



COMMUNITY PROFILE REPORT

Houston Affiliate of
Susan G. Komen for the Cure®



2011

Acknowledgments

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A photograph of two women in white lab coats, likely healthcare professionals, smiling and engaged in conversation. The woman on the right is looking towards the woman on the left. The image has a soft, pinkish-purple tint.

Disclaimer

The information in this Community Profile Report is based on the work of Houston Affiliate of Susan G. Komen for the Cure®. It was prepared by Epidemiology Solutions, LLC. The data used in the current report originate from statistical sources and activities that took place in collaboration with key community partners. The findings of the report are based on a needs assessment public health model but are not necessarily scientific. They are provided “as is” for general information only and without warranties of any kind. Susan G. Komen for the Cure® and its Affiliates do not recommend, endorse or make any warranties or representations of any kind with regard to the accuracy, completeness, timeliness, quality, efficacy or non-infringement of any of the programs, projects, materials, products or other information included or the companies or organizations referred to in the report.

Executive Summary



Introduction

Nancy G. Brinker promised her dying sister, Susan G. Komen, that she would do everything in her power to end breast cancer forever. In 1982 that promise became Susan G. Komen for the Cure®, launching the global breast cancer movement to save lives, empower people, ensure quality of care for all and energize science to find the cure.

The Houston Affiliate of Susan G. Komen for the Cure® was established in 1990 to provide innovative breast cancer education, screening and treatment projects for the medically underserved and uninsured in Southeast Texas. In the Affiliate's 21 year history, it has granted a sum of \$8 million for research nationally and over \$25 million for community grants in Brazoria, Chambers, Fort Bend, Galveston, Harris, Liberty and Montgomery counties (Referred to as the seven county service area or service area). The Affiliate's granting process ensures the impartial allocation of funds to qualified 501c3 organizations helping many breast cancer patients, survivors and their families to get the treatment and support they need.

The Komen Houston Affiliate conducts a Community Profile, also known as a community needs assessment, specifically evaluating breast health and breast cancer in the seven county service area. The Profile is prepared every two years and includes demographics, breast health statistics, an assessment of breast health services and a survey of the community's perceptions regarding breast health and access to care.

The Community Profile:

- Helps establish priorities that guide grant distribution
- Improves the educational programs of the Affiliate
- Determines public policy goals
- Serves to facilitate a better understanding of breast health services for the seven county service area by identifying and prioritizing the areas of most need.

In this year's profile, Montgomery County was selected for additional data gathering activities to better understand the breast health needs of its population.

Statistical and Demographic Review

The overall goal of the Community Profile is to apply the breast cancer continuum of care model. The continuum of care model describes an integrated system of breast cancer health care through a sequential structure of interrelated health services spanning all stages of care. The breast care model facilitates the analysis and understanding of current programs and services available in the breast health care system of the Affiliate service area.

To achieve this goal, various sources of data are used to examine and identify characteristics of interest within the general population, including:

- Summary files by zip code and census tract from the U.S. Census Bureau 2002 to 2010

- The American Community Survey, U.S. Census Bureau 2006-2009
- Demographic information such as population density available from the Economic and Social Research Institute (ESRI)
- Statistical tables including breast cancer incidence and mortality, 2003 to 2007 prepared by the Texas Department of State Health Services, Cancer Epidemiology and Surveillance Branch, Texas Cancer Registry.
- Mammography utilization rates from the Texas Behavioral Risk Factors Surveillance System, 2002-2008

The Komen Houston Affiliate service area encompasses almost 8,000 square miles and overlaps with the Houston - Sugarland - Baytown metropolitan statistical area, which is the sixth largest metropolitan area in the United States, with a 2010 population of 5,946,800 million people (U.S. Census Bureau). It is also one of the fastest growing urban areas in the nation with an estimated 25% increase in population between 1990 and 2007. The city of Houston is the fourth largest city in the nation with an estimated population of approximately 2.1 million people (2010 U.S. Census). The Houston Affiliate service area comprises the seven counties of Brazoria, Chambers, Fort Bend, Galveston, Harris, Liberty and Montgomery counties.

Prevalence is one of the most common measures of frequency used in epidemiology. It is defined as the proportion of individuals in a population who have the characteristic of interest at a specific instant or point in time. A common marker for the assessment of a population's access to health care is the prevalence of persons 18 years of age and older reported to be without health insurance. According to the U.S. Census Bureau, American Community Survey, the prevalence rate of uninsured adults was 27% in Texas during 2009. In the Houston Affiliate

service area, the prevalence varied from as low as 20% in Fort Bend County to as high as 30% in Harris County. During the same period, the prevalence rate of the total U.S. adult population who reported not having health insurance was 17%.

For Texas and for each of the seven counties comprising the Houston Affiliate service area, the prevalence of women ages 40 years and older who reported ever having had a mammogram is low. According to the Texas Behavioral Risk Factor Surveillance System, 2002-2008, the lowest prevalence rates of women ever having had a mammogram was found in Harris County (55%), followed by Fort Bend County (60%), Galveston County (61%), Montgomery County (71%), and Liberty and Brazoria counties (75%). When looking at the race/ethnicity distribution in the Houston Affiliate service area, the highest prevalence of mammography utilization was observed among white women (66%). In contrast, the lowest prevalence of mammography utilization was observed among Hispanic women (43%).

The Texas Cancer Registry estimates that over 3,000 residents of the Komen Houston service area will be diagnosed with breast cancer in 2011. In addition, over 600 residents are expected to die as a result of breast cancer in 2011. The overall estimate is based on expected number of cases for Brazoria, Fort Bend, Galveston, Harris, and Montgomery counties. Expected number of cases for Liberty and Chambers counties was not included as they were too small to be statistically stable. Moreover, as of 2008, the number of persons living with breast cancer (diagnosed in the last 10 years) in Texas is projected to be 96,052 according to the Texas Cancer Registry.

The 2011 Houston Affiliate Community Profile provides an overview of data from the service area. This year, Montgomery County has been select-

ed for additional data gathering because of the high incidence rate of breast cancer experienced among its white female population. Moreover, although the Komen Houston Affiliate has served Montgomery County for over 20 years, until the 2011 Profile no targeted needs assessment of the County had ever been conducted by the Affiliate. Furthermore, until 2011 there was not a Komen grantee funded program in Montgomery County.

Health Systems Analysis

Health systems analysis is a method that assists in the investigation of complex questions facilitating an objective evaluation and identification of optimal courses of action. As part of this health system analysis, the Affiliate assessed a number of sources of information such as:

- Current grantees
- Breast health services listed on the Breast Health Portal
- Results from surveys from key informants
- Results from Participatory Action Research (PAR) activities with breast health providers and navigators
- Results from interviews with experts on end of life care



In order to acquire firsthand information of the breast cancer experience among the target communities, a social science technique known as Participatory Action Research (PAR) was implemented. Essentially PAR is an investigative process that strives to “learn by doing”. It aims to acknowledge the experience and understanding of participants regarding a specific social/health situation in a non-judgmental environment, while giving a voice to their practical

concerns. In addition, it empowers participants to identify or rediscover the linkages between barriers and opportunities available to them while creating collaborative scenarios for future change.

Additionally a self-administered, anonymous, “key informant survey” was designed and applied among breast health providers and patient navigators. In cancer care navigators refers to personnel providing individualized assistance to patients, families and caregivers to help overcome health care system barriers and facilitate timely access to quality medical and psychosocial care. Cancer patient navigation works with a patient from pre-diagnosis through all phases of the cancer experience. The themes addressed in the survey were originally identified during the Houston Affiliate 2009 Community Profile. Additional questions regarding programs offered at each facility, agencies involved in breast health care in the target areas, gaps in services, referral patterns and types of navigation provided by participating agencies were included in the 2011 survey.

Fifty key informants participated in five data gathering activities that were conducted in Harris County at The Rose and United Way of Greater Houston and in Montgomery County at Lone Star Family Health Center and Interfaith Community Health Clinic. The key informants included 26 breast health care providers from agencies targeting breast health care services to low income populations and 24 breast health care navigators from the seven county service area.

Among breast health providers there is consensus that the need exists for new partnerships and collaborations among agencies providing services at different stages of the continuum of care model. All stake holders identified the need for improved communication with their patients, between agencies and providers and among suppliers and providers in

order to negotiate reduced cost and increased savings. They also recognize that in order to make their breast health programs accessible, comprehensive, timely and affordable, they must: 1) expand their plans to target underserved and high risk populations, 2) improve the quality of their programs to address current screening and diagnostic guidelines and 3) make every effort to provide consistent, comprehensive patient care.

Breast health care providers recognized the need for more bilingual community outreach, assistance with transportation, the interaction of survivors with patients undergoing treatment and the creation of culturally sensitive support groups in both rural and urban areas. They also agreed on the positive results achieved from case management and patient navigation, as supported by the available scientific literature. It was reported that patient navigation increased follow up appointments and facilitated the movement of women with breast cancer through the different stages of the continuum of care model. Patient navigation also provides a suitable environment for the distribution of culturally sensitive breast health patient education materials.

Furthermore, providers agreed that changes to almost all of the factors affecting the quality of breast health programs depends on the availability of adequate funding that will finance the cost of specialized physicians, provide new technology and equipment such as electronic management systems, facilitate the access to continuing education for staff and pay for a more evidence-based care system.

Qualitative Data Overview

Qualitative data was collected from breast health providers, navigators, experts in the field of end-of-life care and survivors. The data collected was used

to perform the health system analysis and the breast cancer statistical analysis.

To acquire first hand information about the breast cancer experience among the target communities, three separate Participatory Action Research (PAR) activities were conducted. Thirty one (31) breast cancer survivors gathered at the American Cancer Society Harris County facility, The Rose in Southeast Houston (Harris County) and Lone Star Family Health Center in Montgomery County.

Among breast cancer survivors, emotional support, nutritional counseling, patient navigation, family counseling, social work, transportation and assistance with translation were identified as services needed for women undergoing breast cancer treatment in the target communities.

They also identified resources that assisted women in dealing with the issues they faced after a breast cancer diagnosis. The resources included: faith, prayer, spiritual advisors, psychological help, support groups, the support of family and friends, a good relationship with health care providers, assistance of patient navigators and a positive attitude. All survivors reported facing continuous daily challenges associated with their breast cancer diagnosis. The challenges included: problems with lymphedema, emotional pain, lack of financial resources, side effects of chemotherapy, fear, language barriers, long-term quality of life issues, lack of understanding among family and friends, lack of specialists and cancer counseling.

According to experts in the field of end of life care, in the late terminal stage, breast cancer patients have the same needs and concerns as other patients facing the last days of a terminal illness. These would include anticipatory grief, custodial care needs, financial concerns, caregiver stress and

symptom management, among many other issues and concerns.

Conclusions

The Komen Houston Affiliate is indebted to all who volunteered their time and generously participated in the data gathering activities that provided the invaluable information presented in the 2011 Community Profile Report. It is hoped that this report may be used as a tool to identify opportunities for advocacy and community health organizing and as a platform and resource to develop partnerships and collaborations among breast health providers and advocates.

Overall, breast cancer survivors identified very similar themes to those identified by navigators when asked about services, resources and challenges faced by women with breast cancer of different race/ethnic backgrounds. Services identified by the survivors as needed for women undergoing breast cancer treatment in the target communities were: psychological/emotional support, nutritional counseling, patient navigation (help with making appointments, getting referrals & coordinating follow-up care), family counseling, social work (help with finances/community resources, etc), and transportation and translation services.

Some of the resources recognized by the survivors as being able to assist them in dealing with the challenges they face as a result of the breast cancer diagnosis included: faith, prayer, spiritual advisors, psychological help, support groups, the support of family and friends, having a good rapport with the oncologist and health care providers, obtaining the services of patient navigators, maintaining a positive attitude and never giving up.

All survivors reported continuous challenges faced daily associated with their breast cancer diagnosis, including: issues with lymphedema (assessing treatment, acquiring garments, lack of coverage by health insurance), emotional pain (anger, depression, lack of self esteem, rediscovering how to lead a normal life after breast cancer), lack of financial resources (coverage for health insurance and purchase of prosthesis), living with the side effects of chemotherapy (hot flashes, memory loss, joint pain, inflammation), fear (of death, of the future of daughters and sisters), language barriers, long term quality of life issues (social and sexual life changes, alterations in physical appearance, lack of energy, feeling older), lack of understanding among family and friends and lack of a specialist in cancer counseling.

Findings from the scientific literature search of peer-reviewed studies published between 2005 and 2011 on breast cancer screening, treatment and compliance among low-income women in the United States can be summarized in three groups:

- Disparities in breast cancer diagnosis and treatment
- Access to treatment and barriers to diagnosis
- Predictors of mammography compliance



Overall the themes encountered within the literature review supported the findings of the data gathering activities conducted among the breast health providers and patients. Specifically, in most scientific studies, there was evidence of disparities in breast cancer diagnosis and follow up for treatment according to the race/ethnicity of the women treated. African Americans, Hispanics and other minorities generally experienced worse breast cancer outcomes than White/Anglo American women (Adams et al; Moy et al, Meissner et al, Kaplan et al, Consedine et al). However, racial/ethnic disparities encountered in breast cancer diagnosis and treatment seem to diminish when equal access to health care was provided and effective communication was established with a health care provider (Kerner et al; Harris et al, Abraido-Lanza et al, Alexandraki et al). Individual counseling, personalized outreach interventions and patient navigation also improved screening rates among vulnerable populations (Rimer et al, Velanis et al, Lobb et al).

Predictors of mammography such as perceived susceptibility and perceived risk/benefit ratio also varied by country of birth, age, educational achievement, race/ethnicity and income of the women in each study. Interventions to increase mammography rates among women need to be tailored to each group according to their unique belief system (Cronan et al, Champion et al, MacAlerney et al). The influence of social networks, such as friends, family members and partners should be taken into consideration in the design of breast cancer screening interventions (Erwin et al; Tejada et al, Erwin et al).

Overall, access to health care, low socio-economic status/low income and low educational achievement are the most important predictors associated with low rates of regular mammography screening and delayed diagnosis and treatment of breast cancer (Loerzel et al; Fair et al, Shueler et al, Meissner et al, Ogedegbe et al). However, having access to

health care or health insurance was the most significant factor identified as a predictor for breast cancer screening, according to results in the National Health Interview Survey (NHIS), a randomized national study, (Meissner et al, Halpern et al, Peek et al, O'Malley et al, Alexandraki et al).

Affiliate Action Plan

Based on results from the *Community Profile*, an action plan with priorities was developed. The timeline to complete the priorities listed below is April 1, 2011 to March 31, 2013.

Priority 1 - Increase breast cancer education and reduce cultural barriers of the underserved, minority and high risk populations.

Priority 2 - Increase use of patient navigation services for underserved patients accessing breast healthy services.

Priority 3 - Increase screening, diagnostic and treatment services for the underserved populations, especially in rural areas.

Priority 4 - Increase the quality of and access to continued survivorship care to include follow-up medical care, support services, transportation services, end of life care and other services for underserved breast cancer survivors. Note: The Komen Houston Affiliate defines a breast cancer survivor as someone who has been diagnosed with breast cancer.

Priority 5 - Increase education and reduce barriers related to enrollment in breast cancer clinical trials for underserved and minority women.

Details and specific objectives for each priority are discussed in detail in the action plan section at the end of the Profile.

