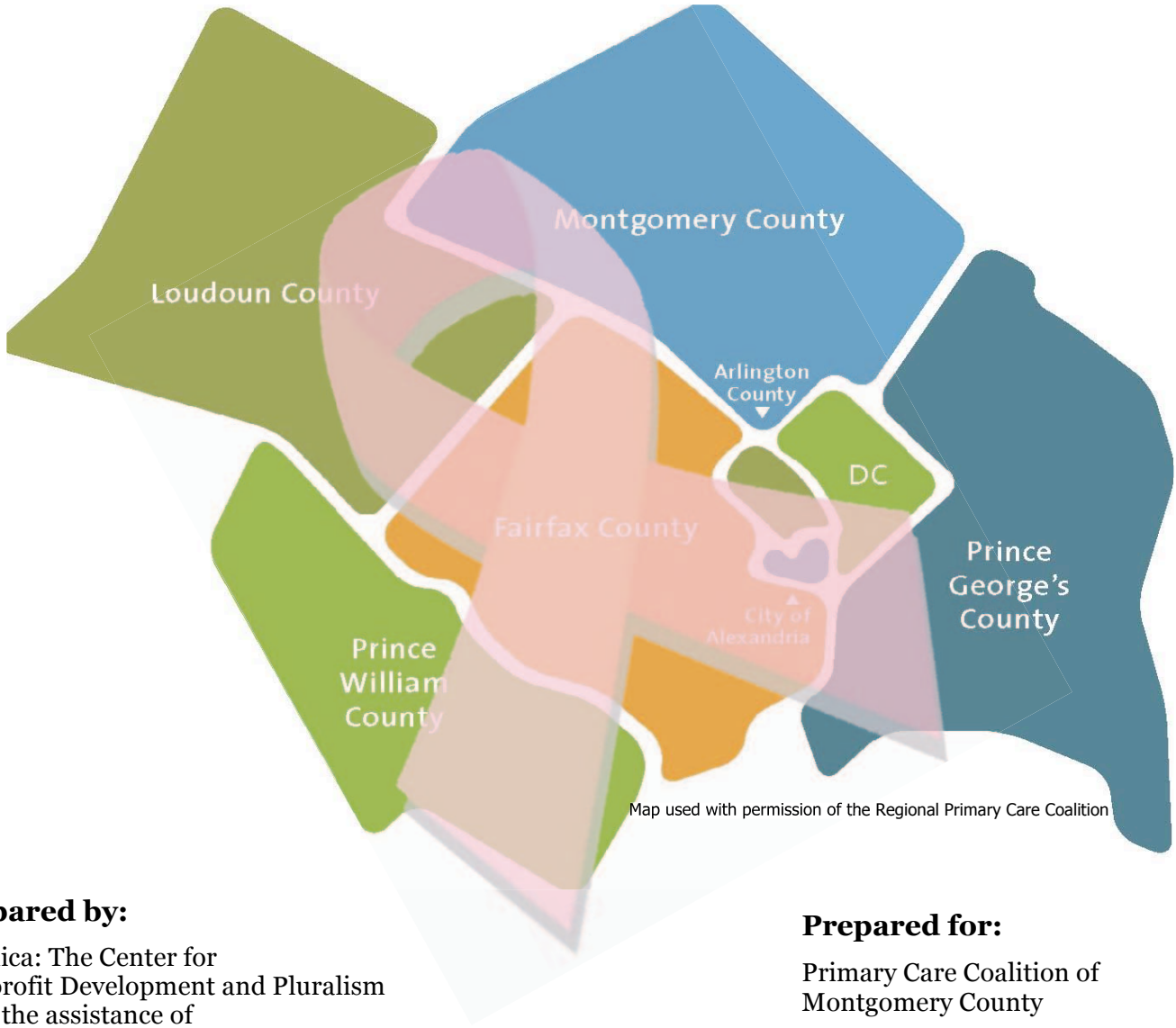
State of the Region Breast Health Care Assessment

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



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With the assistance of
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Prepared for:

Primary Care Coalition of Montgomery County

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Mosaica does all its work in teams, and the State Assessment team worked far beyond normal hours and on weekends to complete the assessment. Senior Consultant Hila Berl participated in every aspect of the work, was primarily responsible for developing the jurisdiction-specific flow charts, and provided quality control. Project Assistant Salem Tsegaye coordinated and developed service matrices and summaries from the four key informant sessions, managed the clinic online surveys, and was primarily responsible for gathering and analyzing population and breast health care data. Office Administrator and Technology Specialist LaTosha Joseph Francis created the flow chart graphics and did layout and desktopping of the report. Administrative Assistant Sara Andalibi provided administrative support, particularly for key informant sessions. Leticia Cazares, part-time Senior Consultant, assisted with early data gathering.

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1. Background/Introduction

The National Capital Area Regional Breast Health Care Improvement Initiative

In early 2010, Susan G. Komen for the Cure made a three-year grant to the Primary Care Coalition of Montgomery County (PCC) to improve the efficiency and effectiveness of breast cancer screening, referral, and follow-up for low-income women in the National Capital Area. The long-term goal of the Regional Breast Health Care Improvement Initiative 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.

The Initiative builds upon the successful PCC 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. The PCC approach incorporates four major components:

- Culturally and linguistically appropriate patient navigation/coordination services at the primary care level
- Monitoring of overall screening and referral rates and the time it takes to get from referral to screening, diagnosis, and treatment
- Identification and replication of practices that improve the process and the identification and elimination of systemic problems that interfere with timely screening, referral and follow-up
- Jurisdiction-wide breast cancer workgroups that bring together organizations in the community that provide breast health care services to low-income, uninsured women, to identify and address specific issues, learn from each other, and improve breast care services

In Montgomery County, PCC project successes after two years include:

1. Increasing the percentage of women 40 and over referred from participating primary care clinics to mammography services providers from 39% to 76%
2. Increasing the percentage of women who are referred for mammography and actually receive screenings from less than 20% to 53%

For this regional expansion, 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 region that provide high quality health care and advance health equity. It includes existing or emerging state, county, and regional primary care coalitions, funders who are members of the Health Working Group of the Washington Regional Association of Grantmakers (Washington Grantmakers), and resource organizations.

As the Komen grantee, PCC provides technical expertise and will manage the replication efforts. RPCC brings the regional primary care coalitions and health philanthropies together, manages the cross-jurisdictional, regional knowledge building, and stimulates process improvement

adoptions. It has established a project advisory committee that has helped to develop relationships and collaborations and will facilitate knowledge sharing within and across jurisdictions.

The Regional Initiative consists of three phases:

- **Phase I - 2010:** Current state of the region breast health care analysis, partnership building, and replication planning
- **Phase II - 2011:** Development, implementation, and monitoring of specific process improvement initiatives at selected clinic sites in three jurisdictions and initiation of regional learning communities
- **Phase III - 2012:** Sustainability, evaluation, and spread, with successes and strategies shared regionally and learning communities continuing

RPCC and PCC see this effort as contributing 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 State of the Region Assessment

The first phase of the Initiative calls for an in-depth assessment of the state of breast health care for low-income women in the National Capital region, to help provide the knowledge base for the replication and expansion of PCC's model. Mosaica: The Center for Nonprofit Development and Pluralism carried out the assessment, obtaining population and breast cancer screening and incidence rates and analyzing existing breast health care services and systems for low-income, uninsured women and determining safety-net clinic interest in and readiness for participation in replication efforts and the regional learning community.

Scope: The assessment focuses on seven potential expansion areas: the District of Columbia, five Northern Virginia Health Districts, and Prince George's County, Maryland. It includes 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.

Mosaica: Mosaica is a multicultural nonprofit organization located in the District of Columbia that exists to provide tools to nonprofits to build just, inclusive, and thriving communities and societies, working locally, regionally, nationally, and sometimes internationally. Established in 1994, it has broad experience in community health research including needs assessment and evaluation. Mosaica recently conducted the Profiles Project, which explored how the Washington, DC suburbs respond to HIV/AIDS.

2. Methodology

Overview

The State of the Region Assessment of breast health care was planned and implemented over a 10-month period from late February through November 2010. It included several types and

phases of information gathering, and was conducted in close collaboration with PCC and RPCC. Initial contacts with coalitions and associations as well as some in-person individual interviews were carried out jointly by Mosaica and PCC and RPCC representatives. Most data gathering sessions also included presentations about the Initiative, and PCC Initiative staff participated in all four key informant sessions.

Methods

Data gathering was done in two phases, which overlapped in time since data collection went more quickly in some jurisdictions than in others:

- An initial **resource inventory phase** to gain an overview of breast health care services, providers, and issues and an understanding of the primary care clinics that serve as medical homes for low-income women 40 and over, through:
  - **Initial discussions with primary care associations and related groups:** Preliminary discussions/interviews with the Northern Virginia Health Services Coalition (NVHSC), clinical directors at member clinics of the District of Columbia Primary Care Association (DCPCA), and key staff of Greater Baden Medical Services (GBMS) in Prince George's County, as well as the Director of the Capital Breast Care Center (CBCC) in Washington, DC. CBCC is a nonprofit mammography provider associated with Georgetown University's Lombardi Cancer Center that provides screening and diagnostic services to women from DC, Northern Virginia, and Maryland and is funded by NBCCEDP programs in both DC and Northern Virginia.
  - **Online surveys:** Development and implementation of a two-part SurveyMonkey online survey with safety-net clinics in Northern Virginia, Prince George's County, MD, and the District of Columbia. The first section provided overview information and enabled clinics to indicate whether low-income women 40 and older were part of their target population; the second section provided detailed information on the breast healthcare services and relationships of those clinics that target this population. The survey identified a number of hospitals, medical practices, and other providers with which clinics collaborate to provide breast health care outreach, screening, diagnosis, treatment, and follow-up.
  - **Interviews with NBCCEDP entities:** In-person or telephone interviews in each jurisdiction with state and when appropriate county staff of the NBCCEDP as operated in that state and county, to obtain information on program eligibility, providers, resources, state and federal funding, coverage, and perceived challenges/gaps.
  - **Other interviews**: Telephone and in-person interviews with state and county staff of the NBCCEDP, other breast health care providers, and staff of several clinics that have extensive knowledge of breast health care systems and providers.

- **Ongoing collection of population and breast cancer data:**
  - **Population data:** Obtaining and analysis of basic population data on number and characteristics of low-income uninsured and publicly insured women 40 and over in the regions/jurisdictions. Mosaica had hoped much of this would be available from the Komen needs assessment completed in the spring of 2010, but the population data were proprietary and not available except for the limited data published in the needs assessment. Mosaica therefore sought from federal, state, and county sources data such as:

  - Number and characteristics of 40 and over low-income uninsured and publicly insured women in each region
  - Number of such women screened each year through BCCEDPs
  - Number of such women screened overall

  Some data were obtained from the Government Accountability Office (GAO), which published an assessment of NBCCEDP overall and by state in 2009. Mosaica contacted the authors of the report, *Medicaid: Source of Screening Affects Women's Eligibility for Coverage of Breast and Cervical Cancer Treatment in Some States,*[1] and obtained some additional data for DC, MD, and VA.
- **Breast cancer data:** Obtaining of incidence and prevalence of breast cancer in each of the seven jurisdictions, and additional data on stage of disease at diagnosis; most information came from state cancer registries, with some use of federal data.
- **Other data on programs and services:** Internet searches to obtain data on populations and services provided by DC community health centers, data on target and service populations of safety-net clinics, studies of "uninsurance" rates, and studies of health care systems.

- **In-depth data gathering** based on the findings of the first phase, including:
  - **Key informant sessions:** In-depth discussions with representatives of safety-net clinics, state and county personnel involved with the National Breast and Cervical Cancer Early Detection Program (NBCCEDP), hospitals and other mammography providers, outreach and education groups, and some surgeons who provide charity care. A separate key informant session was held in each of four jurisdictions: Northern Virginia, Prince George's County, Montgomery County, and the District of Columbia. Each session involved review and additions to a matrix of breast health care services and relationships, a discussion of how the BCCEDP works in the state or county, and identification of what works well and what barriers exist that limit access to timely breast health care services for low-income women.
  - **Reviews of key informant findings:** Emailing of the matrix of breast health care services and summary findings from the key informant meetings to all participants, to enable them to correct or add to findings. There was also a presentation and discussion of preliminary findings with safety-net clinics at NVHSC.
  - **Clinic follow-up:** Calls and emails with clinics to fill data gaps and obtain a better understanding of specific aspects of their breast health care services and partners, clinic population data, and diagnosed cases of breast cancer.
  - **Descriptive data on Montgomery County safety-net clinics:** Mosaica did not survey Montgomery County clinics, because PCC was already implementing the process improvement initiative in that county and had in-depth information about those clinics. However, PCC provided descriptive data about these clinics to supplement the clinic surveys in the other jurisdictions and permit development of a profile of the safety-net clinics in all three major components of the Washington, DC metro area: the District of Columbia, Northern Virginia, and Suburban Maryland.
  - **Interviews:** Interviews to supplement key informant sessions and explore particular topics. These were done primarily by telephone, with non-clinical outreach and support service providers; organizations funded through the state BCCEDP programs and in some

[1] Government Accountability Office, report GAO-09-384, issued May 22, 2009. Available online at http://www.gao.gov/products/GAO-09-384.

cases additional interviews with state and county BCCEDP staff; hospitals providing mammography, diagnosis, and/or treatment. Some of these interviews were done with entities that were unable to participate in the key informant sessions.

Figure 1, below, summarizes data methods and sources.

Figure 1: Data Gathering Matrix

Method	Description	Number of Individuals or Entities Reached*
Key Informant Sessions	4 2-hour sessions	Total: 73 • DC - 17 • NoVA - 22 • Prince George's County - 6 • Montgomery County - 28
Online Clinic Surveys	• Two-part SurveyMonkey online surveys targeting 23 clinics: 11 in NoVA, 1 in Prince George's County, and 11 in DC • 1 DC clinic completed only Part I because it does not target women 40+	Total: 22 clinics • DC - 10 • NoVA - 11 • Prince George's County – 1
NBCCEDP Interviews	• Interviews with State BCCEDP staff in DC, MD, and VA • Interviews with county BCCEDP staff in Prince George's County	6
Education and Outreach (Non-clinical) Provider Interviews	Interviews with education and outreach providers, some of which provide clinical breast exams and navigation or coordination of care	7
Other Interviews	Interviews with primary care association, clinics, and mammography providers	9
Other Group Sessions	DCPCA Medical Directors, Northern Virginia Health Services Coalition	3

* Includes structured formal interviews only; excludes numerous follow-up interviews, informal discussions, and email communications with clinics and other providers.

Limitations

The study has several limitations, most of them data-related.

- **Clinic data gaps due to limited or lack of electronic medical records (EMR).** Limited EMRs or paper records made it impossible for several of the clinics to provide requested information on the population of low-income women 40 and older being served and/or the number of women diagnosed with breast cancer in 2009 and 2010. Some provided estimates rather than precise data on the proportion of their female clients 40 and over who are both low-income and uninsured. Most but not all clinics have electronic medical record systems, and some that now have EMRs are not yet able to generate reports on patient demographics, insurance coverage, or breast cancer diagnoses.

- **Limitations on comparability of population and screening data:** A number of data gaps and limitations complicate presentation and comparison of population and screening data. For example, Mosaica would like to be able to present both population and screening data on women 40 and older. However, data on income and insurance coverage and on mammography screening, provided through the Census Bureau's Small Area Health Insurance Estimates (SAHIE) are available for women 40-64 but not for women 65 and over, while most of the available clinic data are for women 40 and over. The American Cancer Society provides data on screening rates for women 40-64 based on insurance status but not income. Virginia regional data are complicated by the fact that the region is divided into health districts that sometimes include both counties and small cities that are not a part of the county – the cities of Manassas and Manassas Park in Prince William County and Fairfax and Falls Church in Fairfax County. Sometimes data are available for the health district, sometimes it is possible to obtain data by municipality in a format making it possible to aggregate the data, and sometimes data are not available for the small cities within the health districts. Clinic data are generally for 2009, while SAHIE data are for 2007, and cancer data from state cancer registries are often annual averages for 2003-2007. In addition, clinics often serve people from multiple jurisdictions and did not differentiate such patients in their demographic data. These differences and limitations are indicated on the various charts and tables, but limit data comparability. As is noted in the report, there are also some questions about data quality.
- **Categorization of DC Healthcare Alliance.** One challenge of any analysis of insurance coverage in the District of Columbia is the differences in how data systems and studies categorize people who receive health care through the DC Healthcare Alliance. A recent DC uninsurance study conducted for the DC Department of Health Care Finance noted that neither the 2007-2008 Current Population Survey (CPS) March supplement nor the 2008 American Community Survey (ACS) "include the Alliance as an insurance choice, and Alliance members may report themselves as either uninsured or publicly insured." Because SAHIE data are based on the CPS, they share this shortcoming. If the Alliance is viewed as insurance, then SAHIE overestimates the number and percent of low-income uninsured women 40-64. DC clinics also differ on whether they view the Alliance as insurance or some other form of third-party reimbursement system for health care. This confusion in the categorization of DC Alliance and its members leads to higher estimates of uninsurance by national studies and makes it difficult to interpret and compare data on low-income residents of the District of Columbia.
- **Changes in the DC Health Care System.** The new health care reform legislation expands Medicaid by removing the requirement for categorical eligibility for low-income Americans with incomes below 133% of the Federal Poverty Level (FPL). While the transition to expanded Medicaid coverage is not required until 2014, the District of Columbia chose to make the transition in 2010. As of October 2010 it began moving eligible low-income individuals from the DC Alliance (which covers individuals below 200% of FPL) to Medicaid; as of December 1, it also moved individuals between 133% and 200% of FPL onto Medicaid through a waiver. The intent was to move about 35,000 of the 56,000 individuals previously covered by DC Alliance to Medicaid (32,000 under 133% of FPL and 3,000 between 133% and 200% of FPL). While some of those individuals reportedly were unable to document eligibility, most of them will be on Medicaid as of the end of 2010. All the data available to Mosaica, however, were collected prior to this change over – and reflect DC health care financing as of or prior to September 30, 2010.

- **Non-participation.** Most clinics, other providers, and state and county breast health care program staff were extremely helpful, making themselves available for interviews, providing data, and participating in key informant sessions. In a few cases, Mosaica called on colleagues that are members of RPCC or recognized leaders in the health field for assistance in making contacts. Several small suburban clinics that do not serve many low-income women 40 and over did not participate in interviews or key informant sessions. In addition, the District of Columbia Cancer Consortium declined participation.

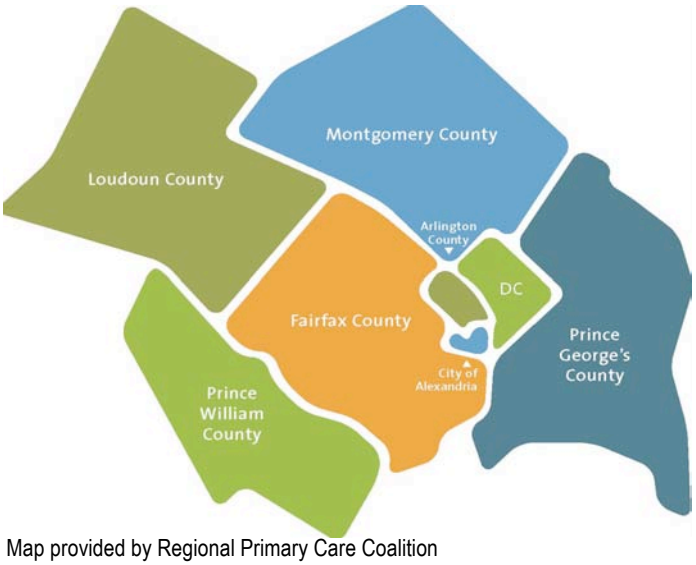
3. Population and Cancer Data

Overview

This section provides summary data on the populations of low-income, uninsured women in the general population of the District of Columbia, Northern Virginia, and Suburban Maryland, as well as data on cancer screening and breast cancer incidence. Such information is useful in targeting the resources of the Initiative to places with a high level of need and in understanding differences by jurisdiction. For similar data presented by state, see the charts in Appendix A.

For purposes of this study (as shown in the map below):

– **Northern Virginia** includes the five health districts that are part of the Northern Region of Virginia as defined by the Virginia Department of Health: Alexandria City, Arlington County, Fairfax Health District (which includes Fairfax County and the cities of Fairfax and Falls Church), Loudoun County, and Prince William Health District (which includes Prince William County and the cities of Manassas and Manassas Park).



Map provided by Regional Primary Care Coalition

– **Suburban Maryland** includes the two counties that are part of the Suburban Washington, DC health region as defined by the Maryland Department of Health and Mental Hygiene: Montgomery and Prince George's County.

The effectiveness of the Initiative has been demonstrated in Montgomery County, and expansion into additional jurisdictions is planned.

Populations of Low-income Uninsured Women

Summary: The National Capital Region includes over 120,000 low-income women aged 40-64, and it is estimated that nearly 47,000 of them are also uninsured. There are great differences

across jurisdictions in the size of the low-income populations of women 40-64, as well as in the number and the percent who are uninsured. There are also some questions about the accuracy of the Census Bureau estimates, since DC Alliance members may sometimes be counted as insured, sometimes as uninsured. The District of Columbia has the highest level of poverty among women 40-64 but the lowest percent of low-income uninsured women 40-64 – almost one-third of women 40-64 are low-income, but an estimated 17.1% of these women, and 5.6% of all women 40-64, are uninsured. This is primarily because the vast majority of DC residents have either private or public health insurance – either Medicaid or the DC Healthcare. Poverty rates are considerably lower in the other jurisdictions, and especially in Northern Virginia. However, low-income women in Northern Virginia and Suburban Maryland are much more likely to be uninsured.

