

susan g. komen.  | **COMMUNITY**
PROFILE REPORT 2015



SUSAN G. KOMEN®
AUSTIN

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Executive Summary

Introduction to the Community Profile Report

Susan G. Komen® Austin was established in 1999 to spread the life-saving message of early detection and to fund and support breast cancer screening, education, medical services, and emotional support through survivorship programs in Central Texas. The Affiliate also works to promote statewide breast health initiatives through advocacy efforts. Komen Austin serves five counties in the Central Texas region including Bastrop, Caldwell, Hays, Travis, and Williamson. The Affiliate's five counties make up an area of 4,284 square miles and encompass a population of over 1.9 million residents ("Population and Population Growth," 2015). In the past five years, Komen Austin funding has provided nearly 64,000 breast health services through its community partners. Today the focus of the Affiliate is on saving lives locally and fighting breast cancer globally.

Komen Austin is the foundation of the Central Texas breast cancer network of providers. Through its community health grant program, Komen Austin has provided the means for quality breast health services focusing on availability and accessibility for persons seeking breast health services. Since inception, the Affiliate has funded 32 local organizations to provide a range of breast health services, including screening, diagnostic, treatment, and support services to underinsured and uninsured populations. The 2015-2016 Komen Austin Community Health Grant program awarded \$614,319 to eight local organizations providing services in the five county service area.

The Komen Austin Race for the Cure®, held every November, is the signature fund raising event of the Affiliate. Since inception, Komen Austin has raised \$25 million dollars. Seventy-five percent of all net funds raised are dedicated to providing direct services in the five county service area. Komen Austin has granted nearly \$11 million in local grants providing clinical breast exams, screenings, diagnostics, treatment, and breast cancer education and outreach. The remaining 25 percent of net funds raised is dedicated to global research. Komen Austin has invested almost \$5 million in breast cancer research.

Volunteer committees are critical in carrying out the mission of Komen Austin. The heart of the organization lies with nearly 2,000 volunteers. While volunteers assist Komen Austin in many events, the Komen Austin Ambassador program is central to education and outreach. Providing sustainability and value to the organization, the grant review panel dedicates time to review grant applications, a process directly tied to the mission of saving lives. New volunteer driven programs were created based on results from the previous Community Profile. Women in Strides was developed to provide education and an outreach support system to Black/African-American women in the service area. Survivor ATX, another program recently established by volunteers, is a support network for breast cancer survivors.

The Community Profile is an assessment of breast health and breast health services in the Komen Austin service area. Every four years, Komen Austin conducts a community assessment to gather and organize information for the purpose of evaluating the state of breast health and

breast health services in the Affiliate service area. The assessment helps determine and prioritize breast health needs found in the communities served by the Affiliate.

The Community Profile will assist the Affiliate in directing community outreach and education, will focus grant funding in targeted areas of need, and facilitate policy goals for the Affiliate. The Community Profile is intended to serve as a guide to direct the services currently funded and to identify any existing gaps and barriers to those services in the five-county service area.

Quantitative Data: Measuring Breast Cancer Impact in Local Communities

The 2014 Susan G. Komen Austin[®] Quantitative Data Report (Susan G. Komen[®], 2014) provides data on female breast cancer incidence and late-stage incidence rates, female breast cancer death rates, screening mammography, population demographics, and socioeconomic indicators. Additional data was collected from the Department of State Health Services Texas Cancer Registry (Texas Cancer Registry, 2014), and the Community Health Needs Assessment Toolkit (CHNA, 2014).

Healthy People 2020 (HP 2020) objectives were used to set priorities and select target communities. *HP 2020* is a major federal government initiative that provides specific health objectives for the United States. There are two breast cancer-related *HP2020* objectives. The first objective is to reduce the female breast cancer death rate to 20.6 per 100,000 women. The second objective is to reduce the late-stage incidence rate to 41.0 per 100,000 women.

National and local data revealed that the age-adjusted female breast cancer incidence rates for Caldwell (129.8 per 100,000 women), Travis (124.0 per 100,000 women), and Williamson (125.9 per 100,000 women) counties are higher than the US incidence rate (122.1 per 100,000 women) (Susan G. Komen, 2014). The data also showed increasing female breast cancer incidence rate trends in Bastrop (1.3 percent), Caldwell (7.2 percent), and Travis (1.8 percent) Counties (Susan G. Komen, 2014).

Of the five counties, Hays County (21.3 per 100,000 women) is the only one with a female breast cancer death rate above the *HP2020* objective. It is projected that it will take four years for Hays County to meet this objective (Susan G. Komen, 2014). Bastrop, Travis, and Williamson counties currently meet this objective, and the Caldwell County death rate was suppressed due to small numbers (Susan G. Komen, 2014). For late-stage incidence rate, Caldwell (55.0 per 100,000 women), Travis (41.6 per 100,000 women), and Williamson (41.8 per 100,000 women) counties have rates above the *HP2020* objective. Based on these rates and annual trends, it is projected that it will take Caldwell County 13 years or longer to meet the late-stage female breast cancer incidence rate (Susan G. Komen, 2014).

Bastrop County currently meets the *HP2020* target, but there is an increasing trend (+1.3 percent) in the breast cancer incidence rate. As a result of this trend, it is projected that it will take 13 years or longer for Bastrop County to achieve the *HP2020* target (Susan G. Komen, 2014b). It is projected that it will take the Komen Austin service area, Travis County, and Williamson County one year to meet this objective, and Hays County currently meets this objective.

The proportion of women ages 50-74 who received screening mammograms in the last two years is 77.1 percent in Hays County, 71.0 percent in Travis County, and 82.0 percent in Williamson County (Susan G. Komen, 2014). The screening mammography rates for Bastrop and Caldwell Counties were suppressed due to small numbers (Susan G. Komen, 2014). Based on the rates described above, each county was given an intervention priority level. Caldwell was given the highest priority, Bastrop County is a medium priority, and Hays, Travis, and Williamson Counties were given a low priority (Susan G. Komen, 2014).

The racial/ethnic demographics of the Komen Austin service area are as follows: 84.5 percent White, 8.6 percent Black/African-American, 5.6 percent Asian/Pacific Islander, and 1.3 percent American Indian/Alaska Native, while 31.2 percent of the total population, including all races, is Hispanic/Latino (Susan G. Komen, 2014). In the Affiliate service area, 12.3 percent of the population has less than a high school education, 28.0 percent is living below the 250 percent poverty guidelines, 7.1 percent is unemployed, 42.8 percent live in medically underserved areas, and 19.2 percent of the population have no health insurance (Susan G. Komen, 2014). Of the five counties in the service area, Bastrop, Caldwell, and Travis Counties have the highest percentages of individuals with less than a high school education with 18.9 percent, 23.2 percent, and 13.3 percent, respectively (Susan G. Komen, 2014). These three counties also have the highest percentages of individuals living below the 250 percent poverty guidelines with 36.4 percent in Bastrop County, 44.8 percent in Caldwell County, and 29.9 percent in Travis County (Susan G. Komen, 2014). In Bastrop, Caldwell, Hays, and Williamson Counties, 100 percent of the population live in medically underserved areas, while only 4.2 percent of the population in Travis County live in medically underserved areas (Susan G. Komen, 2014). The percentages of individuals aged 40-64 with no health insurance in each county are as follows: 24.2 percent in Bastrop County, 27.1 percent in Caldwell County, 19.9 percent in Hays County, 19.4 percent in Travis County, and 16.8 percent in Williamson County (Susan G. Komen, 2014).

The Affiliate selected Bastrop County, Caldwell County, and Travis County as their target communities. Bastrop was selected because it is considered a medium intervention priority based on the time predicted to achieve the *HP2020* late-stage incidence target. In addition, there are a high percentage of individuals who have less than a high school education, are living in rural areas, lack health insurance, and live in a medically underserved area (Susan G. Komen, 2014). Caldwell was selected because it is considered the highest intervention priority based on the time predicted to achieve the *HP2020* late-stage incidence target and because there is a high percentage of the population who have less than a high school education, are living below 250 percent poverty guidelines, lack health insurance and live in a medically underserved area (Susan G. Komen, 2014). Although Travis County is considered a low intervention priority, it was selected as a target community because approximately 59.8 percent of women in the Affiliate service area reside in Travis County). Travis County was also selected because of the high percentage of the population who have less than a high school education, are living in poverty, and lack health insurance (Susan G. Komen, 2014).

Health System and Public Policy Analysis

In the health system analysis, the Affiliate identified strengths and weaknesses of the Continuum of Care in Bastrop, Caldwell, and Travis Counties. The continuum of care is a model that demonstrates how a woman typically moves through the health care system while receiving

breast health services. The continuum of care includes screening, diagnostic, treatment, and support services for breast cancer.

In Bastrop County, the Affiliate identified six breast health service providers: five in Bastrop and one in Smithville. One weakness is that Bastrop County has limited breast health services. In the city of Bastrop, only one provider offers screening mammograms and the other provider offers clinical breast exams. One strength in Bastrop County is that the Smithville Regional Hospital provides three of the four services in the continuum of care yet a weakness in the county is that there are no treatment providers. A strength in this county is the strong relationships and communication between health service providers. The community-based organizations in this county have developed long-lasting bonds. Interagency group meetings help sustain these bonds and communication.

In Caldwell County, the Affiliate identified five breast health service providers: two in Luling and three in Lockhart. A strength of the health service providers in this county is that they all offer screening services and two are able to provide diagnostic mammograms. One weakness is that screening and diagnostic services are the only type of services offered in the continuum of care. Patients have to travel to Austin, San Antonio, or other surrounding cities to receive treatment services. Due to the small size of the community, health service providers are easily able to communicate, which has led to collaboration among providers. Caldwell County also has interagency meetings, which help facilitate collaboration.

In Travis County, the Affiliate identified 51 health service providers: 48 in Austin, one in Bee Cave, one in Cedar Park, and one in Lakeway. Among the 51 providers, approximately 74.5 percent offer screening services, 51.0 percent offer diagnostic services, 27.5 percent offer treatment services, and 37.3 percent offer supportive services. Travis County has many screening and diagnostic service providers, but has fewer treatment and support service providers. Additionally, only 18 providers are certified or accredited by the American College of Surgeons Commission on Cancer, the American College of Radiology Centers of Excellence, and/or the American College of Surgeons National Accreditation Program for Breast Centers.

Komen Austin has strong partnerships with grantees to provide screening, diagnostic, treatment, education, and survivorship services throughout the service area. However, most of these services are not located in rural communities such as Bastrop and Caldwell, where these services are needed the most. Due to a funding shortage in previous years, the Affiliate lost a vibrant network of Komen grantees, many of which served rural communities like Bastrop and Caldwell. Komen Austin works with interagency groups in Bastrop, Caldwell, and Travis Counties that serve as an information and referral network as it pertains to breast health services.

The Texas Cancer Plan strives to reduce the cancer burden across the state and improve the lives of Texans. The Plan serves as the statewide call to action for cancer research, prevention, and control by identifying the issues affecting the state and presenting goals, objectives, and strategies to help guide communities in the fight against cancer. The Texas Cancer Plan is developed with statewide input from state agencies and educational institutions, community leaders, planners, coalition members, cancer survivors, and co-survivors affected by cancer. Statewide objectives are to encourage prevention activities and risk reduction; increase screening and early detection rates; initiate more timely access to diagnosis, treatment, and

palliative care; improve quality of life and survivorship for patients; increase support for cancer research and commercialization projects for better treatments and economic development in Texas; and to develop and strengthen access to health care as well as medical professionals.

The Cancer Alliance of Texas (CAT) is the state cancer coalition, which is the organizing body that addresses the national requirement of the comprehensive Cancer Control Coalition. The purpose of the CAT is to promote, enhance, and expand all public and private partners' efforts to implement the Texas Cancer Plan. CAT aims to advance cooperative efforts that focus on cancer prevention, early detection, screening, and other related efforts among the population of Texas. Komen Austin is a member of the CAT and participates in quarterly meetings along with other Texas Komen Affiliates.

The National Breast and Cervical Cancer Early Detection Program (NBCCEDP) was created by the Centers for Disease Control and Prevention (CDC) following the passage of the Breast and Cervical Cancer Mortality Prevention Act of 1990. The NBCCEDP helps low income, uninsured and underinsured women gain access to breast and cervical cancer screening and diagnostic services.

The Texas Breast and Cervical Cancer Services (BCCS) program offers low income women, ages 18-64, access to screening and diagnostic services for breast and cervical cancer. This program is funded by the NBCCEDP, the CDC, Title XX to Temporary Assistance for Needy Families, and the State General Revenue. In fiscal year 2013, 43 organizations contracted with the Texas Department of State Health Services to provide BCCS program services to 212 clinics across the state. The Medicaid for Breast and Cervical Cancer program provides treatment to uninsured women who have been diagnosed with breast or cervical cancer.

In March of 2010, Congress enacted changes to how Americans will receive health care through the passage of the Affordable Care Act. The Affordable Care Act (ACA) was enacted into law as a response to the crisis over the number of uninsured individuals in the country and the rising costs of medical care. The ACA provides preventive services, including mammograms, without cost sharing. Texas chose not to run a state insurance exchange, which means consumers in the state must choose coverage from a federally run marketplace. Texas also chose not to expand Medicaid coverage for those with incomes up to 133 percent of the poverty level. Had Texas expanded Medicaid, over one million Texans would have access to health care (Henry J. Kaiser Family Foundation, 2014). In Texas, 24.7 percent of the population, between ages 40-64, is uninsured (Susan G. Komen, 2014). Medicaid Expansion in Texas would have a positive impact on the number of uninsured Texas residents.

Based on the findings of the Health System and Public Policy Analysis, the Affiliate made conclusions about the needs of the three target communities. The Affiliate found that Bastrop and Caldwell counties have very limited breast cancer resources. Patients needing diagnostic and treatment services must travel to surrounding counties to obtain these services. Travis has a greater number of service providers than Bastrop and Caldwell, but these providers are not geographically accessible to underserved individuals, especially Black/African-American women. Travis County lacks sufficient treatment, support, and education services for breast cancer and breast health for individuals at all income levels.

With the passing of the Affordable Care Act, more community outreach efforts are needed to connect eligible uninsured patients to insurance access through the marketplace. More than one million Texans will remain uninsured because Texas did not expand Medicaid, which means health care centers and nonprofits will continue to serve a large population in need. The Affiliate will strive to provide grants to organizations serving uninsured or underinsured populations, as well as other communities in most need as identified by the Health System and Public Policy Analysis.

Qualitative Data: Ensuring Community Input

Komen Austin identified key assessment questions and variables for the target communities of Bastrop, Caldwell, and Travis counties. The variables used include breast health education/information, the breast cancer Continuum of Care experience and survivorship, health care accessibility/barriers, insurance, group norms, and local health issues and service.

The Affiliate also developed key questions to assess these variables. The following key questions were developed for health service providers:

- Does your organization provide breast health services?
- How would you describe the health literacy of your patients?
- What barriers to screening and diagnostic services do your clients face?

The following key questions were developed for survivors/co-survivors:

- What health care services are you aware of?
- Where do you go for health care, how often, why/why not?
- Do you get help in reading prescription labels, filling out forms?
- What kind of insurance do you have or have you had?

Key questions that were developed for providers and survivors include:

- What types of initiatives, programs, and activities, can help to improve breast health services in your community?
- What are the typical out of pocket costs?

The Affiliate used focus groups and key informant interviews as the primary data collection methods for each of the three target communities. The purpose of the qualitative data collection was to gather in-depth information about breast cancer knowledge and service in the target communities. Individuals who had breast cancer and those closely affected by breast cancer (i.e., co-survivors and health service providers) were identified as the best target population for data collection. Separate focus groups were conducted with survivors/co-survivors and health service providers and key informant interviews were conducted with survivors/co-survivors. The Affiliate conducted three focus groups in each of the three counties, with 6-12 individuals in each focus group. The Affiliate conducted three key informant interviews in Bastrop County, six in Caldwell County, and 43 in Travis County.

Based on the qualitative data collected, the Affiliate made several conclusions about what is needed in the target communities. Survivors and health service providers in all three target communities indicated a need for more breast health education, particularly for Black/African-American women, Hispanic/Latina women, and young women. Black/African-American and Hispanic/Latina women are more likely not to receive breast cancer screenings for cultural or

religious reasons. Survivor and provider focus group participants stated that many people think that breast cancer only occurs in older women and that you are only at risk if breast cancer runs in your family. For these reasons, many women do not receive regular screenings. The belief that breast cancer is the will of God, a taboo against discussing breast cancer, and a cultural distrust of doctors were all mentioned as barriers to seeking breast cancer screenings. More education in these populations will serve to increase awareness and correct common misconceptions about breast cancer. Providers expressed the need for outreach to the homeless and unemployed populations. Providers in Travis County indicated that they themselves need more education and training on follow-up care and survivorship.

Health literacy and English proficiency are also lacking in the target communities. The Affiliate found that participants' education level did not necessarily correspond with their level of health literacy. Providers stated that many of their patients have low health literacy and learn about breast cancer for the first time when they are diagnosed. Survivors indicated that they had trouble understanding health information and felt that doctors did not adequately explain their cancer or effectively answer questions. Providers admitted that the use of medical terminology creates a barrier between doctors and patients. Survivors indicated that they need more assistance with reading and understanding health information and insurance forms. The target communities have larger populations that are linguistically-isolated compared to the other counties in the Affiliate service area and the United States (Susan G. Komen, 2014). Individuals who are linguistically isolated face linguistic barriers, such as the inability to speak English well. Linguistic barriers may lead to barriers in the utilization of available health care due to low health literacy and limited health provider-patient communication. Bastrop, Caldwell, and Travis Counties need more Spanish-speaking providers to ensure that Spanish-speaking patients are able to communicate with their doctors.

The rural target communities are in need of more breast health and breast cancer services. Many patients in Bastrop and Caldwell Counties have to travel to surrounding counties to receive screening, diagnostic, and treatment services because of the lack of local services. Survivors and providers in Bastrop County indicated that health services are limited, and agreed that the county needs more funding and insurance assistance to improve local breast health services. Transportation to follow-up care is also a barrier for survivors who cannot afford private transportation in Travis County. Transportation assistance and mobile mammography services will help alleviate some of these barriers to receiving care. Individuals who are uninsured or underinsured also experience difficulties obtaining breast health services. The patients in Bastrop, Caldwell, and Travis Counties are in need of patient navigation and support/survivorship services. Navigation services will help guide patients through the complicated and overwhelming process that begins with a breast cancer diagnosis. Survivorship services would provide a support network that allows survivors and co-survivors to share information and experiences.

Mission Action Plan

Komen Austin used findings from the Quantitative, Health System and Public Policy Analysis, and Qualitative data reports to create problem statements, priorities, and objectives that will guide the education, community outreach, grantmaking, and public policy efforts of the Affiliate for the next four years. For each target community, the Affiliate wrote a problem statement, and two to three priorities, including two to four objectives for each priority.

Bastrop County Problem Statement: Bastrop County has an increasing late-stage female breast cancer incidence rate trend. Of the six breast health service providers in Bastrop County, only one offers all four services in the Continuum of Care (screening, diagnostic, treatment, and support). Both survivors and providers agreed that their county needs more funding and insurance assistance to improve local breast health services, as well as more breast health and breast cancer education. .

Priority One: Increase the number of health service providers offering breast health and breast cancer services in the county, as well as the availability and access to these services.

Objective 1- Beginning with the FY 2016-2017 Community Grant RFA, a key funding priority will be providing mobile mammography services in Bastrop County.

Objective 2- By FY 2018, establish at least two new grantee partnerships with community-based organizations or health service providers that provide breast cancer Continuum of Care services in Bastrop County.

Objective 3- Beginning with the FY 2016-2017 Community Grant RFA, a key funding priority will be providing additional funding for breast health programs that serve uninsured and underinsured residents in Bastrop County.

Priority Two: Increase breast health and breast cancer education in Bastrop County, with an emphasis on reaching Black/African-American and Hispanic/Latina populations.

Objective 1- From FY 2016 to FY 2019, annually host at least one Ambassador training in Bastrop County.

Objective 2- From FY 2016 to FY 2019, annually host at least two Breast Cancer 101 educational sessions in Bastrop County.

Objective 3- By FY 2017, Women in Strides will have established a new partnership with an organization that is active in Bastrop County that focuses on the health of Black/African-American and/or Hispanic/Latina women.

Caldwell County Problem Statement: Caldwell County has a higher female breast cancer incidence rate and late-stage incidence rate than the Komen Austin service area, Texas, and the United States. The four health service providers in Caldwell county offer screening services and some diagnostic services, but none are able to offer all four services under the Continuum of Care. Health service providers and survivors indicated that their community needs more breast health and breast cancer education, particularly for young women.

Priority One: Increase breast cancer awareness and education in Caldwell County.

Objective 1- From FY 2016 to FY 2019, annually attend or host at least two Breast Cancer 101 educational sessions in Caldwell County.

Objective 2- From FY 2016 to FY 2019, annually host at least one Ambassador training in Caldwell County.

Objective 3- By the end of FY 2017, hold at least one meeting with medical professionals in Caldwell County to educate providers about the breast cancer screening resources available in the county and to increase provider understanding of breast cancer screening recommendations supported by Susan G. Komen.

Priority Two: Increase access to health care providers offering all four services in the continuum of care in Caldwell County.

Objective 1- From FY 2016 to FY 2019, annually collaborate with a mobile mammography service and host at least one screening event in Caldwell County.

Objective 2- By the end of FY 2017, establish at least two new grantee partnerships with community-based organizations or health service providers that provide breast cancer continuum of care services in Caldwell County.

Objective 3- Beginning with the FY 2016-2017 Community Grant RFA, a key funding priority will be funding programs that provide screening, diagnostic, treatment, and support services in Caldwell County.

Objective 4- By the end of FY 2016, establish at least one new partnership with a local community-based organization or health service provider to provide transportation assistance to Caldwell County residents needing diagnostic or treatment services in the five-county service area.

Travis County Problem Statement: Travis County has a higher female breast cancer incidence rate than the Komen Austin service area, Texas, and the United States. The health systems and public policy analysis found that Travis County lacks treatment and support services for breast cancer. Providers stated that they lack sufficient education and training for follow-up and survivorship. Survivors and key informants identified transportation as a barrier to follow-up care and indicated a need for financial support for insurance and transportation. Both groups also indicated that more education is needed, specifically targeting young women and underserved populations.

Priority One: Increase breast cancer awareness in Travis County, with an emphasis on reaching young women, minority, and homeless populations.

Objective 1- From FY 2016 to FY 2019, annually host at least one Breast Cancer 101 educational session in Travis County targeting young women and minority women.

Objective 2- From FY 2017 to FY 2019, collaborate with one community-based organization or health service provider that works with the homeless population to host at least one education and outreach event in Travis County.

Priority Two: Increase the quality of follow-up care by increasing access to treatment and survivorship services in Travis County.