Introduction

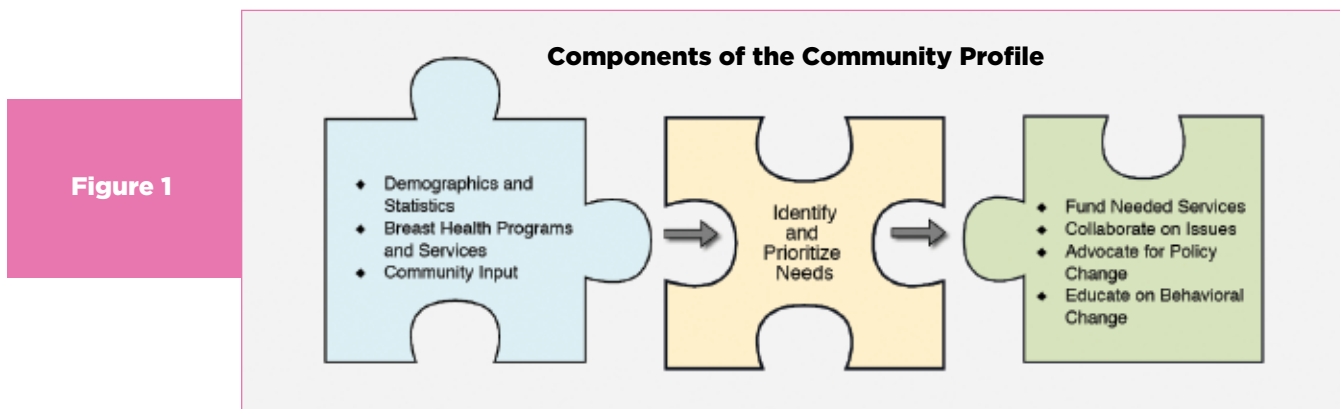
Nancy G. Brinker promised her dying sister, Susan G. Komen, that she would do everything in her power to end breast cancer forever. In 1982 that promise became Susan G. Komen for the Cure®, launching the global breast cancer movement to save lives, empower people, ensure quality of care for all and energize science to find the cure.

The Houston Affiliate of Susan G. Komen for the Cure® was established in 1990 to provide innovative breast cancer education, screening and treatment projects for the medically under-served and uninsured in Southeast Texas. In the Affiliate's 21 year history, it has granted \$8 million for research nationally and over \$25 million for community grants in Harris, Fort Bend, Chambers, Montgomery, Brazoria, Liberty, and Galveston counties (Referred to as *the seven county service area or service area*). The Affiliate's granting process ensures the impartial allocation of funds to qualified 501c3 organizations helping many breast cancer patients, survivors and their families to receive the treatment and support they need.

The Houston Affiliate has consistently been ranked #1 among 122 national Komen Affiliates for granting

the most funds to the community. Today, the Affiliate has more than 1,500 volunteers committed to fulfilling the promise. The Komen Houston Affiliate is governed by a Board of Directors. The Komen Houston Affiliate has a staff of ten with a budget of over \$5 million a year. Under the Board of Directors, there are the Advisory Council and the Montgomery County Advisory Council. Board committees include the Executive, Strategic Missions, Fund Development, Finance and Governance Committees. The Strategic Missions Committee is responsible for the Grants, Education and Public Policy Committees for the Komen Houston Affiliate.

The Komen Houston Affiliate conducts a Community Profile, also called a community needs assessment, specifically evaluating breast health and breast cancer in the seven county service area. The Profile is done every two years and includes demographics, breast health statistics, an assessment of breast health services, and a survey of the community's perceptions concerning breast health and access to care. The Community Profile helps establish priorities that guide grant distributions, improves the educational programs and determines public policy goals of the Komen Houston Affiliate. It also serves to facilitate a better understanding of breast health services for the seven county service area by identifying and prioritizing the areas of most need.



Breast Cancer Impact in Affiliate Service Area

Statistical and Demographic Review

Various sources of data were used to examine and identify general population characteristics of interest in the Houston Affiliate service area. These included:

- Summary files by zip code and census tract from the U.S. Census Bureau 2002 to 2010
- The American Community Survey, U.S. Census Bureau 2006 - 2009
- Demographic information such as population density available from the Economic and Social Research Institute (ESRI)

- Statistical tables including breast cancer incidence and mortality, 2003 to 2007 prepared by the Texas Department of State Health Services, Cancer Epidemiology and Surveillance Branch, Texas Cancer Registry
- Mammography utilization from the Texas Behavioral Risk Factors Surveillance System, 2002-2008

The Seven-County Service Area Statistical Overview

Table 1 below shows the total female population of each county that makes up the service area and the percentage of the female population that is 39 years of age and older in each county and in Texas as a whole.

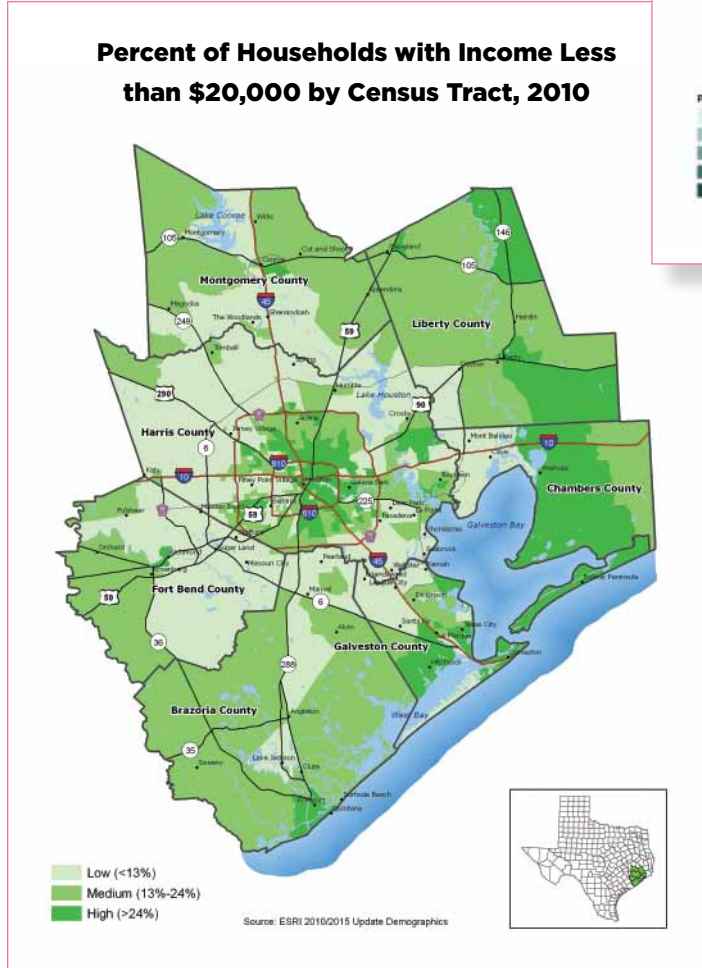
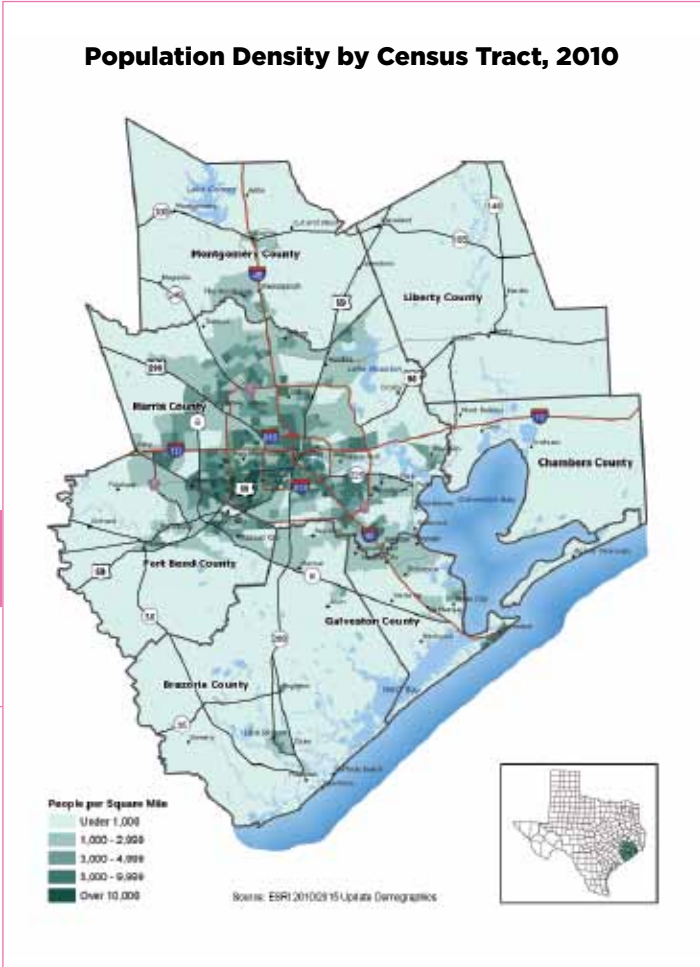
Table 1

Area	Total Female Population	Percent of Female Population over 39 Years of Age
State of Texas	12,673,281	43%
Brazoria County	154,166	43%
Chambers County	17,435	44%
Fort Bend County	298,007	43%
Galveston County	147,075	47%
Harris County	2,055,054	40%
Liberty County	38,453	46%
Montgomery County	229,835	46%

Source: 2010 U.S. Census, Demographic Profiles

Map 1 illustrates the population density distribution or the places where people live throughout the Houston Affiliate seven-county service area according to the 2010 Census. It can be clearly observed that the population is not evenly distributed among the seven counties. The city of Houston and its surrounding neighborhoods are most densely populated with more than 10,000 people living in each square mile. Rural counties located around the greater Houston area and on the outskirts of the service area are more sparsely populated with less than 1,000 inhabitants per square mile.

Map 1



Map 2

Map 2 illustrates the distribution of households with income less than \$20,000 per year by census tract according to the 2010 census statistics. The allotments vary from census tracts where less than 13% of its population reported less than \$20,000 per year found mainly along the suburbs of Harris and Fort Bend Counties, to a high proportion of poverty where 24% or more of the total population of each census tract reported having an annual income of less than \$20,000 per year. Census tracts with a high proportion of

poverty were found in the Houston inner-city as well as in pockets of population located in Chambers, Liberty, Brazoria and Galveston counties. The levels of poverty in the service area guide the Affiliate in determining areas of greater need.

Table 2 below illustrates the diverse race and ethnic distribution of Texas as a whole and of the individual counties that comprise the seven county service area. The data are based on U.S. Census Bureau statistics from 2008. Overall, Whites constitute the majority of the population across all the counties, followed closely by Hispanics and African Americans. The largest percentage of Asian (14%) and African American (20%) populations reside in Fort Bend County. Harris County has the largest percentage of Hispanic population (38%) in the local service area while Montgomery County has the largest percentage of White population (75%).

Table 3 on the following page shows the percentage of persons 18 years of age and older by county reported to be without health insurance according to the U.S. Census Bureau, American Community Survey 2009. In the U.S., 17% of the adult population reported not having health insurance. In Texas during the same time period, the rate of uninsured adults was 27%. The percentage of uninsured adults in the Houston Affiliate service area ranges from 20% in Fort Bend County to 30% in Harris County residents. Almost one in three adults in Harris County lacked health insurance in 2009. According to the U.S. Census Bureau, Texas has the highest rate of uninsured residents in the nation.



Table 2

Race and Ethnicity by County						
County	2009 Total Population	White %	African American %	Hispanic %	Asian %	Other %
Texas	24,782,302	47%	12%	37%	4%	1%
Total Komen Houston Affiliate Service Area	5,778,809	50%	11%	19%	4%	1%
Harris	4,070,989	37%	18%	38%	5%	1%
Fort Bend	556,870	40%	20%	24%	14%	2%
Montgomery	447,718	75%	5%	18%	2%	2%
Brazoria	309,208	58%	10%	26%	4%	2%
Galveston	286,814	60%	14%	21%	3%	2%
Liberty	75,779	71%	12%	15%	1%	1%
Chambers	31,431	71%	11%	16%	1%	1%

Sources: U.S. Census Bureau (Population Estimates; American Community Survey 2006-2008)

Table 3

Percentage of Persons 18 Years of Age and Older Without Insurance by County, 2009	
Area	Percent
Harris	30%
Liberty	29%
Texas	27%
Brazoria	23%
Galveston	22%
Montgomery	22%
Fort Bend	20%
U.S.	17 %
Chambers	n/a

Source: U.S. Census Bureau, American Community Survey 2009

Table 4

Percentage of Persons Without Insurance for Texas by Gender, Race/Ethnicity, Education, and Household Income, 2009	
Texas	
Gender (Persons 18 Years of Age and Older)	
Male	29%
Female	25%
Race/Ethnicity (Persons 18 Years of Age and Older)	
White	15%
African American	27%
Hispanic	46%
Other	40%
Education (Persons 25 Years of Age and Older)	
Less than High School	47%
High School Graduate	29%
Some College	20%
College Graduate	8%
Income (All persons)	
Below \$25,000	36%
\$25,000- \$49,000	32%
\$50,000- \$74,000	23%
\$75,000- \$99,000	15%
\$100,000 and Above	8%

Sources: U.S. Census Bureau, American Community Survey 2009

Table 4 classifies the 2009 adult population of Texas without insurance by gender, race/ethnicity, education, and total household income per year. The groups more affected by the lack of health insurance are adult males, Hispanics and other minority groups, those who have less than a high school degree and those who earn less than \$25,000 per year.

According to Families USA, job-based health insurance is how most Americans get their health coverage. However, the rates began falling nationwide in 2001. Reasons for the decline in job-based coverages include people losing jobs due to the economic downturn, employers ceasing to offer insurance benefits and workers choosing not to enroll.



Table 5 lists the prevalence of women ages 40 years and older who reported ever having a mammogram and a clinical breast examination for Texas and for each county in the Houston Affiliate service area, according to the Texas Behavioral Risk Factor Surveillance System, 2002-2008.



A mammogram is an x-ray of the breast. It is considered the best screening tool available to detect breast cancer early. A clinical breast examination (CBE) is performed by a health care provider. It includes visual examination and palpation (feeling) of the entire breast and underarm area, and is performed in both sitting and lying down positions.

70% nationwide. However, when considering women who have ever had a mammogram or clinical breast exam in their lifetime, the percentage listed in Table 5 is lower for some counties in the Affiliate service area. Shown below, at the county level, Liberty (75%), Brazoria (75%) and Montgomery (71%) counties have the highest prevalence while Harris (55%), Galveston (61%) and Fort Bend (58%) counties have the lowest prevalence of women ever having had a mammogram in their life time in the Affiliate service area.

According to the U.S. Department of Health and Human Services, the Healthy People 2010 mammography goal was to increase the proportion of women aged 40 years and older who have had a mammogram within the past two years to at least

Table 5

Mammogram and Clinical Breast Exam Utilization, Females Ages 40 Years and Over, 2002-2008 Combined		
	Percent who ever had a mammogram	Percent who ever had a clinical breast exam
Texas	60	86
Brazoria County	75	93
Chambers County	n/a	n/a
Fort Bend County	58	85
Galveston County	61	93
Harris County	55	84
Liberty County	75	89
Montgomery County	71	95

Source: Texas Behavioral Risk Factor Surveillance System, 2002-2008 combined. All reported rates are weighted for Texas demographics and the probability of selection



Table 6 categorizes by race and education the mammography utilization of females aged 40 years and older in the Houston Affiliate service area and in Texas between the years 2002 and 2008 combined.

When looking at the race/ethnicity distribution, the highest prevalence of mammography utilization (66%) is observed among white women who reside in the Houston Affiliate service area. The lowest prevalence of mammography utilization is observed among Hispanic women (43%). Moreover, during the period 2002-2008, the proportion of women 40 years and older who utilized mammography increased as their reported educational achievement increased.

Table 6

Mammogram Utilization by Race and Education in Females Ages 40 Years and Over, 2002-2008 Combined		
	Percent (Greater Houston Area) %	Percent (Texas) %
Race/Ethnicity		
White	66	67
African American	58	60
Hispanic	43	49
Other	55	52
Education		
Less than High School	49	55
High School Graduate	56	60
Some College	61	60
College Graduate	63	64

Source: Texas Behavioral Risk Factor Surveillance System, 2002-2008 combined. All reported rates are weighted for Texas demographics and the probability of selection

The Texas Cancer Registry estimates that over 3,000 residents of the Komen Houston service area will be diagnosed with breast cancer in 2011. At the same time, over 600 residents are expected to die as a result of breast cancer. The overall estimate is based on expected number of cases for Brazoria, Fort Bend, Galveston, Harris and Montgomery counties. Expected number of cases for Liberty and Chambers counties was not included as they were too small to be statistically stable. Moreover, as of 2008, the number of persons living with breast cancer (diagnosed in the last 10 years) in Texas is projected to be 96,052 according to the Texas Cancer Registry.

Figure 2 illustrates the proportion of female breast cancer cases categorized by stage of diagnosis and county of residence; including the Houston Affiliate seven county service area and Texas for the combined time period 2003 to 2007. Stages of diagnosis are as follows: Stage I and Stage II or localized, Stage III or regional, Stage IV or distant or unknown.