Low-income and Uninsured Populations of Women 40-64: Figures 2 and 3 provide population data, by jurisdiction, on the number of women 40-64 and the number and proportion of those women who are low-income and low-income uninsured. Figure 2 provides data for the U.S., Virginia, Maryland, and the District of Columbia, as well as for the Northern Virginia (NoVA) and Suburban Maryland regions. Figure 3 provides similar data for each of the counties/health districts in Northern Virginia and Suburban Maryland. Ward data for DC are not available.

As Figure 2 indicates, the District of Columbia has the highest level of poverty among women 40-64 but the lowest percent of low-income uninsured women 40-64 – reflective of the fact that the vast majority of DC residents have private insurance, Medicaid, or DC Healthcare Alliance coverage. The DC Alliance reimburses medical costs for DC residents with incomes below 200% of the Federal Poverty Level (FPL) who do not have private insurance and are not eligible for Medicaid. There is, however, some uncertainty about the actual rate of uninsurance in the District of Columbia. The SAHIE estimate is higher than the estimate reported in the 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. That study 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.[2] The study also found that 55.6% of the uninsured have incomes of less than 200% of FPL, and therefore should be eligible for DC Alliance. 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 there are 4,238 low-income uninsured women in DC. The estimates are for different years, so are not fully comparable, but the 2007 SAHIE estimate as shown in Figure 2 is 28% higher than the 2009 DC estimate.

[2] 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.

Figure 2: Estimated Population of Low-Income Uninsured Women 40-64, 2007

Population Group	U.S.*	VA	NoVA	MD	Suburban MD	DC	Region
Population of Women 40-64	50,098,031	1,337,594	379,822	1,010,686	323,998	96,493	800,313
Number of Low-Income* Women 40-64	14,894,179	240,827	32,747	214,186	55,925	31,725	120,397
Percent of Women 40-64 who are Low-Income	29.7%	18.0%	8.6%	21.2%	17.3%	32.9%	15.0%
Number of Low-Income Uninsured Women 40-64	4,410,509	77,065	17,554	64,416	23,784	5,425	46,763
Percent of Low-Income Women 40-64 who are Uninsured	29.6%	32.0%	53.6%	30.1%	42.5%	17.1%	38.8%
Percent of Women 40-64 who are Low-Income Uninsured	8.8%	5.8%	4.6%	6.4%	7.3%	5.6%	5.8%

* U.S. low-income data are for women below 250% of FPL; other 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.

The poverty rates for women 40-64 are considerably lower in Virginia and Maryland than in DC, and lowest in Northern Virginia, where 8.6% of women 40-64 are low-income, according to 2007 Census estimates, compared to 29.7% of women 40-64 nationwide, 17.3% for Suburban Maryland, and 18% for Virginia as a whole.

However, low-income women in Northern Virginia and Suburban Maryland are much more likely to be uninsured than low-income women in DC, probably because these states have less generous Medicaid programs and lack a state-level public medical care program like DC Alliance. The Suburban Maryland rate of uninsured low-income women is somewhat lower than the Northern Virginia rate (42.5% versus 53.6%), at least partly because of several limited-coverage public programs like the Maryland Health Insurance Program (MHIP) and the Primary Adult Care program that serve some women who are not eligible for Medicaid. Differences in rates of private insurance and unionization may also be contributing factors.

Figure 3 provides data by county, which show that low-income women are most likely to be uninsured in Fairfax, Loudoun, and Arlington Counties, while the percent of all women 40-64 who are uninsured is lowest in Loudoun and highest in Prince George's and Montgomery

Counties. The percent of low-income women who are uninsured is considerably higher in Northern Virginia and in Suburban Maryland than in the states as a whole.

Figure 3: Population of Low-Income Uninsured Women 40-64 by Health District or County, 2007

Population Group	Northern Virginia					Suburban Maryland	
	Alexandria	Arlington	Fairfax	Loudoun	Prince William	Mont-gomery	Prince George's
Population of Women 40-64	24,763	34,873	211,901	43,515	64,770	174,681	149,317
Number of Low-Income Women 40-64	3,169	4,058	17,020	2,638	5,862	25,857	30,068
Percent of Women 40-64 who are Low-Income	12.8%	11.6%	8.0%	6.1%	9.1%	14.8%	20.1%
Number of Low-Income Women 40-64 who are Uninsured	1,470	2,085	9,887	1,448	2,664	12,204	11,580
Percent of All Low-Income Women 40-64 who are Uninsured	46.4%	51.4%	58.1%	54.9%	45.4%	47.2%	38.5%
Percent of All Women 40-64 who are Low-Income Uninsured	5.9%	6.0%	4.7%	3.3%	4.1%	7.0%	7.8%

Sources: Census Bureau, 2007 population estimates, and Small Area Health Insurance Estimates (SAHIE) data for 2007.

A likely partial explanation for the higher rates of low-income uninsured in these counties is that they have large populations of recent immigrants and refugees and undocumented immigrants, who are not eligible for Medicaid. Census averages for 2006-2008 indicate that the Northern Virginia counties have foreign-born populations ranging from 20-28%, Prince George's County 19%, and Montgomery County 30%. Foreign-born populations in Virginia (10%), Maryland (12%), and DC (13%) are much closer to the national percentage of 13%. Approximately one-third of these foreign-born residents are naturalized citizens, and therefore eligible for Medicaid, as are an undetermined number of long-time legal residents (those who have been legal permanent residents for five years or more).

Estimated Safety-Net Clinic Populations of Low-Income Uninsured Women

Summary: Mosaica estimates that the 31 safety-net clinics in DC, Montgomery County, Prince George's County, and Northern Virginia are serving about 34,000 low-income uninsured women 40 and older. The safety-net clinics in the District are serving about 8,000 low-income uninsured

women 40 and older, the Northern Virginia clinics about 16,050, Montgomery County clinics about 8,650, and Prince George's County clinics about 1,300. A very high proportion of clinic clients are low-income. The clinics in the four jurisdictions serve about 59,800 women 40 and older, and an estimated 55,650 – about 93% – are low-income. Because the District of Columbia insured rate, including DC Alliance, is so high, a large majority of DC women patients who are low-income are insured. Some clinics, particularly in the District, serve patients who live in other jurisdictions.

Estimated Clinic Populations Targeted by the Initiative: One of the tasks of the State of the Region Assessment was to estimate the number of women served by safety-net clinics in the District of Columbia, Northern Virginia, and Prince George's County who are 40 and older, low-income, and uninsured. In its online clinic survey, Mosaica asked all participating clinics for this information, and followed up through key informant meetings, email, and individual calls to obtain missing information. Depending upon the status of their medical records systems, some clinics were able to provide specific numbers of women 40 and over and of women in that age group who are uninsured versus ranges or estimates. Some found it easier to provide data on low-income women than on low-income uninsured women. Mosaica also checked websites and reviewed data reported to the federal Bureau of Primary Health Care (BPHC) by the DC clinics that are community health centers. Gaps were filled with information from that source. PCC provided clinic population data for Montgomery County clinics.

As Figure 4 shows, clinic data indicate that the safety-net clinics in the District are serving about 8,000 low-income uninsured women 40 and older, the Northern Virginia clinics about 16,050, Montgomery County clinics about 8,650, and Prince George's County GBMS clinics about 1,300. This means that throughout the region, approximately 34,000 low-income, uninsured women 40 and older are receiving their medical care through safety-net clinics. About 55,650 low-income women 40 and older are served by safety-net clinics in DC, Northern Virginia, and Suburban Maryland. About two-thirds (67%) of low-income clinic patients in DC are insured, most often through public insurance including Medicaid, Medicare, and the DC Healthcare Alliance. About 22% of low-income women patients 40 and older in Montgomery County clinics have insurance, as do an estimated 54% of the low-income women patients in Prince George's County and about 8% in Northern Virginia.

The Italicized lines of the figure provide the estimated number of low-income and low-income uninsured women 40-64 in the population of each jurisdiction, using SAHIE figures. *The data are not directly comparable,* primarily because the SAHIE data do not include women 65 and over and are for 2007, while the clinic data include women 40 and older as of 2009, and include an unknown number of patients who live in other jurisdictions.

The data in Figure 4 are estimates, based primarily on patient data reported by each clinic. As noted, these patients do not necessarily live in the jurisdiction where they receive medical care. The DC clinic data probably include the largest number of women who live outside the District, most often in Suburban Maryland but also in Northern Virginia. Community Health Centers and Federally Qualified Health Centers (CHCs/FQHCs) in all states, which receive considerable federal funding, are required to serve individuals regardless of their place of residence, and there are four FQHCs and one look-alike among the DC clinics, three in Northern Virginia, one in Prince George's County, and two in Montgomery County (one of which, Mary's Center for

Maternal and Child Care) is headquartered in DC but has one facility in the County). Seven of the ten DC clinics surveyed indicated that they serve patients from outside DC, as do CHCs/FQHCs in the other jurisdictions. In addition, Spanish Catholic Center is headquartered in DC but has a clinic in Montgomery County. Separate data were available by facility for the both Mary's Center and Spanish Catholic Center. The population estimate for GBMS in Prince George's County includes some women who live in Maryland counties not included in the study, as well as some DC residents.

Figure 4: Estimated Clinic and Total Populations of Low-Income Uninsured Women 40 and over
[Estimated Clinic Populations rounded to nearest 50]

Patients*	DC	NoVA	Prince George's	Mont-gomery	Total
Number of Reporting Clinics	10	11	1	9†	31
Number of Facilities	25	29	5	33†	92
Reported Number of Women 40+ in Patient Population, 2009	25,700	18,000	2,900	13,200	59,800
Estimated Number of Low-Income Women 40+, 2009	24,200	17,450	2,850	11,150	55,650
SAHIE Estimated Number of Low-Income Women 40-64, 2007	*31,725*	*32,747*	*25,857*	*30,068*	*120,397*
Estimated Number of Low-Income Uninsured Women 40+, 2009	8,000	16,050	1,300	8,650	34,000
SAHIE Estimated Number of Low-Income Uninsured Women 40-64, 2007	*5,425*	*17,554*	*12,204*	*11,580*	*46,763*

* Includes an unknown number of residents of other jurisdictions.
† In addition to 9 safety-net clinics headquartered in Montgomery County, 2 clinics headquartered in DC have 1 facility each in the County.

Source: Clinic 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, primarily 2009 data. Population estimates from Census Bureau Small Area Health Insurance Estimates (SAHIE), 2007.

Some other caveats:

- **Clinics sometimes do not have precise figures on the number or percent of women patients 40 and older who are low-income and uninsured.** The accuracy of these estimates depends on the completeness and accessibility of each clinic's demographic data. Some of the clinics serve only uninsured people, while others, including the community health centers/Federally Qualified Health Centers (CHCs/FQHCs), receive third-party reimbursements, particularly for patients with Medicaid and, in DC, DC Alliance. The estimates of low-income patients obtained from annual reports and other demographic summaries are more accurate than the estimates provided in the survey, so those data were used instead where available.
- **Most clinic data are for 2009, but some adjustments were made using older data.** DC data provided by the clinics were for 2009, with supplementary information from clinic annual reports, usually for 2009, and also Bureau of Primary Health Care (BPHC) used to fill

in data gaps was for 2006. Some estimates were made in the other jurisdictions to fill in missing data when clinics could not provide it. Some clinics, particularly non-FQHCs that do limited or no third party billing or clinics that have either no electronic medical records or system limitations, were unable to provide precise data on insurance status.

Breast Cancer Screening Rates

Summary: 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 residents of all three regional jurisdictions 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.

Screening: Figure 5, below, provides data on cancer screening for states within the region. County and health district data are not available.

Figure 5 shows the proportion of women in the U.S. and in Virginia, Maryland, and the District of Columbia receiving mammograms overall and through the NBCCEDP program, which provides funding to states for breast cancer screening and diagnosis for low-income women who are uninsured or whose insurance does not cover these services.

Figure 5: Breast Cancer Screening Rates: Percent of Women Receiving a Mammogram

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 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%
Percent of eligible women 40-64 screened by other providers (2006-2008)	26%			
Percent of eligible women 40-64 not screened (2006-2008)	60%			

* 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 estimate of women eligible for NBCCEDP who were screened by other sources from GAO 2009 report on NBCCEDP.

As Figure 5 indicates, screening rates for all women 40 and over and for women 40-64 are slightly above the national average in the District of Columbia, Maryland, and Virginia, with rates reportedly highest in DC. The percentage of eligible women 40-64 who received a

mammogram through NBCCEDP was reported to be higher in DC (22.0%) than in the other jurisdictions. The rate of eligible women screened was lowest in Virginia (12.3%).

The NBCCEDP data should be viewed with some caution. The DC NBCCEDP program, Project WISH, has a history of screening many women from Maryland and Virginia. It is not clear how these women are counted in the screening rates. If they are included without differentiation by state of residence, the actual screening rate for DC residents may actually be lower, and the rates for Maryland and Virginia somewhat higher, than reported.

Breast Cancer Incidence and Mortality Rates

Summary: Breast cancer mortality is higher than the national average in DC, Maryland, and Virginia. Incidence in most parts of the region is also higher than for the U.S. as a whole. The District of Columbia has the highest breast cancer incidence rate in the region, and Prince George's County, the District, and Prince William Health District have the highest breast cancer mortality rates. Women in Prince George's and Montgomery Counties are most likely to be diagnosed while their cancer is still at the *Localized* stage and least likely to be diagnosed when it is at the *Distant* stage. Women in Arlington County are most likely to be diagnosed when their cancer is in the *Regional* or *Distant* stage.

Figures 6, 7, and 8 provide data on breast cancer incidence and mortality rates (number of new cases and death rates per 100,000 population) and the percent of women at each stage of breast cancer when diagnosed – an indicator of early versus late diagnosis. Staging data are not available by ward.

Figure 6: Breast Cancer Data by State and Region, 2003-2007

	U.S.	VA	NoVA	MD*	DC
Breast Cancer Incidence Rate (per 100,000)	120.6	122.1	120.4	123.8	144.7
Breast Cancer Mortality Rate (per 100,000)	24.0	25.6	24.4	25.8	28.5
Percentage of Women Diagnosed at *Localized* Stage		44%	46%	56%	47%
Percentage of Women Diagnosed at *Regional* Stage		24%	24%	31%	31%
Percentage of Women Diagnosed at *Distant* Stage		20%	18%	5%	6%
Percentage of Women with *Unstaged* Diagnosis		12%	12%	8%	15%

* Separate data are not available for the Suburban Maryland region.

Sources: U.S. and State rates from State Cancer Profiles, 2003-2007. DC data from District of Columbia Cancer Registry, Maryland Cancer Registry, and Virginia Cancer Registry, all providing annual averages for the period 2003-2007. Incidence and mortality rates are age-adjusted to the 2000 U.S. standard population.

Incidence: As Figure 6 shows, the incidence rate for breast cancer in the District of Columbia (144.7) is about 20% higher than the U.S. rate (120.6), and 17-19% higher than the rates in Virginia (122.1) and Maryland (123.8). Figure 7 shows that all the suburban counties have incidence rates lower than the District, but Montgomery County (129.6) and Fairfax Health District (126.7) have incidence rates considerably above the overall rates in their state. Alexandria has the lowest incidence rate in the region (93.9), and Arlington County (113.5),

Prince William Health District (116.2), and Prince George's County (116.7) all have incidence rates slightly below state and federal levels. The Loudoun County rate (121.3) is slightly below the Virginia state incidence rate. Figure 8 shows the considerable variations in breast cancer incidence and mortality rates by ward. The data indicate that the highest incidence rates are in Wards 2 and 3. While these are five-year averages, the populations are relatively small, so considerable variation might be expected in both DC wards and in the counties and health districts with relatively small populations, such as Alexandria, which has fewer than 34,000 women 40 and older.

Figure 7: Breast Cancer Data by Health District and County, 2003-2007

	Alexandria	Arlington	Fairfax	Loudoun	Prince William	Mont-gomery	Prince George's
Breast Cancer Incidence Rate (per 100,000)	93.9	113.5	126.7	121.3	116.2	129.6	116.7
Breast Cancer Mortality Rate (per 100,000)	17.1	24.7	23.4	26.2	28.1	20.2	30.3
Percentage of Women Diagnosed at *Localized* Stage	44%	41%	47%	48%	44%	56%	49%
Percentage of Women Diagnosed at *Regional* Stage	25%	26%	24%	24%	24%	28%	36%
Percentage of Women Diagnosed at *Distant* Stage	18%	20%	18%	15%	20%	4%	5%
Percentage of Women with *Unstaged* Diagnosis	14%	13%	11%	13%	12%	12%	10%

Sources: Maryland 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.

Figure 8: Breast Cancer Data for Washington, DC by Ward, 2003-2007

	Wards								DC
	1	2	3	4	5	6	7	8	
Breast Cancer Incidence Rate (per 100,000)	128.3	174.4	166.0	132.3	136.2	104.3	118.9	122.9	144.7
Breast Cancer Mortality Rate (per 100,000)	23.9	36.4	25.6	28.0	27.3	20.4	30.8	29.0	28.5

Source: District of Columbia Cancer Registry; annual averages for the period 2003-2007, with rates age-adjusted to the 2000 U.S. standard population.

Incidence among Clinic Patients: Mosaica asked clinics survey to report the number of diagnosed cases of breast cancer in 2009 and in 2010 (generally as of June 2010). Some clinics were unable to provide this information because they do not have electronic medical records systems or their systems cannot yet generate these reports. Reported cases are summarized below.

Figure 9: Breast Cancer Cases Reported by Safety-Net Clinics

Data Category	District of Columbia	Northern Virginia	Prince George's County	Total
Approximate Number of Female Patients	18,200	2009: 24,300 2010: 36,100	7,100	2009: 49,600 2010: 61,400
Number of Clinics Reporting	7	2009: 7 2010: 8	1	2009: 15 2010: 16
Number of Cases, 2009	21	22	1	44
Incidence Rate, 2009	115.4	90.5	14.1	88.7
Number of Cases, 2010 (Incomplete year)	16	82* (29 from clinics reporting both years)	0	98 (45 from clinics reporting both years)

* Includes rough estimate of 53 cases provided by one large clinic based on number of females with a tumor marker CA-27.29.

Sources: Reports from clinics, supplemented by client data in annual reports and FQHC reports submitted to the federal Bureau of Primary Health Care.

As the figure shows, for calendar year 2009, 15 clinics with data on cancer cases reported a total of 44 cases of breast cancer among their patient population of about 49,600 female patients. The rates are considerably below the official incidence rates, probably because of incomplete data. In addition, the populations served by the clinics are relatively small, so a very small number of cases mean a large change in the incidence rates.

Mortality: Figures 6, 7, and 8 also show mortality rates by jurisdiction. The breast cancer mortality rate is highest in Prince George's County (30.3 per 100,000 population), followed by the District of Columbia (28.5) and Prince William Health District (28.1); the rate in Prince George's County is 6% above the DC rate. These incidence rates are 17-25% higher than the U.S. mortality rate (24.0), and well above the rates for Maryland (25.8) and Virginia (25.6). The mortality rates are lowest in Alexandria (17.1) and Montgomery County (20.2), and lower than the national average in Fairfax Health District (23.4). The mortality rate in Loudoun County (26.2) is slightly above the Virginia state rate, while the rate in Arlington County (24.7) is slightly below the state rate. Within the District, Ward 2 has the highest mortality rate (36.4). These rates, even more than the incidence rates, are likely to be quite variable in wards or counties with small populations, where a very few deaths will greatly increase mortality rates.

Stage: Data on stage of cancer at diagnosis indicate that women in Virginia (44%) including Northern Virginia (42%) are more likely to be diagnosed at later disease stages (*Regional* or *Distant*) than women in the District (37%) or Maryland (36%). Comparisons are complicated by differences in the percent of women whose stage of disease at diagnosis was not reported or determined; 15% of DC cases fall into this category, compared to 8-14% of women in the other state and local jurisdictions. County and health district comparisons indicate that women in Montgomery County (56%) are most likely to be diagnosed when their disease is at the *Local* stage and least likely to be diagnosed at the *Regional* or *Distant* stages (32%). Except for the District (37%) and Loudoun County (39%), at least 41% women in each county or health district are diagnosed at these later stages. In Montgomery County, 4% of women with breast cancer are diagnosed when their cancer is at the *Distant* stage, compared to 5% in Prince George's County, 6% in the District, and 15-20% in the other counties and health districts. Women in Prince

William and Arlington County (20%) are most likely to be diagnosed at the *Distant* stage. The data do not appear to show a direct relationship between stage of cancer at diagnosis and mortality rate.

4. Breast Health Care Services

Overview

This section provides information on breast health care services in the region and how they are delivered. It provides information from three perspectives:

1. Because the major source of public funding for breast cancer screening and diagnosis for low-income uninsured women is the National Breast and Cervical Cancer Early Detection Program, information is provided about the programs as they operate in each state and in particular counties or health districts within the metropolitan area.
2. Because the Initiative is clinic-based, the State Assessment included online surveys, follow-up communications, and secondary research on 22 clinics in the District, Northern Virginia, and Prince George's County that serve low-income women 40 and older, and obtaining of more limited data from PCC on 9 clinics headquartered in Montgomery County. The report provides a profile of all 31 of these safety-net clinics, and a more detailed description of the 22 clinics in DC, Northern Virginia, and Prince George's County and their roles in breast health care.
3. To provide an understanding of how clinics and other provides deliver and payers interact in the delivery of breast health care services, Mosaica provides sample flow charts and a narrative description of breast health care services – from outreach through follow-up – in the District, Northern Virginia, Prince George's County, and Montgomery County. More detailed information for each of the four target jurisdictions is provided in Appendix B, including a matrix of services for each geographic area and a narrative description of services, linkages, and challenges. The matrixes not only identify the providers of breast health services but also indicate which clinics refer to and collaborate with which hospitals, private or nonprofit mammogram providers, health departments, non-clinical nonprofits, hospices, and other entities. Appendix C provides a Provider Chart listing providers of breast health care services and specifying the jurisdictions where they provide services.

