COMMUNITY PROFILE REPORT

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2011

Acknowledgments

The Community Profile is the product of a lengthy and arduous process which represents the heart of our mission. As a collaborative, community process, the Community Profile's success is dependent upon the contributions of many people. If you are not mentioned in our acknowledgements, we extend a sincere apology and express our deep appreciation for all your help in the creation of this valuable document.

The North Jersey Community Profile Team expresses its gratitude to all of the individuals who so generously contributed their insights, time and talents to complete this report. We acknowledge the many medical providers, community leaders and breast cancer survivors from our service area who shared their experiences and perspectives on breast health programs and services throughout their respective communities.

We extend our thanks to Dr. Candido Africa III and Margaret Rojewski who provided essential information regarding NJCEED as well as key statistics on the number of women screened at NJCEED sites in the Affiliate's service area. We also thank Peter Costa for his contributions to our asset mapping process.

Thank you to Kiameesha R. Evans, Dr. Patricia H. Virga, and Sharon Smith for their guidance, with regard to finding appropriate resources from which we could obtain relevant breast cancer information and statistics. Thank you to Stasia Burger for helping us navigate the New Jersey Cancer Registry site for breast cancer incidence and mortality rate data. We extend a special thanks to Xiaoling Niu, who compiled stage of diagnosis and survival rate data for the Affiliate. Thank you to Kenneth O'Dowd for providing the Affiliate with screening rate data. And thanks to Susan Goodin for her feedback on preliminary quantitative data collection, organization, and analysis.

The Affiliate is especially grateful for the direction of Dr. Stanley Weiss with regard to quantitative data organization and analysis. In addition, the Affiliate is thankful for the advice and edits offered by Dr. Shawna Hudson with regard to qualitative data collection and analysis.

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March 2011

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Executive Summary

Affiliate History

Susan G. Komen for the Cure® North Jersey Affiliate was founded in 1997 on a promise to a ten-year-old girl who lost her mother to breast cancer. Its mission is to save lives and end breast cancer by empowering people, ensuring quality of care for all and energizing science to find the cures. Since its inception, the Affiliate has invested $17.7 million in mission services: $12.2 million has been dedicated to Community Grants in the service Area and $5.5 million has been directed to Susan G. Komen for the Cure® Grants Program at a national level. From 1998 through 2007, the primary source of revenue for the Affiliate was the annual Pink Tie Ball. The Affiliate held its first Race for the Cure in 2008. The Komen North Jersey Affiliate service area is defined as the nine counties of Bergen, Essex, Hudson, Morris, Passaic, Somerset, Sussex, Union and Warren.

Community Profile Objectives

The objectives of the Community Profile are to complete a statistical profile of breast cancer incidence and mortality, population demographics and behavioral breast health factors for the service area; to evaluate the range and effectiveness of available services for women with breast cancer, their families, friends and associates including programs involving the Affiliate; to evaluate community prevention and education needs for targeted populations; and, to formulate conclusions and recommendations for targeted initiatives as well as to position the organization for maximum effectiveness.

Breast Cancer Impact in Affiliate Service Area: Methodology

Data was collected for the Affiliate's service area regarding demographics, screening rates, incidence and mortality rates, stage of diagnosis and five-year survival rates. To determine target communities, 'red flags' were assigned to counties with demographic or breast cancer statistics that reflected a need in the community. The counties with the most 'red flags' were designated as target communities.

Essex County, Hudson County, Passaic County, and Sussex County were recognized as target communities based on the outstanding demographic and breast cancer statistics in these areas. Black females were also designated as a target group because of concerning breast cancer statistics among this population. Essex County, Hudson County, and Passaic County are characterized by lower than state average median income, higher than state average percentage of people living under the poverty level, higher than state average percentage of uninsured females, and higher than state average percentage of unemployed people. Essex County, Hudson County, and Passaic County also stand out as areas that have low education attainment levels. Specifically, these communities have higher than state average percentages of people that have

not completed lower levels of education and lower than state average percentages of people that have not completed higher levels of education.

With regard to breast cancer statistics, Hudson County has the highest percentage of women over the age of 40 that have not received a mammogram within the last 12 months. Among all races of females, Essex County, Passaic County, and Sussex County have high five year average mortality rates compared to the state five year average mortality rate. Among White populations of females, Passaic County and Sussex County have high five year average mortality rates compared to the state five year average mortality rate. Among Black populations of females, Passaic County has a high five year average mortality rate compared to the state five year average mortality rate. In general, Black female populations have higher mortality rates than White female populations. Black female populations are also characterized by higher percentages of late stage diagnoses compared to White and Asian Pacific Islander female populations. Black female populations also have lower five year survival rates compared to White and Asian Pacific Islander female populations.

Identification of the Target Communities

There are four communities of interest designated by the Affiliate as target communities due to outstanding statistics and trends with regard to socioeconomic factors, education attainment, screening, mortality, stage of diagnosis, and survival. These target communities include Essex, Hudson, Passaic, and Sussex Counties. Specifically, densely populated urban centers within these communities strongly influence the data and become targets within the targets. These cities include Newark and East Orange (in Essex County), Jersey City (in Hudson County), and Passaic and Paterson (in Passaic County) (American Community Survey Five-Year Estimates, 2005-2009). In addition, the Affiliate defined Black females as a target group because of high mortality, high percentage of late-stage diagnoses, and low survival among this population of women.

Health Systems Analysis of Target Communities: Methodology

Once the target communities were identified, medical and community resources in each of these areas were pinpointed. These resources were recognized as the community assets and were defined as sites where insured and uninsured women receive breast health screenings and can proceed through the continuum of care, whether or not a breast cancer diagnosis is made. Community assets also included Affiliate Grantees. An asset mapping specialist plotted the community assets in order to best visualize the breast health services available in each of these areas. Community assets were organized into the following categories: hospital, free standing mammography site, NJCEED site, mobile mammography site, and Grantee.

Health Systems Analysis of Target Communities: Gaps and Barriers

NJCEED provides screening and treatment to those without insurance in the target communities – providing over 6,200 mammograms in the four target communities in 2010. While NJCEED only screened an average of 7.1 percent of eligible women in 2010, the opportunity for more screenings exists. It is critical that funding for this program continue on a federal and state level,

and the Affiliate has recognized the role it has now and can have in the near future to advocate for this program.

From surveys and interviews completed by many medical providers, community leaders, and breast cancer survivors, five major themes emerged. These themes outline major gaps and barriers to the continuum of care in the service area, especially in the target communities. These five themes include 1) underserved groups, 2) lack of financial resources or insurance, 3) lack of education in the community, 4) lack of education among doctors, and 5) importance of community and faith-based organizations. The underserved continue to struggle in accessing breast health care. Specifically, ethnic minority groups, uninsured women, low income women, less educated women, unemployed women and undocumented women are at risk of not receiving proper breast health care. These results are consistent with those obtained from quantitative data analysis. Lack of financial resources or insurance is a huge barrier for women and largely prevents them from seeking breast health services. However, even before the issue of finances is raised, women do not understand the importance of maintaining proper breast health and following up with a breast cancer diagnosis. This is the result of a lack of education regarding breast health among women.

For many of the underserved groups of women seeking breast health services in the target communities, medical doctors play an important role in guiding them to resources such as financial assistance programs and support services. For this reason, doctors need to be knowledgeable about these resources or prepared to direct patients to someone who is knowledgeable. Finally, it is important for the Affiliate to reach out to representatives of community and faith-based organizations in order to better understand the communities of women which it is serving.

From the major themes, it is evident that the Affiliate can develop partnerships with community and faith-based organizations, cancer coalitions, county roundtables, and local medical facilities in order to develop a better understanding of the target communities and how to best serve them. Though there are already some partnerships in existence, including the Hudson County Breast Health Roundtable (See Priority III) and the Sussex County Breast Health Project (See Priority III), the creation of similar groups would benefit Essex County and Passaic County. One of the challenges long faced by the Affiliate has been reaching ethnic minority groups of women, especially Black females. It is the Affiliate's hope that stronger ties with community- and faith-based organizations will facilitate a more open dialogue with this population about breast health education and about gaps and barriers faced in accessing breast health care.

Breast Cancer Perspectives in the Target Communities: Methodology

Qualitative data was collected through online and written surveys and key informant interviews. Online surveys were administered through SurveyMonkey to medical providers and survivors. Fourteen medical providers and 205 survivors completed the online surveys. Written surveys were distributed to medical providers, community leaders, and survivors from the four target communities. Five medical providers, 41 community leaders, and 14 survivors completed the written surveys. The key informant interviews were the centerpiece of the qualitative data collection process with fourteen medical providers and seven community leaders interviewed.

Breast Cancer Perspectives: Overview of Target Communities Findings

The groups of women that continue to be identified as those most in need of breast health programs and services included ethnic minority groups, uninsured women, low income women, less educated women, unemployed women and undocumented women. Lack of financial resources or insurance is a major barrier to healthcare within the target communities. From medical provider, community leader, and survivor responses, it is evident that there is a lack of breast health education in the community. Women are not aware of the importance of maintaining proper breast health and of obtaining regular breast health screenings. Then, if diagnosed with breast cancer, patients do not understand the severity of a breast cancer diagnosis and the need to take action in receiving treatment. There seems to be a gap in the doctor-patient relationship with regard to communication. One consistent theme was the importance of faith-based and community organizations in the target communities and the need to reach women through these vehicles.

Conclusions: What We Learned, What We Will Do

Breast cancer is expensive. From diagnosis to treatment to support services for the uninsured and underserved, the number one barrier is 'lack of financial resources'. The goal is both to provide resources and/or support for services in the community that address this need. Breast cancer information and resources are complicated. Even when services exist they are difficult to learn about. The goal is to increase paid treatment resources for breast cancer patients, with a focus on the target communities, as well as increase the awareness of and access to resources for those that need them the most. Breast cancer is treatable when diagnosed and treated in the early stages. Yet, thousands of women, insured and uninsured, over the age of 40 do not get an annual mammogram. Education about the importance of mammography and good breast health is critical to moving forward. The Affiliate has the opportunity to build capacity in the form of volunteers and collaborations to address the needs identified in the entire Community Profile process.

