



# COMMUNITY PROFILE REPORT

Susan G. Komen for the Cure®

National Capital Area



# ACKNOWLEDGEMENTS

We would like to extend a profound thank you to all who assisted with this effort. We extend a special thank you to the community members who participated in the focus groups and who shared so freely of their time, experience and opinions.

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# EXECUTIVE SUMMARY

## SUSAN G. KOMEN GLOBAL RACE FOR THE CURE® HISTORY

Nancy G. Brinker promised her dying sister, Susan G. Komen, she would do everything in her power to end breast cancer forever. In 1982 that promise became Susan G. Komen for the Cure® and launched the global breast cancer movement.

Today, Komen for the Cure is the world's largest grassroots network of breast cancer survivors and activists fighting to save lives, empower people, ensure quality care for all and energize science to find the cures. Thanks to events like the Komen Race for the Cure, the organization has invested nearly \$1.5 billion to fulfill its promise, becoming the largest source of nonprofit funds dedicated to the fight against breast cancer in the world.

The first Susan G. Komen Global Race for the Cure was held in 1990. Over the years, the Global Race has grown significantly and in 2009, 43,013 participants raised \$4.7 million. Up to 75 percent of the funds raised by the Komen Global Race for the Cure stay in the National Capital Area (NCA) to fund education, screening, and treatment programs. The NCA encompasses the District of Columbia (D.C.); Montgomery and Prince George's Counties in Maryland; and in Virginia, the city of Alexandria, and Fairfax, Prince William, Loudoun and Arlington Counties. The remaining dollars support the Komen Global Promise Fund, which is dedicated to fighting breast cancer around the world.

## PURPOSE OF THE REPORT AND METHODOLOGY

Susan G. Komen for the Cure's promise is to save lives and end breast cancer forever by empowering people, ensuring quality care for all and energizing science to discover the cures. To fulfill this promise, Susan G. Komen for the Cure conducted a Community Profile to investigate the health needs and assets that exist in the NCA. The results of the profile inform Komen's work in the community, specifically determining how resources should be invested to make the greatest impact in communities with the greatest need.

The Community Profile assessment includes a comprehensive review of the demographic and breast cancer statistics in the NCA in order to identify target communities. The statistics allow Komen to pinpoint where efforts will have the most impact. The second element of the assessment is an analysis of NCA breast cancer health systems. The health systems analysis focuses on understanding the gaps, needs and barriers that women encounter in the NCA as they access breast health services. Finally, data is collected from women living in the target communities to gauge breast cancer understanding, knowledge of services, access barriers and the effectiveness of outreach and education efforts.

## TARGET COMMUNITIES

A study of the NCA breast cancer statistics determined the following target communities for the 2011 Community Profile: Wards 7&8 in the District of Columbia, Prince George's County, Maryland and Arlington and Prince William Counties, Virginia.

The health systems review focused on the areas of highest mortality and the analysis quickly brought forth a number of factors that alone or in combination might contribute to the increased mortality rates of the target communities. For example, the lack of breast health services available to women in the target communities may be a determining factor in the high mortality.

Understanding the limited resources in the target communities informed and defined the analysis within the communities, i.e. the information sought from key informants and women in those communities. Since we understood that there were limited services we wanted to understand where the women went for services if they did at all and what, if any, difficulties they faced in accessing care. This knowledge guided the questionnaires developed for both the key informants and the focus group participants.

## FINDINGS

The need for more comprehensive education efforts was a major finding. Both providers and community members talked about the need to teach women about breast cancer rather than just raise their awareness of the disease. In addition, throughout the target communities, capacity at all stages of the continuum of care was also a significant finding. The term capacity was used by providers when discussing their inability to meet the need for breast cancer services because of the lack of funding. When community members discussed capacity in the focus groups it referred to the lack of providers and services. The lack of services for the uninsured was also identified as a concern in the target communities.

### **Wards 7&8**

Wards 7&8 were chosen as target communities because of their mortality rates (32.9 and 30.7 respectively),<sup>1</sup> and the significant socio-economic challenges facing the predominantly African

American women living in those Wards. Both Wards have low average household incomes compared to the rest of the region and according to estimates 25 percent of Ward 7 residents live below poverty and 14 percent are unemployed. In Ward 8, the percent of the population that live below poverty (25%), are unemployed (22%), and did not complete high school education (34%) are greater than Ward 7.<sup>2</sup>

The lack of a stable health infrastructure in Wards 7&8 serves as a major barrier for women needing breast health services. With only one hospital to serve both Wards and providing only limited breast health services, women in these communities are faced with serious access barriers.

Key informants discussed a need for culturally appropriate, multi-level education programs that move the community beyond awareness and clearly define the recommended screening and re-screening guidelines. Additionally, informants expressed the complexity of working with women in Wards 7&8. Women living in resource poor communities, who are fighting to keep jobs and make enough to support their homes and families, do not prioritize their own health and are not able to focus on preventive services, especially when seeking these services is cumbersome due to the system's own limitations. Providers also identified immigrants living in Wards 7&8 as a group requiring special attention in breast health efforts, because of issues related to culture, language and immigration.

Focus group participants stressed the need for more breast cancer education in their communities. Past and current awareness efforts, according to participants, have effectively raised awareness of breast cancer, but the group felt it was time to build on awareness and effectively address the lack of knowledge of the disease that leads to the fear of screening, which for many means hesitation and denial about the importance of seeking services.

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<sup>1</sup> D.C. Cancer Registry, 2002-2006

<sup>2</sup> NeighborhoodInfo D.C., 2009

Women in this group also discussed the need to create a single and consistent message around screening and breast cancer. Participants discussed the abundance of conflicting messages coming from the media, medical professionals and even their neighbors. The fact that everyone has a different message as to the screening recommendations, services available and the disease itself leads to confusion among women in the community. The group also discussed how those who work in breast cancer need to ensure that messaging and education is culturally sensitive and appropriate and reaching those who need to hear it most.

### ***Prince George's County***

Prince George's County was chosen as a target community because of its high mortality rate, its diverse population and the social economic challenges facing women in the northern region. In Prince George's County, screening numbers show that about 81 percent of women 50 and older are getting screened, but mortality data shows that 31.2 women out of 100,000 are dying due to breast cancer.<sup>3</sup> Similar to Wards 7&8 of D.C., Prince George's County has a significant African American population (63%). Unlike Wards 7&8, the population in Prince George's County is considerably wealthier and more educated. The average household income is \$81,912.<sup>4</sup> The focus on Prince George's County for the purpose of this report is limited to the northern region, where there is a large Latino population and its residents have the highest poverty rates and lowest education levels as compared to those living in other regions of the county.<sup>5</sup>

A review of the county's health infrastructure determined that despite the wealth of resources in the county as a whole, the northern region is limited in the services that are available to the uninsured and immigrant population dominant in that region. Free and low cost health care is not available to women living in the northern region; the only Breast and Cervical Cancer Early Detection Program (BCCEDP)

site is in the center of the county, has limited funding and is not easily accessible to many who would benefit from its services. Providers in Prince George's County focused primarily on the challenges they face working with uninsured women in a county where there are limited to no services providing general care let alone charity care.

Women in the community talked about how breast cancer education should be provided in a way that empowers women to take care of their own health, seek services and demand quality care. They believe that there are no culturally appropriate breast cancer education programs available to women in the county and acknowledged that awareness is still needed in their community. Latinas in the county want to be educated about breast cancer, the role and importance of screening and the resources in the community.

The lack of services available to women along with the perceived notion that care provided to the poor is of less quality was heavily discussed in the Prince George's focus group. Participants identified the lack of existing community resources as the most significant barrier to women in their community, and through the experiences they shared, confirmed that the lack of resources in their community added to the number of barriers they had to overcome just to seek care. For example, having to travel outside of the county to get a mammogram requires a woman living in Prince George's to take significant time off work, arrange long distance transportation, deal with travel expenses, and wait hours for her appointment.

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<sup>3</sup> CDC, State Cancer Profiles, 2001-2005

<sup>4</sup> Thomson Reuters ©2009

<sup>5</sup> Lurie, 2009

## ***Arlington County***

Arlington County's mortality rate (25.4),<sup>6</sup> although not as high as in other target communities, and its diverse population prompted the decision to make it a target community. Screening percentages in Arlington are on par with the rest of the NCA, about 79 percent of women 40 and over report having had a mammogram in the last two years in the county.<sup>7</sup>

With an average household income around \$121,000, Arlington County is better positioned economically than many of its neighboring regions in the NCA. Despite the relative wealth in the community, estimates show that 17 percent of women age 45 to 64 are uninsured and 59 percent may be underinsured in Arlington County. Latinos (16%) make up the largest minority group in the county, followed by Asians (9%) and African Americans (8%).<sup>8</sup> As an indicator of its diversity, the county estimates that there are 95 languages spoken in the county representing 128 countries.<sup>9</sup>

Arlington County has no BCCEDP sites available to its residents, therefore women needing free or low cost mammograms have to seek care outside of their county. In Arlington, according to providers, there is little outreach taking place so women in the county are unaware of what services are available to them. The county has a growing number of foreign born residents who don't speak English; therefore immigrant women were identified as a vulnerable group because of language barriers. Immigrant women are therefore less likely to be aware of services. Providers also discussed the specific needs of uninsured women in Arlington. According to providers, uninsured women face significant challenges in accessing breast care. The uninsured are relegated to get care where it is offered free which often delays access and increases the chances that women don't get through the continuum of care.

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<sup>6</sup> Virginia Center for Health Statistics, 2002-2006

<sup>7</sup> Virginia BRFSS, 2004-2006

<sup>8</sup> Thomson Reuters © 2009

<sup>9</sup> Arlington County, [www.arlingtonva.us](http://www.arlingtonva.us)

Participants of the Arlington focus group were aware of breast cancer, but had limited to no understanding of the disease. They had no knowledge of the screening guidelines and had limited knowledge of available breast cancer services. The prevailing thought among the group was the belief that there are no education programs or breast health services in their community. The women shared their opinion that the health systems in the county discriminates against African Americans by denying or delaying care and by redirecting services to the growing Latino population.

## ***Prince William County***

Prince William County was chosen as a target community because of its mortality rate (25.4)<sup>10</sup> as well as its growing diverse population. Latinos make up the largest minority group in Prince William (21%) followed by African Americans (18%) and Asians (7%). Fifty-eight percent of residents report a household income of more than \$75,000. Despite the county's wealth, many residents are living in poverty. The Virginia Workforce Connection reported state unemployment in March 2010 at about 8 percent<sup>11</sup> and according to Thomson Reuters © 2009, 7 percent of households in the county are living on less than \$25,000. Nine percent of women 45-64 are believed to be without health insurance and 30 percent of Prince William residents are underinsured.<sup>12</sup>

Prince William does not have a BCCEDP site in the county so women must travel outside of the county to seek free or low cost mammograms. In Prince William providers discussed the need for more outreach to address specific barriers in their system that prevent women from seeking care. According to providers, women in Prince William don't trust the screening process and don't believe in the value of screening to save lives. In addition, providers discussed how many immigrant women don't seek care in the county because they fear being turned in to immigration.

