susan g. komen®

# COMMUNITY PROFILE REPORT 2015


## SUSAN G. KOMEN®
## GREATER FORT WORTH

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# Acknowledgments

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# Executive Summary

## Introduction to the Community Profile Report

Susan G. Komen® Greater Fort Worth is dedicated to Komen's mission to save lives and end breast cancer forever by empowering people, ensuring quality care for all, and energizing science to find the cures. Komen Greater Fort Worth was founded in 1992 as the Tarrant County Affiliate. In August 2010, Komen Tarrant County became Komen Greater Fort Worth and expanded its service area to include Parker, Johnson, and Hood Counties. Since its inception in 1992, the Affiliate has funded over $23 million in community grants and research for life-saving breast health education, screening, breast cancer treatment, and social support services.

The Affiliate prioritizes grantmaking and community outreach. In the Fiscal Year 2015 grant cycle, the Affiliate invested $600,000 in five community grants that provide the spectrum of breast health services, from screening mammograms to breast cancer treatment. The Affiliate's grantees participate in the Race for the Cure®, which raised over $940,000 in 2014. Community outreach is a key component of the Affiliate's activities, and Affiliate staff and volunteers participate in health fairs and other educational events throughout the year. In 2014, the Affiliate participated in 58 education outreach events, reaching up to 28,100 individuals in Tarrant, Parker, Johnson, and Hood Counties and providing vital breast health education.

Every four years, the Affiliate completes the Community Profile assessment process, which helps the Affiliate understand the state of the breast cancer burden and needs in the service area. The purpose of the Community Profile is to aid the Affiliate in its organizational mission by aligning its community outreach, grantmaking, and public policy activities.

Through the findings of the Community Profile, the Affiliate will fund, educate, and build awareness in the areas of greatest need. The Community Profile will also aid the Affiliate in strengthening relationships in the community and strategizing its marketing and outreach programs to make the greatest impact. Successful grant applicants will read and carefully consider the Community Profile priorities and address them in their grant proposals. The Community Profile Report will be shared throughout the Affiliate's service area and will guide the Affiliate for the next four years.

## Quantitative Data: Measuring Breast Cancer Impact in Local Communities

To begin the Community Profile process, the Affiliate examined the Quantitative Data Report (QDR) provided by Komen Headquarters. The QDR examines female breast cancer incidence, deaths, and late-stage diagnosis; additionally, the QDR provides percentages for screening mammography, population demographics, and socioeconomic indicators such as income and education level. The QDR illustrated that the breast cancer incidence rate and trend in the Affiliate service area is similar to that observed in the US as a whole, but the Affiliate service area's breast cancer incidence rate is significantly higher than the incidence rate for the State of Texas. The Affiliate service area's breast cancer screening proportion, incidence trend, and death rate are not significantly different that those observed for the US as a whole and the state of Texas.

In order to determine priority areas, each county in the service area was categorized into seven potential priority levels based on the estimated time to reach Healthy People 2020 (HP2020) targets for late-stage diagnosis and death rates. HP2020 is a US federal government initiative that provides specific health objectives for communities and for the country as a whole, and has several cancer-related objectives, including reducing the death rate from breast cancer and reducing late-stage diagnoses. According to HP2020, Hood County currently meets the breast cancer targets, Tarrant County is predicted to reach the targets within one year, while Parker and Johnson Counties are predicted to take 13 years or longer to reach the targets. Thus, Parker and Johnson Counties are likely to miss the HP2020 breast cancer death rate target, as well as the late-stage incidence rate target. Based on this information as well as other data in the QDR, it was determined that Parker and Johnson Counties are in the highest priority category, Tarrant County is in the medium-low priority category, and Hood County is in the lowest priority category.

Based on this data and categorization, the Affiliate chose to focus on one target community consisting of Parker and Johnson Counties. Parker and Johnson Counties are combined into one target community because they share similar characteristics in addition to the HP2020 predictions: both counties are largely rural, have similar demographics, and border Tarrant County, where the majority of breast health services in the Affiliate's service area are found.