National Breast and Cervical Cancer Early Detection Programs

Summary: The National Breast and Cervical Cancer Early Detection Program (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 women, primarily aged 40-64. A key element of the national program is that states must provide special categorical eligibility to Medicaid for women with breast cancer screened under the program, if they are low-income and otherwise eligible for Medicaid (e.g., citizens or legal residents for more than five years). State matching funds are required, and some states (including Maryland and DC) 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. The program

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 NBCCEDP programs in the region all provide screening and diagnosis of low-income women 40-64 and have important similarities because of federal guidelines. They also have important differences. Program coverage is especially limited in Virginia, where the program has an income limit of 200% of FPL rather than 250% as in DC and Maryland. It has only four local providers, and the program must enroll women and pay for their screening and/or diagnosis in order for the women to be eligible to apply for categorical Medicaid coverage if diagnosed with breast cancer. 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 provide screening for DC women with incomes of 200-250% and then makes services available for women from the suburbs for at least part of each year.

Overview of the National Program: NBCCEDP provides breast and cervical cancer screening to low-income women between the ages of 18 and 64, with a focus on women 50-64. The Centers for Disease Control and Prevention (CDC) provides funds to the states, which must provide at least a $1:$3 match in nonfederal resources. States set income limits up to 250% of FPL. Under the program, at a minimum, states are expected to provide treatment services through Medicaid for low-income women screened or diagnosed by a CDC-funded provider with NBCCEDP funds. States define what that means. Seventeen states (including Virginia and the District of Columbia) meet only the minimum requirement of offering Medicaid eligibility to women who were *screened or diagnosed with CDC NBCCEDP program funds*. Another 15 states (including Maryland) extend Medicaid eligibility to low-income women screened by CDC-funded providers *even if the screening was not paid for with NBCCEDP funds,* and 19 other states go further and extend eligibility to low-income women *even if they were screened in a non-CDC-funded facility.*

Implementation by the District of Columbia, Maryland, and Virginia: Figure 10 summarizes the structure and scope of the national program and describes the program as implemented in Maryland, Virginia, and the District of Columbia.

As the chart indicates, the Virginia program, Every Woman's Life (EWL), has more limited income eligibility than the DC or Maryland programs (200% of poverty instead of 250%). In addition, Virginia will not consider women for Medicaid coverage unless they have been either screened or diagnosed with project funds, and there are only four funded providers in Northern Virginia. Only one of Northern Virginia's three CHCs/FQHCs (Alexandria Neighborhood Health Services, Inc.) is an EWL provider. There are no state general funds available in Virginia to cover women who are not eligible for Medicaid. Maryland will consider for Medicaid women screened by its funded providers (9-10 each in Prince George's County and Montgomery County) regardless of whether screening was done with NBCCEDP funds. Maryland's Breast and Cervical Cancer Program (BCCP) also uses state general funds to provide treatment for many low-income women who cannot quality for Medicaid, often through paying premiums for MHIP (Maryland Health Insurance Plan).

Figure 10: National Breast and Cervical Cancer Early Detection Programs in the Washington, DC Region

Component/ Characteristic	National Program	District of Columbia*	Maryland	Northern Virginia
Project Name	National Breast and Cervical Cancer Early Detection Program (NBCCEDP)	Project WISH	Maryland Breast and Cervical Cancer Program (BCCP) and two related programs providing diagnosis and treatment	Every Woman's Life (EWL)
Income Eligibility	▪ Low-income, defined as up to 250% of the Federal Poverty Level (FPL) ▪ FPL may be adjusted in late January 2011	▪ Between 200-250% of FPL [Does not target women < 200% of FPL because they are covered by DC Alliance]	< 250% of FPL (income limit of $27,075 for an individual and $55,125 for a family of 4)	< 200% of FPL (200% of FPL is $21,660 for an individual and $44,100 for a family of 4)
Medicaid or other Treatment Coverage	▪ States provide treatment services through Medicaid for women who were *screened or diagnosed* by a CDC-funded provider with NBCCEDP funds – states choose definition ▪ While on Medicaid, women receive full coverage; Medicaid ends when cancer treatment is completed	▪ Policies say Medicaid only for women who meet income guidelines and were screened or diagnosed with Project WISH funds, but providers say in practice, women who meet income and other guidelines are enrolled in Medicaid ▪ If < 200% of poverty, most women not eligible for Medicaid are covered by DC Alliance	▪ Women with abnormal mammograms channeled to Women's Breast and Cervical Cancer Health Program (WBCCHP) if Medicaid-eligible ▪ If not Medicaid-eligible, can apply to the Breast and Cervical Cancer Diagnosis and Treatment Program (BCCDTP) to obtain diagnosis & treatment paid with state general funds	▪ Medicaid access only for women who meet income and other guidelines and were screened or diagnosed through a funded provider, using Every Woman's Life funds ▪ No other public funds available for treatment; efforts to obtain general funds have been unsuccessful

Component/ Characteristic	National Program	District of Columbia*	Maryland	Northern Virginia
Age Eligibility and Priority	▪ Priority: women 50-64 ▪ Eligible: women 18-64 ▪ ≤ 25% of mammograms for women < 50	▪ Priority 50-64 ▪ 25% can be 40-49	▪ 40-64 ▪ Priority group 50-64 ▪ 65+ for women without Medicare Part B	▪ 40-64
Contractors/ Providers	▪ State decides whether to implement program at the state level with state subcontractors and/or provide funds to local health departments for service coordination or subcontracting at the local level	▪ Enrollment through DC Department of Health ▪ Until current suspension of services, 10 providers under contract for screening and diagnosis – 1 nonprofit mammography provider – 3 hospitals – 2 clinics – 2 individual physicians	▪ Enrollment through county health departments ▪ Each county contracts for clinical breast exams, mammograms, and diagnostic services ▪ Montgomery County providers: – 4 hospitals – 3 private radiology groups – 3 physicians ▪ Prince George's County providers: – 1 CHC – 3 other clinics/health centers – 1 private radiology group – 3 hospitals and 1 hospital-related entity	▪ Enrollment through 4 Northern Virginia providers, which screen and/or refer clients to subcontractors for screening and diagnosis: – Alexandria Neighborhood Health Services, Inc. (ANHSI) – Capital Breast Care Center (DC) – Vietnamese Resettlement Association (Fairfax) – Prince William Health Department (new in late 2010)
Key Factors and Issues	▪ Program capacity of program typically insufficient to meet need – one-third of states suspended screening or diagnostic services at some point between 2005-2008 ▪ Nationally, about 15% of eligible women screened ▪ Unclear what will happen to program under health care reform	▪ Program not fully used by DC residents, so has typically paid for screening of VA and MD residents for at least part of the year ▪ Provides funding to groups for education and outreach ▪ Program suspended for review and refinement in October 2010 and expected to resume in January 2011	▪ Program run partly at the state level and partly by county health departments ▪ Application process & documentation requirements for BCCDTP extremely complicated and challenging ▪ Planned Extended Treatment Program to fund counties to contract with treatment providers; not	▪ Program operated at the state level ▪ Women must be screened or diagnosed with EWL funds to get into Medicaid for treatment

Component/ Characteristic	National Program	District of Columbia*	Maryland	Northern Virginia
			yet implemented in Prince George's or Montgomery County, due to "home rule" county contracting issues	

* Program as it existed until activities were suspended as of October 2010.

Sources: National and summary state data obtained from Government Accountability Office (GAO) report, "Medicaid: Source of Screening Affects Women's Eligibility for Coverage of Breast and Cervical Cancer Treatment in Some States", May 2009. State data obtained from DC, Maryland, and Virginia department of health staff responsible for the programs, state department of health websites, and county personnel engaged in implementation at the local level.

Both the Maryland and Virginia programs have insufficient funds to meet demand, while the District of Columbia has focused on women between 200-250% of poverty because most women below 200% of poverty are covered by either Medicaid or DC Alliance. DC has been unable to use all screening funds so has typically screened residents of Northern Virginia and Suburban Maryland during at least part of the year. DC also provides considerable funding for outreach and education.

A temporary change occurred in the District of Columbia program at the beginning of Fiscal Year 2011. Provider contracts under Project WISH were suspended while the project was to be reviewed and refined, which meant no new patients were enrolled from October through December 2010. Follow-up continued for women who had received an abnormal mammogram and for women needing a 6-month diagnostic follow-up. The program's newly assigned staff indicated in early December that new contracts were being negotiated and new patients would be enrolled starting in January 2011. Since the population of eligible women without insurance or related health coverage in the District remains small – primarily women with incomes 200-250% of FPL – Project WISH plans to continue providing services to women from Maryland and Virginia.

Safety-Net Clinics that Serve as Medical Homes

Summary: Safety-net clinics – including CHCs/FQHCs, free, public, hospital-based, and other nonprofit clinics – play a key role in providing and coordinating breast health care services throughout the 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 31 clinics in the region have a total of 92 sites at which they provide health care; they include 9 CHCs/FQHCs. Their target areas vary from several neighborhoods to multiple counties or neighborhoods that cross state lines.

Of the 22 clinics in DC, Northern Virginia, and Prince George's County that were the focus of this assessment, 10 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.

Despite a very high level of insurance coverage, clinics in the District of Columbia report greater difficulties than Northern Virginia and Prince George's County clinics in getting care for their patients. Surgical treatment, non-surgical treatment, and follow-up care represent the greatest challenges.

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 & diagnosis, and treatment. It maintains the patient's medical records.

Description of the Region's 31 Safety-net Clinics

Mosaica carried out online surveys that reached all 22 safety-net clinics in the District, Prince George's County, and Northern Virginia that target low-income women 40 and older. The Primary Care Coalition provided descriptive information about nine additional safety-net clinics headquartered in Montgomery County that serve this population of women. These Montgomery County clinics were not surveyed about their breast health care services, because PCC has already implemented its Regional Initiative with the clinics that are part of the Montgomery Cares network. The clinics are listed below.

Safety-Net Clinics in the Washington, DC Region That Serve Low-income Women 40 and Older

District of Columbia
- Bread for the City
- Carl Vogel Center
- ***Community of Hope***
- Family & Medical Counseling Services
- ***La Clínica del Pueblo***
- ***Mary's Center***
- So Others Might Eat
- Spanish Catholic Center
- ***Unity Health Care***
- Whitman-Walker Clinic

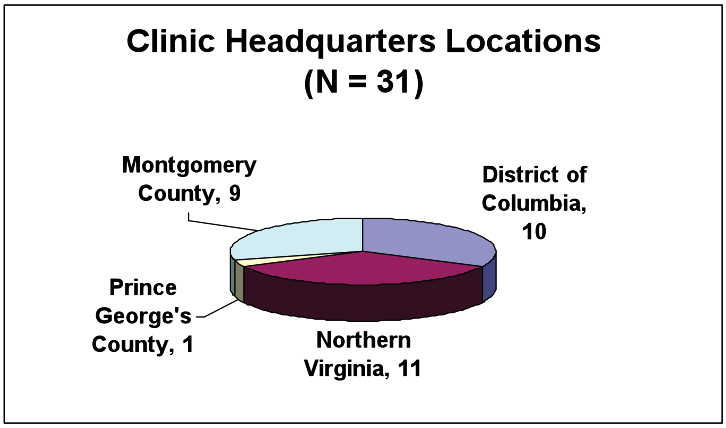
Prince George's County
- ***Greater Baden Medical Services, Inc.***

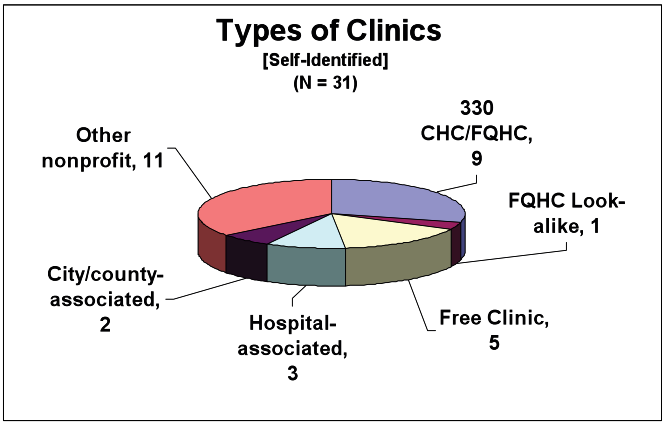
Montgomery County
- Chinese Culture and Communication Center, Inc. (CCACC Pan Asian Volunteer Health Center)
- ***Community Clinic, Inc.***
- Community Ministries of Rockville Mansfield Kaseman Health Clinic
- Holy Cross Health Center
- Mercy Health Clinic
- Mobile Med
- Muslim Community Center
- Proyecto Salud
- People's Community Wellness Center

Northern Virginia
- Alexandria Health District
- ***Alexandria Neighborhood Health Services, Inc. (ANHSI)***
- Arlington Free Clinic
- Community Health Care Network (Fairfax County)
- Culmore Clinic
- Family Health Connection
- ***Greater Prince William CHC***
- Inova Health System
- Jeannie Schmidt Free Clinic
- ***Loudoun CHC***
- Loudoun Free Clinic

* ***Bold Italics*** indicates a CHC/FQHC

As the charts that follow indicate, the 31 clinics vary in structure, size, number of facilities, whether they serve people who live outside their primary target community, use of



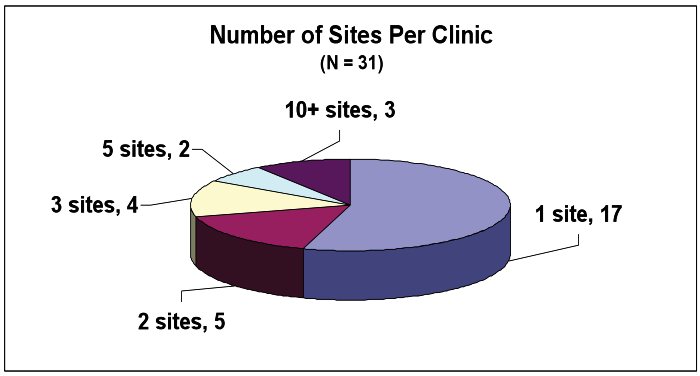


electronic medical records, and many other factors, as described below. They share a focus on providing primary health care to people who might otherwise be unable to obtain needed care.

Clinic location: As the pie charts above show, the clinics are about equally divided by state – 10 are headquartered in the District of Columbia, 11 in Northern Virginia, and 10 in Suburban Maryland. However, there are 9 clinics headquartered in Montgomery County and just 1 in Prince George's County, though the counties have similar population size (about 946,200 in Montgomery County and 835,000 in Prince George's County), and Prince George's County has a higher poverty rate (7.4% versus 5.3%)[3] and a larger number and percent of uninsured residents 0-64 (20.2% versus 14.7%)[4] and therefore likely to need low-cost health care as provided by safety-net clinics.

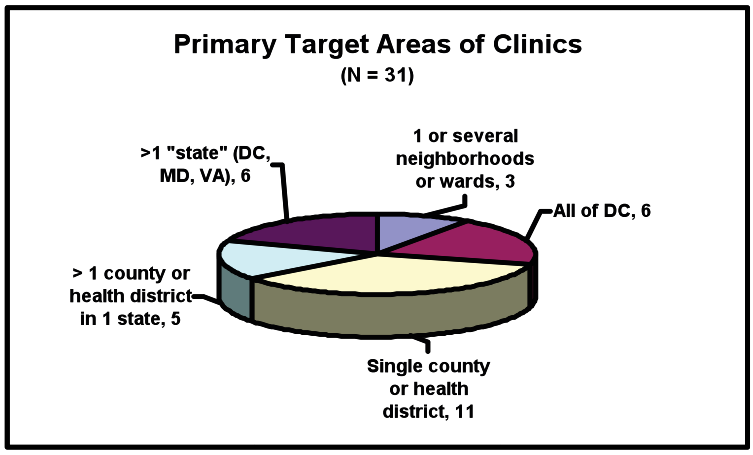
Types of clinics: Nine of the 31 clinics are designated as Community Health Centers or Federally Qualified Health Centers, and 1 more is an FQHC "look-alike." Five of the clinics describe themselves as free clinics – they are nonprofit, tax-exempt safety-net clinics that provide care primarily to individuals and families who have limited incomes and are uninsured, offer care free or at very low cost, and provide essential services regardless of a patient's ability to pay. Most are supported largely through grants and donations, and many do not take third-party reimbursements through sources such as Medicaid and DC Alliance, but this varies by clinic. The National Association of Free Clinics describes free clinics as being volunteer-based, but area free clinics vary in the extent to which they depend on staff versus volunteers.[5] Another three of the region's safety-net clinics are hospital-associated, two are county or city-associated, and 11 are nonprofit clinics that fit none of these categories.

[3] Census Bureau, American Community Survey 5-year averages 2005-2009.
[4] Census Bureau, Small Area Health Insurance Estimates (SAHIE), data showing Health Insurance Coverage Status for All Counties; data for individuals under age 65, all income levels, both sexes, 2007.
[5] See the National Association of Free Clinics website, http://www.freeclinics.us/what_freeclinic.php.

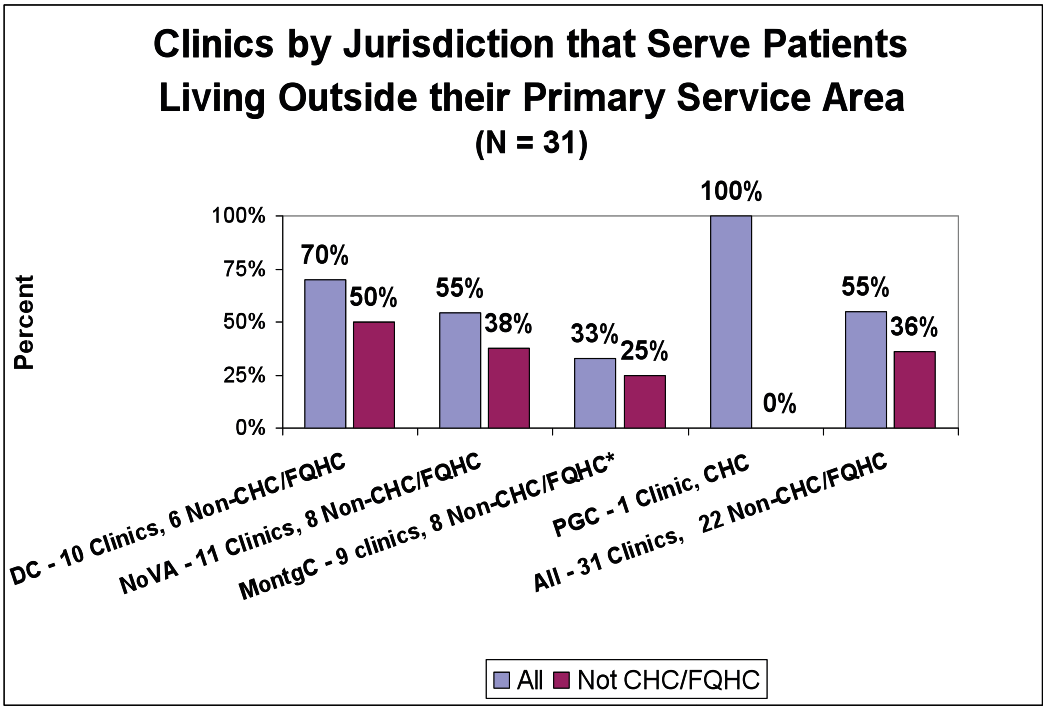


Number of clinic sites: The 31 clinics have a total of 92 sites at which they provide health care. Twenty-nine have clinic facilities only in their headquarters state, but two – both headquartered in the District of Columbia – have one site each in Montgomery County. As the pie chart shows, a majority of the clinics (17) have only one site, 11 have 2-5 sites each, and 3 have ten or more sites. These include two CHCs/FQHCs and one hospital system-associated clinic. One (Unity Health Care) is located in the District of Columbia, one (Greater Baden Medical Services) in Prince George's County, and the other in Northern Virginia (Inova Health System).

Primary target areas: Target areas for the clinics vary from several neighborhoods to multiple counties or neighborhoods that cross state lines. Over one-third (11) of the 31 clinics serve a single county or (in Northern Virginia) a single health district, and 3 others serve one or several neighborhoods or wards within DC or within a single county. The others serve larger areas – 6 target all of DC, 5 target more than one county or health district, and 6 target areas in more than one state – generally the District of Columbia plus Maryland and/or Virginia.



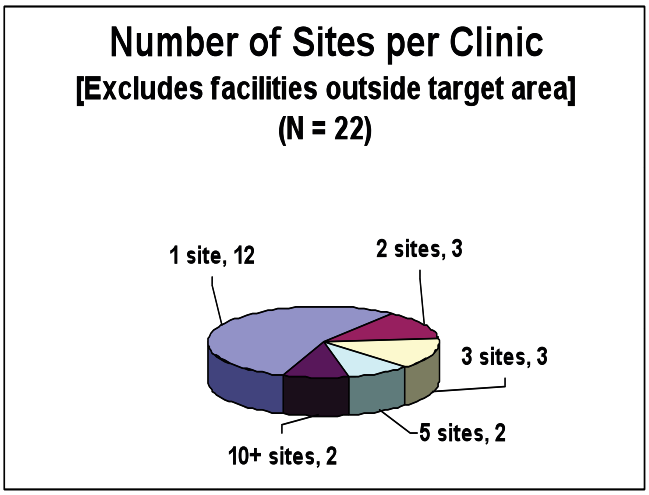
Serving patients who live outside the primary target area: Some clinics serve patients who live outside their target areas; others do not. CHCs/FQHCs are required to serve individuals regardless of their place of residence. As the bar chart shows, a majority of the region's safety-net clinics (55%) and a majority in every jurisdiction except Montgomery County serve people who live outside their primary service area, but – except in DC – a minority of non-CHCs/ FQHCs do so. Clinics associated with cities or counties are particularly likely to have residency requirements.