Incidence is a way to quantify the number of new cases of an event or disease that develop in a population of individuals at risk during a specified time period. A cancer incidence rate is the number of new cases of a specific type of cancer occurring in a specified population during a year, usually expressed as the number of cases per 100,000 of population at risk.

If a breast cancer biopsy shows that a person has breast cancer, the doctor needs to know the extent (stage) of the disease to help the patient choose the best treatment. The stage is based on the size of the cancer, whether the cancer has invaded nearby tissues, and whether the cancer has spread to other parts of the body.

■ **Stage I** is an early stage of invasive breast cancer. Cancer cells have invaded breast tissue beyond where the cancer started, but the cells have not spread beyond the breast. The tumor is not more than two centimeters across.

■ **Stage II** is one of the following:

- The tumor is not more than two centimeters across. The cancer has spread to the lymph nodes under the arm
- The tumor is between two and five centimeters. The cancer has not spread to the lymph nodes under the arm
- The tumor is between two and five centimeters. The cancer has spread to the lymph nodes under the arm
- The tumor is larger than five centimeters
- The cancer has not spread to the lymph nodes under the arm

■ **Stage III** is locally advanced cancer. It is divided into Stage IIIA, IIIB, and IIIC

Stage IIIA is one of the following

- The tumor is not more than five centimeters across. The cancer has spread to the underarm lymph nodes that are attached to each other or to other structures. Or the cancer may have spread to lymph nodes behind the breastbone.
- The tumor is more than five centimeters across. The cancer has spread to the underarm lymph nodes that are either alone or attached to each other or to other structures. Or the cancer may have spread to lymph nodes behind the breastbone.

Stage IIIB is a tumor of any size that has grown into the chest wall or the skin of the breast. It may be associated with swelling of the breast or with nodules (lumps) in the breast skin:

- The cancer may have spread to the lymph nodes under the arm
- The cancer may have spread to underarm lymph nodes that are attached to each other

or to other structures. Or the cancer may have spread to lymph nodes behind the breastbone.

- Inflammatory breast cancer: rare and most aggressive type of breast cancer. It is called inflammatory breast cancer because its main symptoms are swelling and redness of the breast.

Stage IIIC is a tumor of any size. It has spread in one of the following ways:

- The cancer has spread to the lymph nodes behind the breastbone and under the arm
- The cancer has spread to the lymph nodes above or below the collarbone

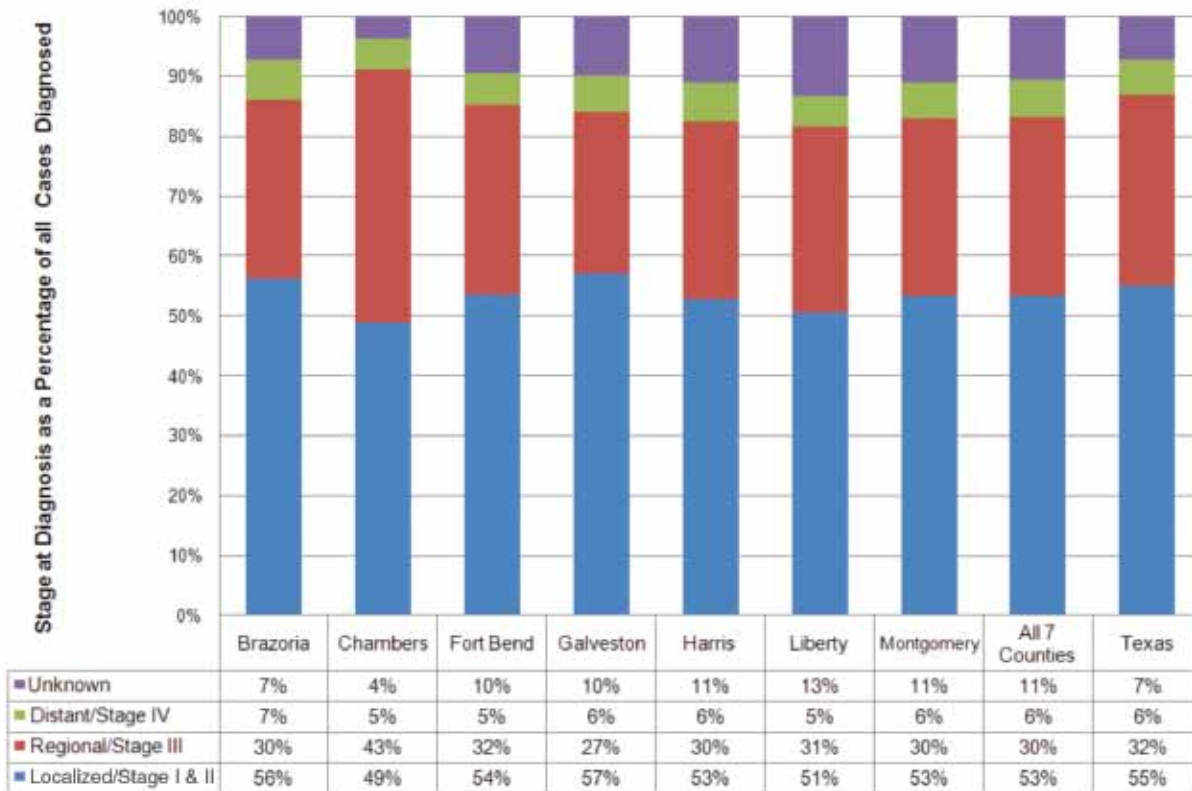
■ **Stage IV** is distant, metastatic cancer.

The cancer has spread to other parts of the body, such as the bones or liver.

Between 2003–2007, all seven counties in the Houston affiliate service area showed roughly the same proportion of female breast cancer cases diagnosed at a localized/stage II, namely between 49% to 57% of all cases. However, the percentage of all cases diagnosed at a regional/stage III varied from as low as 27% in Galveston County to 43% in Chambers County. Additionally, for all counties the proportion of all cases diagnosed at a distant/stage IV varied from 5% to 7%, with only 4% to 13% of all cases classified as of unknown stage in all localities.

Figure 2

Breast Cancer Incidence Rates for Seven County Service Area by Stage at Diagnosis, 2003-2007



Source: Texas Department of State Health Services, Cancer Epidemiology and Surveillance Branch, Texas Cancer Registry

Figure 3 illustrates the female breast cancer age-adjusted incidence rates between 2003-2007 among residents of the Houston Affiliate seven-county service area by race/ethnicity and age at diagnosis. Among all race/ethnic groups, cancer incidence rates were higher among women age 65 years and older and lower among women 39 years or younger.

Although the causes of breast cancer are not fully known, researchers have identified a number of factors that increase an individual's chances of getting breast cancer. There are some risk factors women can control and others that aren't modifiable. Even if a woman does not have any of the risk factors, she can still develop breast cancer. Some women have many risk factors but never develop breast cancer.

According to Susan G. Komen for the Cure®, risk factors that may increase the possibility of breast cancer include:

- Being a woman
- Getting older, the older a woman gets, the greater risk of breast cancer
- Having an inherited mutation in the BRCA1 or BRCA2 breast cancer genes
- Having a previous biopsy showing hyperplasia
- Having lobular carcinoma in situ (LCIS)
- Having a family history of breast cancer
- Having high breast density on a mammogram
- Being exposed to large amounts of radiation
- Having a personal history of breast or ovarian cancer
- Starting menopause after age 55
- Never having children
- Having the first child after age 35
- Having high bone density
- Being overweight after menopause or gaining weight as an adult
- Having more than one drink of alcohol per day

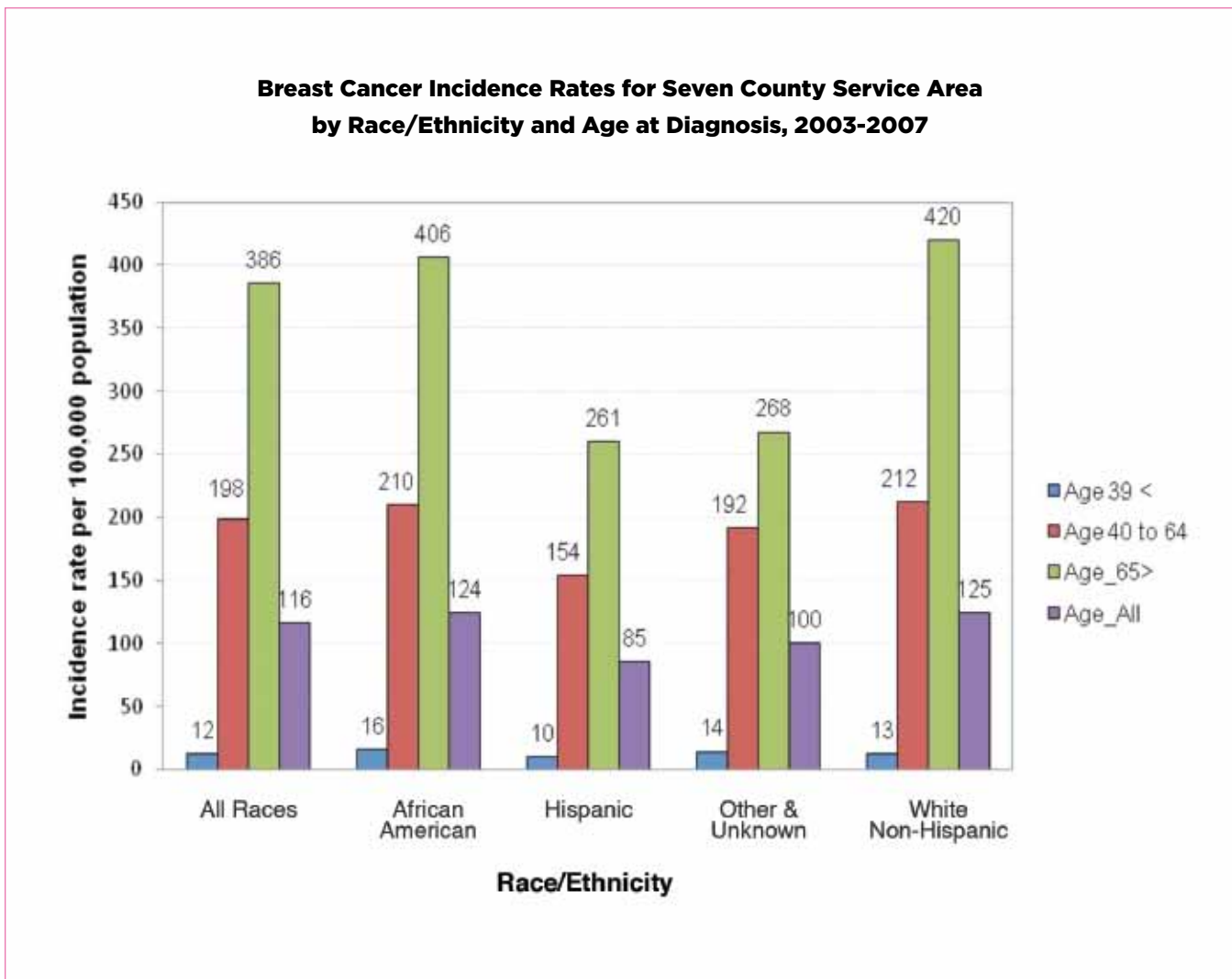
- Postmenopausal hormone use of estrogen or estrogen plus progestin
- Being younger than 12 at the time of first period
- Current or recent use of birth control pills.

In the Houston Affiliate service area from 2003 to 2007 combined, age-adjusted breast cancer incidence rates were highest among white/non-Hispanic women than among any other race/ethnic group. Amongst white/non-Hispanic women 65 years and older, the incidence rate for the five-year period was 420 new cases per 100,000 population at risk, followed by 406 new cases per 100,000 population for African American women. The race group labeled as "Other/Unknown" is composed of Asians, Pacific Islanders, Native Americans and all females reporting mix race/ethnicities. Among women identified in the group "Other/Unknown," up to 86% reported belonging to two or more races, one of which was Hispanic.

According to the American Cancer Society, among all racial or ethnic groups, white non-Hispanic women exhibit the highest incidence rate of breast cancer but, among women under the age 40 years, both white non-Hispanic and African American women have similar incidence rates. However, African American women are more likely to be diagnosed with larger tumors than white non-Hispanic women. Hispanic/Latina women have a lower incidence of breast cancer than white women. As with African Americans, they are more likely to be diagnosed with larger tumors and late stage breast cancer than white non-Hispanic women.

In general breast cancer incidence rates among Asian women are low. Nevertheless, when Asian women migrate to the U.S., their risk of developing breast cancer increases up to six-fold. Asian immigrant women living in the U.S. for as little as a de-

Figure 3



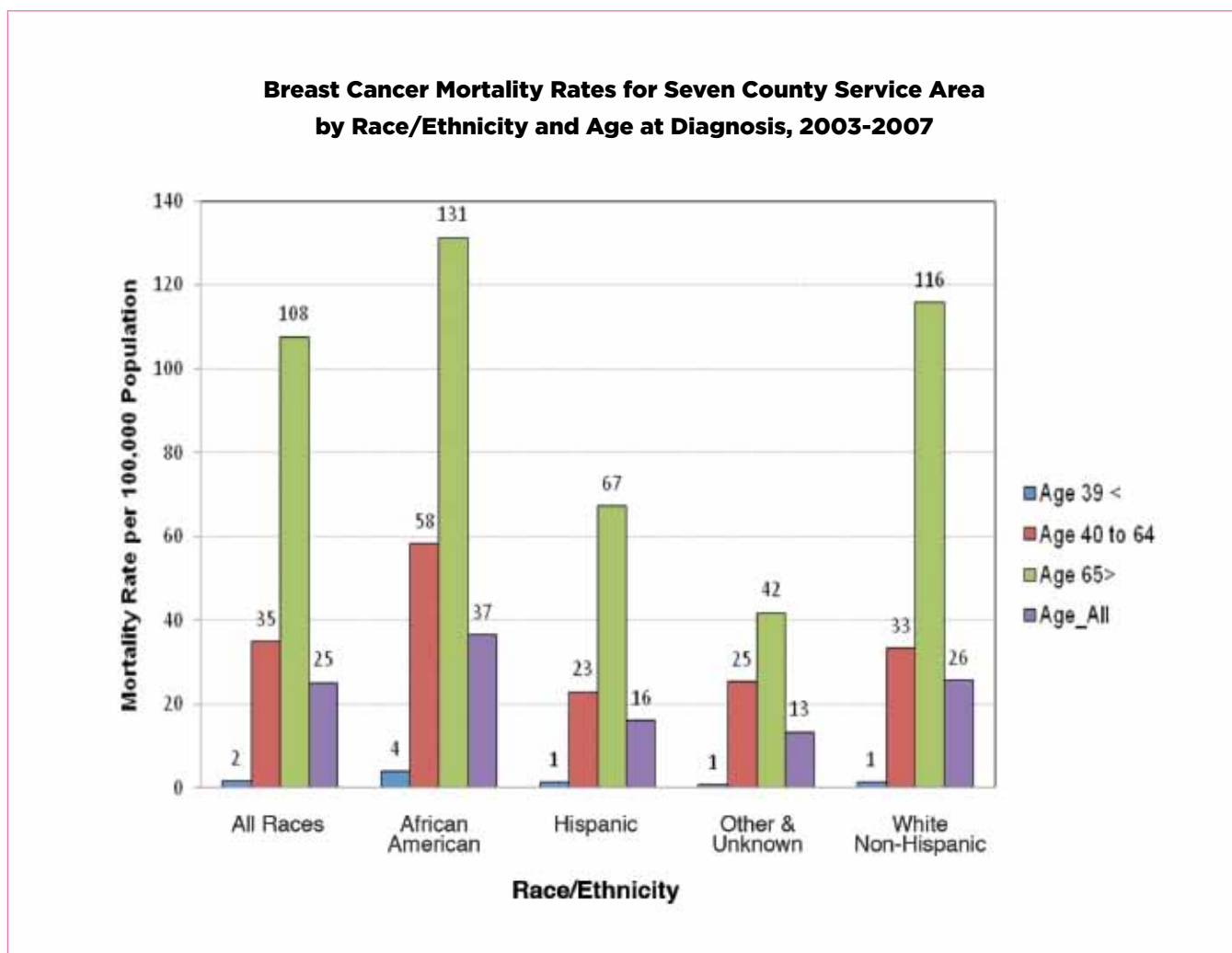
Source: Texas Department of State Health Services, Cancer Epidemiology and Surveillance Branch, Texas Cancer Registry

cade had an 80% higher risk of breast cancer than new immigrants.