Objective 1- By the end of FY 2018, establish at least one new grantee partnership with a community-based organization or health service provider in Travis County that is able to offer additional treatment and support services.

Objective 2- By the end of FY 2016, hold at least one summit in Travis County with breast cancer medical professionals in the five-county service area.

Priority Three: Increase the availability of insurance and transportation for uninsured and underinsured residents of Travis County needing services in the Continuum of Care.

Objective 1- Beginning with the FY 2016-2017 Community Grant RFA, a key funding priority will be providing insurance assistance and transportation assistance to underinsured and uninsured individuals in Travis County.

Objective 2- In FY 2017, meet with or provide information to all Texas legislators of the five-county area to advocate for the continued full funding of programs that provide insurance assistance for breast health and breast cancer services.

Disclaimer: Comprehensive data for the Executive Summary can be found in the 2015 Susan G. Komen Austin Community Profile Report.

Introduction

Affiliate History

Susan G. Komen® Austin was established in 1999 to spread the lifesaving message of early detection and to support access to breast cancer screening, education, medical services and emotional support through survivorship programs. The Affiliate held the first Race for the Cure® in 1997 and has continued to hold the signature fundraising event on an annual basis ever since. Komen Austin is located in the heart of the Central Texas region, servicing Bastrop, Caldwell, Hays, Travis, and Williamson Counties.

Since inception, the Affiliate has been committed to improving health care outcomes in breast cancer through its data driven grant funding, community health, and advocacy programs, all of which are made possible through local fundraising efforts supported by a diverse cross section of the Central Texas community.

Komen Austin has raised \$23 million since its formation. It has granted nearly \$11 million in local grants to provide screenings, education and treatment to men and women who are underinsured or uninsured. Additionally, the Affiliate has invested almost \$5 million in Komen Research Programs by dedicating 25 percent of net revenue raised. This research serves to inform and empower treatment, improve the quality of life for patients and their families, and ultimately, move society closer to solving the medical challenge of finding the cures for breast cancer.

Komen Austin funded the first ever “Pink Bus” in Central Texas. In the early days of the grant-funding program, the Affiliate worked with Seton Health to fund a “mammogram on wheels” grant in Travis County. Komen’s initial support, laid the foundation for a sustainable mobile breast cancer screening program that now serves the Affiliate’s five counties and continues to operate without additional Affiliate financial support.

Komen Austin has played a major role in the development of the breast cancer services network found in Central Texas. Since inception, the Affiliate has funded 32 local organizations that provide screening, diagnostic, treatment, and/or support, including transportation and emergency services. Through the grant program, the Affiliate has contributed to the quality and availability of breast health services throughout Central Texas. Furthermore, barriers to care have been minimized both in urban and rural areas. Most importantly, the Affiliate continues to spread the lifesaving message that was the inspiration for the establishment of the local Komen Affiliate.

The Komen Austin grant program supported four local organizations in 2014-2015 by awarding \$681,266 in community health grants to serve the five-county area.

Community health grantees deliver breast health services ensuring that the continuum of care model is accessible to uninsured and low-income individuals in the five county service area.

Komen Austin is a member of the statewide Cancer Alliance of Texas, the Texas Medical Association’s Cancer Committee, and participates regularly at the monthly interagency meetings for Bastrop, Travis, Hays and Caldwell Counties. The Affiliate monitors the policy work of the Travis County Health District and the Texas Legislature.

In 2014, the Affiliate received the Best Nonprofit Award from Austin Woman Magazine, a prestigious local women’s media organization.

Affiliate Organizational Structure

The Susan G. Komen® Austin has a Board of Directors and a professional staff working daily to advance the mission of the organization.

Komen Austin employs seven full-time and one part-time staff members. The organization maintains a robust intern program; each department is assigned at least one intern from an accredited university. Equally important, the Affiliate is powered by nearly 2,000 volunteers annually. Volunteer support makes it possible for the Affiliate to achieve an impressive 25 percent administration cost enabling funds raised to be spent on mission. Volunteers help carry out the organization's mission by serving on the following committees:

- Race for the Cure®: Assist in the operation of the iconic fundraiser, Race for the Cure
- Pink! Party: Premiere fundraising event and annual gala
- Ambassador Program: Trained volunteers provide support in education and outreach events, e.g., Health fairs, corporate and community based requests and third party events
- Women in Strides : Education and outreach to Black/African-American women
- Survivor ATX: Support network for survivors
- Grant Review Panel: Confidential committee that reviews and recommends the funding of grants

A 13 member Board of Directors meets monthly to provide fiduciary oversight of the organization. The Board of Directors functions as a governing Board. The positions of President, Vice President, Treasurer and Secretary are elected from the Board. A 10 member Advisory Board consisting of respected community and business leaders provides ongoing advice to the Executive Director and the Board.

The Affiliate's organizational chart demonstrates how the Affiliate carries out its mission with the support of all parties referenced and their governing relationship.

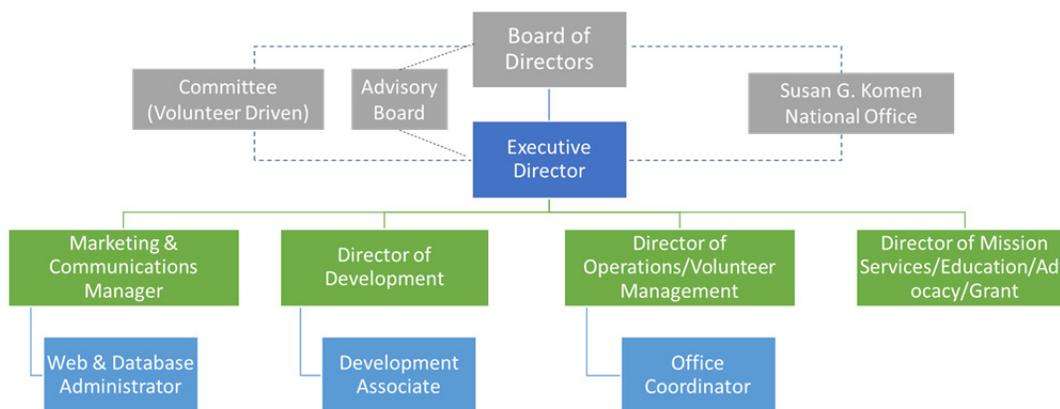


Figure 1.1. Komen Austin Organizational Chart

Affiliate Service Area

The Susan G. Komen® Austin service area encompasses Bastrop, Caldwell, Hays, Travis, and Williamson Counties (Figure 1.2). Encompassing rural, suburban, and urban areas, these counties each provide unique challenges and opportunities in breast health care. According to the 2013 US Census data, over 1.9 million people reside in the Komen Austin service area. There are 50.14 percent males and 49.86 percent females in the Affiliate's five-county service area. (CHNA, 2012)

Komen Austin's service area has a higher percentage of White population and a lower percentage of Black/African-American population, as compared to state and nationwide data. The proportion of Hispanic/Latino data for the Affiliate service area is nearly double to that of the nationwide data. (US Census Bureau-Population Estimates).

The Affiliate's five counties make up 4,284 square miles, including municipalities within the counties. Rural communities are located in the counties of Bastrop, Caldwell, and Hays. Travis and Williamson Counties are considered urban counties; and Travis County is also home to the suburban areas of the City of Austin.

In Bastrop County, the communities of Bastrop, Cedar Creek, Elgin, Paige, Smithville and others are characteristically linked by the rural culture of the county. The county is considered a farming and ranching community that is rapidly becoming a major alternative community to living in Austin. This is largely due to the affordability of housing, lower property taxes, and the county's close proximity to Austin where employment and health care are located. Public transportation is not readily accessible in Bastrop County.

Caldwell County has seven agricultural and farming communities: Dale, Lockhart, Luling, Martindale, Niederwald, Umland and Maxwell. All are small municipalities in a county that has maintained an agricultural economic base. Public transportation is limited, making personal transportation a necessity to get to and from medical appointments which are largely concentrated outside of the county.

Hays County is home to several municipalities: Buda, Driftwood, Dripping Springs, Kyle, San Marcos, and Wimberley. All are experiencing growth. San Marcos, the county's largest city, offers a public transportation system that facilitates easier access to treatment services. San Marcos also has a health care system that provides primary health care.

Travis County and Williamson County are the Affiliate's urban counties. The City of Austin is the center of most economic and business activity, including health care. Smaller municipalities are found in the Travis County's jurisdiction which include Del Valle, Garfield, Jollyville, Jonestown, Lago Vista, Lakeway, Manchaca, Manor, Pflugerville, Rollingwood, and West Lake Hills. These municipalities are within miles of Austin's center, and thus have access to the full spectrum of health services in Travis County. Public transportation is available and transportation options do exist.

Williamson County, a rapidly growing area, includes more than 10 municipalities with Georgetown serving many of the county's needs for both public services and health care. A portion of the county is located inside the city limits of Austin. Round Rock, a suburban community, is located in Williamson County and in parts of northern Travis County. The county is developing a medical corridor that will add to the medical infrastructure for the Affiliate's service area.

KOMEN AUSTIN SERVICE AREA

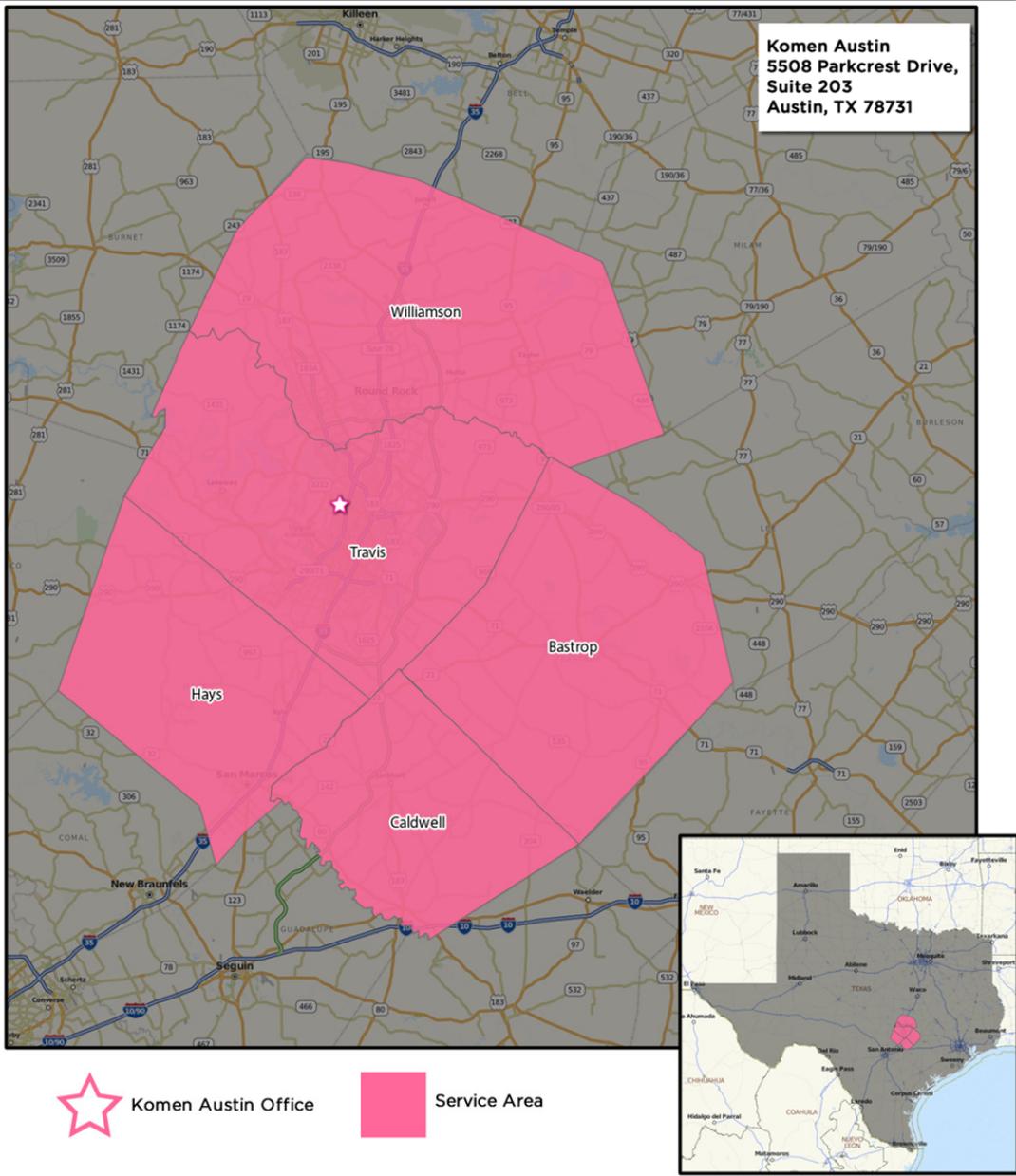


Figure 1.2. Susan G. Komen Austin Service Area

Purpose of the Community Profile Report

The Community Profile is a community assessment of breast health and breast cancer services in the Affiliate’s service area. The assessment prioritizes needs in local communities served by Komen Austin. Main sections of the project include Quantitative Data, Health System and Public Policy analysis, Qualitative Findings, and the Mission Action Plan.

The Community Profile will facilitate the Affiliate’s alignment with its mission of community outreach, grant funding and public policy with needs identified in the report. The Community

Profile is an assessment of the target community's available services and will assist Komen Austin in better aligning its mission in the targeted communities. Moving forward, the Affiliate will outline program plans on how the Affiliate will seek to meet the needs of identified targets to affect behavioral change. Further, the Affiliate will strive to increase access to breast health services while impacting a reduction in breast cancer death rates in the Affiliate's targeted communities.

The Community Profile's relevance is imperative to the work of the Affiliate. The assessment will educate the network of breast health providers in the service area as well as the Affiliate's Grant Review Panel. The assessment will provide prospective grant applicants a snapshot of community need to assist in the preparation of grant applications and inform grant reviewers of the Affiliates targeted communities and breast health service priorities.

Further, the Community Profile will be used to focus education in target communities and establish directions for marketing and outreach. Additionally, the report will assist in strengthening the sponsorship efforts for the Affiliate's fundraising by providing data driven information to prospective donors. Finally, the community assessment will inform policymakers in the five service counties of breast cancer health status and need, thus driving policy at the local level.

The focus areas identified by the Community Profile will be widely distributed to Komen Austin's general database through snapshots of information that will always link back to a website page where the full Community Profile is accessible to those who would like to learn more. For example, Komen Austin posts on Twitter, LinkedIn, Facebook and in the e-newsletter, "Did you know that while White women have higher rates of diagnosis, Black/African-American and Hispanic/Latina women are more likely to pass away from breast cancer? Learn what we're focusing on to re-write the story of breast cancer in our local community."

In addition to educating donors on Komen Austin's stewardship of funds, the Affiliate will hold more in-depth information sessions to present the findings of the Community Profile to local stakeholders. Stakeholders who will be interested in helping Komen Austin re-write the story of breast cancer in the community include: other local breast cancer organizations, public officials, public health students, oncologists and interest groups for the populations most negatively affected by breast cancer (Black/African-Americans and Hispanics/Latinos). Komen Austin is the only organization doing a local, in-depth assessment of breast health needs, thus it is the Affiliate's responsibility to present the facts to stakeholders and encourage them to commit to change. To advertise these information sessions, Komen Austin will write a press release and target local media and others who can help drive change.

Quantitative Data: Measuring Breast Cancer Impact in Local Communities

Quantitative Data Report

Introduction

The purpose of the quantitative data report for Susan G. Komen[®] Austin is to combine evidence from many credible sources and use the data to identify the highest priority areas for evidence-based breast cancer programs.

The data provided in the report are used to identify priorities within the Affiliate's service area based on estimates of how long it would take an area to achieve Healthy People 2020 objectives for breast cancer late-stage diagnosis and deaths (<http://www.healthypeople.gov/2020/default.aspx>).

The following is a summary of Komen[®] Austin's Quantitative Data Report. For a full report please contact the Affiliate.

Breast Cancer Statistics

Incidence rates

The breast cancer incidence rate shows the frequency of new cases of breast cancer among women living in an area during a certain time period (Table 2.1). Incidence rates may be calculated for all women or for specific groups of women (e.g. for Asian/Pacific Islander women living in the area).

The female breast cancer incidence rate is calculated as the number of females in an area who were diagnosed with breast cancer divided by the total number of females living in that area. Incidence rates are usually expressed in terms of 100,000 people. For example, suppose there are 50,000 females living in an area and 60 of them are diagnosed with breast cancer during a certain time period. Sixty out of 50,000 is the same as 120 out of 100,000. So the female breast cancer incidence rate would be reported as 120 per 100,000 for that time period.

When comparing breast cancer rates for an area where many older people live to rates for an area where younger people live, it's hard to know whether the differences are due to age or whether other factors might also be involved. To account for age, breast cancer rates are usually adjusted to a common standard age distribution. Using age-adjusted rates makes it possible to spot differences in breast cancer rates caused by factors other than differences in age between groups of women.

To show trends (changes over time) in cancer incidence, data for the annual percent change in the incidence rate over a five-year period were included in the report. The annual percent change is the average year-to-year change of the incidence rate. It may be either a positive or negative number.

- A negative value means that the rates are getting lower.

- A positive value means that the rates are getting higher.
- A positive value (rates getting higher) may seem undesirable—and it generally is. However, it's important to remember that an increase in breast cancer incidence could also mean that more breast cancers are being found because more women are getting mammograms. So higher rates don't necessarily mean that there has been an increase in the occurrence of breast cancer.

Death rates

The breast cancer death rate shows the frequency of death from breast cancer among women living in a given area during a certain time period (Table 2.1). Like incidence rates, death rates may be calculated for all women or for specific groups of women (e.g. Black/African-American/African-American women).

The death rate is calculated as the number of women from a particular geographic area who died from breast cancer divided by the total number of women living in that area. Death rates are shown in terms of 100,000 women and adjusted for age.

Data are included for the annual percent change in the death rate over a five-year period.

The meanings of these data are the same as for incidence rates, with one exception. Changes in screening don't affect death rates in the way that they affect incidence rates. So a negative value, which means that death rates are getting lower, is always desirable. A positive value, which means that death rates are getting higher, is always undesirable.

Late-stage incidence rates

For this report, late-stage breast cancer is defined as regional or distant stage using the Surveillance, Epidemiology and End Results (SEER) Summary Stage definitions (<http://seer.cancer.gov/tools/ssm/>). State and national reporting usually uses the SEER Summary Stage. It provides a consistent set of definitions of stages for historical comparisons.

The late-stage breast cancer incidence rate is calculated as the number of women with regional or distant breast cancer in a particular geographic area divided by the number of women living in that area (Table 2.1). Late-stage incidence rates are shown in terms of 100,000 women and adjusted for age.

Table 2.1. Female breast cancer incidence rates and trends, death rates and trends, and late-stage rates and trends.

Population Group	Incidence Rates and Trends				Death Rates and Trends			Late-stage Rates and Trends		
	Female Population (Annual Average)	# of New Cases (Annual Average)	Age-adjusted Rate/ 100,000	Trend (Annual Percent Change)	# of Deaths (Annual Average)	Age-adjusted Rate/ 100,000	Trend (Annual Percent Change)	# of New Cases (Annual Average)	Age-adjusted Rate/ 100,000	Trend (Annual Percent Change)
US	154,540,194	182,234	122.1	-0.2%	40,736	22.6	-1.9%	64,590	43.8	-1.2%
HP2020	.	-	-	-	-	20.6*	-	-	41.0*	-
Texas	12,251,113	13,742	114.4	-0.4%	2,610	21.8	-1.8%	4,905	40.7	-3.2%
Komen Austin Service Area	810,386	863	121.9	0.0%	130	19.3	NA	300	41.4	-5.1%
White	688,623	765	123.0	-0.5%	117	19.5	NA	263	41.3	-5.7%
Black/African American	68,671	57	108.7	6.2%	12	24.4	NA	25	46.7	0.1%
American Indian/Alaska Native (AIAN)	9,820	SN	SN	SN	SN	SN	SN	SN	SN	SN
Asian Pacific Islander (API)	43,271	21	68.8	-7.5%	SN	SN	SN	8	27.2	-3.3%
Non-Hispanic/ Latina	567,514	735	128.5	0.5%	114	20.5	NA	250	43.0	-4.2%
Hispanic/ Latina	242,871	128	93.9	-1.6%	16	12.5	NA	50	35.5	-8.9%
Bastrop County - TX	35,309	38	98.5	1.3%	7	18.8	-1.7%	15	38.2	1.0%
Caldwell County - TX	18,605	25	129.8	7.2%	SN	SN	SN	10	55.0	1.3%
Hays County - TX	73,374	70	109.5	-3.1%	13	21.3	-1.1%	24	38.2	-5.9%
Travis County - TX	484,563	504	124.0	1.8%	75	19.6	-2.5%	172	41.6	-4.9%
Williamson County - TX	198,535	226	125.9	-3.9%	33	19.0	-2.8%	78	41.8	-8.1%

*Target as of the writing of this report.

NA – data not available.

SN – data suppressed due to small numbers (15 cases or fewer for the 5-year data period).

Data are for years 2006-2010.

Rates are in cases or deaths per 100,000.

Age-adjusted rates are adjusted to the 2000 US standard population.

Source of incidence and late-stage data: North American Association of Central Cancer Registries (NAACCR) – Cancer in North America (CINA) Deluxe Analytic File.

Source of death rate data: Centers for Disease Control and Prevention (CDC) – National Center for Health Statistics (NCHS) mortality data in SEER*Stat.

Source of death trend data: National Cancer Institute (NCI)/CDC State Cancer Profiles.

Incidence rates and trends summary

Overall, the breast cancer incidence rate in the Komen Austin service area was similar to that observed in the US as a whole and the incidence trend was slightly higher than the US as a whole. The incidence rate of the Affiliate service area was **significantly higher** than that observed for the State of Texas and the incidence trend was not significantly different than the State of Texas.

For the United States, breast cancer incidence in Blacks/African Americans is lower than in Whites overall. The most recent estimated breast cancer incidence rates for Asians and Pacific Islanders (APIs) and American Indians and Alaska Natives (AIANs) were lower than for Non-Hispanic Whites and Blacks/African Americans. The most recent estimated incidence rates for Hispanics/Latinas were lower than for Non-Hispanic Whites and Blacks/African Americans. For

the Affiliate service area as a whole, the incidence rate was lower among Blacks/African Americans than Whites and lower among APIs than Whites. There were not enough data available within the Affiliate service area to report on AIANs thus, comparisons cannot be made for this racial group. The incidence rate among Hispanics/Latinas was lower than among Non-Hispanics/Latinas.

The incidence rate was significantly lower in the following county:

- Bastrop County

The rest of the counties had incidence rates and trends that were not significantly different than the Affiliate service area as a whole.

It's important to remember that an increase in breast cancer incidence could also mean that more breast cancers are being found because more women are getting mammograms.