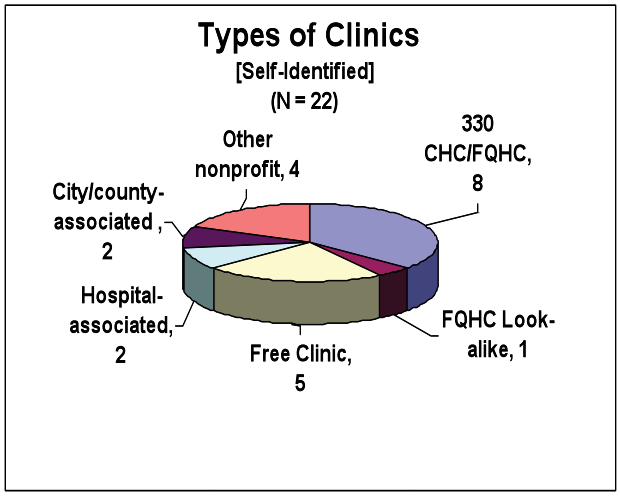


Overall 36% of non-CHCs/FQHCs report serving patients living outside their service area; the proportion is lowest in Montgomery County, at 25%, and highest in DC, at 50%.

Description of the 22 Safety-Net Clinics in Washington, DC, Northern Virginia, and Prince George's County

Summary: Of the 31 safety net clinics in the region, 22 (11 in Northern Virginia, 10 in DC, and 1 in Prince George's County) were surveyed about their involvement in breast health care for

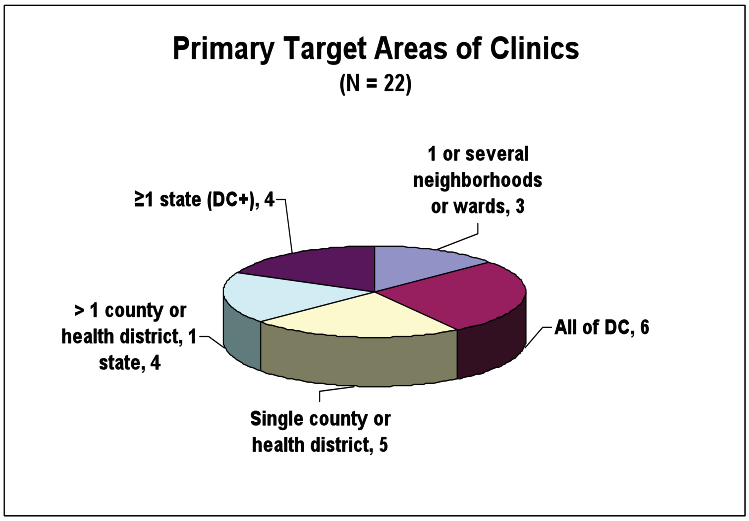




women 40 and older. All these clinics provide or coordinate breast health care services to low-income and uninsured women 40 and older. They vary in size, type, target area, number of sites, funding for breast health care services, partnerships for providing such services, and other characteristics.

Types of clinics: The clinics include 8 CHCs/FQHCs and 1 FQHC look-alike, 5 free clinics, 2 hospital-associated, 2 city/county-related, and 4 other nonprofit clinics. Together they have a total of 61 facilities.

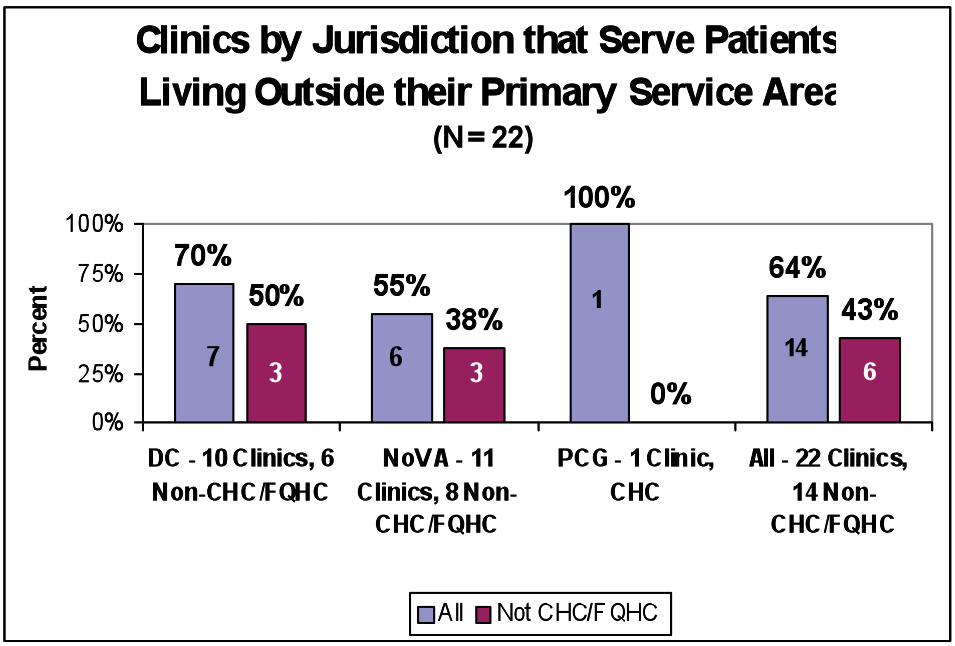
Number of clinic sites: A majority of clinics (12) have just 1 clinic site; four (4) have 5 or more sites: Unity - 14, Inova -10, GBMS – 5 in Prince George's County (and 2 in other Maryland counties), and ANHSI - 5. Two clinics, Mary's Center and Spanish Catholic Center, are headquartered in DC but have a facility in Montgomery County that serves patients from both Montgomery and Prince George's County. The Unity clinics now include Columbia Road Health Center, formally an independent FQHC. In addition to its clinics, Unity has 11 shelter- and jail-based sites.



Target areas: Most of the clinics

target either all of DC (6) or a single county or health district (5); 4 have target areas that cross state lines, and 7 target areas that are smaller than a county or include several DC wards.

Serving patients who live outside the primary target area: A majority of the clinics (14 of 22) but a minority of non-CHC/FQHC clinics (6 of 14) accept patients from outside their target area. The 8 CHCs/FQHCs are *required* to serve patients regardless of residence. Clinics in the District of Columbia are more likely than clinics in Northern Virginia to report serving patients outside their primary service area, as shown below. They are particularly likely to report serving patients who live in Prince George's County.

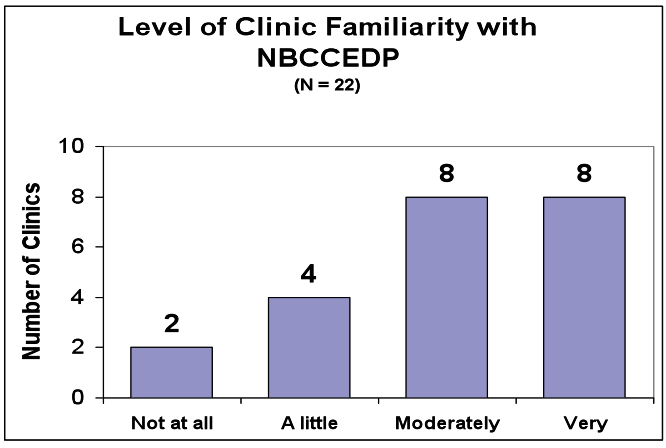


Several DC clinics indicated that they find it particularly difficult to serve patients from Virginia, noting the challenges they face in finding treatment options for uninsured Virginia residents. The Northern Virginia clinics that are either run by or funded largely by county health departments typically do not serve patients from outside the county, except for particular services provided with federal funds, such as HIV testing. Free clinics are also particularly likely to indicate that they serve only residents of the county or city in which they operate.

Clinic Breast Health Care-related Funding and Services

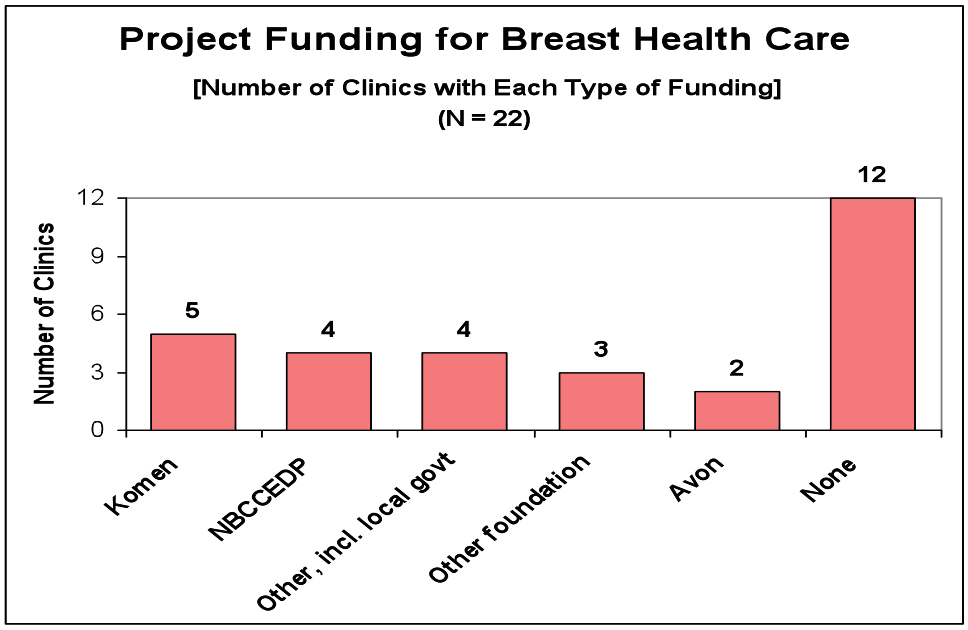
Familiarity with NBCCEDP: The safety-net clinics vary considerably in the breast health care services they provide, funding to support such services, and knowledge of and involvement with their state's NBCCEDP program.

About three-fourths (73%) of clinics indicated that they are they are *moderately* or *very* familiar with the program. However, half the clinics – 8 of 11 in Northern Virginia 3 of 10 in the District of

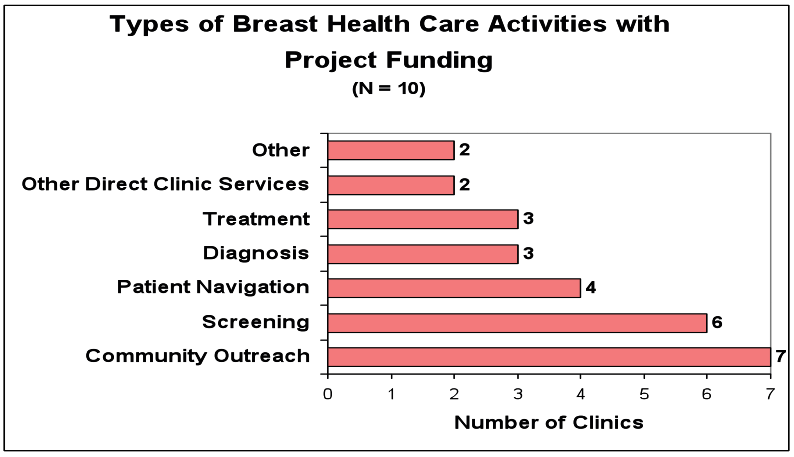


Columbia – said they do not refer any of their patients for screening under the program. Every Woman's Life requires that women be screened or diagnosed under the program in order to qualify for the special categorical Medicaid coverage for women with breast cancer, so unless they make a referral to the program after screening, their patients diagnosed with breast cancer cannot qualify for Medicaid-funded treatment under the program even if they meet eligibility guidelines.

Funding for Breast Health Care Services: Ten (45%) of the safety-net clinics report some form of funding to support their breast health care services. As the bar chart indicates, they are most likely to report funding from Susan G. Komen for the Cure (5) or from their state's NBCCEDP program (4). None of the clinics reported receiving corporate funding for such services.



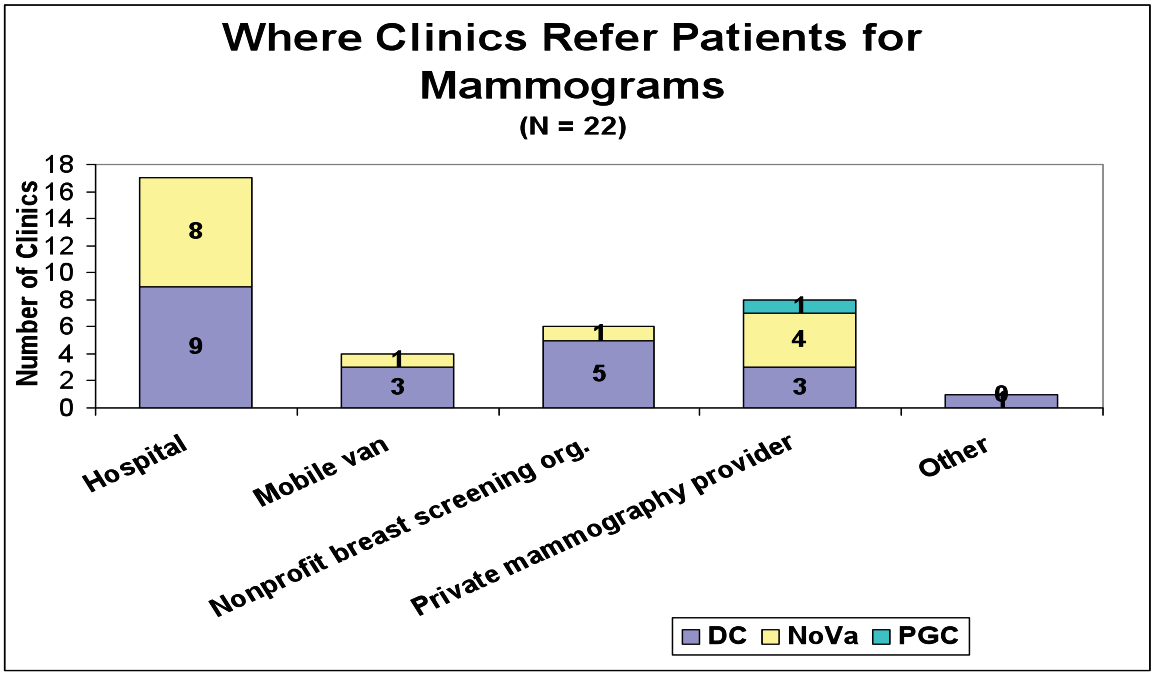
The ten clinics with breast health care funding use these resources for a variety of services, as shown below. Most often, funding supports community outreach and screening (including clinical breast exams as well as mammograms).



Referrals for Screening: Most of the safety-net clinics refer patients to hospitals for mammograms. Referrals in DC are more varied than in Northern Virginia, and the Prince George's County clinic reported primarily using a private mammography provider funded under the Maryland BCCP program. Both several hospitals and the nonprofit breast screening organization, Capital Breast Care Center, are funded under Project WISH, and several hospitals also accept reimbursement through DC Alliance.

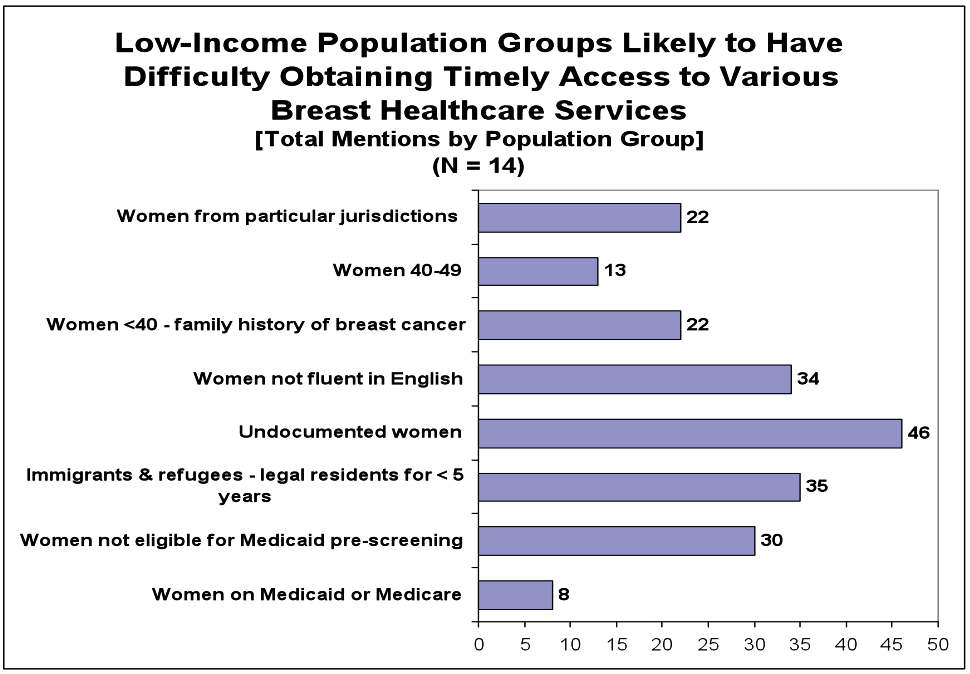
Policies and Practices: Twenty clinics provided information on clinic policies regarding referrals for mammograms. Of these, 16 (80%) said they have a referral policy, 3 (15%) said they have no policy, and 1 (5%) was unsure. Policies vary:

– Some have adopted the new federal guidelines for annual mammograms beginning at age 50 (instead of 40) unless there is a family history of breast cancer, with biannual mammograms recommended for women 40-49

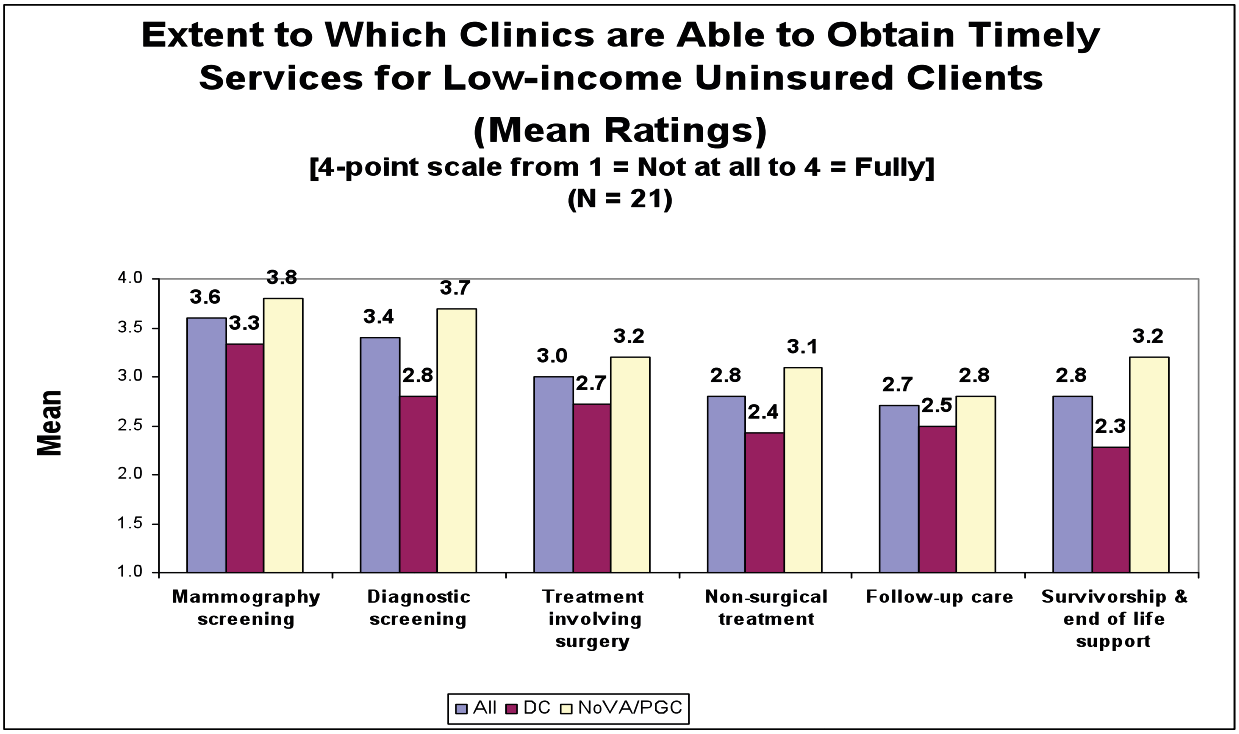


– Some continue to refer women for annual mammograms at age 40
– Most indicated that because they take family histories, they identify women with a family history of breast cancer and refer them for mammograms at an earlier age
– Most offer clinical breast exams, and some have a policy of always providing a clinical breast exam and then making a mammography referral

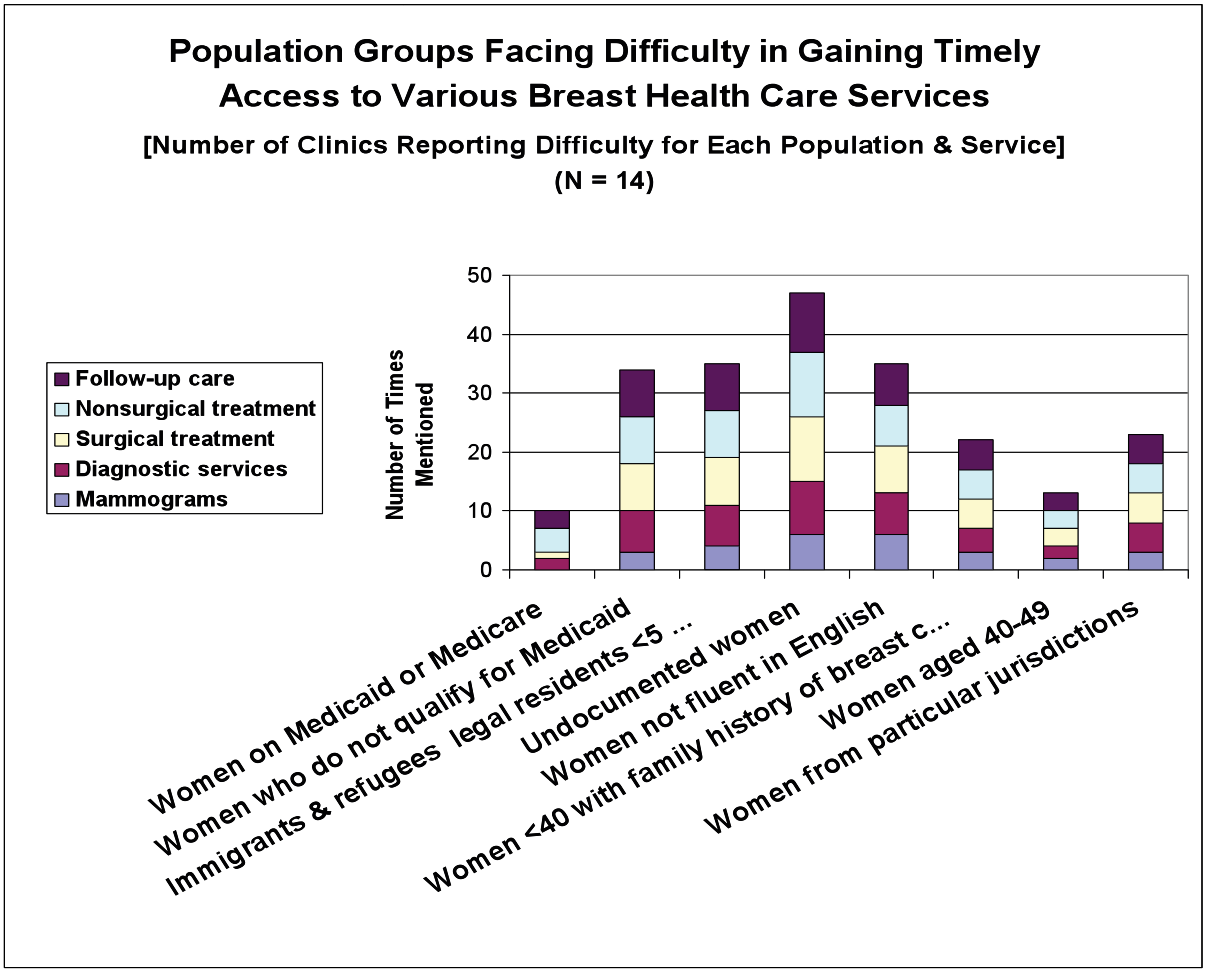
Reported Accessibility of Services for Low-Income Uninsured Clients: Clinics were asked to indicate the extent to which they are able to obtain timely breast health care services for patients who are low-income and uninsured. As the figure below indicates, clinics generally report moderate success in obtaining timely services for their clients. Clinics in the District of Columbia report more difficulties than Northern Virginia and Prince George's County clinics, particularly in getting non-surgical treatment, follow-up care, and survivorship and end of life care. Note that data are combined for Northern Virginia and Prince George's County, since there is only one Prince George's County clinic included in the survey. The ratings use a 4-point scale, where 1 = Not at all able and 4 = Fully able to obtain timely care.



