the need for primary care among low-income residents. The county provides some clinic services but does not allocate county funds to ensure a primary care safety-net.
- **In Montgomery County**, mammography capacity remains insufficient to meet the need and a high proportion of patients are immigrants or refugees, many of them not eligible for Medicaid. However, the Montgomery Care network of safety-net clinics is supported financially by the county. An active group of providers (clinics, hospitals, community-based organizations, and the County Health Department) is working under PCC’s leadership to improve breast health care through process improvements.

Implications of Findings for Breast Health Care in the Region



The State Assessment offers information and insights to help increase understanding of breast health care in the Washington, DC region and to shape the replication phase of the Regional Initiative. These implications are summarized below.

1. **Need for systems change and service integration:** Throughout the region, there is a need for an integrated system of breast health care screening, diagnosis, treatment, and follow-up for low-income women, especially those who are uninsured. While process improvements at clinics and the addition of more navigators to a dysfunctional system are much-needed, they will be far less effective alone than an approach that combines these efforts with changes to the “system” of breast health care. For some clinics, the prospect of addressing systemic issues is a major motivator for involvement in the Regional Initiative. Consistent policies and procedures and improved communication are needed to overcome the administrative delays that prevent timely diagnosis and treatment for women enrolled in MCOs or seeking access to treatment if not eligible for Medicaid coverage through NBCCEDP. Process improvements at the clinic level are also an essential part of that effort. In every jurisdiction, such improvements will enhance the level and timeliness of breast cancer screening and reduce delays between screening and diagnosis and between diagnosis and treatment. Many of the successful components of the PCC model as implemented in Montgomery County, such as a close relationship between the clinic and a mammography provider, should yield similar benefits in other jurisdictions.
2. **Provider coordination:** Early detection and timely, high quality care require deliberate, ongoing provider coordination. Currently, most providers in the region work long and hard to provide services, but provider coordination is limited and tends to occur informally or on a personal contact basis. Often, individual providers operate largely independently instead of being closely linked to other entities offering complementary services. Clinics that serve as medical homes find it extremely challenging to help their low-income patients get needed screening, diagnosis, surgical and non-surgical treatment, medications, and follow-up. Among the important areas for provider coordination:

- **Community-based outreach and education providers need to be closely linked to safety-net clinics** – so that low-income woman facing breast cancer all have a medical home, and so that clinics can ensure culturally relevant services for diverse patients.
- **Clinics need to have close relationships with mammography providers**, including the ability to make a woman’s mammography appointment during her clinic visit and to obtain timely reports of screening results and any need for additional diagnostics.
- **Hospitals need to establish a coordinated process for arranging hospital-based charity care.** The current situation often requires a clinic to separately arrange each component of that care, from the surgeon to the anesthesiologist, medications, and hospital stay.
- **The role of patient navigators should be enhanced so they can arrange patient access to a continuum of services.** For many clinics and other providers, patient navigators are playing extremely important roles in helping low-income women obtain a mammogram, get a timely diagnosis after an abnormal mammogram, and obtain access to treatment, supportive services, and follow-up. Patient navigators are a core component of the PCC model. Careful definition of roles and strategic use of navigators appear particularly important. Considerable benefit might be obtained from joint use of appropriately trained bilingual navigators to play roles such as helping Maryland women meet the extremely complex documentation requirements of its Breast and Cervical Cancer Diagnosis and Treatment Program (BCCDTP), including dealing with requirements for notarized letters and other documents. More communication among navigators in the District could lead to a common understanding of how best to manage some of the challenging MCO requirements and perhaps to sharing information on the availability of charity care options and resources. What constitutes the best training and assignment of navigators is a topic that would benefit from joint consideration by providers.

Some improvements in coordination can occur through regular meetings of appropriate personnel, perhaps as a part of the Initiative’s learning community. Others will require structured discussion, negotiation, and joint action, including changes to public programs.

3. **Funding coordination and the need for a regional strategy:** Improving breast health care for low-income and uninsured women requires a regional perspective and strategy, as well as funding coordination from both public and private funders. Many issues affecting breast health care are common to all jurisdictions – from administrative barriers to lack of coordinated charity care to the internal challenges of electronic medical records systems. Breast health care services are often viewed as state-specific, partly because of differences in public programs like Medicaid. However, low-income, uninsured women with breast cancer often are not eligible for Medicaid. This is a highly mobile region, and residents frequently move across state lines seeking homes and jobs.