Death rates and trends summary

Overall, the breast cancer death rate in the Komen Austin service area was lower than that observed in the US as a whole and the death rate trend was not available for comparison with the US as a whole. The death rate of the Affiliate service area was significantly lower than that observed for the State of Texas.

For the United States, breast cancer death rates in Blacks/African Americans are substantially higher than in Whites overall. The most recent estimated breast cancer death rates for APIs and AIANs were lower than for Non-Hispanic Whites and Blacks/African Americans. The most recent estimated death rates for Hispanics/Latinas were lower than for Non-Hispanic Whites and Blacks/African Americans. For the Affiliate service area as a whole, the death rate was higher among Blacks/African Americans than Whites. There were not enough data available within the Affiliate service area to report on APIs and AIANs so comparisons cannot be made for these racial groups. The death rate among Hispanics/Latinas was lower than among Non-Hispanics/Latinas.

None of the counties in the Affiliate service area had substantially different death rates than the Affiliate service area as a whole or did not have enough data available.

Late-stage incidence rates and trends summary

Overall, the breast cancer late-stage incidence rate in the Komen Austin service area was slightly lower than that observed in the US as a whole and the late-stage incidence trend was lower than the US as a whole. The late-stage incidence rate and trend of the Affiliate service area were not significantly different than that observed for the State of Texas.

For the United States, late-stage incidence rates in Blacks/African Americans are higher than among Whites. Hispanics/Latinas tend to be diagnosed with late-stage breast cancers more often than Whites. For the Affiliate service area as a whole, the late-stage incidence rate was higher among Blacks/African Americans than Whites and lower among APIs than Whites. There were not enough data available within the Affiliate service area to report on AIANs so comparisons cannot be made for this racial group. The late-stage incidence rate among Hispanics/Latinas was lower than among Non-Hispanics/Latinas.

None of the counties in the Affiliate service area had substantially different late-stage incidence rates than the Affiliate service area as a whole.

Mammography Screening

Getting regular screening mammograms (and treatment if diagnosed) lowers the risk of dying from breast cancer. Screening mammography can find breast cancer early, when the chances of survival are highest. Table 2.2 shows some screening recommendations among major organizations for women at average risk.

Table 2.2. Breast cancer screening recommendations for women at average risk.

American Cancer Society	National Cancer Institute	National Comprehensive Cancer Network	US Preventive Services Task Force
Mammography every year starting at age 40	Mammography every 1-2 years starting at age 40	Mammography every year starting at age 40	<p>Informed decision-making with a health care provider ages 40-49</p> <p>Mammography every 2 years ages 50-74</p>

Because having mammograms lowers the chances of dying from breast cancer, it's important to know whether women are having mammograms when they should. This information can be used to identify groups of women who should be screened who need help in meeting the current recommendations for screening mammography. The Centers for Disease Control and Prevention's (CDC) Behavioral Risk Factors Surveillance System (BRFSS) collected the data on mammograms that are used in this report. The data come from interviews with women age 50 to 74 from across the United States. During the interviews, each woman was asked how long it has been since she has had a mammogram. BRFSS is the best and most widely used source available for information on mammography usage among women in the United States, although it does not collect data that aligns with Susan G. Komen breast self-awareness messaging (i.e. from women age 40 and older). The proportions in Table 2.3 are based on the number of women age 50 to 74 who reported in 2012 having had a mammogram in the last two years.

The data have been weighted to account for differences between the women who were interviewed and all the women in the area. For example, if 20.0 percent of the women interviewed are Hispanic/Latina, but only 10.0 percent of the total women in the area are Hispanic/Latina, weighting is used to account for this difference.

The report uses the mammography screening proportion to show whether the women in an area are getting screening mammograms when they should. Mammography screening proportion is calculated from two pieces of information:

- The number of women living in an area whom the BRFSS determines should have mammograms (i.e. women age 50 to 74).
- The number of these women who actually had a mammogram during the past two years.

The number of women who had a mammogram is divided by the number who should have had one. For example, if there are 500 women in an area who should have had mammograms and 250 of those women actually had a mammogram in the past two years, the mammography screening proportion is 50.0 percent.

Because the screening proportions come from samples of women in an area and are not exact, Table 2.3 includes confidence intervals. A confidence interval is a range of values that gives an idea of how uncertain a value may be. It's shown as two numbers—a lower value and a higher one. It is very unlikely that the true rate is less than the lower value or more than the higher value.

For example, if screening proportion was reported as 50.0 percent, with a confidence interval of 35.0 to 65.0 percent, the real rate might not be exactly 50.0 percent, but it's very unlikely that it's less than 35.0 or more than 65.0 percent.

In general, screening proportions at the county level have fairly wide confidence intervals. The confidence interval should always be considered before concluding that the screening proportion in one county is higher or lower than that in another county.

Table 2.3. Proportion of women ages 50-74 with screening mammography in the last two years, self-report.

Population Group	# of Women Interviewed (Sample Size)	# w/ Self-Reported Mammogram	Proportion Screened (Weighted Average)	Confidence Interval of Proportion Screened
US	174,796	133,399	77.5%	77.2%-77.7%
Texas	3,174	2,348	72.0%	69.9%-74.0%
Komen Austin Service Area	485	386	74.9%	69.4%-79.7%
White	421	337	79.3%	73.6%-84.0%
Black/African American	35	26	66.1%	43.1%-83.4%
AIAN	SN	SN	SN	SN
API	SN	SN	SN	SN
Hispanic/ Latina	43	34	59.5%	40.9%-75.8%
Non-Hispanic/ Latina	439	349	78.0%	72.5%-82.6%
Bastrop County - TX	SN	SN	SN	SN
Caldwell County - TX	SN	SN	SN	SN
Hays County - TX	22	18	77.1%	50.7%-91.7%
Travis County - TX	382	302	71.0%	64.3%-76.9%
Williamson County - TX	67	54	82.0%	69.0%-90.3%

SN – data suppressed due to small numbers (fewer than 10 samples).

Data are for 2012.

Source: CDC – Behavioral Risk Factor Surveillance System (BRFSS).

Breast cancer screening proportions summary

The breast cancer screening proportion in the Komen Austin service area was not significantly different than that observed in the US as a whole. The screening proportion of the Affiliate service area was not significantly different than the State of Texas.

For the United States, breast cancer screening proportions among Blacks/African Americans are similar to those among Whites overall. APIs have somewhat lower screening proportions than Whites and Blacks/African Americans. Although data are limited, screening proportions among AIANs are similar to those among Whites. Screening proportions among Hispanics/Latinas are similar to those among Non-Hispanic Whites and Blacks/African Americans. For the Affiliate service area as a whole, the screening proportion was not significantly different among Blacks/African Americans than Whites. There were not enough data available within the Affiliate service area to report on APIs and AIANs so comparisons cannot be made for these racial groups. The screening proportion among Hispanics/Latinas was not significantly different than among Non-Hispanics/Latinas.

None of the counties in the Affiliate service area had substantially different screening proportions than the Affiliate service area as a whole or did not have enough data available.

Population Characteristics

The report includes basic information about the women in each area (demographic measures) and about factors like education, income, and unemployment (socioeconomic measures) in the areas where they live (Tables 2.4 and 2.5). Demographic and socioeconomic data can be used to identify which groups of women are most in need of help and to figure out the best ways to help them.

It is important to note that the report uses the race and ethnicity categories used by the US Census Bureau, and that race and ethnicity are separate and independent categories. This means that everyone is classified as both a member of one of the four race groups as well as either Hispanic/Latina or Non-Hispanic/Latina.

The demographic and socioeconomic data in this report are the most recent data available for US counties. All the data are shown as percentages. However, the percentages weren't all calculated in the same way.

- The race, ethnicity, and age data are based on the total female population in the area (e.g. the percent of females over the age of 40).
- The socioeconomic data are based on all the people in the area, not just women.
- Income, education and unemployment data does not include children. These demographics are based on people age 15 and older for income and unemployment and age 25 and older for education.
- The data on the use of English, called “linguistic isolation”, are based on the total number of households in the area. The Census Bureau defines a linguistically isolated household as one in which all the adults have difficulty with English.

Table 2.4. Population characteristics – demographics.

Population Group	White	Black /African American	AIAN	API	Non-Hispanic /Latina	Hispanic /Latina	Female Age 40 Plus	Female Age 50 Plus	Female Age 65 Plus
US	78.8 %	14.1 %	1.4 %	5.8 %	83.8 %	16.2 %	48.3 %	34.5 %	14.8 %
Texas	81.5 %	12.9 %	1.1 %	4.5 %	62.5 %	37.5 %	42.9 %	29.4 %	11.7 %
Komen Austin Service Area	84.5 %	8.6 %	1.3 %	5.6 %	68.8 %	31.2 %	39.9 %	26.0 %	9.3 %
Bastrop County - TX	88.8 %	8.2 %	1.7 %	1.3 %	68.0 %	32.0 %	49.4 %	35.0 %	13.0 %
Caldwell County - TX	89.7 %	7.7 %	1.4 %	1.2 %	52.1 %	47.9 %	45.2 %	32.1 %	13.4 %
Hays County - TX	92.6 %	4.3 %	1.3 %	1.8 %	64.2 %	35.8 %	38.8 %	26.3 %	9.6 %
Travis County - TX	82.1 %	9.8 %	1.5 %	6.6 %	66.9 %	33.1 %	38.3 %	24.7 %	8.5 %
Williamson County - TX	86.0 %	7.3 %	1.0 %	5.7 %	76.7 %	23.3 %	42.0 %	26.8 %	10.2 %

Data are for 2011.

Data are in the percentage of women in the population.

Source: US Census Bureau – Population Estimates

Table 2.5. Population characteristics – socioeconomics.

Population Group	Less than HS Education	Income Below 100% Poverty	Income Below 250% Poverty (Age: 40-64)	Un-employed	Foreign Born	Linguistic-ally Isolated	In Rural Areas	In Medically Under-served Areas	No Health Insurance (Age: 40-64)
US	14.6 %	14.3 %	33.3 %	8.7 %	12.8 %	4.7 %	19.3 %	23.3 %	16.6 %
Texas	19.6 %	17.0 %	37.1 %	7.3 %	16.2 %	8.2 %	15.3 %	32.2 %	24.7 %
Komen Austin Service Area	12.3 %	14.0 %	28.0 %	7.1 %	14.5 %	6.0 %	12.8 %	42.8 %	19.2 %
Bastrop County - TX	18.9 %	14.2 %	36.4 %	7.7 %	10.2 %	4.9 %	63.9 %	100.0 %	24.2 %
Caldwell County - TX	23.2 %	20.7 %	44.8 %	11.0 %	5.4 %	4.1 %	42.3 %	100.0 %	27.1 %
Hays County - TX	11.4 %	16.4 %	27.1 %	7.0 %	6.9 %	2.9 %	31.7 %	100.0 %	19.9 %
Travis County - TX	13.3 %	16.6 %	29.9 %	6.9 %	18.0 %	7.6 %	5.5 %	4.2 %	19.4 %
Williamson County - TX	8.1 %	6.3 %	21.0 %	7.0 %	10.4 %	3.0 %	12.0 %	100.0 %	16.8 %

Data are in the percentage of people (men and women) in the population.

Source of health insurance data: US Census Bureau – Small Area Health Insurance Estimates (SAHIE) for 2011.

Source of rural population data: US Census Bureau – Census 2010.

Source of medically underserved data: Health Resources and Services Administration (HRSA) for 2013.

Source of other data: US Census Bureau – American Community Survey (ACS) for 2007-2011.

Population characteristics summary

Proportionately, the Komen Austin service area has a substantially larger White female population than the US as a whole, a substantially smaller Black/African American female population, a slightly smaller Asian and Pacific Islander (API) female population, a slightly smaller American Indian and Alaska Native (AIAN) female population, and a substantially larger Hispanic/Latina female population. The Affiliate’s female population is substantially younger than that of the US as a whole. The Affiliate’s education level is slightly higher than and income level is slightly higher than those of the US as a whole. There are a slightly smaller percentage of people who are unemployed in the Affiliate service area. The Affiliate service area has a slightly larger percentage of people who are foreign born and a slightly larger percentage of people who are linguistically isolated. There are a substantially smaller percentage of people living in rural areas, a slightly larger percentage of people without health insurance, and a substantially larger percentage of people living in medically underserved areas.

The following county has substantially larger Hispanic/Latina female population percentages than that of the Affiliate service area as a whole:

- Caldwell County

The following counties have substantially lower education levels than that of the Affiliate service area as a whole:

- Bastrop County
- Caldwell County

The following county has substantially lower income levels than that of the Affiliate service area as a whole:

- Caldwell County

The following county has substantially lower employment levels than that of the Affiliate service area as a whole:

- Caldwell County

The following counties have substantially larger percentage of adults without health insurance than does the Affiliate service area as a whole:

- Bastrop County
- Caldwell County

Priority Areas

Healthy People 2020 forecasts

Healthy People 2020 (HP2020) is a major federal government initiative that provides specific health objectives for communities and for the country as a whole. Many national health organizations use HP2020 targets to monitor progress in reducing the burden of disease and improve the health of the nation. Likewise, Komen believes it is important to refer to HP2020 to see how areas across the country are progressing towards reducing the burden of breast cancer.

HP2020 has several cancer-related objectives, including:

- Reducing women's death rate from breast cancer (Target as of the writing of this report: 41.0 cases per 100,000 women).
- Reducing the number of breast cancers that are found at a late-stage (Target as of the writing of this report: 41.0 cases per 100,000 women).

To see how well counties in the Komen Austin service area are progressing toward these targets, the report uses the following information:

- County breast cancer death rate and late-stage diagnosis data for years 2006 to 2010.
- Estimates for the trend (annual percent change) in county breast cancer death rates and late-stage diagnoses for years 2006 to 2010.
- Both the data and the HP2020 target are age-adjusted.

These data are used to estimate how many years it will take for each county to meet the HP2020 objectives. Because the target date for meeting the objective is 2020, and 2008 (the middle of the 2006-2010 period) was used as a starting point, a county has 12 years to meet the target.

Death rate and late-stage diagnosis data and trends are used to calculate whether an area will meet the HP2020 target, assuming that the trend seen in years 2006 to 2010 continues for 2011 and beyond.

Identification of priority areas

The purpose of this report is to combine evidence from many credible sources and use the data to identify the highest priority areas for breast cancer programs (i.e. the areas of greatest need).

Classification of priority areas are based on the time needed to achieve HP2020 targets in each area. These time projections depend on both the starting point and the trends in death rates and late-stage incidence.

Late-stage incidence reflects both the overall breast cancer incidence rate in the population and the mammography screening coverage. The breast cancer death rate reflects the access to care and the quality of care in the health care delivery area, as well as cancer stage at diagnosis.

There has not been any indication that either one of the two HP2020 targets is more important than the other. Therefore, the report considers them equally important.

Counties are classified as follows (Table 2.6):

- Counties that are not likely to achieve either of the HP2020 targets are considered to have the highest needs.
- Counties that have already achieved both targets are considered to have the lowest needs.
- Other counties are classified based on the number of years needed to achieve the two targets.

Table 2.6. Needs/priority classification based on the projected time to achieve HP2020 breast cancer targets.

		Time to Achieve Late-stage Incidence Reduction Target				
		13 years or longer	7-12 yrs.	0 – 6 yrs.	Currently meets target	Unknown
Time to Achieve Death Rate Reduction Target	13 years or longer	Highest	High	Medium High	Medium	Highest
	7-12 yrs.	High	Medium High	Medium	Medium Low	Medium High
	0 – 6 yrs.	Medium High	Medium	Medium Low	Low	Medium Low
	Currently meets target	Medium	Medium Low	Low	Lowest	Lowest
	Unknown	Highest	Medium High	Medium Low	Lowest	Unknown

If the time to achieve a target cannot be calculated for one of the HP2020 indicators, then the county is classified based on the other indicator. If both indicators are missing, then the county is not classified. This doesn't mean that the county may not have high needs; it only means that sufficient data are not available to classify the county.

Affiliate Service Area Healthy People 2020 Forecasts and Priority Areas

The results presented in Table 2.7 help identify which counties have the greatest needs when it comes to meeting the HP2020 breast cancer targets.

- For counties in the “13 years or longer” category, current trends would need to change to achieve the target.
- Some counties may currently meet the target but their rates are increasing and they could fail to meet the target if the trend is not reversed.

Trends can change for a number of reasons, including:

- Improved screening programs could lead to breast cancers being diagnosed earlier, resulting in a decrease in both late-stage incidence rates and death rates.
- Improved socioeconomic conditions, such as reductions in poverty and linguistic isolation could lead to more timely treatment of breast cancer, causing a decrease in death rates.

The data in this table should be considered together with other information on factors that affect breast cancer death rates such as screening percentages and key breast cancer death determinants such as poverty and linguistic isolation.

Table 2.7. Intervention priorities for Komen Austin service area with predicted time to achieve the HP2020 breast cancer targets and key population characteristics.

County	Priority	Predicted Time to Achieve Death Rate Target	Predicted Time to Achieve Late-stage Incidence Target	Key Population Characteristics
Caldwell County - TX	Highest	SN	13 years or longer	%Hispanic, education, poverty, employment, rural, insurance, medically underserved
Bastrop County - TX	Medium	Currently meets target	13 years or longer	Education, rural, insurance, medically underserved
Hays County - TX	Low	4 years	Currently meets target	Rural, medically underserved
Travis County - TX	Low	Currently meets target	1 year	
Williamson County - TX	Low	Currently meets target	1 year	Medically underserved

SN – data suppressed due to small numbers (15 cases or fewer for the 5-year data period).

Map of Intervention Priority Areas

Figure 2.1 shows a map of the intervention priorities for the counties in the Affiliate service area. When both of the indicators used to establish a priority for a county are not available, the priority is shown as “undetermined” on the map.

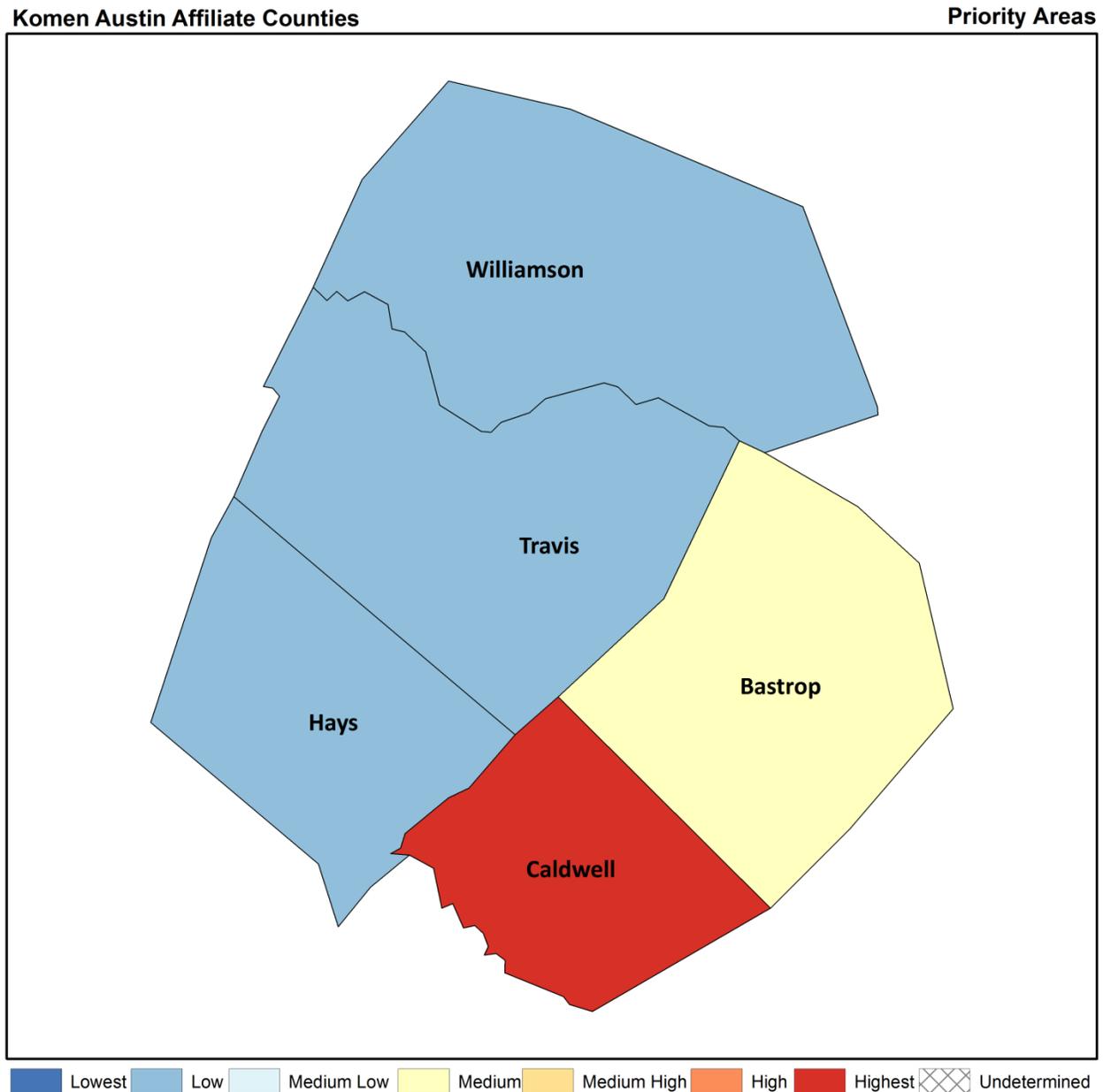


Figure 2.1. Intervention priorities.

Data Limitations

The following data limitations need to be considered when utilizing the data of the Quantitative Data Report:

- The most recent data available were used but, for cancer incidence and deaths, these data are still several years behind.
- For some areas, data might not be available or might be of varying quality.
- Areas with small populations might not have enough breast cancer cases or breast cancer deaths each year to support the generation of reliable statistics.

- There are often several sources of cancer statistics for a given population and geographic area; therefore, other sources of cancer data may result in minor differences in the values even in the same time period.
- Data on cancer rates for specific racial and ethnic subgroups such as Somali, Hmong, or Ethiopian are not generally available.
- The various types of breast cancer data in this report are inter-dependent.
- There are many factors that impact breast cancer risk and survival for which quantitative data are not available. Some examples include family history, genetic markers like HER2 and BRCA, other medical conditions that can complicate treatment, and the level of family and community support available to the patient.
- The calculation of the years needed to meet the HP2020 objectives assume that the current trends will continue until 2020. However, the trends can change for a number of reasons.
- Not all breast cancer cases have a stage indication.

Quantitative Data Report Conclusions

Highest priority areas

One county in the Komen Austin service area is in the highest priority category. Caldwell County is not likely to meet the late-stage incidence rate HP2020 target. Caldwell County has a relatively large Hispanic/Latina population, low education levels, high poverty rates and high unemployment.