Clinics were asked to identify the types of clients for whom it is most difficult to find breast health care services, and the types of services that are most difficult to obtain. As the chart indicates, clinics most often reported service access problems for undocumented women, immigrants/refugees in the U.S. for less than five years, and those not fluent in English.



The chart below shows the frequency with which clinics mentioned problems with obtaining specific types of services for each identified group of women. Clinics typically reported that all services can be challenging to obtain for undocumented women. Overall, they most often reported challenges in obtaining diagnostic, surgical treatment, and non-surgical treatment.



Flow Charts and Description of Services by Area

Summary: 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. While many entities are working together effectively to provide timely, comprehensive services for low-income and uninsured women to specific patients, none of the jurisdictions has a coordinated system of breast health care services. Financial issues are important – though in different ways – in every jurisdiction. 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.

The Flow Charts: Mosaica has developed a set of flow charts that describe how specific groups of low-income women 40 and over in each jurisdiction (DC, Northern Virginia, Prince George's County, and Montgomery County) obtain breast health services, from clinical breast exams to mammography, diagnosis if the mammogram is abnormal, and treatment and follow-up care (including support groups and end-of-life care) as needed if they are diagnosed with breast cancer. Descriptions below describe more broadly how low-income, often uninsured women 40 and over in each jurisdiction move through the existing continuum of care, what roadblocks they are likely to face, and where and why they are most likely to "fall out" of the system without getting needed services.

District of Columbia

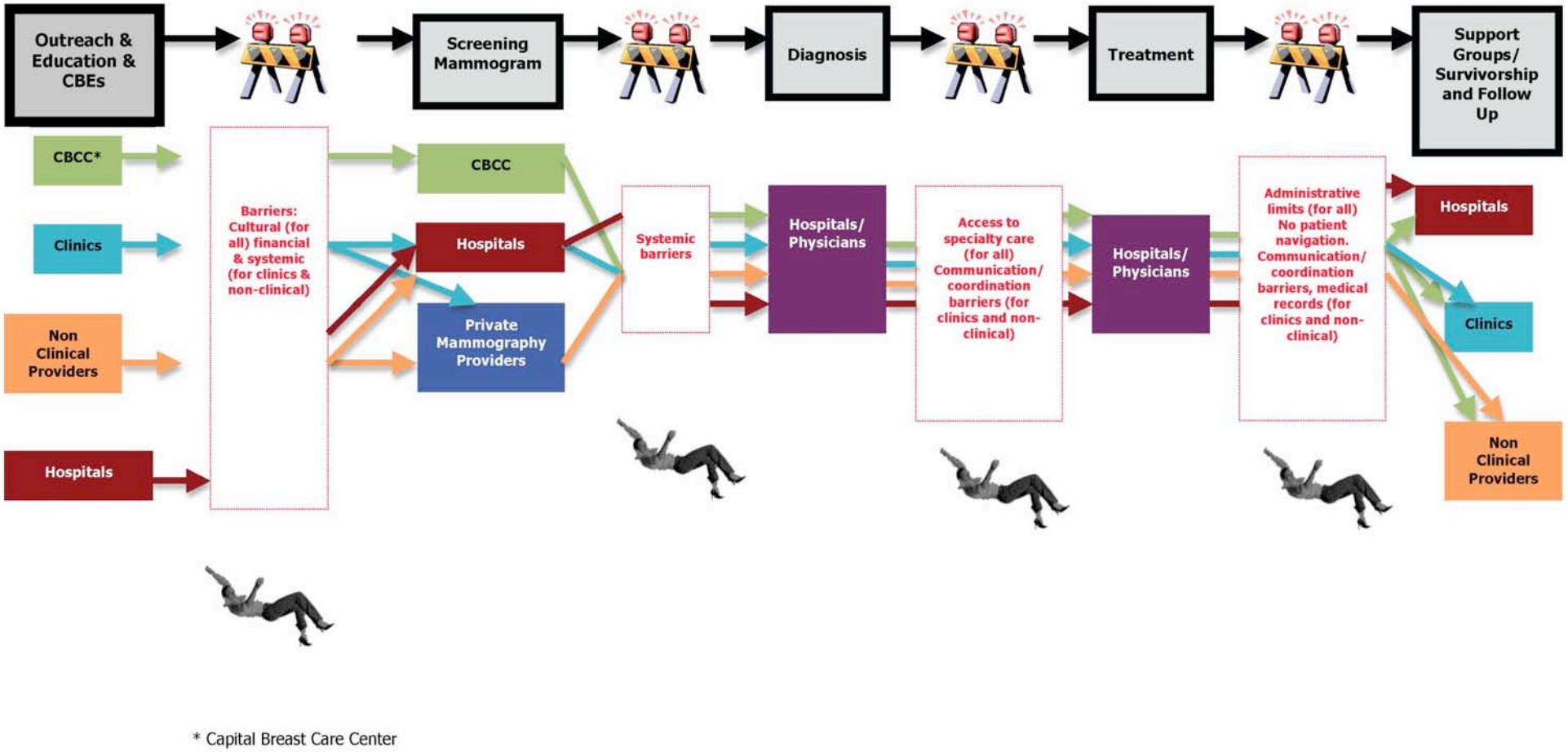
Low-income women 40 and older in DC have a variety of mammogram providers, sources of diagnosis and treatment, and navigators through clinical and non-clinical sources that help them obtain needed breast health care services. Unlike women in other jurisdictions, most low-income women in DC have access to health care including surgery and hospital care paid for by public funds. Those not eligible for Medicaid (e.g., refugees and immigrants who have legal status but have not been legal residents for five years and undocumented immigrants, as well as other temporary residents) can generally obtain health care through the DC Alliance. Most of the barriers to coordinated, timely breast health care in the District are not related to a lack of funding, although women with incomes above 200% of poverty who do not qualify for Medicaid and women above 250% of poverty do face financial roadblocks. For all women, many non-financial barriers exist.

The flow chart for the District of Columbia (Figure 11) focuses on women who receive care through DC Alliance or Medicaid, and highlights barriers and challenges for Medicaid patients, particularly those served under Medicaid Managed Care Organizations (MCOs). With the changes occurring in DC health care, many of the women who were previously served through DC Alliance will be served through MCOs in the future.

The District has a wide range of service providers at various points in the continuum, but a less-than-coordinated system of breast health care:

- **Outreach and education:** Many providers offer outreach and education, from safety-net clinics to cancer centers, the nonprofit mammography provider CBCC, and several ethnic-focused non-clinical nonprofits, most of which target Africans and Latinos. These services often target low-income women, but are generally available regardless of insurance status or income.
- **Clinical breast exams:** Women with medical homes typically receive clinical breast exams within clinics. Hospital cancer centers and the nonprofit mammography provider, Capital Breast Care Center (which is associated with Georgetown University's Lombardi Cancer Center), also offer clinical breast exams.
- **Mammograms:** Women are then referred for mammography to one of several providers, among them CBCC, several hospitals, (most often Howard, George Washington (GW), or Providence), and several private radiology groups. Women with incomes of 200-250% of care are the specific target group of Project WISH, since it does not pay for mammography for women covered by the DC Alliance. Women who are covered by Medicaid or the Alliance can obtain mammograms from multiple sources, although some entities, such as GW Hospital, do not take DC Alliance patients.
- **Diagnosis:** Barriers often appear when a mammogram is abnormal. Often, the same hospital that does the initial mammogram also does diagnosis, but the process is often delayed while the authorization for diagnostic services is being obtained. Getting additional screening or a biopsy can be challenging due to a number of factors, most of them involving not money but complex and differing approval procedures, time delays, and communications gaps. These challenges appear to be greatest for patients who have Medicaid which is provided through Management Care Organizations (MCOs). Often, safety-net clinics are the medical homes coordinating services for these women, but they must meet a variety of administrative requirements to get diagnostic tests authorized. For example:
  - Some MCOs require that the additional screening receive prior approval from the MCO, which requires a written request signed by a physician. Others will accept a referral from a resident, nurse practitioner, or physician's assistant.
  - Some MCOs permit providers to accept a faxed authorization; others require that the original paperwork be taken to the provider by the patient.
  - Sometimes authorization faxed to a hospital goes to the unit performing the diagnostic tests, but that unit does not inform the intake unit that the authorization has been received, so women may be turned away at intake.
  - Sometimes hospitals have automated systems but do not return calls when a message is left by a patient navigator.
  - If a hospital does a mammogram and it is abnormal and the patient needs a biopsy, the hospital staff may immediately schedule the procedure on the first available date, without communicating with the clinic that is the individual's medical home. Medicaid managed care providers generally require prior authorization for such diagnostics, and this usually takes 48 hours. By the time the clinic is informed of the need for a biopsy, that time may be up. The procedure is delayed because the authorization is not there.

Figure 11: Breast Health Care Flow Chart – District of Columbia
DC Alliance/Medicaid-eligible Low-income Women



* Capital Breast Care Center

- Some providers, like CBCC, have a regular source of diagnostics (CBCC has an agreement with Washington Hospital Center) and report fewer delays, particularly with patients funded through Project WISH or other private sources.

Clinic personnel report that sometimes patients become discouraged and fall out of care when diagnostic services are delayed.

- **Treatment:** Obtaining treatment for women with breast cancer also presents challenges, some financial, many not. Women who enroll in Project WISH (which must be done at the DC Department of Health), are citizens or long-time legal residents, and have incomes below 250% of poverty, are often enrolled in Medicaid. Women with DC Alliance coverage who cannot qualify for Medicaid (usually because they are undocumented or are refugees or immigrants who have been legal residents for less than five years) receive care, but sometimes face delays. Women with no source of insurance and not eligible for Project WISH may be referred to a hospital or an individual physician for charity care. Howard, GW, and Providence Hospitals provide different segments of treatment: GW provides radiology services but does not accept DC Alliance, Providence provides oncology and does accept DC Alliance, and Howard provides both and does accept DC Alliance. Greatest challenges are reported in obtaining specialty care for uninsured women. The Catholic Archdiocese Health Care Network helps provide specialists for some women, upon referral from a safety-net clinic. CBCC and many of the clinics report relationships with private physicians and sometimes from the National Institutes of Health (NIH), which may have appropriate treatment available through a clinical trial. Some extremely helpful programs and services are only irregularly available due to limited slots, and the uncertainty complicates referrals. For example, the Kaiser Permanente Bridge program provides health coverage for up to three years to eligible applicants for a low monthly premium, usually ranging from $20 to $60 a month. The program, however, is not appropriate for all patients and may or may not be accepting new clients at any given time.

  Delays between diagnosis and treatment reportedly lead some DC residents to fall out of care, and also can cause great emotional pain, since these women are aware that their survival depends on getting appropriate care. Some women also face cultural barriers that may cause them to drop out of care before receiving treatment, particularly if entry into care is delayed.

- **Support groups:** Both non-clinical providers and hospitals run support groups. None of the safety-net clinics offer them. Finances are usually not a barrier to such services.
- **Follow-up services**: Women with medical homes receive follow-up services, such as regular referrals for follow-up mammograms and medical visits. A few of the non-clinical providers also provide follow-up. Some clinics report that their electronic medical records systems enable them to flag women with breast cancer so that clinicians are automatically reminded when it is times for follow-up appointments.
- **End-of-life support**: The hospitals provide end-of-life support, and there are hospice services available to uninsured patients. For example, Capital Hospice provides services for anyone in need, regardless of ability to pay.
- **Patient navigation:** Many providers, including most safety-net clinics, as well as non-clinical nonprofits, CBCC, and hospitals including their cancer institutes, have navigators

who coordinate services. These navigators work hard to develop and maintain relationships with MCOs and other providers in order to minimize and overcome barriers and get needed diagnostic tests completed in a timely manner, arrange treatment, and provide follow-up. Navigators report that the greatest challenges they face involve getting timely authorization for diagnostics so the woman does not become discouraged or "get lost" and arranging timely and coordinated treatment. Efforts are under way to learn more about what navigation approaches work best with underserved populations. George Washington University Cancer Institute manages a DC City-wide Patient Navigation Research Program, focusing principally on breast cancer, designed to test and evaluate two different methods of helping African-Americans, Latinas, and other women from underserved populations navigate DC's health care system.[6]

One important note to the current flow chart: The DC flow chart is based on service provision as of early fall 2010. However, as noted in the Limitations section, an important change in the system has occurred since that time. The District of Columbia has begun to implement health care reform provisions that extend Medicaid eligibility. By the end of 2010, the majority of individuals who have been receiving health care through the DC Healthcare Alliance will have been transferred to a revised Medicaid program, made possible through the Affordable Care Act. It authorizes non-categorical Medicaid coverage for low-income citizens and long-time legal residents with incomes below 133% of the federal poverty level, and the District has obtained a waiver to increase coverage up to 200% of FPL.

These changes will not necessarily affect other barriers to screening, diagnosis, or treatment. The implications of the transfer of DC Alliance patients to Medicaid are not yet clear for safety-net clinics. Many received fees for service under DC Alliance, but they may or may not have agreements to provide services for the MCOs providing Medicaid services to newly eligible DC residents. The switch to Medicaid could exacerbate some challenges, such as the reported complexities of getting timely authorization for diagnosis and treatment from some MCOs.

Northern Virginia

The Northern Virginia flow chart (Figure 12) focuses on low-income, uninsured women 40 and older. As the flow chart shows and the narrative below indicates, low-income uninsured women in the five health districts of Northern Virginia face considerable barriers to timely breast health care services. Unlike the District of Columbia and Maryland, Virginia has no statewide public alternative for low-income women who do not qualify for Medicaid. Clinics and other providers face considerable challenges in arranging charity care for women with breast cancer, including women who were not screened or diagnosed through Every Woman's Life and therefore cannot apply for special Medicaid funding during treatment even if they would otherwise qualify, as well as women with incomes slightly above 200% of FPL. The clinic survey in Northern Virginia determined that 8 of 11 safety-net clinics never refer women for screening or diagnosis under Every Woman's Life. Following is a summary of services and linkages.

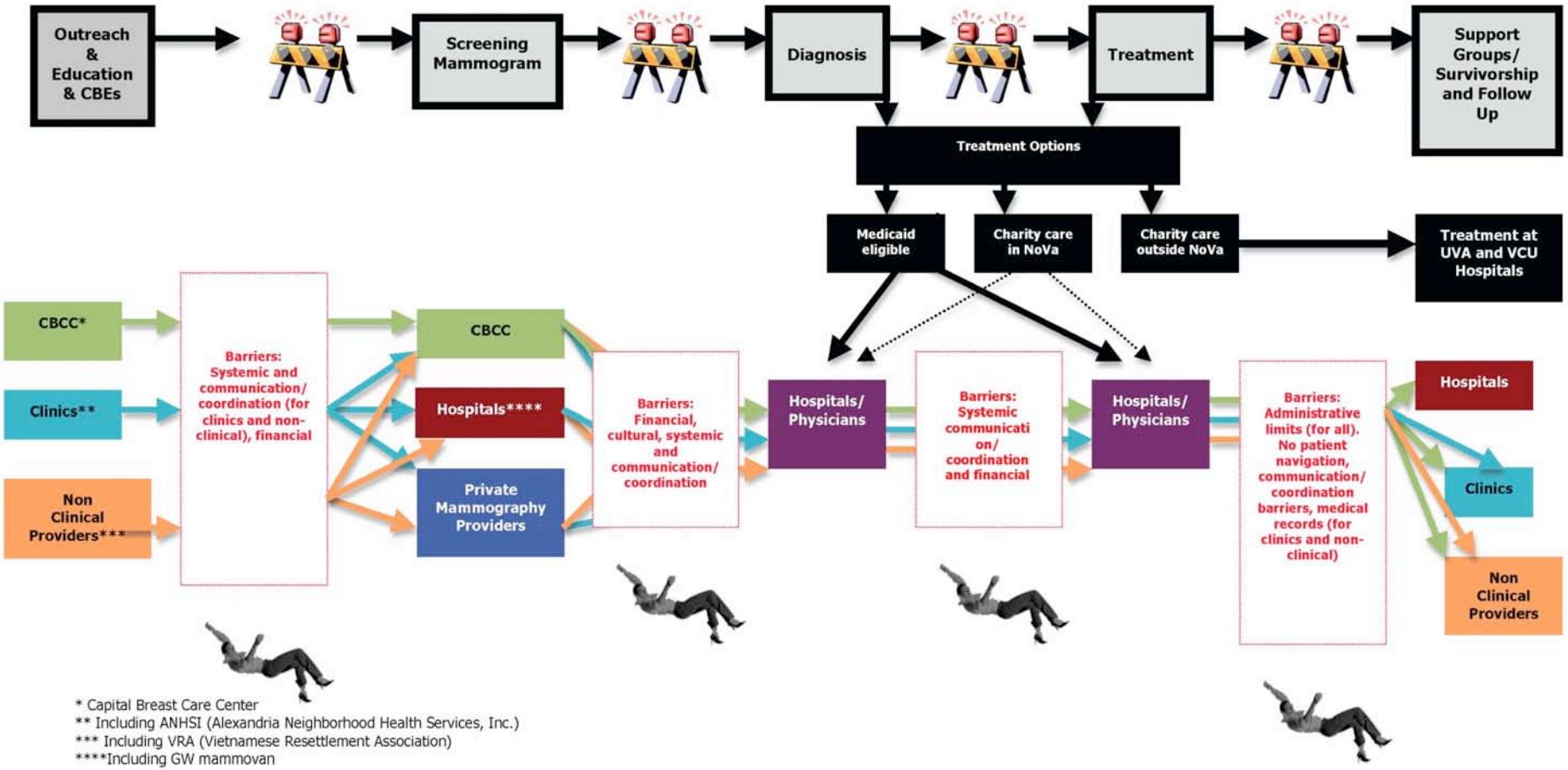
- **Outreach and education:** Many types of entities report some level of outreach and community education. Included several non-clinical community groups with an ethnic focus (e.g., Nueva Vida, Somali Family Care Network, Vietnamese Resettlement Association) do

[6] For more information about the program, see http://crchd.cancer.gov/pnp/pi-patierno-description.html.

targeted outreach. A number of providers noted insufficient linkages between these non-clinical providers and both safety-net clinics and mammography providers.

