COMMUNITY PROFILE REPORT

Susan G. Komen for the Cure® Maryland

2011

Disclaimer:

The information in this Community Profile Report is based on the work of the Maryland Affiliate of Susan G. Komen for the Cure® in conjunction with key community partners. The findings of the report are based on a needs assessment public health model but are not necessarily scientific and are provided "as is" for general information only and without warranties of any kind. Susan G. Komen for the Cure and its Affiliates do not recommend, endorse or make any warranties or representations of any kind with regard to the accuracy, completeness, timeliness, quality, efficacy or non-infringement of any of the programs, projects, materials, products or other information included or the companies or organizations referred to in the report.

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Additionally, while we cannot name each person who contributed to this process we would like to extend thanks to community members, survivors, and providers who participated in key informant interviews and focus groups.

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Executive Summary

Introduction

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®, which is the world's largest breast cancer organization and the largest source of nonprofit funds dedicated to the fight against breast cancer with more than $1.3 billion invested to date.

The Maryland Affiliate was founded in 1993. The first Race had 3,000 participants and raised $250,000 in revenue. In 1994 the Affiliate began awarding grant money to local direct service providers. The Maryland Race for the Cure has continued to expand over the years, and in 2010 had 28,500 participants and raised $3 million. In 2011, the Affiliate funded almost $2.5 million to 29 large grant programs across the state providing a comprehensive range of breast health services. The Affiliate service area covers the entire state of Maryland with the exception of Montgomery and Prince George's Counties.

The Affiliate regularly conducts a needs assessment to gather information on the state of breast cancer in our service area and to set priorities that ensure we serve the people who most need help. The resulting Community Profile guides our priorities and communication with community members, grantees, partners, sponsors and policy makers. The 2011 Community Profile report is the sixth report published since the first was released in 1997. Each consecutive report builds upon the target areas identified in the last report and grows more sophisticated in the level of data collection and analysis. The report includes an overview of demographic and breast cancer data, an analysis of local health systems, and qualitative data from local providers and women in the community. The Affiliate chose four communities of interest by examining a combination of factors including, breast cancer death rates, percentage of late-stage diagnoses, screening rates, representation of minority populations and various socio-economic factors such as poverty level. The resulting priorities and action plan engages vulnerable and at-risk populations and addresses gaps found in the continuum of care with special attention paid to four target communities. The priorities and action plan will influence the direction of strategic planning, budgeting and staffing for the Affiliate over the next two years.

Statistics and Demographic Overview

In order to characterize the demographic and breast cancer related patterns within Maryland multiple data resources were utilized: US Census Bureau, 2007-2009 data from the American Community Survey, The Maryland Behavioral Risk Factor Surveillance System (MBRFSS) 2008 and 2009, Maryland Cancer Registry, State Cancer Profiles, and American Cancer Society Facts and Figures publications.

Based on the US Census Bureau population estimate, approximately 3,893,318 people or 68.3 percent of the total state population live within the 22 jurisdiction Affiliate service area. The most populous areas are located in the central region of the state. Females made up over 50% of the population. Minorities made up 33.4 percent of the service area population: 24.7 percent African American, 3.6 percent Hispanic, 3.3 percent Asian Pacific Islander, and 1.8 percent all other Races. Maryland ranks first in the nation in median household income ($69,272 for 2009); however, levels of affluence vary greatly across the state (US Census Bureau). About 72.6

percent of women ages 50+ had a mammogram and breast exam in the past two years, but only 39.1 percent of women without any kind of health insurance reported the same (MBRFSS). The overall percentage of women who reported never having a mammogram was 8.3 percent for women with health insurance and 23.3 percent for women without any insurance coverage.

It is estimated that approximately 4,850 new cases of breast cancer will be diagnosed among women in Maryland in 2011 and 800 women are expected to die from the disease (ACS, 2011). While Maryland's age-adjusted breast cancer incidence rate of 122.4 cases per 100,000 population is similar to the national rate of 120.6/100,000, the age-adjusted breast cancer death rate (25.8/100,000) is the fifth highest in the nation (Maryland Cancer Registry). This means that Maryland women are not more likely to be diagnosed with breast cancer than women in other parts of the county, but women diagnosed in Maryland are more likely to die.

The Affiliate chose to focus on four communities of interest: Baltimore City, Calvert, Charles and Somerset Counties. A combination of factors including breast cancer mortality rates above the state rate, percentage of late-stage diagnoses, screening rates and various socio-economic factors lead to the determination of the four areas. Additionally, three of the four selected communities have the largest proportions of African Americans in the service area. The Affiliate chose to focus on the African American population due to the breast cancer disparities faced by this population. Nationally and in Maryland, breast cancer is the most common cancer among African American women; they have higher rates of distant stage breast cancer than white women and are less likely than white women to survive five years: 77 percent vs. 90 percent respectively. (ACS, 2009-2010).

Health Systems Analysis Overview

The purpose of the health systems analysis was to determine what resources and facilities currently exist in each community of interest; Baltimore City, Calvert, Charles, and Somerset Counties. The analysis also provided information about needed community services and gaps in the continuum of care that may explain low screening rates, high mortality rates or late stage diagnoses. The breast cancer continuum of care is a model that can be used as a guide to assess 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 health systems analysis was completed using the Food and Drug Administration's Mammography Facility Database of MQSA certified facilities, Komen Maryland's grant applicant and recipient database, and responses from 25 key informant interviews. The Affiliate conducted phone interviews with key providers, community leaders and breast cancer advocates in the communities of interest using a 20-question questionnaire. Notes taken during the key informant interviews were analyzed using NVivo9 software to organize the data and identify themes.

The health systems analysis and discussions with key informants revealed a number of key issues across each community of interest and some issues unique to each area. The populations identified as most in need or least likely to be screened included in rank order:

- low income women
- uninsured women

- racial and ethnic minority women (specifically African America and Hispanic)
- women under 40 with symptoms and older women

Key informants in all target areas also identified the same barriers for women in accessing the continuum of care, presented in rank order:

- financial barriers/lack of insurance
- lack of transportation
- fear
- lack of knowledge

Financial barriers and lack of transportation were identified throughout the state, but seemed to be more often mentioned in the rural counties. Lack of knowledge covers a range of issues including, a lack of knowledge of breast cancer risks, screening recommendations, and resources in the community. Oftentimes, providers were put at fault for not preforming or referring women to needed screenings. Many women without insurance or financial means do not know about the availability of free screening services offered through Maryland's Breast and Cervical Cancer Early Detection Program (BCCP).

The rural communities in Calvert, Charles and Somerset Counties lack choices in breast screening facilities. However, each county has at least one mammography site which presents the opportunity for expanded services. There is also a clear need for transportation services in the three rural counties for both screening services and for women in treatment. There are opportunities to address these issues together to make it easier for women to access screening facilities. Paradoxically, in Baltimore City, an area filled with medical resources, many women still do not access screening services. While transportation was cited as one issue, a larger issue exists within the State Primary Adult Care (PAC) Program and other health insurance providers which do not cover mammograms performed in hospitals. Therefore, women have to go outside of the city to free-standing facilities which can cause transportation difficulties for many women.

Additionally, the main barriers to screening and entering the continuum of care; financial, transportation, fear and lack of knowledge are a concern because each is a barrier by itself, but also compounds the others. Therefore, it is important to address all of these barriers simultaneously rather than one at a time and in isolation.

Qualitative Data Overview

In order to gain the full perspective of each community of interest the Affiliate spoke with women in those communities. Their perspective helped to reinforce the conclusions drawn from the health systems analysis. The Affiliate conducted five key informant interviews with non-medical community members and/or survivors in Calvert, Charles and Somerset Counties. In Baltimore City, the Affiliate conducted a focus group in the Cherry Hill neighborhood with seven women: six African Americans, one Hispanic, two survivors. The average age of the group was 47.5. The recording of the focus group and the key informant interview notes were analyzed using NVivo9 software.

The most frequently mentioned barriers discussed by women in all of the communities mirrored the same barriers found in the health systems analysis: financial difficulties and transportation

needs. However, women in each community also emphasized the need for greater awareness and outreach as well as facilitation of screenings, whether through discount coupons or reminders from providers. In rural areas, transportation was also identified as a need and barrier to screening and treatment.

Outreach and education needs to occur earlier for women and in settings that are comfortable for them (e.g. church groups) and the community needs to be made aware of the state resources for screening and treatment. Especially in the African American community, churches could be a strong partner for the Affiliate to reach women. It is also vital that outreach workers be from the communities of need. Women in the communities also felt that media campaigns and advertising may be useful throughout the year to keep breast cancer screening in people's minds. There continues to be confusion about screening recommendations for women. Respondents relied on their providers to know the recommendations and refer women to screening programs.

Conclusions and Communities of Interest

The quantitative and qualitative data gathered identified specific gaps in the continuum of care in each targeted community and also presented opportunities to improve breast cancer awareness and screening rates. For example, at least one screening facility is present in each targeted area. The challenge is how to raise awareness and educate women about screening and also to make use of existing facilities to increase screening rates. Transportation was cited as a barrier across each area in addition to the limited access to and hours of the screening facilities. Many women are either eligible for the state's BCCP or have access to PAC to cover annual screening mammograms, but the challenge is making women and their providers aware of coverage for mammograms and then facilitating those annual screenings. Furthermore, there are many opportunities to expand the Affiliate's presence and funding in the targeted communities, both the geographical targeted areas and in the African American communities in those areas and throughout the service area.

Baltimore City

Baltimore City continues to be a target area and was specifically chosen due to the combination of a high breast cancer mortality rate (30.9/100,000) (State Cancer Profiles), the high percentage of late stage diagnosis and the high proportion of vulnerable populations in the community, including African Americans (63.2 percent of the population) and those living below poverty (20.1 percent) (American Community Survey). While the City has many medical facilities and resources available, low-income women without insurance or who use the PAC Program face specific challenges in entering the continuum of care in order to access screening and therefore any necessary diagnosis, treatment or follow-up care. In addition to lack of referrals from providers for mammograms, these women faced barriers relating to transportation in the city and to available screening facilities. In discussions with women in Baltimore City, they highlighted the need for more awareness and education about breast cancer risks, screening recommendations and how to access services. Women recommended using the churches for outreach and education as well as making use of mass media, advertising and social media.

Calvert County

Calvert County is a new target area and was chosen primarily because of its high breast cancer mortality rate (33.9/100,000) and the high rates specifically among white women and women age

65 and older (State Cancer Profiles). The county presents a paradox when looking at the demographic data. The county does not have a high proportion of vulnerable populations that we might expect to contribute to high mortality rates, such as those living in poverty, those with low-levels of education or minority populations. There are opportunities to improve early stage diagnosis as 5.64 percent of cases were diagnosed at a distant stage and only 51.88 percent of cases were diagnosed at a local stage (Maryland Cancer Registry).

Through further investigation into the area and in speaking with local providers, it was found that only two screening facilities exist in a county that has seen a tremendous population growth of almost 20 percent in the past nine years (US Census Bureau). Most women seem capable of accessing the continuum of care: almost 93 percent have access to some kind of health insurance and almost 78 percent report having had a mammogram in the past two years (MBRFSS). Key informants in the community felt that it may be the small pockets of uninsured as well as the elderly who are facing challenges in getting screening and accessing care. Additionally, key informants felt that transportation and the location and hours of the available screening facilities was a barrier to women getting mammograms. The Affiliate does not have a strong presence in the county and until 2011 had never funded a small or large grant in the area. There are opportunities to form collaborations with the new breast center in the area and support the growing community in ensuring mammograms and facilities are easily accessible.