## Health System and Public Policy Analysis

After completing the Quantitative Data section, the Affiliate conducted the Health System and Public Policy Analysis. The analysis revealed the strengths and weaknesses in the continuum of care in the target community of Parker and Johnson Counties. In both counties, there are medical and imaging centers, hospitals that offer screening and diagnostic mammography, as well as cancer centers that offer oncology services. However, these facilities are located in the larger cities in the counties, so individuals living in more rural areas must travel to the larger cities to obtain services.

In order to find implications for public policy in the state of Texas, the Affiliate analyzed the National Breast and Cervical Cancer Early Detection Program, the state comprehensive cancer control coalition, and the Affordable Care Act. The analysis revealed that low-income women ages 18-64 can access screening and diagnostic services for breast and cervical cancer; however, the overall impact of the Affordable Care Act in Texas on the uninsured will take time to unfold.

There are still thousands of women in Texas who need access to breast cancer screening, treatment, and recovery services. The target community of Parker and Johnson Counties has large areas with no access to screening mammograms, diagnostic exams, and breast cancer treatment services. The Affiliate will continue to serve uninsured and underserved individuals in these counties, as well as Tarrant and Hood Counties, through community grants and partnerships with local organizations.

## Qualitative Data: Ensuring Community Input

Based on issues raised from the Quantitative Data Report and the Health Systems and Public Policy Analysis, Komen staff and researchers from the University of North Texas Health Science

Center (UNTHSC) sought to find answers to key assessment questions about what factors impact access and utilization of breast health care in Parker and Johnson Counties, what factors serve as barriers to breast health care in these counties, and how to best assist breast cancer survivors. The Affiliate also formed key questions about breast health outreach and education in Parker and Johnson Counties. In order to find answers to the key questions, Affiliate staff and UNTHSC researchers utilized focus groups and an online qualitative survey. For both study components, participants included breast cancer survivors, breast cancer co-survivors, and health care professionals that were 18 years or older and work and/or reside in Parker or Johnson Counties. These specific groups were surveyed because of their unique perspectives on breast health care in Parker and Johnson Counties, as well as their ability to offer insight into the key questions assessed by the researchers. Six focus groups were conducted: three in Parker County and three in Johnson County. For the online survey, there were 150 respondents: 50 from Parker County, 46 from Johnson County, and 46 who did not specify their county. Although some respondents did not specify their county, the Affiliate is confident that they reside and/or work in Parker or Johnson Counties because the recruitment emails and flyers specifically requested that only individuals associated with those counties participate in the survey.

Researchers used three stages of coding and developed 12 primary themes to correspond to the emergent issues unique to the focus group and survey. The themes included communication and knowledge, affordability, survivor supports, accessibility, availability and location, personal factors, adequacy, community resources, service coordination and navigation, subpopulations, and no problems or concerns. Analysis of these themes revealed that in Parker and Johnson Counties, increased communication and knowledge is needed, affordability of care is an issue, various forms of survivor support are needed, lack of desirable and adequate facilities is an issue, there is a need for service coordination and patient navigation, and several subpopulations are in particular need of services, outreach, and education; these subpopulations include uninsured individuals and minority racial/ethnic groups.

## Mission Action Plan

The culmination of the Community Profile involved forming the Mission Action Plan. Through triangulation of data from the other sections of the Community Profile, the Affiliate determined four needs statements about the target community, as well as priorities and objectives to meet the needs.

The Affiliate identified three main need statements for the target communities and developed corresponding priorities and objectives to address the identified problems.

The first needs statement is that Parker and Johnson Counties have higher breast cancer death rates than the rest of the Affiliate service area and the state of Texas, and are projected to be delayed in meeting Healthy People 2020 breast cancer targets. In order to address this need, the priority is to increase potential availability and access to breast health services for individuals in Parker and Johnson Counties. In order to work towards accomplishing this, the Affiliate Community Grant RFA will include programs that provide mammograms and treatment services in Parker and Johnson Counties as a funding priority. Additionally, the Affiliate will hold grantwriting workshops that target organizations serving individuals in Parker and Johnson Counties.

Need statement: As indicated in the Quantitative Data Report, Parker and Johnson Counties have higher breast cancer death rates than the rest of the Affiliate service area and the State of Texas, and are projected to be delayed in meeting Healthy People 2020 breast cancer targets.