Medium priority areas

One county in the Komen Austin service area is in the medium priority category. Bastrop County is not likely to meet the late-stage incidence rate HP2020 target. Bastrop County has low education levels.

Additional Quantitative Data Exploration

Additional data were collected to support Komen Austin's Quantitative Data Report, 2014 (Susan G. Komen, 2014). Further, statistics for demographic and socioeconomic characteristics, female breast cancer incidence rates, female breast cancer death rates, and late-stage female breast cancer rates were reviewed. This additional data is used to justify and support the selected target communities.

The Community Health Needs Assessments (CHNA, 2014) toolkit was used to provide a better understanding of what variables are influencing health outcomes in the Affiliate's service area. A full health indicator report with relevant statistical data was analyzed for the five-county service area. The CHNA toolkit provided data not included in the QDR report, e.g., indicators such as language barriers and access to health care and providers, which ultimately provided a county by county comparison for the identification of targeted communities.

The additional data complements and expands the data from the QDR to develop a comprehensive assessment of the communities under study.

Community Health Needs Assessment (CHNA) Report:

Limited English Proficiency

This indicator reports the percentage of the population age five and older who speak a language other than English at home and speak English less than "very well." This indicator is relevant because an inability to speak English well creates barriers to health care access, provider communications, and health literacy/education.

Table 2.8. Population with Limited English Proficiency.

Report Area	Total Population*	Population Age 5+	Population Age 5+ with Limited English Proficiency	Percent Population Age 5+ with Limited English Proficiency
Report Area	1,603,821	1,603,821	177,554	11.07%
Bastrop County, TX	69,095	69,095	6,710	9.71%
Caldwell County, TX	35,535	35,535	2,671	7.52%
Hays County, TX	147,847	147,847	9,927	6.71%
Travis County, TX	958,478	958,478	132,396	13.81%
Williamson County, TX	392,866	392,866	25,850	6.58%
Texas	23,280,056	23,280,055	3,346,914	14.38%
United States	289,000,832	289,000,824	25,081,124	8.68%

Note: This indicator is compared with the state average.

Data Source: US Census Bureau, [American Community Survey](#): 2008-12. Source geography: Tract.

**Total population as listed in the table is only the population ages 5 and over. Those under 5 are not included in the total population values. As mentioned in the introduction, the accepted US Census total population of Austin in 2013 is 1.9 million.*

Methodology

Population counts for population by language proficiency and total area population data are acquired from the US Census Bureau's American Community Survey (ACS). Data represent estimates for the five year period 2008-2012. Mapped data are summarized to 2010 census tract boundaries. Persons are considered to have limited English proficiency if they indicated that they spoke a language other than English and if they spoke English less than "very well". Area demographic statistics are measured as a percentage of the total population aged five plus based on the following formula: **Percentage = [Subgroup Population] / [Total Population Age five plus] * 100**

Data Limitations

Beginning in 2006, the population in group quarters was included in the ACS. The part of the group quarters population in the language universe (for example, people living in group homes or those living in agriculture workers' dormitories) may have different levels of English proficiency than the general population. Direct comparisons of the data would likely result in erroneous conclusions about the English language proficiency of all people living in the area.

Selection of Target Communities

Breast cancer is the most common cancer among women in the United States. In Texas, the leading cause of female cancer deaths is breast cancer (Texas Cancer Registry, 2014).

Community assessments identify community needs while recognizing health system barriers affecting health outcomes.

Breast cancer had the highest incidence rate among all female races and ethnicities in Texas between the years 2006 and 2010 with a rate of 114.2 per 100,000 people and an average number of cases of 13,742.

Komen Austin selected the following target communities to focus on over the next four years:

- Caldwell County
- Bastrop County
- Travis County

The Quantitative Data Report classified counties from the lowest to the highest priority based on the Healthy People 2020 (HP2020) breast cancer targets. These targets include reducing late-stage female breast cancer rates to 41.0 per 100,000 women while reducing the female breast cancer death rate to 20.6 per 100,000 women by 2020. Counties are identified as high priority (Table 2.6) when they require a minimum of 13 years to meet these goals.

HP2020 target goal rates are based on the period between 2008- 2020. Caldwell County is identified as highest priority while Bastrop County is identified as medium priority (Table 2.7).

Many demographic and socioeconomic characteristics are indicators for health system barriers, therefore impacting breast cancer rates. Barriers are identified as an impediment that prevents, discourages, limits, or inhibits a woman from having access to the continuum of care. Utilization of services relates to how often people use health care, the types of health care they use, and the timing of that care. Access to care is the availability to timely health care, high quality of care, culturally relevant, affordable and coordinated health care. Multiple counties within the Affiliate service area present demographic and socioeconomic indicators leading to health system barriers.

Caldwell County

Caldwell County data reveals:

1. Breast cancer incidence rate of 129.8 per 100,000 women, higher than the Komen Austin service area and Texas (Table 2.1);
2. An increasing trend of 7.2 percent for breast cancer incidence rate and an increasing trend of 1.3 percent for late-stage incidence rate (Table 2.1);
3. The late-stage female breast cancer rate of 55.0 per 100,000 women which is higher than all other counties in the Affiliate service area (Table 2.1), this rate does not meet the HP2020 target of 41.0 cases per 100,000.

Thus, Caldwell County is identified as the highest priority county in the Affiliate service area (Table 2.7).

Caldwell County demonstrates multiple demographic and socioeconomic indicators which may contribute to the county's inability to meet the HP2020 goals (Tables 2.4 and 2.5).

Caldwell County has substantially lower education levels when compared to other counties in the Affiliate area with 23.2 percent of the population having less than a high school education (Table 2.5). Research suggests that education is one of the strongest predictors of health status (CHNA, 2014).

Caldwell County has 20.7 percent of the population, ages 40-64, with income below the 100 percent Federal Poverty Guidelines, and 44.8 percent of the population ages 40-64 with income below the 250 percent Federal Poverty Guidelines (Table 2.5). These percentages are substantially higher than the other counties in the Affiliate's service area, Texas, and nationally (Table 2.4). Caldwell County has an unemployment percentage of 11.0 percent which is higher than the other counties in the Affiliate's service area, Texas, and nationally (Table 2.5). Poverty and unemployment percentages are indicators that contribute to financial limitations. These create barriers to access to health services, nutritional and healthy food sources, and other necessities, which ultimately, contribute to poor health status (CHNA, 2014).

A substantially large percentage of Caldwell County's population ages 40-64 are uninsured, 27.1 percent; this rate is higher than the Affiliate service area, the state, and nationally (Table 2.5). Lack of insurance is a primary barrier to access to health care, including regular primary care, specialty care, and other services, thus contributing to poor health status (CHNA, 2014).

Caldwell County has 7.5 percent of its population age five plus with limited English proficiency, which is higher than that of Williamson and Hays counties (Table 2.8). Linguistic barriers, or an inability to speak English "very well," create barriers to access and utilization of health care such as health provider-patient communications and health literacy and education (CHNA, 2014). At 45.2 percent, Caldwell County is the only county in the Affiliate service area with a total female population age 40 plus that is substantially different from the Affiliate service area. This percentage indicates a high percentage of women at risk (Table 2.4).

Further, 42.3 percent of Caldwell's population lives in rural areas (Table 2.5). Living in rural areas can cause barriers to good health status due to the lack of access to health care such as regular health screenings and routine tests, which affect the reduction of late-stage breast cancer diagnosis and death rates (CHNA, 2014).

Bastrop County

Bastrop County data reveals:

1. An increasing trend for female breast cancer incidence rate, 1.3 percent, higher than Komen Austin's service area, Texas, and nationally (Table 2.1);
2. A late-stage female breast cancer rate of 38.2 per 100,000 women, which is lower than the HP2020 target goal, yet the county has an increasing trend for late stage breast cancer, 1.0 percent (Table 2.1).

Thus Bastrop County is identified as a medium priority county in the Affiliate service area (Table 2.7).

The county has multiple demographic and socioeconomic indicators which may contribute to the county's abilities to meet the HP2020 goals. Data demonstrates that Bastrop has a higher concentration of these indicators than the Affiliate service area.

Bastrop County has a population of 18.9 percent with less than a high school education, which is higher than the national rate and the Affiliate service area (Table 2.5). In Bastrop, the population ages 40-64 with an income below 250 percent of the Federal Poverty Guidelines is 36.4 percent, higher than the Affiliate service area and the nation (Table 2.5). The county has an unemployment percentage of 7.7 percent, higher than Texas and the Komen Austin service area (Table 2.5).

The county's underinsured population, for ages 40-64, is 24.2 percent, a percentage that is higher than the Affiliate's service area and nationally (Table 2.5). Bastrop County has 9.7 percent of its population age five plus with limited English proficiency (Table 2.8), which is higher than the national rate. Bastrop's female population age 40 plus is 49.4 percent, placing the county at higher risk than females nationally, statewide, and in the Komen Austin service area (Table 2.4).

Nearly 70.0 percent of Bastrop County's population lives in rural areas, a percentage that is higher than that of the state, the Affiliate's service area, and nationally (Table 2.5). The Black/African-American female population of 8.2 percent is comparable to that of the Affiliate service area of 8.6 percent (Table 2.4).

Travis County

Travis County alone comprises over half of the female population in the Affiliate's service area with almost 60.0 percent of the total female population residing in Travis County (Table 2.1). The county holds the second highest female breast cancer incidence rate trend of 1.8 percent in the five county service area (Table 2.1). The Black/African-American female population is 9.8 percent; this represents a larger population than that of the Affiliate service area of 8.6 percent (Table 2.4).

Travis County presents a population of 13.3 percent with less than a high school education, which is higher than the Affiliate's service area (Table 2.5). A population of 16.3 percent lives below the 100 percent Federal Poverty Guidelines, once again, higher than the service area (Table 2.5). In Travis County, when applying the 250 percent Federal Poverty Guidelines, 29.9 percent of the population, between the ages of 40-64, lives below the federal guidelines, a percentage higher than the Affiliate's service area (Table 2.5).

Travis County has a population of 19.4 percent, between the ages 40-64, who are uninsured (Table 2.5). The county has a linguistically isolated population of 7.6 percent, which is higher than the other four counties in the Affiliate service area (Table 2.5). This indicator points to linguistic barriers, or the inability to speak English "very well" which may lead to barriers in the utilization of available health care due to limited health provider-patient communications and might affect health literacy and education.

Travis County has a population of 13.8 percent with limited English proficiency, higher than the Affiliate service area and that of the national rate (Table 2.8). The county has a foreign born population of 18.0 percent, which is larger than that of the Affiliate service area (Table 2.5).

This indicator reflects that the foreign born population may experience linguistic barriers, cultural barriers, and other socioeconomic barriers that may come with immigration.

Health Systems Analysis

The health systems analysis will include interviews with a variety of representatives in each of the five counties. A complete list of breast health service providers spanning the continuum of care will be compiled for each county to identify deficits in health care provision. Further, for each of the target priorities, health indicators and demographics will be investigated with more depth and scope.

In Caldwell County, demographic and socioeconomic barriers may provide an understanding as to why this population continues to have increasing trends in breast cancer incidence as well as late-stage female breast cancer rates. For Bastrop County, demographic and socioeconomic barriers will be investigated with the goal of understanding why these breast cancer rates are prevalent. In Travis County, demographic and socioeconomic indicators will be examined to assess what may be preventing or reducing the utilization of services, and equally important, access to care found in the county.

Health Systems and Public Policy Analysis

Health Systems Analysis Data Sources

Komen Austin sources used to collect program and service data included an online search of numerous databases listed below:

- *Mammography Centers*
(<http://www.accessdata.fda.gov/scripts/cdrh/cfdocs/cfMQSA/mgsa.cfm>)
- *Hospitals*
(<https://data.medicare.gov/Hospital-Compare/Hospital-General-Information/v287-28n3>)
- *Local Health Departments*
(<http://www.naccho.org/about/lhd/>)
- *Community Health Centers*
(http://findahealthcenter.hrsa.gov/Search_HCC.aspx)
- *Free Clinics*
(<http://www.nafcclinics.org/clinics/search>)
- *American College of Surgeons Commission on Cancer*
(http://datalinks.facs.org/cpm/CPMAApprovedHospitals_Search.htm)
- *American College of Radiology Centers of Excellence*
(<http://www.acr.org/Quality-Safety/Accreditation/Accredited-Facility-Search>)
- *American College of Surgeons National Accreditation Program for Breast Centers (NAPBC)* (<http://napbc-breast.org/resources/find.html>)
- *National Cancer Institute Designated Cancer Centers*
(<http://www.cancer.gov/researchandfunding/extramural/cancercenters/find-a-cancer-center>)

The Affiliate also referred to its five-county service inventory that was compiled over a two year period, with monthly interagency meetings and interviews with key informants in the targeted counties.

The Affiliate followed the sources provided in the template and searched current service providers in Caldwell, Bastrop, and Travis Counties. For each provider, within the target communities, a review of organizational websites was conducted to identify services provided and geographical locations. The Affiliate interviewed key contact people with specific organizations to better identify service provision in target communities.

The Affiliate chose five indicators to analyze the data acquired, including number of service providers, location of service providers, type of service providers, type of services provided, and the quality of care. The Affiliate used those indicators for each target community to assess its strengths and weaknesses, and analyzed the gap between service need and service provision.

Health Systems Overview

The Breast Cancer Continuum of Care (CoC) (Figure 3.1) is a model that shows how a woman typically moves through the health care system for breast care.

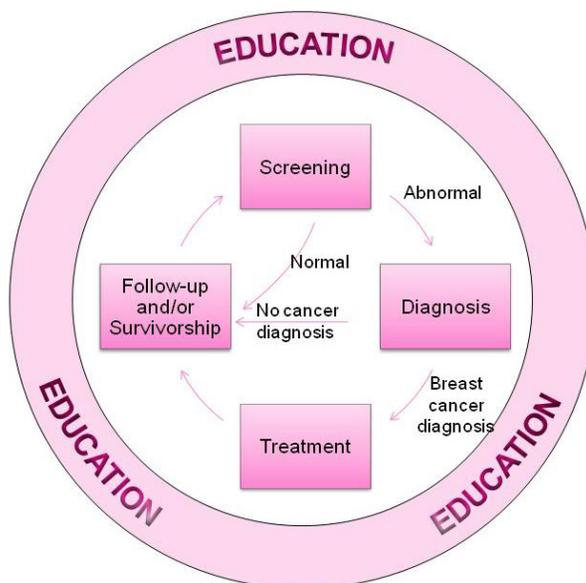


Figure 3.1. Breast Cancer Continuum of Care (CoC)

A woman would ideally move through the CoC quickly and seamlessly, receiving timely, quality care in order to have the best outcomes. Education can play an important role throughout the entire CoC.

While a woman may enter the continuum at any point, ideally, a woman would enter the CoC by getting screened for breast cancer, with a clinical breast exam or a screening mammogram. If the screening test results are normal, she would loop back into follow-up care, where she would get another screening exam at the recommended interval. Education plays a role in both providing education to encourage women to get screened and reinforcing the need to continue to get screened routinely thereafter.

If a screening exam resulted in abnormal results, diagnostic tests would be needed, possibly several, to determine if the abnormal finding is in fact breast cancer. These tests might include a diagnostic mammogram, breast ultrasound or biopsy. If the tests were negative (or benign) and breast cancer was not found, she would go into the follow-up loop, and return for screening at the recommended interval. The recommended intervals may range from three to six months for some women to 12 months for most women. Education plays a role in communicating the importance of proactively getting test results, keeping follow-up appointments and understanding what it all means. Education can empower a woman and help manage anxiety and fear.

If breast cancer is diagnosed, she would proceed to treatment. Education can cover such topics as treatment options, how a pathology report determines the best options for treatment,

understanding side effects and how to manage them, and helping to formulate questions a woman may have for her providers.

For some breast cancer patients, treatment may last a few months and for others, it may last years. While the CoC model shows that follow up and survivorship come after treatment ends, they actually may occur at the same time. Follow up and survivorship may include things like navigating insurance issues, locating financial assistance, symptom management, such as pain, fatigue, sexual issues, bone health, etc. Education may address topics such as making healthy lifestyle choices, long term effects of treatment, managing side effects, the importance of follow-up appointments, and communication with their providers. Most women will return to screening at a recommended interval after treatment ends, or for some, during treatment (such as those taking long term hormone therapy).

There are often delays in moving from one point of the continuum to another – at the point of follow-up of abnormal screening exam results, starting treatment, or completing treatment – that can all contribute to poorer outcomes. There are also many reasons why a woman does not enter or continue in the breast cancer CoC. These barriers can include things such as lack of transportation, system issues including long waits for appointments and inconvenient clinic hours, language barriers, fear, lack of information, or the wrong information (myths and misconceptions). Education can address some of these barriers and help a woman progress through the CoC more quickly.

Summary of Health Systems

At the time of initial analysis, the Affiliate identified all of the providers indicated on the following service maps. Since that time, the Affiliate has become aware of changes in the number and services of providers. The following narrative reflects the most current understanding of health care providers. Thus, the accompanying maps may or may not be current.

Caldwell County

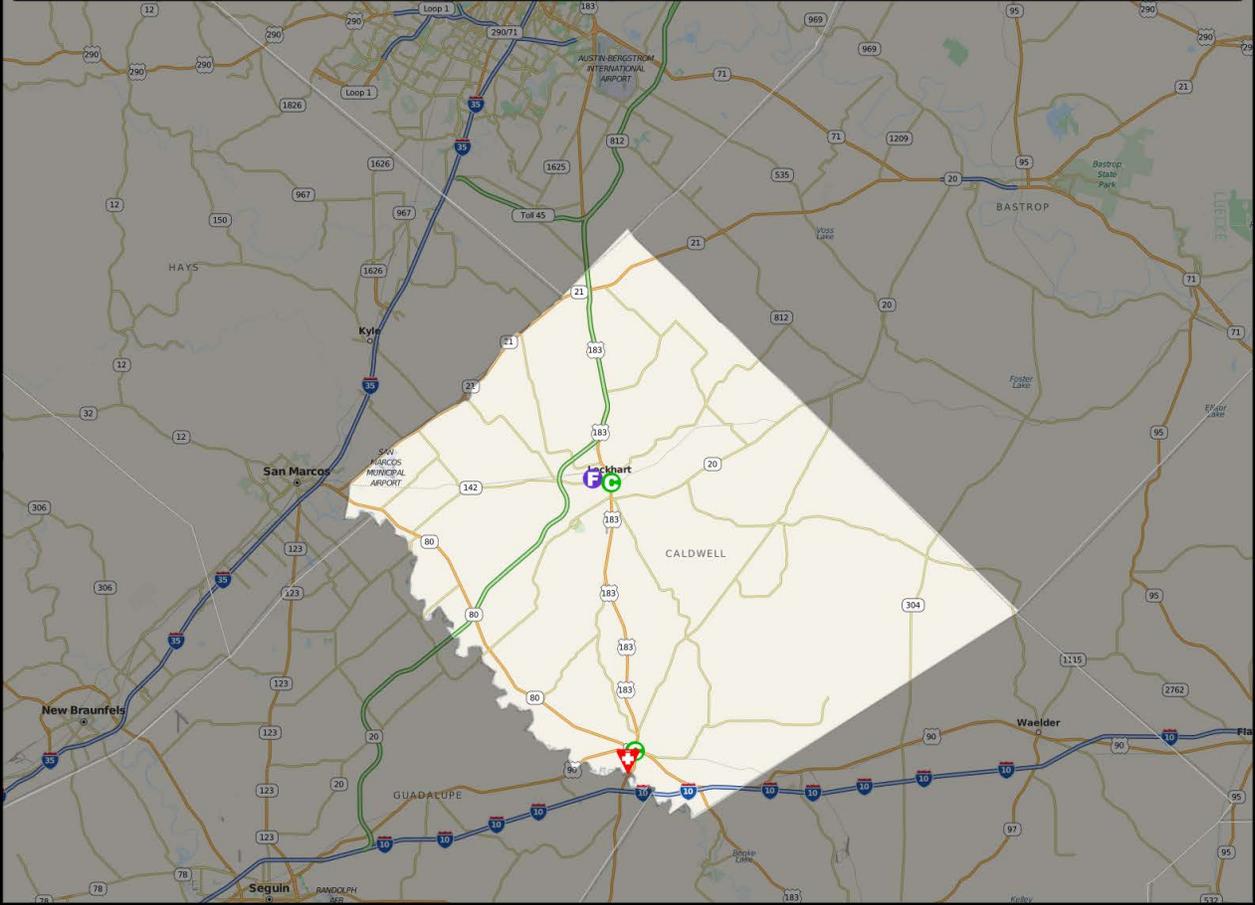
In Caldwell County, the Affiliate identified five in-county health service providers: two in Luling and three in Lockhart (Figure 3.2). Four of the five service providers offer general screening services, but none are able to provide all services under the CoC in their respective communities. Three organizations offer limited diagnostic services, one provider offers limited treatment options, and four provide some survivorship/support services. In addition, Komen Austin provides funding for three additional organizations to provide a wide range of services in the county.

People living in Caldwell County have difficulty gaining access to diagnostic, treatment, and supportive services for breast cancer or breast health in their respective communities. For example, Lockhart residents must drive to Austin for diagnostic services when follow up health services like diagnostic or treatment are needed. Patients have to commute or be referred to other nearby communities such as Austin, San Antonio, or San Marcos. Therefore, limited breast cancer service resources, such as a lack of further diagnosis and treatment services, as well as a lack of enough local health providers in Caldwell County, creates barriers for local residents, especially for those women who are living in poverty and are either uninsured or underinsured.

The Affiliate found there is good collaboration among service providers. The relatively small communities facilitate easier communication and strong bonds with each other compared to large numbers of providers in a large community. The Affiliate ascertained this via the interagency group meetings.

Caldwell County

 Hospital	 Community Health Center	 Other
 Free Clinic	 Department of Health	 Affiliate Office



Statistics

Total Locations in Region: 5

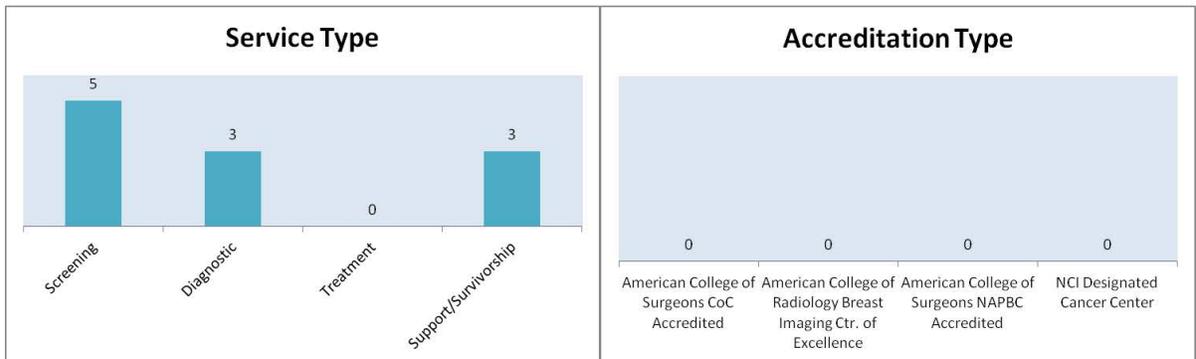


Figure 3.2. Breast Cancer Services Available in Caldwell County

Bastrop County

In Bastrop County, the Affiliate was able to identify six health service providers; while five of them are in Bastrop, only one is in Smithville (Figure 3.3). Bastrop County has limited health service resources, and no in-county providers offer the complete scope of the CoC model. Three providers offer screening mammograms, and two provide clinical breast exams. The Affiliate found two providers offering diagnostic services and two providing limited treatment. In addition, there are two providers offering support and survivorship programs. Komen Austin also funds five organizations that offer services in the county, ranging in all four areas of the continuum of care.