Charles County

Charles County continues to be a target area. Since the 2009 Community Profile report, the county has shown improvement in their breast cancer mortality rate. It dropped from 35.0/100,000 for 2001-2005 to a rate of 29.7/100,000 for 2003-2007 (State Cancer Profiles). However, there are still reasons for concern in the area. The African American population, which traditionally faces breast cancer disparities, continues to grow and now makes up 40.1 percent of the county's population. Additionally, the county has the worst breast cancer screening rates in the Affiliate service area: only 58.5 percent of women ages 50 and older report having had a mammogram in the past two years and 15.4 percent report they have never had a mammogram MBRFSS). These low screening rates could influence the breast cancer incidence and mortality rates in the county. If women are not being screened they are also not being diagnosed. Additionally, in the southwest part of the county there is an area of extreme poverty and local key informants identified women in this area as high-risk for not entering the continuum of care.

Charles County has just one hospital and four screening facilities. Key informants in the community identified transportation as the biggest barrier for women in accessing the continuum of care. Additionally, they felt that a lack a facilities and providers impacted women getting screening and treatment. Key informants agreed that many women go out of county for breast cancer treatment and there is a need for improved care and a "one-stop-shop" facility for treatment. The key informants also felt that African American women without health insurance were the most vulnerable members of the community and needed specific outreach and education efforts.

Somerset County

Lastly, Somerset County was again chosen as a target area. The breast cancer mortality rate in this county also fell since the last Community Profile report. Data for 2001-2005 showed a rate

of 40.0/100,000 and in 2003-2007, the rate was 33.7/100,000 (State Cancer Profiles). Because the population of Somerset County is so small, just 25,959 people, the rates can vary greatly and may not be reliable. However, the county has many populations that are considered at-risk for breast cancer; 41.3 percent of the population is African American and 18.1 percent of the population lives below poverty. The health systems analysis found that there is just one hospital which houses the one screening facility in the county. Providers related alarming anecdotal information about most women only coming in to get a mammogram once they feel a lump. Just over 50 percent of cases are diagnosed at a local stage, so there is room to increase the rate of early stage diagnosis for better outcomes (Maryland Cancer Registry). If diagnosed, women usually travel out of the county for treatment, which presents additional barriers. The local key informants identified outreach and education as the most important needs in conjunction with easier access to the screening facility. The key informants felt it was vital to have trusted local women from the community to educate and raise awareness.

Priorities and Action Plan

After completing analysis of the data the Community Profile Team brainstormed the best ways for the Affiliate to address the problems identified. From this list, the team then organized the ideas into larger priority areas and narrowed the focus. With additional input from Affiliate staff, the final proposed priorities and objectives were presented to the Board of Directors.

The Affiliate will continue to fund and support proven grant programs and outreach events. The priorities and objectives in the following action plan do not exclude other models and best practices, rather the action plan in a way to move beyond what we know works. The action plan will influence the Affiliate's strategic plan, fiscal year (FY) 2013 and 2014 grant funding priorities and other mission and non-mission efforts.

Priority 1: Support policy and system changes to increase annual screening rates across the affiliate service area.

Objective 1: By end of 2012, meet with the State Primary Adult Care Program and Medical Assistance Program to identify ways to collaborate to ensure providers complete clinical breast exams and make appropriate referrals for annual mammograms. Develop a timeline for implementing identified means and estimate amount of funding support need from Affiliate and/or other sources for development of systems.

Objective 2: In 2012 investigate use of mobile/e-health applications for mammogram reminder system. By August 2012, incorporate funding for mobile/e-health direct to consumer/patient reminder systems to be used across medical institutions into FY 2014 large grant request for applications (RFA).

Priority 2: Support expanded screening and facilitation of screening especially in each community of interest; Baltimore City, Calvert, Charles and Somerset Counties.

Objective 1: Incorporate funding for patient transportation to and from screenings in outlying areas (through model of mammogram day/group transport) into FY 2013 and 2014 large grant RFA.

Objective 2: Incorporate funding for extended evening/weekend screening hours into the FY 2013 and 2014 large grant RFA.

Objective 3: Incorporate funding for mammography vans in Affiliate service area into the FY 2013 and 2014 large grant RFA.

Priority 3: To address disparities, increase small and large grant funding to African American community organizations for awareness, outreach and screening programs in Baltimore City, Calvert, Charles and Somerset Counties.

Objective 1: In 2012 and 2013 conduct one intensive grant writing workshops in each of four communities of interest, targeting the faith-based community (coalition of African American ministers, county ministerial alliances, parish nurses) and other African American community groups.

Objective 2: In 2012 and 2013 partner with academic and non-profit institutions to provide additional technical assistance to potential and current grantees. (For example, student grant writing classes partner with community organizations).

Priority 4: Support development of breast cancer coalitions in Southern Maryland (Calvert and Charles County specifically) and Baltimore City.

Objective 1: Incorporate funding for development of coalitions in Southern Maryland and Baltimore City into the FY 2012 and 2013 small grant RFA.

Objective 2: Staff will publicize the development of coalitions and available funding in Southern Maryland and Baltimore City and provide technical support in the form of best practices/models, presence at meetings, and consultation.

The Community Profile report presents an overview of the state of breast cancer in the 22 jurisdiction service area of the Affiliate and highlights four regions as targeted communities. As a leader in the field of breast cancer and as a grantmaker the Affiliate has a responsibility to strategically focus our efforts and resources to address the greatest needs, build meaningful partnerships in the community, and support best practice models that will improve the state of breast cancer across our service area and the state of Maryland.

Introduction

Affiliate History

Nancy G. Brinker promised her dying sister, Susan G. Komen, that 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®, we have invested more than $1.3 billion to fulfill our promise, becoming the largest source of nonprofit funds dedicated to the fight against breast cancer in the world.

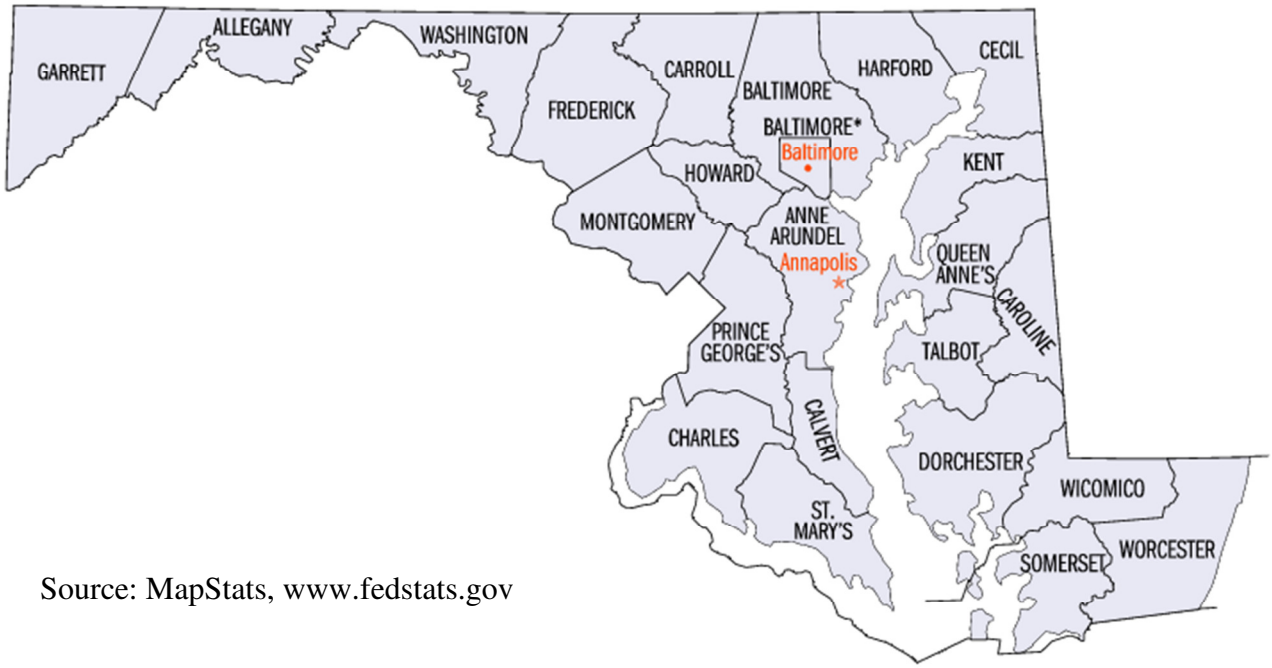
The Maryland Affiliate was founded in 1993 by Brenda Brinker Bottom, stepdaughter to Nancy Brinker. As is the case with most Affiliates, Komen Maryland began as a volunteer-run Race for the Cure. The first Race, held in 1993, had 3,000 participants and raised $250,000 in revenue. In 1994 the Race grew and Komen Maryland began awarding grant money to local direct service providers. The Maryland Race for the Cure has continued to expand over the years, and in 2010 had 28,500 participants and raised $3 million. In 2011, the Affiliate funded almost $2.5 million to 29 large grant programs across the state providing a comprehensive range of breast health services.

In 2001, beginning with the hire of Robin Prothro as Executive Director, the Maryland Affiliate began the transition from a volunteer-run organization to a fully-staffed office. In 2007, Komen Maryland was honored by being named the Affiliate of the Year. The Maryland Affiliate is seen as a leader in breast cancer in the state. The Executive Director was appointed by the governor to serve a three-year term on the Maryland State Council on Cancer Control. Additionally, the Grants and Education Program Manager sits on the Maryland Comprehensive Cancer Control Plan breast cancer committee and writing committee.

Description of Service Area

While Maryland is small compared to many western states, it is geographically diverse and divided into four distinct regions: Western Maryland, Southern Maryland, Central Maryland, (which includes Baltimore City) and the Eastern Shore. The Affiliate's service area covers the entire state of Maryland with the exception of Montgomery and Prince George's Counties which are considered greater Washington, DC and served by the Global Race for the Cure (see Figure 1). The Affiliate provides services for the remaining 21 counties and Baltimore City which span Maryland's distinct regions including both urban centers and rural areas. The service area population was estimated to be 3,893,318 in 2009 with a diverse population: 66.6 percent White, 24.7 percent African American, 3.6 percent Hispanic, 3.3 percent Asian Pacific Islander, and 1.8 percent all other Races (US Census Bureau).

Just over two-thirds of the service area population resides in Central Maryland, made up of five counties and Baltimore City. Western Maryland, made up of four counties, is the second most populous area with approximately 12.2 percent of the service area population. The Eastern Shore is made up of nine counties, two of which are the least populated counties in the state, and holds 11.4 percent of the population. Southern Maryland, with just three counties, makes up the remaining 8.6 percent of the population (US Census Bureau).



Source: MapStats, www.fedstats.gov

Figure 1: Map of Maryland by County: Service area excludes Montgomery and Prince George's

Organizational Structure

The Affiliate is based in Towson in Central Maryland. The organizational components of the Affiliate are the Board of Directors, the Executive Committee, various standing committees, and the staff, shown in Figure 2. A 14-member Board of Directors currently works with an 11-person staff to fulfill the Komen promise: to save lives and end breast cancer forever by empowering people, ensuring quality care for all and energizing science to find the cures. Beginning in 2009, the Affiliate began hiring staff who work remotely on the Eastern Shore of Maryland. Currently, the Eastern Shore Field Coordinator position is filled and an Eastern Shore Race Manager will be hired to coordinate the second Race for the Cure location in Ocean City, Maryland.