Priority 1: Increase potential availability and access to breast health services for individuals in Parker and Johnson Counties.

Objective 1.1: By November 2015, Community Grant RFA will include programs that provide mammograms and treatment services in Parker and Johnson Counties as a funding priority.

Objective 1.2: By November 2015, hold at least one grantwriting workshop targeting organizations that serve individuals in Parker County to encourage grant applications.

Objective 1.3: By November 2016, hold at least one grantwriting workshop targeting organizations that serve individuals in Johnson County to encourage grant applications.

The second needs statement is that individuals in the target community sometimes must travel long distances to obtain services, which may delay care. To address this need, the priority is to increase potential availability and access to transportation assistance for individuals in Parker and Johnson Counties to obtain breast health services. The Affiliate will work towards this priority by participating in meetings to discuss transportation initiatives and apply for at least one grant that addresses transportation issues in Parker and Johnson Counties.

Need statement: Residents in Parker and Johnson Counties indicated that individuals sometimes have to travel long distances to obtain services, which may delay care.

Priority 2: Increase potential availability and access to transportation assistance for individuals in Parker and Johnson Counties to obtain breast health services.

Objective 2.1: By December 2015, participate in at least one meeting to discuss transportation initiatives in Parker and Johnson Counties.

Objective 2.2: By December 2017, apply for at least one grant that addresses transportation issues in Parker and Johnson Counties.

The third needs statement is that there is a need to develop partnerships to improve community outreach and collaboration in Parker and Johnson Counties, and the priority is to increase community outreach and breast health partnerships. This priority will be accomplished by participating in or hosting health fairs in Parker and Johnson Counties, as well as meeting with organizations, providers, and legislators in the target community.

Need statement: In Parker and Johnson Counties, residents indicated there is a need to develop partnerships to improve community outreach and collaboration.

Priority 3: Increase community outreach and breast health partnerships in Parker and Johnson Counties.

Objective 3.1: By December 2016, participate in or host at least one educational health event in Parker County.

Objective 3.2: By December 2016, participate in or host at least one educational health event in Johnson County.

Objective 3.3: By December 2017, meet with at least two organizations or providers in Parker County to form partnerships and explore how to reach rural residents to provide breast health education and increase awareness.

Objective 3.4: By December 2018, meet with at least two organizations or providers in Johnson County to form partnerships and explore how to reach rural residents to provide breast health education and increase awareness.

Objective 3.5: By December 2018, meet with at least two legislators or government officials who serve Parker and Johnson Counties to discuss public policy and Komen's breast health priorities.

The final needs statement in the Mission Action Plan is that several subpopulations in Parker and Johnson Counties need increased access to services, including non-English-speaking residents and uninsured individuals. To address this need, two priorities were developed; the first priority is to increase access to culturally competent breast health education among non-English-speaking residents in Parker and Johnson Counties. In order to work towards this goal, the Affiliate will participate in at least one health event that reaches non-English speaking residents in Parker and Johnson Counties. The final priority to address this need is to increase access to breast health services for uninsured individuals in Parker and Johnson Counties. Affiliate staff will aim to meet with at least one elected official to discuss this priority, and will participate in at least three health events which target attendees who are uninsured or underserved in Parker and Johnson Counties to increase awareness of available no-cost and reduced cost services.

Need statement: Focus group and survey participants indicated that there are several subpopulations in Parker and Johnson Counties need increased access to breast cancer education and services. These subpopulations include non-English-speaking residents and uninsured individuals.

Priority 4: Increase access to culturally competent breast health education among non-English-speaking residents in Parker and Johnson Counties.

Objective 4.1: By December 2016, participate in at least one health education event that reaches non-English speaking residents in Parker County.

Objective 4.2: By December 2017, participate in at least one health education event that reaches non-English speaking residents in Johnson County.

Priority 5: Increase access to breast health services for uninsured individuals in Parker and Johnson Counties.

Objective 5.1: By December 2018, participate in at least three health events which target attendees who are uninsured or underserved in Parker and Johnson Counties to increase awareness of available no-cost and reduced cost services.