<sup>10</sup> Virginia Center for Health Statistics, 2002-2006

<sup>11</sup> Virginia Workforce Connection, 2010

<sup>12</sup> Thomson Reuters © 2009

The availability of care for the uninsured is also fragmented and limited in Prince William as in the other target communities and the lack of support after a diagnosis is a significant gap for women in the county.

In Prince William, education was the main theme of the focus group discussion. Participants expressed the need to approach education efforts differently for women in their community, recognizing that minority and immigrant women still need awareness campaigns to get them as “comfortable” talking about breast cancer as the general public. However, there was also considerable discussion on the need to move beyond the basics when doing community education on breast cancer and how the knowledge these efforts would impart would serve as a powerful empowering tool to women in their community.

### NATIONAL CAPITAL AREA PRIORITIES

Although there were variations to the findings depending on the region being discussed, two main themes were clear throughout the NCA. Findings indicate that current education efforts need to be reconsidered and that a comprehensive education approach should be explored. Education efforts in the NCA need to move the communities beyond awareness by providing more in-depth education on screening, breast cancer and resources. The education approach should be tailored to specific groups and provide consistent and clear messages that ideally lessen fear, confusion and motivate women to take care of their health.

The second theme in the NCA pertains to the lack of continuity of care throughout the continuum of care for women who are uninsured and underinsured because of lack of funding. Providers in the target communities are at, or above, capacity and therefore not able to meet the need in the communities. The lack of providers in certain regions and the lack of access to services in others put women at risk and may be contributing to women dying from cancer in the NCA.

### PRIORITIES AND ACTION PLAN

After the final analysis of the data had been reviewed and discussed, the Community Profile Team developed a list of 12 priorities that reflected the findings of the data analysis. Following considerable discussion, the Team ranked the priorities. This process (rank and discuss) was repeated until four priorities were selected. In separate meetings, the Community Profile Team and Komen staff established objectives for each priority based on capacity and resources. The timeline to complete all activities listed in the Action Plan is April 1, 2010 – March 31, 2012. While many of these priorities apply to the NCA, special emphasis will be placed on Wards 7&8, Prince George’s County, Arlington and Prince William County.

**Priority 1:** Increase provider competency and community knowledge and understanding of breast cancer screening recommendations as they apply to priority populations.

Objective 1: Identify and fund educational opportunities to inform providers of the screening guidelines and also improve their working knowledge of the various referral processes to better navigate patients.

Objective 2: Partner with community-based collaboratives in Wards 7&8, Prince George’s County, Arlington and Prince William to develop and implement a symposium to reinforce correct screening guideline messages to the community.



**Priority 2:** Assist partners and grantees in strengthening current breast cancer education content to include targeted awareness messaging, understanding of the disease, and survivorship.

Objective 1: Fund multi-faceted education programs that follow the Ecological Model<sup>13</sup> and are tailored to the target communities.

Objective 2: Develop a curriculum on correct messaging that can be tailored and adapted for use with diverse populations.

**Priority 3:** Influence partners and grantees to strengthen or incorporate culturally competent education messaging.

Objective 1: Fund cultural-sensitivity provider training(s) in the National Capital Area.

Objective 2: Share research findings from the Community Profile and encourage community-based organizations to apply culturally appropriate findings to their community efforts.

**Priority 4:** Reduce fragmentation and enhance the health care system's capacity to screen and provide follow-up care in the National Capital Area. Create continuity between referral, screening, diagnosis, and treatment within the region.

Objective 1: Increase the number of organizations serving Wards 7&8, Prince George's, Arlington and Prince William County that receive Komen funding.

Objective 2: Identify or design a model for an integrated system of care, thereby improving referrals from screening to follow-up care within and between the target communities.

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<sup>13</sup> The Ecological model addresses multiple levels of behavior influence and provides a comprehensive health promotion model that is multi-faceted, concerned with environmental change, behavior and policy that helps individuals make healthy choices in their daily lives.

# INTRODUCTION

## SUSAN G. KOMEN GLOBAL RACE FOR THE CURE® HISTORY

Nancy G. Brinker promised her dying sister, Susan G. Komen, she would do everything in her power to end breast cancer forever. In 1982 that promise became Susan G. Komen for the Cure® and launched the global breast cancer movement.

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The first Susan G. Komen Global Race for the Cure was held in 1990. Over the years, the Global Race has grown significantly and in 2009, 43,013 participants raised \$4.7 million. Up to 75 percent of the funds raised by the Komen Global Race for the Cure stay in the National Capital Area (NCA) to fund education, screening, and treatment programs. The remaining dollars support the Komen Global Promise Fund, which is dedicated to fighting breast cancer around the world.

## DESCRIPTION OF SERVICE AREA

The NCA encompasses the District of Columbia (D.C.); Montgomery and Prince George's Counties in Maryland; and in Virginia, the city of Alexandria, and Fairfax, Prince William, Loudoun and Arlington Counties. This region includes approximately 4.4

million people.<sup>14</sup> According to a recent report by the Brookings Institution, the large majority of the population is concentrated in D.C., Alexandria city, Arlington County, Fairfax County, and Prince George's County. However the more suburban counties, Prince William and Loudoun, have the most rapid population growth rates.<sup>15</sup>

### *Race and Ethnicity*

A review of the region's racial and ethnic makeup indicates that the population in the NCA is very diverse. Although Whites are the largest racial group in the region (46%), people of color make up more than half of the population: African Americans (27%), Latinos (14%), and Asians (10%).<sup>16</sup> The District of Columbia, Prince George's County, Alexandria, and the eastern part of the region all have significant African American populations. The Latino and Asian populations are concentrated in the north and west parts of the region. Prince William and Arlington Counties have the highest percentages of Latino residents, while the District of Columbia and Loudoun County have the lowest percentages.<sup>17</sup>

The NCA also has a growing number of immigrants. In fact, the NCA has the seventh highest number of foreign-born residents among all metropolitan areas in the U.S.<sup>18</sup> Over one quarter of the population speak languages other than or in addition to English. In the city of Alexandria and the counties of Arlington and Fairfax — more than 30 percent of the population speaks a language other than English at home.<sup>19</sup>

<sup>14</sup> Thomson Reuters © 2009

<sup>15</sup> Greater Washington Research at Brookings for Venture Philanthropy Partners, 2009

<sup>16</sup> Thomson Reuters © 2009

<sup>17</sup> Greater Washington Research at Brookings for Venture Philanthropy Partners, 2009

<sup>18</sup> Ibid

<sup>19</sup> US Census, American Communities Survey, 2005-2007



### ***Income and Age***

When taken together, the cities and counties that comprise the NCA are relatively affluent. The median household income throughout the region, estimated at \$90,251, exceeds the U.S. median household income (\$69,376). However, there is wide variation within the region. For example, the median household income in Loudoun County for 2009 was \$124,311 compared to \$86,220 in the District of Columbia.<sup>20</sup> Variance in income is also evident between racial groups. Throughout the NCA, median income levels for African American and Latino households fall below the region's average.<sup>21</sup>

The proportion of the population that is age 65 and older is relatively small (10%). More than 10 percent of those over age 65 in Arlington County, 11 percent in Alexandria, and 15 percent in the District of Columbia live below the Federal Poverty Level.<sup>22</sup>

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<sup>20</sup> Thomson Reuters © 2009

<sup>21</sup> Greater Washington Research at Brookings for Venture Philanthropy Partners, 2009

### ***Education***

The percentage of adults 25 and over with a bachelor's degree or higher in the NCA is above the national percentage (25%) at 35 percent. However, as with income, education varies by region. For example, in 2009, 32 percent of adults in Prince William County and 31 percent of adults in Prince George's had attained a bachelor's degree or greater. However, in Arlington County those with a bachelor's degree or higher in 2009 was 60 percent. The population of adults over the age of 25 with less than a high school degree is highest in D.C. (8%) and lowest in Loudoun (2%).<sup>23</sup>

### ***Purpose of Report***

Susan G. Komen for the Cure conducts a Community Profile to investigate the health needs and assets that exist in the community. The results of the profile inform Komen's work in the community, specifically determining how resources should be invested to make the greatest impact in communities with the greatest need.

<sup>22</sup> Ibid

<sup>23</sup> Thomson Reuters © 2009

# BREAST CANCER IN THE NATIONAL CAPITAL AREA

## METHODOLOGY

The Community Profile is a systematic process whereby quantitative and qualitative data is collected and analyzed. This process allows for objective and comprehensive conclusions to be drawn about the needs of the communities. The first step of the Community Profile process was to collect demographic data and breast cancer statistics for each region in the NCA.

United States — National mortality, incidence and screening data were obtained from the National Cancer Institute (NCI), 2002-2006 and Behavioral Risk Factor Surveillance Survey (BRFSS), 2008 at <http://www.statecancerprofiles.cancer.gov>.

District of Columbia — District and Ward level mortality, incidence and staging data was provided by the District of Columbia Cancer Registry (2002-2006). Screening data were obtained from NCI, BRFSS, 2008 at <http://www.statecancerprofiles.cancer.gov>.

Maryland — Mortality (2001-2005) and screening (2008) data came from the NCI and incidence rates were obtained from the Maryland Cancer Registry (1999-2003).

Virginia — Mortality rates at the state and county level were provided by the Virginia Center for Health Statistics (2002-2006). Incidence rates and staging data were obtained from Virginia Cancer Registry (2001-2005). Screening data at the state level was generated from SCP (2008) and at the county level provided by the Virginia BRFSS (2004-2006).

Demographic and insurance estimates at the District and county level were obtained from Thomson Reuters © 2009. Ward level demographic data, based on the 2000 Census, was obtained from the NeighborhoodInfo D.C. project website located at <http://www.neighborhoodinfoDC.org/>.

## OVERVIEW OF BREAST CANCER STATISTICS

Table 1 summarizes mortality, incidence and screening data for the NCA. The focus in the NCA is to save lives by decreasing breast cancer mortality rates. Therefore, emphasis was placed on identifying communities with high mortality rates. A quick review of the available data reveals that over half of the cities and counties within the NCA have mortality rates that exceed the national rate.

Table 1.