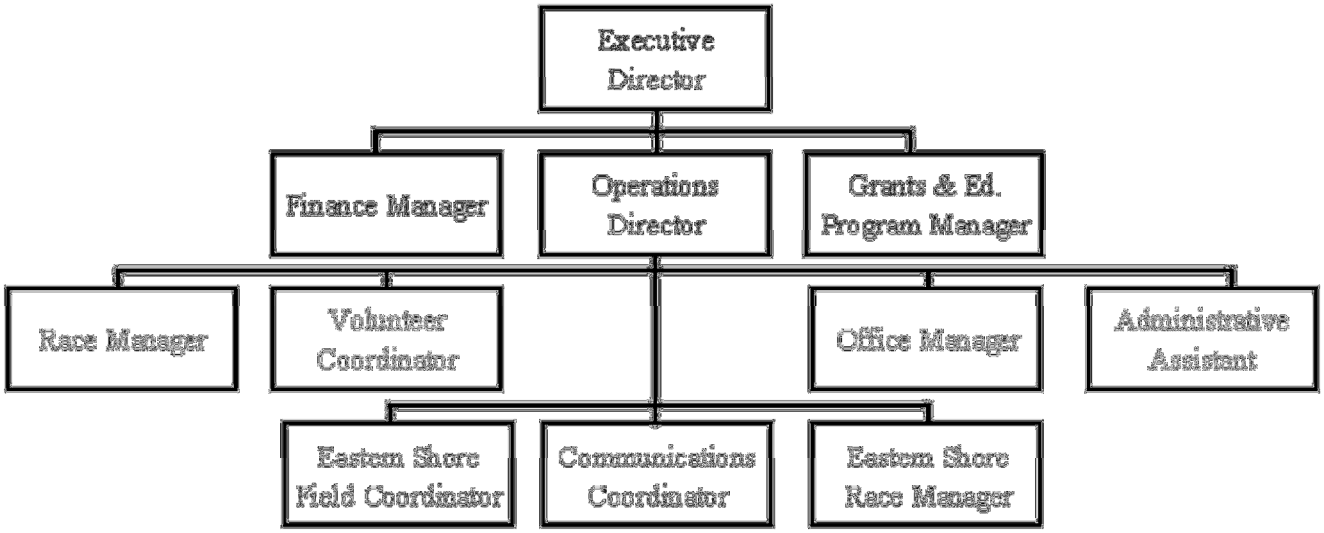


Figure 2: Komen Maryland Affiliate Staff Organizational Chart

Purpose of Report

To meet our promise, the Affiliate regularly conducts a needs assessment to gather information and set priorities to ensure that we serve the people who most need help. The resulting Community Profile guides our priorities and communication with community members, grantees, partners, sponsors and policy makers. The 2011 Community Profile report is the sixth report published since the first was released in 1997. Each consecutive report builds upon the target area identified in the last report and grows more sophisticated in the level of data collection and analysis.

The Community Profile includes an overview of demographic and breast cancer statistics that highlight target areas, groups, or issues. The Affiliate relies on this data to help identify regions, communities, and populations where our efforts are most needed and will have the most impact. Once several communities of interest are identified, the Affiliate investigates each area in more depth, analyzing the local health systems, interviewing local providers and speaking with women in the community. These various perspectives ensure that the Affiliate has a comprehensive picture of each community and understands the needs and barriers women face in accessing the continuum of care from screening through diagnosis, treatment and follow-up. The Affiliate then develops priorities and an action plan based on the quantitative and qualitative data gathered from each community of interest in order to address gaps in the continuum of care as well as opportunities to engage vulnerable and at-risk populations.

A quality Community Profile strives to provide current breast health and breast cancer data and the status of services in communities of interest. The final report helps to ensure that local efforts backed by the Affiliate are targeted and non-duplicative and allows the organization to:

- Drive inclusion efforts in the breast cancer community
- Strengthen sponsorship efforts – "tell the story"
- Establish focused granting priorities
- Establish focused education needs
- Establish directions for marketing and outreach
- Drive public policy efforts

The priorities and action plan influences the direction of strategic planning for the Affiliate over the next two years. The Affiliate board of directors, with staff input, incorporates the findings of the community profile into the strategic plan. The 2009 Community Profile report identified the Eastern Shore region of Maryland as an area that could benefit from a greater Affiliate presence. Based on data and recommendations from the report, the board of directors approved and budgeted for staffing on the Eastern Shore. In 2010 a Field Coordinator was hired on the Eastern Shore and in 2011 a Race Manager will be hired to coordinate the Race for the Cure in its second location in Maryland on the Eastern Shore. The 2011 Community Profile Report will continue to influence budgeting and staffing decisions in order to meet new priority areas.

Breast Cancer Impact in Affiliate Service Area

Methodology

In order to characterize the demographic and breast cancer related patterns within Maryland multiple data resources were utilized. In addition to general population estimates from the Census Bureau, 2007-2009 data from the American Community Survey provided the basis for information concerning the state population distribution, racial/ethnic composition, and socioeconomic characteristics. The Maryland Behavioral Risk Factor Surveillance System 2008 and 2009 results and the Maryland Cancer Survey both provided valuable information for understanding breast cancer screening patterns. Breast cancer incidence data was acquired from the Maryland Cancer Registry. The National Cancer Institute's web-based information system, State Cancer Profiles, was the primary source for the most current breast cancer mortality data.

In addition to characterizing overall state and Affiliate service area characteristics, efforts were also directed toward identifying high-risk geographic areas and populations within the state. Age-adjusted breast cancer mortality rates were heavily weighted in the initial identification of potential target geographic areas. However, to choose the final four interest of communities, the Affiliate took into account a combination of factors including, annual death rates above the state rate, percentage of late-stage diagnoses, low screening rates, minority population and various socio-economic factors such as poverty level. The four targeted communities of interest include Baltimore City, Calvert, Charles and Somerset Counties.

Overview of Maryland Affiliate Service Area

Based on the US Census Bureau population estimate, 5,699,478 individuals resided in Maryland in 2009. Of the total state population, approximately 68.3 percent (3,893,318 people) live within areas served by the Affiliate. The most populous service areas are located in the central region of the state including in rank order: Baltimore County, Baltimore City, Anne Arundel County and Howard County. All other counties within the service area have populations of less than 240,000, with the majority of counties on the Eastern Shore having populations less than 50,000. Females make up over 50% of the population at 2,002,771 (US Census Bureau).

Minorities made up 33.4 percent of the service area population in 2009: 24.7 percent African American, 3.6 percent Hispanic, 3.3 percent Asian Pacific Islander, and 1.8 percent all other Races (US Census Bureau). Service area jurisdictions with the largest minority populations include:

- Baltimore City (69.1 percent)
- Charles County (49.3 percent)
- Somerset County (46 percent)
- Howard County (37.5 percent)
- Baltimore County (34.7 percent)
- Dorchester County (32 percent)
- Wicomico County (30.8 percent)

The Western region (Allegany, Garrett, Washington) and Upper Eastern Shore area (Caroline, Cecil, Kent, Queen Anne's, Talbot) of Maryland are less racially/ethnically diverse in comparison to other parts of the state with minority population percentages of 12.3 percent and 17.6 percent, respectively. Between 2000 and 2009, the largest minority population increases within the service area have been observed in Baltimore (+74,008), Howard (+38,617), Anne Arundel (+35,161) and Charles (+30,950) Counties (American Community Survey, 2007-2009).

While such growth has primarily been driven by increases within the African American community in Baltimore (+49,395), Anne Arundel (+14,832), and Charles (+25,425) Counties, the largest increase in minority population size within Howard County in recent years has been observed within the Asian community (+15,535). According to the American Community Survey, 2007-2009, the areas with the greatest increases in the Hispanic population between 2000 and 2009 include:

- Anne Arundel (+12,740)
- Baltimore (+12,606)
- Frederick (+9,666)
- Baltimore City (+8,214)

New US census data released in February 2011 shows the Hispanic/Latino population in Maryland increased 106.5 percent since the 2000 Census.

Maryland ranks first in the nation in median household income ($69,272 for 2009); however, levels of affluence vary greatly across the state. Within the service area, the highest median household income estimates are observed in:

- Howard ($101,003)
- Calvert ($90,621)
- Charles ($86,141)
- Anne Arundel ($81,824)
- Frederick ($80,970)

Not surprisingly, these counties also exhibit the lowest poverty rates (4.0 percent-5.4 percent) in the state. Allegany County ($36,810), Baltimore City ($38,738), and Somerset County ($41,615) represent the areas of the state with the lowest median household incomes and highest poverty rates, ranging from 14.1 percent to 20.1 percent. Based on most income-related economic measures, the Lower Eastern Shore (Dorchester, Somerset, Wicomico, and Worcester), Western region (Allegany, Garrett, and Washington), and Baltimore City represent the poorest areas of the state. As measured by the percentage of individuals 25 years of age and older with a high school degree or equivalent, these regions also represent the least educated areas of the state (American Community Survey).

Based on estimates from the 2009 Maryland Behavioral Risk Factor Surveillance System (MBRFSS), approximately 9.1 percent of the female population in Maryland does not have any type of health insurance coverage. The highest female uninsured estimates in Maryland are observed in:

- Wicomico (23.3 percent)
- Garrett (17 percent)
- Worcester (15.9 percent)
- Caroline (13.7 percent)
- Baltimore City (12.1 percent)

Breast Cancer Screening

Susan G. Komen for the Cure recommends that women 40 and over have a mammogram and clinical breast exam every year. The 2008 MBRFSS asked women ages 50+ if they had a mammogram and breast exam in the past two years; overall 72.6 percent of women reported that they did. However, only 39.1 percent of women without any kind of health insurance reported having had a mammogram and breast exam in the past two years. The overall percentage of women who reported never having a mammogram was 8.3 percent for women with health insurance, but the percentage almost triples to 23.3 percent for women without any insurance coverage.

The percentage of women ages 50+ receiving a mammogram and breast exam in the past two years varies greatly across the state. The counties with the highest report of women never having had a mammogram include:

- Charles (15.4 percent)
- Wicomico (13.9 percent)
- Caroline (12.2 percent)
- Baltimore City (12 percent)
- Baltimore (11.4 percent)

Correspondingly, the counties with the lowest report of women ages 50+ who had a mammogram and breast exam in the past two years are as follows:

- Charles (58.5 percent)
- Harford (64.2 percent)
- Queen Anne's (67.6 percent)
- Kent (70.1 percent)
- Baltimore City (70.2 percent)

Regular screening mammograms and clinical breast exams are vital in the fight against breast cancer as these screening tests are the best way for women to reduce their risk of dying from breast cancer. Screening tests can find breast cancer early, when it's most treatable. In fact, the survival rate for women diagnosed with breast cancer before it has spread outside of the breast is 98 percent (ACS, 2010).

Breast Cancer Incidence and Mortality Rates

It is estimated that approximately 4,850 new cases of breast cancer will be diagnosed among women in Maryland in 2011 and 800 women are expected to die from the disease (ACS, 2011). This report will examine breast cancer incidence rates, this is the number of new breast cancer cases, as well as breast cancer death rates, which is the number of deaths from breast cancer. Both of these rates are displayed per 100,000 people in order to compare rates across the state, however, not all counties have populations of 100,000. The report also examines the stage of breast cancer at the time of diagnosis and various socio-economic factors.

The most recent data available from Maryland Cancer Registry (2003-2007), see Figure 3, documents an age-adjusted incidence rate of 123.8 cases per 100,000 population, a rate similar to that observed nationally (120.6/100,000). The incidence rates refer to invasive breast cancer only and do not count Stage 0 or carcinoma in situ, cancers which are in the earliest stages and sometime called "pre-cancer." As evidenced in Figure 3, age-adjusted breast cancer incidence rates are not uniform across the varying regions of the state; however such variation should be interpreted with caution. In particular, consideration should be given to the fact that the age-adjusted incidence rates observed in the less populous areas of the state are based on smaller population sizes and often a relatively low number of breast cancer cases, resulting in less reliable estimates. Consequently, rates that appear particularly high in less populous counties may actually not differ significantly from that observed statewide from a statistical standpoint. Additionally, regional variations in age-adjusted breast cancer incidence rates within the state may partially be a product of demographic and/or screening rate differences between counties, as opposed to true geographic differences in the underlying risk of developing breast cancer. Consistent with that observed nationally, the most recent age-adjusted Maryland breast cancer incidence estimates document a higher rate among White women (126.4/100,000) in comparison to African American women (116/100,000).