Affiliate Priorities and Action Plan

Priority I: Increase the capacity of breast cancer resources for those uninsured, underinsured and underserved, both through building capacity and by making information about resources more accessible.

Goal: NJCEED provides low-income, uninsured and underinsured women with free breast cancer screenings. The Affiliate's goal is to advocate for flat and/or increased funding for the NJCEED Program and ensure that women in need of screenings have continued access to and information about the Program.

Goal: The Affiliate's goal is to continue supporting local community partners and resources to help build capacity of programs and services which address the screening and treatment needs of the uninsured, underinsured and underserved.

Priority II: Increase the education of women regarding the importance of mammography and breast self awareness

Goal: The Affiliate's goal is to partner with community-based outreach/health organizations to effectively promote awareness of breast health.

Priority III: To build upon the success of the work done through the 2009 Komen North Jersey Community Profile, specifically addressing the ongoing needs of the target communities of the Affiliate's service area: Sussex, Hudson, Essex and Passaic Counties. African American women continue to be the most at-risk population throughout the North Jersey service area and are identified as an additional target population.

Goal: The Affiliate has had successful outcomes from establishing the Sussex County Breast Health Project in partnership with Grantee, Project Self-Sufficiency of Sussex County, Inc., throughout 2009 and 2010; namely greater awareness and increased screening rates. The model was developed to address the breast health gaps/needs in this target County which was identified through exploratory data in the 2009 Community Profile; e.g. highest mortality rates in the Affiliate's service area. The ultimate goal is to replicate the community breast health model in three additional Target Communities -- Hudson, Essex and Passaic Counties.

Priority IV: Komen North Jersey Affiliate Capacity Building
In addition to the priorities outlined, the Community Profile process has amplified the needs of the Affiliate to build volunteer capacity and organizational support capacity around several areas.

Goal: Build the volunteer and organizational capacity to support the 2011 Community Profile needs as well as Mission Initiatives.

Introduction

Affiliate History

Susan G. Komen for the Cure® North Jersey Affiliate was founded in 1997 on a promise to a ten-year-old girl who lost her mother to breast cancer. Its mission has been to save lives and end breast cancer by empowering people, ensuring quality of care for all and energizing science to find the cures.

Figure 1. Map of the North Jersey Affiliate nine county service area.

The Komen North Jersey Affiliate service area is defined as the nine counties of Bergen, Essex, Hudson, Morris, Passaic, Somerset, Sussex, Union and Warren.

Since its inception the Affiliate has invested $17.7 million in mission services: $12.2 million has been dedicated to Community Grants in the service area and $5.5 million has been directed to Susan G. Komen for the Cure® Grants Program at a national level. From 1998 through 2007, the primary source of revenue for the Affiliate was the annual Pink Tie Ball which grossed from $500,000 to $2.2 million during its history. The Affiliate held its first Race for the Cure in 2008.

Affiliate Organizational Structure

The Affiliate has a staff of nine full and part-time employees. From 1997 through 2010, Deborah Q. Belfatto served as the Affiliate's Executive Director in a volunteer capacity. At the end of 2010, Ms. Belfatto transitioned into an advisory role as *Founder* and the Board of Trustees hired a full-time paid Executive Director who started in June 2010. The Affiliate has operated from offices in Summit, NJ since 1998. The Affiliate will be moving its office location at the end of 2011.

The Board of Trustees is in a transitional stage – both in growing its size as well as committees of the Board. It is the goal of the Board to develop working committees during 2011 to address the needs of Finance, Education/Outreach, Communications and Development. Through 2011 the active committees of the Affiliate included those related to Special Events as well as the Grants Committee.

Description of Service Area

The Affiliate serves nine New Jersey counties. The entire service area is relatively small geographically but densely populated. The service area is characterized by widely diverse racial, economic and social characteristics (Table 1).

Table 1.
Socioeconomic Characteristics and Racial/Ethnic Breakdown of the Affiliate's Service Area

	Socioeconomic Characteristics				Race/Ethnicity						
	Total Pop.	Median Household Income	People Below Poverty Line (%)	Uninsured Females (%)	White (%)	Black (%)	Hispanic (%)	American Indian and Alaska Native (%)	Asian (%)	Native Hawaiian and Other Pacific Islander (%)	All Other (%)
County											
Bergen	888,546	$81,350	5.6%	15.4%	74.3%	5.7%	14.5%	0.1%	14.0%	0.0%	4.2%
Essex	771,353	$54,176	14.5%	17.1%	42.7%	40.9%	18.5%	0.3%	4.3%	0.0%	9.6%
Hudson	593,615	$53,475	14.8%	21.5%	58.5%	13.6%	40.6%	0.4%	11.2%	0.0%	14.3%
Morris	485,828	$96,316	3.5%	11.0%	83.8%	3.1%	10.5%	0.4%	8.4%	0.1%	3.0%
Passaic	488,793	$54,888	15.0%	18.2%	59.7%	12.5%	34.6%	0.6%	4.6%	0.0%	21.4%
Somerset	320,712	$96,233	3.4%	11.9%	74.1%	8.5%	12.0%	0.1%	12.3%	0.0%	3.5%
Sussex	151,239	$81,488	4.7%	11.9%	93.7%	1.9%	5.7%	0.2%	1.9%	0.0%	1.5%
Union	522,050	$66,433	8.7%	20.8%	59.9%	21.4%	24.9%	0.5%	4.5%	0.1%	12.6%
Warren	109,567	$69,767	6.3%	13.3%	90.9%	3.1%	6.3%	0.0%	2.6%	0.0%	1.9%
New Jersey	8,650,548	$68,981	8.8%	15.1%	70.2%	13.6%	15.9%	0.2%	7.4%	0.0%	6.8%

American Community Survey Five-Year Estimates, 2005-2009 and Small Area Health Insurance Estimates, 2007

Note: *Specifically, percentage of people whose income within the last 12 months is below poverty level
**Specifically, percentage of uninsured females under 65 years old and of all income levels

Community Profile Objectives

The specific objectives of this Community Profile are:

- To complete a statistical profile of breast cancer incidence and mortality, population demographics and behavioral breast health factors for each of the nine counties in the service area;
- To evaluate the range and effectiveness of available services for women with breast cancer, their families, friends and associates including programs involving the Affiliate;
- To evaluate community prevention and education needs for targeted populations, especially minority, uninsured and underinsured women;
- To formulate conclusions and recommendations for targeted initiatives for each county as well as to position the organization for maximum effectiveness

Breast Cancer Impact in Affiliate Service Area

Methodology

County and State level demographic data were obtained from Thomson Reuters © 2010 estimates (population size and ethnic composition), from the U.S. Census Bureau's 2005-2009 American Community Survey Five-Year Estimates (median household income, people living under poverty level, education attainment, and unemployment status), and from the Small Area Health Insurance Estimates (health insurance status). Demographic data was organized and studied in Microsoft Excel.

Screening rate data organized by county, race, and age was obtained from the 2007-2009 New Jersey Behavioral Risk Factor Survey. Screening rate data was also obtained from Thomson Reuters © 2010 estimates. Incidence rate and mortality rate data were obtained from the New Jersey State Cancer Registry (NJSCR), which is managed by the New Jersey Department of Health and Senior Services (NJDHSS). Incidence rate data and mortality rate data were organized by county and by race for each year between 1990 and the most recent year available (which was 2007 and 2006, respectively). Screening, incidence, and mortality data were organized and studied in Microsoft Excel.

Stage of diagnosis data (2003-2007) and five-year relative survival rate data (1998-2002) were provided by the New Jersey State Cancer Registry, New Jersey Department of Health and Senior Services (NJDHSS) and were organized by county and by race. Stage of diagnosis and survival data were organized and studied in Microsoft Excel.

To determine target communities, 'red flags' were assigned to demographic and breast cancer statistics that were much higher or lower (as appropriate) than in New Jersey overall. The median values for the nine counties that were analyzed are displayed, as these help identify those statistics that are above or below. A 'red flag' identifies a community in need, and the counties with the most 'red flags' were designated as target communities.

It is important to note that, with only nine counties under consideration (and 21 counties in all in New Jersey), the sample size does not warrant formal statistical calculations. Although the 'red flags' are subjective, they do objectively identify patterns.

It is also important to note that the county-specific data do not accurately reflect demographic and breast cancer statistics for all parts of the counties in the service area. That is, the diversity of the counties is masked by the statistics. Several densely populated urban centers largely influence the statistics. These include Newark, Irvington, East Orange, and Orange in Essex County; Jersey City, Union City, and West New York in Hudson County; Passaic and Paterson in Passaic County; and Elizabeth in Union County (Thomson Reuters © 2010).

Overview of the Affiliate Service Area

Demographic Data

socioeconomic characteristics.

It is well-understood that there is a positive correlation between socioeconomic status and health (Culter, Lleras-Muney, & Vogel, 2008). For this reason, the Affiliate organized and analyzed socioeconomic characteristics for each of the nine counties in its service area (Table 2).