Figure 4 on page 22 illustrates the age-adjusted female breast cancer mortality rates among residents of the Houston Affiliate service area by race/ethnicity and age at death from 2003 to 2007. Breast cancer mortality rates were higher among women

age 65 years and older in all race/ethnic groups, and lower among women aged 39 years or younger. A cancer mortality rate is the number of deaths, with cancer as the underlying cause of death, occurring in a specific population during a year. Cancer mortality rate is usually expressed as the number of deaths due to cancer per 100,000 of the population at risk.

Figure 4



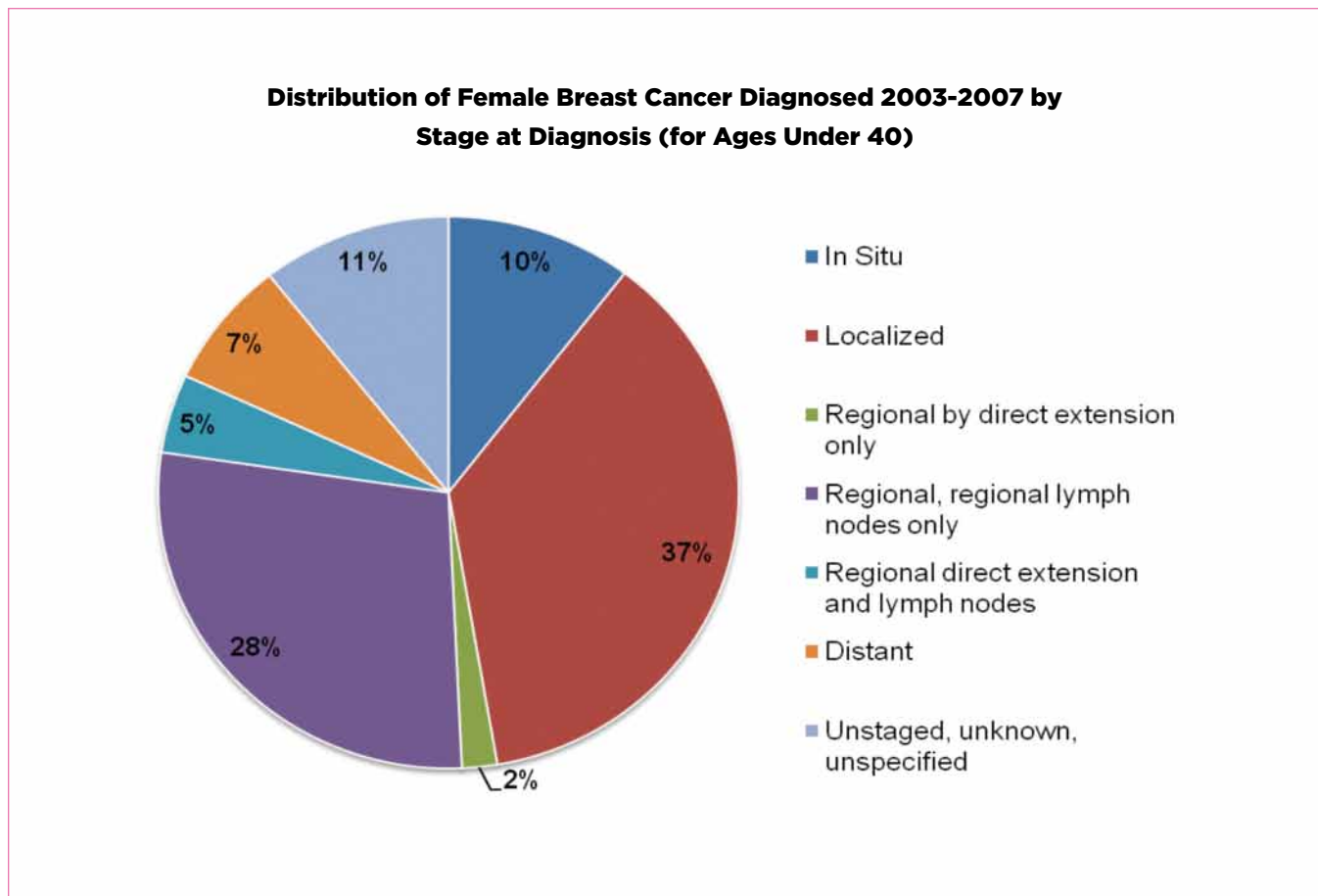
Source: Texas Department of State Health Services, Cancer Epidemiology and Surveillance Branch, Texas Cancer Registry.

In the Houston Affiliate service area for the time period 1995-2007, African American women exhibited the highest breast cancer mortality rate in all age groups. After African Americans, white-non-Hispanic women displayed the second highest breast cancer mortality rates in all age groups. The race group labeled as “Other/Unknown” is composed of Asians, Pacific Islanders, Native Americans and all females reporting mix race/ethnicities. Up to 86% of women identified in this group reported belonging

to two or more races, one of which was Hispanic. Even though white women get breast cancer at higher rates, African American women are more likely to die from it.

Several research projects are currently being conducted to address the breast cancer disparities that are seen in the Komen Houston affiliate service area. They are described in the community asset section of this profile.

Figure 5



Source: Texas Department of State Health Services, Cancer Epidemiology and Surveillance Branch - Texas Cancer Registry

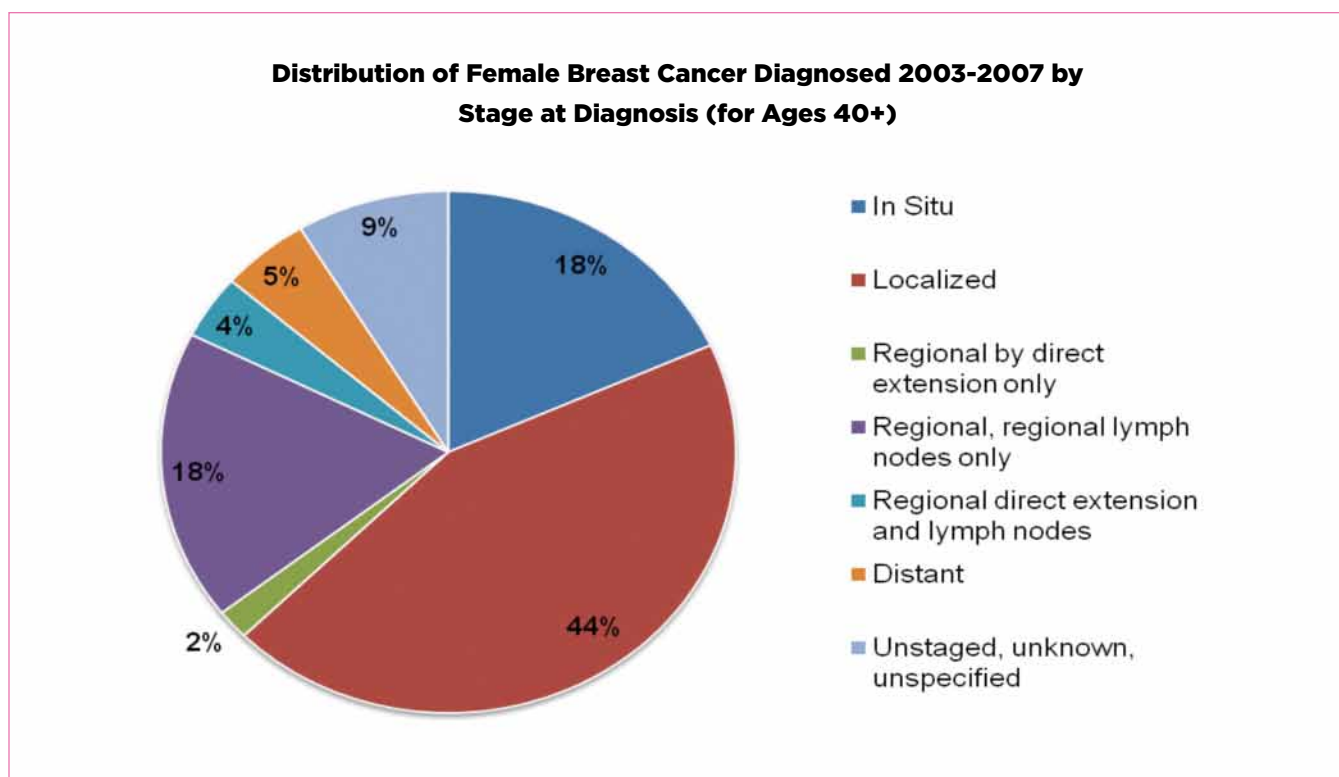
Figure 5 illustrates the distribution of all female breast cancer cases by stage of diagnosis among women younger than 40 years of age between 2003 and 2007 for residents of the Houston Affiliate service area.

According to the American Cancer Society, diagnosing breast cancer in young women can be challenging because their breast tissue is often more dense than the breast tissue of older women. By the time a lump can be felt in young women, it is often large enough and advanced enough to lower their chances of survival. Additionally the cancer

may be more aggressive and less responsive to hormonal therapies.

The highest percentage of cases of breast cancer among young women less than 40 years of age was diagnosed at a localized stage (37%), followed by 35% of cases diagnosed at all regional stages. Only 7% of cases were diagnosed at the distant stage or metastatic involvement. It is important to note that there were more advanced cases of breast cancer (all regional and distant) diagnosed among younger women (42%) than among women 40 years or older (29%). See **Figure 6**.

Figure 6



Source: Texas Department of State Health Services, Cancer Epidemiology and Surveillance Branch, Texas Cancer Registry, Incidence - Texas, 1995-2007.

Figure 6 illustrates the distribution of all female breast cancer cases by stage of diagnosis among women 40 years of age or older between 2003 and 2007, for residents of the Houston Affiliates service area.

The highest percentage of cases of breast cancer among women 40 years old and older was diagnosed at a localized stage (44%), followed by cases diagnosed at all regional stages (24%). Only 5% of cases were diagnosed at the distant stage or metastatic involvement. It is important to note that there were more cases of “non-invasive” ductal carcinoma in situ (DCIS) diagnosed among women 40 years or older (18%) than among women younger than 40 years at the time of diagnosis (10%).

Precancerous cells that remain in one location rather than invading other tissue are called in situ. The expression “In Situ” means “in place.” Ductal carcinoma in situ (DCIS), is diagnosed when cancer cells are found in a duct of the breast, and is limited to the inside of the duct, without any breakthrough into surrounding tissue.

DCIS is the most common type of non-invasive breast cancer. Ductal means that the cancer starts inside the milk ducts. Carcinoma refers to any cancer that begins in the skin or other tissues that cover or line the internal organs. DCIS is not life-threatening, but having DCIS can increase the risk of developing an invasive breast cancer later.

The 2011 Houston Affiliate Community Profile provides an overview of data on the seven counties serviced by Houston Affiliate. This year Montgomery County has been selected for additional data gathering because the high incidence rate of breast cancer experienced among the white female population. Additionally, although Komen Houston Affiliate has served Montgomery County for over 20 years, until 2011 no targeted needs assessment of the County had ever been conducted by the Affiliate. Furthermore, until 2011 there was not a Komen grantee funded program in Montgomery County.

Montgomery County is one of the seven counties that make up the Houston affiliate service area. The County is located north of Harris County. Forty-five miles separate Conroe, the Montgomery County seat, to downtown Houston in Harris County. It covers a land area of 1,044 square miles and according to the 2010 U.S. Census Bureau it possesses a population of 455,746 people.

According to the 2008 Population Statistics of the U.S. Census Bureau, the racial makeup of the county

was 75% White, 5% African American, 18% Hispanic, 2% Asian, and 2% Other.

According to the 2010 U.S. Census statistics, the median income in Montgomery County for a household was \$65,130. About 8% of families and 11% of the population were below the poverty line. Of the total population of the county age five and older, 17% spoke a language at home other than English. Among people 25 years and older, 85% had graduated from high school and 29% had a bachelors degree or higher.

The 2009 American Community Survey of the Census Bureau reported that in Montgomery County 22% of the adult population 18 years of age or older was uninsured. Among women 40 years and older the prevalence of mammogram examination was reported as 71% in 2008 (Texas Behavioral Risk Factor Surveillance System, 2002-2008 combined).

Figures 7 and 8 illustrate the 2003-2007 five year female breast cancer incidence and mortality age-adjusted rates among all age/race/ethnicity resi-

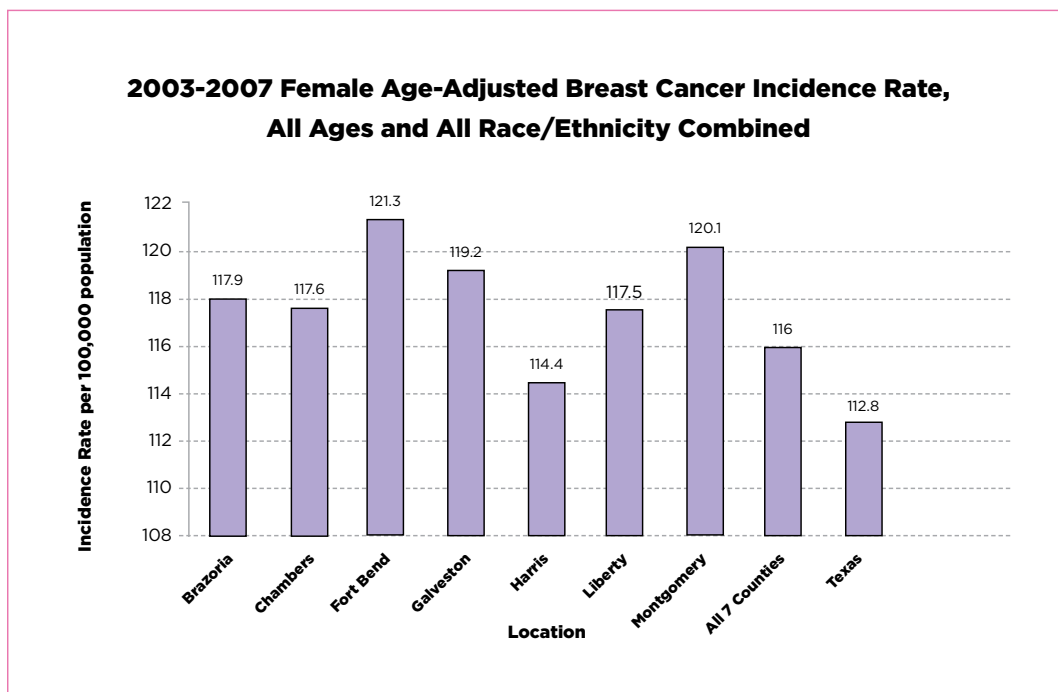


Figure 7



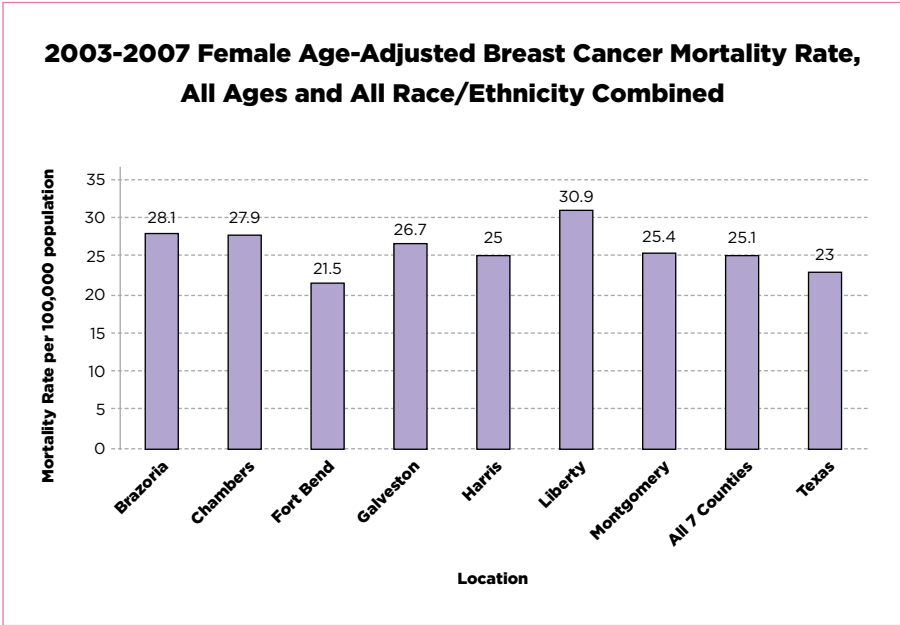


Figure 8



Source of data for figures 7 and 8:
Texas Department of State Health Services,
Cancer Epidemiology and Surveillance
Branch, Texas Cancer Registry,
Incidence/Mortality - Texas

dents for each county of the Komen Houston Affiliate service area and Texas. In Montgomery County, the five year age-adjusted incidence rate of breast cancer was 120.1 cases per 100,000 of population for all race/ethnicities combined (**Figure 7**). In addition, the 2003-2007 female breast cancer age-adjusted mortality rate for all ages/race/ethnicity combined was 25.4 per 100,000 population in Montgomery County (**Figure 8**).