Figure 3. Female Invasive Age-adjusted Breast Cancer Incidence Rates, 2003-2007

	All Races	White	Black	<50	50+	65+
US (SEER + NPCR)	120.6 (120.4-120.9)	121.8 (121.6-122.1)	114.7 (114-115.5)	42.8 (42.6-43)	326.5 (325.8-327.3)	395.5 (394.3-396.8)
Maryland	123.8 (122-125.5)	126.4 (124.3-128.6)	116 (112.7-119.4)	47 (45.7-48.3)	327.2 (321.8-332.6)	386.3 (377.4-395.3)
County	**All Races**	**White**	**Black**	**<50**	**50+**	**65+**
Allegany County	114.9 (101.2-130.1)	116.3 (102.3-131.8)	*	37.9 (27.1-51.5)	318.5 (278.3-362.7)	360.5 (302.5-426.3)
Anne Arundel County	123.8 (117.9-129.9)	122 (115.7-128.6)	128.6 (111.7-147.3)	44.2 (40.1-48.6)	334.5 (316.2-353.6)	406 (374.6-439.3)
Baltimore City	106.2 (101.5-111)	109.6 (101.4-118.2)	103.3 (97.5-109.3)	40.8 (37.2-44.6)	279.4 (265.3-294)	332.8 (309.9-356.8)
Baltimore County	129.7 (125.1-134.4)	128.6 (123.5-133.9)	130.2 (119.1-142.2)	47.3 (43.8-51)	347.6 (333.9-361.7)	412.3 (390.5-435)
Calvert County	122.2 (107.9-137.8)	124.1 (108.4-141.4)	117.3 (82.5-162)	52.2 (41.8-64.5)	308 (264.4-356.8)	357.2 (284.3-443.1)
Caroline County	144.7 (120.6-172.3)	148.5 (122.1-179.1)	*	53.3 (35.6-76.7)	386.8 (314.5-470.6)	518.4 (395.2-667.3)
Carroll County	131 (120.7-142.1)	129.9 (119.4-141.2)	140.8 (82.9-222.9)	50.1 (42.6-58.5)	345.6 (313.7-379.7)	419 (365.6-477.8)
Cecil County	119.7 (106.4-134.1)	121.7 (108-136.8)	*	42 (33-52.7)	325.2 (283.8-370.9)	387.5 (319.2-466.1)
Charles County	112.5 (101.2-124.8)	109 (95.6-123.8)	119.8 (98.3-144.6)	45.5 (37.8-54.3)	290.4 (255-329.5)	309.9 (251.1-378.3)
Dorchester County	108.7 (89.4-131.2)	111.2 (88.8-138.1)	87.6 (55.3-132.3)	35.9 (21.5-56.5)	301 (243.9-367.4)	366.9 (278-475)
Frederick County	140.7 (130.9-151)	140.5 (130.3-151.3)	127.1 (93.1-169.2)	50.1 (43.6-57.3)	380.4 (349.6-413.2)	480 (427.1-537.5)
Garrett County	128.6 (106.6-154.2)	126.3 (104.4-151.8)	*	37.8 (23-58.7)	368.5 (300.1-447.7)	453.2 (345.4-583.6)
Harford County	114 (105,9-122.6)	114.2 (105.6-123.4)	123.3 (95.7-156.1)	43.3 (37.5-49.8)	301.3 (276.2-328.1)	349.9 (305.5-395.4)
Howard County	131 (122.4-140)	138.2 (128-148.9)	117.8 (97.5-141)	51.4 (45.6-57.8)	342 (314.8-370.9)	405.8 (358-458.2)
Kent County	147 (118.3-181.2)	160.5 (127.8-199.7)	*	58.1 (34.2-92.6)	382.9 (302.7-477.5)	457.2 (337.4-605.2)
Queen Anne's County	107 (89.9-126.5)	108.7 (90.4-129.7)	*	36.2 (24.5-51.8)	294.2 (241.4-355.1)	364.5 (275.9-472.4)
Somerset County	118.9 (93.8-148.8)	114.7 (85.6-151.4)	121.7 (76.8-183.2)	*	324.8 (251.2-413)	367.3 (258.1-506.7)
St. Mary's County	111.8 (98.4-126.6)	117.5 (102.3-134.1)	77.8 (50.7-114)	41.2 (32.2-51.9)	298.9 (256.8-345.9)	323.4 (256.2-402.7)
Talbot County	145.3 (124.7-168.8)	144.5 (122.2-170.1)	149.6 (96.7-222.9)	48.3 (32-70.3)	401.9 (341.9-469.1)	438 (353.3-536.4)
Washington County	115.4 (105.1-126.5)	117.4 (106.7-128.9)	*	40.2 (32.6-49.2)	314.4 (282.9-348.3)	396.6 (346.3-452.1)
Wicomico County	130.1 (116.4-145)	132.7 (116.9-150.1)	121.8 (95.1-154.8)	45.7 (35.6-57.8)	353.4 (311.9-398.8)	367.3 (305.8-437.4)
Worcester County	140.7 (123.1-160.4)	137.3 (118.5-158.7)	116.3 (76.8-169.7)	42.6 (29.7-59.6)	399.6 (346.6-458.3)	400 (331-479)

Source: Death data provided by the National Vital Statistics System public use data file. Death rates calculated by the National Cancer Institute using SEER*Stat.

(*) Data have been suppressed to ensure confidentiality and stability of rate estimates. Counts are suppressed if fewer than 16 cases were reported in a specific area-sex-race category.

Figure 4. Age Adjusted Death Rates for Maryland, 2003-2007

	Breast, Female, All Ages			Breast, Female, All Races		
	Annual Death Rate, Deaths over 100,000 (95 percent Confidence Interval)					
	All Races	White	Black**	Ages <50	Ages 50+	Ages 65+
United States	24 (23.9-24.1)	23.4 (23.2-23.5)	32.4 (32-32.8)	5.2 (5.1-5.2)	73.2 (72.9-73.5)	105.3 (104.7-105.9
Maryland	25.8 (25-26.6)	24.2 (23.2-25.1)	31.8 (30.1-33.7)	6.2 (5.7-6.7)	77.3 (74.7-79.9)	109.9 (105.3-114.7)
County	**All Races**	**White**	**Black****	**Ages <50**	**Ages 50+**	**Ages 65+**
Allegany County	25.6 (19.8-32.8)	24.8 (19.1-32.1)	*	*	78.7 (60.5-100.7)	113.2 (83.7-149.9
Anne Arundel County	26.2 (23.5-29.1)	25.6 (22.7-28.7)	31.3 (23.2-41.3)	5.9 (4.5-7.7)	79.2 (70.3-88.9)	112.5 (96.3-130.7)
Baltimore City	30.9 (28.5-33.6)	26.9 (23.1-31.2)	33.2 (30-36.7)	8.5 (6.9-10.4)	89.6 (81.8-97.9)	123.8 (110.4-138.5)
Baltimore County	25.3 (23.4-27.4)	24.4 (22.3-26.7)	31 (25.5-37.3)	5.3 (4.2-6.6)	77.9 (71.6-84.5)	115.7 (104.6-127.6)
Calvert County	33.9 (26.4-42.8)	33.4 (25.3-43.3)	*	*	107.5 (82-138.5)	168.2 (120-229.4)
Caroline County	23.9 (15.1-36.1)	24 (14.6-37.6)	*	*	78.1 (48.1-119.7)	*
Carroll County	25.4 (21-30.5)	25.4 (20.9-30.6)	*	5.4 (3.2-8.7)	77.6 (63-94.6)	107.6 (81.9-138.8)
Cecil County	24.8 (19-31.9)	25.3 (19.3-32.7)	*	*	76.7 (57.4-100.5)	115.2 (80.2-160.5)
Charles County	29.7 (23.8-36.6)	30 (22.9-38.5)	28.5 (18.3-42.1)	7.6 (4.7-11.6)	87.8 (68.1-111.3)	125.4 (89-171.5)
Dorchester County	15.2 (8.9-24.8)	*	*	*	46 (26-75.3)	*
Frederick County	24.8 (20.8-29.4)	24.6 (20.5-29.4)	*	5 (3.1-7.6)	76.9 (63.5-92.4)	118.9 (94-148.5)
Garrett County	35.9 (24.8-50.6)	36.1 (24.9-50.9)	*	*	109.2 (73.7-155.7)	145.9 (89.9-224.1)
Harford County	24.9 (21.1-29.2)	23.7 (19.8-28.1)	39 (23.7-60)	5.4 (3.5-8)	75.9 (63.4-90.2)	107.9 (85.3-134.8)
Howard County	18.8 (15.5-22.6)	20.5 (16.6-25.2)	19.1 (11.4-29.8)	4.7 (3.1-6.9)	55.8 (44.7-68.7)	90.5 (68.8-116.9)
Kent County	24.9 (15.3-39.9)	24.5 (14.1-41.5)	*	*	90.3 (55.3-139.5)	164.1 (96.1-261)
Queen Anne's County	31.4 (22.5-42.9)	31.7 (22.1-44.3)	*	*	91.7 (63.3-128.5)	135.6 (83.9-207.2
Somerset County	33.7 (21.3-51.1)	31.1 (17.8-52.1)	*	*	86.8 (51.9-136.5)	*
St. Mary's County	24.6 (18.5-32.1)	26.4 (19.5-34.9)	*	*	74.5 (54.2-99.9)	108.7 (72.2-157.4)
Talbot County	20.1 (13.2-30)	18.6 (11.6-29.2)	*	*	58.3 (38.1-85.6)	87.9 (54.7-134.4)
Washington County	24.8 (20.2-30)	25 (20.3-30.4)	*	*	73.5 (59.2-90.2)	105.6 (81.6-134.6)
Wicomico County	28.9 (22.7-36.2)	29.5 (22.5-38.1)	28.6 (16.3-46.4)	*	81.4 (62.5-104.3)	107.7 (76.4-147.6)
Worcester County	26.8 (19.8-36)	26.1 (18.6-36.2)	*	*	88 (64.3-117.4)	97.7 (65.4-140.3)

Source: Death data provided by the National Vital Statistics System public use data file. Death rates calculated by the National Cancer Institute using SEER*Stat.

(*) Data have been suppressed to ensure confidentiality and stability of rate estimates. Counts are suppressed if fewer than 16 cases were reported in a specific area-sex-race category.

(**) Includes Hispanic.

The most recent (2003-2007) data available from the National Cancer Institute, see Figure 4, documents an age-adjusted breast cancer mortality rate of 25.8 deaths per 100,000 population in Maryland, ranking the state fifth in the nation. Although the age-adjusted breast cancer mortality rate has declined an average of 2.1 percent per year from 1991 through 2007, Maryland remains above the Healthy People 2010 goal of 22.3 deaths per 100,000 population and significantly above the rate observed nationally (24.0/100,000). Within the Affiliate service area, the highest age-adjusted breast cancer mortality rates are observed in Garrett County (35.9/100,000), Calvert County (33.9/100,000), Somerset County (33.7/100,000), Queen Anne's County (31.4 /100,000) and Baltimore City (30.9/100,000). However, because of the small populations of many of those counties, particularly Garrett, Somerset and Queen Anne's, and often a relatively low number of breast cancer deaths, the rates can be less reliable estimate.

Only Baltimore City's rate of 30.9/100,000 is reliable or statistical significant. Calvert County's age adjusted breast cancer mortality rate for White women (33.4/100,000) is also reliable. As expected from national trends, the age-adjusted breast cancer mortality rate in Maryland is higher among African American (31.8/100,000) women in comparison to that observed among White (24.2/100,000) women. This racial difference is in contrast to the previously discussed higher age-adjusted state breast cancer incidence rate documented among White women in comparison to African American women. As might be expected, statistically significant differences in mortality risk are evident based on age, with older age groups exhibiting higher age-adjusted breast cancer mortality rates in comparison to those documented younger age categories (Figure 4). The 95 percent confidence interval is also included in Figure 4 due to the fact that the rates are based on small numbers of events. The confidence intervals have an upper and lower limit in which the actual rate should fall with 95 percent confidence.