Table 2.
Socioeconomic Characteristics of the Affiliate's Service Area

County	Median Household Income	Percentage of People Living Under Poverty Level*	Percentage of Uninsured Females**	Percentage of Unemployed People (Age 16 and Over)
Bergen	$81,350	5.6%	15.4%	5.3%
Essex	$54,176	14.5%	17.1%	9.5%
Hudson	$53,475	14.8%	21.5%	8.0%
Morris	$96,316	3.5%	11.0%	4.8%
Passaic	$54,888	15.0%	18.2%	6.6%
Somerset	$96,233	3.4%	11.9%	5.2%
Sussex	$81,488	4.7%	11.9%	5.9%
Union	$66,433	8.7%	20.8%	7.0%
Warren	$69,767	6.3%	13.3%	5.7%
Nine County Median	$69,767	6.3%	15.4%	5.9%
New Jersey	$68,981	8.8%	15.1%	4.6%

American Community Survey Five Year Estimates, 2005-2009 and Small Area Health Insurance Estimates, 2007

Note: *Specifically, percentage of people whose income within the last 12 months is below poverty level
**Specifically, percentage of uninsured females under 65 years old and of all income levels

Socioeconomic characteristics of the service area were carefully studied to determine areas in most need of breast health care programs and services. The highlighted counties are those that, when compared with the nine county median values, tended to have low median household income, high percentage of people living under poverty level, high percentage of uninsured females, or high percentage of unemployed people.

education attainment.

It has been shown that there is a positive relationship between education attainment and health status (Cutler & Lleras-Muney, 2006). For this reason, the Affiliate gathered education attainment data for all nine counties in its service area (Table 3).

Education attainment data was studied to determine what areas could be potentially susceptible to poor health outcomes due to low education attainment. The Affiliate determined that the

highlighted counties demonstrate low education attainment, defined as higher than the nine county median values for high school and college education attainment and lower than the nine county median values for post-graduate education attainment. Education attainment patterns for Sussex and Warren Counties are unusual and are therefore not highlighted. These patterns are most likely attributed to the small population sizes in those counties.

Table 3.
Education Attainment for Populations over Age 25

	Less than 9th grade	9th to 12th grade, no diploma	High school graduate, includes equivalency	Some college, no degree	Associate's degree	Bachelor's degree	Graduate or professional degree
Bergen	4.4%	5.1%	25.1%	15.3%	5.8%	27.5%	16.6%
Essex	8.3%	10.6%	29.5%	15.9%	5.0%	18.7%	12.0%
Hudson	10.5%	9.7%	27.3%	14.8%	4.2%	22.2%	11.3%
Morris	2.8%	4.4%	23.5%	15.2%	6.0%	29.4%	18.7%
Passaic	10.5%	9.5%	35.1%	15.3%	5.3%	16.9%	7.4%
Somerset	3.7%	3.9%	22.8%	13.8%	6.5%	28.0%	21.3%
Sussex	2.2%	5.0%	33.9%	20.7%	7.5%	20.2%	10.4%
Union	8.0%	7.9%	31.4%	15.9%	5.6%	19.6%	11.7%
Warren	3.4%	8.0%	34.5%	18.4%	7.8%	19.2%	8.7%
Nine County Median	4.4%	7.9%	29.5%	15.3%	5.8%	20.2%	11.7%
New Jersey	5.6%	7.6%	29.9%	16.6%	6.2%	21.5%	12.7%

American Community Survey Estimates, 2005-2009

Breast Cancer Statistics

screening.

Screening rate data obtained from the 2007-2009 New Jersey Behavioral Risk Factor Survey were reviewed. It was noted that the sample sizes were small, especially when broken down into racial and age groups. For this reason, Thomson Reuters © 2010 estimates, which are based on larger samples, were organized and analyzed (Table 4).

Table 4.
Percentage of Women over the Age of 40 without a Mammogram in the Last 12 Months

County	Percentage
Bergen	32.6%
Essex	35.1%
Hudson	37.3%
Morris	30.4%
Passaic	34.4%
Somerset	30.9%
Sussex	32.8%
Union	34.1%
Warren	33.5%
Nine County Median	33.5%

Thomson Reuters © 2010

According to the American Cancer Society, low screening rate is associated with late stage breast cancer diagnoses and, consequently, higher mortality rates. Because of the relatively high percentages of women without a mammogram in the highlighted counties, the Affiliate considers these counties as communities in need.

incidence.

Incidence rate data was organized and studied separately by county for all races and broken down by White populations, Black populations, Hispanic populations, and non-Hispanic populations. Trends for incidence rate across different groups were analyzed, but it rapidly became apparent that conclusions could not validly be drawn from ascending or descending incidence rate trends alone, in the counties over time. However, incidence rate trends over time for White and Black populations in each of the nine counties of the Affiliate's service area demonstrate that there is a clear trend of higher incidence rates for White populations of women compared to Black populations of women (NJSCR, 1990-2007). When incidence rate trends are examined over time for Hispanic and non-Hispanic populations in each of the nine counties of the Affiliate's service area, the data demonstrate that there is a clear trend of higher incidence rates for non-Hispanic populations of women compared to Hispanic populations of women (NJSCR, 1990-2007). Sussex and Warren Counties were not included in either of these analyses due to the fact that these counties did not have any available numbers for Black and Hispanic female populations.

mortality.

Breast cancer mortality rate was examined over time in each of the nine counties, for all races and for White and Black populations separately. These data demonstrate a decrease in mortality rate from 1990 through 2006 (NJSCR, 1990-2006). One of several of these analyses appeared to show a reverse trend, but when examined statistically the R^2 value was very low, consistent with this result being by chance.

In organizing and analyzing mortality rate data, a few of the counties in the Affiliate's service area showed large fluctuations in mortality rate from year to year, due to factors such as small population size. In order to adjust for this discrepancy, five-year averages of the data were organized and analyzed, across counties and races. Five-year average mortality rate was studied over time in each of the nine counties, for all races and for White and Black populations separately. These data demonstrate a decrease in mortality rate from 1992-2006 (NJSCR, 1992-2006). As in the previous analyses on mortality rate across counties and races, although one of several of the analyses showed an increasing trend in mortality rate, the very low R^2 value was consistent with this being by chance.

Though the five-year average mortality rates across counties and races give a more accurate description of breast cancer mortality trends, the five-year average mortality rate results should not be considered definitive. Nevertheless, the most recent five-year average mortality rates can guide the Affiliate's fund-targeting efforts by demonstrating where breast cancer mortality rate is the highest in the service area (Table 5). Highlighted numbers indicate rates higher than the nine county median value for the period between 2001-2006.

Though mortality rate data is limited for Black populations in the service area, where the data is available, it is evident that five-year average mortality rates among Black female populations are higher than those among White female populations (NJSCR, 2001-2006). As of now, the New Jersey State Cancer Registry does not break down racial groups beyond White and Black populations.

Table 5.
Five-Year Average Mortality Rates for Period between 2001-2006

	Bergen	Essex	Hudson	Morris	Passaic	Union	Somerset	Sussex	Warren	Nine County Median	New Jersey
All Races	26.0	28.7	25.1	28.6	28.6	25.6	26.5	33.4	24.2	26.5	27.5
White	26.6	26.0	24.7	29.5	27.4	24.3	26.4	33.8	23.6	26.4	27.3
Black	35.0	33.5	33.6	N/A	38.6	32.7	N/A	N/A	N/A	33.6	33.6

New Jersey State Cancer Registry, 2001-2006

stage of diagnosis and survival.

The Affiliate studied counties that were characterized by high percentages of late stage diagnoses (Table 6). In general, percentages of Black females diagnosed at late stages of breast cancer were higher than those percentages for White and Asian Pacific Islander (API) populations (NJSCR, 2003-2007). This is also consistent with the trend of stage of diagnosis data on the state level. According to the American Cancer Society, the stage at which cancer is diagnosed is a critical factor in determining prognosis. A late stage diagnosis corresponds with a shorter average survival. New Jersey data support this statement: in New Jersey between 1998-2002, the five-year relative survival rates for females (of all races) diagnosed with late stages of breast cancer (regional: 83.2%; distant: 19.8%) were lower than those for females (of all races) diagnosed at early stages (in situ: 100.0%; localized: 98.4%) (NJSCR, 1998-2002).

Table 6.
Percentages of Late Stage Diagnoses by County and by Race

	Late Stage Diagnoses*								
	Regional			**Distant**			**Unstaged**		
County	*White*	*Black*	*API*	*White*	*Black*	*API*	*White*	*Black*	*API*
Bergen	21.9%	27.1%	27.1%	4.0%	4.8%	3.5%	2.2%	3.1%	1.7%
Essex	21.9%	28.3%	21.4%	4.9%	7.5%	N/A	2.6%	3.4%	N/A
Hudson	28.1%	37.0%	20.8%	4.9%	7.6%	6.6%	3.5%	3.4%	N/A
Morris	24.2%	28.6%	29.6%	3.6%	9.5%	5.6%	2.3%	3.2%	N/A
Passaic	25.0%	29.2%	26.5%	4.3%	8.7%	8.8%	2.9%	5.9%	N/A
Somerset	22.3%	27.8%	21.9%	4.4%	2.8%	N/A	2.3%	4.6%	N/A
Sussex	28.5%	N/A	N/A	5.7%	N/A	N/A	1.7%	N/A	N/A
Union	24.1%	27.6%	32.0%	5.0%	6.9%	N/A	2.2%	3.1%	N/A
Warren	24.7%	N/A	N/A	5.6%	N/A	N/A	1.2%	N/A	N/A
New Jersey	23.5%	28.8%	25.2%	4.4%	6.9%	4.2%	2.5%	3.2%	1.5%

New Jersey State Cancer Registry, 2003-2007

Note: *Numbers of Hispanic females diagnosed with late stage breast cancer diagnoses were not considered in these analyses because, according to the New Jersey Cancer Epidemiology Services (NJDHSS), Hispanic race and ethnicity are not mutually exclusive. Hispanics who identify themselves as White or Black are included in that category as well as the Hispanic category. In New Jersey, the majority of Hispanics (89%) self-identify as White.

Because of the higher percentage of late stage breast cancer diagnoses among Black females compared to White and Asian Pacific Islander females, it is expected for Black females to have lower survival rates and therefore higher mortality rates. Black females have higher mortality rates compared to White females, which corresponds with evidence that Black females have lower survival rates than White females. Among all invasive first primary cases of breast cancer in women, Black females had lower five-year survival rates (77.5%) than White and Asian Pacific Islander females (88.9% and 89.4%, respectively) (NJSCR, 1998-2002).