The Affiliate held the qualitative data collection activities in Harris County but invited survivors, breast health providers and navigators from all the counties that comprise the Affiliate service area.

Harris County has a female population of 2,055,054 people residing in the county, accounting for roughly 70% of the total female population of women in the Affiliate service area. Harris County residents experienced the lowest prevalence of mammography utilization (55%), and the highest proportion of uninsured adults (30%) off all counties in the affiliate service area.

Harris County is the most populous in the state of Texas and the third most populous in the United States. The County covers an area of 1,778 square miles. According to the U.S. Census Statistics Harris County had in 2010 a total estimated population of 4,092,459 people with 2,367 residents per square mile.

According to the 2008 Population Statistics of the U.S. Census Bureau, the racial and ethnic make-up of Harris County was 38% Hispanic, 37% White, 18% African-American, 5% Asian and 1% Other.

The median income for a household in the county was \$50,577. In 2010 the per capita income of the county (the sum of total income of everyone in the County divided by the County population) was \$26,498. About 14% of families and 17% of the population were below the poverty line.

Within Harris County, hospital services for the indigent and low income patients are provided by the Harris County Hospital District, a separate govern-

mental entity. Harris County Hospital District operates three hospitals: LBJ General Hospital, Quentin Mease Community Hospital and Ben Taub General Hospital, as well as many clinics. Additionally, numerous private and public hospitals operate in Harris County, including institutions in Texas Medical Center and throughout the county.

Health Systems Analysis

The breast cancer “Continuum of Care” is a model describing an integrated system of breast health care through a sequential structure of interrelated health services spanning all stages of care, from the initial screening, diagnosis, treatment and survivorship, to end of life care.

The breast cancer “Continuum of Care” model (Figure 9) is used as a conceptual framework to identify the requirements, deficiencies and oppor-

tunities for all stakeholders involved in the care of breast cancer patients in the Affiliate service area.

Methodology

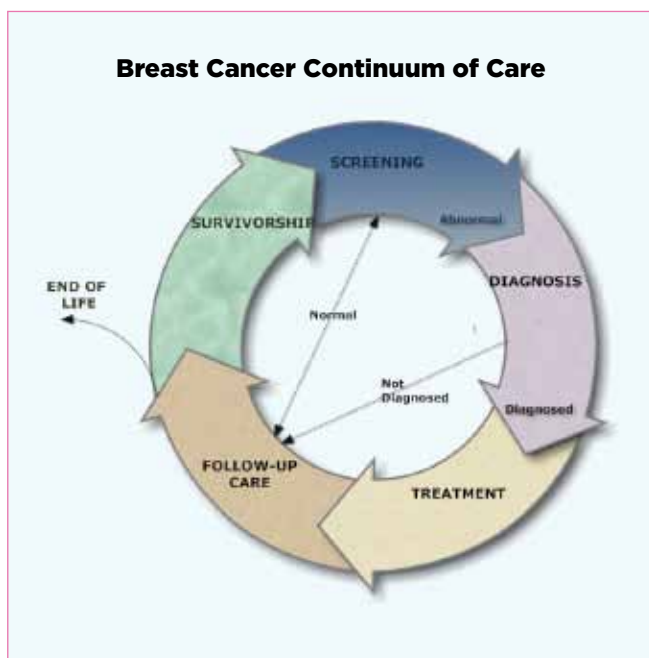
As part of the health system analysis, the Affiliate assessed:

- Services offered by current grantees on the continuum of care
- Breast health service providers listed on the Breast Health Portal
- Breast and Cervical Cancer Services providers
- Public Policy Issues and Partnerships
- Grant Opportunities
- Montgomery County activities
- Surveys from key informants
- Results from Participatory Action Research (PAR) group activities
- Interviews from experts on end of life care

Overview of Community Assets

Twenty-two agencies and programs received grants from the Komen Houston Affiliate for the 2011-2012 year. All funded programs will serve low income women from different race/ethnic backgrounds in communities that make up part of the Houston Affiliate seven county service area. For the first time in 2011, the Houston Affiliate has at least one funded program in each of the seven counties it serves. The Affiliate grant program has grown dramatically during the last year; as a result it was able to award funds to six grantees that were not funded during the previous grant year. Additionally, for the first time Komen Houston Affiliate has a grantee located in Montgomery County.

Figure 9



The Houston community has a long and strong history of inter-agency collaboration. One example of this collaboration is how The Rose partners with over six different Houston Komen grantees to provide mobile mammography to clients at their different facilities. In addition, The Rose also has Memorandums of Understanding that allow the agency to provide breast diagnostic services to the patients of over nine other Komen grantees. To help with the transportation challenges in our region, the service area has five mobile mammography units located at UTMB at Galveston, Harris County Hospital District, The Rose (two units) and MD Anderson Cancer Center.

Houston is also home to the Harris County Hospital District. Four of the current grantees provide services to patients at the Hospital District. These grantees are Harris County Hospital District Foundation, Baylor College of Medicine (Ben Taub Hospital) and two grants for MD Anderson Cancer Center (LBJ Hospital).

Patient navigation in the Affiliate service area is offered by several grantees to help clients navigate the health care system and move through the continuum of care model from screening to treatment. One focus of the 2009 Community Profile was to perform an extensive assessment of patient navigation in the service area, including navigator's responsibilities, achievements and obstacles. According to Wells et al, a patient navigator is "an individual who provides any type of service that assists others in overcoming obstacles along the continuum of cancer care system." This includes assistance during the screening or treatment stages of care, as well as support for coping with the challenges of survivorship.

Several research projects are currently being conducted to address the disparities in breast cancer mortality rates that exist in the Affiliate service area.

Starting in 2008, the Avon Foundation of Women funded the Center for Research on Minority Health, Division of Cancer Prevention & Population Sciences, Department of Health Disparities Research at the University of Texas MD Anderson Cancer Center, lead by Dr. Lovell A. Jones, to study the access and capacity of breast health services in Harris County. A taskforce was formed with the goal to develop a plan to reduce breast cancer mortality for African Americans and Hispanics by identifying the capacity and access of screening and diagnostic treatment facilities in Harris County. The preliminary survey was modeled after the Chicago Study, "Breast Cancer in Chicago: Improving Mammography Quality and Eliminating Disparities" which provided a comprehensive look at the epidemiology of breast cancer in Chicago. In 2010 the study was expanded to include the seven counties that border Harris County. For 2011, the study will conduct an assessment of issues surrounding accessibility, availability and barriers to breast health services in the Hispanic and African American communities; and develop educational initiatives and reports to increase mammography usage.

In 2010, the Avon Foundation for Women funded a collaborative initiative between the Breast Health Collaborative of Texas and St. Luke's Episcopal Health Charities to launch a research and outreach program with the intent on changing behaviors; creating and expanding access to breast health screening facilities and continuum of care services available to minority women; and creating future access to care options. In addition to the mortality disparity between African American and white women, the incidence rate in Hispanic women continues to increase disproportionately. For years mobile mammography has been used throughout the Houston area, yet the 'no-show' rate continues to be excessively high (33% among African American and 26% among Hispanic populations). Different strategies

are needed to reach and educate the low-income, uninsured women. Priority goals involve creating new or expanding existing safety net services focused on serving these two target populations. The Charities has involved community-based participatory focus groups, and in 2011, they are finalizing the questionnaire to identify barriers and to achieve the ultimate goal of earlier detection of disease impacting mortality rates due to delay of diagnosis and treatment within minority communities.

Komen Houston has been part of both of these projects in various capacities. Once the final reports and next steps are complete, Komen will review the findings for any recommendations applicable to our programs.

The Breast Health Portal is a joint effort between St. Luke’s Episcopal Health Charities and the Breast Health Collaborative of Texas. The objective of the project is to consolidate all information regarding breast health services offered in the state of Texas into one online database with mapping capabilities. The website, www.breasthealthtexas.org, contains demographic information related to population and insurance status, incidence/mortality data, and location of city clinics, county clinics, Federally Qualified Health Centers (FQHC’s), Hospital District services, and non-profit organizations offering breast health services. Currently, the database contains information from 70 sites including Affiliate grantees, members of the Breast Health Collaborative of Texas and several other non-profit breast health providers in 39 counties. Future efforts will be dedicated to expanding the Portal to include sites from all of Texas. The Portal can help individuals, patient navigators and researchers identify breast health services.

Map 3 shows the location of facilities offering breast health services in the Affiliate service area, encompassing Brazoria, Chambers, Fort Bend, Galveston,

Harris, Liberty and Montgomery counties, according to the Breast Health Resource Mapping Project. The flags represent the location of the: Federally Qualified Health Centers (FQHC’s), hospital district facilities, city clinics, county clinics, and non-profit organizations currently active in the Affiliate service area.

They include 10 Federally Qualified Health Centers (FQHC):

- Fort Bend Family Health Center, Inc.
- Good Neighbor Healthcare Center-North
- Good Neighbor Healthcare Center
- HOPE Clinic
- Legacy Community Health Services
- Legacy Community Health Services at Lyons
- Legacy Community Health Services-Baker Ripley
- Legacy Community Health Services-Southwest Clinic
- Lone Star Family Health Center
- West Chambers Medical Clinic

Fifteen Hospital District facilities:

- Aldine Community Health Center
- Acres Home Clinic
- Conroe Regional Medical Center
- Bayside Community Hospital
- Ben Taub General Hospital
- El Franco Lee Clinic
- Lyndon B Johnson General Hospital
- Martin Luther King Jr. Health Center
- Northwest Clinic
- People’s Health Center
- Quentin Mease Community Hospital
- Settegast Clinic
- Strawberry Health Center
- Baytown Health Clinic
- Casa De Amigos Clinic

Seven private-non-profit service providers:

- American Cancer Society
- Light and Salt Association-Cancer Support Network
- San Jose Clinic
- Shalom Health Ministry, Inc.
- The Rose Galleria
- The Rose Southeast
- CanCare, Inc.

Thirteen non-profit hospitals/clinics:

- The University of Texas Medical Branch
- UTMB Angleton Clinic
- UTMB Pearland Regional Maternal Child Health Programs Clinic
- UTMB Stafford Regional Maternal Child Health Programs Clinic
- MD Anderson Cancer Center Mobile Mammography
- Memorial Hermann Northeast
- Memorial Hermann The Woodlands Hospital
- San Jacinto Methodist Hospital
- The Mermaid Project, Brazosport Regional Health System
- UTMB Conroe Regional Maternal Child Health Programs Clinic
- UTMB New Caney Regional Maternal Child Health Programs Clinic
- CHRISTUS St. John Hospital
- UTMB Katy Regional Maternal Child Health Programs (RMCHP) Clinic

Breast and Cervical Cancer Services

The Texas Department of State Health Services' Breast and Cervical Cancer Services program

Map 3

Breast Health Service Providers for Service Area, 2010



(BCCS) offers clinical breast examinations, mammograms, pelvic examinations and Pap tests throughout Texas at no or low-cost to eligible women. BCCS is partly funded by the Centers for Disease Control and Prevention National Breast and Cervical Cancer Early Detection Program.

The breast and cervical cancer screening and diagnostic services are provided at no cost to low income women who have no health insurance at over 200 sites throughout Texas by local and regional health departments, community health centers, university-

based teaching institutions, public and private hospitals, and other community based organizations.

The main challenge that the State faces in serving qualified women is that current funding levels can only serve a small percentage of BCCS's target (50-64 year old) population in Texas. The target population includes approximately 200,000 eligible women and there are approximately 15,000 being screened per year (as of June 2010). On September 1, 2007, Texas Senate Bill 10 went into effect, extending Medicaid coverage for low-income women who have been diagnosed with breast or cervical cancer, regardless of the clinic or provider who diagnosed the cancer.

Previously, only women who were screened from designated state contractors were eligible for Medicaid for Breast and Cervical Cancer (MBCC) through the BCCS program. Senate Bill 10 extended this coverage to all low-income women that: are currently uninsured, have a family gross income that is \leq 200% of the federal poverty level, are documented U.S. citizens or qualified aliens, are Texas state residents, and are under age 65. For eligible women under the BCCS program, MBCC coverage begins on the day after their date of diagnosis.

Once enrolled, the women benefit from full Medicaid coverage--not solely coverage of services related to breast and cervical cancer. Their MBCC eligibility continues for the period of time that the woman is considered to be in active treatment for breast cancer. Once treatment is over and MBCC eligibility has thus expired, if a woman should then experience a breast cancer recurrence, she must reapply to be eligible for MBCC (Texas Department of State Health Services, 2008).

The program has had great success in the number of women who were treated under MBCC. Accord-

ing the Texas Department of State Health Services, 1,730 applications were processed for MBCC from July 2009 to June 2010. If MBCC were not available, women would have had more delays in treatment, received fragmented cancer care or received no cancer care at all.

The Komen Houston Affiliate grantees and subcontractors who are also BCCS providers include:

- Galveston County Health District
- Harris County Hospital District
- Health Center of Southeast Texas
- Lone Star Community Health Center
- The Rose
- The University of Texas Medical Branch at Galveston

Komen Houston Affiliate Current and Future Role in Breast Health Policy

Texas has felt the impact of the economic recession. In 2011, access to state funded safety-net programs was in jeopardy of severe and debilitating cuts by the Texas Legislature. Economic conditions forced legislators to make difficult decisions with regards to the budget. The Komen Houston Affiliate advocated for:

- Continued funding of the Breast and Cervical Cancer Services Program
- Continued and full funding of the Cancer Prevention and Research Institute of Texas
- Breast density legislation relating to information on mammography reports regarding dense breast tissue.

Komen Houston has an active Public Policy Committee to monitor and support key legislative issues at a state and federal level. The Committee attends

Komen Advocacy Days in Austin and Washington, D.C. to ensure continued funding for breast cancer research and access to breast cancer services for the most vulnerable women in Texas.

Grant Opportunities

The Komen Houston Affiliate has been able to support the funding needs of a very strong pool of applicants throughout the years. However, given the new legislative environment and upcoming changes in the health care system nationwide, it is imperative that current and future grantees make an additional effort to measure the baseline utilization of services at their agencies, applying evidence-based practices and developing concrete short and long term outcomes to guide their program development and funding requirements.

An example of the need for more baseline information came during the needs assessment activities conducted as part of the current community profile. Fifty breast health providers were asked the question: “In the areas served by your facility/program, what percent of women over 40 years of age have had a mammogram?” Unfortunately, only 43% of the breast health providers asked was able to provide an informed response.

Public Policy Partnerships

The Komen Houston Affiliate is also an active member of the state cancer coalition, Cancer Alliance of Texas. The mission of the Cancer Alliance of Texas (CAT) is to engage organizations, agencies, institutions and individuals to work collaboratively to reduce the impact of cancer in Texas and promote the Texas Cancer Plan.

In 2005, the Komen Houston Affiliate was one of the founding members of the Breast Health Collaborative of Texas. The Collaborative is composed of over 275 members from all over Texas, including Houston, Galveston, San Antonio, Austin, El Paso, Dallas and the Panhandle area. It’s mission is to unite breast health advocates and providers in order to educate, promote and leverage resources in Texas. The Breast Health Collaborative of Texas meets on a bi-monthly basis. Additionally, the Collaborative hosts an annual Breast Health Summit, a two-day, statewide Summit that is open to anyone interested in breast health issues and attracts physicians, nurses, community health workers, social services workers, survivors, caregivers and advocate/supporters. The exchange of information and strategic alliances facilitated by the Collaborative are increasing clinical pathways for the medically underserved who are in need of breast cancer education, screening and treatment.