- **Clinical breast exams:** Several clinics that serve as medical homes report doing clinical breast exams and then referring patients to mammography providers. Some non-clinical providers provide breast exams, as does CBCC.
- **Mammograms:** Most clinics report referring patients to hospitals or private mammography providers for mammograms. Hospital referrals depend on location within Northern Virginia as well as availability of charity care; clinics reported referrals to several Inova hospitals, Virginia Hospital Center (Arlington), and Sentara Potomac. Some clinics use the GW Mammovan. Several refer women to CBCC, located in the District of Columbia but funded by Every Woman's Life. Three clinics – including Alexandria Neighborhood Health Center, Inc. (ANHSI), which is funded by Every Woman's Life – said they always refer eligible women for screening under EWL; the other eight said they *never* refer through EWL. Mammography screening is seen as generally available for low-income uninsured women, although some of the community-based outreach groups reported difficulties in obtaining free mammograms for the women they serve. Clinics often report referring to more than one mammography provider in order to obtain sufficient free or low-cost screening.
- **Diagnosis:** Diagnostics following an abnormal mammogram are typically provided by the hospitals that do the mammograms or by referral from another type of mammogram provider. Some clinics and non-clinical providers report considerable difficulty in getting diagnostics that require specialists or surgery (biopsies). Women screened under EWL receive diagnostics under the program, and eligible women can be enrolled in EWL after an abnormal mammogram, to obtain diagnostic services. Several hospital-based physicians will provide biopsies at no cost if the patient is referred by her primary care physician. It can be challenging to arrange a pathologist or other services needed in relation to the biopsy, since there is no coordinated system that arranges everything needed. Women sometimes fall out of the system at diagnosis due to delays in arranging diagnostics. Several clinics reported referring women to the University of Virginia (UVA) or Virginia Commonwealth University (VCU) hospitals for diagnostics, despite the distance. Cultural factors can complicate the process. For example, several providers described African immigrant women who believed they could not get breast cancer because they breastfed their children, and who refused diagnostic tests after an abnormal mammogram; many of the clinics said they lack experience with this or other specific populations.
- **Treatment:** Getting timely treatment for women with breast cancer is often extremely challenging, unless they are diagnosed through EWL and qualify for the special Medicaid coverage during treatment. There is no other public source of treatment funding to support treatment in Northern Virginia. Clinics, CBCC, and non-clinical providers depend upon a patchwork of charity care, which may take several months to arrange. For example:
  - Some clinics report referring women for treatment to hospitals outside the region, in Charlottesville (University of Virginia) or Richmond (Virginia Commonwealth University) because they provide free surgery and non-surgical treatment. Transportation is a huge issue for women who receive ongoing care such as radiation or chemotherapy at these facilities.

Figure 12: Breast Health Care Flow Chart – Northern Virginia Uninsured Low-income Women



- Area hospitals provide some charity care. Nine board-certified surgeons and 15 surgical residents at Inova will perform *pro bono* surgery. A Reston Hospital Center surgeon also indicated that *pro bono* services are available there. These opportunities have proven very valuable to clinics. However, there is no established system to arrange for an anesthesiologist, pathologist, hospital stay, and related services, so the process can take considerable effort by a patient navigator or other clinic staff.
- Some individual physicians provide free care on a case-by-case basis, and have relationships with particular clinics or with CBCC.
- Clinics report great difficulties in obtaining specialty care, especially from oncologists and surgeons. Some clinics put together a group of providers that they call upon, depending on the woman's medical needs, income, county of residence, and other factors. One clinic described arranging care through a private surgical group, a private oncology practice, a hospital, and several individual surgeons.
- Medications are often very expensive and difficult to obtain.

- **Support groups:** Support groups are available at several hospitals and are provided by one ethnically focused non-clinical provider.
- **Follow-up services:** Clinics that serve as medical homes provide follow-up care, helping to ensure that patients receive regular screening after treatment ends. Some non-clinical providers and CBCC also arrange follow-up care.
- **End-of-life support:** End-of-life support is arranged by medical homes, some non-clinical providers, and CBCC.
- **Patient navigation:** Patient navigators play a critical and reportedly very effective role in Northern Virginia. Eight of the 11 Northern Virginia safety-net clinics have navigators, as do several hospitals, non-clinical community-based organizations, and CBCC. Some have different navigators for screening/diagnosis and treatment, and others use the same navigator throughout the process. Navigators often work only on breast care, but sometimes serve patients with various needs. Navigation can help a patient obtain services within a large institution like a hospital or across providers. There was agreement on the need for more navigators, especially more bilingual navigators, especially Spanish-English.

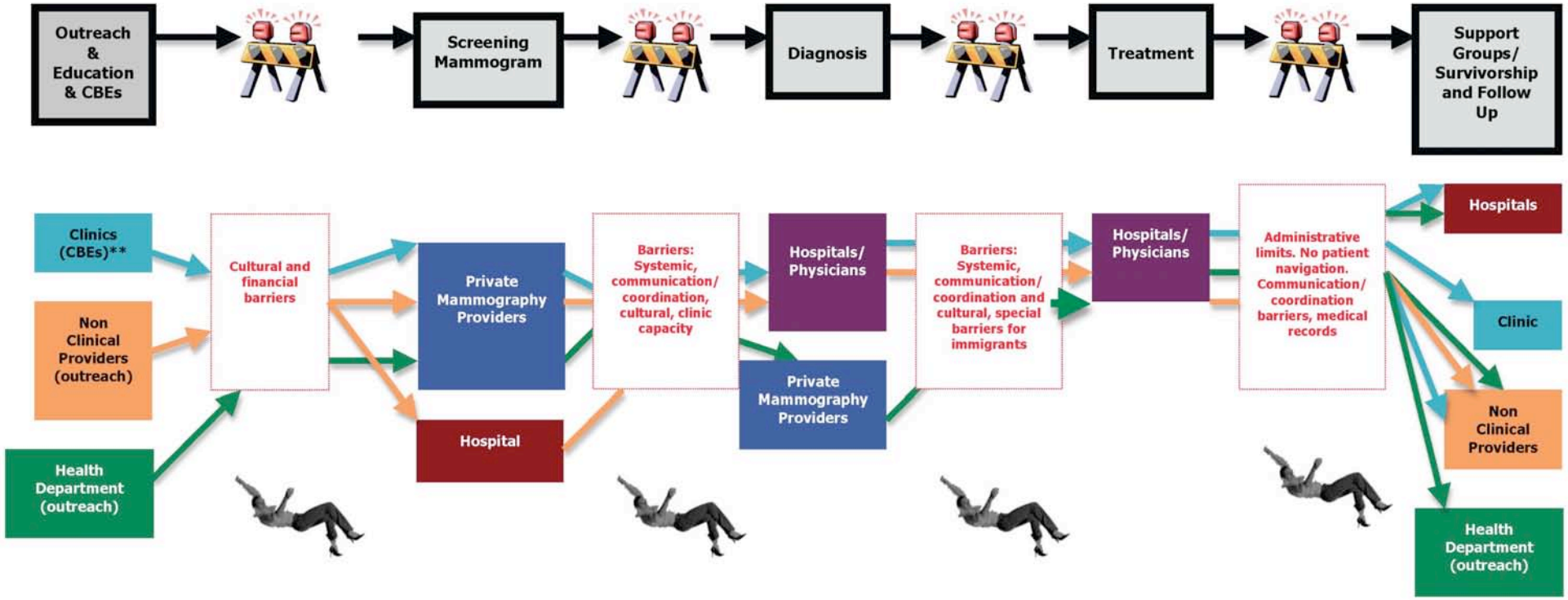
Financial barriers are a significant obstacle to timely breast health care in Northern Virginia. In addition, at nearly all stages of breast health care, clinics and other service providers described a patchwork of services with varied eligibility and accessibility and limited cross-communication or coordination. Hospitals report high no-show rates for mammograms. Community-based outreach and education programs bring needed cultural competence, but are not closely linked to medical homes, have varied contacts and knowledge of resources, and report problems getting their clients screened, diagnosed, and treated. Clinics prefer patients who want a medical home, and sometimes have waiting lists (though most will immediately accept a new patient who needs immediate care). There is limited awareness of available *pro bono* services. For example, most participants were not aware that a group of surgeons at Inova are willing to provide *pro bono* surgery until the physicians made the announcement at the project's Northern Virginia key informant meeting. Navigators provide valuable help, but some patients fail to get needed services on a timely basis. Several small foundations provide small but extremely valuable grants to help fill service gaps. They include, for example, the Prevent Cancer Foundation, the Abshire Fund, and the Sharon McGowan Breast Health Fund.

Prince George's County

The Prince George's County flow chart (Figure 13) focuses on low-income uninsured women who qualify for Medicaid through the Maryland's BCCP. Prince George's County has a limited number of safety-net clinics and one community health center, Greater Baden Medical Services (GBMS). The other clinics serve a limited number of women 40 and over and focus on particular target groups. A variety of breast health care services are available within the county and nearby in Montgomery County; Maryland BCCP funds 10 providers and several non-clinical community-based nonprofits are active in education, outreach, and patient navigation. The NBCCEDP program provides a more flexible path to Medicaid than the Virginia program, but women who are not eligible for Medicaid and their care providers face considerable administrative challenges in documenting eligibility for diagnosis and treatment paid for through public but non-Medicaid sources.

- **Outreach and education:** Several non-clinical nonprofits provide outreach and education in the county, some ethnically based, some not. The Health Department also does outreach with Komen funding.
- **Clinical breast exams:** Clinical breast exams are provided routinely by GBMS and the other three clinics that receive funding through BCCP.
- **Mammograms:** Private mammography providers do the screening under Maryland BCCP and for GBMS, which tries to develop MOUs with radiology providers. Washington Adventist Hospital also provides mammography services for some low-income uninsured women.
- **Diagnosis:** A wide range of hospital-based diagnostic services and a surgeon under contract to the county are available to provide diagnostics for women under Maryland BCCP. Women who need biopsies but do not qualify for Medicaid need to apply to a companion Breast and Cervical Cancer Diagnosis and Treatment Program. If they are able to document that they meet income requirements and live in Maryland, these services are provided either through payment of premiums for the Maryland Health Insurance Plan, which covers women with chronic illness, or through state general funds. Some charity care is also available to women who are not part of BCCP through hospitals including Holy Cross.
- **Treatment:** Treatment options depend upon eligibility for specific services.
    - Women in the BCCP program who qualify for special Medicaid (as shown in the flow chart) are enrolled through the Women's Breast and Cervical Cancer Health Program (WBCCHP**)** and receive full Medicaid services while they undergo cancer treatment. They are free to use any provider that accepts Medicaid.
    - Women in BCCP who do not qualify for Medicaid face the same issues as those needing biopsies – they must apply for services under the Breast and Cervical Cancer Diagnosis and Treatment Program (BCCDTP). Providers agree that it is often very difficult and time consuming for women, particularly immigrants, to provide required identification, document residence in Maryland (particularly if they live with someone else and do not.

Figure 13: Breast Health Care Flow Chart – Prince George's County BCCP*/Medicaid-eligible Low-income Women



* Maryland Breast and Cervical Cancer Program
** Including four BCCP providers

have their names on a lease or utility bill), and document low-income (particularly if they are separated or divorced but don't have legal documentation). If they and their caregivers are successful in establishing eligibility, these women have access to treatment funded through state general funds, sometimes through state payment of MHIP premiums.

GBMS patients who are not part of BCCP get services through a local surgeon and various hospitals providing charity care

- **Support groups:** Two of the non-clinical groups, the African Women's Cancer Awareness Association (AWCAA) and Breast Health, Inc., provide support groups or referrals to support groups for women with breast cancer. Prince George's Health Department also provides support groups.

- **Follow-up services:** AWCAA recently began providing follow-up services to clients in Prince George's County. Breast Health, Inc. also provides follow-up services. The County's BCCP-contracted sites provide follow-up throughout the continuum of care and after treatment is completed. CASA de Maryland no longer has staff to do follow-up, but refers to Nueva Vida, Holy Cross Hospital, and the GW Mammovan for follow-up coordination and screening. GBMS provides follow-up to its patients, but does not yet have a way of obtaining automatic reminders of needed follow-up appointments through its electronic medical records system.
- **End-of-life support:** Medical homes are able to arrange end-of-life support through Capital Hospice.
- **Patient navigation:** Patient navigation in Prince George's County is provided primarily through several non-clinical community groups. AWCAA and the Ethiopian Community Development Council target African immigrants, Breast Health, Inc. targets African Americans and recently began targeting Latinas, and CASA de Maryland targets Latinas.

Women in Prince George's County benefit from a flexible BCCP program, but face challenges due to inadequate funding for the program. It typically runs out of funds for screening before the end of the year. The situation is usually helped by the extra slots provided through Project WISH in DC, although the number or continuation of such slots is not assured. The county health department is able to closely monitor patients enrolled in BCCP for their original screening, but communications between Medicaid and the clinics is lacking. GBMS does not receive notification from Medicaid when its patients receive Medicaid approval, which sometimes results in delayed care. Providers also report insufficient coordination between community-based outreach and education providers and medical homes and mammography providers. Common barriers to care include fear of obtaining services, inability to provide required documentation – particularly for diagnosis and treatment through state general funds – and cultural myths and stigma associated with cancer. Clinic services are stretched, and women are sometimes referred to Montgomery County or the District of Columbia for breast health care services.

Montgomery County

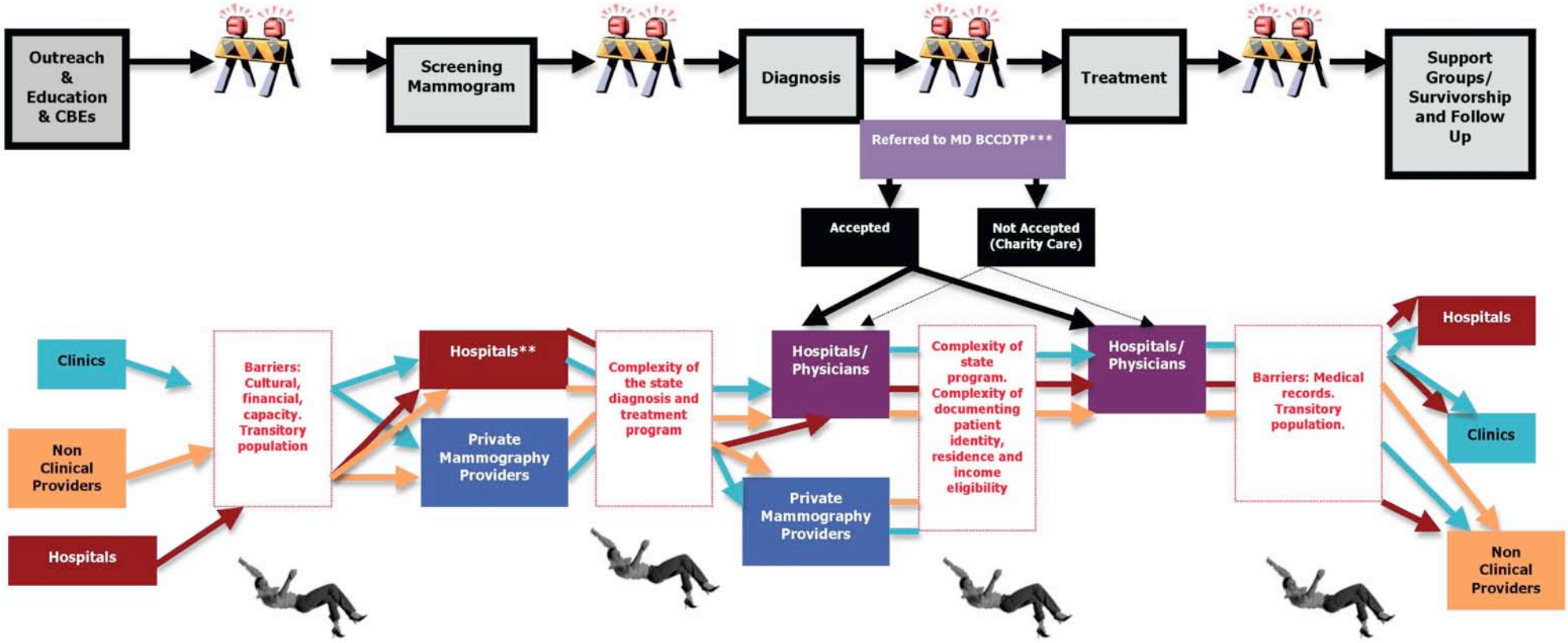
The flow chart for Montgomery County (Figure 14) focuses on low-income uninsured women who do not qualify for Medicaid under Maryland BCCP, many of them immigrants and refugees.

Low-income uninsured women in Montgomery County have the benefit of a coordinated county-funded system of primary care clinics, Montgomery Cares, a network of nonprofit safety-net clinics coordinated by PCC. These clinics target a variety of populations, among them Latinas, African Americans, Muslims, and Asian Americans. The process improvement model PCC will be replicating elsewhere in the metropolitan area was developed and tested successfully in Montgomery County, beginning with three Montgomery Cares clinics, then expanded to six, with plans for adding two more. So this group of clinics has been focusing on improving breast health care screening and referral for several years.

No survey was done of Montgomery County clinics, but the State Assessment did include a key informant session with 28 providers. They described the services, processes, and challenges shown in the flow chart and described below. Maryland BCCP is partially decentralized, so the Montgomery County Department of Health and Human Services chooses its own screening and diagnostic providers, but the BCCP-related treatment options are currently the same in both counties.

- **Outreach and education:** At least 11 entities, including safety-net clinics, ethnically focused community-based groups, and hospitals, do patient education and/or outreach. The Maryland BCCP program at the Health Department does some limited patient outreach. African Women's Cancer Awareness Association, CASA de Maryland, the Chinese Culture and Community Service Center, Nueva Vida, and the African Wellness Center together provide outreach and education to women in Spanish, Chinese, French, Amharic, Swahili, Portuguese, Igbo, and Yoruba.
- **Clinical breast exams:** Clinical breast exams are provided by several of the ethnically focused community-based organizations, most of the clinics, and area hospitals.
- **Mammograms:** Women receive mammograms at hospitals, private radiology groups, and the GW Mammovan. Clinics often have arrangements with a single mammography provider and make appointments for patients to maximize successful referrals for screening. Sites vary somewhat based on each clinic's location within the county. Holy Cross and both Shady Grove and Washington Adventist Hospitals all provide screening for more than one clinic, as does Community Radiology Associates. The community-based organizations refer to both hospitals and the GW Mammovan. The county's BCCP program funds four hospitals and three radiology groups, and clinics often refer patients to these providers.
- **Diagnosis:** Diagnosis is often provided by the same entity that does the mammograms, most often hospitals and radiology groups. Several providers indicated that they read mammograms on site so can move forward immediately with additional screening when necessary. Montgomery General Hospital often goes ahead with diagnostic tests following an abnormal mammogram, covering the costs and then seeking reimbursement from the state through BCCP. The hospital has one surgeon to whom it refers patients for biopsies. Shady Grove Adventist indicated that it often does additional screening on the same day as the original mammogram. Several individual physicians also provide diagnostic services. Holy Cross uses charitable care funds for mammograms and covers biopsies.

Figure 14: Breast Health Care Flow Chart – Montgomery County
BCCP*-eligible but not Medicaid-eligible Low-income Women



* Maryland Breast and Cervical Cancer Program
** Including GW Mammovan
***Maryland Breast and Cervical Cancer Diagnosis and Treatment Program

- **Treatment:** Treatment options depend on whether the patient is able to qualify for one of the BCCP programs.
  - As in Prince George's County, low-income uninsured women diagnosed with breast cancer often receive treatment through the BCCP program, which accepts women screened and diagnosed by funded providers even if these services were not paid for with BCCP funds. Women who appear eligible for Medicaid under the program are channeled to the Women's Breast and Cervical Cancer Health Program (WBCCHP).
  - Women who do not qualify for Medicaid under BCCP can apply for services under the Maryland Breast and Cervical Cancer Diagnosis and Treatment Program (BCCDTP), which pays premiums for MHIP or provides care through a variety of contract providers paid with state general funds. Documenting income eligibility and Maryland residence can be extremely challenging. Several providers receiving funds through the program noted that careful documentation of services is required for reimbursement; for example, a CAT scan or X-ray is covered provided the script requesting the test notes that it is related to breast cancer.
  - For women who cannot qualify for either of these options, charity care is sought. Treatment may be provided by a hospital or a physician or physician group. Holy Cross Hospital provides infusion therapy and chemotherapy but, as of the end of November, was planning to hire but did not have a breast surgeon. Montgomery General Hospital has a medical oncologist. Providers reported relationships with several private physicians. Clinics indicated that finding specialists to provide charity care is often difficult.
  - The National Institutes of Health (NIH), which is located in Montgomery County and runs a number of breast cancer clinical trials, and sometimes providers are able to find a good match for their patient. Nueva Vida reported successful referrals to NIH.
- **Support groups:** Mary's Center runs support groups in the District of Columbia, and the Muslim Community Center Medical Clinic reported a start-up support group. The African Women's Cancer Awareness Association has support groups, and Nueva Vida provides mental health services including support groups for cancer survivors, their family members, and caregivers. Participants noted that some hospitals and other entities operate support groups, and it would be very helpful to have a regularly updated listing of available support groups indicating target populations and languages.
- **End-of-life support:** Palliative care and hospice care are generally available to women under 250% of FPL. Several hospitals provide hospice care to their patients. Respite Care of Montgomery County provides help to caregivers. The community-based organizations often arrange for end-of-life support.
- **Follow-up care:** Clinics and community-based organizations report doing follow-up; some clinics now have computerized systems that automatically inform them when a cancer survivor is due for follow-up screening. Both clinics and community-based organizations noted that some patients are hard to find for follow-up. They may move, return temporarily to a home country, or not have a telephone number. Educating women about the disease and the need to stay in touch is very important. Providers sometimes ask for multiple telephone numbers of relatives to increase the likelihood of being able to reach a patient for her six-month follow-up.

- **Patient navigation:** At least a dozen clinics, hospitals, and community-based providers have navigators. Some follow a patient from outreach through follow-up. Navigation may be done by a person who does only patient navigation, or it may be a shared responsibility for several staff. A key role for navigators in Montgomery County is helping patients establish income eligibility and Maryland residency for state-supported treatment. Navigators play a wide range of roles, such as discussing treatment options, following up with other providers regarding test results, linking patients to specialists, arranging child care or transportation, accompanying patients to the surgeon's office, and providing or arranging interpretation. They may provide financial counseling and make arrangements for partial payment for services. They arrange help from groups like the Red Devils, which provide small grants to some hospitals for cancer patients.