In addition, unstaged breast cancer diagnosis data was studied. There are many possible reasons for why a breast cancer diagnosis is assigned as unstaged, including loss to follow-up care. Unstaged breast cancer diagnosis data may reflect socioeconomic factors or non-compliance issues. In general, Black females have higher percentages of unstaged breast cancer diagnosis compared to White females and Asian Pacific Islander females (where information is available) (NJSCR, 2003-2007).

Communities of Interest

The total number of 'red flags' in each county was determined, and four communities emerged as having the highest number of 'red flags.' These areas were designated by the Affiliate as target communities due to outstanding statistics and trends with regard to socioeconomic factors, education attainment, screening, mortality, stage of diagnosis, and survival. These target communities include Essex County, Hudson County, Passaic County, and Sussex County. Specifically, densely populated urban centers within these communities strongly influence the data. These cities include Newark, Irvington, East Orange, and Orange in Essex County; Jersey City, Union City, and West New York in Hudson County; Passaic and Paterson in Passaic County (Thomson Reuters © 2010). In addition, the Affiliate defined Black females as a target group because of high mortality, high percentage of late stage diagnoses, and low survival among this population of women.

Conclusions

After analysis of demographic and breast cancer statistics in each of the counties in the Affiliate's service area, four counties were designated as target communities:

Essex County is the second largest county in the Affiliate's service area. It is also one of the most diverse counties. Essex County is characterized by:

- Low median income ($54,176 compared to the nine county median value of $68,981)
- High percentage of people living under the poverty level (14.5% compared to the nine county median value of 6.3%)
- High percentage of uninsured females (17.1% compared to the nine county median value of 15.4%)
- High percentage of unemployed people (9.5% compared to the nine county median value of 5.9%)
- Low education attainment (high percentages of population–compared to nine county median value—over age 25 that have completed only lower levels of education, and low percentages of population—compared to the nine county median value—that have not

completed higher levels of education. Table 3 displays these percentages.)
- High percentage of women over the age of 40 without a mammogram within the last 12 months (35.1% compared to the nine county median value of 33.5%)
- High five year average mortality rate among all races (28.7 per 100,000 compared to the nine county median value of 26.5 per 100,000)

Hudson County is the third largest county in the Affiliate's service area. It is also one of the most diverse counties. Hudson County is characterized by:
- Low median income ($53,475 compared to the nine county median value of $68,981)
- High percentage of people living under the poverty level (14.8% compared to the nine county median value of 6.3%)
- High percentage of uninsured females (21.5% compared to the nine county median value of 15.4%)
- High percentage of unemployed people (8.0% compared to the nine county median value of 5.9%)
- Low education attainment (high percentages of population–compared to nine county median value—over age 25 that have completed only lower levels of education, and low percentages of population—compared to the nine county median value—that have not completed higher levels of education. Table 3 displays these percentages.)
- High percentage of women over the age of 40 without a mammogram within the last 12 months (37.3% compared to the nine county median value of 33.5%)

Passaic County is the fifth largest county in the Affiliate's service area. It is also one of the most diverse counties. Passaic County is characterized by:
- Low median income ($54,888 compared to the nine county median value of $68,981)
- High percentage of people living under the poverty level (15.0% compared to the nine county median value of 6.3%)
- High percentage of uninsured females (18.2% compared to the nine county median value of 15.4%)
- High percentage of unemployed people (6.6% compared to the nine county median value of 5.9%)
- Low education attainment (high percentages of population–compared to nine county median value—over age 25 that have completed only lower levels of education, and low percentages of population—compared to the nine county median value—that have not completed higher levels of education. Table 3 displays these percentages.)
- High percentage of women over the age of 40 without a mammogram within the last 12 months (34.4% compared to the nine county median value of 33.5%)
- High five-year average mortality rate among all races (28.6 per 100,000 compared to the nine county median value of 26.5 per 100,000)
- High five-year average mortality rate among White female population (27.4 per 100,000 compared to the nine county median value of 26.4 per 100,000)
- High five-year average mortality rate among Black female population (38.6 per 100,000 compared to the nine county median value of per 33.6 per 100,000)

Sussex County is the second smallest county in the service area. The characteristics of Sussex County are distinct from those of the other target communities. Unlike the other target communities, Sussex County is largely rural and home to a mostly White population. However, Sussex County is characterized by certain breast cancer statistics that raise it to target community status:

- High five year average mortality rate among all races (33.4 per 100,000 compared to the nine county median value of 26.5 per 100,000)
- High five year average mortality rate among White females population (33.8 per 100,000 compared to the nine county median value of 26.4 per 100,000)

Health Systems Analysis of Target Communities

Overview of Continuum of Care

The continuum of care is defined as a tool used to review existing breast health programs and services in the Affiliate's service area and to identify gaps and barriers that prevent proper access to care by underserved women. It consists of four components: screening, diagnosis, treatment, and follow-up care. Using the continuum of care and knowledge about community assets, existing partnerships and collaborations are revealed. It also helps inform where such relationships may be beneficial. In addition, the continuum of care helps to identify how advocacy efforts and legislative support might assist women in obtaining access to care. By using the continuum of care moving forward, the Affiliate can guide efforts with regard to education, grants, advocacy, and outreach.

Methodology

Asset-mapping

Once the target communities were identified, medical and community resources in each of these areas were pinpointed. These resources were recognized as the community assets and were defined as sites where insured, underserved and uninsured women receive breast health screenings and can proceed through the continuum of care, whether or not a breast cancer diagnosis is made. Community assets also included four grantees that provide one or more components of the continuum of care.

Community assets were found through review of each target community's 2004 edition of "Early Detection Saves Lives: A County Guide to Breast Cancer Screening in New Jersey." These documents outline valuable breast health resources in each county including mammography providers, New Jersey Cancer Education and Early Detection (NJCEED) sites, local health departments, sites of the American Cancer Society, and county support services. Extensive internet research and communication with each of the county resources confirmed the existence of these community assets and the services they offer.

County health department websites were reviewed to confirm the hospitals serving each of the target communities. Further, the Affiliate's Grants Directory provided a listing of all Grantees in each of the target communities.

An asset mapping specialist plotted the community assets in each of the target communities in order to best visualize the breast health services available in each of these areas. Community assets were organized into the following categories: hospital, free standing mammography site, NJCEED site, mobile mammography site, and Grantee.

Qualitative Data

To develop a well-rounded understanding of the Affiliate's service area and of the target communities in particular, a wide variety of individuals were selected for their input. Medical providers, community leaders, and breast cancer survivors from throughout the service area and then specifically in the target communities were surveyed and interviewed (a detailed explanation of this process can be found in the Breast Cancer Perspectives section). Medical providers and community leaders in the target communities were selected based on their experience in working with groups of underserved women. Breast cancer survivors from the target communities were selected because they had overcome breast cancer at some time in their lives and are considered as underserved women living in their communities.

There were 33 medical providers, 48 community leaders, and 219 survivors that contributed to the qualitative data. Medical providers represented a number of hospitals, private practices, and organizations functioning at the local, state and national levels. Community leaders also represented a broad range of hospitals and organizations as well as public health departments, a federally qualified health center (FQHC) and several cancer coalitions. The majority of survivors surveyed was reached through the Affiliate's survivor database and represented White, insured female breast cancer survivors from throughout the service area. Survivors specifically from the target communities represented female breast cancer survivors from underserved populations. A comprehensive explanation of who was represented in the surveys and interviews can be found in the Breast Cancer Perspectives section.

Through the qualitative data collection process, a wealth of knowledge was gathered from medical providers, community leaders, and breast cancer survivors from throughout the service area and especially in the target communities. However, the data does have some limitations. With regard to the survivor data, most of the surveys were completed by White, insured women. Though this information provided the Affiliate with useful information regarding this population's breast cancer experiences, their responses largely reflected the outstanding quality of health care they received from major hospitals and medical centers in northern New Jersey and the ease with which they were able to handle financial expenses and understanding their disease. Though written surveys were completed by 14 underserved, female breast cancer survivors from the target communities, more input from this population of women would have been beneficial. It would have been especially helpful to obtain information through focus groups from a larger group of Black women, since this population is largely at risk of late stage diagnoses and high mortality rate.

In addition, it would have been useful to get more information from undocumented women regarding their breast health care experiences. The surveys did not address citizenship status of participants because it was believed that doing so would be unnecessarily invasive and potentially frighten the survey participants. Focus groups with underserved populations of women in the target communities would have been a strategic way to develop an understanding of breast health care issues facing undocumented women.

Overview of Community Assets

Essex County

Population: 771,353
Square Miles: 126.27
Population Density: 6,108.76

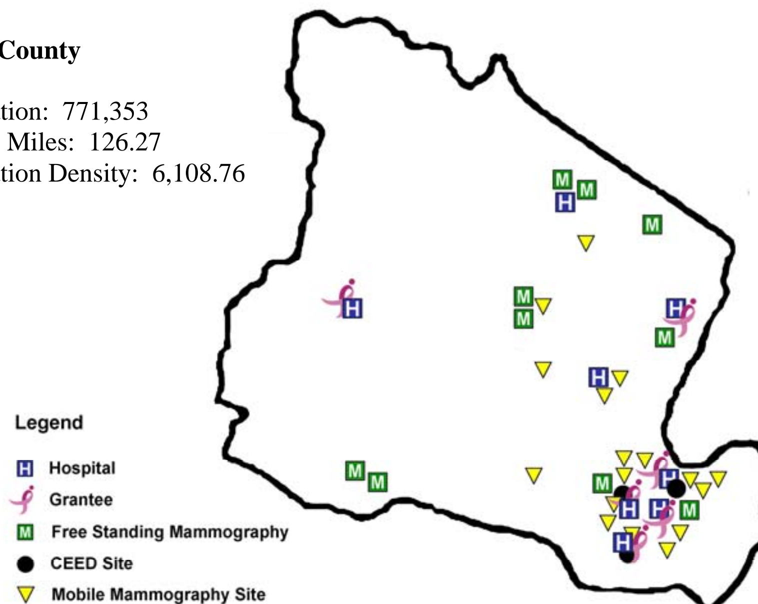

Figure 2. Breast health programs and services available in Essex County.