Objective 5.2: By December 2017, meet with at least one elected State of Texas official to advocate for Medicaid Expansion and/or continued funding of the Breast and Cervical Cancer Services program which would increase access to services for uninsured individuals.

Through addressing these issues in Parker and Johnson Counties relating to HP2020 breast cancer targets, transportation, community outreach and collaboration, and the need for increased access to services for subpopulations, the Affiliate will promote breast health in Parker and Johnson Counties for the next four years and beyond.

**Disclaimer:** Comprehensive data for the Executive Summary can be found in the 2015 Susan G. Komen® Greater Fort Worth Community Profile Report.

## Affiliate History

The Affiliate began in 1992 when Fort Worth resident Rozanne Rosenthal chartered the Tarrant County Affiliate of Komen in honor of her friend and three-time breast cancer survivor, Joan Katz. Through their own grassroots efforts and the help of over 1,800 volunteers and participants, Rozanne and Joan raised over $100,000 at the Affiliate's first Race for the Cure® in 1993. Over the next 18 years, the Affiliate raised millions of dollars through its annual Race for the Cure, and funded community grants providing breast health services to women in Tarrant County. In order to respond to needs identified in outlying and rural areas, Komen Tarrant County became Susan G. Komen® Greater Fort Worth in August 2010 and expanded its service area to include Parker, Johnson, and Hood Counties.

Since its inception, the Affiliate has funded more than $22 million in local grants for life-saving breast health education, screening, treatment, and social support services. The 2014 Race for the Cure raised over $940,000, and the Affiliate invested $600,000 in six community grants and contributed $259,660 to Komen Research Programs. Of the net funds raised, 75.0 percent stays in the Greater Fort Worth community, while the remaining 25.0 percent goes to Komen Research Programs to find the cure.

The Affiliate is a breast health and breast cancer leader and expert in the community. The Affiliate is a member of the Texas state cancer coalition, the Cancer Alliance of Texas, as well as the Tarrant County Cancer Disparities Coalition (TCCDC). In addition to its membership in local and state cancer coalitions, the Affiliate is also a member of the Texas Breast Health Collaborative; Affiliate staff members have participated in the annual Breast Health Summit sponsored by the Texas Breast Health Collaborative. Throughout its history, the Affiliate has been a leader in the community, with plans to strengthen and expand its relationships and presence throughout the service area.

## Affiliate Organizational Structure

Figure 1.1 illustrates the organizational structure of the Affiliate. The Board of Directors has four committees: the Governance Committee, the Development/Marketing Committee, the Finance Committee, and the Mission Committee. There are six staff members, and the Executive Director manages all other staff. The Development and Marketing Director oversees fundraising events and race sponsorships; the Mission Coordinator oversees grants, the Community Profile, and education initiatives; the Operations Coordinator oversees general operations and finance; and the Race and Special Events Coordinator oversees third party events and the Race for the Cure.