*Breast Cancer Statistics for National Capital Area*

	MORTALITY PER 100,000 ALL RACES	INCIDENCE PER 100,000 ALL RACES	SCREENING WOMEN 40+ HAD A MAMMO LAST 2 YEARS
US	23.4	119.3	76.0%
State: District of Columbia	28.1	137.1	80.8%
Ward 1	25.1	129.4	-
Ward 2	32.5	153.8	-
Ward 3	23.3	139.7	-
Ward 4	26.9	122.6	-
Ward 5	25.3	127.8	-
Ward 6	17.4	89.1	-
Ward 7	32.9	116.8	-
Ward 8	30.7	121.3	-
State: Maryland	27.4	130.4	77.0%
Prince George's County	31.2	120.7	81.3%*
Montgomery County	27.1	139.3	83.8%*
State: Virginia	25.8	120.1	78.2%
Alexandria City	18.0	103.1	82.2%
Arlington County	25.4	130.1	78.5%
Fairfax County	24.0	130.2	76.0%
Loudoun County	26.2	122.6	79.9%
Prince William County	27.9	115.4	80.1%

Sources: National mortality and incidence (NCI, State Cancer Profiles , 2002-2006); D.C. mortality and incidence (District of Columbia Cancer Registry, 2002-2006); National and D.C. Screening (NCI, SCP, BRFSS, 2008); Virginia mortality (VA Center for Health Statistics, 2002-2006); Virginia incidence (VA Cancer Registry, 2001-2006); Virginia state screening (NCI, SCP, BRFSS, 2008) and Virginia county screening (BRFSS, 2004-2006); Maryland mortality (SCP, 2001-2005); Maryland incidence (Maryland Cancer Registry, 1999-2003); Maryland state screening (SCP, BRFSS, 2008); \*Maryland county level screening-women 50+ every 2 yrs (Rand Corporation © 2009, BRFSS, 2005-2006)

The U.S. mortality rate according to the National Cancer Institute's State Cancer Profiles (NCI) is 23.4 (2002-2006). In the NCA, the District (28.1) and the States of Maryland (27.4) and Virginia (25.8) all report higher mortality rates than the U.S. rate. In general, mortality rates within the District and the regions within each state that make up the NCA are considerably higher than the U.S. rate. In D.C., six of

the eight Wards have rates above the U.S. rate, but mortality rates are highest in Wards 2, 7 and 8 (32.5, 32.9 and 30.7, respectively). In Maryland, Prince George's reported mortality rate is 31.2 compared to Montgomery County whose mortality rate is 27.1. All the NCA counties in Virginia have mortality rates that exceed the U.S. rate. However, Prince William County has the highest mortality rate at 27.9.

The reported incidence rate for the U.S. is 119.3 (NCI, 2002-2006). In D.C., incidence levels in six of the eight Wards are above the U.S. rate. Only Wards 6 and 7 report lower incidence rates and Ward 2 reports the highest in the District at 153.8. In Maryland, Montgomery County's incidence rate is 139.3 compared to Prince George's rate of 120.7. Despite Prince George's lower breast cancer incidence, more women in the county are dying from breast cancer. Of the five jurisdictions in Virginia that make up the NCA, two have higher incidence rates than the U.S. rate — these include Arlington County (130.1) and Fairfax County (130.2).

Nationally, 76 percent of women over 40 report having had a mammogram in the last two years; numbers reported in the- NCA are equal or higher. Screening numbers are unavailable at the Ward level, but in D.C. about 81 percent of eligible women report having had a mammogram in the last two years. Screening percentages reported in the state of Maryland vary from the rest of the region in that they reflect adherence among women 50 and over. Both counties in Maryland report screening among women above 80 percent. In Virginia, Alexandria City has the highest screening percentages at 82 percent and Fairfax County the lowest at 76 percent.

## TARGET COMMUNITIES

After a review of demographic and breast cancer data for the NCA was completed, five areas were selected as target communities: Prince George's County in Maryland; Prince William and Arlington Counties in Virginia; and Wards 7&8 in the District of Columbia. Ward 2 in D.C. was not chosen as a target community despite a high mortality rate because Wards 7&8 were determined higher priority. The selection of target communities was influenced by mortality rates; however the final decision also considered key demographic variables for each community. The subsequent overview will provide a comprehensive snapshot of each target community identified.

## District of Columbia - Wards 7&8

Geographically, D.C. is divided into four quadrants: northwest, northeast, southwest and southeast. Politically, it is divided into eight Wards (Figure 1). Ward 7 falls in both the northeast and southeast quadrants. Ward 8 spans the southwest and southeast quadrants.

Women in Wards 7&8 have a lower breast cancer incidence rate when compared to the U.S. rate. However, the mortality rates of these wards are higher than the U.S. rate (Table 2).

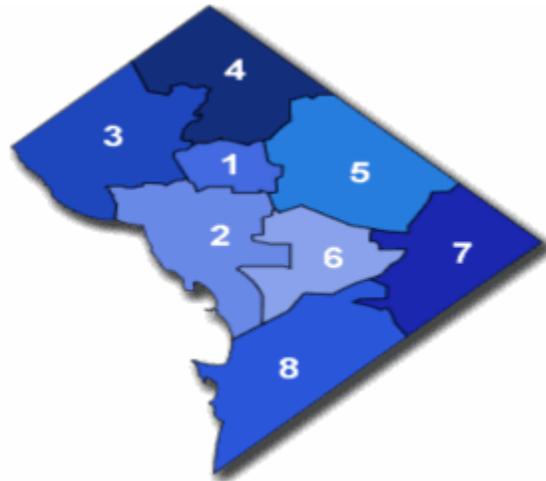


Figure 1. District of Columbia ward map.

In addition, statistics show that when diagnosed, approximately 40 percent of African American women in the District are diagnosed at a local stage. This means a higher percentage of women are being diagnosed at later stages in these communities, despite the appearance of high screening adherence (80%) among eligible women. These statistics confirm national trend research which indicates that African American women are less likely to be diagnosed with breast cancer but are more likely to die and are more likely to be diagnosed at later stages.<sup>24</sup>

<sup>24</sup> American Cancer Society, 2009

Ward 7 has a population of approximately 70,539 residents. Ninety-seven percent of the population is African American. The average household income is \$45,039. According to estimates provided by Thomson Reuters © 2009, 25 percent of Ward 7 residents live below poverty level and 14 percent are unemployed. Correspondingly, 29 percent of Ward 7 residents have less than a high school diploma. A large majority of households with children in this ward are headed by females (67%).

Table 2.  
District of Columbia, Wards 7&8

Breast Cancer Statistics		
	Ward 7	Ward 8
Mortality (per 100,000)	32.9	30.7
Incidence (per 100,000)	116.8	121.3
Percent Local Staging District (Black females)	39.7%	
Screening (district level)	80%	

Demographic Data		
	Ward 7	Ward 8
Total Population	70,539	70,915

Race/Ethnicity		
	Ward 7	Ward 8
African American	97%	93%
White	2.2%	5.1%
Latino	.8%	1.3%

	Ward 7	Ward 8
Average Household Income	\$45,039	\$35,228
Percent Below Poverty	25%	36%
Unemployment Rate	14%	22%
Percent w/out HS Education	29%	34%
Female HH w/children	67%	68%

District Insurance Estimates	
Uninsured 45-64	17%
Insured at Risk 45-64	83%

Sources: Breast cancer statistics and screening data (D.C. Cancer Registry, 2002-2006); Demographic data (NeighborhoodInfo D.C., 2009) Insurance estimates (Thomson Reuters © 2009)

Ward 8 has a slightly smaller population (70,915) than Ward 7 of which 93 percent is African American. The average income of Ward 8 is \$35,228. Accordingly, the percent of the population that live below poverty (25%), are unemployed (22%), and did not complete high school education (34%) are greater than Ward 7.

District level insurance estimates show that 17 percent of women age 45 to 64 are uninsured and that 83 percent are covered by at risk insurance through Medicaid, Medicare or Private insurance carriers. “At risk” refers to the co-pays set by the insurance carrier and the capitation of certain services that limit service coverage (Thomson Reuters © 2009). Although there are no numbers specific to Wards 7&8 available – based on poverty and unemployment rates – a logical conclusion is that a large portion of the population is uninsured or underinsured.

### Prince George’s, County, Maryland

Prince George’s County is divided by Interstate 495 (the Beltway) to the inner and outer regions of the county (Figure 2).



Figure 2. Prince George’s County.

In Prince George's, screening numbers show that about 81 percent of women 50 and older are getting screened in the county, but mortality data shows that 31.2 women out of 100,000 are dying due to breast cancer in the county.

Table 3.

*Prince George's, Maryland*

<b>Breast Cancer Statistics</b>	
Mortality (per 100,000)	31.2
Incidence (per 100,000)	120.7
Screening	81.3%
Percent Local Staging	Unavailable

<b>Demographic Data</b>	
2009 Total Population	822,854
2009 Female Population	428,134

<b>Race/Ethnicity</b>	
African American	63%
Asian	4%
Latino	13%
White	18%

<b>Household Income</b>	
<b>Average Household Income</b>	<b>\$81,912</b>
Less than \$25,000	12%
\$25,000-\$75,000	43%
More than \$75,000	45%

<b>Education</b>	
BA or above (pop. 25+)	28%

<b>Insurance Estimates (females)</b>	
Uninsured 45-64	29%
Insured at Risk 45-64	72%

Sources: Mortality and screening (SCP, 2001-2005, 2008); Incidence (Maryland Cancer Registry, 1999-2003); Demographic and insurance data (Thomson Reuters © 2009)

Prince George's County has a population of about 822,854. Similar to Wards 7&8 of D.C., Prince George's County has a significant African American population (63%). Unlike Wards 7&8, the population in Prince George's County is considerably wealthier and more educated. The average household income is \$81,912. Table 3 provides an overview of other key county demographic variables.

The focus on Prince George's County for the purpose of this report is limited to the northern region, inside the Beltway and closest to the D.C. border because of the region's higher proportion of minority residents with limited access.<sup>25</sup> According to a report put out by RAND Corporation (2009), Prince George's has the largest population of Latino and non-English-speaking residents (13%) in the state of Maryland. This is primarily attributed to an influx of Latinos now living in the northern region of the county. The report found residents who live in the northern part of Prince George's have the highest poverty rates and lowest education levels as compared to those living outside the Beltway. It is estimated that 29 percent of women age 45 to 64 are uninsured and many women (72%) have an at risk insurance status. This raises serious concern about access to breast health services, especially for Latina women in the northern part of the county.

<sup>25</sup> Lurie, 2009

## Arlington, County, Virginia

Arlington is an urban county of about 26 square miles located directly across the Potomac River from Washington, D.C. (Figure 3). With a population of about 207,000, Arlington County is among the most densely populated jurisdictions in the country.

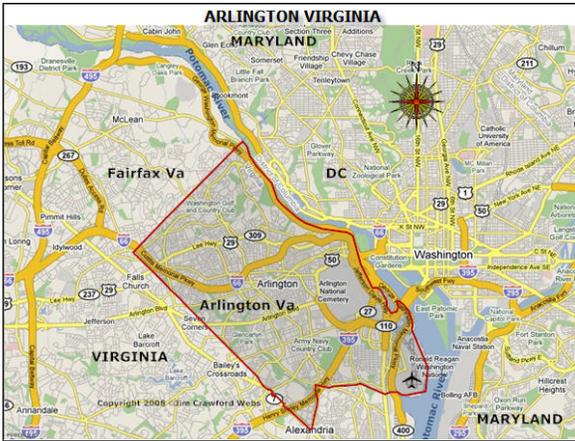


Figure 3. Arlington County map.