Essex County

Essex County is a socio-economically diverse county. The Affiliate target area in the county is the cluster of cities of Newark, Irvington, East Orange, and Orange. Seven acute care hospitals with strong Affiliate grantee programs serve the county. Among these hospitals, two have NJCEED contracts. The University of Medicine and Dentistry of New Jersey (UMDNJ) is an NJCEED site with a program called the Screening Access of Value to Essex Women and Men program (S.A.V.E.). UMDNJ is an Affiliate grantee that uses grant money to fund staffing associated with a mobile mammography van which brings breast health screenings to sites throughout Essex County. The second NJCEED site is Saint Michael's Medical Center, which has a comprehensive Breast Center, willing to serve women with limited or no resources. The Affiliate partners with these grant recipient hospitals to reach underserved women, especially Black females.

From key informant interviews, it was found that many families living in urban centers such as Newark, Irvington, East Orange, and Orange, struggle financially. Before women in these communities access breast health services, many face socio-economic issues, such as difficulty in paying for rent, utilities, child care, and transportation. These issues create barriers which often prevent women from gaining access to care.

The Affiliate can work to reduce these barriers through education and grant initiatives. The Affiliate can build stronger partnerships with the Essex County Cancer Coalition members, FQHC sites, houses of worship and community centers to bring education and information about resources to the community.

Hudson County

Population: 593,615
Square Miles: 46.69
Population Density: 12,713.96

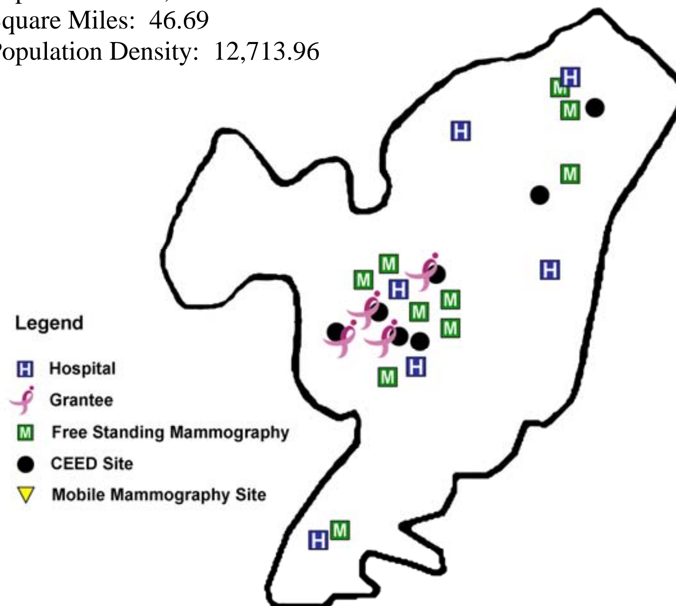

Figure 3. Breast health programs and services available in Hudson County.

Hudson County

Hudson County has the third largest population among the counties in the service area and is comprised of a highly diverse population. It is the most densely populated of the target counties and, according to key informant responses, has a relatively large population of women over the age of 65. There are five hospitals located throughout the county, though not one of these has a major commitment to breast health services. The assets lie within community organizations with which the Affiliate has strong grant relationships. One of these organizations is Metropolitan Family Health Network, Inc., which has an NJCEED contract. Another organization is Hoboken Family Planning, which is an FQHC sub-contract agency. These organizations are responsible for the majority of breast health screenings for underserved women.

Though thousands of underserved women are screened each year, Hudson County still has the highest percentage of women over the age of 40 who have not had a mammogram within the last 12 months. The Hudson County Breast Health Roundtable has emerged as a group committed to addressing breast health needs. The Hudson County Breast Health Roundtable is composed of representatives from hospitals, community agencies, the Hudson County Cancer Coalition, and the local NJCEED sites, and is chaired by the Hudson Perinatal Consortium, Inc., a long-standing Affiliate grantee. From key informant interviews, it was understood that there are numerous gaps and barriers to the continuum of care in Hudson County. Sites that offer screening services are limited by tight budgetary constraints and limited funding prevents access to treatment by underserved women. In addition, there is a lack of information regarding financial assistance programs. Also, more translation services are needed to reach such a diverse population.

Passaic County

Population: 488,793
Square Miles: 185.29
Population Density: 2,637.99

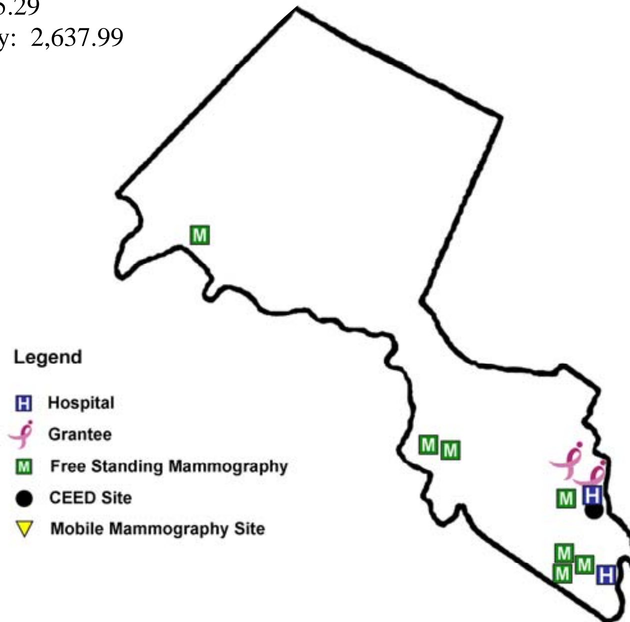

Figure 4. Breast health programs and services available in Essex County.

Passaic County

Passaic County is a target community where the primary areas of need are Paterson and Passaic. These cities also have a high poverty rate due to multiple socio-economic factors (American Community Survey, 2005-2009). The principal asset is St. Joseph's Hospital and Medical Center, which is a long-standing Affiliate grantee and the only NJCEED site in Passaic County. The hospital provides services predominantly to Black, Hispanic and Arabic populations. With a high poverty level and an extremely diverse community in need of health care services, the City of Passaic has felt the closure of two hospitals, including an NJCEED site. The only existing hospital in the city provides services for primarily insured patients. The City of Passaic Health Department, in partnership with the Passaic County Cancer Coalition, provides breast health education. However, underserved women in Passaic County still experience limited access to screening and treatment services.

According to responses from key informant interviews, women in Passaic County are largely dependent on the NJCEED program at Saint Joseph's Medical Center. Passaic County is in need of multiple breast health interventions to ensure proper access to the continuum of care. In addition, there is a need for increased collaboration between and among local organizations.

There is an opportunity for the Affiliate to work in a focused way in Passaic County with our current grantee, St. Joseph's Hospital, and the Paterson and Passaic community leaders to identify other potential partners and opportunities for community grants as well as education and outreach programs.

Sussex County

Population: 151,239
Square Miles: 521.26
Population Density: 290.14

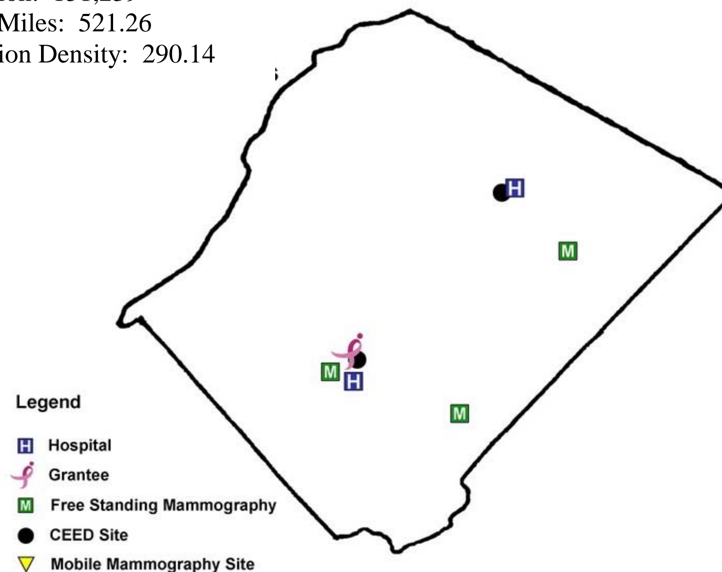

Figure 5. Breast health programs and services available in Sussex County.

Sussex County

Sussex County, the most rural of the target communities, has a small population relative to the populations of other counties in northern New Jersey. There is one major acute care hospital and a smaller sub acute care hospital holding the NJCEED contract. An Affiliate grantee, Project Self Sufficiency of Sussex County, Inc., is a social service agency that serves as the lead in Sussex County for promoting breast health education and disseminating information about breast health programs and services. Project Self Sufficiency also leads the Sussex County Breast Health Project, a group of community partners that leads a breast health awareness campaign which targets older women. The Sussex County Cancer Coalition, the Sussex County Department of Environmental and Public Health Services, and the Sparta Health and Wellness Center promote breast health education throughout the County. Free breast health screenings and access to treatment are available to underserved women through NJCEED. Freestanding radiology centers and hospitals offer breast health screenings for women with insurance. From key informant interviews it was discovered that women often seek breast health services outside the County. Gaps in the continuum of care were noted with regard to gaining access to breast surgeons and breast reconstruction, due to a lack of doctors in the County. Transportation to and from medical facilities is also a barrier for women seeking breast cancer treatment in the County.

The Affiliate continues to be active in Sussex County by supporting the Sussex County Breast Health Project and by advocating for improvements to women's access to care.