The Affiliate's quantitative analysis indicates that Bastrop County has an increasing trend for late-stage breast cancer, but currently the majority of Bastrop residents cannot get diagnosed or treated locally.

Health service providers in Bastrop have strong relationships with each other and do not have barriers in communication often found in bureaucratic health systems. Community-based organizations have community relationships that have existed for many years. Because the area is a rural community, the community based organizations tend to develop long-lasting bonds quickly.

Bastrop County



Hospital



Community Health Center



Other



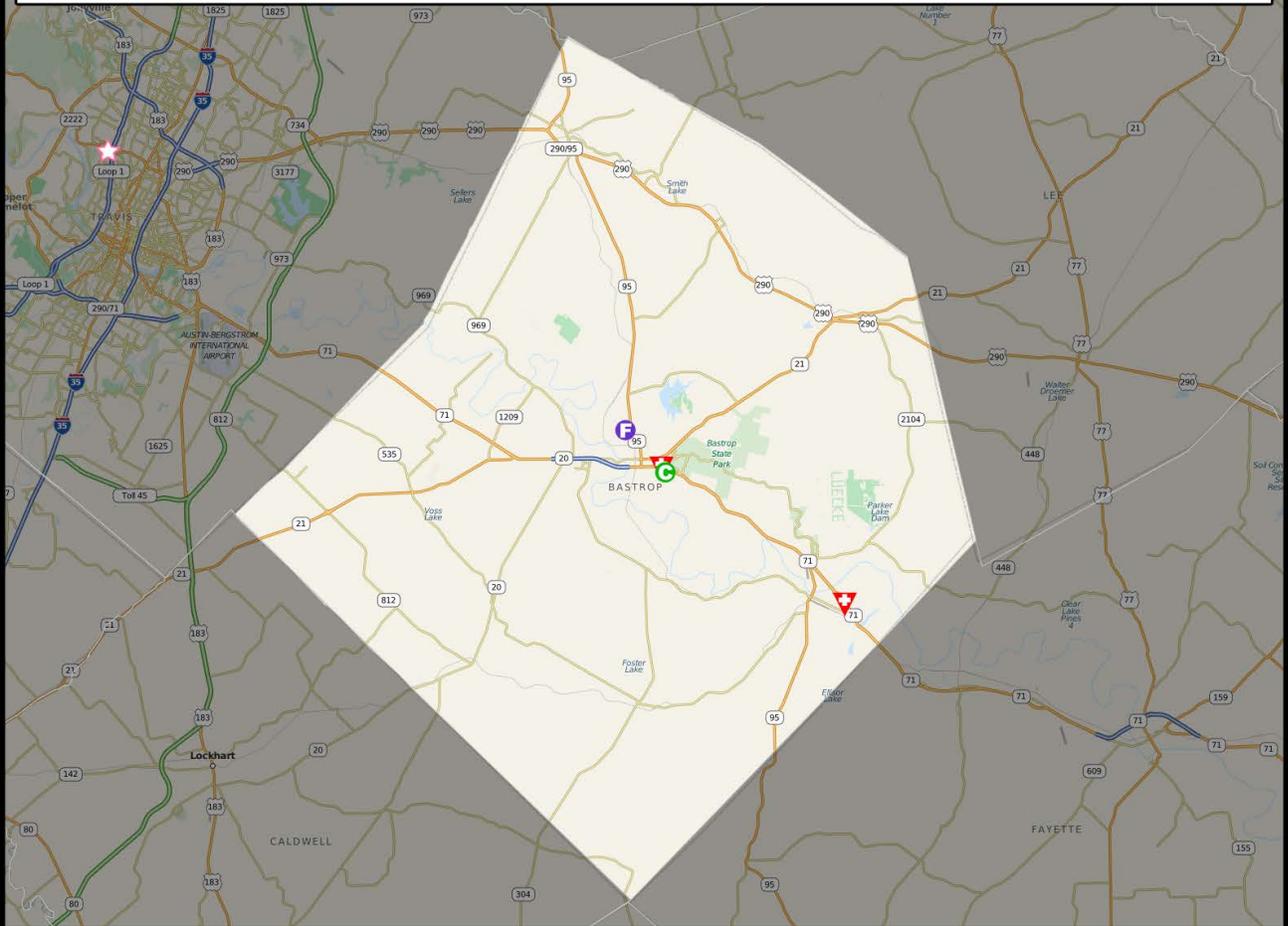
Free Clinic



Department of Health



Affiliate Office



Statistics

Total Locations in Region: 4

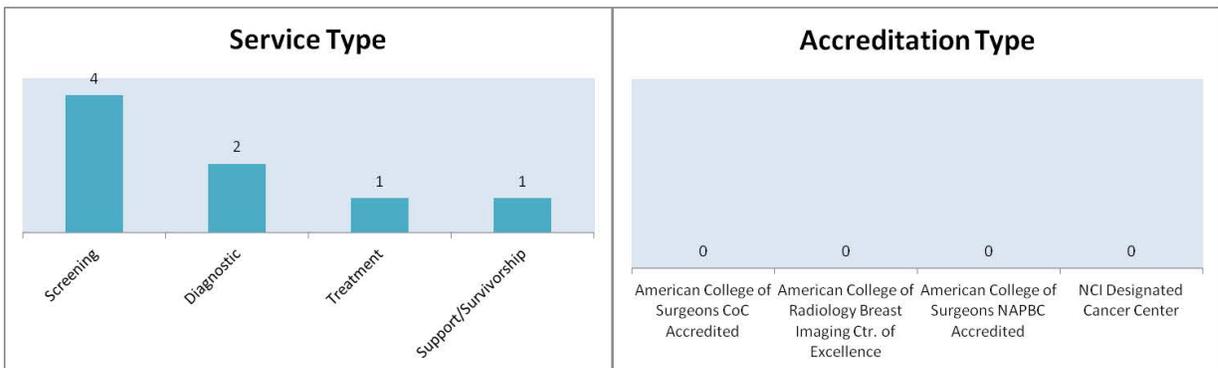
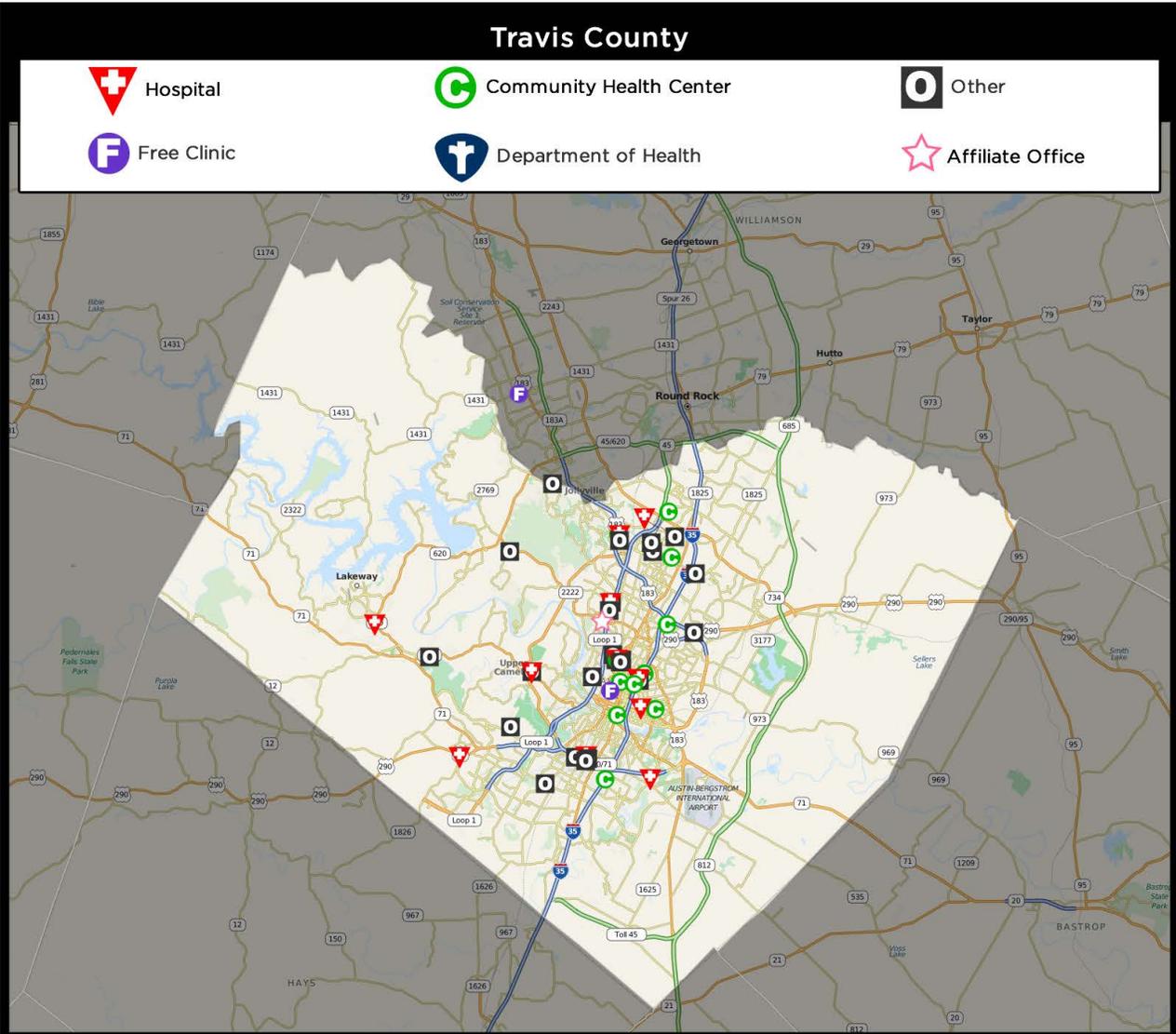


Figure 3.3. Breast Cancer Services Available in Bastrop County

Travis County

In Travis County, the Affiliate identified 51 health service providers. In Austin, there are 48 providers and the remaining three are located in Bee Cave, Lakeway, and Cedar Park (Figure 3.4). The health system in Travis County differs greatly from those in Caldwell and Bastrop Counties since it has many more comprehensive service providers that are spread across Austin and throughout the county. Among the 51 providers, approximately 74.5 percent offer screening services, approximately 51.0 percent offer diagnostic services, approximately 27.5 percent offer treatment services, and approximately 37.3 percent offer supportive services.

Travis County has many resources for breast cancer screening and diagnosis; however, it is insufficient in the areas of treatment and supportive services. In addition, only 17 providers are certified or accredited by the American College of Surgeons Commission on Cancer, American College of Radiology Centers of Excellence, and/or American College of Surgeons National Accreditation Program for Breast Centers (NAPBC). Travis County does not as of this writing have a provider that is recognized by the National Cancer Institute as a Designated Cancer Center. The University of Texas at Austin is constructing the Dell Medical School slated to be completed in 2016. The medical school will bring research and cancer treatment options to the service area promising the opportunity for the national designation.



Statistics

Total Locations in Region: 51

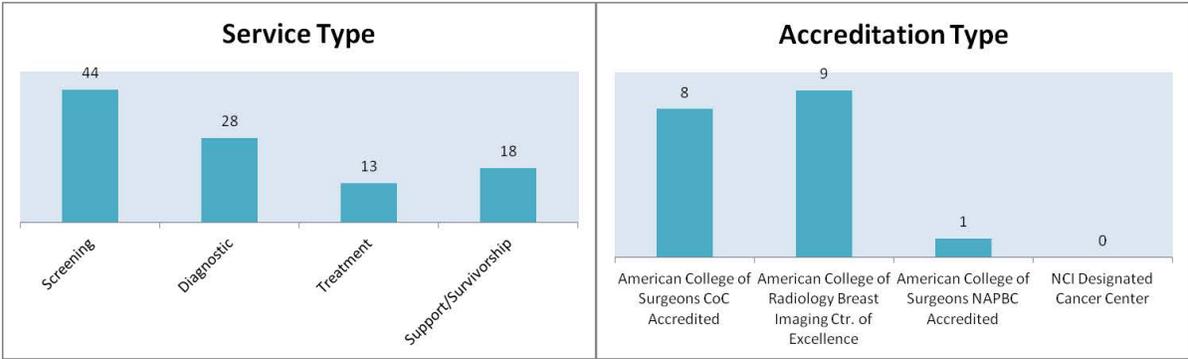


Figure 3.4. Breast Cancer Services Available in Travis County

Summary of Affiliates Partnerships in Target Communities

Komen Austin is a member of the local interagency committees in Caldwell, Bastrop and Travis Counties. In Travis County, the Affiliate monitors the activities of Central Health, the local policy and funding arm for the underinsured and uninsured in Travis County.

The Affiliate awards grant funds to numerous agencies to provide breast cancer services in its service area. While the Affiliate makes grant awards from year to year, the Affiliate maintains ongoing relationships with all providers of breast cancer services. The Affiliate collaborates with a local network of breast health and cancer resource providers which include current and past grantees to assist with information and referral to screening, diagnostic, office visits and treatment. The Affiliate makes referrals to community based organizations and to the public school system for education and outreach.

Komen Austin funds Community Health Grants in the target communities of Caldwell, Bastrop and Travis Counties:

- Alliance for African-American Health in Central Texas aims to increase the number of Black/African-American women who get screened annually for breast cancer. It provides culturally appropriate outreach and education for women. It also offers evidence-based breast cancer screening, diagnostic, treatment, and support service interventions.
- Breast Cancer Resource Centers of Texas works in Travis and Williamson counties to provide biopsies, patient navigation, and transportation assistance to women diagnosed with breast cancer.
- Community Action, Inc of Central Texas offers patient navigation, client transportation, emergency assistance, treatment support, survivorship assistance, and education. It also provides referrals for no-cost physician consultations, clinical breast exams, screening mammograms, diagnostic mammograms and other diagnostic services.
- CommUnity Care provides client transportation and education services, as well as clinical breast exams, screening mammograms, diagnostic mammograms, and other diagnostic services (Travis County only).
- Helping the Aging, Needy, and Disabled, Inc. provides transportation assistance as well as in-home services and social services in all counties except Travis.
- Planned Parenthood of Greater Texas offers clinical breast exams and screening mammograms to women in all five counties.
- Samaritan Health Ministries, Inc. works to provide clinical breast exams in addition to screening and diagnostic mammograms to Austin area women. The organization also offers breast ultrasounds and client transportation assistance.
- Women Involved in Nurturing, Giving, and Sharing, Inc. provides medical treatment, treatment support, and survivorship assistance.

The Affiliate has also established strong partnerships with multiple organizations that provide services to women with breast cancer, such as The University of Texas at Austin Family Wellness Center. These partnerships are the basis for the education and referral of women who cannot afford insurance or are underinsured in the Affiliate's service area. Further, the partnerships ensure that through their referrals to the Affiliate's grantees, the continuum of care is made available to the intended population.

Public Policy Overview

National Breast and Cervical Cancer Early Detection Program (NBCCEDP)

To improve access to screening, Congress passed the Breast and Cervical Cancer Mortality Prevention Act of 1990, which directed the Centers for Disease Control and Prevention (CDC) to create the NBCCEDP. The program helps low-income, uninsured, and underinsured women gain access to breast and cervical cancer screening and diagnostic services.

In addition to funds from the NBCCEDP, the state Breast and Cervical Cancer Services (BCCS) program is funded by the CDC (which funds federal cancer prevention and controls programs for the state), territorial and tribal organizations, Title XX to Temporary Assistance for Needy Families (TANF), and State General Revenue funded by the Texas Legislature.

Texas opted to convert a portion of its Temporary Assistance for Needy Families (TANF) funds to Social Services Block Grant (Title XX) funds which can be used for clinical women's health services.

BCCS Enrollment

Services are provided through contracts with local health departments, community-based organizations, private nonprofit organizations, Federally Qualified Health Centers (FQHCs), hospitals and hospital districts. Contractors bill the Department of State Health Services (DSHS) on a fee-for-service basis. In fiscal year 2013, 43 organizations contracted with DSHS to provide BCCS services at 212 clinics across the state.

Breast and cervical cancer screening services are available through health care providers across Texas. A list of contractors and the counties they serve is available at <http://www.dshs.state.tx.us/bccscliniclocator.shtm>.

BCCS Eligibility

The Texas BCCS program offers low-income women, ages 18-64, access to screening and diagnostic services for breast and cervical cancer.

To qualify for breast cancer services, a woman must be:

- Low-income (at or below 200 percent of the Federal Poverty Income Guidelines)
- Uninsured or underinsured
- Age 40 – 64 years for breast cancer screening and diagnostic services

The high priority population for the BCCS program is for women with breast cancer ages 50-64.

Medicaid for Breast and Cervical Cancer (MBCC)

Access to BCCS is facilitated by contracted health clinics, the gateways to cancer treatment and determination of a woman's eligibility for the Medicaid for Breast and Cervical Cancer (MBCC) program. BCCS contractors are required to:

- Collect the verifying documents for identity, income, and qualifying diagnosis
- Complete the MBCC application
- Send all the documents to DSHS for review of the qualifying diagnosis

MBCC Eligibility

Woman must be:

- Diagnosed and in need of treatment for one of the following biopsy-confirmed in definitive breast or cervical diagnoses: CIN III, severe cervical dysplasia, cervical carcinoma in-situ, invasive cervical cancer, ductal carcinoma in situ or invasive breast cancer, as defined by BCCS policy
- Family gross income at or below 200 percent of the Federal Poverty Income Guidelines, as defined by BCCS policy; see Table at: <http://www.dshs.state.tx.us/bcccs/eligibility.shtm>
- Uninsured, without creditable coverage (including current enrollment in Medicaid)
- Under age 65
- A Texas resident
- A US citizen or qualified alien

MBCC Enrollment

- A BCCS contractor will screen for eligibility and, if applicable, complete the Medicaid Medical Assistance Application (form 1034). The BCCS contractor will review and collect required documentation of eligibility
- DSHS will verify the patient's qualifying diagnosis and send Form 1034 to the Health and Human Services Commission (HHSC)
- HHSC Centralized Benefits Services makes the final Medicaid eligibility determination

MBCC Coverage

A woman is entitled to full Medicaid coverage beginning on the day after the date of diagnosis (services are not limited to the treatment of breast and cervical cancer). Medicaid eligibility continues as long as the Medicaid Treatment provider certifies that the woman requires active treatment for breast or cervical cancer.

Should a woman have a recurrent breast or cervical cancer, the BCCS contractor must reapply for the woman to be eligible for Medicaid.

Advocacy efforts for the next four years include increased communication with Breast and Cervical Cancer Services while learning methods to enable Komen Austin to be helpful in ensuring BCCS serves more of the working poor, uninsured and underinsured. The program currently serves only 6.0 percent of eligible women. The Affiliate will collaborate with appropriate state programs and to ensure program delivery as warranted.

Texas Cancer Plan/Comprehensive Cancer Control Coalition

According to the Cancer Prevention Research Institute of Texas (CPRIT) website (<http://www.cprit.state.tx.us/about-cprit/texas-cancer-plan/>), the Texas Cancer Plan aims to reduce the cancer burden across the state and improve the lives of Texans. As the statewide call to action for cancer research, prevention, and control, the Texas Cancer Plan identifies the challenges and issues that affect the state and presents a set of goals, objectives, and strategies to help inform and guide communities in the fight against cancer.

The intent of the Texas Cancer Plan is to provide a coordinated, prioritized, and actionable framework that will help guide efforts to fight the human and economic burden of cancer in Texas. The Texas Cancer Plan is developed with statewide input from state agencies and educational institutions, such as university research departments, as well as community leaders, planners, coalition members, cancer survivors, and co-survivors affected by cancer.

The Texas Cancer Plan includes the following statewide objectives:

- Encourage prevention activities and risk reduction
- Increase screening and early detection rates
- Initiate more timely access to diagnosis, treatment, and palliative care (pain management)
- Improve quality of life and survivorship for patients
- Increase support for cancer research and commercialization projects for better treatments and economic development in Texas
- Develop and strengthen access to health care as well as medical professionals

At the local level, the Texas Cancer Plan encourages community-based organizations and stakeholders to pursue the following objectives:

- Support policy, environmental, and systems changes for cancer control
- Provide cancer prevention awareness information and screening programs for clients
- Provide navigation services for clients
- Encourage participation in clinical trials
- Collaborate to provide community prevention programs

The objectives include:

- To increase screening for breast cancer according to the national guidelines and
- To reduce the rate of late stage diagnosis of breast cancer.

More information about these objectives can be found in the complete version of the Texas Cancer Plan (Cancer Alliance of Texas). See link: <http://www.cprit.state.tx.us/about-cprit/texas-cancer-plan/>

Komen Austin is a member of the Cancer Alliance of Texas (CAT), the state cancer coalition. The CAT is the organizing body that addresses the national requirement of the comprehensive Cancer Control Coalition. It exists to promote, enhance and expand all public and private partners' efforts to implement the Texas Cancer Plan. CAT aims to advance cooperative efforts that focus on cancer prevention, early detection, screening, and other related or supportive efforts among the population of Texas, which advance the goals of the Texas Cancer Plan. The cardinal principle is to assure that well-integrated and sustained initiatives address every facet

of planning, implementation, evaluation, and propagation of the best efforts and programs allied against cancer.

Together with other Texas Komen Affiliates, Komen Austin participates in quarterly CAT meetings. With budget and staffing limitations, Texas Komen Affiliates, including Komen Austin, will seek ways to collaborate with other CAT agencies for advocacy, especially those working on Medicaid Expansion and issues relating to increased access to care for breast cancer services and education.

Affordable Care Act in Texas

In March 2010, Congress enacted sweeping changes to how Americans will receive their health care through the passage of the Affordable Care Act. The Affordable Care Act (ACA) was enacted into law as a response to the crisis over the number of uninsured in the country and the rising costs of medical care.