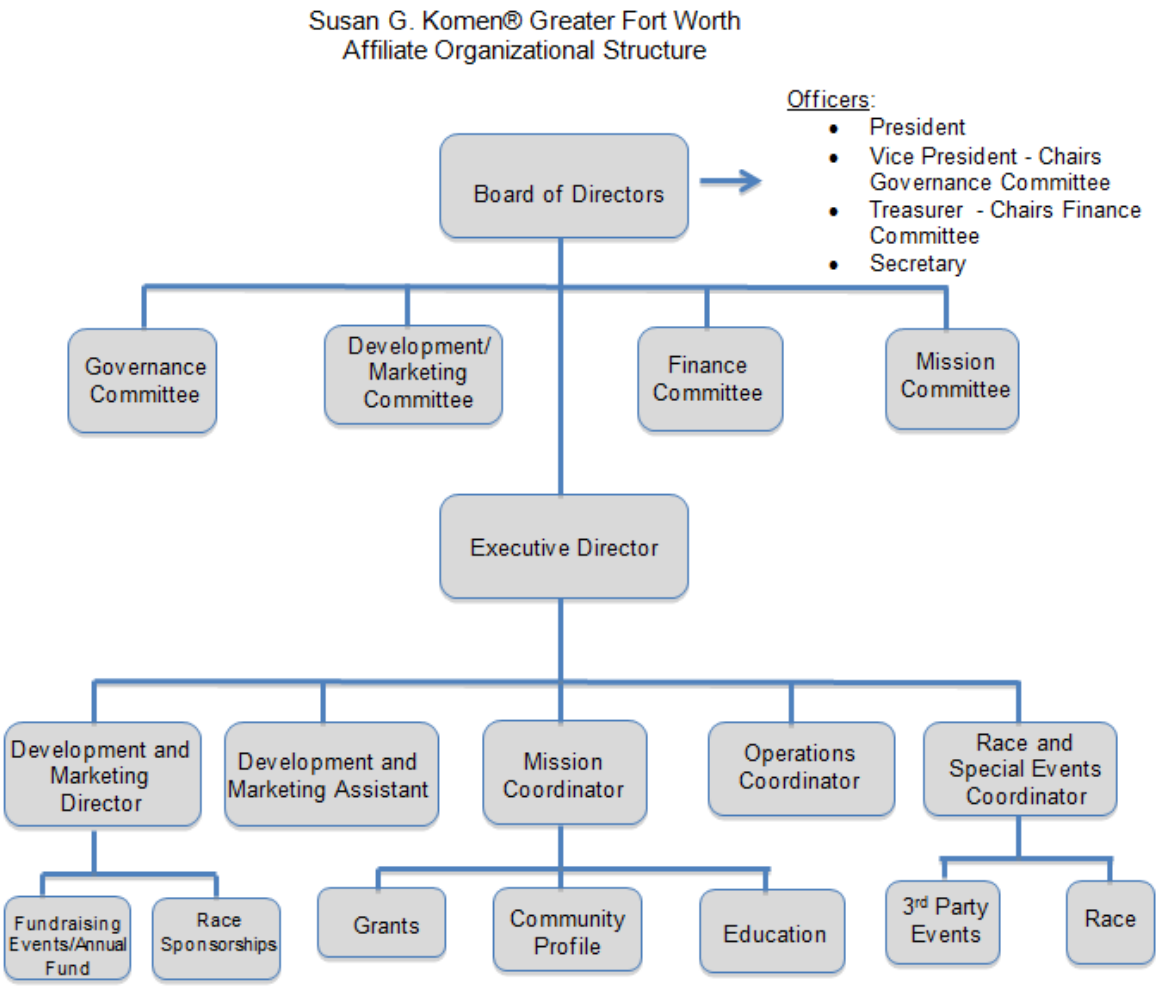


**Figure 1.1.** Susan G. Komen Greater Fort Worth organizational structure

## Affiliate Service Area

The Affiliate service area is comprised of Tarrant, Parker, Johnson, and Hood Counties (Figure 1.2). Fort Worth is the largest city in Tarrant County, Weatherford is the largest city in Parker County, Cleburne and Burleson are the largest cities in Johnson County, and Granbury is the largest city in Hood County. Tarrant County is the most populated county in the service area, with a population of 1.8 million people according to the 2010 US Census (US Census Bureau, 2015). Hood County is the least populated county in the service area, with a population of approximately 51,000 people. Tarrant County has public transportation options such as bus service and commuter rail, but the other counties in the service area have more limited public transportation options.

According to the 2010 US Census, 51.0 percent of the Affiliate service area is female. Out of all individuals in the Affiliate service area, 78.5 percent are White, 13.9 percent are Black/African-American, 4.4 percent are Asian, and 0.009 percent are American Indians and Alaska Natives. Hispanic/Latino individuals comprise 25.7 percent of the population in the service area, and 14.1 percent of the population was born outside of the United States. Regarding education level, 84.7

percent of individuals over age 25 have a high school education or higher and 28.2 percent have a bachelor's degree.

Poverty is an issue faced by many individuals in the service area, with 14.7 percent of the population living at or below the federal poverty level. Unemployment and lack of health insurance also impact individuals in the service area, with an unemployment percentage of 7.6 percent and 21.9 percent of individuals ages 40-64 without health insurance. Johnson County has the highest percentage of uninsured residents (25.0 percent), while Parker County has the lowest percentage of uninsured residents (22.0 percent) (County Health Rankings, 2014). A majority of the service area population has access to medical care, but 5.7 percent of individuals live in medically underserved areas.