End of Life Care

Based on feedback from the community, Komen Houston and the researchers wanted to enquire further concerning end of life care for breast cancer patients. This aspect of the continuum of care is often omitted from the list of priorities. The Affiliate intentionally included questions with regard to end of life care needs to the key informants in the self-administered surveys, few responses were offered. Although, some key informants reported referred women in the late stage of breast cancer disease to hospice, no direct services were listed. Therefore Komen Houston contacted two experts in the hospice field to better understand the issues breast cancer patients may encounter if the disease progresses to a terminal stage.

According to directors and providers of end of life care, in the late terminal stage, breast cancer patients have the same needs and concerns as other patients facing the last days of a terminal illness. These would include anticipatory grief, custodial care needs, financial concerns, caregiver stress and symptom management, among other issues and concerns. Hospice facilities recommend a palliative care program including the reduction of suffering and the improvement of quality of life.

Hospice care is available to patients who have life-limiting disease with a prognosis of six months or less if the disease follows its natural course. Medicare, Medicaid and third party payers provide coverage to varying degrees. Not for profit and some for profit hospices serve non-funded patients. Hospice care is optimized when patients are admitted earlier in their course of their disease, with a prognosis of at least a few months of life.

A patient qualifies for palliative care when the physician cannot do any more for the patient during the last six months to a year of life. Patients with six months to a year of life remaining are usually referred from the hospitals to an outside Hospice, or to home care. Patients too ill to go to an outside Hospice are usually referred to in-patient hospice, where staff addresses their clinical needs in partnership with Hospice staff. If the patient has hospice or some palliative services, an interdisciplinary or multidisciplinary team would provide information and support. In the case of hospice, this would include physician, nurse, social worker, volunteers, bereavement coordinators and chaplaincy.

Patients and care givers need to be educated about early recognition of potential end of life situations. Patients should be given an opportunity to discuss all options available with their physicians and staff. Care givers should not focus only on treatment success. Quality of life goals of

the patient need to be discussed and respected, therefore providing patients with the opportunity to complete their preparation.

Needs and concerns of end of life cancer patients certainly do vary by age, ethnicity, income, education and religion. Although there aren't differences by gender, when it comes to differences in education and income, better educated patients and families have generally investigated options before hand and are more open to alternative care options. Additionally, less educated families have a hard time understanding the consequences of keeping a patient alive when the condition is not survivable.

Montgomery County

In 2009, the Montgomery County Advisory Council was created to lead the breast cancer movement in Montgomery County by advancing the mission of the Komen Houston Affiliate to meet the local needs of the community. The Council created a two-year plan to implement its objectives and strategies. Strategies included building an Advisory Council of at least ten organizations, hosting a Komen Houston grant writing workshop and building a group of volunteers.

The Council members include local businesses and health organizations, including Memorial Hermann Hospital The Woodlands, St. Luke's Hospital The Woodlands, MD Anderson Cancer Center The Woodlands, The Rose, Lone Star Family Health Center and Texas AgriLife.

In 2010, the Council hosted the 2010 Komen Houston Race for the Cure® press conference and kick-off event, several volunteer orientations and the Affiliate's first grant writing workshop outside of Harris County.

Currently there is only one Hospital district, one FQHC, three BCCS clinics, and four non-profit hospitals located in Montgomery County serving the breast health and treatment needs of the low income population.

- The University of Texas Medical Branch - Conroe Clinic
- Lone Star Community Health Center - Conroe
- Interfaith Community Clinic
- St. Luke's Hospital The Woodlands
- Memorial Hermann Hospital The Woodlands
- MD Anderson Cancer Center The Woodlands
- The University of Texas Medical Branch - Regional Maternal and Child Health Program - New Caney Clinic
- Conroe Regional Medical Center

Key Informant Activities: Methodology

The qualitative data, collected through a self-administered, anonymous, structured survey, were analyzed and reported in aggregate. Validity issues exist with self-reported data as responses may be affected by recall bias or information bias. Although care was taken to structure questions in a neutral manner, to use an appropriate reading level, and to translate survey materials into Spanish, validity issues may persist. A participatory approach, by its very nature public and collaborative, was used to gather key informants' views and opinions during the community needs assessment activities.

To acquire first hand information of the breast cancer experience among the target communities, a social science technique known as Participatory Action Research (PAR) was implemented. This methodology is also known as collaborative inquiry, action learning and contextual action research. Essentially

PAR is an investigative process that strives to “learn by doing”. It aims to acknowledge the experience and understanding of participants regarding a specific social/health situation in a non-judgmental environment, while giving a voice to their practical concerns. In addition, it empowers members to identify or rediscover the linkages between barriers and opportunities available to them while creating collaborative scenarios for future change.

All activities conducted during the PAR were guided by a trained facilitator whose main role was to implement the selected methods in a manner that assisted dialogue and promoted reflective analysis among the different groups of participants. To achieve this, the facilitator acted as a leader, moderator, listener, observer, synthesizer and lastly as a reporter of the conclusions agreed by all participants. The different roles were played in response to the participants interactions during the process.

A self-administered, anonymous “key informant survey” was designed and applied among participating providers and navigators. The themes addressed in the survey were originally identified during the Houston Affiliate 2009 Community Profile. Additional questions regarding programs offered at each facility, agencies involved in breast health care in the target areas, gaps in services, referral patterns and types of navigation services provided by each agency interviewed were included. Each participant had the opportunity to ask questions about the activities, read about the goals of the research and sign an individual consent form. Consent forms, surveys and activities were available in English and Spanish.

Agencies providing breast health care services to low income populations were identified and contacted. These agencies also referred the researchers to local breast cancer support groups. The PAR

activities and themes were adapted to the different key informant groups participating in the data gathering: providers, navigators, etc.

Regional breast health care providers and navigators were identified with the assistance of the Affiliate and through referrals and suggestions made by key informants during the data gathering activities. An open invitation was extended to all identified regional stakeholders. The Affiliate provided gift cards as incentive for navigators to participate in the two hour data gathering activities. Health care providers received a tote bag as a thank you gift from the Komen Houston Affiliate.

Fifty key informants participated in five data gathering activities conducted in Harris County at The Rose and United Way and in Montgomery County at Lone Star Family Health Center and Interfaith Community Health Clinic. They included 26 breast health care providers from agencies targeting breast health care services to low income populations and 24 breast health care navigators from seven counties.

The data gathering process used among navigators began with a brief introduction from the facilitator and an ice-breaker among the participants. Participants were directed to read and sign the informed consent form and to complete the ten minute self administered surveys. The interactive PAR activity was conducted as follows:

- Participants were divided into small groups, and a question to be discussed was assigned to each group
- A list of responses was prepared by each group
- Each member of the group selected the three most important responses from their list by placing a sticker next to their choice
- A speaker for the group presented the final results to the whole audience

- The whole audience was invited to provide additional comments
- An observer from the research team recorded comments and observations made by participants during the large group discussion

Among breast health care providers and administrators the introductory activities described above were implemented. However, data was collected using a card storming technique in response to a particular topic. The steps of the process were as followed:

- Participants were divided into small groups, and a question to be discussed was assigned to each group
- Each person wrote ONE characteristic/idea per card
- The facilitator grouped similar cards together as the participants placed them
- Participants worked together to identify the same or similar ideas by placing the cards in clusters
- The group decided on a name for the cluster/concept
- A large poster of cluster categories identified by the participants was prepared
- Similarities and differences between group responses were identified and discussed by the large group and a final list of ideas/characteristics was developed

Responses from participants' surveys were analyzed calculating frequencies and percentages. Open ended questions were re-coded by themes and categories. Analysis was conducted according to the type of key informant (survivor, navigator and provider) and by the County of residence for the survivors or location of the facility for the breast health care navigators/providers. Each PAR analysis consisted of reviewing all factors identified by the groups for

each topic discussed. Tables were created listing the results of the group discussion. Group members voted for the top three most important factors for each topic.



Figure 10

Key Informants Activities: Results

In **Figure 10**, breast health navigators and providers from the Affiliate service area identified a list of factors that according to race/ethnicity background, affect whether women will seek and receive appropriate breast health care.

In **Figure 11**, breast health navigators and providers identified proposed actions to address the previously identified factors that in their view affect