The ACA provides Americans with an accessible health care system by providing comprehensive health insurance reforms that would:

- Expand coverage
- Hold insurance companies accountable
- Lower health care costs
- Guarantee more choice
- Enhance the quality of care for all Americans

(See Link <http://www.medicaid.gov/AffordableCareAct/Affordable-Care-Act.html>)

The Affordable Care Act is still early in its implementation process, and as a result Texas has not been able to fully realize the effects of the ACA's widespread changes. Texas forfeited its option to run a state insurance exchange, thus consumers in the state must choose coverage from a federally run marketplace. Insurance offerings with providers vary from county to county. Texas also did not expand Medicaid coverage for those with incomes up to 133 percent of the poverty level. Had the state expanded Medicaid, access to health care would have covered approximately 1,046,430 people in the state (Henry J. Kaiser Family Foundation, 2014). Medicaid Expansion could also mean an overall increase in economic activity through the addition of federal funds for the program (The Council of Economic Advisors, 2014).

In not expanding Medicaid, the state lost the opportunity to draw down additional federal dollars that would increase the states economies. This would have created jobs in Texas. States that have expanded Medicaid will boost employment by 356,000 jobs through 2017. Additionally, states that have expanded Medicaid have boosted their economies by \$62 Million in total economic activity through 2017 (The Council of Economic Advisors, 2014).

Prior to the insurance mandate, more than 6.2 million people were uninsured in Texas, making up about 24 percent of the total population (Henry J. Kaiser Family Foundation, Health Insurance Coverage, 2014). The ACA insurance mandate for the public went into effect January 2014, but its impact on the current uninsured percentage is still being determined.

There has been minimal impact to the National Breast and Cervical Cancer Early Detection Program by the implementation of the ACA. Most individuals do not qualify for marketplace

subsidies because their incomes are too high to meet the low standards. However, their income is still at an insufficient level for them to be able to afford health care. .

The impact of health reform on access to health care providers varies among states, with some exchange plans offering a larger network of providers. Currently, challenges exist for patients with lower-cost exchange plans in accessing specialty care, like oncology. Those with lower incomes tend to choose exchange plans with lower premiums, and higher deductibles resulting in problems affording care. Some consumers face cultural barriers and literacy challenges in understanding plans.

In interviews with local providers such as Breast Cancer Resource Centers of Texas and Planned Parenthood of Greater Texas, there does not seem to be a recent influx of newly insured patients through exchanges. However, current efforts to navigate people through the ACA continue.

The ACA does not completely solve the problem of the uninsured seeking breast health screenings. Texas has the highest rate of uninsured people in the nation. According to the Henry J. Kaiser Family Foundation, 53.0 percent of the population has been uninsured for at least five years, and 40.0 percent have incomes below the poverty level.

Medicaid expansion in Texas would have eased eligibility requirements for 56.0 percent of the uninsured population group in Texas (The Henry J. Kaiser Family Foundation, 2014). The ACA provides preventive service including mammograms, without cost sharing. In Texas, restrictions on annual and lifetime limits, restraints on out-of-pocket costs and required coverage of pre-existing conditions could alleviate barriers to health care access for those who fall within the insurance gap in Texas. The federal health exchange provides tax subsidies to people making between 100 percent and 400 percent of the poverty level to help offset insurance costs through the marketplace (Internal Revenue Service, 2014).

Community outreach efforts are needed to connect eligible uninsured to insurance access through the marketplace, particularly for the 31.0 percent of the uninsured reporting never having coverage in their lifetime (Henry J. Kaiser Family Foundation, 2014). However, with over one million uninsured people in the state who are unable to access affordable insurance even with Affordable Care Act provisions and tax credits, health care centers and nonprofits will continue to serve a large population in need.

The overall impact of the Affordable Care Act in Texas on the uninsured will take time to assess. In the meantime, thousands of uninsured women continue to need breast cancer screening, treatment, education, and survivorship services.

The current prevalence of access to care issues means that Texas Komen Affiliates, Austin included, will continue to serve high volumes of uninsured and underinsured constituencies through community-based grants. Through ACA outreach collaborations, Komen Austin may be able to use grant funding more efficiently, by ensuring that persons without insurance options receive screenings.

Komen Austin Public Policy Activities

Komen Austin maintains relationships with local and federal elected officials to ensure Komen's policy priorities are reinforced through education. This education is conducted through individual meetings and phone calls. Komen Austin hosts legislative events to promote breast cancer awareness with local legislators.

The Affiliate is a member of Komen Texas Advocacy Collaborative (KTAC). KTAC is the state level advocacy and public policy coordinator for the Texas Komen affiliates. The Affiliate participates in conference calls with the collaborative to discuss updates from state health agencies and advocacy organizations. This body is responsible for public policy planning and decides KTAC's role for local advocacy. Most Affiliates are ready to engage legislators beyond initial contact, including Komen Austin, with more emphasis on policy changes affecting breast cancer patients and survivors.

In order to assure that CAT's objectives are met, Komen Austin plans to continue its roles with the state's cancer coalition during the next four years. This includes working with the KTAC to achieve:

- A presence for Komen Affiliates with Cancer Alliance of Texas and work in the various subcommittees of the Alliance to advocate a stronger platform for breast cancer dialogue, education advocacy and goal setting
- Integration of breast cancer policy objectives with the KTAC advocacy agenda
- Expansion of Medicaid, a top priority for KTAC and the CAT

Komen Affiliates seek to strengthen the KATC structure through public policy, especially through volunteers willing to support KTAC's legislative goals. The KTAC will focus on the expansion of Medicaid in Texas.

Komen Austin is also a member of the Texas Medical Association Cancer Committee and participates in quarterly meetings where the latest trends in breast cancer research and care are discussed. Komen Austin participates in Cancer Prevention Research Institute of Texas (CPRIT) meetings and Legislative hearings of interest.

Future goals include working with more cancer and health coalitions to learn about patient issues and to develop Komen's advocacy presence to weigh in on the need for Medicaid expansion.

Health Systems and Public Policy Analysis Findings

Through the health system research, the Affiliate explored the needs in the three target communities in terms of health system and CoC.

The Affiliate's Quantitative Report found that Caldwell and Bastrop Counties have increasing trends for breast cancer incidence rate and are in need of more breast health service providers. The Affiliate found that both Caldwell County and Bastrop County have very limited local breast health resources. With few screening, diagnostic and treatment services available for people in need in those counties, patients are referred to neighboring counties for further services.

In Travis County, the Affiliate found that even though there are a greater number of breast health providers, they are not geographically accessible to people in need, especially for

Black/African-American women in the county. In addition, Travis County lacks enough treatment, support, and education services for persons in all income brackets. Concluding that only a very few providers are able to offer the full breast health continuum of care.

Komen Austin has strong partnerships with grantees to provide screening, diagnostics, treatment, education, and survivorship services in the service area, including the target communities. Within the grantee network, patient navigation is at the cornerstone of the services provided. However, most of these services are not located in rural communities that need it the most: Caldwell and Bastrop Counties. Residents from these counties must travel out of their respective counties to receive services.

Outside of the grantee network, the Affiliate also works with interagency groups in Bastrop, Caldwell, and Travis counties that serve as an information and referral network as it pertains to breast health services. The Affiliate is a member of the cancer committee of the Texas Medical Association, and works in collaboration with the Hays County Healthy Community Collaborative. In addition to these groups, the Affiliate also has partnerships in Travis County at the Integrated Care Collaboration (ICC) and Community Care Collaborative (CCC), and in Caldwell County with the Community Health Coalition. As a community and health resource, the Affiliate collaborates with the Community Health Centers of South Central Texas in Luling, Lockhart, and Bastrop, and works in conjunction with the Ventanilla de Salud, an organization within the Mexican Consulate that serves the Affiliate's service area. This relationship is essential in connecting with immigrant populations and serves as an outlet for information referrals and public education. Other education and outreach efforts are made possible by the Affiliates partnership with St. David's Foundation, Seton Hospital, and the Central Texas Univision Television Network. The primary objective of these partnerships is to ensure that all women seeking breast health services receive the full continuum of care by providing information and referrals to the Affiliate's grantees.

Texas has the highest rate of uninsured people in the nation. According to the Kaiser Family Foundation (2014), 53.0 percent of the population has been uninsured for at least five years, and 40.0 percent have incomes below the poverty level.

Without Medicaid Expansion in Texas, more than one million Texans will remain uninsured (Kaiser Family Foundation, 2014).

The Affordable Care Act provisions listed below will continue to elude the more than one million uninsured in Texas. These provisions are:

- Preventive services without cost sharing (including mammograms)
- Restrictions on annual and lifetime limits
- Restraints on out-of-pocket costs
- Required coverage of pre-existing conditions
- Tax credits for those with incomes between 100-400 percent of the poverty level help make insurance coverage possible for the working poor

More community outreach efforts are needed to connect eligible uninsured to insurance access through the marketplace, especially with 31.0 percent of the uninsured reporting never having coverage in their lifetime (Kaiser Family Foundation).

With over one million uninsured people in the state who are unable to access affordable insurance even with the Affordable Care Act, health care centers and nonprofits will continue to serve a large population in need. Further, Komen Austin grants will continue to be welcomed by these nonprofits as the grantmaking program is filling a gap in the coverage puzzle. Thousands of women will continue to need breast cancer screening, treatment, education, and survivorship services that are not otherwise eligible for any of the health service programs discussed in this report.

The current prevalence of access to care issues means that Texas Komen Affiliates will continue to serve high volumes of uninsured and underinsured constituencies through community based grants. Through the Affordable Care Act outreach collaborations, Komen can use its grant funding strategically to cover the ACA and Medicaid gaps.

Komen Austin will continue to work in collaboration with the KTAC and other public policy groups discussed to ensure that maximum opportunities for breast health screening and treatment are addressed by the policy makers. Further, the Affiliate will endeavor to provide grants to organizations serving communities in most need as identified by this report.

Qualitative Data: Ensuring Community Input

Qualitative Data Sources and Methodology Overview

Methodology

The Affiliate identified key assessment questions and variables for the target communities of Bastrop, Caldwell, and Travis Counties. Variables used include:

- Breast health education/information
- Breast cancer continuum of care experience, survivorship
- Health care accessibility/barriers
- Group norms, insurance, and local health issue and service

The Affiliate developed the following key assessment questions to ask participants:

- What health care services are you aware of?
- Does your organization provide breast health services?
- Where do you go for health care? How often? Why/why not?
- How would you describe the health literacy of your patients?
- Do you get help in reading prescription labels, filling out forms?
- What barriers to screening and diagnostic services do your clients face?
- What types of initiatives, programs, and/or activities can help to improve breast health services in your community?
- What kind of insurance do you have or have you had?
- What are the typical out of pocket costs?

For each target community, the Affiliate used focus groups and key informant interviews as the primary data collection methods. Following the best practice of qualitative inquiry, the Affiliate planned three focus groups and 12 key informant interviews within the target community.

The qualitative inquiry purpose is to gather in-depth information about breast cancer knowledge and service in target communities. Persons who have had breast cancer and/or are closely affected by breast cancer (i.e. co-survivors and service providers) were identified as the best target population for data collection. Focus groups and key informant interviews would yield the best collection of key information regarding breast cancer in the respective target communities.

The Affiliate ruled out the use of a survey as a data collection method due to limitations in obtaining a statistically appropriate sample size within the prescribed time and budget. Additionally, for this assessment, the Affiliate would not be able to collect open ended responses with surveys. The Affiliate ruled out document review as a data collection method because too few literature documents in target communities were available, especially for Bastrop and Caldwell Counties. The use of observation was also ruled out due to the time-consuming nature of the method. In addition, it was assessed that this method was not effective to gather the most valuable information needed.

The Affiliate Community Profile Team conducted the data collection. The focus group and key informant interview questions were designed in collaboration with a Ph.D. Anthropologist and Komen volunteer who is a social scientist and conducts field work in ethnic communities nationwide.

The Affiliate distributed sign-in sheets and demographic forms to all participants of the focus groups and the key informant interviews. The Affiliate took notes and recorded the conversations on an audio recorder. The use of focus groups and key informant interviews with breast cancer survivors and health providers in Bastrop County allowed the Affiliate to identify similar health care experiences and common barriers to Continuum of Care.

In Caldwell County, the key informant interviews and focus groups were both very effective. The group setting within the focus groups prompted organic conversations about breast cancer and service experience. The open ended question format of the key informant interviews provided the Affiliate with a detailed understanding of the unique barriers to accessing care in rural community.

Travis County is characterized by a diverse range of income and education levels and a large cultural and ethnic population. Key informant interviews and focus groups yielded different perspectives for the various groups within the county as well as in understanding the different barriers Travis County experiences. Although the Affiliate learned that some barriers are similar, Bastrop and Caldwell Counties are in great contrast to the urban county of Travis.

Sampling

The Affiliate's goal was to investigate breast cancer service gaps in the target communities. It was determined that the best method to gather qualitative information would be through the information provided by people who had an association with breast cancer in those communities. Therefore, the Affiliate reached out to breast cancer survivors or co-survivors, breast cancer health service providers, and persons at high risk. The Affiliate sought people able to provide intensive and crucial information about local breast cancer services. The interaction with breast cancer and/or breast cancer services, and knowledge of their own communities was important to collect. The Affiliate invited breast cancer survivors, women 40 and older, families and community members to participate in focus group and key informant interviews in each of the target communities. Sources of data collection include Komen Austin volunteers, health service providers, public school teachers, and community members active in other organizations such as religious establishments and support groups.

The Affiliate selected purposive sampling in selecting the participants. Purposive sample ensures that the participants studied come from the target population. Once the focus group and key informant information was sent out to the target population, the Affiliate gathered data from persons who participated in the focus groups and key informant interviews within each targeted community.

The target population is not known and access is difficult, thus the Affiliate is not able to conduct probability sampling (simple random, systematic random, and/or stratified random). It is also invalid to conduct a quota sample or convenience sample because those methods cannot ensure that the participants are representative of the target population.

The focus groups had 66 participants in total for seven focus groups. The Affiliate conducted 52 key informant interviews. The number of focus groups and interviews per target area was not equal due to data limitations discussed later in this report. Table 4.1 shows the number of participants for the sampling methods used.

Table 4.1. Number of participants for qualitative sampling methods

	Focus Groups (Scheduled)	Focus Groups (Conducted)	Key Informant Interviews (Scheduled)	Key Informant Interviews (Conducted)
Bastrop County	3 (6-12 People/each)	3 (18 Total)	12 participants	3
Caldwell County	3 (6-12 People/each)	3 (18 Total)	12 participants	6
Travis County	3 (6-12 People/each)	3 (30 Total)	12 participants	43

Figure 4.1 presents the education level of the survivors and co-survivors who participated in the focus groups/key informant interviews from three target communities. Eight percent of all participants have not graduated from high school and are considered low-literate, while 33.0 percent have bachelor’s degree or higher. Based on the questions asked in the focus group and the feedback recorded, the Affiliate found that participants lacked a basic understanding about breast cancer and medical terminology, regardless of education level.

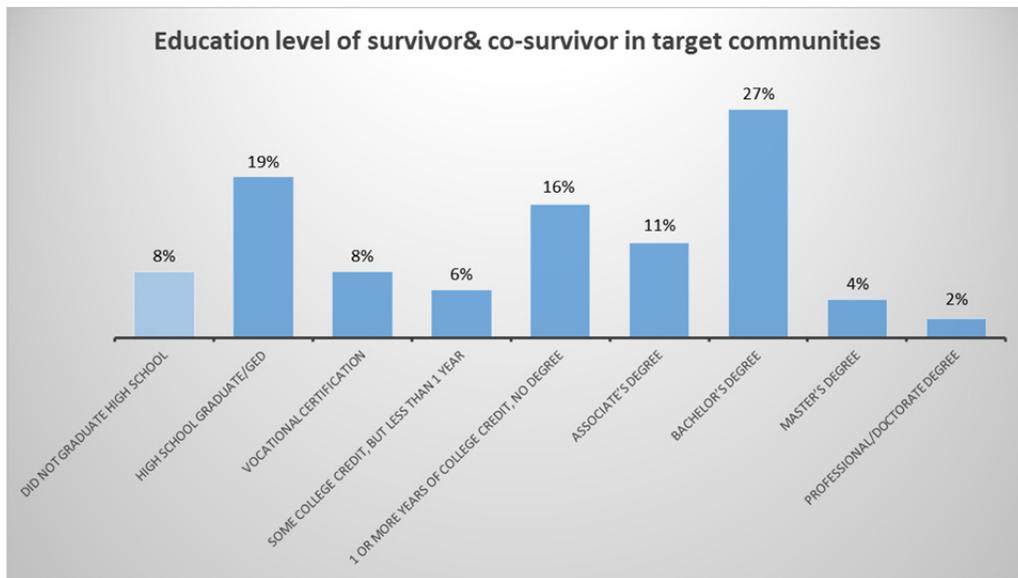


Figure 4.1. Education level of survivors and co-survivors- focus groups/key informants

The data in Figure 4.2 demonstrates that 15.0 percent of participants use mixed insurance plans to pay for treatment. In addition, 61.0 percent of the participants have private insurance for breast health treatment, and the second largest single payment category (11.0 percent) is government assistance/Medicaid/Medicare.

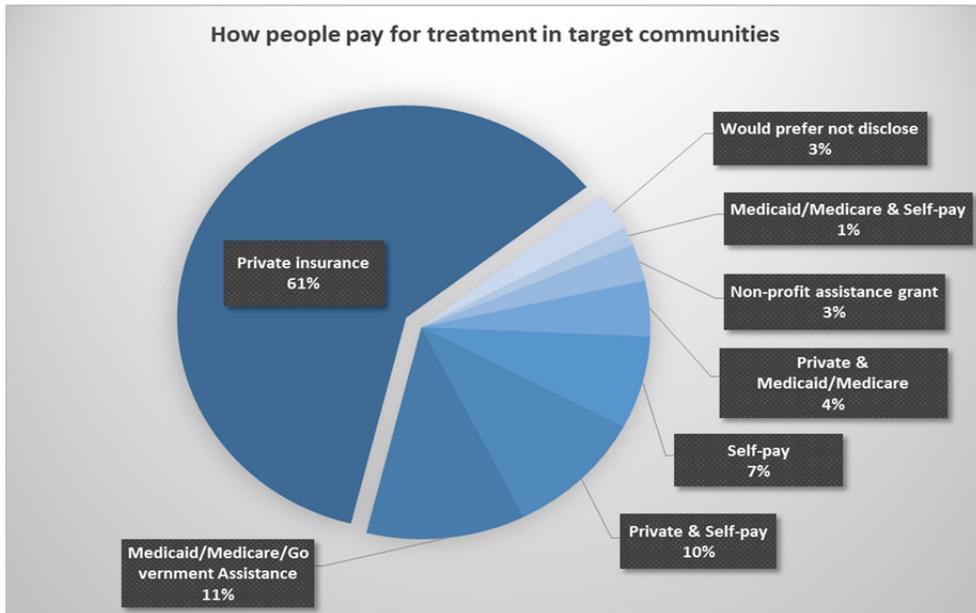


Figure 4.2. Treatment payment

In the public policy analysis section, the Affiliate cited that Texas did not expand Medicaid coverage, which means only families that are under 100 percent of the federal poverty line can receive Medicaid and government assistance in Texas. Therefore, families whose income levels fall between the 100 percent and 133 percent of federal poverty line are left without affordable insurance. The federal poverty guidelines in relationship to family size and annual income are depicted in Table 4.2.

Table 4.2. Federal poverty guidelines

2014 Annual Poverty Guidelines				
Family Size	Percent of poverty guidelines			
	100%	120%	133%	135%
2	15,730.00	18,876.00	20,920.90	21,235.50
3	19,790.00	23,748.00	26,320.70	26,716.50
4	23,850.00	28,620.00	31,720.50	32,197.50
5	27,910.00	33,492.00	37,120.30	37,678.50

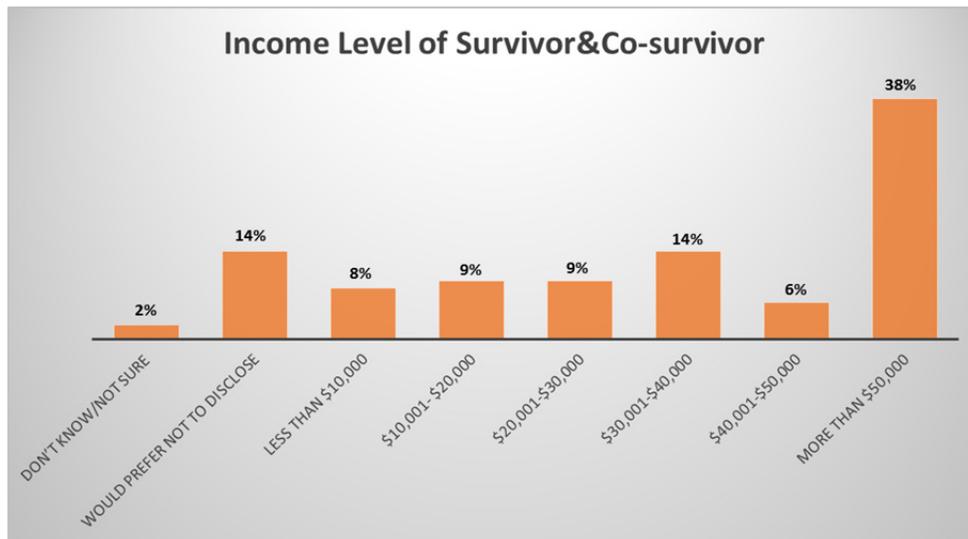


Figure 4.3. Income level of survivors and co-survivors interviewed

By comparing the 2014 annual poverty guidelines (Table 4.2) with the income level of the survivors/co-survivors in the focus groups (Figure 4.3), the Affiliate found that 9% of survivors interviewed have incomes that fall between 100 percent and 133 percent of federal poverty line, with an average family size of three (According to US Census Bureau 2010 demographic profile, the average household size in Texas is 2.75). This group of people will neither qualify for government assistance nor be able to afford insurance provided by the ACA market place. About 17 percent fall below the 100 percent federal poverty line and would qualify for Medicaid though they are not receiving government aid.

Ethics

Prior to conducting the interviews, Komen Austin asked each participant/source to complete a consent form. The form described that their attendance and participation was voluntary, that any identifying information provided would be confidential, and that direct quotes could be taken from their statements. Participants/sources were also informed that there were no physical risks associated with participation, nor would any of their responses affect their future or current assistance from Susan G. Komen Austin.

The anonymity of the participants/sources was protected through careful maintenance of the records provided; any identifying information from the consent forms was only handled by Komen Austin staff working on the report and was kept in a secure facility. No names or other identifying information provided by the source were used in the report itself, nor was any of the personal information discussed outside of the interview with the source.

The data collected were not disclosed to any other source or individual. All hard copies of the data collected are kept in a secure, locked facility. Electronic representations of the data are stored on the secure network of Susan G. Komen Austin. Data collected are only presented in the Affiliate's Community Profile Report and are not reproduced in any other form.