Clinics and mammogram providers in Montgomery County have been working together for several years with support from PCC's original Komen project. They have developed relationships and maintained communications in order to improve successful referrals for mammograms and facilitate timely diagnosis and treatment. The high level of participation in the key informant session was viewed as an indicator of the high level of commitment and cooperation around breast health care. Providers in the county report considerable success but continue to face challenges.

One problem is that there are not enough available mammography slots. This is partly a question of funds and partly one of capacity. Holy Cross and Adventist have increased their mammography capacity. BCCP has limited slots and sometimes runs out of funds before the end of the program year. Current capacity to provide additional mammograms may also be an issue, although mammography providers indicated that they could increase capacity through weekend hours or additional equipment of sufficient, consistent funding was assured. Capacity is often grant-dependent, and funds are not consistently available. Montgomery Cares works with providers to purchase mammography slots at the best possible price, and sometimes purchase mammography slots and "bundles" services. Mercy Health Clinic is working with Adventist to reduce no-shows. The clinics find the best approach is to make appointments for patients, and to carry out diagnostic screening even if it has not yet been approved.

Another barrier in Montgomery County, as in Prince George's County, is the complexity of helping patients document identity, Maryland residence, and income eligibility for Maryland's BCCDTP. Women must have official identification, though it need not be issued in the U.S. They need written documentation of residence, which can be difficult for women who do not have their name on a lease or utility bill. Proving there is no other source of income can be extremely difficult for a woman who is separated or divorced but does not have a copy of the divorce degree or court documents indicating a legal separation. Some problems can be solved through notarized letters – such as a letter from a relative who holds the lease, certifying that the woman is a resident of that home. Several providers say it is very important to have access to a notary and to have someone who can spend the time to help solve documentation problems. One provider described an immigrant patient who did not have official identification of any kind, and was denied services.

Strengths of Breast Health Care Services in the Region

Summary: Many aspects of breast health care services in the region work well, especially the high level of commitment among providers to arrange timely, comprehensive services to low-income women, 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.

Strengths: The safety-net clinics and other providers across the region identified a number of strengths related to breast health care. Those most often identified across the region include the following:

- In all three jurisdictions, a high level of commitment to providing timely, comprehensive breast health care – even when doing so requires a very large expenditure of navigator, clinician, or other staff time.
- In Maryland, general funds-supported options for diagnosis and treatment available to women who are uninsured and cannot qualify for regular or special BCCP Medicaid.
- In Washington, DC, public funding through the DC Healthcare Alliance that makes health care coverage including inpatient care available to the vast majority of otherwise uninsured residents.
- Because so few DC residents require mammograms through NBCCEDP, excess funding through Project WISH that is made available to screen women from Northern Virginia and Suburban Maryland, both of which have insufficient funding in their own programs to meet demand.
- In all jurisdictions, individual relationships between clinics and mammography providers, hospitals, physicians and physician practices, and community-based organizations that help arrange and ensure breast health care services for low-income, uninsured patients.
- Some individual physicians including surgeons who provide *pro bono* services, such as the Inova group and the Reston Hospital surgeon who publicly stated their willingness to provide free biopsies and surgery at the State Assessment's key informant meeting in Northern Virginia and are now assisting several of the safety-net clinics. CBCC reported a specialist in Prince George's County who has provided care for a number of its patients, and many clinics have similar relationships.
- The availability of nonprofit community-based groups committed to improving breast health care for women, usually for women from specific language and cultural groups.
- The use of patient navigators – attached to clinics, community-based organizations, the nonprofit mammography provider, and hospitals – to guide patients through the various stages of screening, diagnosis, treatment, and follow-up.
- The Capital Breast Care Center model, which includes service coordination from outreach through follow-up and direct mammography services, including what appears to be an unusually smooth transition from screening to diagnosis – and the availability of these

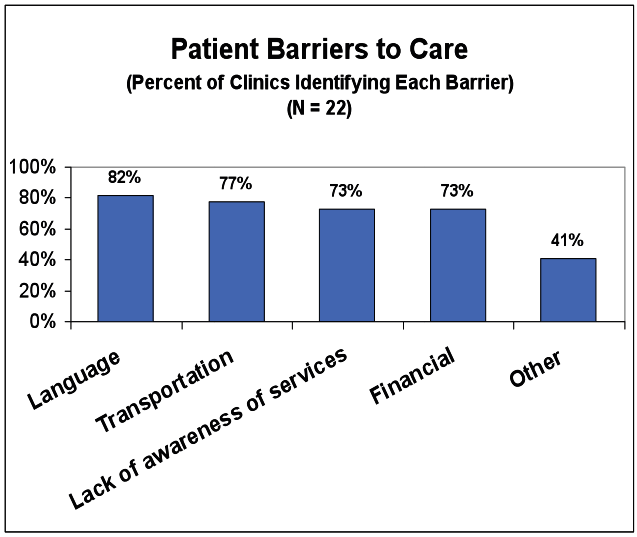
services to women from all three jurisdictions through Project WISH and to Northern Virginia residents through BCCP.

- The lessons learned in Montgomery County about use of process improvements to increase screening rates and decrease delays along the continuum of screening, diagnosis, and treatment.

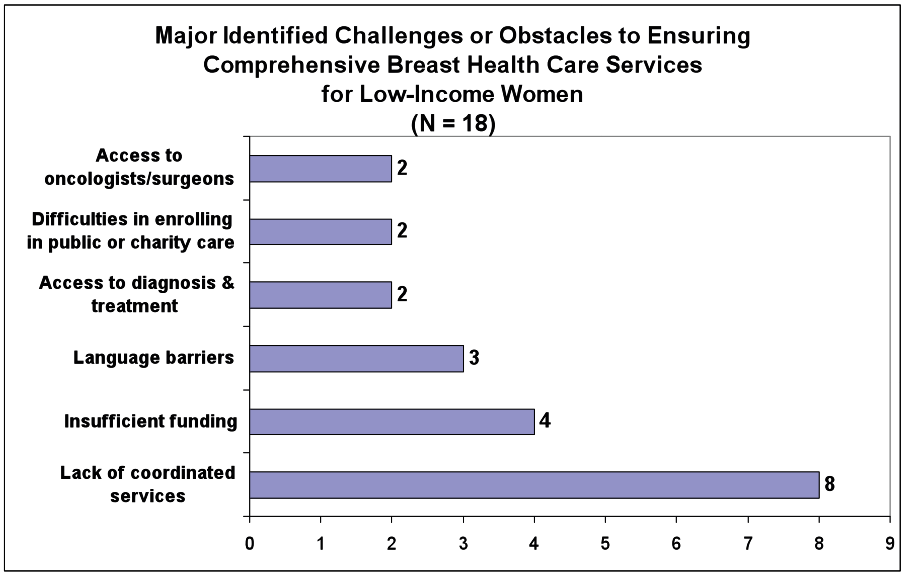
Service Barriers/Gaps

Summary: Clinics and other providers identify numerous service barriers and gaps that make it difficult to ensure comprehensive, timely, coordinated breast health care services to low-income, often uninsured women. Among the most commonly noted were patient-based language, transportation, and financial barriers, and a lack of awareness of available services. Among the most frequently noted systemic barrier noted was a lack of coordination of breast health care services.

Patient-based Barriers: Clinics were asked in the surveys to identify the importance of several specific service barriers, and to identify what they perceive to be the greatest challenges in providing breast health care. Clinics and other breast health care providers were asked to identify which of the following patient-based service barriers: language, transportation, a lack of awareness of available services, and financial/low-income. A large majority in all jurisdictions indicated that their low-income uninsured patients were dealing with all four of these barriers. As shown in the bar chart, 82% of clinics identified language as a barrier for some of their patients. Many noted that safety-net clinics typically have bilingual staff, particularly staff who speak Spanish and English. Many clinics also reported staff fluent in languages needed to serve African immigrants. Clinics reported that specialists are much less likely to have either bilingual staff or easy access to interpreters. Clinics and other coordinators of care sometimes need to accompany patients or arrange for bilingual staff or interpreters. Language issues reportedly complicate enrollment in programs like BCCDTP in Maryland, which require extensive applications and documentation. A large majority of clinics (77%) – including most clinics in the District – identified transportation as an issue. Clinics are clustered in central business areas and in Ward 1 of the District, and many clients cross jurisdictional lines for services. Patients living in the more rural parts of the suburban jurisdictions may have very limited access to public transportation. Financial barriers are seen as a major issue by 73% of clinics, and are a concern in all jurisdictions, as are a lack of patient awareness of available services. Nine clinics mentioned other barriers, from a lack of sufficient diagnostic services and follow-up care to fear, cultural issues, inconvenient service hours for working women, low educational and literacy levels, and patient co-morbidities such as mental illness and homelessness.



Clinic Challenges: Clinics were also asked to identify what they consider to be the major challenges or obstacles to ensuring comprehensive breast health care services. The bar chart below shows that the single most frequently identified barrier is a lack of coordinated services. As one clinic representative put it, "It is a patchwork for each patient." Insufficient funding for charity care was also identified frequently. Only one of the 18 clinic respondents said his/her clinic is not encountering any problems. This clinic credited volunteer clinicians and access to Medicaid as important in providing treatment options. One clinic representative noted that patients who lack a medical home face challenges in obtaining follow-up care. At key informant sessions, clinics and other breast health care providers confirmed these obstacles and challenges, particularly:



- Lack of service coordination
- Limitations in scope or funding for NBCCEDP programs
- Administrative complexities in helping patients obtain charity care and/or apply for state-supported diagnostic or treatment services
- Lack of access to specialty care, particularly oncology and surgery
- Lack of affordable services for women with limited incomes who are slightly above income limits for BCCEDP or state programs – generally women with incomes 200-400% of the poverty line
- Jurisdictional challenges in a metropolitan area with three "states" and a number of jurisdiction-specific systems and programs
- Challenges, particularly for clinics, of serving patients who live in another jurisdiction
- Age-related issues such as obtaining services for women under 40 with a family history of breast cancer, women 40-49, given NBCCEDP priority on serving women 50-64, and women 65 and older who do not qualify for Medicare

Jurisdictional and cross-jurisdictional barriers and their implications are explored further in Section 5.

Summary of Key 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 older, spread almost equally among Washington, DC (10), Northern Virginia (11), and Suburban Washington (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 older 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 Programs 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 poverty
- 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.

5. Analysis and Implications

Overview

This section further explores information gathered, largely by jurisdiction, in the State of the Region Assessment and its implications for the replication phase of the Regional Initiative. Primarily from a clinic perspective, it:

- Summarizes key findings
- Reviews and summarizes key issues affecting breast health care in the specific jurisdictions and the region as a whole
- Explores regional issues in this three-"state" metropolitan area
- Summarizes the implications of the assessment for the replication phase
- Reviews clinic capacity for and interest in participation in the Initiative
- Identifies some topics and issues that might be addressed by the learning community

Jurisdictional and Common Issues

Summary: The State of the Region Assessment identified a number of issues that affect breast health care in all four jurisdictions, as well as some jurisdictional-specific issues, focusing on their implications for safety-net clinics and their low-income, often uninsured patients. All jurisdictions struggle with arranging and coordinating charity care and especially with identifying specialists to serve low-income uninsured women with breast cancer. However, there are important differences by jurisdiction. A key issue in Northern Virginia is the lack of a state-funded treatment alternative for women with breast cancer who are unable to obtain Medicaid coverage through Every Woman's Life. For the District of Columbia, where the vast majority of low-income residents have health care coverage through Medicaid or DC Alliance, a critical issue is the administrative challenges of getting payers, particularly Medicaid Managed Care Organizations, to authorize diagnostic services and treatment. In Montgomery and Prince George's Counties, the Maryland Breast and Cervical Cancer Diagnosis and Treatment Program offers a treatment option for low-income women who cannot qualify for Medicaid, including immigrants and refugees, but it is often extremely difficult for women and their caregivers to document identification, Maryland residence, and income eligibility.

Key Issues by Jurisdiction: Figure 15, on the following page, identifies issues that affect breast health care services in the region. The majority of issues apply in all three "states" and in both Prince George's and Montgomery Counties. A few – like the lack of state-funded treatment available to women in Virginia who cannot qualify for Medicaid under NBCCEDP – are specific to a single jurisdiction, or apply in some but not all jurisdictions, such as the lack of coordination between community-based non-clinical breast care organizations and the area's safety-net clinics and hospitals identified in Northern Virginia and Prince George's County.

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:

- **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 if a woman has an abnormal mammogram. Since DC is already implementing the Affordable Care Act's Medicaid expansion and expects ultimately to move 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 program funded through NBCCEDP, 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, for women who do not qualify for Medicaid, there is no alternative state-funded treatment program. This means that charity care is the primary treatment option, and some women are referred to Richmond or Charlottesville for treatment (sometimes including radiation or chemotherapy). The situation is complicated by a lack of coordination among service providers, and the absence of an organized process for accessing charity care.

- **Maryland:** Maryland's BCCP is partially decentralized, with each county contracting with ten providers of outreach and education, screening, and diagnosis and flexible access that enables 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 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 begin to 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.

Figure 15: Frequently Identified Issues in Providing Breast Health Care – by Jurisdiction

Issue	District of Columbia	Northern Virginia	Prince George's County	Mont-gomery County
1. Service fragmentation/coordination	✓	✓	✓	
2. Patient education about breast health care & available services	✓	✓	✓	✓
3. Linkages between non-clinical outreach providers & other providers		✓	✓	
4. Availability of free or low-cost screening slots		✓	✓	✓
5. No-show rates for mammograms	✓	✓		✓
6. Access to diagnostic services, especially biopsies		✓	✓	✓
7. Administrative issues in obtaining authorization for diagnostic services or treatment	✓			
8. Use of clinics as referral agents	✓	✓	✓	✓
9. Communications and reports to clinics from mammography providers and Medicaid	✓	✓	✓	
10. Public treatment alternatives for women who do not qualify for special NBCCEDP Medicaid		✓		
11. Complex applications for state-funded diagnostic and treatment services			✓	✓
12. Clinic capacity to accept new patients		✓	✓	✓
13. Complexities in accessing charity care	✓	✓	✓	✓
14. Payer-based service complexities	✓	✓	✓	✓
15. Charity care outside the region		✓		
16. Forced changes in medical homes	✓	✓		✓
17. Access to specialty care	✓	✓	✓	✓
18. Support services, especially transportation	✓	✓	✓	✓
19. Vanishing clients	✓	✓		✓
20. Availability of patient navigators (esp. bilingual)		✓	✓	✓
21. Delays between referral & screening, screening & diagnosis, and diagnosis & care	✓	✓	✓	✓
22. NBCCEDP program structure and capacity	✓	✓	✓	✓
23. Language	✓	✓	✓	✓
24. Cultural issues & variations in provider cultural competence	✓	✓	✓	✓
25. Patient residence – serving patients from other jurisdictions	✓	✓	✓	✓
26. Access to services for women slightly above income limits (200-250% of FPL) but unable to pay for care	✓	✓	✓	✓
27. Age-based access limitations	✓	✓	✓	✓
28. Data availability/electronic medical records systems	✓	✓	✓	

- 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. There is an active group of providers (clinics, hospitals, community-based organizations, and the County Health Department) working under PCC's leadership to improve breast health care through process improvements.

Many of the breast health care issues listed in Figure 15 were identified and described in the previous section. These issues are categorized and explored below, from the perspective of the safety-net clinics. All of these factors can lead to delays or breakdowns between referral and screening, screening and diagnosis, and diagnosis and care.

Patient-based challenges: In all jurisdictions, clinics report challenges in obtaining services for particular populations of women:

- Undocumented or recent refugee/immigrant women who are not eligible for Medicaid even under NBCCEDP
- Women who are not fluent in English, regardless of immigration status
- Women 65 and over who do not qualify for Medicare and are not targeted by NBCCEDP programs
- Women under 40 with a family history of breast cancer
- Women with cultural barriers to care, including myths and stigma
- Women who do not have a medical home and are therefore less likely to get regular screening and to have a clinician or navigator to coordinate their care

Providers in all jurisdictions vary in their capacity to serve particular populations. For example, the metro area is home to a diverse and growing African immigrant and refugee population. Clinical providers described difficulties in helping African women with screening, diagnosis, and treatment, citing language and cultural barriers. One apparently common myth is that a woman who breastfed her children cannot get breast cancer. At least four ethnically focused community-based organizations serve this population (African Women's Cancer Awareness Association, African Wellness Center, Ethiopian Community Development Council, and Somali Family Care Network). They know how to reach, communicate with, and engage this population, educating them about breast health care and available services and offering varied language capacity and a range of supports for women. Latino-focused groups serve a similar role for low-income Latinas, and for other populations, though few, such as Breast Health, Inc., focus on African American women. The presence and services offered by these groups varies by jurisdiction. In some jurisdictions their linkages with clinics and hospitals are close and mutually beneficial; in others, they are very limited – which weakens access to screening and care for such populations.

Interpretation can be a major challenge. National Limited English Proficiency (LEP) guidelines require all federally funded providers to make trained interpreters available at no cost to clients, and clinics typically have both bilingual staff and interpretation arrangements. Hospitals usually have some means of interpretation, which varies from in-house interpreters to telephone interpretation. Interpretation is most likely to be a problem when a woman is referred to a

specialist or private practice, and when the woman speaks a language that is less common in the area, rather than Spanish, French, or Amharic.

Overall, low-income uninsured women can be challenging patients because of the other life challenges they face. They may move often, have no stable telephone number of contact information, and face demanding family and employment issues. Immigrant women who do not qualify for publicly funded treatment in the U.S. may travel to their home country with their diagnosis, understanding that care will be less expensive and in some cases more family support will be available there. This can be frustrating to a caregiver who is committed to finding services in the region and complicates follow-up care.

Clinic internal issues: Clinic policies, practices, and relationships affect women's breast health care options and timeliness. Clinics vary in the extent to which they systematically provide breast health education to their patients, contact patients to inform them that it is time for a mammogram, provide extra support to get women to screening, and document patient status at each step in the process. The PCC model calls for clinics to develop a relationship with a mammography provider that enables them to make screening appointments for their patients and provide other support to reduce no-show rates. Such arrangements vary. Other clinic issues include:

- *Capacity:* some clinics, particularly in Northern Virginia and Prince George's County, operate near capacity and may have waiting lists for new patients.
- *Electronic medical records and related use of technology:* some clinics are unable to easily generate data on breast health care services or the number of breast cancer diagnosis; only a few have in place automated systems to tell them when a patient is due for a mammogram or a cancer survivor needs follow-up screening.

Payer-based systemic issues: Often the most challenging issues are external and systemic. This includes basic issues like whether enough free or low-cost mammography slots are available in a jurisdiction for low-income uninsured women. It also includes factors like limited treatment options in Virginia, challenging documentation requirements for Maryland's BCCDTP, and complex and varied MCO administrative requirements for obtaining authorization to provide diagnostic or treatment services in the District. Similarly challenging are Medicaid systems, MCOs, and mammogram and diagnostic service providers that do not keep clinics informed about the progress or problems faced by their patients – failure to provide timely mammography reports, inform medical homes that a diagnostic test is needed and has been scheduled (without providing time for the referring physician to obtain payer authorization), or tell the clinic when a patient has been approved for Medicaid and treatment can be arranged. These delays are costly for clinics and damaging to both the physical and emotional health of women who know they may have a life-threatening disease and must wait for others to provide information and treatment options.

Other systems issues: A lack of service coordination is a significant problem in Northern Virginia and the District of Columbia. Clinics and breast health care providers reportedly have limited knowledge about what services are provided by whom, and clinics may not have established relationships with a hospital or other mammography provider. Patient navigators play a crucial role for many providers. Some patient navigators are extremely knowledgeable, but

many struggle to learn about service availability in multiple jurisdictions and may be responsible for a wide range of patients, not just women with breast cancer. Navigators are extremely prevalent in the District, less so in some suburban jurisdictions, and there is a reported need for more bilingual navigators.

Charity care: Most hospitals and many private physicians and private radiology groups provide some *pro bono* care. Archdiocese Health Care Network (AHCN) in the District of Columbia provides access to specialists. A number of philanthropic groups, often small and local or regional, provide limited funding for diagnosis and treatment and for supportive services like transportation and child care. Examples include the Red Devils in Maryland, the Sharon McGowan Breast Health Fund in Northern Virginia. Some funds are provided through the American Cancer Society as well. However, access to charity care is limited and generally uncoordinated. Typically no process exists to obtain coordinated services from hospitals that offer such care. For example, a surgeon may agree to provide breast surgery, but the navigator or primary care provider must separately arrange for an anesthesiologist, a hospital stay, and other necessary components of the surgery. All jurisdictions report difficulties in obtaining specialty care for uninsured women, including radiation and chemotherapy. Costly medications are also hard to obtain. The fact that Northern Virginia women are not infrequently sent all the way to Richmond or Charlottesville for care – even recurring treatment like radiation and chemotherapy – is an indication of the difficulties clinics face in obtaining timely care within Northern Virginia or elsewhere in the metro area, despite the number of hospitals, specialists, and treatment providers and the presence of the National Institutes of Health.

Clinic roles: Two identified issues involve the role of clinics in providing breast health care and the implications of changes in the health care system on clinic roles and patient populations.