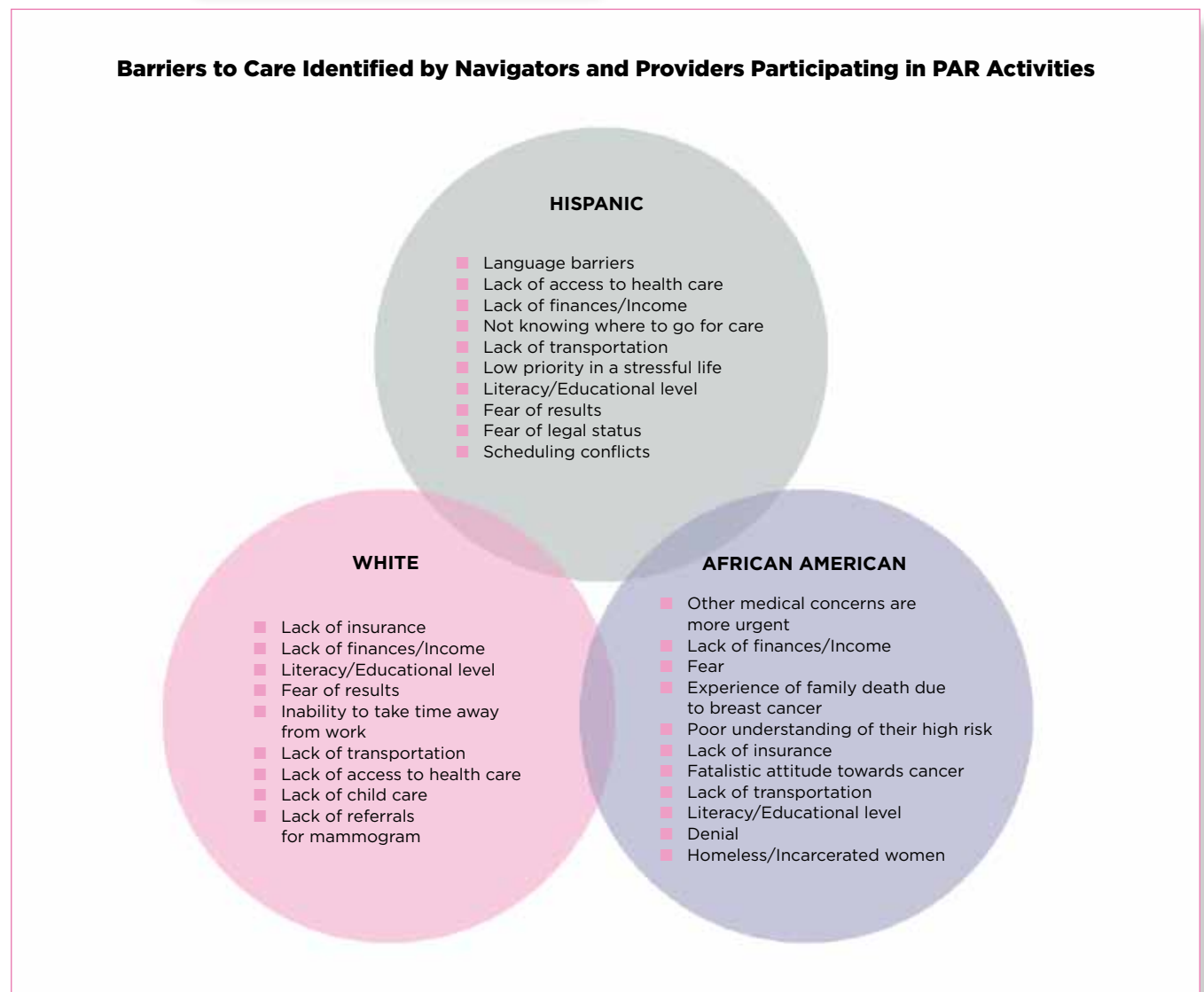


Figure 11

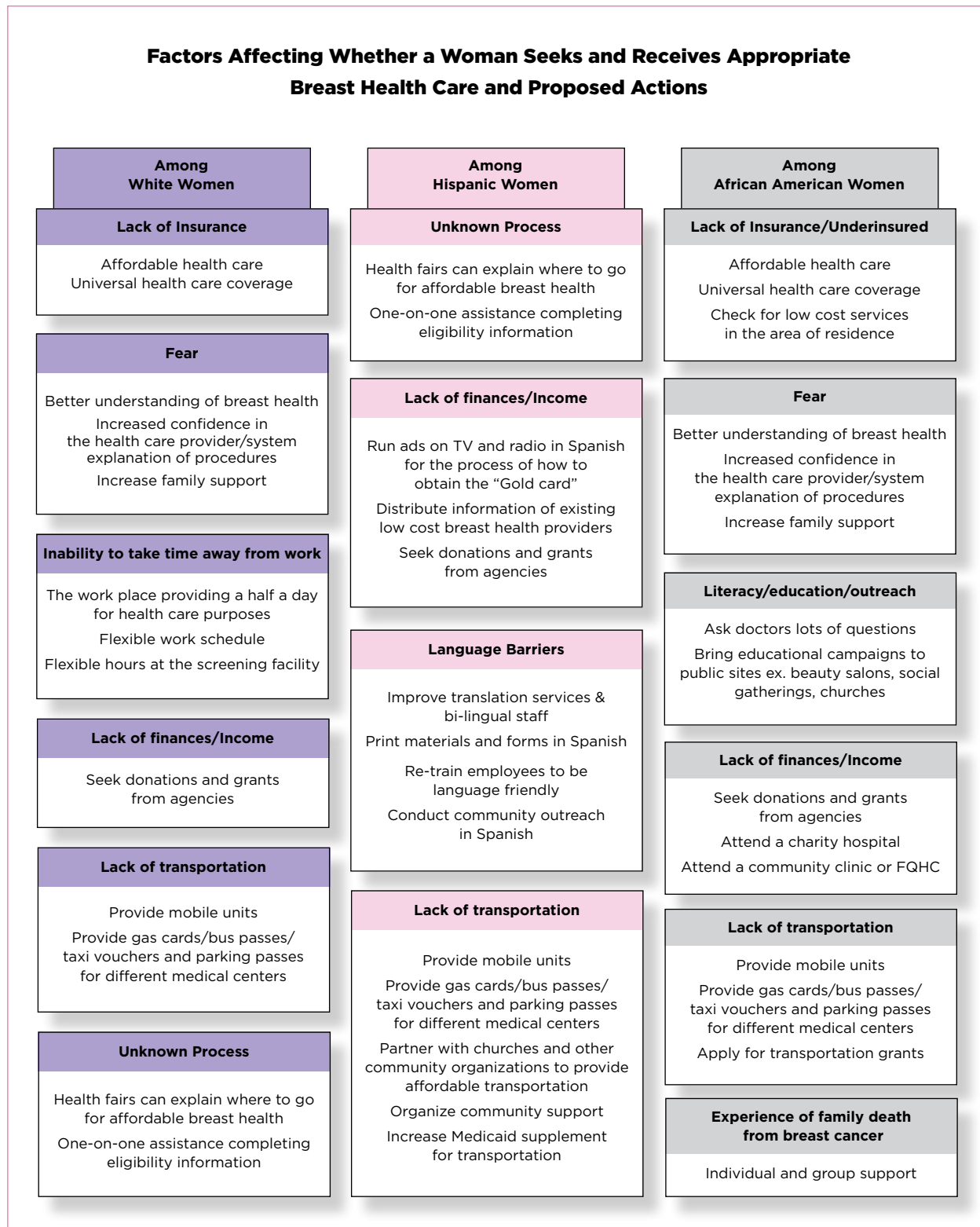
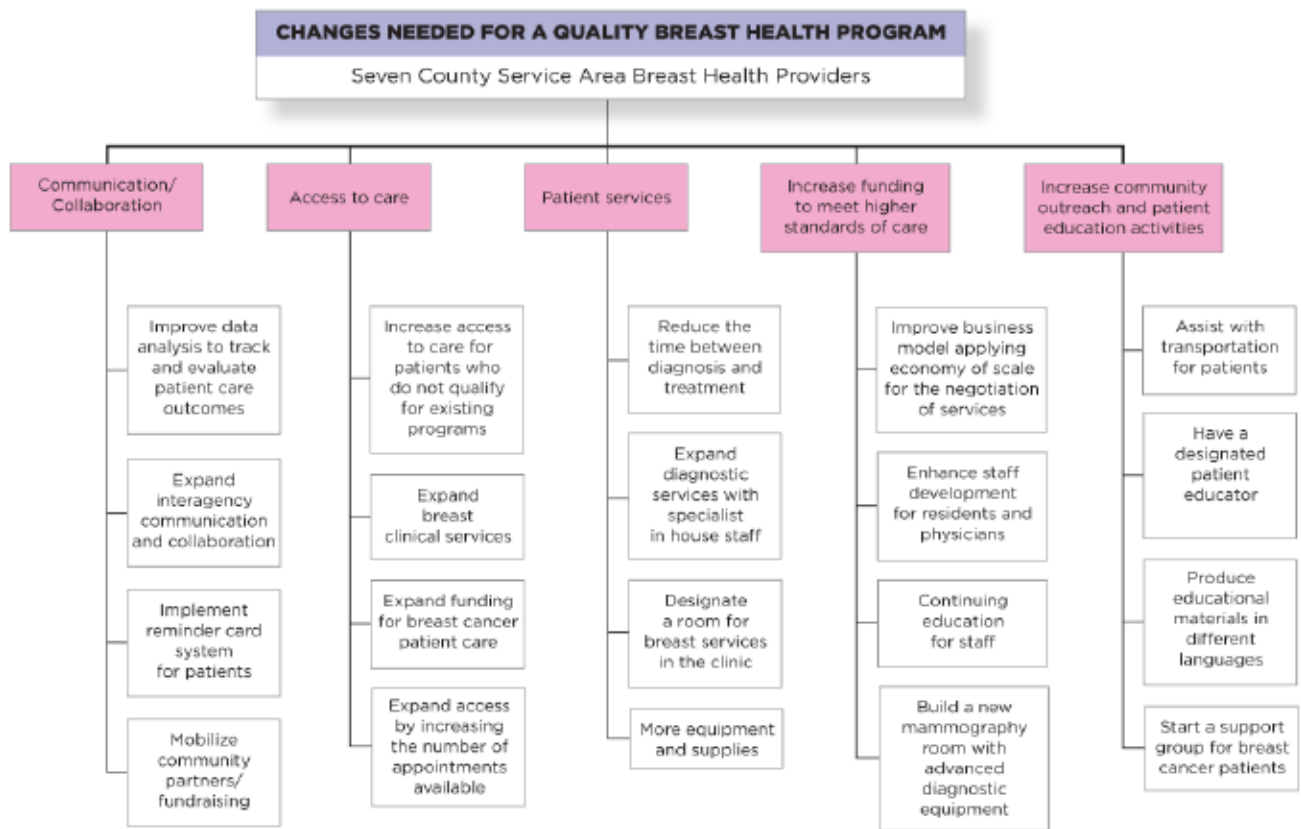
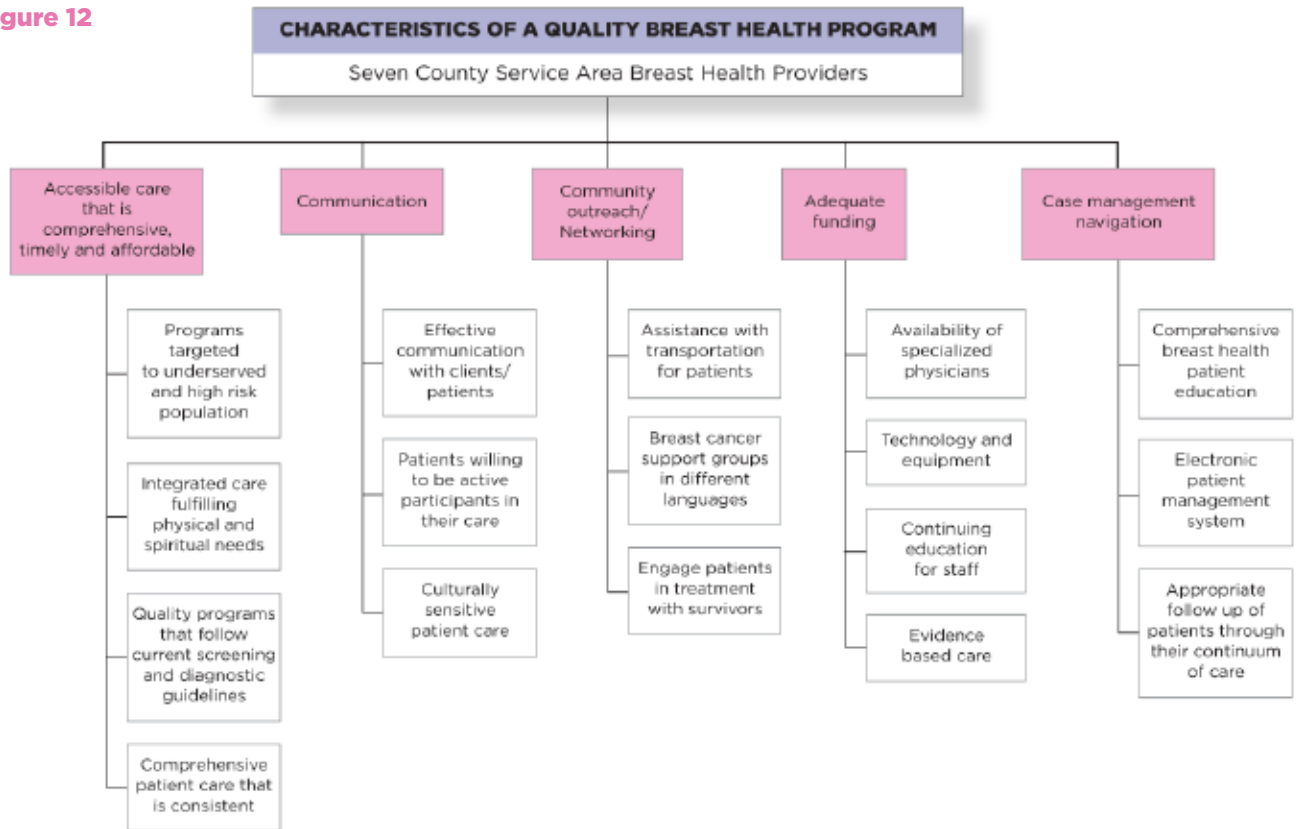


Figure 12



whether women of different race/ethnicity will seek and receive appropriate breast health care.

In **Figure 12**, 20 breast health providers from the seven county service area identified the characteristics of a quality breast health program and the changes needed in their facilities.

The following tables illustrate responses to the self-administered survey completed by 50 key informants from the Houston Affiliate service area (26 breast health providers/24 breast health navigators). **Table 7** lists the breast health related services offered and the facilities represented by the breast health navigators and breast health providers surveyed.

Key informants were asked who they thought were the most credible people providing general health

information to patients in the geographic areas served by their facility/programs. Eighty four percent of navigators and 86% of providers identified “Medical doctors/clinic staff/nurses and other health professionals”, followed by “friends and family members” selected by 16% of all the navigators and 14% of all providers.

When asked: “Where is someone likely to go for breast health information in the geographic areas served by your facility/programs?”, medical doctors/clinic staff/nurses and other health professionals were identified by 84% of navigators and 70% of providers, while friends and family members were identified by 16% of navigators and 30% of providers. Breast health navigators from the target communities identified the following resources as the most effective way to disseminate breast health information in the geographic areas served by their facil-

Table 7

Description of Services Available Among Breast Health Care Providers and Navigators, 2011 (All that apply)				
	Navigator		Provider	
	n	%	n	%
What Breast Related Services Are Offered By Your Agency/Program?				
Screening: Mammography, Mobile Unit and Bone Density	24	100	19	73
Diagnostic: Biopsy/Breast Specific Gamma Imaging (BSGI)	22	92	9	35
Treatment: Surgical/Radiation/Chemotherapy	16	67	2	8
Cancer Education	18	75	7	27
Patient Navigation/Case Management/Referral/Screening Eligibility for Medicare	4	17	7	27
Support Groups	13	54	1	4
Community Outreach/Health Fairs	15	63	5	19



ity/program: public presentations (15%), television (14.5%), newspapers or brochures/pamphlets (12%), Internet (11%), church bulletins/announcements (11%), radio (11%), with billboards (7%) and videos (6%). On the other hand, breast health providers identified the following resources as the most effective way to disseminate breast health information: radio and television (16.5%), brochures/pamphlets (16%), billboards and newspapers (12%), public presentations (11%), church bulletins/announcements (8%), with internet (6%) and videos (2%).

Table 8 illustrates the need for financial assistance among breast health clients seeking services at the programs/agencies identified in the target communities. Not being able to pay for services was identified by 27% of the navigators and 22% of the providers, followed by using Medicare/Medicaid assistance to cover the cost of breast health services (23% navigators/19.5% providers).

Table 8

In The Geographic Areas Served By Your Program/Facility, How Do Most Women Pay For The Breast Health Services?				
Resources	Navigator		Provider	
	n	%	n	%
Private insurance including HMOs	5	8	13	16
Cash	5	8	12	15
Medicare/Medicaid	14	23	16	20
Public funds/Trusts/ Charities	9	15	12	15
Can't pay	16	27	18	22
Community medical services	11	18	11	13

Table 9

What Type Of “Navigation” Services For Women With Breast Cancer Are Provided At Your Facility?				
Services	Navigator		Provider	
	n	%	n	%
Translation services	18	75	4	15
Transportation	14	58	4	15
Case management/Navigation	21	88	12	46
Referrals	14	58	11	42
Schedule appointments /Reminder calls	2	8	2	8
Social worker/Assistance with financial eligibility	-	-	3	12
Community outreach/ Community health worker	-	-	1	4
End of life care	4	17	1	4
Survivorship care	3	13	1	4
Assistance locating wigs/bras/supplies	2	8	-	-
Education/Literature	5	21	-	-

Table 9 shows the different type of navigation services and whether or no they are offered by the facilities represented by the breast health navigators and providers surveyed.

Table 10 on page 42 shows the response of 50 breast health providers to the question: “In your opinion, among patients in your community, what causes gaps in treatment services for women with breast cancer?”

Sixty-six percent of the providers identified: lack of financial resources or financial eligibility, lack of transportation and language barriers as the top factors affecting women’s ability to receive breast

treatment services in the Affiliate seven county service area.

Limitations of Qualitative Data

As with any qualitative data methodology, information gathered through Participatory Action Research (PAR) techniques may be affected by potential biases, including researcher bias that could prejudice the design of a study or enter into data collection. The validity of the information depends on the quality of the sources of data or the participants, some of whom may not be equally credible. Therefore, selecting participants with similar experi-

Table 10

In The Geographic Area Served By Your Facility What Causes Gaps In Treatment Services For Women With Breast Cancer?		
Services	Provider	
	n	%
Lack of financial resources	11	22
Lack of transportation	9	18
Language barriers	7	14
Income eligibility Gap/FPL >200%	6	12
Lack of Education/Low health literacy	5	10
Lack of insurance	3	6
No time off from work	2	4
Advertisement Barriers	2	4
Lack of documentation	2	4
Lack of access to services	1	2
Scheduling challenges	1	2
Residency Requirements	1	2

ence level and backgrounds is important. Every effort was made to standardized procedures, include participants without perceived biases, and analyze all data without a preset agenda. Also, it takes time to build trust with participants to facilitate full and honest self-representation. Fortunately these limitations were mitigated by the continuous presence of Komen in the communities served.

Key informants voluntarily completed a self administered, anonymous survey. All responses are to be considered opinions from a group of knowledgeable professionals. Given space limitations only a summary of the main ideas and questions answered are presented in this report.



Conclusions

The Komen Houston Affiliate has a long and continuous presence in the communities served, allowing the agency to successfully engage and facilitate novel inter-agency collaborations among strategic breast cancer health providers. Houston is the home to the largest medical center in the world. The Houston Affiliate benefits from the local presence of strategic partners, advocates and key players in the area of breast cancer service delivery and research activities.

Currently the Affiliate also has an active partnership with 22 agencies that are recipients of grants for the 2011-2012 time period. The Affiliate also plays an important role as a member of the state cancer coalition, Cancer Alliance of Texas. Moreover, six grantees and subcontractors are also BCCS providers including: Galveston County Health District, Harris County Hospital District, Health Center of Southeast Texas, Lone Star Family Health Center, The Rose and the University of Texas Medical Branch at Galveston.

Among breast health providers in the seven county service area, there is consensus on the need for new partnerships/collaborations among agencies providing services at different stages of the continuum of care model. Additionally, all stake holders stated the need for improved communication with their clients/patients, between agencies/providers and among suppliers/providers in order to negotiate improved cost/saving schemes.

Providers also recognized that in order to make their breast health programs accessible, comprehensive, timely and affordable, they have to expand their plans to target underserved and high risk populations, as well as to improve the quality of their programs to incorporate current screening and di-

agnostic guidelines and to make every effort to provide consistent, comprehensive patient care.

Among all providers, there was widespread agreement regarding the need for more bilingual community outreach, assistance with transportation, the potential engagement of survivors with patients undergoing treatment and the creation for culturally sensitive support groups in both rural and urban areas in the target communities.

Key informants agreed on the positive results achieved from resources spent on case management and patient navigation, as reported in current scientific literature. It was found that client navigation increases appointment follow-up and facilitates the movement of women with breast cancer through the different stages of the continuum of care model. Additionally, the interaction with patient navigators provides a suitable environment for the distribution of culturally sensitive breast health patient education.

Changes to nearly all of the factors affecting the quality of breast health programs was conditional on the availability of adequate funding to finance the cost of specialized physicians, afford new technology and equipment such as electronic management systems, facilitate access to continuing education for staff and pay for evidence-based patient care.

Overall, factors identified as barriers to breast health care among low income women included: lack of financial resources, lack of transportation, language barriers, and income eligibility gaps with clients being classified as low incomes but above the "Federal Poverty Level" guidelines, lack of education/low health literacy, and lack of insurance.

Among local breast health care providers and key informants, Susan G. Komen for the Cure®, The Rose and the “Texas Breast & Cervical Cancer Screening Program” (BCCS) are consistently recognized as the major partners in funding and sources of information and assistance.

The breast health navigators from the seven county service area expressed appreciation for the opportunity that the PAR activities provided to meet each other for the first time and to learn about new resources that could be used with their patients. They also requested a system of communication to keep in touch after the data gathering activities were concluded.

Breast Cancer Perspectives

Methodology

To acquire first hand information about the breast cancer experience of low income breast cancer survivors, three separate Participatory Action Research (PAR) activities were conducted among 31 breast cancer survivors. These activities took place at the American Cancer Society office in Houston, The Rose in Southeast Houston and Lone Star Family Health Center in Montgomery County.

We would like to recognize the assistance offered by The Rose, who facilitates more than five support groups. The Rose was extremely helpful in gathering women to participate in our activities including those taking part in the “The Rosebuds,” “The Rose Gardens” and “Las Rosas Vivas” support groups. Komen Houston also contacted the Lone Star Family Health Center in Conroe and “Breast Friends” a sup-

port group in The Woodlands in order to organize a meeting with low income breast cancer survivors in Montgomery County.

A self-administered, anonymous questionnaire was completed by the participating breast cancer survivors. The survey aimed to identify basic socio-demographic information, current and past health insurance history, breast health history, time to diagnosis and treatment, and general information regarding existing and suggested breast health services in the participant’s area of residence. Each participant had the opportunity to ask questions about the activities, read about the goals of the research and sign an individual consent form. Consent forms, surveys and activities were available in English and Spanish.

The Komen Houston Affiliate provided gift cards as an incentive for survivors to participate in the activities. The data gathering process used among survivors began with a brief introduction from the facilitator and an ice-breaker among the participants. Participants were directed to read and sign the informed consent form and to complete the ten-minute self-administered surveys. The interactive PAR activity (described in the previous chapter for the navigators) was conducted.

Results

The following tables include the responses of breast cancer survivors to the self-administered survey as well as a summary of the themes identified during the PAR activities, grouped in categories or clusters according to the participant wishes. Tables were created listing the results of the group discussion. Group members voted for the top three most important factors for each topic.