Legislative Issues

The biggest legislative issue facing the Affiliate service area with regard to breast health care is federal and state funding to support screening, treatment, and follow-up care services. NJCEED plays a critical role in providing health care services for the underserved (Table 7). Due to budget constraints already in place, NJCEED is only able to screen an average of 7.1 percent of eligible women (Table 8). This Program faces enormous challenges if federal and state funding cuts are made. If budget cuts are made, large numbers of underserved women are at risk of not receiving appropriate breast health care services.

Table 7.
Number of Eligible Women Screened at NJCEED Sites in Target Communities in 2010

County	Women Screened	Eligible Women	% Women Screened
Essex	2150	31420	6.8%
Hudson	2893	28840	10.0%
Passaic	1060	23063	4.6%
Sussex	186	5477	3.4%
Total	6289	88800	7.1%

C. Africa III, Personal Communication, February 11, 2011

NJCEED offers breast health services at 23 sites statewide and at 14 sites in the Affiliate's target communities. Women eligible for the Program must meet the following criteria:

- be between the ages of 40-64 years
- be living at or below 200 percent of the federal poverty level
- be uninsured or underinsured

If a woman meets the NJCEED criteria and has been diagnosed at an official NJCEED site, she is eligible to receive full treatment benefits through Medicaid beginning the day of her breast cancer diagnosis and continuing throughout the course of her treatment. If a woman has a recurrence, she must re-apply for Medicaid.

New Jersey has selected Option II of the State Medicaid Options, which denies treatment to otherwise eligible women who were not screened at a participating NJCEED site (Table 8). By moving from Option II to Option III within the Medicaid Treatment Program in New Jersey, a woman who is not diagnosed at an NJCEED site would be eligible for full treatment coverage through Medicaid.

Table 8.
State Medicaid Options through the Breast and Cervical Treatment Program

Option I	Eligible only if clinical service was was provided by NJCEED
Option II	Eligible if clinical service was provided within the scope of a grant, sub-grant, or contract under NJCEED
Option III	Eligible when screened by any provider

M. Rojewski, Personal Communication, February 11, 2011

Qualitative Data Findings

Based on the results of the qualitative data collection and analysis, if a woman in the Affiliate's service area is insured, her passage through the continuum of care is smooth and straightforward. There are a number of outstanding medical facilities in northern New Jersey at which a woman can be screened and, if diagnosed with breast cancer, can be carefully attended by excellent medical staff from treatment through follow-up care. An insured woman also has a wide selection of doctors and ample access to information regarding treatment, financial assistance programs, and support services.

If a woman is uninsured, her passage through the continuum of care depends on the facility where her path in the continuum of care begins. Based on qualitative data results, most low-income, underserved women throughout the service area receive routine breast health care at their local community clinic. If a breast cancer diagnosis is made at such a facility, patients are directed to a variety of hospitals and medical centers that offer charity care for their treatment. The experience of an uninsured woman in the service area, then, depends on the facility where she is diagnosed and the facilities to which she is directed if a breast cancer diagnosis is made.

If a woman meets the eligibility criteria to receive breast health care services through NJCEED, she will receive free screening. If a breast cancer diagnosis is made, patients are referred to Medicaid. If the patient meets the Medicaid eligibility criteria, she receives full treatment benefits through Medicaid. In this process, then, women must pass through a number of checkpoints in order to gain access to the next step in the continuum of care. If they do not meet the eligibility criteria for NJCEED or Medicaid and cannot pay for breast health care services, they may seek alternative resources.

The path through the continuum of care for an undocumented woman is the least understood. An undocumented woman may receive a free mammogram through NJCEED or may gain access to treatment through charity care. However, details about this path are not easily available and vary widely.

Conclusions

A better understanding of the target communities was developed through the identification, mapping and assessment of the community assets in each of the target communities. Qualitative data from medical providers, community leaders, and breast cancer survivors supplemented the information gathered from the asset mapping and further revealed where gaps and barriers in breast health care exist. As was concluded in the quantitative data, most of the women in the target communities (especially within the cities that were identified within each of the target counties) are of low socioeconomic status and cannot afford health care services. Therefore, the NJCEED Program, which largely provides breast health screening and breast cancer treatment services, plays an extremely important role. The legislative issue of federal and state funding cuts must be addressed in order to ensure that underserved women in northern New Jersey continue to benefit from breast health care services provided by NJCEED.

Breast Cancer Perspectives in the Target Communities

Methodology

Data Collection

Qualitative data was collected through online surveys, written surveys and key informant interviews. First, five surveys were developed for each of five groups of interest. The first survey was designed for medical providers with whom the Affiliate had a long-standing relationship and could engage in deep conversation on issues regarding community breast health. The second survey was developed for medical providers with whom the Affiliate had a working relationship and who wished to complete an abbreviated version of the first medical provider survey. The third survey was created for community leaders in the Affiliate's service area that could provide in-depth knowledge on the populations of women living in northern New Jersey and seeking breast health programs and services. The fourth survey was designed for community leaders involved with women's breast health care in the Affiliate's service area and were interested in completing a shortened version of the first community leader survey. The fifth survey was generated for survivors and asked about their experiences with breast cancer with regard to medical diagnosis, treatment, and support services.

online surveys.

The online surveys were administered through SurveyMonkey to medical providers and survivors. The abbreviated medical provider survey and survivor survey were implemented in this process. These surveys were comprised of solely close-ended questions. The medical provider survey link was sent to 84 medical providers in the service area. The survivor survey link was sent to 1,318 survivors, from the Affiliate's survivor database. From the pool of individuals to which the surveys were sent, 14 medical providers and 205 survivors completed the online surveys.

written surveys.

The written surveys were distributed to medical providers, community leaders, and survivors from the four target communities in the service area. The abbreviated medical provider survey, the shortened community leader survey, and the survivor survey were used. These surveys had both open-ended and close-ended questions. Five medical providers, 41 community leaders, and 14 survivors completed the written surveys.

key informant interviews.

The key informant interviews were the centerpiece of the qualitative data collection process. The extended, semi-structured versions of the medical provider and community leader surveys were used. These surveys had both open-ended and close-ended questions. These interviews deeply engaged medical providers and community leaders from the target communities and provided the Affiliate with invaluable insight into the barriers faced by underserved populations of women

seeking breast health and breast cancer programs and services. Fourteen medical providers and seven community leaders were interviewed.

Data Sources

The **medical providers** who took part in completing online surveys, written surveys, and key informant interviews were defined as individuals who are involved in one or more aspects of women's breast health care including screening, diagnosis, treatment, and support. These medical providers included 19 doctors, two nurse practitioners, six nurses, two Grantees, a health educator, a genetic counselor, a social worker, an outpatient hospital administrator, a cancer program data manager, and the president and CEO of a non-profit organization that represents organizational providers and affiliates of community-based ambulatory health care in New Jersey. Medical providers represented 12 different hospitals, four private practices, the New Jersey Primary Care Association, the American Cancer Society, the Cancer Institute of New Jersey, the Women's Health and Counseling Center, and NJCEED. Doctors, nurse practitioners, and nurses that participated in the survey represented a variety of medical fields related to women's breast health care, including radiology, medical and surgical oncology, and breast surgery.

The **community leaders** who completed written surveys and key informant interviews were defined as individuals that were deeply involved in maintaining the medical and social well-being of women in their communities. They were also considered highly knowledgeable about the barriers to health care of women in their community, especially with regard to breast health care. Responses from 48 community leaders provided extensive perspective into the lives of women seeking breast health programs and services throughout the service area. Community leaders held positions of authority at a variety of medical centers and organizations including seven hospitals, the American Cancer Society, Atlantic Health System, CancerCare of New Jersey, the Shrine of Saint Joseph, Hoboken Family Planning, the New Jersey State Senate, Gilda's Club, Screen for Life, and NJCEED. Community leaders also included heads of public health departments, non-profit organizations functioning at the local and state levels, an FQHC, and several cancer coalitions.

The **survivors** who completed online and written surveys were defined as women who had lived with and overcome breast cancer at some time in their lives. The Affiliate connected with survivors through the Affiliate's survivor database, which included female breast cancer survivors throughout the service area. The Affiliate also reached out to three particular community leaders who work primarily with breast cancer patients and survivors in Hispanic and Black communities. These three leaders brought survivor surveys to the communities of women with which they work and had survivors complete the surveys.

Data Analysis

The data collected from the online surveys was analyzed separately from the data collected from the written surveys and key informant interviews.

online surveys.

All of the data was collected and organized through SurveyMonkey. The frequency of responses to each of the questions was also calculated through SurveyMonkey.

written surveys and key informant interviews.

The qualitative data collected from the written surveys and key informant interviews of medical providers, community leaders, and survivors, was recorded and organized in Microsoft Excel. Reponses to open-ended questions were analyzed by the investigators for key themes. The frequency of responses for each close-ended question that corresponded to a topic of interest was calculated using Microsoft Excel.

Review of Qualitative Findings

Online Surveys

medical provider survey.

Fourteen medical providers from throughout the service area completed the medical provider online survey (Table 9).

Table 9.
Question Topics and Most Common Responses from Medical Providers through Online Survey

Question Topic	Most Common Response
Biggest barrier to health care	Lack of financial resources or insurance (n=14, 100.0%)
Best strategy to reduce barriers to health care	Educate the public in preventive health care (n=14, 85.7%)
Most common ways women pay for their health care	Private Insurance (including HMO's) and Medicare/Medicaid (n=14, 85.7%)
Most effective way to disseminate breast health information	Newspaper (n=14, 64.3%)
Most common reason women don't seek breast health screenings	Scared of procedure or results (n=14, 85.7%)
Most common force that motivates women to obtain regular mammograms	Physicians told them to (n=14, 100.0%)

The medical providers who completed the survey were from throughout the service area and not limited to the target communities. Therefore, the responses to this survey reflect a broad spectrum of medical providers' thoughts on issues facing underserved women within their respective communities. Though all of the questions to the survey were close-ended, there was a space for additional comments. These comments highlighted the themes outlined above.

survivor survey.