Stage of breast cancer diagnosis is another important factor to examine as the stage can impact chances of survival. Distant, or metastatic cancer, has spread to other organs of the body, usually the bones, lungs, liver or brain. At a distant stage, five-year survival rates are much lower than breast cancer found and treated at earlier stages. Metastatic breast cancer cannot be cured, only treated. One of the best strategies to fight breast cancer is to diagnoses the disease early when treatment options are good and chance of recovery is strong. According to the Maryland Cancer Registry, approximately 57.18 percent of new breast cancer cases in Maryland are diagnosed locally, 31.22 percent regionally, 5.05 percent distantly, and 6.55 percent are reported un-staged from 2003-2007. Notably, Baltimore City has one of the highest percentages of breast cancer cases diagnosed at a distant or late stage: 6.41 percent.

Communities of Interest

The Affiliate chose to focus on four communities of interest, which are profiled in detail below. A combination of factors including breast cancer mortality rates, percentage of late-stage diagnoses, screening rates and various socio-economic factors lead to the determination of the four areas. Additionally, three of the four selected communities have the largest proportion of African Americans in the service area. The state of Maryland is among the top ten states with the largest African American population. The Affiliate chose to focus on the African American population due to the breast cancer disparities faced by this population. Nationally and in Maryland, breast cancer is the most common cancer among African American women. African American women also experience disparities compared to white women: they have higher rates

of distant stage breast cancer than white women and are less likely than white women to survive five years: 77 percent vs. 90 percent respectively. (ACS, 2009-2010). The four targeted communities of interest include Baltimore City, Calvert, Charles and Somerset Counties.

Baltimore City

Baltimore is an independent city with an estimated population of 637,418 in 2009. Women make up approximately 53.4 percent of the population. Baltimore is a minority-dominated city with African Americans making up 63.2 percent of the population, Whites 33.1 percent, Hispanics 3 percent and Asians 2 percent (US Census Bureau). The city has the highest percentage of people living below the poverty level (20.1 percent), the lowest percentage of high school graduates (76.9 percent), and the largest African American population in the service area. The median household income in 2009 was $38,738 (American Community Survey).

According to the MBRFSS, about 88 percent of women in the city have access to some kind of health insurance. Among women age 50 and older, 12 percent have never had a mammogram, the fourth highest percentage in the state.

Because of the city's large African America population, it mirrors the national breast cancer trends in the African American population. The city has the lowest incidence rate of breast cancer but the fifth highest mortality rate at 30.9/100,000 (and the only statistically significant rate for all races) (Figure 3 and 4). The high proportion of African Americans may also impact the annual death rate for women under 50. It is the highest in the state at 8.5/100,000. Baltimore City has the second highest annual death rate for African American women of all ages, at 33.2/100,000 (State Cancer Profiles). The incidence rate by stage at diagnosis in Baltimore City stood out as one of the worst in the service area according to the Maryland Cancer Registry which reported 6.41 percent of cases diagnosed at a distant stage. Across the state and nation, African American women are diagnosed at Stage 4 at almost twice the rate of other women.

Calvert County

Calvert County presents something of a paradox between its demographic and breast cancer data. The population of this southern Maryland County was estimated to be 89,212 people in 2009. It is a predominantly White county (81.9 percent) with African Americans making up just 14.7 percent of the population, Hispanics 2.7 percent and Asians 1.3 percent. But the county has experienced tremendous growth since 2000. The population has increased by 19.8 percent in just nine years (US Census Bureau). The county is the second most affluent county in the service area and just 4.8 percent of the population is below the poverty line. The county population is also well educated, 91.4 percent are high school graduates and 28.5 percent have a bachelor's degree of higher (American Community Survey). Almost 93 percent of female residents have some kind health insurance coverage and almost 78 percent of women 50+ have had a mammogram in the past two years (MBRFSS). The incidence rate of breast cancer is similar to the state's rate at 122.2/100,000 but the mortality rate is cause for alarm. The age-adjusted death rate for all races is the second highest in the service area, 33.0/100,000. Calvert County's age adjusted breast cancer mortality rate for White women (33.4/100,000) is statistically significant. Calvert County also has the highest age-adjusted death rate for women over 65 years at 168.2/100,000 (Figure 4). The percentage of breast cancer cases diagnosed at a distant stage,

5.64 percent, is higher than the Maryland average and the percentage of cases diagnosed locally is the third lowest at 51.88 percent.

Charles County

Charles County is also a southern Maryland county. It is larger than Calvert County with an estimated population of 142,225 in 2009. The county has also seen a large increase in population in the past nine years with a growth of 18 percent (US Census Bureau). While Charles and Calvert are very similar in their affluence and education levels, 25.4 percent of the population has a bachelor's degree or higher and the median income is the third highest in the service area at $86,141, the biggest difference between the two counties is their ethnic makeup (American Community Survey 2005-2009). Charles County is much more diverse; 54.1 percent of the population is White, 40.1 percent is African American, 3.9 percent is Hispanic and 2.6 percent is Asian (US Census Bureau). Almost 94 percent of female residents in the county have some kind of health insurance coverage. The standout statistic for Charles County is their mammography screening rate. The county has the lowest percentage of women ages 50+ getting mammograms in the state with just 58.5 percent having had a mammogram in the past 2 years and has the highest percentage of women 50+ that have never had a mammogram at 15.4 percent (MBRFSS). The county has a death rate (29.7/100,000) well above the state rate of 25.8/100,000 (Figure 4).

Charles County also has a large and very rural area called Nanjemoy in the southwest part of the county. While just 50 miles from the nation's capital, this area has pockets of extreme poverty with some residents living in trailers without heat or running water.

Lower Eastern Shore (Somerset, Wicomico, Worcester):

Three counties make up the lower Eastern Shore region. They can naturally be grouped together as they share many resources. Somerset County is the second smallest county by population in the state with just 25,959 residents estimated in 2009, of which 46.4 percent are female.

Somerset County has the second largest percentage of African Americans in the Affiliate service area at 41.3 percent of the population. It is a poor county; the median income of $41,615 is the third lowest in the service area and 18.1 percent of the population lives below poverty (American Community Survey). Mammography screening rates are high; 74.9 percent of women ages 50+ reported having a mammogram in the past two years. The county has the lowest percentage of women, just 1.9 percent, reporting never having had a mammogram, however, this data relies on self-report which can often be unreliable as people state what they believe others want to hear (MBRFSS). Somerset has the third highest mortality rate in the state, 33.7/100,000. The percent of breast cancer cases diagnosed at a distant stage in the county has been suppressed by the Maryland Cancer Registry because of the low number. However, the county does have the lowest percentage of women diagnosed at a local stage, 51.35 percent, and a regional stage, 28.88 percent.

Somerset County is home to Smith Island, Maryland's only inhabited off-shore island in the Chesapeake Bay. People traveling to and from Smith Island can only use boats and the passenger-only ferries to the mainland. The median age on Smith Island is 50 years. About 14.4

percent of families and 22.1 percent of the population were below the poverty line, including 67.9 percent of those age 65 or over (US Census).

Wicomico County has a population of approximately 94,222. It is the most populous county on the Eastern Shore with the exception of Cecil which is the northernmost county. Wicomico is also home to Salisbury, the most populated city on the Eastern Shore. Whites make up 72.5 percent of the population, African Americans 24 percent, Hispanics 3.8 percent and Asians 1.9 percent (US Census Bureau). The median household income is $51,352, and 12.4 percent of the population lives below the poverty level (American Community Survey). Wicomico County has the second highest percentage of woman ages 50+ who have never been screened at 13.9 percent (MBRFSS) and the county ranks seventh in the service area for breast cancer death rates at 28.9/100,000 (Figure 4).

Worcester County is the last county to make up the lower Eastern Shore. It is a county synonymous with Ocean City, an ocean resort town that sees up to 345,000 people on summer weekends. The county has a population of 49,122. Whites make up most of the population at 83 percent; 14.8 percent of the population is African American, 2.8 percent Hispanic and less than 1 percent Asian (US Census Bureau). The median household income is $52,600 and 9.8 percent of the population lives below the poverty level (American Community Survey). The county ranks eighth in the service area for breast cancer death rates at 26.8/100,000 (Figure 4).

Health Systems Analysis of Target Communities

Overview of 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. While not made explicit in the continuum, awareness, education and outreach/case management can impact entry into the system as well as progress made through the continuum. The following section describes the four stages of the continuum:

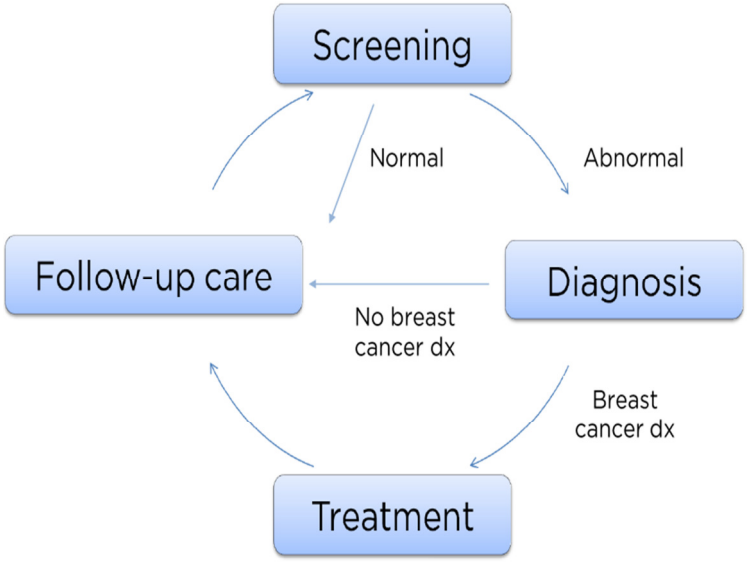


Figure 5: Breast Cancer Continuum of Care

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 three years starting at age 20 and every year starting at age 40
• Know what is normal for you and report any changes to your health care 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.

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.

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 (National Capitol Area Affiliate, Community Profile Report 2010).

Methodology
The purpose of the health systems analysis is to determine what resources and facilities currently exist in each community of interest; Baltimore City, Calvert, Charles, and Somerset Counties. The analysis also provides information about possible gaps in the community and gaps in the continuum of care that may explain low screening rates, high mortality rates or late stage diagnosis. Our analysis includes an overview of providers, programs, services and Komen Maryland relationships in the communities of interest. An inventory of providers and programs was compiled using the 2011 edition of the Affiliate *Resource Guide for Breast Health and Healing,* the Food and Drug Administration's Mammography Facility Database of MQSA certified facilities, the Health Resources and Services Administration's health center database, and responses from key informant interviews.

The Affiliate conducted interviews with 25 key providers, community leaders and breast cancer advocates in the communities of interest. Healthcare providers such as doctors, nurse navigators and BCCP coordinators were interviewed as well as support group leaders, case managers and others in the community who could help to give a comprehensive picture of the path women take through the continuum of care. The Affiliate conducted interviews with eleven key informants in Baltimore City, four each in Calvert and Charles counties and six in Somerset County. The key

informant interviews were completed over the phone using a 20-question questionnaire. Notes taken during the key informant interviews were analyzed using NVivo9 software to organize the data and identify themes. Additional data was supplied by the Maryland Breast and Cervical Cancer Detection Program (BCCP) and Komen Maryland's grant applicant and recipient database.