Table 11

Sociodemographic Characteristics of 31 Female Breast Cancer Survivors, 2011		
	Count (n)	Percent (%)
Age (years)		
30 - 39	21	6
40 - 59	17	55
60 - 64	12	39
Race/ethnicity		
White/Non Hispanic	10	32
African American	3	10
Hispanic/Latina	16	52
Asian/Pacific Islander	1	3
Native American	1	3
Education level		
1st - 5th	3	10
6th - 8th	6	19
9th - 11th	5	16
High school graduate/GED	2	6
Trade school/Vocational training	3	10
Some college /University	7	23
College/University graduate	4	13
Other: PhD	1	3
Marital status		
Married	16	52
Widowed	6	19
Divorced	4	13
Separated	3	10
Never married	1	3
Living with a partner	1	3
Health insurance		
Yes	27	87
No	2	6
Missing	2	6
Type of health insurance		
Through current/former employer (self/family member)	10	32
Directly purchased from insurance company (self/family member)	2	6
Medicare	7	23
Medicaid or government assistance plan	7	23
Gold Card (Harris County Hospital District Financial Assistance)	5	16

Table 12

Sociodemographic Characteristics of 31 Female Breast Cancer Survivors, 2011		
	Count (n)	Percent (%)
Total combined household income/ (past year)		
\$ 0 - \$14,999	5	16
\$ 15,000 - \$ 22,999	4	13
\$ 23,000 - \$ 39,999	3	10
\$ 40,000 +	8	26
Do not know	11	35
Number of people living in the household		
2 or less	12	39
3 - 5	12	39
6+	4	13
Missing	3	10
Place of birth		
In the U.S.	13	42
Outside the U.S.	18	58
County of residence		
Harris	12	39
Montgomery	9	29
Fort Bend	5	16
Liberty	2	6
Galveston	3	10
How long living in the county of residence (years)?		
Less than 1	3	10
1 - 5	4	13
6 - 10	3	10
11 or more	21	68
Language spoken most often at home		
English	16	52
Spanish	15	49
Current employment status		
Employed	8	26
Retired	5	16
Unemployed	3	10
Unable to work/disabled	3	10
Homemaker / other	12	39

Table 13

Mammogram History among 31 Female Breast Cancer Survivors, 2011		
	Count (n)	Percent (%)
About how old were you at your first mammogram?		
29 years or less	3	10
30 - 39 years	9	29
40 - 49 years	11	35
50 and above	5	16
Missing	3	10
Why did you go for your first mammogram?		
Physician/nurse referral	18	58
Advice from family/friends	2	6
Information from media (Radio/TV/Print)	1	3
Felt the lump/mass	6	19
Other: By chance/using my health care benefits at a health fair	2	6
Missing	2	6

Table 14

Breast Cancer History among 31 Female Breast Cancer Survivors, 2011		
	Count (n)	Percent (%)
Did you have health insurance at the time of breast cancer diagnosis?		
Yes	20	65
No	9	29
Missing	2	6
Type of health insurance when first diagnosed		
Through current/former employer (self/family member)	15	48
Directly purchased from insurance company (self/family member)	1	3
Medicare	3	10
Medicaid/Government assistance plan	3	10
Missing	9	29

Table 15

Breast Cancer History among 31 Female Breast Cancer Survivors, 2011		
	Count (n)	Percent (%)
Age at first breast cancer diagnosis (years)		
29 years or less	1	3
30 - 39 years	4	13
40 - 49 years	9	29
50 and above	12	39
Do not know	5	16
How was your lump/mass discovered?		
During routine check up by health care provider	1	3
Routine screening test	11	35
Felt the lump/mass and went to the physician	13	42
Other	2	6
Missing	4	13
Time between finding lump/mass and confirmed breast cancer diagnosis		
Less than a month	13	42
1 - 2 months	8	26
3 - 6 months	0	0
More than 7 months	1	3
Do not know/Missing	9	29
Time between breast cancer diagnosis and beginning of treatment		
Less than 1 Month	16	52
1 - 2 months	9	29
3 - 4 months	4	13
Missing	2	6
At the time of diagnosis were different types of treatment discussed?		
Yes	22	71
No	7	23
Missing	2	6

Figure 13

Themes Identified Among 31 Breast Cancer Survivors as a Result of PAR Activities

FACTORS THAT INTERFERE WITH WOMEN GETTING SCREENED

- Not knowing where to go for care
- Fear, taboo, denial
- Lack of transportation
- Lack of economic resources
- Can't take time off from work
- Risk not recognized because of a lack of family history of breast cancer
- Lack of health insurance/no referral for mammogram
- Language barriers
- Procrastination
- Not knowing where to go for care
- Lack of education regarding breast cancer screening

RESOURCES YOU HAVE FOUND

- Spiritual advisors, prayer and faith
- Family and friends
- Support groups in different languages
- Assistance from patient navigators
- The financial assistance of Medicaid, BCCS and the Gold card
- Good rapport with oncologist and surgeons
- Psychological help
- A strong positive attitude
- Support and information at the ACS, The Rose, etc.

WHAT TO DO TO ENSURE TIMELY ADEQUATE QUALITY CARE

- Assistance with transportation for screening and treatment
- Assistance obtaining breast prosthesis, bras, wigs, etc.
- Provide information in Spanish and other languages and translators
- Provide support groups in different areas of the region
- Assist agencies that can provide screening exams and treatment at a low cost and in different locations
- Provide more mobile mammogram units with a doctor to write orders for mammography
- Assist women that need financial assistance for screening exams
- Advocate providers for timely results and follow-up at same site

CHALLENGES YOU ARE FACING NOW

- Side effects from chemotherapy
- Alteration of physical appearance
- Quality of life issues
- Fear of death and the future
- Emotional pain, anger, depression
- Low self esteem
- Lymphedema issues
- Lack of access to health care
- Lack of financial resources to cover prosthesis, bras, counseling, etc.

Conclusions

The PAR activities conducted among thirty one women breast cancer survivors and relatives were very rewarding not only in terms of the human connection shared between the facilitators and participants but in terms of the valuable results achieved.

Based on sociodemographic information shared by the participants on the “Breast cancer survivor key informant survey” (Tables 11-12), the group of women was relatively young, with 54% of them between the ages of 40 and 59 years, and 52% were married. The group was diverse in regard to race/ethnic distribution with 51% Hispanic, 32% Anglo/Caucasian, 10% African American and 7% other, and with a very mixed educational attainment, with 45% of women having earned less than a high school degree.

Although 68% of the women have been living in their county of residence for more than 11 years (71% Harris County/29% Montgomery County), originally 51% were born in a country outside the U.S. Among the respondents who reported their annual income, 39% were living on an income of less than \$39,999. And, 61% of the survivors depend on Medicare, Medicaid or the Gold Card (Harris County Hospital District Financial Assistance) as a source of health insurance.

The following services were identified for the survivors as needed for women undergoing breast cancer treatment in the target communities: psychological/emotional support, nutritional counseling, patient navigation (help with making appointments, getting referrals & coordinating follow-up care), family counseling, social work (help with finances/community resources, etc), and transportation and translation services.



Some of the resources recognized by the survivors helpful in dealing with the challenges they face as a result of the breast cancer diagnosis included: faith, prayer, spiritual advisors, psychological help, support groups, the support of family and friends, having a good rapport with the oncologist and health care providers, obtaining the services of patient navigators and maintaining a positive attitude and never giving up.

All survivors reported facing daily challenges as a result of their breast cancer diagnosis, including: issues with lymphedema (accessing treatment, acquiring garments, lack of coverage by health insurance), emotional pain (anger, depression, lack of self esteem, rediscovering how to lead a normal life after breast cancer), lack of financial resources (coverage for health insurance and purchase of prosthesis), living with the side effects of chemotherapy (hot flashes, memory loss, joint pain and inflammation), fear (of death, of the future of daughters and sisters), language barriers, long term quality of life issues (social and sexual life changes, alterations in physical appearance, lack of energy, feeling older), lack of understanding among family and friends and lack of a specialist in cancer counseling.

In **Table 16**, overall breast cancer survivors identified very similar themes to those identified by navigators when asked about factors that deter women of different race/ethnic backgrounds from getting screened for breast cancer.

Table 16

General Themes Identified by Breast Cancer Survivors and Navigators by Race/Ethnicity	
Breast Cancer Survivors	Breast Cancer Navigators
Hispanic	Hispanic
Not knowing where to go for care	Not knowing where to go for care
Lack of transportation	Lack of transportation
Lack of health insurance	Language barriers
Fear of a cancer diagnosis	Lack of finances/Income
White	White
Lack of transportation	Lack of transportation
Literacy/Education	Literacy/Education
Fear of death	Fear of results
Fear of pain related to the mammography	Lack of finances/Income
Fear of disfigurement related to surgery	Lack of insurance
African American	African American
Fear of death	Fear
Lack of finances/Income	Lack of finances/Income
Lack of time	Other medical concerns are more urgent
Misinformation	Underinsured
Taboo subject not discussed	Experience of family death due to breast cancer

Conclusions: **What We Learned, What We Will Do**

The staff of Komen Houston Affiliate is indebted to all who generously volunteered their time and participated in the data gathering activities that provided the invaluable information presented in the 2011 Community Profile Report. It is hoped that this report may be used as a tool to identify opportunities for advocacy and community health organizing and as a platform and resource to develop partnerships and collaborations among breast health providers and advocates.

Findings from the scientific literature search of peer-reviewed studies published between 2005 and 2011 on breast cancer treatment and compliance among low-income women in the United States could be summarized in three groups:

- Disparities in breast cancer diagnosis and treatment
- Access to treatment and barriers to diagnosis
- Predictors of mammography compliance

In general the themes encountered within the literature review supported the findings of the data gathering activities conducted among all key informants, breast health providers, navigators and breast cancer survivors.

In most scientific studies, evidence was found of disparities in breast cancer diagnosis and follow up for treatment according to the race/ethnicity of the women treated. African Americans, Hispanics and other minorities generally experienced worse breast cancer outcomes than White/Anglo Americans (Adams et al; Moy et al, Meissner et al, Kaplan et al, Consedine et al). However racial/ethnic disparities encountered in breast cancer diagnosis and treatment seem to diminish when equal access to health care was provided and effective communication with a health care provider was established (Kerner et al; Harris et al, Abraido-Lanza et al, Alexandraki et al). Individual counseling, personalized outreach interventions and patient navigation services also improved screening rates among vulnerable populations (Rimer et al, Velanis et al, Lobb et al).

Predictors of mammography such as perceived susceptibility and perceived risk/benefit ratio also varied by country of birth, age, education attainment, race/ethnicity and income of the women in each study. Interventions to increase mammography rates among women need to be tailored to each group according to their unique belief system (Cronan et al, Champion et al, MacAlerney et al). The influence of social networks, such as friends, family members and partners should be taken into consideration during the design of breast cancer screening interventions (Erwin et al; Tejada et al, Erwin et al).

Overall, access to health care, low socio-economic status/low income and low education achievement are the most important predictors associated with

low rates of regular mammography screening and delayed diagnosis and treatment of breast cancer (Loerzel et al; Fair et al, Shueler et al, Meissner et al, Ogedegbe et al). According to results in the National Health Interview Survey (NHIS) a randomized national study, having access to health care or health insurance was the most significant factor identified as a predictor for breast cancer screenings (Meissner et al, Halpern et al, Peek et al, O'Malley et al, Alexandraki et al).

The Komen Houston Affiliate primarily uses the findings of the Community Profile to guide its funding decisions for the Grants Program, education activities and public policy issues. An action plan was created based on the findings of the Community Profile Report and the in-depth topic areas (clinical trials, patient navigation and women under 40 years of age who are diagnosed with breast cancer) that the Affiliate researched for the 2009 Community Profile. The action plan is part of the Affiliate's strategic plan that was developed and approved by the Komen Houston Affiliate Board in 2011.

The Community Profile team identified six priorities after grouping the findings by topic. The Strategic Mission Committee eliminated overlapping items reducing the number of priorities to five. Each priority has measurable objectives that will be assigned to the Grants Committee, Education Committee, Public Policy Committee or Strategic Mission Committee for implementation. The timeline to complete plan listed below is April 1, 2011 to March 31, 2013.

The Affiliate used these definitions for underserved populations and minority populations in our Action Plan. Underserved populations are defined by the Health Resources and Service Administration of the U.S. Department of Health and Human Services as populations having too few primary care providers, high infant mortality, high poverty and a high pro-

portion of elderly within the population. They usually include low-income individuals, uninsured persons, immigrants, racial and ethnic minorities and the elderly.

The term majority-minority population almost always refers to ethnic/racial distribution, where the traditional majority is the group with more than 50% of the total allocation. However, it may also refer to other criteria, such as age, disability, religion, gender, etc.



Action Plan

Priority 1 - Promote breast cancer education and reduce cultural barriers of the underserved, minority and high risk populations

- a.** Create a comprehensive plan for identifying training needs, activities and impact measures of the Komen Houston Affiliate's Educational Program to target underserved, minority and high risk populations as defined by the Community Profile
- b.** Create and implement an Outreach Program for outlying counties of the Komen Houston service area

- c.** Identify and fund evidence-based programs to increase breast cancer education and reduce cultural barriers for underserved, minority and high risk populations to increase breast cancer screening rates
- d.** Identify and fund evidence-based programs to increase education about risk assessment, screening options and screening recommendations for providers and women at greater risk of developing breast cancer before age 40*

**Women who are diagnosed at a younger age are more likely to have a mutated BRCA1 or BRCA2 gene. Having a mother, father, daughter or sister who has had breast cancer also increases a young woman's risk of developing breast cancer.*

- e.** Affiliate representatives attend Advocacy day at least once a year in Washington, DC, and every other year in Austin, Texas, to educate elected officials on the following issues: importance of increased access to care in our service area; the issues facing breast cancer survivors; importance of the role of patient navigators in breast healthcare; and issues that impact enrollment of patients in breast cancer clinical trials

Priority 2 - Increase the use of patient navigation services for underserved patients accessing breast health services

- a.** Identify and fund programs to increase patient navigation services from initial screening to treatment in order to increase screening rates, reduce time from abnormal results to treatment and increase number of women who complete treatment

- b.** Identify and fund programs to increase knowledge about breast health resources for underserved, minority and high risk populations by developing a patient navigators' network for navigators employed in breast health services

Priority 3 - Increase screening, diagnostic and treatment services for the underserved populations

- a.** Revise Komen Houston Affiliate's promotion resources to increase awareness of breast cancer screening, diagnostic and treatment services for the underserved populations
- b.** Identify and fund programs to increase access to and quality of breast cancer screening, diagnostic and treatment services to underserved women, especially in rural areas
- c.** Establish outcome measures to ensure quality of care in the Grants Program

Priority 4 - Increase continued survivorship care to include follow-up medical care, support services, transportation services, end of life care and other services for underserved breast cancer survivors.

Note: The Komen Houston Affiliate defines a breast cancer survivor as someone who has been diagnosed with breast cancer.

- a.** Create and implement a communication plan for the Affiliate Committees and constituents to increase awareness of the needs of breast cancer survivors to include support services, follow up care and end of life care
- b.** Revise the Komen Houston Affiliate's Request for Funding Application to include descriptions and outcome measures for programs that provide breast cancer support, follow up care

and end of life services to underserved and minority breast cancer survivors

- c.** Identify and fund programs to increase quality of and access to follow up medical care, support services, transportation services, end of life services and other services to decrease the burden of illness and increase quality of life for underserved breast cancer survivors

Priority 5 - Increase education and reduce barriers related to enrollment in breast cancer clinical trials for underserved and minority women

- a.** Identify and fund programs that provide education to increase awareness, allay fears, dispel misconceptions and address cultural barriers related to breast cancer clinical trials in order to increase enrollment of underserved and minority women in clinical trials
- b.** Identify and fund programs that provide support services for underserved and minority women that facilitate participation in breast cancer clinical research studies
- c.** Identify and fund education for health care providers that increases awareness of breast cancer clinical trials being conducted in their area and offers providers the tools to easily share information with the patients they serve

The Affiliate will develop a communication plan to distribute the findings of the Community Profile to the Affiliate's Board, staff, committees and advocates; the legislative members in the service area; current and potential grantees; donors and the general public. Strategies for the dissemination of the Profile will include presentations, distribution of the Community Profile report, posting on the Affiliate's website and press releases.





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