Two hundred five survivors from the Affiliate's survivor database completed the online survey (Table 10). A written summary following the table explains additional survivor comments.

Table 10.
Question Topics and Most Common Responses from Survivors through Online Survey

Question Topic	Most Common Response
Race/ethnicity	White (n=204, 87.3%)
Age diagnosed with breast cancer	Between the ages of 40-49 (n=201, 45.3%)
Where diagnosis took place	Major medical center (n=200, 40.5%)
Stage of breast cancer upon diagnosis	Stage I (n=200, 41.5%)
Who women turned to when they needed more information about breast cancer	Medical specialist (n=200, 78.0%)
Motivation for women to follow up with diagnosis and seek treatment options	Self-motivated (n=200, 66.0%)
Insurance status upon diagnosis	Insured (n=199, 98.0%)

The themes that emerged from the survivor data revealed that the population of women in the Affiliate's survivor database is mostly White and insured. Most of the women were diagnosed with Stage I breast cancer within the last decade and responded quickly and appropriately to this diagnosis. Those women who were not insured at the time of their diagnosis sought financial assistance through programs such as NJCEED and facility charity care.

Though most women who participated in the survivor survey followed up with their diagnoses and sought treatment within a month after being diagnosed, the "Other" responses reflected the complicated nature of a breast cancer diagnosis. Survivors explained the time frames in which their surgical treatments took place, followed by the chemotherapy and/or radiation treatments they subsequently received. Some survivors explained that they sought additional medical opinions and/or testing, which delayed their treatment. Survivor comments reflected that the women had a working understanding of breast cancer and of the resources they could use to seek medical and financial assistance.

Most survivors were satisfied with their medical experiences. They had a lot of positive comments related to the hospitals and medical centers where they were treated as well as the sensitive and supportive doctors and staff that took care of them. Though they had much positive feedback about their experiences, many women suggested that more support services could be made available. Specifically, survivors recommended that support services in which they could speak with a breast cancer survivor would have been helpful. Support services targeted for young women with breast cancer would have also been effective. In addition, several women would have liked to be informed of alternative support services including jin shin jyutsu, reiki, reflexology, massages, acupuncture, and stress reduction classes.

With regard to barriers that could have been removed to improve their medical experiences, survivors agreed that financial barriers were the largest obstacles. Many women also expressed that there was a lack of information about different types of treatment, about financial assistance options, and about support services. There seemed to be a gap between physicians and patients, with regard to communication.

Regarding support services, the majority of survivors participated in a social support program. Most of these women participated in a group support program and found it to be effective. Support through an organized program, from family or friends, or from doctors and medical staff played a vital role in survivors' recoveries.

Written Surveys and Key Informant Interviews

medical providers.

Both the abbreviated and extended medical provider surveys had the same close-ended questions. For this reason, responses to these questions were analyzed together (Table 11). There were 19 respondents to the close-ended questions. These respondents represented medical providers from the target communities.

Table 11.
Question Topics and Most Common Responses from Medical Providers through Written Surveys and Key Informant Interviews

Question Topic	Most Common Response
Biggest barrier to health care	Lack of financial resources or insurance (n=19, 89.5%)
Best strategy to reduce barriers to health care	Educate the public in preventive health care (n=19, 73.7%)
Most common ways women pay for their health care	Medicare/Medicaid (n=19, 89.5%)
Most effective way to disseminate breast health information	Church bulletins/announcements/events (n=19, 84.2%)
Most common reason women don't seek breast health screenings	Don't have money or insurance to pay for services (n=19, 94.7%)
Most common force that motivates women to obtain regular mammograms	Physician told them to (n=19, 100%)

Medical providers who completed the written surveys and key informant interviews responded that the most common way women pay for their health care is with Medicare/Medicaid, though the second most frequently chosen response was with private insurance. These results are consistent with those from the medical provider online surveys. A unique difference that separated the responses was in the most effective way to disseminate breast health information to women in their communities. The majority of medical providers from the target communities expressed that the best way to reach women was through the Church. Further, responses from medical providers from the target counties demonstrated that the most common reason women don't seek breast health screenings is because they cannot afford those services.

Responses to the open-ended questions expanded upon responses to the close-ended questions. Medical providers from the target areas explained that the women in their communities least likely to receive breast health screenings are among the following groups:

- Ethnic minority groups including Black and Hispanic women
- Uninsured women
- Low income women
- Less educated women
- Unemployed women
- Undocumented women

These same groups of women were identified by medical providers to be least likely to receive effective breast health services. Then, when asked to describe the gaps in the community with regard to breast health screening and services, medical providers outlined the following issues:

- Lack of financial resources or insurance
- Lack of knowledge about available resources
- Lack of knowledge about proper health care and about breast cancer
- Lack of understanding in doctor-patient relationship due to language barriers

***community leaders*.**

The abbreviated and extended community leader surveys had the same close-ended questions. For this reason, these questions were analyzed together (Table 12). There were 48 respondents to the close-ended questions. There were two additional close-ended questions included in the abbreviated community leader survey. The question topics for these two questions are noted. These two questions were analyzed separately from the other questions and had 41 respondents.

Table 12.
Question Topics and Most Common Responses from Community Leaders through Written Surveys and Key Informant Interviews

Question Topic	Most Common Response
Biggest barrier to health care	Lack of financial resources or insurance (n=48, 77.1%)
Best strategy to reduce barriers to health care	Educate the public in preventive health care (n=48, 77.1%)
Most common way women pay for their health care	Private insurance (including HMO's) (n=48, 68.8%)
Most effective way to disseminate breast health information	Church bulletins/announcements/events (n=48, 64.6%)
Most common reason women don't seek breast health screenings	Don't have money or insurance to pay for services (n=48, 81.3%)
Most common forces that motivate women to obtain regular mammograms	Physician told them to (n=48, 70.8%)
Source from which most women in the community seek breast health information*	Medical doctors (n=41, 70.7%)
Site where low-income or underserved women obtain their routine breast health care*	Community clinic (n=41, 73.2%)

Note: *Questions analyzed separately, due to the fact that they were included in the abbreviated community leader survey but not in the extended community leader survey.

As was expressed by medical providers serving in the target communities, community leaders' most common response to the most common barrier to health care for the women in their communities is financial resources or insurance. Interestingly, the second most frequently chosen response was fear. This barrier is broad in that it covers a number of fears associated with breast health care including fear of painful medical procedures, fear of the results of medical tests, fear of a breast cancer diagnosis, fear of being unable to pay for their medical services, fear of being unable to work and support family if diagnosed with breast cancer, and fear of dying. As fear stems from a lack of knowledge about health care, it is consistent that community leaders agreed that the best strategy to reduce barriers to health care is to educate the public in preventive health care.

As medical providers had expressed, the most common way women pay for breast health care is through private insurance. Payment through Medicare/Medicaid was the second most common response, which is consistent with the responses from the medical providers as well. As the

medical providers from the target communities expressed, community leaders agreed that the best way to disseminate breast health information is through the Church. Also, women are motivated to obtain mammograms as a result of physicians' instruction.

Community leaders' responses reflected that the most common source of breast health information for women in the community is medical doctors. Physicians play a major role in motivating women to take care of their breast health and to obtain mammograms. Medical doctors at community clinics are especially important figures, considering that community clinics are where most women in the target communities get their routine breast health care.

With regard to the open-ended questions, the groups of women least likely to receive breast health screenings were consistent with those groups outlined in the medical providers' responses. When asked to address gaps in breast health care, community leaders' responses largely pointed to the lack of education about proper health care, especially with regard to breast health. They expressed a lack of understanding among women in these communities regarding the severity of breast cancer and the importance to follow up with a breast cancer diagnosis. Community leaders also explained that there is a lack of knowledge about resources for medical and financial assistance for health care services.

survivors.

The written survivor survey had close-ended questions with space for additional comments. Fourteen respondents from within the Affiliate's target communities were surveyed (Table 13).

Table 13.
Question Topics and Most Common Responses of Survivors through Written Surveys

Question Topic	Most Common Response
Race/ethnicity	Hispanic or Latino (n=14, 64.3%)
Age diagnosed with breast cancer	Between the ages of 40-49 (n=14, 50.0%)
Where diagnosis took place	NJCEED Site (n=14, 35.7%)
Stage of breast cancer upon diagnosis	Stage I (n=14, 42.9%)
Who women turned to when they needed more information about breast cancer	Primary care/Family physician (n=14, 42.9%)

Responses related to age at which survivors were diagnosed and the stage of breast cancer upon diagnosis, were similar for survivors who took the online survey and those that completed the written surveys. However, the majority of the women that participated in the written surveys identified as Hispanic or Latino whereas the majority of survivors that completed the online survey classified themselves as White. In addition, while the majority of women from the Affiliate's survivor database were diagnosed at a major medical center, most of the women that participated in the written surveys were diagnosed at an NJCEED Site. Further, to obtain breast cancer information, survivors turned to their primary care/family physicians. This is distinct from most of the survivors from the Affiliate's survivor database who turned to their medical specialists for breast cancer information. Like the survivors from the Affiliate's survivor database, survivors who completed the written surveys expressed that the support services they sought and received were critical to their recovery.

Conclusions

The findings from the qualitative data collection and analysis were broken down into five major themes. These themes emerged from the responses to surveys and interviews completed by a variety of medical providers, community leaders, and survivors throughout the service area and then specifically within the Affiliate's target communities.

Underserved groups

The groups of women that continue to be identified as those most in need of breast health programs and services included ethnic minority groups, uninsured women, low income women, less educated women, unemployed women, and undocumented women. These results confirm that the target communities chosen by the Affiliate are where education/outreach, grant-making, and public policy strategies can be most effectively implemented.

Black women continue to have higher mortality rates than White women. The Affiliate's target communities are home to a large percentage of the Black female population. Further, large populations of Hispanic women reside in the target communities.