Breast health care is already being provided across state lines through NBCCEDP – through the contract between Virginia’s Every Woman’s Life and the DC-based Capital Breast Care Center and the continuing practice of Project WISH in DC to screen women from Northern Virginia and Suburban Maryland. A majority of safety-net clinics, including all 9 CHCs/FQHCs, serve women who live outside their jurisdiction. Women often cross county and state lines for hospital care. These starting points need to provide the base for additional regional planning and service provision across state lines. Addressing systemic issues related

to breast health care also provides valuable lessons for how to approach other health issues on a regional level.

Private philanthropy plays an important role not only in supporting breast health care services, but also in influencing priorities and encouraging a regional strategy. Small philanthropic entities help fill service gaps. Larger grants from local and national foundations, including Susan G. Komen for the Cure, provide much of the support for community-based non-clinical providers, including groups that target specific ethnic groups, support outreach by hospitals and clinics, and pay for patient navigators. These grants support needed services, but do not necessarily require provider coordination or encourage a regional strategy. For example, grants to community-based outreach providers do not necessarily include an expectation for linkages with safety-net clinics. The information gained from the PCC State Assessment, replication, and learning community regarding coordinated care and regional service models should be shared with funders, to help them refine funding criteria and expectations of grantees.

4. **Need for better data collection and tracking of low-income population health data:** The State Assessment identified significant challenges in obtaining and comparing data on the number of low-income women 40 and over (especially women 65 and over) in a population, their insurance status, and their health status. Efforts to compare health data across jurisdictions and to understand the safety-net clinic population are complicated by such factors as the lack of SAHIE estimates for women 65 and older, differing definitions of low-income (200% or 250% of the federal poverty level), variations in what income and other demographic data are collected and reported by safety-net clinic patients, and differing capacity of electronic medical records and reporting systems. Efforts to establish a regional strategy for breast health care would benefit greatly from regional consistency in data collection and reporting on the size, age, characteristics, and health status of low-income women.
5. **Social determinants of health:** The high breast cancer mortality rates in Prince George's County and the District of Columbia – and the slightly lower rate in Prince William Health District – are not easily explained in terms of breast cancer incidence, late diagnosis, or high uninsurance rates. The explanations may well differ by jurisdiction. Other research suggests the importance of possible inequities in care and social determinants of health. These three jurisdictions have the highest proportions of non-White residents in the region.
6. **Clinic interest in and capacity for participation in the Initiative:** Safety-net clinics have indicated a high level of interest in participating in the Regional Process Improvement Initiative. Several clinics would like to serve as targeted replication sites, others to be part of a group of involved clinics, still others to participate in jurisdiction-specific or regional learning communities. Some navigators and other staff of non-clinical providers would also like to be part of knowledge-sharing sessions. Most of the safety-net clinics collect the data needed to document a woman's progress along the breast health care continuum, although the information may not yet be available or accessible through the clinic's electronic medical records system.
7. **Learning and action community:** During the State Assessment, clinics and other providers identified many issues and topics for the learning community. The process also suggests some roles for the learning community. For example:

- Because of the agreed-upon need for systems change as well as process improvement, the proposed regional learning community will need to be a learning and *action* community. Some planning will be needed to determine what that means in terms of strategies, who should be at the table, staff support, etc.
- Some topics of great interest to the clinics directly affect breast health care services but are much broader in their impact – such as charity care systems and access to specialty care. While the Initiative focuses on the implications of these issues for breast health care, RPCC should take advantage of the opportunity to gain an understanding of how these broader issues influence other aspects of health care for low-income women and what potential they offer for regional systems of care.
- Some learning community meetings will be at the jurisdictional level. Since there is only one participating safety-net clinic in Prince George’s County, and some systems issues are state-based, probably the two Suburban Maryland counties should be merged for such purposes.
- There will probably need to be a core learning community of clinics, PCC and RPCC representatives and consultant experts that is consistently invited to regional meetings, plus subsets of that group who are always part of jurisdiction-specific meetings. Other entities – hospitals, other providers, state and county NBCCEDP personnel – should be part of some but not all discussions.
- The Initiative may want to encourage the development of some work or information-sharing groups such as patient navigators, where such efforts seem likely to have important benefits for breast health care services for low-income women.
- The learning community should develop and explore what the RPCC Director calls a “change agenda.” This agenda will include some jurisdiction-specific priorities as well as regional priorities. Some topics have already emerged from the State Assessment and related discussions with clinics; others are likely to emerge during the replication process.

The Regional Initiative’s learning and action community will need to set priorities among many areas of interest, but clearly has the opportunity to address issues that have significant impact on breast health care in the region. It also has the opportunity to learn lessons that can be applied to other health care issues.