Overview of Target Communities

The Maryland Breast and Cervical Cancer Early Detection Program (BCCP) was cited as a community asset in all communities of interest. Started in 1992 and funded by grants from the State of Maryland and the Centers for Disease Control (CDC), BCCP provides breast and cervical cancer screening for women 40-64 years of age who are Maryland residents, uninsured or underinsured (having insurance that does not cover these services or with a high deductible), and have incomes of less than 250% of the Federal Poverty Level. In addition to an annual screening mammogram and clinical breast examination (CBE), the program will also pay for diagnostic mammograms and breast ultrasounds. Funding is available for additional diagnostic tests and treatment for breast cancer when necessary. The key to BCCP is its provision of case management for women in need of a diagnostic work-up or who have been diagnosed with breast cancer.

The BCCP in Maryland is a decentralized program. Overall program management and reporting is the responsibility of the central staff. Program coordinators are located in 22 county health departments and two hospitals (in Baltimore City and Calvert County). Enrollment, screening, re-screening, case management, follow-up and public education are the responsibility of program coordinators.

Baltimore City

Baltimore City has the unique asset of being home to multiple world renowned medical institutions. In Baltimore City alone, there are 18 hospitals and health systems. In Baltimore City, the BCCP is run from two hospitals, Harbor Hospital and Union Memorial Hospital. In addition to the BCCP, the city also has its own Baltimore City Cancer Program to pay for clinical breast exams and mammograms. In fact, Baltimore's BCCP is not at capacity and has funding to screen more women. Key informants feel that what is needed is advertising and outreach to promote the services and navigate women through the program. Baltimore also has six Federally Qualified Health Centers (FQHCs) with 33 facilities and additional nonprofit community health centers. Additionally, support services from educational outreach to support groups and financial assistance programs for breast cancer patients are abundant in the city. While Baltimore City has many economic and development issues, existing coalitions within neighborhoods, housing associations, churches and schools are open to education, resources and partnerships with health care providers.

> "There is space in my screening program [BCCP] that is not filled. There are women out there who need to be screened and don't know about us."

In Fiscal Year 2011, the Affiliate awarded 11 grants based in Baltimore City, including to the Baltimore City Cancer Program. Other programs funded included screening and outreach/navigation programs, support programs (mentoring, meal delivery and financial assistance) and clinical trial enrollment programs.

One barrier specific to completing a mammogram in Baltimore City, however, is the lack of free-standing radiology facilities. While the city has many screening facilities located in hospitals, there are no facilities located outside of hospitals. This can present a barrier for women with insurance coverage that will not cover a mammogram within a hospital due to the higher cost. Women in Maryland's Primary Adult Care (PAC) Program cannot get a mammogram in a hospital. The issue then becomes a transportation issue as women have to go outside the city to get a mammogram. Women in the BCCP can receive their mammograms in hospital facilities contracted with the program.

One current Affiliate grantee has addressed the challenge of free-standing mammogram facilities by contracting with a mobile mammography van in Pennsylvania. The van is scheduled to come to the clinic about four times a year to screen women. The women being screened feel very comfortable using the service because it is a part of the health care clinic they already trust. No mobile mammography vans are currently based in and operate in the Affiliate service area. Supporting a mobile mammography van that can be not only in Baltimore City but throughout the service area may be an opportunity to affect screening rate and help women enter the continuum of care.

Calvert County

Calvert Memorial Hospital, the only hospital in the county, recently opened its new Center for Breast Care, the first facility of its kind in Southern Maryland. The goal of the facility is to provide local women with access to an experienced team of breast health experts and the most sophisticated technology available in one comfortable and convenient location. An experienced breast care navigator has also joined the center. The BCCP in Calvert County is run by Calvert Memorial Hospital. Additionally, those in the community characterize it as a very generous and giving community.

Two accredited mammography screening facilities are located in Calvert County; one in the only hospital in the county. Both facilities are located in the city of Prince Fredrick, the centrally located county seat. While centrally located, these facilitates are not located near the northern or southern tip population clusters. The County does not have any FQHCs but it does have a non-profit organization providing access to health care services for uninsured residents, Calvert Health Care Solutions. The Affiliate has never funded a small or large grant in Calvert County until 2011.

Charles County

Charles County has two strengths in its burgeoning support programs, The Pink Ladies and Sisters at Heart. These support groups go beyond just providing groups for women diagnosed with breast cancer to talk; these groups bring awareness to the community through educational events and fundraiser and also partner with local clinics and Affiliate grantees. The groups even publish a blog of resources and events in the county. The Affiliate is just beginning to forge

relationships in Charles County. A large screening and navigation/outreach grant to a local clinic was first awarded in the county in Fiscal Year 2011.

The BCCP is run through the Charles County Health Department. There are four accredited mammography facilities in Charles County, one located in the only hospital in the county. All of the facilities are located in the central northern part of the county, which is also the most populous area of the county. Free and low-cost care is available through two clinics, Health Partners, Inc. and one FQHC, Greater Baden Medical Services.

Somerset County

While the sole hospital in the county is a small community hospital, it is cited by residents as a "trusted provider" and has recently updated to digital mammography equipment and is the only mammogram facility in the county. In Somerset County, the BCCP is run through the Health Department, which has received both large and small grants from the Affiliate. Somerset is also fortunate to have a support organization, Women Supporting Women, which provides education, support groups and mentoring. There is one FQHC, Three Lower Counties (TLC) Community Services, with two facilities in the county. The Affiliate has provided both small and large grants to the Somerset County Health Department in the past.

In Salisbury, the closest urban center to Somerset County in neighboring northern county, Wicomico, Peninsula Regional Medical Center provides comprehensive cancer diagnostic and treatment services. Additionally, the Affiliate just began funding in Fiscal Year 2011 of a Clinical Trial Enrollment grant at the medical center.

Key Informant Findings

Common groups and themes were identified by the 25 key informants across the target areas while discussing populations most in need of services and the barriers they face. Results specific to the different jurisdictions are discussed after the common themes below.

Populations in Need

- **Low income (19)**
  The low income population was consistently identified as the least likely to get screened. Nineteen respondents identified this group in their top three. Respondents pointed out that the cost of a mammogram is prohibitive for this population, and perhaps more important, that health screening was not likely to be a high priority for women who are "barely making ends meet."
- **Uninsured (17)**
  Almost equally likely to be identified as a population least likely to get screened are those who are uninsured or underinsured. In addition to the chronically low income population, respondents identified women who are recently unemployed and have lost health insurance, and those who are confused about their insurance benefits.
- **Race and Ethnicity (15)**
  Respondents identified African American and Hispanic/Latina women as the least likely to get screened. Korean women were also mentioned as a population least likely to be screened.

- **Age (11)**
  Younger women at high risk and older women were also identified as groups least likely to get recommended screening. One respondent in Somerset indicated that older women living on Smith Island don't want to leave the island. This same respondent felt that older women don't get screened because "they are caretakers and have other priorities."

Barriers to screening

The most common barriers identified included financial barriers, lack of transportation, fear, and lack of knowledge. Financial barriers and lack of transportation were identified throughout the state, but seemed to be more often mentioned in the rural counties.

- **Financial barriers (12)**
  Inability to pay for screening and lack of insurance were mentioned as barriers by many respondents, especially in the rural areas. Poverty may act in another way, creating problems (unemployment) that take precedence over preventive health care.
- **Lack of Transportation (11)**
  Eleven respondents also mentioned problems women have getting to screening facilities. Women in the city complain about the number of buses they have to take to get to the free screenings. In the rural areas, transportation problems are frequent, and when combined with a lack of facilities, may involve traveling to another county. Financial barriers can also exacerbate transportation issues through cost of gas and cost of public transportation or taxis.
- **Fear (11)**
  Fear was mentioned by eleven of the respondents as a barrier to breast cancer screening and was mentioned by respondents in all four communities of interest. The nature of the fear was often unspecified, but some respondents mentioned that it could involve fear of the pain of a mammogram, fears of the treatments and/or their side effects (e.g. fear that husbands won't accept them with a mastectomy) and of course, fear of having cancer. Because of these fears, as one respondent says, "many women don't seek care until it is too late."
- **Lack of knowledge (10)**
  Lack of knowledge included not understanding the importance of mammograms as well as lack of awareness of programs and resources available for screening. One respondent laid the blame squarely on physicians: "Most women don't get screened because doctors do not inform them."
- **Other barriers**
  Other barriers were mentioned infrequently. One respondent said that "women think that they are not at risk. In general, people don't think about prevention until a problem pops up." Two respondents stated that "culture" or "cultural beliefs" are a barrier. Finally, stigma and secrecy about medical problems was mentioned by several respondents. One person mentioned that people think "I am going to die from something anyway."

Baltimore

In addition to the gaps mentioned above, Baltimore respondents mentioned gaps in follow-up programs for survivors and services for those under 40 (that is, women who are under 40 and who have lumps or concerns are turned away). Many of the comments from Baltimore respondents related to the needs of poor populations. They highlighted the lack of financial

support for standard living expenses while women are undergoing breast health services. One respondent mentioned that women who are "stressed or strapped for time and money" do not follow through on screening recommendations. Transportation services also have gaps. For example, the "those underinsured must go to the free standing services located outside of the city."

An issue that outreach workers in FQHC settings related was the challenge in getting the medical providers to do a CBE or make a referral for a mammogram. Often the time the provider has with a patient is spent on so many other basic health issues, that breast health is not a priority. The outreach workers in various settings have begun to use text messages to remind women of their appointments and to remind them to advocate for their CBE and mammogram referral. Clinics and other community organizations expressed interest in developing that technology further.

Calvert

Every respondent in Calvert County felt that transportation was a barrier to screening and treatment. Compounding the poor transportation as a barrier to screening is the fact that there are just two radiology facilities, neither or which have evening or weekend hours. Most respondents felt resources existed in the community, but there was a lack of awareness and for those not engaged in their medical care, like the uninsured or elderly, there may be issues accessing services. Two respondents also felt that the county could benefit from a more structured collaboration between community organizations and nonprofits around breast health in the form of a community coalition.

Charles

Respondents in Charles County also identified transportation as the biggest barrier to breast health services followed by a lack of local services. For example, there are no breast surgeons or plastic surgery/reconstruction surgeons available at the one hospital in the county. One respondent felt there is a need to "put services all together in one place" to make a patient friendly "one-stop shop." Respondents also expressed concern for the very rural, poor and desolate community in the Nanjemoy area. The African American women in that community were specifically singled out as at risk, without insurance, money, or facilities nearby.

> "Transportation; there is no public transportation system."

Somerset

Respondents in Somerset County identified the lack of outreach in rural areas as a gap in services. Education is needed to "make clear to people what services are covered by free programs." One respondent also identified the need to educate men, "Men need to be educated about the need for screening. Some men tell their wives that they don't need to be screened." The other barrier to screening and care is the lack of services in the county. While the local hospital is trusted in the community, it does not have medical oncologists or radiology therapy available.

"There is a need for a good physician who is well versed in various methods of treatment. Insured women with breast cancer and transportation choose to go to Salisbury or Baltimore for treatment because of the lack of choices here."

The one screening facility does not have evening or weekend hours. Women who are diagnosed with breast cancer often end up traveling out of county for treatment. Lack of funding for screening of symptomatic or high risk women under 40 was also mentioned, as well as "funding for the 'working poor' who make too much money to qualify for government programs, but can't afford to pay for individual insurance."

Almost all respondents from Somerset County said that one of the reasons women came in for mammograms was because they were already symptomatic. "Some patients feel that providers pressure them to schedule appointments for mammograms. They schedule the appointments to 'get the providers off their backs,' but have no intention of going for their appointment."
Similar to Baltimore, Somerset County respondents discussed how poverty interferes with screening programs. "Poverty prevents some residents from getting care – they have other priorities."