Screening percentages in Arlington are on par with the rest of the NCA, about 79 percent of women 40 and over report having had a mammogram in the last two years in the county. Although the breast cancer mortality rate (25.4) is not as high as the other target communities, the county was chosen because of its mortality rate, its high incidence rate (130.1) and its racial and ethnic diversity (Table 4).

Latinos (16%) make up the largest minority group in the county, followed by Asians (9%) and African Americans (8%). As an indicator of its diversity, the county estimates that there are 95 languages spoken in the county representing 128 countries.<sup>26</sup>

It is estimated that in 2009, about 60 percent of adults age 25 and older had a bachelor’s degree or higher. With an average household income around \$121,000, Arlington County residents are economically better positioned than many of its neighboring regions in the NCA. Despite the relative

wealth in the community, estimates show that 17 percent of women age 45 to 64 are uninsured and 59 percent may be underinsured in Arlington County.

Table 4.

### Arlington, Virginia

Breast Cancer Statistics	
Mortality (per 100,000)	25.4
Incidence (per 100,000)	130.1
Screening	78.5%
Percent Local Staging	59.2%

Demographic Data	
2009 Total Population	206,674
2009 Female Population	102,459

Race/Ethnicity	
African American	8%
Asian	9%
Latino	16%
White	65%

Household Income	
Average Household Income	\$121,000
Less than \$25,000	9%
\$25,000-\$75,000	31%
More than \$75,000	60%

Education	
BA or above (pop. 25+)	60%

Insurance Estimates (females)	
Uninsured 45-64	17%
Insured at Risk 45-64	59%

Sources: Mortality (Virginia Center for Health Statistics, 2002-2006); Incidence data (Virginia Cancer Registry, 2001-2006); Screening data (Virginia BRFSS, 2004-2006); Demographic and insurance data (Thomson Reuters © 2009)

<sup>26</sup> Arlington County, [www.arlingtonva.us](http://www.arlingtonva.us)

## Prince William, County, Virginia

Prince William is the second largest county in the Commonwealth of Virginia, and lies at the center of the northern Virginia region which is part of the Washington, D.C. Metro Area (Figure 5). Prince William has a mortality rate of 27.9 and according to the Virginia Cancer Registry, the breast cancer incidence rate is low (115.4) and only 56 percent of diagnosed cancers are detected at the local stage.

As outlined in table 5, Prince William has a diverse population of about 389,000. Latinos make up the largest minority group in Prince William (21%) followed by African Americans (18%) and Asians (7%). Thirty-two percent of Prince William residents hold a bachelor's degree and 58 percent report a household income of more than \$75,000.

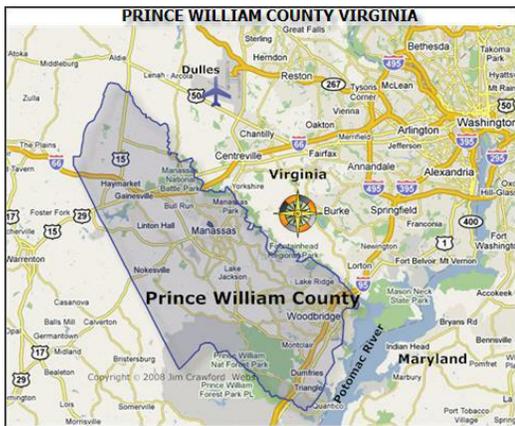


Figure 4. Prince William County map.

Despite the county's wealth, many residents are living in poverty. The Virginia Workforce Connection reported state unemployment in March 2010 at about 8 percent<sup>27</sup> and according to Thomson Reuters © 2009, 7 percent of households in the county are living on less than \$25,000. Nine percent of women 45-64 are believed to be without health insurance and 30 percent of Prince William residents are underinsured.

Table 5.  
Prince William, Virginia

Breast Cancer Statistics	
Mortality (per 100,000)	27.9
Incidence (per 100,000)	115.4
Screening	80.1%
Percent Local Staging	56.0%

Demographic Data	
2009 Total Population	389,207
2009 Female Population	194,568

Race/Ethnicity	
African American	18%
Asian	7%
Latino	21%
White	50%

Household Income	
Less than \$25,000	7%
\$25,000-\$75,000	35%
More than \$75,000	58%

Education	
BA or above (pop. 25+)	32%

Insurance Estimates (females)	
Uninsured 45-64	9%
Insured at Risk 45-64	30%

Sources: Mortality (Virginia Center for Health Statistics, 2002-2006); Staging and incidence data (Virginia Cancer Registry, 2001-2006); Screening data (Virginia BRFSS, 2004-2006); Demographic and insurance data (Thomson Reuters©2009)

<sup>27</sup> Virginia Workforce Connection, 2010



## SECTION OVERVIEW

In order to understand the breast cancer burden in the NCA, key variables such as mortality and incidence rates, staging data and screening percentages were reviewed. The data highlighted five target communities within the region that warranted further investigation — Wards 7&8 in D.C, Prince George’s County in Maryland and Arlington and Prince William Counties in Virginia.

All target communities have high mortality rates when compared to the US rate. These mortality rates were high, while incidence rates were lower or about the same as the US incidence rates, with the exception of Arlington County. Staging data was not available for Prince George’s, but in the other target communities women diagnosed with local breast cancer ranged from 40 percent in the District to almost 60 percent in Arlington. Despite screening percentages indicating that women are getting mammograms, too many women are still being diagnosed at later stages.

The proportion of women dying in the target communities was the primary factor that informed the decision to further explore the health systems in these communities. However, the data clearly shows the race and ethnic diversity as well as the social economic disadvantages within the target communities which were also key factors influencing the decision of the target communities.

The statistics and demographic data helped determine target communities, however they do not tell what institutional and system barriers, gaps and needs may be contributing to the elevated death rates due to breast cancer. Understanding these health systems issues is imperative in any effort to decrease breast cancer deaths in the NCA.

# HEALTH SYSTEMS ANALYSIS: ISSUES AFFECTING WOMEN'S ACCESS

## CONTINUUM OF CARE

The Breast Cancer Continuum of Care (Figure 5) represents how a woman typically moves through the health care system to be screened for breast cancer, and if necessary, receives follow-up diagnostic tests and treatment for breast cancer. This model can be used as a guide when assessing why some women do not receive regular screening and why others who are screened may not receive timely diagnostic tests, treatment or follow-up care.

The following section describes the four stages of the continuum.

### **Stage 1: Screening**

Breast cancer screening is the first step in the continuum. Komen's screening recommendations are:

- Ask your doctor which screening tests are right for you if you are at a higher risk
- Have a mammogram every year starting at age 40 if you are at average risk
- Have a clinical breast exam at least every 3 years starting at age 20 and every year starting at age 40
- Know what is normal for you and report any changes to your healthcare provider right away

### **Stage 2: Diagnosis**

For most women who have a mammogram or clinical breast exam, the results will be normal. For some women, the results may be abnormal. An abnormal test may indicate the need to do more tests. It is important that women receive timely follow-up tests after an abnormal mammogram or clinical breast exam.

Usually, the health care provider will begin with less invasive tests like a diagnostic mammogram or ultrasound. If these tests cannot rule out cancer, he or she may recommend a biopsy. If further testing

reveals that the abnormality is not cancer, the woman will need to continue to follow screening recommendations. For those that have a diagnosis of breast cancer, they will then need to enter the treatment stage of the continuum.

### **Stage 3: Treatment**

A breast cancer diagnosis will lead to the treatment stage of the continuum. Health care providers will work with the patient to determine a course of treatment. The best treatment plans are typically determined when the patient and provider work together. Treatment may involve one of the following or a combination:

- Surgery
- Radiation therapy
- Chemotherapy
- Hormonal therapy
- Targeted therapy

### **Stage 4: Follow-up Care**

Follow-up care includes regular screening as recommended by a health care provider following normal or abnormal results. Women with normal screenings need support to continue and maintain proper screening practices. For those diagnosed with cancer, follow up care ensures their needs are met post treatment in order to address quality of life issues. Some survivors receive care related to side-effect management, long-term treatment, reconstruction and end-of-life care.

In the next section, we share the findings of a health systems analysis completed in the target communities in an attempt to understand the gaps or barriers that delay an individual's transition through the continuum of care.

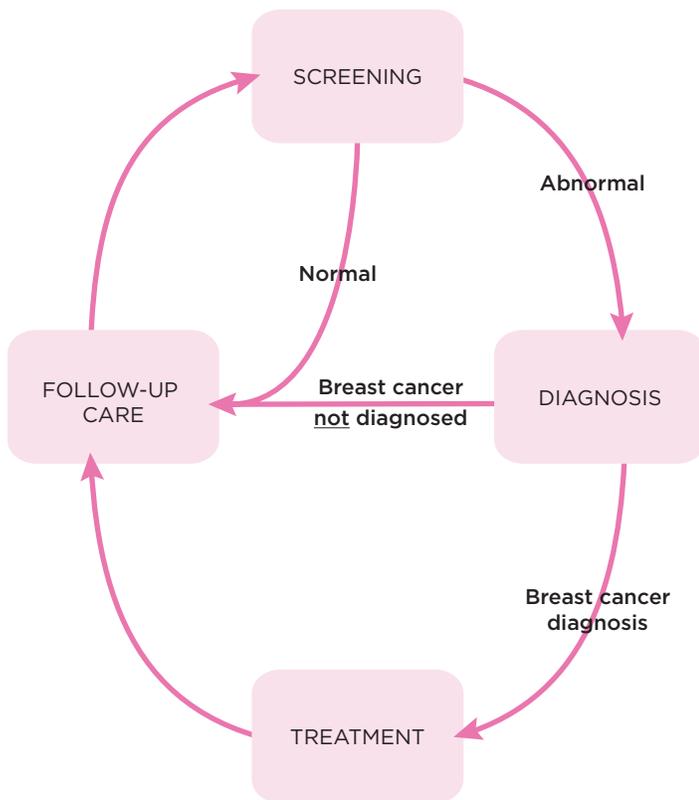


Figure 5. Continuum of care.

## METHODOLOGY

The health systems analysis seeks to answer questions such as: How does the continuum of care work in the target communities? Is the continuum of care effective and timely? Are certain populations able to navigate the continuum with more ease or less ease than others?

The first step of the health systems analysis was a review of the literature. The literature review was an essential component of the health systems analysis because it is important to build on existing research and add to existing knowledge. A web search was completed to identify state cancer plans, reports, articles, and other existing health access research completed in the target communities. The literature review produced a number of reports that were used to inform the questionnaire used for the key informant interviews.

The second step of the analysis was to conduct an extensive inventory of programs and services available to the women living in the target

communities. This was done using the Internet, local resource directories, interviews, and focus groups.