In addition, the target communities are characterized by high percentages of uninsured women, of households with low median income, and of unemployed women. Education attainment beyond a high school diploma is also low within these communities. With regard to undocumented status, these statistics are difficult to accurately obtain.

Lack of financial resources or insurance

As determined through the quantitative analysis and confirmed through qualitative data collection and analysis, lack of financial resources or insurance is a major barrier to health care within the target communities. These areas are characterized by high percentages of uninsured women, of households with low median income, and of unemployed women. These communities are struggling financially and when the burden of a health care expense arises, women avoid it. Medical providers and community leaders from the target communities even expressed that the most common reason women do not seek breast health screenings is because they cannot afford them. If options regarding financial assistance or insurance were made available to women within these communities, there would be greater incentive for them to actually seek breast health screenings and avoid the risk of developing late stage breast cancer diagnoses.

Lack of education in the community

From medical provider, community leader, and survivor responses, it is evident that there is a lack of breast health education in the community. Women are not aware of the importance of maintaining proper breast health and of obtaining regular breast health screenings. Then, if diagnosed with breast cancer, patients do not understand the severity of a breast cancer diagnosis and the need to take action in receiving treatment. There is a disconnect in the doctor-patient relationship that results in a lack of understanding about treatment options. Further, there are

limited resources for women to obtain information regarding financial assistance and support services.

It is difficult enough to navigate the health care system as a fluent English speaker. For non-English speakers, of which there are large populations in the target communities, receiving health care and forms of financial and social support make breast cancer an even bigger obstacle. Therefore, besides more available information, breast cancer information needs to be translated so that all populations of women can access and understand it.

Lack of education among doctors

As was already established, the target communities are characterized by a diverse population of women. For this reason, doctors and other medical staff treating these patients must strive to be culturally sensitive and understanding. Survivors expressed that they would have liked for their doctors to be more sensitive, as well as more informative. There seems to be a gap in the doctor-patient relationship with regard to communication. Doctors are perceived to be withholding information or not completely explaining information that is important to patients. Doctors should be instructed in how to best explain test results, treatment options, and financial and social assistance information to their patients. Further, from community leader and survivor survey responses, it is evident that women in the community largely rely on physicians for medical information. This is a large responsibility for doctors and medical staff, but they must be prepared with information for their patients or able to guide patients to individuals who are more knowledgeable, especially regarding financial assistance options and support services.

Importance of community and faith-based organizations

Many groups of women in the Affiliate’s service area are not being reached. Medical providers and community leaders suggest that more be done to carry the Affiliate’s messages of breast health awareness and care. Specifically, they recommend implementing education programs at community and faith-based organizations. Many medical providers and community leaders explained that women within their communities gather and talk in such places. Therefore, to most effectively educate women about breast health care, information should be shared to women at community and faith-based organizations.

Final Conclusions: What We Learned, What We Will Do

Review of the Findings and Final Conclusions

Breast cancer is expensive. From diagnosis to treatment to support services for the uninsured, underinsured and underserved, the number one barrier is 'lack of financial resources'. The goal is both to provide resources and/or support for services in the communities that address this need. Breast cancer information and resources are complicated. Even when services exist; they are difficult to learn about. The goal is to increase paid treatment resources for breast cancer patients, with a focus on the target communities, as well as increase the awareness of and access to resources for those that need them the most. Breast cancer is treatable when diagnosed and treated in the early stages. Yet, thousands of women, insured and uninsured, over the age of 40 do not get an annual mammogram. Education about the importance of mammography and good breast health is critical moving forward. The Affiliate has the opportunity to build capacity in the form of volunteers and collaborations to address the needs identified during the Community Profile process.

Action Plan

The Affiliate Priorities are intended to:

- Address gaps and barriers to services across the continuum of care
- Improve access, utilization and quality of services
- Develop and enhance community partnerships and collaborations
- Expand grant programs and curriculum
- Devise and implement health communication, marketing and funding strategies
- Support health policy and advocacy efforts that are in line with Komen National and the Affiliate

Priority I: Increase the capacity of breast cancer resources for those uninsured, underinsured and underserved, both through building capacity and by making information about resources more accessible.

Goal: NJCEED provides low-income, uninsured and underinsured women with free breast cancer screenings. The Affiliate's goal is to advocate for flat and/or increased funding for the NJCEED Program and ensure that women in need of screenings have continued access to and information about the Program.

> Public Policy Objective: Beginning in March 2011 partner with the Komen Central/South Jersey Affiliate and other community partners, including the County Cancer Coalitions to provide support for this objective.
>
> Education/Outreach Objective: Provide information about NJCEED screening opportunities to constituents and inquiries via Affiliate website, phone support and informational materials.

Education/Outreach and Awareness Objective: Collect and share *Success Stories* regarding those served by NJCEED and Affiliate Grantees to personalize these services.

Goal: The Affiliate's goal is to continue supporting local community partners and resources to help build capacity of programs and services which address the screening and treatment needs of the uninsured and underserved.

Grant Making Objective: Throughout the 2011 and 2012 Grant Cycles, provide grant funding to community programs, with an emphasis on target communities, which provide a variety of support services, including, but not limited to, emergency funds, patient navigation, transportation, childcare, wigs and prostheses. Serve as a lead facilitator for Grantees to learn about resources available at other institutions to ensure access to more services.

Education/Outreach Objective: By March 31, 2012, complete research regarding challenges for undocumented women accessing the health care system and develop appropriate responses for our partners and the women we serve.

Education/Outreach Objective: By March 31, 2012, gain a better understanding of the New Jersey Hospital Care Payment Assistance Program (Charity Care) and develop tools to help women navigate it for breast health care.

Education/Outreach Objective: By December 31, 2011 provide updated resources regarding free screenings, supportive services and other resources vital to those going through breast cancer diagnosis and treatment. Additionally, identify either partnership opportunities with other organizations to collaborate in a comprehensive resource guide and/or identify opportunities to build this capacity for the community.

Education/Outreach Objective: By March 31, 2012 convene a group of scientists, physicians and other leaders from the medical community to explore the possibility of developing a sharing mechanism for clinical trials available in the service area.

Priority II: Increase the education of women regarding the importance of mammography and breast self-awareness

Goal: The Affiliate's goal is to partner with community-based outreach/health organizations to effectively promote awareness of breast health

Grant Making Objective: Identify all educational opportunities funded by the Affiliate for the 2011 and 2012 Grant Cycles and work proactively with Grantees to promote these events.

Education/Outreach Objective: By September 30, 2011 complete an external education action plan which will support the continuum of care in target communities by addressing breast health gaps and barriers identified in the Community Profile.

Education/Outreach Objective: Co-sponsor and co-produce community education and screening events, with an emphasis on target communities, e.g., partner with The Prostate Network to co-produce an awareness / education / screening event in Newark (Essex County) in September 2011.

Education/Outreach Objective: Explore new opportunities for partnerships and collaborations, including faith based organizations, local businesses, poverty fighting networks and social service networks that exist in each of the target counties and throughout the Affiliate's service area, with a minimum of one new partnership/opportunity identified and implemented each quarter.

Priority III: Build upon the success of the work done through the 2009 Komen North Jersey Community Profile, specifically addressing the ongoing needs of the target geographic communities of the Affiliate's service area: Sussex, Hudson, Essex and Passaic Counties. African American women continue to be the most at-risk population throughout the North Jersey service area and are identified as an additional target population.

Goal: The Affiliate has seen successful outcomes from establishing the Sussex County Breast Health Project in partnership with Grantee, Project Self-Sufficiency of Sussex County, Inc., throughout 2009 and 2010. Namely, Sussex County has experienced wider breast health awareness and increased screening rates. The model was developed to address the breast health gaps and barriers that were identified through exploratory data analysis in the 2009 Community Profile. The ultimate goal is to replicate this community breast health model in Essex County, Hudson County, and Passaic County.

Objective: Throughout 2011 and 2012 support ongoing implementation of the Sussex County Breast Health Roundtable plan through grants, education, awareness and advocacy.

Objective: Replicate the success of the initiatives in Sussex County in Hudson County by expanding the Hudson County Roundtable, partnering with Affiliate Grantees and Hudson Perinatal Consortium, Inc., and identifying available community resources and partners to grow this initiative.

Hudson County Breast Health Roundtable Objective: By end of 2011, partner with Liberty Health, through the Hudson County Breast Health Project, to initiate a pilot program, focusing on education and screening: "The Doctor is in the House," in four Senior Housing establishments in Jersey City to address screening non-compliance of women over age 65, with a focus on African-Americans. Complete six programs by April 2012.

Hudson County Breast Health Roundtable Objective: Start a collaborative public awareness campaign using multi-generational women telling their stories about the importance of screening. Implement PSA campaign by December 2011.

Objective: To lay the groundwork in both Essex and Passaic Counties for Breast Health Roundtables by meeting with physicians, Grantees, community leaders and other breast cancer service providers. The goal is to facilitate a Roundtable in either Essex County or Passaic County by January 2012.

Priority IV: Komen North Jersey Affiliate Capacity Building
In addition to the priorities outlined, the Community Profile process has amplified the needs of the Affiliate to build volunteer capacity and organizational support capacity around several areas.

Goal: Build the volunteer and organizational capacity to support the 2011 Community Profile needs as well as Mission Initiatives.

Public Policy Objective: The potential NJ Budget issues amplify a need for the Affiliate to make Public Policy/Advocacy a regular committee and actively build its list of both Grasstops and Grassroots supporters to be at the ready for any action needed to preserve funding for free breast cancer screenings, or any other Komen priority advocacy issues.

Education Objective: Build an Education Committee with an active cadre of volunteers who can help strategize and implement the outreach efforts of the Affiliate both with Grantees and with community partners.

Communications Objective: Build a Communications Committee which can assist with key messaging for mission, survivors and fundraising activities throughout the year.

Survivorship: Build a Survivor Recognition Program which is not just highly visible at the annual North Jersey Race for the Cure, but regularly surfaces outside Race day.

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