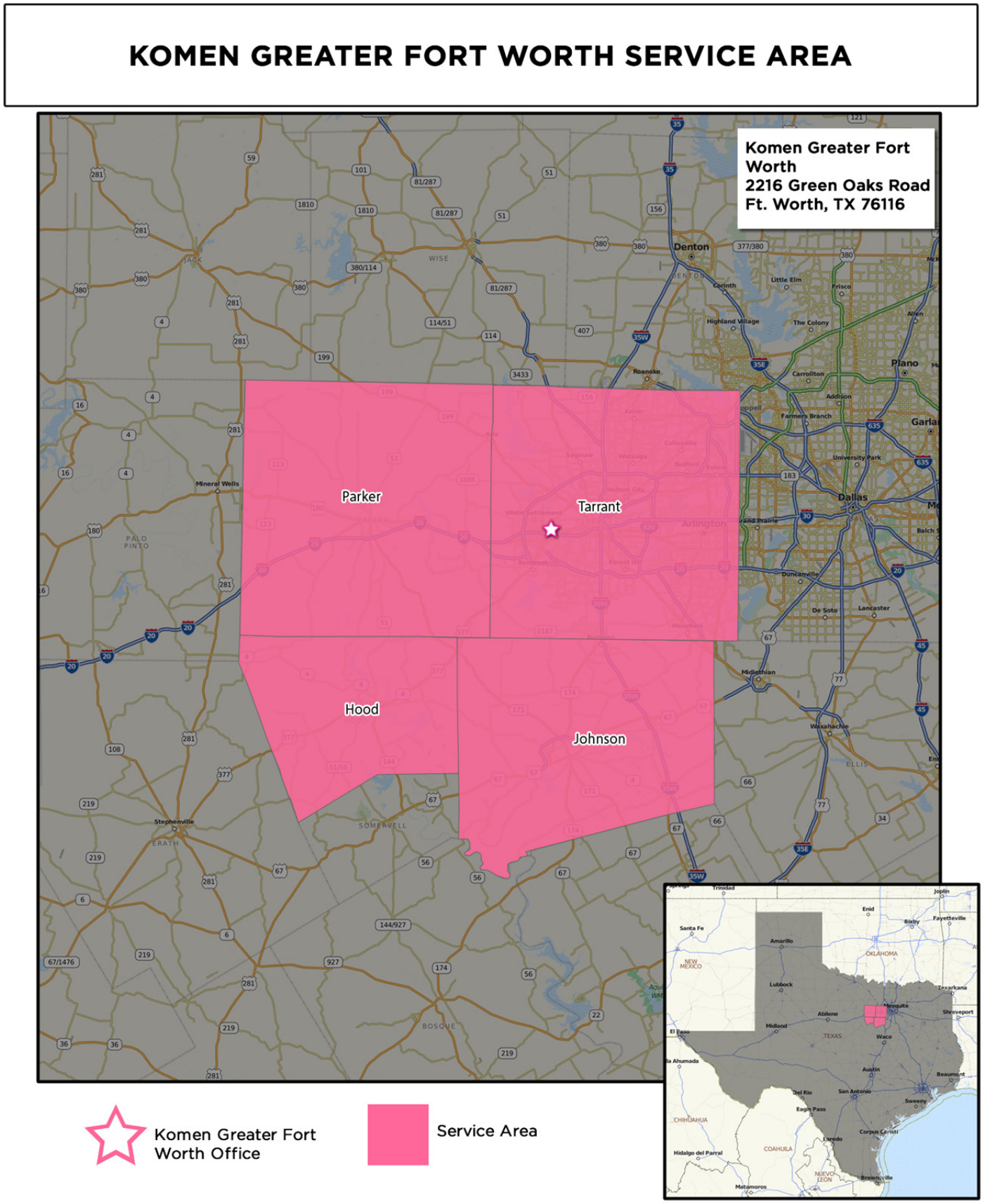


**Figure 1.2.** Susan G. Komen Greater Fort Worth service area

## Purpose of the Community Profile Report

The Community Profile is an assessment process the Affiliate completes every four years in order to understand the state of the breast cancer burden and needs in the service area. There are four main components of the Community Profile: quantitative data, health systems and public policy analysis, qualitative data, and the mission action plan.