Qualitative Data Overview

Format of original data

The format of original data includes demographic forms, interview notes and audio records. For each focus group and key informant interview, participants complete the demographic forms at the beginning of the meetings. In addition, the Affiliate had a questionnaire and team members took notes during the meetings while recording the conversation.

Rationale for choice of data management method

The Affiliate created spreadsheets of demographic information for focus groups and key informant interviews. The Team developed a codebook according to the demographic form, and recorded each form with the codes. In this way, the data were easily organized and analyzed.

The Team also created narratives for each focus group and key informant interview after reviewing the interview notes. By doing this, the Team was able to summarize ideas and comments that the participants expressed and equally important, highlight key words and findings.

How themes and/or descriptions were generated and used

The Affiliate examined the data generated by the interview questions asked in survivor and provider focus groups and in key informant interviews, as well as the narratives of interview notes. The Affiliate conducted an analysis of the information collected, which revealed common themes.

Five themes emerged as priority topics during the qualitative inquiry. These include the continuum of care experience, health literacy/English proficiency, group norms/acclimation, health care experience, and local community health care needs. The Affiliate used these five themes to further categorize its findings.

Common findings within the qualitative data collected from each method

The Affiliate derived the following common findings for each target community as recorded in the focus groups and key informant interviews.

Bastrop County

Continuum of Care experience

Bastrop County focus group participants and key informant interviewees indicated a need for more breast cancer education, as well as information about services available in their county and urban areas closest to them. Both key interviewees and focus group participants were aware of the importance of mammograms. This was especially true among the Black/African-American women in the focus groups. However, providers stated that some patients know very little about breast cancer itself, and that patients have limited access to breast health information noting little access to the internet and/or computers. In addition, providers said that “some cannot read,” thus identifying a lack of literacy as a barrier.

Survivors and co-survivors agreed that they would like to have known about support/survivorship services available in their respective communities. One person said, “I did not know nothing, no one to ask, did not have family that knew nothing.” Survivors hoped to be better prepared for the challenges of cancer and to learn how to cope with the diagnosis,

because as they collectively said, “there was no one to talk to much less that knew about my breast cancer.”

The survivor focus group participants indicated they were in need of navigation services that would have provided them with information about the steps forward, what to expect, and the financial burden associated with a breast cancer diagnosis. Survivors indicated that individuals often experience totally different lives after treatment, and stated that they needed support networks to share information and to aid in their recovery.

Health Literacy/English Proficiency

Survivors in the focus group, even those with a higher education, stated they had difficulty understanding health information. Survivors pointed to problems communicating with doctors and nurses because medical terms are too professional and technical to understand. In addition, focus group participants said “It is even harder for people speaking other than English (i.e., Spanish).” In the provider group, one participant who works in public health said, “they do not come in because no one can come with them to translate.” In the provider group, it was identified that people with disabilities and people with low-literacy levels need more assistance stating, “sometimes there are not enough of us to help them.” Survivors/Co-survivors asked that, “Health information be straight...simple with bigger print, and doctors need explaining things clearer.”

Additionally, one focus group participant said, “people get discouraged by all the red tape...” referring to the many insurance forms, questionnaires, and multiple questions patients go through before they see their doctor. One person said, “we go through all that...takes an hour, then see the doctor for 5 minutes.” In one focus group, all agreed that “patients need assistance with filling out forms and surveys...” As stated by one participant. Both provider and survivor focus group participants stated that doctors and nurses need to focus more attention on patients’ educational needs, saying that spending more time with them answering their questions would help. Key interviewees and focus group participants concurred that group education sessions would be very beneficial for patients. A key informant interviewee said that understanding her diagnosis was what she “...could not get.”

Group Norms/Acculturation

Some patients believe that “breast cancer is a death sentence.” regardless of their education and income levels. According to providers and survivors, young women are not informed about breast health, screenings and breast cancer. Focus group participants said that people think that adult health is not valued or considered as important as child health. Therefore when issues regarding their own health arise, people will not place the same value for medical attention on themselves, stating “...they won’t fix the problem until things go wrong.”

In one focus group, survivors and co-survivors agreed that race/ethnicity is an issue, and that some Black/African-American women have experienced disrespect from doctors. In this same group, some participants pointed out that the disrespect is not necessarily because of race/ethnicity, but “...because we are poor,” and of a lower economic status. Survivors and some providers agreed that persons without insurance are treated differently, citing that some providers have told their patients that they will “need to find a new doctor that takes patients with Medicare/Medicaid.”

Health care Experience

In the focus group, several persons said that many barriers exist in accessing breast health care in Bastrop County. One key informant stated that fear and attitude toward breast cancer often hinder people from getting screenings. It was learned through the focus group that even if the population desires screenings, some cannot afford the transportation to a service location. Additionally, it was also learned in the focus group that often people must travel outside the county to secure their screenings and any follow up care. Both survivors and providers identified mobile mammogram services as limited in the county. Providers and survivors alike are concerned about a lack of funding for the mobile screening service and most importantly, the continuation of the program.

In addition, focus group and key informants said that many of the uninsured and low-income community members cannot afford health services, even with the availability of the Affordable Care Act (ACA). The ACA allows persons to choose a plan based on affordability. Informants said that they knew of people who would actually spend more out of pocket costs with an ACA plan, because plans with adequate preventive and diagnostics services have high deductibles.

Community Health Service Needs

According to information gathered from survivors and providers, health service is limited in Bastrop County. They identified that people need more locally available services at lower or no cost. In addition, survivors and providers stated that their community needs more funding and insurance assistance to improve local breast health service. In these focus groups, it was recorded that “there are many who are uninsured or underinsured who live here.”

Overwhelmingly, survivors and providers believed that the community lacks effective educational materials. Survivors stated there is a need to reach out to the Black/African-American and Hispanic/Latino population to raise awareness of breast cancer and its implications. Participants said that they hoped that Komen Austin could have more partnership with local clinics.

Caldwell County

Continuum of Care Experience

Caldwell County provider and survivor focus group participants agreed that different understandings and misconceptions about breast cancer among Caldwell County residents prevailed. In the survivor group, some survivors “...knew about breast cancer...” before their diagnosis, and received regular mammograms because they were aware that they were “suppose” to get these screenings. In contrast, in the provider group, some said that people have misunderstandings about breast cancer. In both groups, they said people think breast cancer is only found in older women, or that there is “...no need to get checked if cancer doesn’t run in the family.” Because of this, providers said many women don’t believe they are at risk, and won’t seek primary care or screening. Survivors and co-survivors said that they would like to have known about breast cancer at an earlier age and said “young women” in their area are uninformed. This information gathered from the survivor focus group, was confirmed by the provider focus group. In the provider focus group, when asked, “What do your clients/patients know or believe about breast cancer screening? What is your impression of their screening behavior?” providers responded by saying that they believed that a growing number of young women are being diagnosed with breast cancer because the younger demographic is not informed of breast cancer risks.

Survivors said that when diagnosed with breast cancer, they were “shocked” at receiving the diagnosis, and often had “no one to check up on them,” and no supportive source for follow up care. Survivors said that support groups would have helped because cancer impacted “almost everything in their life.” In addition, providers said that patients need positive support, which may include information on the diagnosis, time, money, and survivorship services.

Health Literacy

Survivors and co-survivors agree that they have trouble reading and understanding health information, and that they need services to help them understand it. Some survivors and co-survivors said that they would search the Internet to help with their understanding, in addition to asking family and friends for assistance.

Survivors and co-survivors mentioned that some doctors did not adequately explain the cancer to them, nor did their doctors effectively answer questions. Providers admitted that using medical terminology between doctors and patients is often ineffective and creates a communication barrier. For instance, many patients only have a basic understanding of preventative care so they cannot understand the difference between a clinical breast exam and a mammogram.

In one survivor focus group, it was noted that some Spanish-speaking patients felt that they faced problems because there are limited Spanish-speaking employees in the clinics. Translation by their children makes it difficult for doctors to effectively communicate with the adult patients. A teenage co-survivor said it was “hard” helping her mom out at the doctor’s office.

Group Norms/Acculturation

A key informant stated that cultural and/or religious beliefs affected their ability to get a clinical breast exam. In some cultures such as Middle Eastern and with older Hispanic/Latina women, it was recorded that “...husbands do not allow their wife to be touched by male doctors, and that they require female doctors to do the examination.”

In the focus group, one woman believed that breast cancer is “God’s will,” thus would not seek treatment. In addition, in the Hispanic/Latina community, as stated by one survivor, people do not discuss breast cancer and believe that “it will not happen to them.” This prevailing thought makes it challenging to recruit Hispanic/Latina women for screenings and survivor groups. An interviewee said that she thought that some Black/African-American patients will not show up to their appointments, due to a culture of “distrust” within the Black/African-American community.

Both Survivors and co-survivors said that some service providers “...treat people differently,... think Black and Hispanic people are not treated,” with the best quality of care. However, some participants said that this is more an issue of economic status than of race. People who are at a lower socioeconomic status and who have no insurance have to wait longer for appointments. One low-income White woman mentioned that she had to fight the insurance company because “...the company did not like the amount of phlebotomy treatments,” she was receiving, even though the treatments were necessary.

Health care Experience

In Caldwell County, most follow up care is outside the county, requiring travel to Austin, San Marcos, or Kyle. Survivors and co-survivors said that travelling outside their county, caused hardship as it is “physically uncomfortable and inconvenient” to travel out of town. Survivors said that they need more time and money to get to health services not available in their own community. The survivor focus group revealed that working women, particularly those of low-incomes, experienced difficulty in making out of town trips to diagnostic and treatment services. In response to this reality, the provider focus group identified the need for clinics and the need for convenient operational hours to expand appointment scheduling times.

In Caldwell County, survivors in the focus group said that some of them have no insurance, and some said they do have Medicaid to cover costs associated with breast cancer. Providers said that some insurance companies reject applications of immigrants, and that social security does not recognize breast cancer as terminal or a disability.

Local Community Health Service Needs

There is a high rate of late-stage breast cancer diagnosis in Caldwell County. However, the incidence rate among White women is higher than the Affiliate service area as a whole. While this may be reflective of good screening rates for White females, there are very limited screening services available in Lockhart. Some focus group survivors believe that local primary care providers’ standard of care is not equal to that of the standard found in urban areas.

According to focus group participants, medical support services available include a hospital in Luling, a few general practitioners such as dentists, cardiologists, and entomologists in the clinics, and a handful of general practice physicians. In Lockhart, survivors identified a nonprofit clinic and a family health center. In addition, a few national chain pharmacies and local food stores with a pharmacy are available to them in Lockhart. Survivors said mobile mammography is available in Lockhart on a limited basis. Most of the survivor group participants stated that they go outside the county for mammogram services and breast health care.

Focus group participants said that health education in the community would be beneficial, such as flyers and health fairs at schools or churches. In addition, they identified a need for navigation service to help them understand their treatment and get support. A strong need for expanded mobile services such as the “Pink Bus” mobile mammography was consistently identified by both providers and survivors. Informants said that they hope that Komen could provide more availability of mobile facilities with trained professionals.

Travis County

Continuum of Care Experience

Survivors and co-survivors who were key informant and focus group participants agreed that mammograms are important, but many of them admitted that they did not know about breast cancer before they were diagnosed, especially among the Spanish-speaking focus group. Providers identified that some patients receive misleading information from the media, and that information does not address the real risks of breast cancer.

Some survivors said that they received navigation services in addition to “sister group support” after treatment, which they believe was very helpful. In the key informant interviews, several survivors said they were part of a survivorship group that helped them understand the emotional support that was necessary to get through their treatment. According to providers, screening

and survivor follow-up is insufficient in the breast health community, and medical staff and physicians lack sufficient education and training for follow-up and survivorship.

Health Literacy

Survivors in focus groups agreed that medical terms are difficult to understand. Spanish-speaking survivors stated that they were “overwhelmed and stressed” with health information provided because information and diagnosis was presented when they were “shocked” about learning that they had a cancer diagnosis. In addition, all information provided was in English. In the providers group, providers said that many patients they work with have low health literacy. Providers said that many patients learn about breast cancer only when the problem presents itself.

Group Norms/Acculturation

In some cases, race/ethnicity limits ability to receive health care services. In a survivor focus group with Black/African-American women, various women said that some Black/African-American women don't want to talk about breast cancer. Providers pointed out that some patients, especially Black/African-American patients, distrust doctors and their medical teams. This is influenced by a history of exclusion and a lack of understanding and communication between medical professionals and racial minorities. On the contrary, in a survivor group of Hispanic/Latina women, survivors said that they respect the doctors' and nurses' recommendations and were exceptionally grateful for the care that they were receiving.

In the Spanish-speaking survivor's focus group, women said that their immigrant status hinders them from receiving health care services rather than that of their race or ethnicity. Immigration status dictates the type of programs that may or not be available to them.

Health care Experience

Some survivors get regular health care such as oncology and mammogram services, while others do not. Both survivors and providers agreed that it is hard for people without insurance to get health care service. These individuals must overcome insurance barriers and “red tape” when dealing with insurance companies, which frustrates them and “influences” their decision on receiving services.

Survivors also identified transportation as a big barrier to follow up care because some patients cannot afford to travel by car, and thus rely on public transportation which is not very accessible according to the survivors of the group.

Women in the survivor focus group, who work in wage earning jobs, disclosed that they miss follow-up appointments, because they lack sick leave. Further, they explained that if they miss work, they lose wages and fear another employee getting their shift when they are absent from work. In the Spanish-speaking group, most survivors agreed that their experience with their medical providers was “good” and expressed gratitude toward the people who have provided assistance.

In one survivor group, some said that doctors and nurses could be more helpful and supportive. In several instances, per focus group comments, when told about their diagnosis, the physician was not empathetic, but was straightforward, lacking emotional or instructive support. According to one woman, when she learned of her diagnosis, the doctor came in to give her “the bad

news,” and then left again without attempting to explain the condition to her or educate her to limit and contain her fear. This survivor continued, “The nurse that followed did not address concerns that I had.” Experiences such as these complicate the emotional experience patients face in light of the “shocked and hopeless” emotions that they are feeling. Survivors who were not Spanish-speaking said, “It is even worse among Spanish-speaking women who already have limited interaction with doctors because of language barrier.” A key informant expressed the hope that doctors would respect patient “emotions” and well as “their body,” and demonstrate more care for patients on a personal level.

Local Community Health Service Needs

Many survivors and key informants know about breast health services and resources in their community, such as Komen Austin, Breast Cancer Resource Center, St. David’s, Livestrong Foundation, American Cancer Society, church events, and public school events. However, they wished that they had a navigator or a support group to provide more in-depth information about breast cancer and with whom to share their journey with the disease. Key informants identified that financial support for insurance and transportation for breast health appointments are needed.

Key informants said that education on breast cancer, as well as how to stay healthy before, during, and after treatment is needed. A young breast cancer informant said that more information targeting young women is necessary. She was 18 when diagnosed, and only knew that she did not have to get screened until later in her life. Providers said that although they see more people coming in the clinics because of breast health education efforts, especially among younger women, there are many more young women to reach.

Providers said that outreach is needed, especially to those that are homeless and unemployed. Outreach to the homeless population remains almost nonexistent according to some providers and key informants. Providers stated that it is hard to reach out to the Black/African-American community, saying that it is difficult to help Black/African-American women even with insurance. Some providers believe that cultural influences affect Black/African-American women’s decisions about health care and access to it.

Qualitative Data Findings

The Qualitative data findings provide evidences to support the quantitative data used in determining the target communities, and also indicate how the current health system affects the target communities.

There are limited local health providers in the communities as well as a lack of navigation and survivorship services to ensure the effective implementation of the Continuum of Care. Many people do not access primary or preventive health care and do not confront health issues until medical problems can no longer be ignored. Patients often weigh the benefits and the costs of accessing services before making appointments, but this makes treatment and survivorship more difficult because it often delays the diagnosis of breast cancer and results in later stage diagnoses.

Insurance is a major barrier to accessing health care as noted by focus group participants. The Affiliate found through the focus group that many survivors cannot afford market place insurance. When asked, “What kind of health insurance do you have? What are the typical out of pocket costs you have?” group participants responded that even with the emergence of the ACA, they could not access insurance. In the focus group, participants familiar with market place insurance, said that necessary coverage with a single insurance plan is insufficient, thus most need supplement policies with alternate coverage options. Treatment with a mixture of payment can be expensive, but it does allow individuals and families to customize insurance plans to fit unique health needs as stated by one group participant. Figure 4.2 above, captures the types of payment used for breast cancer treatment identified by the survivors and participants in the focus group.

During the qualitative inquiry, the Affiliate was able to involve key stakeholders who hold strong opinions on breast cancer and breast health services at the local level. Within the focus group setting, participants exchanged information and had great input based on others’ opinions and experiences. The focus groups enabled people with different backgrounds (providers, survivors, co-survivors, community members, etc.) to talk about breast cancer from different perspectives, providing the Affiliate with a comprehensive understanding of issues.

From key informant interviews, the Affiliate obtained in-depth facts and comments about breast cancer services in the target communities, while simultaneously gathering useful recommendations for the Affiliate to consider.

It was challenging for the Affiliate to recruit the desired number of participants for the focus groups, especially in targeted rural communities. The Affiliate planned three focus groups in each target community with at least six participants per meeting. In Bastrop and Caldwell Counties, the Affiliate only held two successful focus groups, respectively. In two different scheduled focus groups, only one person attended. The Affiliate could not count these as a focus group and instead the meetings were categorized as key informant interviews.

Recruiting 12 participants for key informant interviews in each target community was also challenging. It was difficult to enlist interviewees as key informants in the rural communities where the Affiliate experienced no show participation in phone and in person interviews. In addition, it was difficult to schedule key individual interviews with persons who lived in the rural counties. Further complicating the challenge of proximity, the Affiliate encountered issues related to the required release forms; interviewees in rural and urban areas faced limited access to internet and/or mail. Because the Affiliate office is located in Travis County, more interviews were conducted in Travis County than in Bastrop and Caldwell Counties.

All information gathered in this section of the report came from breast cancer survivors and their family members, commonly referred to as “Co-survivors”. Feedback gathered from focus groups and key informants provides the Affiliate with rich data. There is potential bias with the data collected because information collected can be subjective and represents the viewpoints of those whom participated in the interviews and focus groups. The results do not represent a larger population as a non-random sampling method was used. Therefore, the data provided represents only the perspective of those individuals that participated in the interviews and focus group, and are not representative of the general population, breast cancer survivors or providers as a whole.

Conclusions

Target communities lack full access to preventive care

From the data collected during the focus groups and key informant interviews, the Affiliate concluded that the target communities need more available and comprehensive breast health education services. The Affiliate determined that a respondents' own education level did not necessarily correspond with health literacy. That is to say, a high education level does not necessarily predetermine sufficient health literacy and does not predetermine a person's awareness of breast cancer. Health literacy, however, is a key factor affecting a person's ability to read and/or understand information about health related matters.

People need more educational information about breast cancer and available service resources. Educational resources need to be simple and easy for people to understand, especially for persons at high risk. These resources should include information on:

- What breast cancer is
- How to recognize breast cancer
- Breast cancer risk factors and how to limit them
- Where and how to access breast health services specific to an individual's community

Navigation service is important and largely needed for patients and survivors in target communities. The medical system is complicated for the public at large. It is especially difficult for breast cancer patients who lack basic education and understanding for best practices in health care and prevention. Thus, it is necessary for services to guide patients through the intensive, confusing, and overwhelming process of breast cancer diagnosis be made available. The communities at highest risk would benefit from the implementation of a support network for breast cancer survivors and co-survivors. This support network would allow survivors to share information and experiences, while receiving positive support to overcome fear, personal challenges, and/or cultural barriers in taking charge of their breast health.

Target communities lack health literacy/English proficiency

Health literacy and English proficiency need to be improved in target communities. The assessment has shown that it is necessary for both well-educated and non-highly educated populations to better understand health information. Assistance for patients in reading and understanding health information, insurance, and forms is absent. In order for this service to be available, providers would need staff that are knowledgeable about details and requirements on forms, for both treatment and insurance purposes, and who are able to translate technical medical jargon into simpler terms. Furthermore, this same assistance is lacking for persons with limited English skills.

Target community providers lack language assistance for non-English speaking groups, such as Spanish-speaking people. Participants suggested that health providers need to increase the number of professionals that speak languages other than English for non-English speaking populations. For example, Spanish speaking employees should be present in the health care setting to ensure that the Spanish speaking population has an adequate understanding of their care.

Target communities need to overcome barriers to access health care services

Rural communities lack local health care providers with a lower cost and high quality of care. With more local health care providers, residents would be able to receive services directly and conveniently, minimizing the burden of travel out of county. Residents would also be able to receive health education and navigation if providers are near their homes and workplaces.

Target communities lack transportation assistance for people to access health care screening. The availability of transportation vouchers would remove the transportation barrier thus enhancing follow up rates. Many providers do not offer mobile services such as mobile mammography services. Those that do, do not have these mobile unit services widely available, especially in rural counties. Mobile services would be beneficial since mobile units are a cost-effective, and highly efficient method of making health care and screening convenient for local residents. In addition to transportation issues, providers currently do not provide operation schedules to accommodate working populations.

In reference to cultural barriers influencing health care, focus group participants felt that some providers lack cultural sensitivity and fail to recognize some group norms and race/ethnicity issues. Groups that have limited awareness and knowledge about breast cancer do not receive enough educational information or outreach, or conversely, education and outreach efforts are not getting to these communities. Therefore, target communities experience misconceptions about breast cancer's risks, causes, and treatment or diagnostic services. Health providers need educational and supportive services to eliminate the misunderstandings and change attitudes about preventive and primary care among some cultural groups.

There is a need to recognize insurance limitations

The uninsured and underinsured are in need of affordable services, in particularly the rural targeted communities. Data from Greater Austin Region Cancer Care White Paper indicate that Bastrop and Caldwell Counties have the highest percentages of uninsured adults under age 65, 27.0 percent and 28.0 percent respectively (Health Resources in Action, 2013). According to the analysis from the Council of Economic Advisers, having health insurance improves access to health care, especially in the area of preventive care such as screening and mammograms.

Focus group participants and key informant interviewees suggested there be patient navigation and education for people who have difficulty managing red-tape and specific requirements of health care or understanding insurance. There is a lack of outreach to provide information on Komen funded organizations to the community at large. This service would increase the number of persons accessing preventive breast health care and minimize the risk of people being declined for treatment due to the inability to pay.

Mission Action Plan

Breast Health and Breast Cancer Findings of the Target Communities

Komen Austin selected Bastrop, Caldwell, and Travis Counties as target communities. The following summary provides an overview of the findings from each county as well as a description of how the findings led to the selection of each target community.