Once identified, the organizations were plotted on a map for analysis. Organizations that were included in the mapping provide community outreach, education, screening, diagnostic services, treatment services, and follow-up care. They ranged from small grassroots organizations that work with specific cultural groups to safety net clinics and large hospitals. The provider mapping process in the target communities aided the identification of the providers approached to serve as key informants.

The third step of the health systems analysis was key informant interviews with providers. The continuum of care was the main tool used in the development of the key informant questionnaire. The questionnaire was produced to understand the issues individuals in the target communities face as they transition through each phase of the continuum. Nineteen key informant interviews with providers were completed in the target communities. A total of 13 questions were asked to gauge the existing barriers that may contribute to someone getting lost or not moving in a timely way through the continuum. The interviews were conducted by phone and facilitated by a trained interviewer and note-taker. On average, the interviews lasted about one hour.

## HEALTH SYSTEMS FINDINGS

Provider interviews were analyzed for main themes for each phase of the continuum of care. The following section includes a discussion of the themes shared throughout the NCA. Any themes unique to specific target regions are also included in the discussion and quotes from key informants are included to enrich the descriptions. Furthermore, a brief overview of existing breast cancer programs and services is provided by target community.

## OVERVIEW OF PROVIDER INTERVIEW THEMES

### ***Referrals and Outreach***

Outreach was a key component discussed as part of the health systems analysis. It was critical to first identify existing outreach efforts that promote screening. Additionally, the referral process that providers utilize was explored to determine how women are typically connected with screening services in the target communities.

According to the providers that were interviewed, many of the women are self-referrals or walk-ins. The providers believed word-of-mouth to be the most effective marketing tool for many screening programs. In their experience, patients who received services and had a good experience often told other women from their neighborhood where to go and what to expect.

**“If you are good in the community, people will come to you.”**

Common outreach programs utilized in the NCA include health fairs and faith based programs. The providers consider the use of lay health educators as an effective way to reach out to specific cultures, such as African immigrants. Of the 19 providers interviewed, all reported being aware of outreach efforts but the effectiveness of many of the efforts was not known. Providers believe that most outreach programs are targeted and culturally appropriate. Interestingly, outreach was not identified as a high priority for many providers because many did not have the staff to dedicate to the effort nor the funding to meet increased demand.

**“The BCCEDP doesn’t do any rigorous outreach as they don’t have the capacity to take many women so they don’t want to promote what they can’t provide.”**

### ***Unique to Prince George’s County***

Providers working in Prince George’s County specifically discussed the limitations in current outreach efforts. For example, current Promotora programs target Latina women through health fairs and church events; however, there is a limited and sporadic availability of services. This indicates potential gaps between outreach and screening.

### ***Unique to Arlington County***

Providers in Arlington County reported that little outreach was being provided to the community. As it relates to awareness/education programs that are being offered, they are limited and little is unknown about their effectiveness. Despite the capacity issues, providers maintained that an awareness campaign is needed in Arlington, especially among minority and immigrant populations.

**“We get complacent and think everyone knows, but they may not”**

### ***Unique to Prince William County***

In Prince William County providers shared that lack of funding limits outreach efforts. While wellness vans that target Latinas are believed to be effective, providers observed that services targeted to African American and Asian women are limited — a significant barrier considering the growing numbers of these groups in the community.

### ***Screening***

Providers were asked to share their perception of barriers to mammography services. The barriers discussed fell in two categories: knowledge/behavioral and institutional barriers.

Despite outreach efforts, there is still a lack of awareness in the community about the resources available to women. Providers also believed that women lack knowledge of the screening recommendations, the benefits of early detection, and the success of current treatment.

According to providers, women fear the disease and continue to believe myths about both the screening process and the disease. This is especially true for immigrant women who maintain certain cultural beliefs that serve as barriers to screening. Other commonly known barriers discussed include: lack of insurance, cost of services (co-pays), fear of deportation and conflicting priorities for women (work, children, family).

As with outreach, all providers interviewed identified capacity as a key barrier to screening. Lack of funding result in waitlists and limit the number of new patients that can be screened.

**“Outreach is effective in increasing interest, but when people call, sometimes I have to tell people there is no screening available”**

The system requirements that must be fulfilled to access services are also believed to be challenging for women. For example, providers described how challenging it is for some women to provide proof of residency or income.

### ***Unique to Wards 7&8***

Providers working with women in Wards 7&8 shared the opinion that the screening recommendations released by the U.S. Preventive Services Task Force at the time this research was being conducted are confusing women and adversely affecting their decisions to actively seek screening. Providers also expressed their concern that shifting screening to every two years for women over the age of 50 will create additional gaps for women age 40 to 49.

### ***Unique to Prince George’s County***

The primary health systems barrier identified in Prince George’s County was the lack of providers in the community and the limited capacity of providers outside the community trying to meet the need of Prince George residents. Providers recognized that women face the typical access barriers related to having to travel long distances to seek care outside the county: transportation and work restrictions. Some Latina residents of the county also encounter

language barriers because of the lack of services available in Spanish. Uninsured or underinsured women face the following additional challenges/ barriers: no medical home, no primary care provider, cost of co-pays or the full cost of services even if low cost.

### ***Unique to Prince William County***

Prince William providers believed that women in their county choose not to get screened because they distrust the process and fear the pain.

**“(I) have to try to convince many women that it (mammogram) is not as painful as they might think and try to get them to keep their appointment...”**

In addition, women lack access to screening services because of the cost, they don’t have insurance or are underinsured, and many immigrant women fear that if they seek care they will be deported.

### ***Screening to Diagnosis***

Providers were asked to discuss possible barriers that would prevent or delay a diagnosis. Throughout the NCA, providers agreed that delays can occur because of the lack of support available to women after they are screened. For example, women are not made to understand the sequence of events after an abnormal screening result nor the urgency of the next step. As a result, providers maintain that women often deal with anxiety and fear that could be prevented if women understood diagnostic process and felt comfortable asking questions.

**“Women fear what they don’t know”**

**“When patients don’t make appointments, it is because they did not understand what was happening”**

Providers acknowledged that women experience a high level of fear, anxiety and depression after an abnormal result. They also acknowledged that the health system is not set up to offer support during this phase. Women may delay or avoid diagnosis to ultimately avoid a potential negative result.

Additional barriers to timely diagnostic care discussed include: health systems issues such as the lack of funding for diagnostics for the uninsured, the amount of paperwork required to get funding for diagnostic services, and provider capacity to provide free or low cost services.

### ***Unique to Prince George's County***

For uninsured women living in Prince George's County, providers identified a number of key health systems issues that impact women's access to diagnostic services after an abnormal screen. The most significant barrier discussed was the lack of diagnostic and treatment providers in the county resulting in long wait lists with current providers.

**“Due to the wait list, many women become frustrated and give up basically ending the process here (after screening) because it is difficult for the patient to get a primary care physician and (a diagnostic) appointment”**

Providers in Prince George's County also pointed out that uninsured women are the most difficult to keep in the continuum at this phase. Wait lists for follow-up tests and the time required for funding approval increase the time to diagnosis. During this lag time women are susceptible to not completing a diagnostic work-up because of fear, work restrictions or lack of a permanent address.

### ***Unique to Arlington County***

Providers believe that the risk of women falling out of the continuum of care is highest as patients move from screening to diagnosis. This is especially true for immigrant patients in Arlington County where education and language are barriers. Providers struggle with helping women understand the process they must follow and the paperwork that is required because of limited capacity.

**“Many of the patients only have an elementary education or less and cannot read so they need help filling out the financial assistance applications...I know when I see the puzzled looks...”**

### ***Diagnosis to Treatment***

When a cancer is diagnosed, the next phase of the continuum is treatment. Providers described the options for uninsured women as “piece meal pro bono care” that typically causes delays because it is based on the availability of providers willing to provide free care. Currently, the health system in the NCA has few treatment resources available for the uninsured. Providers are forced to provide charity care and absorb the related costs. This limits both provider willingness and capacity. Uninsured women who are diagnosed with breast cancer must often wait up to 60 days to begin treatment.

According to providers, women don't really understand what a diagnosis means and lack education on the disease, their treatment, and prognosis.

**“Patients don't understand the test or the test results that they receive”**

The lack of understanding at this phase of the continuum can increase a woman's risk of not seeking recommended treatment. This could potentially be a major gap in the system. Lack of family support can deter women who are caregivers from seeking treatment and lack of navigation may also serve as a barrier to seeking treatment. According to providers, navigation has three benefits: navigators simplify coordination of care thereby addressing delays; they educate patients on the disease; and they provide psychological support.

### ***Unique to Arlington County***

Immigrant patients were again identified as the group facing significant barriers in seeking treatment following a diagnosis in Arlington. Language and family dynamics such as lack of support, caregiver roles, and competing basic needs were identified by providers as the biggest challenges facing immigrant women.

Women who are uninsured or on Medicaid have limited options because of the lack of funds to cover costs related to surgery or radiation for the uninsured and because few providers take Medicaid, thereby resulting in long wait lists for women trying to seek treatment.

**“Few doctors take Medicaid so it is difficult to get them (patients) in and they could be on hospital waiting lists for months.”**

Providers in Arlington County discussed a significant gap in the provision of quality care noting that many women going through treatment in the county lack social and psychological support.

**“We have tried to recruit volunteer navigators and interpreters to go with the patients for specialty type care, but that hasn’t worked and we don’t have time...”**

#### ***Unique to Prince William County***

According to providers working with diagnosed women in Prince William County, depression is a huge barrier and puts women at risk of delaying or avoiding treatment.

**“...mental health is a big deal...prevents women from completing treatment and follow-up...”**

Additionally, for those women who are uninsured or underinsured, reliance on limited charity care is problematic and often results in a long wait time for treatment.

**“systems are complicated...poorer people have to wait two months to see a radiologist because they don’t have insurance and have to go several places for a surgeon, an oncologist, a plastic surgeon, nutrition, wigs...nothing is in one place or happens quickly...”**

#### ***Treatment to Follow-up***

Once women complete treatment, providers again identified the uninsured as the group less likely to get appropriate follow-up. The uninsured experience delays in care because the process requires more navigation to identify sources of care. Care available to the uninsured is not available in one place; thereby increasing delays, complexity, and the risk of being unable to adhere to an intricate care plan.

#### ***Unique to Wards 7&8***

According to providers, women in Wards 7&8 face significant barriers that may hinder their ability to complete treatment. The barriers, consistent with the demographic data discussed in a previous section, include income and insurance coverage. These populations are more vulnerable in a system where they are required to travel extensively to get services and have limited options as to therapies and medications. Providers also discussed the role many of the women in these communities have as female heads of household and caregivers, strongly influencing their decisions to delay or refuse treatment.