The purpose of the Community Profile Report is to aid the Affiliate in aligning its community outreach, grantmaking, and public policy activities towards the organizational Mission to save lives and end breast cancer forever. The Community Profile process includes a broad range of individuals and stakeholders, bringing diversity to the Affiliate. The Community Profile allows the Affiliate to fund, educate, and build awareness in the areas of greatest need, and make data-driven decisions about how to best utilize resources in order to have the greatest impact. Furthermore, the Community Profile aids the Affiliate in strengthening relationships in the community, providing information to public policymakers, and strategizing direction to marketing and outreach programs to make the greatest impact.

Successful grant applicants will read and carefully consider the Community Profile priorities and address them in their grant proposals. The Community Profile will assist in community outreach by allowing the Affiliate to hear directly from individuals in the service area and respond to their needs. Partnerships will also be strengthened through the process of completing the Community Profile, including partnerships with local hospitals, clinics, sponsors, and other stakeholders. Community ties will also be made with breast cancer survivors and co-survivors.

Through these community ties and partnerships, the Community Profile Report will be shared throughout the community. The Affiliate will publish the report on its website and distribute it to local health care systems and public policymakers. The Affiliate may also present findings from the Community Profile through town hall meetings, press releases, and local newspaper articles. The Community Profile will be publicized and findings will be shared throughout the Affiliate's service area.

# Quantitative Data: Measuring Breast Cancer Impact in Local Communities

## Quantitative Data Report

### Introduction

The purpose of the quantitative data report for Susan G. Komen® Greater Fort Worth 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 death rates (http://www.healthypeople.gov/2020/default.aspx).

The following is a summary of Komen Greater Fort Worth'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 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

| | | Incidence Rates and Trends | | | Death Rates and Trends | | | Late-stage Rates and Trends | | |
|---|---|---|---|---|---|---|---|---|---|---|
| Population Group | 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 Greater Fort Worth Service Area | 1,041,223 | 1,224 | 122.3 | -0.1% | 213 | 21.7 | NA | 426 | 41.9 | -4.2% |
| White | 840,134 | 1,054 | 124.4 | -0.4% | 177 | 21.0 | NA | 353 | 41.4 | -4.3% |
| Black/African-American | 144,078 | 131 | 118.3 | 2.3% | 31 | 31.4 | NA | 58 | 51.1 | -3.9% |
| American Indian/Alaska Native (AIAN) | 9,742 | 5 | 51.1 | -1.3% | SN | SN | SN | SN | SN | SN |
| Asian Pacific Islander (API) | 47,269 | 25 | 65.3 | -2.2% | 4 | 11.2 | NA | 10 | 26.5 | -1.3% |
| Non-Hispanic/ Latina | 803,948 | 1,104 | 125.6 | 0.3% | 197 | 22.5 | NA | 372 | 42.1 | -4.3% |
| Hispanic/ Latina | 237,276 | 120 | 91.7 | -4.5% | 16 | 14.2 | NA | 53 | 36.6 | -5.1% |
| Hood County - TX | 25,324 | 47 | 128.0 | -7.8% | 8 | 18.5 | -3.5% | 13 | 36.3 | -2.6% |
| Johnson County - TX | 73,708 | 82 | 106.0 | 5.6% | 20 | 26.4 | -0.2% | 29 | 37.5 | 0.8% |
| Parker County - TX | 55,249 | 79 | 130.6 | 7.2% | 16 | 26.6 | -0.6% | 24 | 39.9 | 7.2% |
| Tarrant County - TX | 886,941 | 1,015 | 122.9 | -0.8% | 169 | 20.9 | -2.2% | 359 | 42.6 | -5.8% |

*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) death 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 and trend in the Komen Greater Fort Worth service area were similar to that observed in 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, lower among APIs than Whites, and lower among AIANs than Whites. The incidence rate among Hispanics/Latinas was lower than among Non-Hispanics/Latinas.