Legislative Issues in Target Communities
Few specific legislative issues were revealed in the target communities. There may be opportunities to work with Maryland's Primary Adult Care (PAC) Program, administered through the Department of Mental Health and Hygiene, to mandate behaviors around breast cancer screening. While the BCCP is fortunate to receive funding from both the Centers for Disease Control and Prevention (CDC) and State of Maryland, the Affiliate does supplement local BCCP with both large and small grants to fund outreach workers and case managers and to cover costs of CBEs and mammograms. The Affiliate must remain engaged in the advocacy efforts to ensure that funding for BCCP continues.

Maryland is fortunate to also have the Breast and Cervical Cancer Diagnosis and Treatment Program (BCCDTP), a state-funded program unique to Maryland. It pays for a diagnostic work-up and treatment for Maryland residents who have received a positive screening result for breast (and cervical) cancer. Entrance into this program is not age-dependent, unlike BCCP screening. Applicants (male or female) must be Maryland residents, prove medical need, meet income guidelines (250% of the federal poverty level) and be uninsured or underinsured. This program is in addition to the federal Breast Cancer, Prevention, and Treatment Act which provides full Medical Assistance during the period that women are undergoing treatment. In Maryland the Medical Assistance program is known as the Women's Breast and Cervical Cancer Health Program (WBCCHP). BCCP patients who are not eligible for the WBCCHP can have their treatment paid by the Maryland Breast and Cervical Cancer Diagnosis and Treatment Program. This is a vital program and one the Affiliate must also be vigilant in supporting.

Conclusions
The health systems analysis and discussions with key informants revealed a number of key issues across each community of interest and some issues unique to each area. Across the communities of interest, the same groups of people were identified as most at-risk: low-income, uninsured, African American women and women under the age of 40 or over the age or 65. Key informants in all target areas also identified the same barriers for women in accessing the continuum of care: lack of finances, lack transportation, fear and a lack of knowledge. Lack of knowledge covers a range of issues including, a lack of knowledge of breast cancer risks, screening recommendations and resources in the community. Oftentimes, providers were put at fault for not preforming or referring women to needed screenings. But many women do not know about the availability of free screening services.

The rural communities in Calvert, Charles and Somerset Counties lack choices in breast screening facilities. However, each county has at least one mammography site for collaboration. There is also a clear need for transportation services in the three rural counties for both screening services and for women in treatment. There are opportunities to address these issues together to make it easier for women to access screening facilities. Paradoxically, in Baltimore City, an area filled with medical resources, many women still do not access screening services. While transportation was cited as one issue, a larger issue exists within the State Primary Adult Care (PAC) Program and other health insurance providers which do not cover mammograms performed in hospitals. Therefore, women have to go outside of the city to free-standing facilities which can cause transportation difficulties for many women.

Unique to Calvert and Charles Counties is the great increase in their populations, almost 20 percent, in the past nine years. The effects of this growth can be seen reflected in the health systems analysis. Each county has issues with public transportation, a lack of screening facilities, and limited treatment options. There is a possibility that the infrastructures of each county still need to catch up to the tremendous growth in population.

Additionally, the main barriers to screening and entering the continuum of care; financial, transportation, fear and lack of knowledge are a concern because each is a barrier by itself, but also compounds the others. Women without financial means may also be thwarted by transportation issues. Women who are fearful of screening or cancer may use other barriers as excuses not to get screened. Conversely, if a woman does enter the continuum of care and go to a physician, but that physician does not refer her to a mammogram and the woman does not know the rights under her coverage, the end result is a woman who is not screened. Therefore, it is important to address all of these barriers simultaneously rather than one at a time.

Breast Cancer Perspectives in the Target Communities

Methodology
In order to gain the full perspective of each community of interest the Affiliate spoke with women in each community of interest. Their perspective helped to reinforce the conclusions drawn from the health systems analysis and speaking with healthcare providers. The Affiliate planned to conduct focus groups in each target areas and utilized various means of advertising

and outreach through local health departments, grant partners, clinics, local papers and city email lists. However, due to lack of registration, focus groups were canceled in Calvert, Charles and Somerset Counties. Instead, the Affiliate conducted five key informant interviews with non-medical community members and/or survivors in each of these three communities. Notes taken during the key informant interviews were analyzed using NVivo9 software to organize the data and identify themes. The lack of respondents for these areas is a weakness in the data presented and also indicates the need for a stronger Affiliate presence and partnering in these areas.

In Baltimore City the focus group took place on Thursday, December 9 in the Cherry Hill neighborhood. The Affiliate utilized various means of advertising and outreach through local health departments, grant partners, clinics, local papers and city email lists. Seven women participated in the focus group: six African Americans, one Hispanic, two survivors. The average age of the group was 47.5. Light refreshments were provided to the group and participants received $15 in grocery and Subway gift cards. The Baltimore City focus group was facilitated by a trained focus group consultant. The group proceedings were recorded and two Community Profile team members took notes. The recording was then analyzed using NVivo9 software.

Review of Qualitative Findings

Common themes specific to awareness and outreach, screening and treatment barriers were identified by the five key informants and the Baltimore City focus group participants that span across the target areas. Results specific to each jurisdiction are discussed after the common themes below.

Awareness and Outreach

Advertising was mentioned by key informants and focus group participants in all communities of interest as an important way that women learn about breast cancer screening. Specifically mentioned were TV media/news, brochures, neighborhood door hangers, billboards, bus advertisements, and subway advertisements (in Baltimore). Breast cancer awareness month was also mentioned as a way to get women's attention but respondents felt there was a need to increase public education and continue to keep women informed throughout the year, not just in October. Hospital advertising was also mentioned as a way women learned about screening and resources.

The internet was not seen as a source of information about screening. One woman said, "Most of our population does not have internet access." Another said, "Even if the information is available many do not access it."

The church community was identified as a partner for education and outreach in each community of interest and was specifically mentioned as a good means to reach the African American community. One respondent in Baltimore City made sure to note that not only mega-churches should be targeted for outreach and education, but also the small community churches.

Screening

The key informants and focus group participants felt that where women go for breast cancer screening depends on whether they are insured, underinsured or uninsured. For insured women, local hospital radiology programs and private radiology facilities were most often mentioned.

Health departments and community health centers were frequently mentioned as places uninsured and underinsured women got for screening.

When asked what kinds of things encourage women to get mammograms, the most common responses were that having a close friend or family member diagnosed spurs women to have mammograms. Also, if there is support for mammography among family, friends and peers, then women are more likely to get a mammogram annually. Family members can be a motivation for screening according to one respondent, "[s]ome women do it for their children." Unfortunately, respondents also noted that many women go to get a mammogram only once they have symptoms.

Things like health insurance coverage for mammography, free mammograms, or financial incentives (coupon for discounted mammogram) were mentioned frequently as ways to ensure women complete their mammogram. Being reminded by physicians was also frequently mentioned. Some respondents mentioned that mammography facilities send out annual reminders. One woman said, "Women will go for exams when providers treat them with respect."

Barriers to Treatment

The most frequently mentioned barriers to treatment mirrored the same barriers for entering the continuum of care: financial difficulties and transportation needs.

- **Financial**
  Financial strain created by the cost of treatment and everyday household expenses (meals, childcare) was mentioned. The possibility of losing her job, inability to pay, high out of pocket expenses, lack of insurance, and high deductibles and copays are all factor in treatment barriers. Programs that help with financial burdens were the most popular suggestions. It was suggested that programs should provide financial support for women receiving care by helping to pay other household bills. It was also suggested that there needs to be help in understanding insurance and gaps in insurance coverage.
  One respondent mentioned that the Maryland Breast and Cervical Cancer Diagnosis and Treatment Program has a very difficult application. The time it takes to enroll a patient can take two or three weeks to find out if they are enrolled. This is difficult when a patient needs an urgent biopsy. If a woman's application is denied she must the find a different route to pay for care.
- **Lack of transportation**
  The difficulty getting to appointments during the day, "distance to the care facility", and difficult bus schedules are barriers for those in living in Baltimore. It was also mentioned that "older women need support getting to and from appointments." Outside of Baltimore the distance to treatment facilities is a barrier.
- **Emotional**
  Women who are undergoing treatment experience fear about the side effects of treatment, shock, and confusion about treatment. One respondent mentioned that "women don't share experiences." Another noted that they need support services because some patients may be diagnosed with multiple diagnoses that can lead to mental health issues. Respondents believe that survivor programs should be available to allow survivors to share their stories. One respondent also mentioned that "families need assistance through

the whole process from the providers from the providers but are not getting it."

- **Other barriers**
  Other barriers to treatment included adverse treatment effects, cultural and language issues, including problems for those without government issued identification, and lack of a navigator. Competing demands on their time, fatalism, lack of choice in local providers and lack of collaboration between physicians were also mentioned as potential barriers.

Making Things Easier

A number of suggestions dealt with ways that the process of getting treatment could be made easier for women. For example, things like:

- Hospital Navigator to explain the treatment options and process.
- Combine services for those who travel out of their county for treatment "One-stop-shop"
- Longer office hours (weekend and evening)
- Providing childcare
- More specialized physicians/surgeons

Baltimore

The focus group participants felt strongly that the recommendations for breast cancer screening were confusing. One woman said, "They change it all the time." The group also agreed with the key informants that lack of insurance was the number one reason women did not get screened.

> "[Health insurance] is the main thing…that's really huge. You can't get good care without health insurance."

Women in the focus group also shared barriers encountered in the PAC program. One woman's PAC provider did not give her a referral for a mammogram. She had previously gotten mammograms through BCCP which provided her with case management. When she switched to PAC and her provider never mentioned mammograms she just assumed it wasn't covered for her anymore (mammograms are covered through the program). The group also spent a fair amount of time discussing reminders and reminder systems. Some women in the group had never gotten reminders for annual mammograms and did not know that issuance companies and doctors sent annual mammogram reminders. The women who received reminders and the rest of the group felt this would be very beneficial. Combined with a discussion on how to reach out and educate younger women, the focus group participants also suggested new ways to reach out, even using cellphones and twitter. The group was interested in a cell phone application that could serve as education and reminders for mammograms.

One respondent said, "Needs of the low-income population are not always medical (gas cards, toll fees, energy/bill assistance, dental assistance) such as practical needs that go along with being poor that are still unmet when diagnosed with cancer. There are many social gaps and physical needs that remain unmet."

Charles

A respondent from Charles County said, "There are not too many educational programs in this area. The program we host each year (open to the public) is one of the only ones in Charles County. We are lacking in this area." Additionally, respondents agreed with the health systems analysis in identifying transportation as one of the biggest barriers in Charles County. Women in treatment had a difficult time getting to all their appointments. "We live in such a rural area and the bus timetable is not easy."

Somerset

Respondents from Somerset County also agreed with the health systems analysis that there is a lack of services for women needing breast cancer treatment. "There is no medical oncologist or radiation therapy available in Somerset County. Patients must travel to Salisbury for these services." Respondents also noted that there was a need to increase public education, especially in the churches. "Need outreach workers from the community so the community will trust them."

Conclusions

Greater awareness and outreach as well as facilitation of screenings, whether through discount coupons or reminders from providers, were two of the main themes identified from the target communities. In rural areas, transportation was also identified as a need and barrier to screening and treatment.

Outreach and education needs to occur earlier for women and in settings that are comfortable for them (e.g. church groups) and the community needs to be made aware of the state resources for screening and treatment. Especially in the African American community, churches could be a strong partner for the Affiliate to reach women. It is also vital that outreach workers be from the communities of need. Women in the communities also felt that media campaigns and advertising may be useful throughout the year to keep breast cancer screening in people's minds. There continues to be confusion about screening recommendations for women. Respondents relied on their providers to know the recommendations and refer women to screening programs.