Providers believe that although most insured women in Wards 7&8 complete treatment and get adequate follow-up care, the uninsured and immigrants living in these communities are the most at risk of not completing treatment. This is believed to be a result of fragmentation, which creates opportunities for them to get lost within the health systems.

#### ***Unique to Arlington County***

Providers in Arlington discussed the main barrier uninsured women face as they move from treatment to follow-up care is the fragmentation that exists in the health systems. The absence of a “one stop shop” for those unable to pay, leaves only a fragmented option for the uninsured. This opens the door to miscommunication, confusion, and makes it easier for women to fall out of the system.

“(a past patient) did not follow-up because there was miscommunication about her need to call the doctor’s office for an appointment...she did not call the doctor for 10 months so the cancer metastasized...”

Another system barrier identified in Arlington was process related. Currently, the health systems in Arlington do not have a central or standardized tracking system for all providers to ensure patients complete treatment and adhere to follow-up care.

### ***Unique to Prince William County***

Barriers to women in Prince William for this phase of the continuum as discussed by providers are specific to the health systems. Providers discussed three specific gaps in the system which include: no standard tracking system to know if women complete treatment; complicated charity care system for uninsured; and the lack of more comprehensive nurse navigation that offers education and mental health services, in addition to paperwork and care coordination.

### ***Re-screening***

Three general themes emerged from provider interviews regarding barriers to re-screening for women in the NCA: 1) lack of providers and provider capacity; 2) lack of education on rescreening recommendations and benefits of rescreening; and 3) access barriers such as childcare, transportation, and time.

### ***Unique to Prince George’s County***

A main barrier to re-screening for a woman living in Prince George’s according to providers is distrust of the system. Providers specifically discussed concern among women that they would be billed for services despite the fact they were offered as “free.” They also discussed fears related to deportation that exist in the Latino community.

For women who are already fearful or resistant to get re-screened, the lack of providers and funding (i.e. capacity) for existing providers offer an opportunity for women to delay, postpone or not

get re-screened. When funding dries up, patients are scattered and sent from place to place, making it easy to lose patients to follow-up and transportation becomes a considerable access barrier.

### ***Unique to Arlington County***

Providers in Arlington discussed that despite the use of established reminder/follow-up protocols in the community; women don’t return because they can’t be found. An equally significant barrier addressed by the providers related to education and how current education efforts don’t focus on re-screening. This lack of emphasis on the importance of re-screening may influence how important a woman thinks it is to keep up with the annual recommendations. Lastly, providers shared that language demands for the diverse population in Arlington are not being met so immigrant women are not getting the appropriate messages.

### ***Unique to Prince William County***

Women in Prince William County may have difficulties getting re-screened because providers are not able to meet the demand for services. Providers also believed that primary care providers lack awareness of guidelines and resources. As a result women are not properly educated or referred to services.

## ***Overview of Target Community Assets***

### ***Wards 7&8***

Wards 7&8 are health resource poor communities. Ward 7 has no hospital but is home to two community health centers. For residents needing mammograms, the closest breast centers are in Ward 6 and 8. However, there are four primary care health centers available in Ward 7. United Medical Center is the only full service hospital and BCCEDP mammography site located beyond the Anacostia River and is located in Ward 8. The hospital serves 20 percent of D.C.’s population. In addition, Ward 8 has six primary care health centers that provide services to adults and children.

Although there are few health providers in Wards 7&8, there are multiple libraries, recreational centers, schools, and several family-friendly organizations within the communities. The presence of these establishments offers potential opportunities for community-based education programs.

### *Prince George's County*

Prince George's County is home to seven hospitals that offer breast cancer screening and support group services. Three of the hospitals are located in the northern part of the county. There are also 23 Food and Drug Administration (FDA) certified mammography centers in the county, 12 of which are located in the northern region. It would appear that the county has a wealth of services to address the breast health needs in the community; however, after further review it is apparent that there is a serious gap in the services for the county's low income, uninsured and underinsured populations. Access to free and low cost services is a significant barrier for women living in the northern region of the county.

Greater Baden Medical Services, Inc is a federally qualified health center (FQHC) provider in Prince George's County. Greater Baden has four clinics, three of which are located in the northern region and cater to the needs of low income residents and the uninsured. The free clinics are key in connecting women to screening services and follow-up care when needed. However, there is only one BCCEDP site located at the Prince George's County Health Department in the center of the county. The program offers free and low cost mammograms, but currently has a waiting list for screening because of lack of funding. Women must therefore wait to access services in their county when screening becomes available or travel outside the county to access free and low cost breast cancer services. Barriers persist outside of the county. Organizations that could once offer services to women from Prince George's have had to turn them away because of insufficient funding. For those organizations still able to provide services, such as D.C. Department of Health or Howard University Hospital, time and distance remain barriers.

### *Arlington County*

There are only two FDA accredited mammography centers in Arlington County, one of which is Virginia Hospital Center (VHC). VHC is home to the Center for Breast Health and provides screening services and ongoing community education outreach in the community. Arlington has no BCCEDP sites in the county. Residents are able to access services at three nearby BCCEDP sites located in Falls Church, Alexandria, and D.C.; however, they face the same type of access barriers as women in other target communities who must seek care outside of their community.

For low income and/or uninsured residents, the Arlington Free Clinic (AFC) provides free and low-cost comprehensive women's health services including access to free mammograms. Arlington Free Clinic is a key partner in trying to coordinate breast cancer services to low income women who are diagnosed and don't have insurance.

### *Prince William County*

Prince William County is home to two hospitals, Prince William and Sentara Potomac Hospital, several cancer centers and eight FDA credited mammography sites. There is no BCCEDP mammography site in Prince William. Residents who need access to low cost or free mammograms might go to one of three locations outside the county: Falls Church, Alexandria, and D.C.

The Prince William Area Free Clinic operated by the Prince William Department of Health, serves county residents who do not have private health insurance. The department provides medical care and access to medication. The Greater Prince William Community Health Center has two clinics in the county and also provides health services to residents regardless of their ability to pay, residency or insurance status.

## ***The National Capital Area Network – Partners in Care***

As part of the health systems analysis, questions were asked of providers regarding existing key partners and collaborations in the NCA. Most every provider interviewed was able to share a long list of partner organizations that they work with throughout the NCA. The exception to this was Prince George's County. The scarcity of existing providers and the limited number of outside organizations working with Prince George's residents was evident in the responses.

Providers freely discussed how they are working with partners to meet the breast health needs of women throughout the NCA. In addition, providers were asked their views as to the role Komen might play to help address the barriers women face in the NCA, especially in the target communities. The following suggestions were offered:

- Komen should increase its presence at the local level in the NCA and partner with organizations in target communities
- Komen should become involved with key breast cancer coalitions in the NCA such as the D.C. Cancer Consortium
- Komen should take a lead in training providers and community organizations
- Komen needs to address the need for the uninsured and work closely with safety net clinics and hospitals that provide charity care and address the gaps in the continuity of care
- Komen should play the role of convener in the NCA — “sometimes we feel isolated and coming together would certainly help that”
- Komen needs to be the voice of breast cancer in the community — expanding outreach efforts and increasing access to effective education
- Komen needs to lead the way in providing culturally sensitive and appropriate education for high risk groups in the target communities
- Komen should lead the way in advocacy — according to one provider “advocacy is out of our realm, we are in the trenches doing the everyday work of awareness and screening”

## ***Section Overview***

Throughout the NCA a number of key issues emerged from the health systems analysis. Providers reflected on the fact that despite their efforts, lack of funding, staffing, and resources limit their ability to meet the need in the community. Limited capacity influences their ability to do outreach, provide more effective education programs and focus on high risk populations.

Provider responses indicated a need to educate women, especially minority and immigrant women about breast cancer — the disease and the entire continuum of care. The system is acutely focused on getting women into screening — but the continuity of care falls short after a woman gets a mammogram, regardless of the outcome. Uninsured were identified as high risk throughout the NCA because their options are limited to a charity care system that lacks funding and stability.

Despite the limitations in the NCA, providers are doing their best to ensure women successfully go through the continuum of care. To achieve this in an environment with limited resources and tremendous need, programs and service organizations have partnered and are pooling resources to overcome system barriers and ensure that all women have access to care.

The following section summarizes findings from focus groups completed with women living in the target communities. Women were asked to share their opinion and knowledge of breast cancer, outreach efforts, and breast cancer services in their communities.

# COMMUNITY PERSPECTIVES ON BREAST CANCER AND ACCESS TO CARE

## METHODOLOGY

**Criteria:** The following eligibility criteria were used to recruit participants for the NCA focus groups. Participants needed to be females who had never been diagnosed with cancer, ranging in age from 40-64 and living in one of the four target communities. In Prince George's county, recruitment was limited to uninsured Latina women to better understand the barriers impacting the population largely represented in the northern portion of the county.

**Recruitment:** Participants were recruited with the support of community-based organizations who work in the target communities or with women from the target communities. Women from Wards 7&8 were recruited through the Ward 8 Health Council. Participants were also recruited during a tenant's meeting at the Dupont Adventist Apartments located on the southern-most side of Ward 8. Women in Prince George's were recruited by the Spanish Catholic Center of Langley Park, a safety-net clinic that works with low-income and uninsured patients, most of whom are Latino. In Arlington, women were recruited through Macedonia Baptist Church and by reaching out to various affordable housing units. Women in Prince William were recruited through the Prince William Health Department.

**Incentives:** Light meals or snacks were provided at each group and participants were offered a \$50 dollar gift card for participating.

**Procedures:** The focus groups averaged an hour long in discussion. The groups were facilitated by a Susan G. Komen for the Cure® bilingual staff person who recorded and transcribed the sessions. A total of seven questions were asked of women to gauge their general knowledge of breast cancer,

recommended guidelines, and services. Participants were also asked about existing outreach, education efforts, and access barriers.

**Participants:** A total of four focus groups were completed in the target communities. One of the focus groups was in Spanish. Attendance ranged by group, the smallest having six women and the largest fourteen. A total of 36 women participated and the average age of participants was 53.

## FOCUS GROUP FINDINGS

### Wards 7&8

Fourteen participants took part in the focus group held for Wards 7&8. All participants were African American and the average age of the group was 59. Participants in the group represented a broad range of residents of Wards 7&8. For example, about half of the participants had some college education, three were college graduates and four were high school graduates. Most of the participants reported household incomes less than \$25,000 and four reported incomes over \$50,000. Thirteen participants identified themselves as female head of household. Of those who reported insurance information — seven said they had private insurance and five reported being on Medicaid or D.C. Alliance. Eleven women said they had a primary care provider and the majority reported having had a clinical breast exam and a mammogram in the last 12 months.

Four key themes emerged from the Wards 7&8 focus group: death/survivorship, education, insurance, and distrust/provider insensitivity.

### **Death/Survivorship**

One of the first questions presented to the focus groups probed their feelings about breast cancer and their understanding of breast cancer. When asked to share immediate thoughts upon hearing the words breast cancer, it was readily apparent that perceptions were individual. Although many acknowledged that a survivor can live many years after a diagnosis and even have a good quality of life, death was a pervasive component of the discussion.