- *Use of clinics as referral agents:* With few exceptions, the clinics surveyed and brought together during the State Assessment serve as medical homes for their patients – they take responsibility for providing or arranging services to meet patient health care needs. Even clinics operating at full capacity make it clear that they will take new patients who have an urgent health care need. Some clinics, particularly the CHCs/FQHCs, reported that they not infrequently are asked to serve not as primary care providers but rather as referral agents. A low-income uninsured woman who has been receiving care from a private physician will be referred to a clinic once the physician determines that she has breast cancer. Rather than arranging treatment, the physician sends her to an FQHC, with the assumption that the FQHC will arrange cancer treatment but she will return to the physician for other care. The FQHC takes on the responsibility because it does not refuse clients, but this is not its desired model of care, and it places a considerable burden on its staff.
- *Forced changes in medical homes:* Changes in the insurance status of a woman with breast cancer can lead to a forced change in her medical home. A woman who becomes eligible for Medicaid through NBCCEDP now has coverage for primary care visits and other health care. However, the clinic previously serving as her medical home may not be a Medicaid-certified provider, or may not have a contract with a Medicaid MCO to which she is assigned. She may be assigned to a different medical home. It can be very difficult for a woman to be forced to change physicians at such a time, and can negatively affect her treatment experience. Similarly, as the District of Columbia moves people from DC Alliance to Medicaid, a few clinics that were part of the Alliance but do not take Medicaid are losing

clients. The Spanish Catholic Center has reported a loss of clients due to early DC implementation of Medicaid expansion. Other free clinics in other jurisdictions are likely to face similar changes under Medicaid expansion. This will mean a rethinking of roles and populations for some clinics

Some of these issues would be useful topics for the Initiative's regional learning community.

Regional Issues

Summary: Washington, DC and its inner suburbs encompass parts of three "state" jurisdictions, and being a multi-state offers both opportunities and challenges for breast health care. The challenges – particularly for safety-net clinics – include the barriers created by different Medicaid system, the need to learn about resources and regulations in multiple jurisdictions, and differing levels of state support for health care targeting low-income residents. The opportunities include a wide array of service providers and the potential for regional learning and regional collaboration on service delivery. Considerable cross-jurisdictional activity already exists. The area's CHCs/FQHCs serve patients regardless of residence, and two safety-net clinics have facilities in both DC and Maryland. DC's Project WISH uses some of its funds to screen women from Maryland and Virginia, and Virginia contracts with CBCC for screening and diagnosis under Every Woman's Life. In addition, clinics, hospitals, non-clinical community-based organizations, private mammography providers, and individual physicians all refer women to services in other jurisdictions.

Benefits and Challenges of a Multi-state Region; A key priority of the Regional Primary Care Coalition, a partner in the Regional Initiative, is to "foster the creation of coordinated, patient-centered systems of community-based primary care that make excellent, affordable, linguistically and culturally appropriate health services available to all across the region." The State Assessment highlighted some of the ways in which being part of a multi-state metropolitan area influences breast health care services.

All jurisdictions identified both opportunities and challenges associated with being part of a multi-jurisdictional metropolitan area. The challenges are perhaps more obvious than the benefits. The three jurisdictions have three different Medicaid and other public health systems, as well as very different political and financial perspectives on providing health care to low-income residents. Efforts to coordinate services and make them available across state lines are complicated by the fact that, as one clinic official noted, "Care delivery systems and reimbursement are very different between DC, Maryland, and Northern Virginia." The report has explored the differences in Medicaid systems, NBCCEDP programs, and providers. These differences become particularly clear to clinics that either operate in or accept patients from more than one state.

Serving Patients across State Lines: Many of the safety-net clinics serve patients across state lines, and two clinics – Spanish Catholic Center and Mary's Center for Maternal and Child Care – have facilities in both the District of Columbia and Montgomery County. All CHCs/FQHCs are required to serve patients regardless of residence. DC clinics appear to be especially likely to serve patients from another jurisdiction, perhaps because many low-income uninsured people

live in the suburbs but work – and seek health care – in the District. Demand is also created due to cultural issues. DC is home to the region's three Latino/immigrant clinics, La Clinica del Pueblo, Mary's Center, and Spanish Catholic Center, and to what was for many years primarily a gay/lesbian/bisexual/transgender provider, the Whitman-Walker Clinic. Patients who move from one jurisdiction to another may choose to continue getting primary care from a clinic they consider their medical home, regardless of its location. Health care providers other than clinics typically provide services regionally. Nearly all hospitals serve patients from across state lines. So do most of the non-clinical community-based organizations engaged in breast health outreach, education, and patient navigation. While they may provide some services (such as clinical breast exams) only in their headquarters location, most of the ethnically focused groups work in all three jurisdictions.

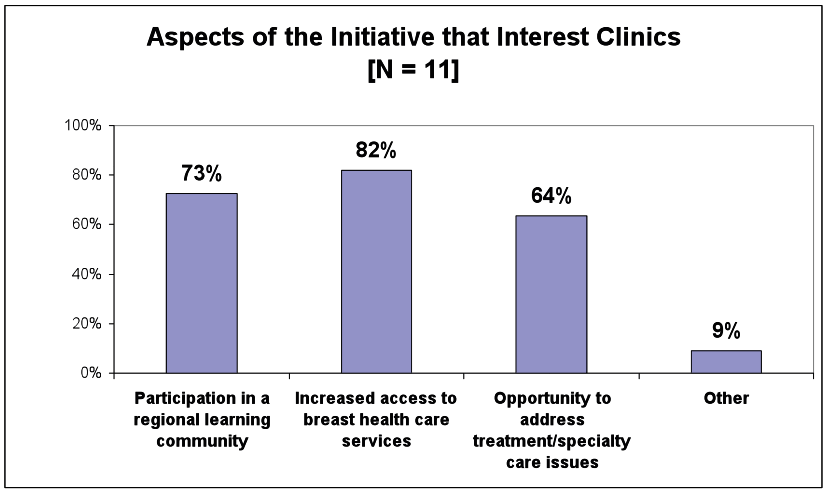
There is more available FQHC capacity in the District than in Northern Virginia or Maryland, and DC clinics are generally able to take and immediately serve new patients. Some clinic staff outside DC refer patients to DC clinics because they will receive more immediate care. However, most safety-net clinics that are not FQHCs serve primarily patients from within a single state. Some clinics serve patients only from their own county, health district, or other narrowly defined geographic target area. Public clinics (like the one run by the Alexandria Health Department), clinics funded primarily by counties (like the Community Health Care Network in Fairfax County), and free clinics (like the Arlington Free Clinic) typically serve only residents of their county. The health department clinics sometimes make an exception for services like HIV or STD testing that is funded by the federal government.
Clinics identified the following challenges to serving patients who live in another state:

- **Differences in state policies, programs, and access to reimbursements:** The differences in payers and programs by state mean that screening, diagnostic, and treatment options may be different depending upon state of residence – and a clinic may not be eligible for payment from other states. A DC clinic often can bill the DC Alliance for services to an immigrant who is a DC resident, regardless of immigration status, but cannot receive reimbursement for a Virginia resident. Medicaid in Virginia is much more restrictive than in DC or Maryland, but regardless of benefits, clinics generally are not certified to receive Medicaid reimbursements except in their own states.
- **Differences in service availability and resources:** It is often harder to find care for a low-income woman in Northern Virginia than in the District of Columbia. A few clinics indicated that hospitals tend to use their community benefit dollars for patients who live in the jurisdiction where they operate. One DC clinic indicated that its staff would prefer not to serve patients from Virginia, because it is so difficult to arrange charity care there.
- **Limited provider knowledge and experience:** Provider staff report less knowledge about providers and services and fewer personal relationships with providers in jurisdictions other than their own. They have more opportunity to update knowledge and maintain contacts in their own jurisdiction, since they use these contacts every day. They don't necessarily know who to call to arrange needed services for someone who lives in another jurisdiction. Several clinics that have waiting lists emphasized that they would never turn away a patient with urgent health care needs, such as breast cancer treatment – but clinic staff in other jurisdictions may not know who to call to arrange such access.

Despite these challenges, CHCs/FQHCs do serve patients from other jurisdictions, as do other providers. The DC contracted Project WISH providers regularly provide screening and diagnosis for residents of Northern Virginia and Suburban Maryland. Virginia funds CBCC, located in DC, to provide mammograms and diagnosis under Every Woman's Life. Community-based organizations may operate in several jurisdictions but have particular expertise and provider relationships in its home jurisdiction. As a result they sometimes refer people to providers in other jurisdictions.

Clinic Interest and Capacity

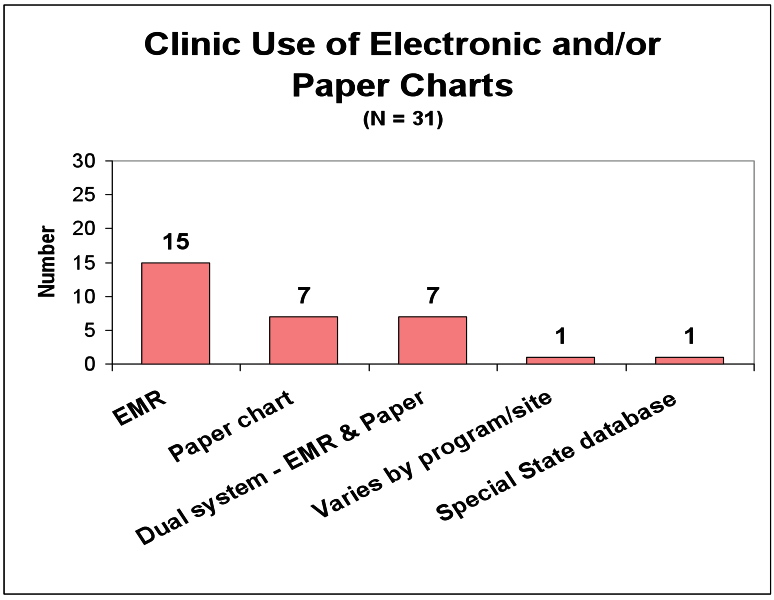
Summary: Clinics have indicated a high level of interest in participating at some level in the Regional Process Improvement Initiative. Several clinics would like to serve as targeted replication sites, others to be part of a group of involved clinics, still others to participate in jurisdiction-specific 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.



Interest in Participation in the Initiative: Clinics had multiple opportunities during the State Assessment to indicate interest in the Initiative. Northern Virginia and Prince George's County clinics were asked about their interest in the clinic survey and at several meetings held with groups of clinics. PCC and RPCC representatives then met with NVHSC, Greater Baden Medical Services, and DCPCA and several member clinics to explore interest.

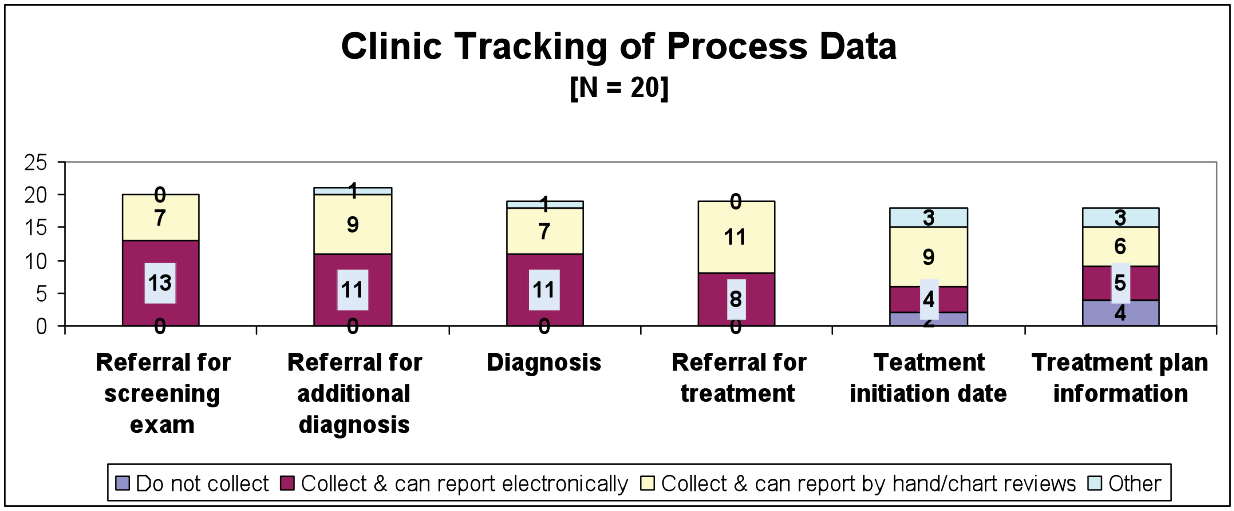
There is great interest in the Initiative as a way of improving and increasing access to breast health care services throughout the jurisdiction or region. A large majority (9 or 75%) of the 12 clinics surveyed in Northern Virginia and Prince George's County expressed interest in being a part of the Initiative, 2 said they weren't sure, and 1 said no. The one that isn't interest explained that "We don't see how this new project will increase the number of oncologists and surgeons willing to see this population." However, two interested clinics emphasized their hope that participation would lead to "better treatment options." As the bar chart shows, these clinics indicated greatest interest in increased access to services, followed by participation in a regional learning community. As one clinic respondent put it, "I am most interested in engaging local providers to try to increase options within our community for women to receive care. I think we all face the same issue of a lack of resources for the uninsured patients we serve and I would like to work on addressing that." Several clinics would like to become targeted replication sites and

are willing to devote the necessary time to do so. Others would like to participate at a more limited level in process improvements, and be part of the regional learning community. A particular interest was expressed in working together for systems change to address some of the identified barriers to care.



The required time commitment is an important consideration for clinics in deciding whether they would like to participate as targeted replication sites or in more limited ways. A related factor is the extent to which the clinics can monitor and report process improvements through an electronic medical records (EMR) system. As shown in the bar chart that follows, 15 of the 31 safety-net clinics in the region indicated that they have an EMR system, while 7 reported paper charts and 7 have dual systems. Some clinics indicated that while they have EMRs, they are not yet able to easily generate reports that would simplify review of process improvements related to breast health care. Others do not collect data on all the measures useful for clinic tracking of breast health care process data.

The stacked bar chart below shows what breast care data 20 responding clinics (in DC, Northern Virginia, and Prince George's County) can track. A majority of the clinics (55-65%) indicated they can report electronically referrals for screening exams, referrals for additional diagnostic exams, and diagnosis. Less than half can report electronically on referral for treatment, the treatment initiation date, and treatment plan information. However, most clinics can report and report all these data by hand or chart review. Three clinics do not collect the treatment initiation date or treatment plan information.



Implications of Findings for the Regional Initiative

Summary: The State Assessment offers information and insights to help shape the replication phase of the Regional Initiative. The assessment confirms the importance of process improvements within clinics and the value of patient navigators, both important components of the PCC model. Data on insurance coverage and reported barriers to diagnosis and care in the District of Columbia indicate that, at least in that jurisdiction, the Initiative's focus should be low-income women without regard to their insurance status. Findings from all jurisdictions highlight systems issues that impede efforts to provide comprehensive, timely, high quality breast health care services to low-income women. Safety-net clinics in all the jurisdictions are interested in being a part of the replication and in working with others to address systemic issues. Clinics and other providers want to be part of a learning community that shares knowledge and experience, and an action community that works to improve systems and eliminate many of the current barriers to breast health care for low-income women.

Implications: The State of the Region Assessment provides information for use in choosing replication sites, identifying possible refinements in the PCC process improvement model, and targeting community learning efforts. Following are findings and observations that Mosaica feels have particular significance for the later phases of the Initiative.

1. **Importance of process improvement:** It is clear that in every jurisdiction, process improvements at the clinic level 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, such as a close relationship between the clinic and a mammography provider, should yield similar benefits in other jurisdictions.
2. **Value of patient navigators:** 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 benefits might be obtained from joint use of appropriately trained bilingual navigators to play roles such as helping Maryland women meet the documentation requirements of BCCDTP, 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. Best training and assignment of navigators is a topic that would benefit from careful consideration by the learning community.
3. **Need for systems change:** Process improvements at clinics and the addition of more navigators to a dysfunctional system will be far less effective 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.

4. **Provider coordination:** In each jurisdiction, a variety of community-based organizations, safety-net clinics, hospitals, private mammography providers (profit and nonprofit), and physicians and physician practices are engaged in providing breast health care – but in most jurisdictions, there is no coordinated system of services. This creates unnecessary and costly barriers, especially to diagnosis and treatment. Some aspects of coordination will be difficult to achieve, while others can be accomplished more easily. For example, community-based providers and clinics need to be closely linked – 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 close relationships with mammography providers including the ability to make a woman's mammography appointment during her clinic visit. A coordinated process is needed to arrange hospital-based charity care to replace the current situation, which requires a clinic to separately arrange each component of that care. The key informant sessions and the experience of Montgomery County suggest that some improvements in coordination will 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.

5. **Regional issues:** The Regional Initiative and its learning community have important opportunities to address this major health care issue from a regional perspective. Despite some unique issues in each jurisdiction, a very large number of 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. In addition, breast health care is already being addressed across state lines through the contract between Every Woman's Life and the DC-based Capital Breast Care Center, Project WISH's screening and diagnosis of women from Northern Virginia and Suburban Maryland, and the large number of clinics, particularly CHCs/FQHCs, serving women who live in other jurisdictions. Addressing systemic as well as clinic-based and coordination issues related to this disease also provides valuable lessons for how to approach other health issues.

6. **Focus on *low-income* rather than only *low-income uninsured* women:** In Montgomery County, the Initiative's focus has been on low-income uninsured women, and this was the original assumption for the Regional Initiative. At least in the District of Columbia, the focus will need to be on low-income women who are patients of safety-net clinics, regardless of insurance status, especially if enrollment in the DC Healthcare Alliance is considered insurance coverage. Since DC has chosen to implement health care reform's Medicaid expansion early, a majority of the approximately 56,000 former DC Alliance clients (who must have incomes below 200% of FPL) will be receiving Medicaid. The rest will remain eligible for DC Alliance. The 2009 DC uninsurance study indicated that nearly 56% of the uninsured in the District have incomes below 200% of FPL, and therefore are probably eligible for either Medicaid or the Alliance; 55% said they were not aware of public insurance programs.[7] The low-income uninsured population of the District is small and likely to shrink further.

   Yet it is clear that low-income women on Medicaid or receiving DC Alliance benefits still face considerable barriers to needed breast cancer services. As the Brookings Institution's December 2010 report on the Alliance noted, DC now has one of the lowest uninsured rates

[7] Urban Institute, *op. cit.*

in the country, and the Alliance has provided a revenue stream to safety-net clinics that previously were serving this population without reimbursement. However, "Access to primary and specialty care is still inadequate, and the city is still struggling to create an integrated model of care."[8]

7. **Social determinants of health:** The breast cancer mortality rates in Prince George's County and the District of Columbia – and the slightly lower but still high 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. While it is beyond the scope of this needs assessment to explain these data, other research suggests the importance of possible inequities in care and social determinants of health. This seems particularly important since these are the three areas with the highest proportions of residents who are not White non-Hispanics – communities of color make up 78% of the population in Prince George's County, 68% in the District of Columbia, and 48% in Prince William County. African American populations are also highest in these jurisdictions, accounting for 63%, 54%, and 19% of the population.[9]
8. **Role of private grant making:** Private philanthropy plays an important role not only in supporting breast health care services, but in influencing priorities and service models. Small philanthropic entities like the Red Devils and the Sharon McGowan Breast Health Fund help fill service gaps. Larger grants from local and national foundations, including Susan G. Komen for the Cure, have provided much of the support for community-based non-clinical providers, including groups that target specific ethnic groups, supported outreach by hospitals and clinics, and paid for patient navigators. The information gained from the State Assessment, replication, and learning community should be shared with funders, to help them use their funds innovatively and effectively.
9. **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 because some systems issues are state-based, probably the two Suburban Maryland counties should be merged

[8] Brookings Institution, "Expanding Health Coverage in the District of Columbia: D.C.'s Shift from Providing Services to Subsidizing Individuals and Its Continuing Challenges in Promoting Health, 1999-2009." December 10, 2010. Available online at http://www.brookings.edu/papers/2010/1210_dc_healthcare.aspx.
[9] Bureau of the Census 2006-2008 American Community Survey 3-year averages.

for such purposes. PCC and GBMS would help lead the Maryland group, NVHSC the Northern Virginia group, and DCPCA the DC group.

- 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.

Following are some topics for learning and action community attention:

- How does having a medical home versus not having a medical home influence breast health care access and timely services including follow-up?
- How can access to community benefit dollars and charity care be coordinated and maximized for low-income uninsured women? What can hospitals do and how can access to diagnosis and treatment be made more structured and coordinated?
- How can access to specialists be improved?
- How can administrative barriers to diagnosis and treatment be lessened? What can be done through coordination and information sharing, and what requires systems change?
- What can we learn from DC's early implementation of Medicaid expansion and its effects on breast health care? What are the implications for clinics that do not take Medicaid?
- How can each jurisdiction and the region as a whole maximize access to NBCCEDP for eligible patients, including those who are likely to qualify for Medicaid under the program?
- What can be done to improve communications between clinics and payers, including Medicaid and Medicaid MCOs?
- What specific action are clinics taken to use electronic medical records systems and other technology to improve breast health care services?
- How accurate are regional and jurisdictional data on breast cancer screening and diagnosis, as well as estimates of the number and percent of women 40 and older who are low-income or low-income uninsured, and how can these data be improved?

Some of the topics addressed as part of the learning community will require additional data, copies of studies, or collection and summarizing of information. RPCC and PCC staff or fellows may be able to provide this support. For example:

- To determine whether requiring a second authorization for diagnostic screening following an abnormal mammogram, it would be helpful to see if cost studies have been done in relation to such requirements.
- Review of effective breast health care models may benefit from information on models used by both safety-net clinics and respected providers (like the Mayor Clinic or Cleveland Clinic) in other locations, particularly providers serving low-income uninsured women.
- An effort to better understand current services as a foundation for improving service coordination, some work may be needed to better understand how community benefit dollars are used and charity care is organized at hospitals and health care systems in the region.
- Efforts to better explain the differences in breast cancer incidence and mortality rates by geographic location and race/ethnicity, particularly among low-income and uninsured women, will require a better understanding of data reporting and comparability.
- Efforts to better link clinics and community-based organizations might benefit from models in other cities and regions.

The Regional Initiative's learning and action community will need to set priorities among these 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.