Conclusions: What We Learned, What We Will Do

Review of the Findings

A review of demographic and breast cancer data revealed that the Affiliate's service area overall is suffering acutely from the impact of breast cancer, especially with regard to death rates. There are many areas and populations in the state disproportionately affected by breast cancer. The Affiliate chose four counties and regions in Maryland as current targeted communities of interest due to a combination of factors including, annual death rates above the state rate, percentage of late-stage diagnoses, screening rates, and proportion of minority populations and those living below poverty. The four targeted communities of interest include Baltimore City, Calvert, Charles and Somerset Counties.

Further exploration of the four communities of interest was done through analysis of the local health systems and discussions with key informants to find gaps in the continuum of care for

breast cancer. This data revealed similar issues across the targeted communities including a lack of providers and screening facilities or issues in accessing those resources, lack of transportation for screening and treatment, and a lack of action on the part of providers to remind women or refer them for mammograms. The Affiliate gathered further exploratory data from the targeted areas by speaking with women in the communities. These discussions highlighted a need for education, outreach, and facilitation of screening for the most vulnerable populations of low income, uninsured and minority women, especially African American women.

Baltimore City continues to be a target area and was specifically chosen due to the combination of a high breast cancer mortality rate (30.9/100,000), the high percentage of late stage diagnosis and the high proportion of vulnerable populations in the community, including African Americans (63.2 percent of the population) and those living below poverty (20.1 percent). While the City has many medical facilities and resources available, low-income women without insurance or who use the State's Primary Adult Care Program face specific challenges in entering the continuum of care in order to access screening and therefore any necessary diagnosis, treatment or follow-up care. In addition to lack of referrals from providers for mammograms, these women faced barriers relating to transportation in the city and to available screening facilities. In discussions with women in Baltimore City, they highlighted the need for more awareness and education about breast cancer risks, screening recommendations and how to access services. Women recommended using the churches for outreach and education as well as making use of mass media, advertising and social media.

Calvert County is a new target area and was chosen primarily because of its high breast cancer mortality rate (33.9/100,000) and the high rates specifically among white women and women age 65 and older. The county presents a paradox when looking at the demographic data. The county does not have a high proportion of vulnerable populations that we might expect to contribute to high mortality rates, such as those living in poverty, those with low-levels of education or minority populations. In examining the stage of diagnosis for breast cancer cases in the area it was found that 5.64 percent of cases were diagnosed at a distance stage and only 51.88 percent of cases were diagnosed at a local stage. There is room for improvement to diagnosis breast cancer earlier when treatment outcomes are likely to be better.

Through further investigation into the area and in speaking with local providers, it was found that only two screening facilities exist in a county that has seen a tremendous population growth of almost 20 percent in the past nine years. The one hospital in the county opened a breast center in 2010 and a breast care navigator is now on staff. Most women in the community seems to be accessing the continuum of care as almost 93 percent have access to some kind of health insurance and almost 78 percent report having had a mammogram in the past two years. Key informants in the community felt that it may be the small pockets of uninsured as well as the elderly who are facing challenges in getting screening and accessing care. Additionally, key informants felt that transportation and the location and hours of the available screening facilities was a barrier to women getting mammograms. The Affiliate does not have a strong presence in the county and until 2011 has never funded a small or large grant in the area. There are opportunities to form collaborations with the new breast center in the area and support the growing community in ensuring mammograms and facilities are easily accessible.

Charles County continues to be a target area. Since the 2009 Community Profile report, the county has shown improvement in their breast cancer mortality rate. It dropped from 35.0/100,000 for 2001-2005 to a rate of 29.7/100,000 for 2003-2007. However, there are still reasons for concern in the area. The African American population, which traditionally faces breast cancer disparities, continues to grow and now makes up 40.1 percent of the county population. Additionally, the county has the worst screening rates in the Affiliate service area. Only 58.5 percent of women ages 50 and older report having had a mammogram in the past two years and 15.4 percent report they have never had a mammogram. These low screening rates could influence the breast cancer incidence and mortality rates in the county. If women are not being screened they are also not being diagnosed. Additionally, In the southwest part of the county there is an area of extreme poverty and local key informants identified women in this area as high-risk for not entering the continuum of care.

Like Calvert County, Charles has also seen tremendous growth in its population, about 18 percent, in the past nine years. The county has just one hospital and four screening facilities. Key informants in the community identified transportation as the biggest barrier for women in accessing the continuum of care. Additionally, they felt that a lack a facilities and providers impacted women getting screening and treatment. Key informants agreed that many women go out of county for breast cancer treatment and there is a need for improved care and a "one-stop-shop" facility for treatment. The key informants also felt that African American women without health insurance were the most vulnerable members of the community and needed specific outreach and education efforts.

Lastly, Somerset County was again chosen as a target area. The breast cancer mortality rate in this county also fell since the last Community Profile report. Data for 2001-2005 showed a rate of 40.0/100,000 and in 2003-2007, the rate was 33.7/100,000. Because the population of Somerset County is so small, just 25,959 people, the rates can vary greatly and may not be reliable. However, the county has many populations that are considered at-risk for breast cancer; 41.3 percent of the population is African American, 18.1 percent of the population lives below poverty. The health systems analysis found that there is just one hospital which houses the one screening facility in the county. Providers related alarming anecdotal information about most women only coming in to get a mammogram once they feel a lump. Just over 50 percent of cases are diagnosed at a local stage, so there is room to increase the rate of early stage diagnosis for better outcomes. If diagnosed, women travel out of the county for treatment, which presents additional barriers. The local key informants the Affiliate spoke with identified outreach and education as the most important needs in conjunction with easier access to the screening facility. The key informants felt it was vital to have trusted, local women in the community to educate and raise awareness.

Conclusions

The data gathered identified specific gaps in the continuum of care in each targeted community and also presented numerous opportunities to improve breast cancer awareness and screening rates. For example, at least one screening facility is present in each targeted area. The challenge is how to raise awareness and educate women about screening and also to make use of existing facilities to increase screening rates. Transportation was cited as a barrier across each area in addition to the limited access to and hours of the screening facilities. Many women are either

eligible for the state's BCCP or have access to PAC to cover annual screening mammograms, but the challenge is making women and their providers aware of coverage for mammograms and then facilitating those annual screenings. Furthermore, there are many opportunities to expand the Affiliate's presence and funding in the targeted communities, both the geographical targeted areas and in the African American communities in those areas and throughout the service area.

Priorities and Action Plan

After completing analysis of the data the Community Profile Team brainstormed the best ways for the Affiliate to address the problems identified. From this list, the team then organized the ideas into larger priority areas and narrowed the focus. With additional input from the Affiliate staff, the final proposed priorities and objectives were presented to the Board of Directors.

The Affiliate will continue to fund and support proven grant programs and outreach events. For example, the use of population specific outreach workers to provide case management services in conjunction with BCCP is a model in use by three county health departments. One county grant program shows that in nine years the diversity represented in BCCP clients almost tripled. The outreach workers have gained access and trust in these specific communities and help women navigate the health care system and also provide translation services. The priorities and objectives in the following action plan do not exclude other models and best practices, rather the action plan in a way to move beyond what we know works. The action plan will influence the Affiliate's strategic plan, fiscal year (FY) 2013 and 2014 grant funding priorities and other mission and non-mission efforts.

Priority 1: Support policy and system changes to increase annual screening rates across the affiliate service area.

Objective 1: By end of 2012, meet with the State Primary Adult Care Program and Medical Assistance Program to identify ways to collaborate to ensure providers complete clinical breast exams and make appropriate referrals for annual mammograms. Develop a timeline for implementing identified means and estimate amount of funding support need from Affiliate and/or other sources for development of systems.

Objective 2: In 2012 investigate use of mobile/e-health applications for mammogram reminder system. By August 2012, incorporate funding for mobile/e-health direct to consumer/patient reminder systems to be used across medical institutions into FY 2014 large grant request for applications (RFA).

Priority 2: Support expanded screening and facilitation of screening especially in each community of interest; Baltimore City, Calvert, Charles and Somerset Counties.

Objective 1: Incorporate funding for patient transportation to and from screenings in outlying areas (through model of mammogram day/group transport) into FY 2013 and 2014 large grant RFA.

Objective 2: Incorporate funding for extended evening/weekend screening hours into the FY 2013 and 2014 large grant RFA.

Objective 3: Incorporate funding for mammography vans in Affiliate service area into the FY 2013 and 2014 large grant RFA.

Priority 3: To address disparities, increase small and large grant funding to African American community organizations for awareness, outreach and screening programs in Baltimore City, Calvert, Charles and Somerset Counties.

Objective 1: In 2012 and 2013 conduct one intensive grant writing workshops in each of four communities of interest, targeting the faith-based community (coalition of African American ministers, county ministerial alliances, parish nurses) and other African American community groups.

Objective 2: In 2012 and 2013 partner with academic and non-profit institutions to provide additional technical assistance to potential and current grantees. (For example, student grant writing classes partner with community organizations).

Priority 4: Support development of breast cancer coalitions in Southern Maryland (Calvert and Charles County specifically) and Baltimore City.

Objective 1: Incorporate funding for development of coalitions in Southern Maryland and Baltimore City into the FY 2012 and 2013 small grant RFA.

Objective 2: Staff will publicize the development of coalitions and available funding in Southern Maryland and Baltimore City and provide technical support in the form of best practices/models, presence at meetings, and consultation.

The Community Profile report presents an overview of the state of breast cancer in the 22 jurisdiction service area of the Komen Maryland and highlights four regions as targeted communities. Each jurisdiction in the service area faces its own unique challenges in providing breast health care for its residents and supporting those diagnosed with breast cancer; each community also has its own strengths and success stories. The four areas selected as priority target areas do not overshadow the needs in other areas. As a leader in the field of breast cancer and as a grantmaker the Affiliate has a responsibility to strategically focus our efforts and resources on addressing the greatest needs, building meaningful partnerships in the community, and supporting best practice models that will improve the state of breast cancer across our service area and the state of Maryland.

References

American Cancer Society. *Cancer Facts & Figures 2011*. Atlanta, GA: American Cancer Society; 2010. [Data file]. Retrieved from http://www.cancer.org/Research/CancerFactsFigures/CancerFactsFigures/cancer-facts-figures-2011

American Cancer Society. *Cancer Facts & Figures for African Americans 2009-2010*. Atlanta, GA: American Cancer Society; 2009 [Data file]. Retrieved from http://www.cancer.org/Research/CancerFactsFigures/cancer-facts-figures-for-african-americans-2009-2010

Kirkland, Deb, Mayers, Corinne and McCoy, Rebecca (Eds.). (2011). Resource Guide for Breast Health and Healing. Baltimore, MD.

Maryland Behavioral Risk Factor Surveillance Survey (2008 and 2009) [Data File]. Baltimore, MD. The Office of Health Policy and Planning, Family Health Administration. Department of Health and Mental Hygiene. Retrieved from http://www.marylandbrfss.org/cgi-bin/broker.exe

Maryland Cancer Register, Breast Cancer Incidence Data (2003-2007) [Data file]. Baltimore, MD. Maryland Cancer Registry, Center for Cancer Surveillance and Control. Department of Health and Mental Hygiene.

Susan G. Komen for the Cure, National Capitol Area Affiliate, Community Profile Report 2010.

State Cancer Profiles – Breast Cancer Mortality Data (2003-2007) [Data File]. Hyattsville, MD: National Center for Health Statistics, National Vital Statistics System. Retrieved from http://statecancerprofiles.cancer.gov/

US Census Bureau, 2007-2009 American Community Survey [Data file]. Washington, DC: US Census Bureau. Retrieved from http://factfinder.census.gov/servlet/GRTTable?_bm=y&-_box_head_nbr=R1901&-ds_name=ACS_2007_1YR_G00_&-_lang=en&-format=US-30&-CONTEXT=grt

U.S Census Bureau. US Census Bureau: State and County QuickFacts. Maryland and Maryland Counties. Retrieved from http://quickfacts.census.gov/qfd/states/24000.html