**“You hear cancer you think of death because it is a sure killer”**

**“I think of my sister, how she has gone through the ordeal...having it and surviving it”**

In fact, participants talked freely about their own lack of understanding as to why for some, cancer equals death and yet others survive many years.

**“I had a girlfriend who died of breast cancer and I’m trying to figure out what is the difference between her and my sister. I don’t know if she found out later...one let me know it (cancer) is not a death sentence, the other let me know it can be...”**

### **Education**

Education was a central theme during the focus groups. Participants acknowledged that awareness campaigns have successfully increased the importance of early detection and healthy living within the community.

**“...even my daughter who is six years old knows what the pink ribbon stands for — it is everywhere you go...”**

However, the women discussed fear that exists in the community as a result of women not truly understanding the disease or the screening process. They correlated lack of understanding with getting screened. A number expressed that existing education is not always appropriate or effective. In other cases, the group believed that education wasn’t reaching certain communities or “hard to reach” populations.

**“A lot of people in the community are not educated on what is happening... you have trucks that go around...whatever...”**

**“People don’t know! People that need it...they don’t get it (information)...”**

**“There is a disconnect between the distribution of information...Ward 8 has programs... but it is more important that (people) know where these programs are. We have not passed knowledge on them...”**

**“More education (is needed) and not in the typical way...it needs to be something that is more grassroots...”**

One the more predominant sub-themes regarding education was messaging about screening guidelines. Participants talked about the harm conflicting messages have on women’s decisions to get mammograms. For example, the U.S. Preventive Services Task Force had recently released new screening recommendations and participants talked about how the new information in the media was confusing to women. In addition, the messaging about the mammogram process, specifically the level of pain involved, is inconsistent.

**“They are telling us to do it (mammogram) every other year...or not at all...”**

**“...I hate for the media...I hate for people to give you misinformation and a lot of that is misinformation and it is not fair to us and that is why a lot of us won’t even have the tests...you are afraid and they do hurt...”**

### **Insurance**

Participants were also asked to discuss barriers to screening services. This discussion brought to light the perception that uninsured women are limited to the type and quality of care available to them.

**“Depending on what your insurance does...that’s what depends on whether you are going to do well in your treatment or not”**

**“Without insurance — (women) go to clinics for them but the doctor might be alright, the doctor might not be alright...If I don’t have insurance... you are not going to get any proper treatment”**

**“Something truly needs to be done...give people equal places to go to the doctor... you know they need it, give them what they need...”**

### ***Distrust/ Provider Insensitivity***

Another issue discussed in the focus groups was distrust and provider insensitivity. Women shared personal stories about encountering insensitive providers and feelings of not trusting providers:

**“Everybody should be educated...so we know we are getting the true information. Lots of doctors will tell you something is wrong with you, when in fact nothing is wrong with you...”**

Before the end of the group, participants re-emphasized the role of education and how more was needed to empower women to be their own advocates. Participants shared ideas about reaching out to young women and organizing more neighborhood campaigns in Wards 7&8. Participants stressed the importance of tailoring education efforts to meet the community and their needs.

### **Prince George’s, County, Maryland**

Six participants took part in the Prince George’s focus group. All participants were Latina monolingual residents of Prince George’s County. Complete demographic data is not available for this group, however participants were all uninsured women with a household income of less than \$15,000 and most reported household size of 2-3 persons. None of the participants had a primary care physician.

In Prince George’s County, five main themes came out of the focus group discussion: education, availability of services, and quality of care, racial/ethnic barriers, and health systems barriers.

### **Education**

According to participants, Latinas are aware of breast cancer but there is uncertainty about the recommended guidelines and a lack of knowledge about the services available for screening and treatment. Those that are aware of the screening guidelines cannot afford screening services. As a result, time passes until they can figure out where to go for care.

**“I knew from friends who have had cancer that I needed to get a mammogram after 40, but I did not know where to go since I can’t afford to pay and don’t have insurance — I just didn’t know where to go”**

Participants reported hearing breast cancer information on the radio and at church health fairs. However, the women acknowledged a lack of education in general and culturally-appropriate education in the county.

**“I have not heard that you can get education at the hospital/clinics — I have not heard of education in our language...”**

The group talked about the role of education empowering women to know what is normal and when to advocate for their own care.

**“If you suspect something is wrong and the doctor doesn’t send you to get tested you should push, because sometimes the doctor doesn’t want to send for the tests because they are expensive — we can’t pay so they let us die.”**

### ***Availability of Services***

The group discussed the access barriers they know women in their community face and how challenging it is for many to just make it to an appointment.

Transportation was discussed as a real barrier since many of the services available are outside of the county. Language is a barrier to many monolingual immigrant women living in Prince George’s. For women who are most likely to seek services through free clinics and low cost providers — fear of being charged is a real concern that will often prevent a woman from seeking services.

The women in the groups also shared their frustration related to the lack of services in their own community.

**“It is necessary that more help is given where we live — there isn’t enough”**

**“It is incredible that in our community people are not getting health services because they can’t afford them. They are turned away everywhere they go.”**

They discussed other challenges that compound the limited availability of services such as distance, long appointment times, and provider capacity.

### ***Quality of Care***

The women expressed gratitude for the availability of free care through the local safety-net clinic but questioned the quality of care available to uninsured women.

**“My friend was diagnosed at late stage...she went to doctor and was leaking from breast...doctor told her it was milk and not to worry...”**

### ***System Barriers***

A couple of the women in the group were familiar with charity care from personal experiences with needing diagnostic procedures after having an abnormal mammogram. While they were grateful for the support, they pointed out the barriers that delayed their care. The women reported waiting three months to get their mammogram and six months after getting abnormal results to get a biopsy.

The application requirements pose a challenge to many women, requiring proof of income and residency. In addition, they expressed fragmentation in the system for those reliant on free services. This directly addresses a potential gap in the continuum of care.

**“We can get cholesterol checks, mammograms at health fairs, but after that...follow up...doesn’t exist...and it should...”**

**“The problem is also that there are emergency services, but nothing consistent...because then we could go regularly, get checkups...”**

### ***Racial/Ethnic Barriers***

The group questioned whether or not the perceived barriers that impact Latinas also impacted women of other race/ethnicities.

**“Sometimes women put up with the pain they feel because they don’t have the means to get help. Is help being denied to only Hispanics or is it being denied to everyone?”**

### ***Arlington, County, Virginia***

Eight women made up the Arlington focus group. Of the eight participants, seven were African American and one was Caucasian. The average age of the participants was 50. All the participants live in Arlington County and seven of the eight reported being female head of household. Most participants (6) were single, had a high school degree or less and reported a household income of less than \$25,000. Three reported having private insurance, four Medicaid and one was uninsured and had no primary care provider. About half of the participants reported having had a clinical breast exam and mammogram in the last 12 months.

The main themes that emerged from the Arlington County focus group were barriers to rescreening, lack of education as a barrier to access, race/ethnic barriers and barriers to mammography.

### ***Barriers to Mammography and Rescreening***

When asked about barriers to mammography services participants talked about the general lack of knowledge in the community, but focused heavily on the fact that people don't know where to go or what resources they have access to. Transportation was also brought up as an issue for many women – especially if they have to go outside the county for free care because of the lack of free services in Arlington. Fear was again discussed as a barrier for many women and not just as a barrier to rescreening.

Participants in this focus group were aware of mammograms and their importance through personal experiences. However, the women specifically shared their personal difficulty responding to a mammogram reminder. Rescreening is especially difficult for those who receive regular and normal screenings. Conversely, one woman talked about her experience with cysts and abnormal screening results and the stress she felt every time she was reminded she had to go through the screening process again.

### ***Education***

Participants were aware of breast cancer, but had limited or no understanding of the disease. They had no knowledge of the screening guidelines and had limited knowledge of available breast cancer services. The prevailing thought among the group was the belief that there are no education programs or breast health services in their community.

### ***Racial/Ethnic Barriers***

The group talked about the perceived racism in the health system and how programs and services were being directed to the Latino population in Arlington County. Additionally, there was discussion and agreement that services are denied or delayed to women who are African American.

***“I called the clinic to make an appointment and they asked me my race. When I told them they said that they didn't have openings and I would have to wait.”***

### ***Prince William, County, Virginia***

The average age of the eight participants in the Prince William focus group was 50. The group included three African American women, three Caucasian women and two Latina women. Six of the eight participants had some college or a graduate degree. Five participants reported being female head of household and income distribution was pretty even throughout the group. Four women reported having private insurance, three reported being uninsured and one was on Medicare. Six of the eight participants reported having a primary care provider as well as a clinical breast exam and mammogram in the last 12 months.

Participants in the Prince William focus group were diverse and expressed a variety of opinions on issues specific to immigrant residents of the county. This was the overarching theme of the discussion. The women pointed out a need to educate and empower immigrant women to prioritize their own health and recognize the importance of screening.

### ***Culturally-Appropriate Education***

The group talked about the type of education being done and questioned how appropriate it was for women from other cultures. The women agreed that immigrants have not had access to the same type of breast cancer education as women born or raised in the United States. General awareness was believed to be a necessary message for immigrant women. The group discussed how current education efforts in the county are not reaching minorities or immigrants effectively. These groups need to be “bombarded” with messages to raise their level of breast cancer awareness to that of the “average” population.

“...this is what we should be doing. I don’t know what percent of education is geared toward other ethnic groups coming from countries that don’t have the same education (breast cancer) that we do...”

“We need to help other cultures who are stepping in and bombard them with the information so that it is not such a taboo anymore...and it needs to be something that needs to be followed through on”

### ***Access Barriers***

The group discussed the access barriers faced by low income and minority women in the county — lack of insurance and fear.

“We (Latinas) don’t go to the doctor until we are dying...we don’t go because we have no insurance, scared about results, scared about a lot of things...”

“There is a large number of Latina women that go to the free clinic with lumps and have had no access to care and by the time they get care it is already breast cancer.”

### ***Education Messaging and Delivery***

The women pointed out gaps in how education is commonly delivered and suggested that efforts might be more effective if more was done beyond just distributing pamphlets and brochures.

“People are handed materials...if they read it...can they read it...it isn’t taboo anymore, but the subject is dropped after you get the information...it is.”

In addition, the group recognized the need to educate women beyond just screening. According to the group, women need to be informed on what happens after they get a mammogram. Participants recommended incorporating empowering messages in education efforts and discussed how this was critical to getting women to take action.

“...when someone had chemo 10 years ago it is totally different now...people need to be educated that it is not your grandmother’s chemo (because of) advancements in care with new drugs...”

“Women don’t love herself...so don’t follow health advice...importance of support groups to empower and learn from other women”

### ***Capacity***

The group discussed the issues of provider capacity that exist in the county. As the economy has worsened, more people require free services as a result of unemployment and loss of health benefits. Free clinics are unable to meet the demands. The lack of funding in the free clinics results in waitlists for services and limits the funding that can be directed to follow-up care.

