COMMUNITY PROFILE REPORT

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Executive Summary

2011

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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.

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.