For Bastrop County, the quantitative data showed an increasing trend for female breast cancer incidence rate and late-stage female breast cancer incidence rate. Although the late-stage female breast cancer incidence rates falls below the *Healthy People 2020* target of 41.0 per 100,000 women, the increasing incidence trends make Bastrop a medium priority (Table 2.7). The female breast cancer death rate falls below the *Healthy People 2020* target of 20.6 per 100,000 women and the trend is decreasing. For Bastrop County, the proportion of women ages 50-74 who received a screening mammogram were suppressed due to small numbers (Table 2.3).

In Bastrop County, 36.4 percent of the population is living below the 250 percent Federal Poverty Guidelines, which is higher than the Affiliate service area and the United States (Table 2.5). Bastrop also has a higher unemployment percentage and a larger female population age 40 plus than the Affiliate service area and Texas (Tables 2.4 and 2.5). Most shockingly, Bastrop has 29.3 physicians per 100,000 members of the population, which is less than the Affiliate service area, Texas, and the United States (Community Health Needs Assessment, 2014). These statistics, along with Bastrop's high uninsured percentages and large percentage of the population living in rural areas makes this county one of Komen Austin's target communities.

Through the health systems and public policy analysis, the Affiliate identified six health service providers in Bastrop County. Five of these providers are in Bastrop and one is in Smithville. Bastrop County has limited breast cancer and breast health services. Three providers offer screening mammograms and four providers offer clinical breast exams. Two providers offer limited diagnostic services, two provide treatment options, and two provide some support and survivorship services. These limited services contribute to the increasing trend in female breast cancer incidence rate and late-stage female breast cancer incidence rate that was found in the quantitative data report.

The qualitative data from Bastrop County revealed that both survivors and health care providers believe that their community needs more breast health and breast cancer education, as well as information about breast health services available in Bastrop and surrounding counties. Survivors and providers also indicated that health services are limited in Bastrop County, and agreed that the county needs more funding and insurance assistance to improve local breast health services. Survivors stated that education efforts should be focused on the Black/African-American and Hispanic/Latina populations to increase their breast cancer awareness. Survivors and providers also feel that young women need to be more informed about breast health, breast screenings, and breast cancer. Focus group participants vocalized hopes for more partnerships between the Affiliate and local clinics in the future.

Focus group participants in Bastrop County stated that a lack of health literacy or limited English proficiency was also an issue in their community. Survivors stated that they had difficulty understanding health information and communicating with doctors and nurses due to technical medical terms. Providers said that many Spanish-speaking patients do not go to receive health services because they have no one to translate for them. Participants also indicated that patients need assistance when filling out medical paperwork, and survivors and providers agreed that health care providers should spend more time answering patient questions.

In focus groups and key informant interviews, participants gave many barriers to accessing breast health services in Bastrop County. One key informant said that fear often keeps individuals from getting breast cancer screenings. Focus group participants said that some individuals want to get screened, but they cannot afford the transportation to the screening location. Mobile mammography services can help alleviate transportation issues, but these services are limited in Bastrop. Lack of insurance or being underinsured is often another barrier to receiving breast health services. Lack of respect from health care providers was also discussed in focus groups. Some Black/African-American women had experienced disrespect from doctors, and survivors agreed that race/ethnicity is an issue in receiving care. They also believed that being of a lower socioeconomic status could lead to mistreatment by health care providers. Survivors and some providers agreed that patients without insurance are treated differently.

Survivors indicated that they would like more information about the survivorship and support services that are available in Bastrop County. Survivors wish that they had been better prepared for the challenges of fighting breast cancer. They also agreed that they need patient navigation services, which would have helped them through the process and provided them with information on what to expect and how to handle the financial burden of a breast cancer diagnosis.

The quantitative data revealed that Caldwell County has a female breast cancer incidence rate of 129.8 per 100,000 women, which is higher than that of Komen Austin's service area, Texas, and the United States (Table 2.1). The late-stage female breast cancer incidence rate is 55.0 per 100,000 women, which is higher than the Affiliate service area, Texas, and the United States (Table 2.1). This rate is also higher than the *Healthy People 2020* objective of reducing the late-stage female breast cancer incidence rate to 41.0 per 100,000 women. It is projected that it will take at least 13 years for Caldwell County to reach this target rate, which makes it a highest priority (Table 2.7). For Caldwell County, the female breast cancer death rates and the proportion of women ages 50-74 who received a screening mammogram were suppressed due to small numbers (Table 2.3).

Caldwell County has a large population with less than a high school education and high poverty, unemployment, and uninsured percentages (Table 2.5). The Community Health Needs Assessment (2014) shows that education is one of the strongest predictors of health status, and that poverty, unemployment, and lack of insurance are barriers to access to health care. A large percentage of the Caldwell County population also lives in rural areas and lack a personal doctor or health care provider (Table 2.5). Living in rural areas can be a barrier to good health status because of the lack of access to health care and the lower number of health care providers in the area (CHNA, 2014). All of these indicators, along with the greater number of

females age 40 and over living in this county, makes Caldwell a target community for Komen Austin (Table 2.4).

The health systems and public policy analysis showed that Caldwell County has five health service providers: two in Luling and three in Lockhart. These five service providers offer general screening services and limited diagnostic, treatment, and survivorship services, but none of them are able to provide all services under the Continuum of Care. Individuals in Caldwell have difficulty accessing services for breast cancer and breast health in their communities and must drive to Austin, San Antonio, or San Marcos to these access services. The lack of widely available diagnostic, treatment, and support services in Caldwell is a barrier to residents, especially for women living in poverty and those that are uninsured or underinsured. These barriers also contribute to the increased late-stage female breast cancer incidence rate that was found in the quantitative analysis.

In Caldwell County, the qualitative data revealed that focus group participants feel that health education in the community would be beneficial. Providers and survivors agreed that there are many misconceptions about breast cancer in Caldwell. Both groups stated that young women in particular need more breast health and breast cancer education. Providers and survivors indicated a need for expanded mobile mammography services. Key informants stated that they hoped the Affiliate could offer greater availability of mobile mammography services staffed with trained professionals.

Much like survivors in Bastrop County, survivors and co-survivors in Caldwell County agreed that they had trouble understanding health information and felt that doctors did not adequately explain their cancer or effectively answer questions. Providers also admitted that the use of medical terminology creates a barrier between doctors and patients. Spanish-speaking survivors indicated a need for more Spanish-speaking employees in health clinics to help with translation.

As stated in the health systems and public policy analysis report, the lack of diagnostic, treatment, and supportive services in Caldwell County is a barrier to residents. Survivors and co-survivors stated that they had to travel outside of Caldwell to receive diagnostic and treatment services, which is inconvenient and costly. Providers indicated a need for more clinics and expanded operational hours to allow for more appointments to be scheduled. While some survivors do have Medicaid to cover the costs associated with a breast cancer diagnosis, other survivors were uninsured.

Caldwell County focus group participants and key informants described many misconceptions about breast cancer and cultural and religious beliefs that are barriers to women seeking screening services. Survivor and provider focus group participants stated that many people think that breast cancer only occurs in older women and that you are only at risk if breast cancer runs in your family. For these reasons, many women do not receive regular screenings. The belief that breast cancer is the will of God, a taboo against discussing breast cancer, and a cultural distrust of doctors were all mentioned as barriers to seeking breast cancer screenings. Much like survivors from Bastrop, Caldwell survivors felt that Black/African-American and Hispanic/Latina patients do not receive the best quality of care. Participants also stated that this lower quality of treatment might be due to socioeconomic status more than race or ethnicity.

Caldwell County survivors indicated a need for patient navigation services to guide them through the treatment process and help them get support. They also stated that having support groups would have been helpful when coping with the way cancer impacted every part of their lives. Providers agreed that patients need supportive services to help them through various issues that come with a breast cancer diagnosis.

In Travis County, the female breast cancer incidence rate is 124.0 per 100,000 women, which is higher than the Affiliate service area, Texas, and the United States (Table 2.1). Travis County currently meets the *Healthy People 2020* death rate objective. The late-stage incidence rate is 41.6 per 100,000 women, which is only slightly above the *Healthy People 2020* objective of 41.0 per 100,000 women (Table 2.1). It is projected to take one year for the county to meet the late-stage incidence rate objective, which makes Travis a low priority (Table 2.7). In Travis County, 71.0 percent of women ages 50-74 received a screening mammogram (Table 2.3).

The quantitative data showed that about 60 percent of females in Komen Austin's service area reside in Travis County (Table 2.4). In Travis County, 7.6 percent of the population is linguistically isolated, which is a higher percentage than the Affiliate service area and the United States (Table 2.5). Individuals who are linguistically isolated face linguistic barriers, such as the inability to speak English well. Linguistic barriers may lead to barriers in the utilization of available health care due to low health literacy and limited health provider-patient communication. Travis County also has a foreign-born population of 18 percent, which is larger than the Affiliate service area, Texas, and the United States (Table 2.5). Due to these indicators, along with the large population with less than a high school education, high poverty percentages, and high uninsured percentages, Travis County is one of the Komen Austin's target communities (Table 2.5).

The health systems and public policy analysis of Travis County identified 51 health service providers. Forty eight providers are in Austin and the other three are in Bee Cave, Lakeway, and Cedar Park. Among the 51 providers, approximately 74.5 percent offer screening services, 51.0 percent offer diagnostic services, 27.5 percent offer treatment services, and 37.3 percent offer supportive services. Travis County has many screening and diagnostic service providers, but has fewer treatment and supportive service providers. Although Travis has a greater number of service providers than Bastrop and Caldwell Counties, these providers are not geographically accessible to underserved individuals, especially Black/African-American women. Travis County lacks sufficient treatment, supportive, and education services for breast cancer and breast health for individuals at all income levels.

The qualitative data report showed that survivors and key informants in Travis County were well-informed about breast health services in the community. Key informants indicated a need for financial support for transportation to breast health services. Key informants also expressed a need for educational information about breast cancer and healthy living before, during, and after treatment. Much like the other target communities, participants expressed the need to focus on educating younger women about breast health and breast cancer. Providers also expressed the need for outreach to the homeless and unemployed populations.

In Travis County survivor focus groups, participants agreed that medical terminology was difficult to understand. Spanish-speaking survivors experienced greater difficulties because the information they received was in English. Providers stated that many of their patients have low health literacy and learn about breast cancer for the first time when they are diagnosed.

Providers and survivors indicated several barriers to receiving breast health services in Travis County. Providers and survivors agreed that it is more difficult for uninsured individuals to receive health care. Transportation to follow-up care was also a barrier for survivors who cannot afford private transportation. Survivors also stated that providers could be more supportive and empathetic when delivering a diagnosis and addressing patient concerns. Cultural beliefs also present barriers to receiving breast health services. Black/African-American women in a survivor focus group stated that some Black/African-American women do not like to talk about breast cancer. Providers stated that many Black/African-American patients do not trust their doctors. The cultural taboo against discussing breast cancer and the distrust of doctors present barriers to Black/African-American women receiving breast health services.

Some survivors in Travis County received patient navigation services and were involved in support groups, while others felt that these services were lacking. Those that did have navigation services and were involved in support groups stated that these services provided them with the emotional support that helped them get through treatment. Providers indicated that screening and follow-up care is insufficient in Travis County's breast health community. They also feel that health care providers need more education and training on follow-up care and survivorship.

Komen Austin has strong partnerships with a number of grantees in the community who provide screening, diagnostic, treatment, education, and survivorship services in the Affiliate service area. Patient navigation is one of the central services that is provided by community organizations in the Affiliate's grantee network. However, there is a shortage of grantees that provide these services in Caldwell and Bastrop Counties, which are the counties that need these services the most.

In Texas, 24.7 percent of the population is uninsured, which is more than the United States (Table 2.5). Medicaid Expansion did not occur in Texas, which leaves over one million Texans uninsured (Kaiser Family Foundation, 2014). The Affiliate is a member of the Komen Texas Advocacy Collaborative (KTAC), which is the state level advocacy and public policy coordinator of the Texas Komen Affiliates. The Affiliate will continue to work in collaboration with KTAC and other public policy groups to ensure that policy makers are addressing the need for breast health screening and treatment in underserved populations. The Affiliate will also strive to provide grants to organizations that serve uninsured and underinsured populations and rural communities.

Based on the qualitative data collected, the Affiliate made several conclusions about what is needed in target communities. The target communities need more breast health education, particularly for Black/African-American, Hispanic/Latina, and younger populations. Black/African-American and Hispanic/Latina women are more likely to not receive breast cancer screenings for cultural or religious reasons. More education in these populations will work to increase awareness and correct common misconceptions.

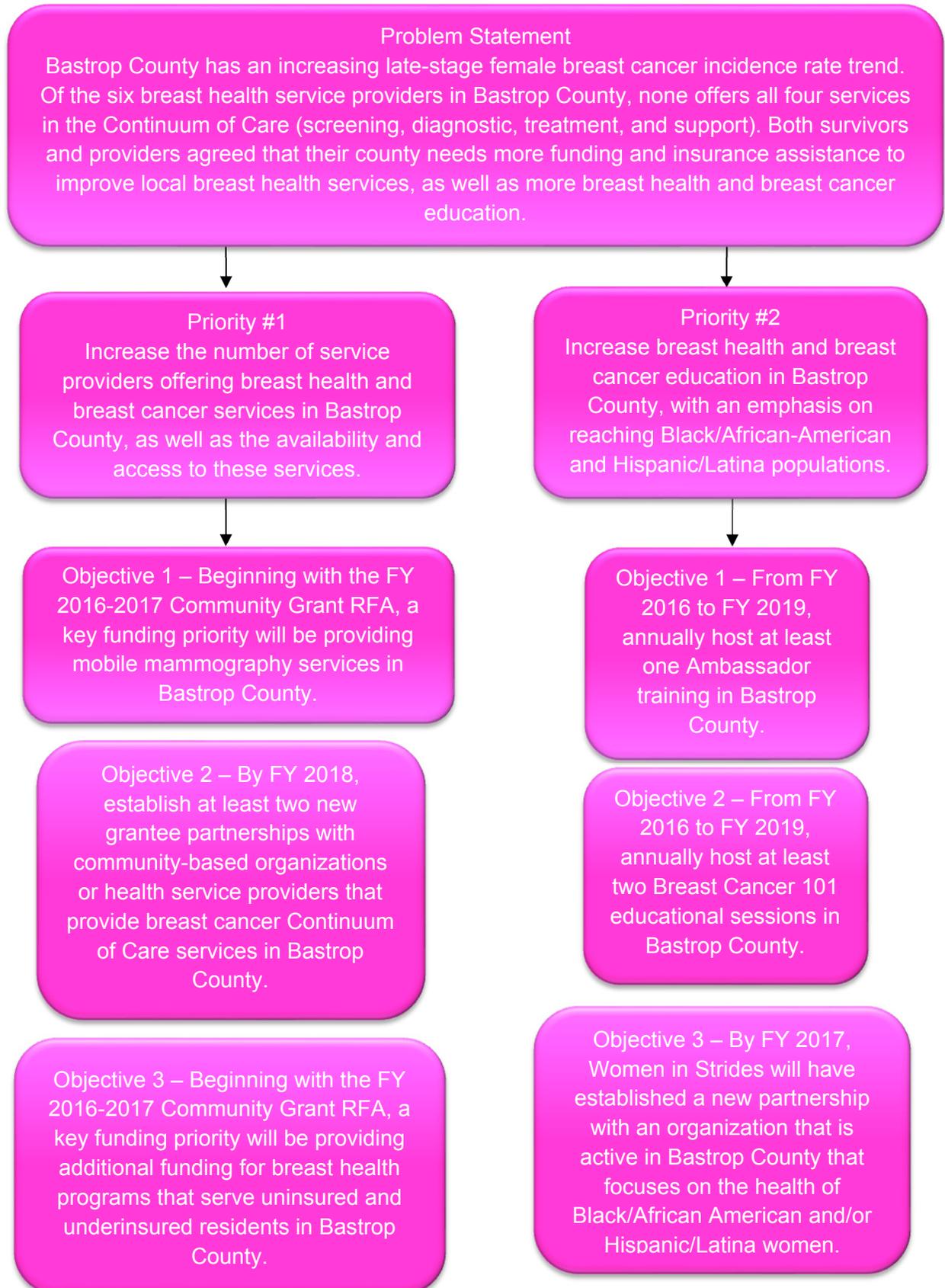
The target communities are also in need of more breast health and breast cancer services. The rural communities are in need of more affordable, high-quality health care services. Many patients in Bastrop and Caldwell Counties have to travel to surrounding counties to receive care because of the lack of local services. Transportation assistance and mobile mammography

services would help alleviate some of the barriers to receiving care. The patients in these communities are also in need of patient navigation and survivorship services. Patient navigation services would guide patients through the complicated and overwhelming process that starts with a breast cancer diagnosis. Survivorship services would provide a support network that allows survivors and co-survivors to share information and experiences.

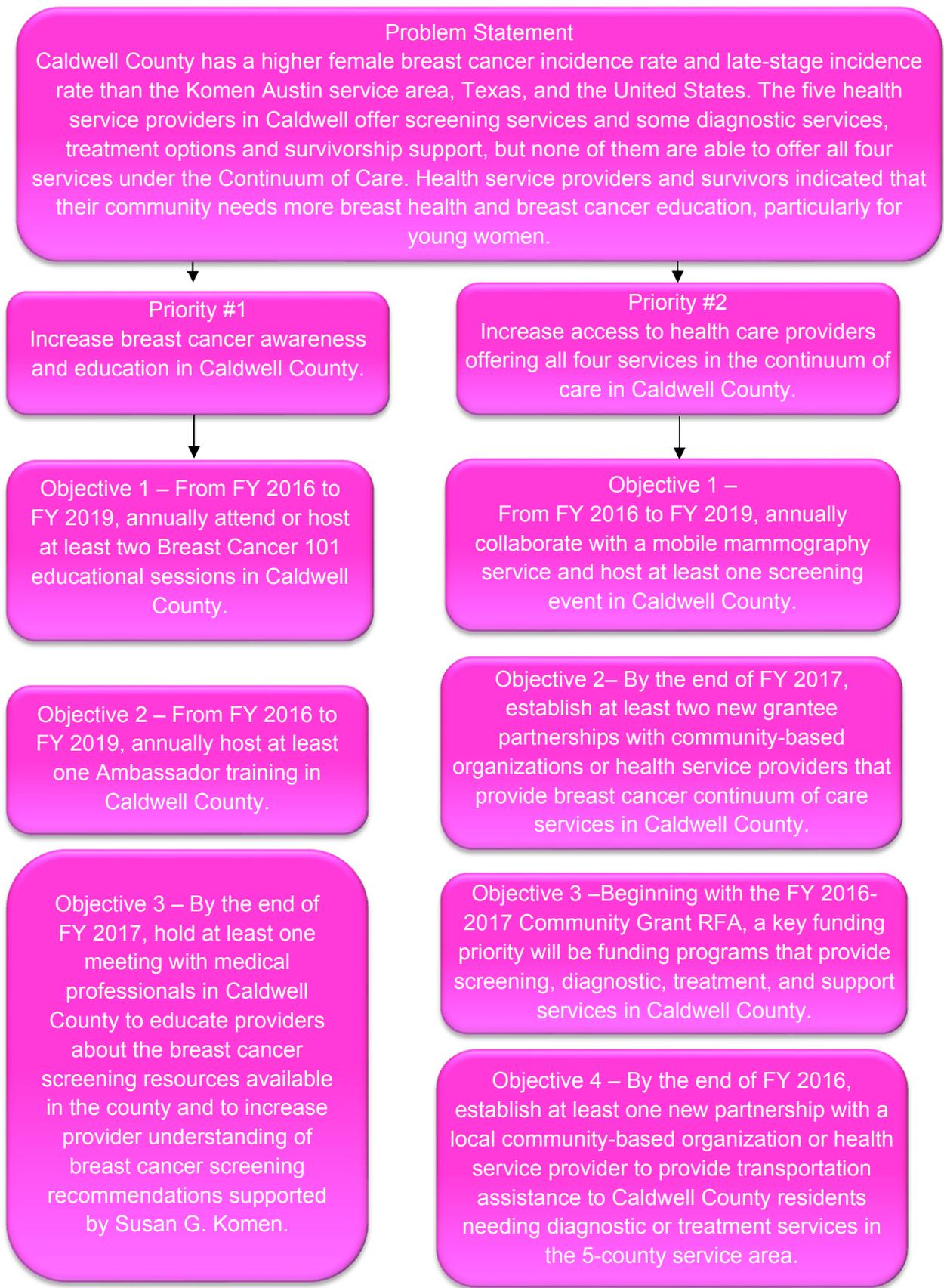
Health literacy and English proficiency are also lacking in the target communities. The Affiliate found that participants' high education level did not necessarily correspond with their level of health literacy. The target communities have larger populations that are linguistically-isolated compared to the other counties in the Affiliate service area and the United States (Table 2.5). These communities need more Spanish-speaking providers to ensure that Spanish-speaking patients are able to communicate with their doctors.

Mission Action Plan

Bastrop County



Caldwell County





For Bastrop County, the first priority was chosen because the Affiliate feels that it important to stop the increasing female breast cancer incidence trends. Bastrop lacks health service providers that offer all services in the Continuum of Care and more comprehensive service coverage is needed. The lack of breast health services in Bastrop may contribute to the increasing incidence rate trends. The second priority was chosen based on what was identified as a need for the community. Survivors feel that more education is needed, particularly in the Black/African-American and Hispanic/Latina communities, to increase breast cancer awareness. Women in Strides is a Komen Austin education and outreach group that works in the Black/African-American community. Their partnership with a similar organization based in Bastrop will increase the outreach targeted at minority populations.

For Caldwell County, the first priority was chosen because the incidence rates in this county are higher than the Affiliate service area, Texas, and the United States, and the Affiliate feels that it is important to focus on decreasing these incidence rates. The second priority was chosen because there are no health providers in Caldwell County that offer screening, diagnostic, treatment, and support services. The lack of screening and diagnostic services may contribute to the increased incidence rates in Caldwell. The second priority will work to provide more services in the Continuum of Care to Caldwell residents by increasing the availability of these services in the county, as well as by increasing access to these services outside of Caldwell through transportation assistance.

For Travis County, the first priority was chosen because the Affiliate feels that it is important to decrease the female breast cancer incidence rate. More breast cancer awareness through education will help to promote healthy behaviors and screening practices, which the Affiliate hopes will reduce the incidence rate. The second priority was chosen because Travis County needs more treatment and survivorship services, which was indicated in the health systems and public policy analysis and from providers in the qualitative data. The Affiliate will work to address this need by making providers more aware of these issues and by increasing the availability of treatment and support services in Travis County. The final priority was chosen because survivors and key informants indicated that transportation was an important barrier to accessing follow-up care. This priority was also chosen because providers and survivors indicated that uninsured individuals have difficulty accessing health care services. This priority will be addressed by making this issue a funding priority and by continuing to advocate for programs that serve uninsured and underinsured individuals.

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