“...problem is after initial screening, someone has problem there are no significant resources in order to access care. No access beyond mammograms”

“Women outside of system, where there is no capacity don’t get care. Need to increase capacity to get new women in — get more screening options.”



## SECTION OVERVIEW

Education was the prevailing theme throughout the four focus groups completed in each of the target communities. While immigrant populations still need to hear messages about general awareness, education directed toward the target communities should include the following: clarification of the screening guidelines; comprehensive content that incorporates education about the basics of the disease; and emphasis on the correlation between early detection and survivorship. Another common theme was the need for culturally-appropriate education.

Provision of care was another core theme discussed by participants of all four focus groups. Participants questioned the quality of care received by uninsured and minority women, specifically African American and Latina women. Community members from all target communities identified limited availability of services and provider capacity as significant barriers. The women confirmed the natural consequences of not having enough providers in their community: long office visits, transportation, work time lost, and travel expense.

All focus group participants shared ideas on how to provide education and outreach in their communities. They offer suggestions about appropriate methods and potential partners in the community. Examples included partnering with culturally-specific radio stations, utilizing health educators, and reaching out to older women through direct mailings.

## TRANSLATING RESEARCH FINDINGS

Breast cancer statistics determined the target areas for NCA 2011 Community Profile. Therefore, the purpose of the follow-up data collection was to better understand from a health systems perspective as well as a community perspective what factors could be contributing to the elevated breast cancer statistics in Wards 7&8 of the District of Columbia, Prince George's, Maryland as well as Arlington and Prince William, Virginia.

The provider review was focused on the areas of highest mortality and the analysis quickly brought forth a number of factors that alone or in combination might contribute to the increased mortality rates of the target communities. For example, the dearth of breast health services available to women in the target communities may be a determining factor in the high mortality.

Understanding the limited resources in the target communities informed and defined the analysis within the communities, i.e. the information sought from key informants and women in those communities. Since we understood that there were limited services, we wanted to understand where the women went for services if they did at all and what, if any, difficulties they faced in accessing care. This knowledge guided the questionnaires developed for both the key informants and the focus group participants.

### FINDINGS

The need for more comprehensive education efforts was a major finding for the NCA. Both providers and community members talked about the need to teach women about breast cancer rather than just raise their awareness of the disease.

Throughout the NCA, capacity was a significant finding at all stages of the continuum of care. The term capacity was used by providers when discussing their inability to meet the need in the community because of lack of funding. When community members discussed capacity in the focus groups it referred to the lack of providers and services in their community. The lack of services for the uninsured specifically was also identified as a major concern in the target areas. The uninsured are forced to navigate a complicated and fragmented system with minimal and stressed support from providers who are at capacity and doing what they can with limited options. These system barriers build on the personal barriers women contend with in seeking health care such as fear, competing priorities and culture to name a few.

### *Wards 7&8*

Wards 7&8 were chosen as target communities because of high mortality rates, and the significant socio-economic challenges facing the predominantly African American women living in those wards. In addition, the lack of a stable health infrastructure in the community serves as a major barrier for women needing breast health services. With only one hospital to serve both Wards and providing only limited breast health services, women in these communities are faced with serious access barriers.

Key informants discussed a need for culturally appropriate, multi-level education programs that move the community beyond awareness and clearly define the recommend screening and re-screening guidelines. Additionally, informants expressed the complexity of working with women in Wards 7&8. Women living in resource poor communities, who are fighting to keep jobs and make enough to support their homes and families do not prioritize their

own health and are not able to focus on preventive services, especially when seeking these services is cumbersome due to the system's own limitations. Providers also identified immigrants living in Wards 7&8 as a group requiring special attention in breast health efforts, because of issues related to culture, language and immigration.

Focus group participants stressed the need for more breast cancer education in their communities. Past and current awareness efforts, according to participants, have effectively raised awareness of breast cancer, but the group felt it was time to build on awareness and effectively address the lack of knowledge of the disease that leads to the fear of screening, which for many means hesitation and denial about the importance of seeking services.

Women in this group also discussed the need to create a single and consistent message around screening and breast cancer. Participants discussed the abundance of conflicting messages coming from the media, medical professionals and even their neighbors. The fact that everyone has a different message as to the screening recommendations, services available and the disease itself leads to confusion among women in the community. The group also discussed how those who work in breast cancer need to ensure that messaging and education is culturally sensitive and appropriate and reaching those who need to hear it most.

### ***Prince George's County***

Prince George's County was chosen as a target community because of the county's high mortality rate, its diverse community and the social economic challenges facing women in the northern region.

A review of the county's health infrastructure determined that despite the wealth of resources in the county as a whole, the northern region is limited in the services that are available to the uninsured and immigrant population dominant in that region. Free and low cost health care is not available to women living in the northern region; the only BCCEDP site is in the center of the county, has limited funding

and is not easily accessible to many who would benefit from its services. Providers in Prince George's County focused primarily on the challenges they face working with uninsured women in a county where there are limited to no services to provide general care let alone charity care.

Women in the community talked about how breast cancer education should be provided in a way that empowers women to take care of their own health, seek services and demand quality care. Participants believe that there are no culturally appropriate breast cancer education programs available to women in the county and acknowledged that awareness is still needed in their community, however, according to the group; Latinas in the county want to be educated about breast cancer, the role and importance of screening and the resources in the community.

The lack of services available to women along with the perceived notion that care provided to the poor is of less quality was heavily discussed in the Prince George's focus group. Participants identified the lack of existing community resources as the most significant barrier to women in their community and through the experiences they shared confirmed that the lack of resources in their community added to the number of barriers they had to overcome just to seek care. For example, having to travel outside of the county to get a mammogram requires a woman living in Prince George's to take significant time off work, arrange long distance transportation, deal with travel expenses, and have to wait long periods of time.

### ***Arlington County***

Arlington County's mortality rate, although not as high as in other target communities, and its diverse population prompted the decision to make it a target community. Arlington County has no BCCEDP sites available to its residents therefore women needing free or low cost mammograms have to seek care outside of their county.

In Arlington, according to providers there is no outreach taking place so women in the county are unaware of what services are available to them. The county has a growing number of foreign born residents that don't speak English therefore, immigrant women were identified as a vulnerable group because of language barriers and because they are less likely to be aware of services. Providers also discussed the specific needs of uninsured women in Arlington. According to providers, uninsured women face significant challenges in accessing breast care. The uninsured are relegated to get care where it is offered free which often delays access and increases the chances that women don't get through the continuum of care.

Participants of the Arlington focus group were aware of breast cancer, but had limited to no understanding of the disease. They had no knowledge of the screening guidelines and had limited knowledge of available breast cancer services. The prevailing thought among the group was the belief that there are no education programs or breast health services in their community. The women shared their opinion that the health system in the county discriminates against African Americans by denying or delaying care and by redirecting services to the growing Latino population.

### ***Prince William County***

Prince William County was chosen as a target community because of its mortality and incidence rates as well as its growing diverse population. Prince William does not have a BCCEDP site in the county so women must travel outside of the county to seek free or low cost mammograms. In Prince William providers discussed the need for more outreach to address specific barriers in their system that prevent women from seeking care. Women in Prince William, according to providers, don't trust the screening process and don't believe in the value of screening to save lives. In addition, providers discussed how many immigrant women don't seek care in the county because they fear being turned in to immigration.

The availability of care for the uninsured is also fragmented and limited in Prince William as in the other target communities and the lack of support after a diagnosis is a significant gap for women in the county.

In Prince William education was the main theme of the focus group discussion. Participants expressed the need to approach education efforts differently for women in their community, recognizing that minority and immigrant women still need awareness campaigns to get them as "comfortable" talking about breast cancer as the general public. However, there was also considerable discussion on the need to move beyond the basics when doing community education on breast cancer and how the knowledge these efforts would impart would serve as a powerful empowering tool to women in their community.

## **CONCLUSIONS**

Although there were variations to the findings depending on the region being discussed, two main themes were clear throughout the NCA. Findings indicate that current education efforts need to be reconsidered and that a comprehensive education approach should be explored. Education efforts in the NCA need to move the communities beyond awareness by providing more in-depth education on screening, breast cancer and resources. The education approach should be tailored to specific groups and provide consistent and clear messages that ideally lessen fear, confusion and motivate women to take care of their health.

The second theme in the NCA pertains to the lack of continuity of care throughout the continuum of care for women who are uninsured and underinsured because of lack of funding. Providers in the target community are at or above capacity and therefore not able to meet the need in the community. The lack of providers in certain regions and the lack of access to services in others put women at risk and may be contributing to women dying from cancer in the NCA.

# NATIONAL CAPITAL AREA PRIORITIES

After the final analysis of the data had been reviewed and discussed, the Community Profile Team developed a list of 12 priorities that reflected the findings of the data analysis. Following considerable discussion, the Team ranked the priorities. This process (rank and discuss) was repeated until four priorities were selected. In separate meetings, the Community Profile Team and Komen staff established objectives for each priority based on capacity and resources. The timeline to complete all activities listed in the Action Plan is April 1, 2010 – March 31, 2012. While many of these priorities apply to the NCA, special emphasis will be placed on Wards 7&8, Prince George's County, Arlington and Prince William County.

## PRIORITIES AND ACTION PLAN

**Priority 1:** Increase provider competency and community knowledge and understanding of breast cancer screening recommendations as they apply to priority populations.

Objective 1: Identify and fund educational opportunities to inform providers of the screening guidelines and also improve their working knowledge of the various referral processes to better navigate patients.

Objective 2: Partner with community-based collaboratives in Ward 7&8, Prince George's County, Arlington and Prince William to develop and implement a symposium to reinforce correct screening guideline messages to the community.

**Priority 2:** Assist partners and grantees in strengthening current breast cancer education content to include targeted awareness messaging, understanding of the disease, and survivorship.

Objective 1: Fund multi-faceted education programs that follow the Ecological Model and are tailored to the target communities.

Objective 2: Develop a curriculum on correct messaging that can be tailored and adapted for use with diverse populations.

**Priority 3:** Influence partners and grantees to strengthen or incorporate culturally competent education messaging.

Objective 1: Fund cultural-sensitivity provider training(s) in the National Capital Area.

Objective 2: Share research findings from the Community Profile and encourage community-based organizations to apply culturally appropriate findings to their community efforts.

**Priority 4:** Reduce fragmentation and enhance the health care system's capacity to screen and provide follow-up care in the National Capital Area. Create continuity between referral, screening, diagnosis, and treatment within the region.

Objective 1: Increase the number of organizations serving Ward 7&8, Prince George's, Arlington and Prince William County that receive Komen funding.

Objective 2: Identify or design a model for an integrated system of care, thereby improving referrals from screening to follow-up care within and between the target communities.

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