The incidence rate was significantly lower in the following county:

- Johnson County

The rest of the counties had incidence rates and trends that were not significantly different than the Affiliate service area as a whole or did not have enough data available.

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 Greater Fort Worth service area was similar to 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 not significantly different 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 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 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.

***Late-stage incidence rates and trends summary***

Overall, the breast cancer late-stage incidence rate in the Komen Greater Fort Worth 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 Comprehensive Cancer Network | US Preventive Services Task Force |
|---|---|---|
| Informed decision-making with a health care provider at age 40<br><br>Mammography every year starting at age 45<br><br>Mammography every other year beginning at age 55 | Mammography every year starting at age 40 | Informed decision-making with a health care provider ages 40-49<br><br>Mammography every 2 years ages 50-74 |

*As of October 2015

Because having regular 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. 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 Greater Fort Worth Service Area | 244 | 189 | 79.2% | 71.5%-85.2% |
| White | 213 | 163 | 77.2% | 69.1%-83.6% |
| Black/African-American | 19 | 17 | 87.7% | 56.0%-97.6% |
| AIAN | SN | SN | SN | SN |
| API | SN | SN | SN | SN |
| Hispanic/ Latina | 12 | 10 | 94.3% | 61.6%-99.4% |
| Non-Hispanic/ Latina | 232 | 179 | 77.4% | 69.6%-83.6% |
| Hood County - TX | SN | SN | SN | SN |
| Johnson County - TX | 22 | 16 | 73.8% | 47.0%-89.9% |
| Parker County - TX | 24 | 16 | 70.5% | 44.1%-87.9% |
| Tarrant County - TX | 189 | 153 | 81.3% | 72.7%-87.6% |

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 Greater Fort Worth 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 don't include children. They're 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 Greater Fort Worth Service Area | 79.9 % | 14.3 % | 1.0 % | 4.8 % | 75.5 % | 24.5 % | 43.3 % | 28.8 % | 11.0 % |
| Hood County - TX | 97.2 % | 0.9 % | 0.9 % | 1.0 % | 90.0 % | 10.0 % | 59.1 % | 46.9 % | 23.3 % |
| Johnson County - TX | 94.4 % | 3.1 % | 1.1 % | 1.4 % | 82.1 % | 17.9 % | 46.5 % | 32.4 % | 13.0 % |
| Parker County - TX | 96.5 % | 1.6 % | 1.0 % | 1.0 % | 89.6 % | 10.4 % | 50.6 % | 35.2 % | 13.5 % |
| Tarrant County - TX | 77.2 % | 16.4 % | 1.0 % | 5.4 % | 73.6 % | 26.4 % | 42.1 % | 27.7 % | 10.3 % |

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 Greater Fort Worth Service Area | 15.9 % | 13.7 % | 31.9 % | 7.6 % | 14.1 % | 6.0 % | 7.7 % | 5.7 % | 21.9 % |
| Hood County - TX | 14.3 % | 11.3 % | 27.9 % | 6.5 % | 5.3 % | 1.2 % | 32.8 % | 0.0 % | 21.0 % |
| Johnson County - TX | 17.9 % | 10.8 % | 33.7 % | 7.1 % | 7.0 % | 2.9 % | 37.9 % | 17.7 % | 24.5 % |
| Parker County - TX | 13.4 % | 10.9 % | 25.5 % | 6.0 % | 4.1 % | 1.4 % | 56.1 % | 0.0 % | 19.8 % |
| Tarrant County - TX | 16.0 % | 14.2 % | 32.4 % | 7.8 % | 15.6 % | 6.7 % | 1.3 % | 5.2 % | 21.8 % |

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 Greater Fort Worth service area has a slightly larger White female population than the US as a whole, a slightly larger 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 slightly younger than that of the US as a whole. The Affiliate's education level is slightly lower than and income level is slightly higher than those of the US as a whole. There is 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 is a substantially smaller percentage of people living in rural areas, a substantially larger percentage of people without health insurance, and a substantially smaller percentage of people living in medically underserved areas.

The following county has substantially older female population percentages than that of the Affiliate service area as a whole:

- Hood 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: 20.6 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 Greater Fort Worth 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 | | | | |
|---|---|---|---|---|---|---|
| **Time to Achieve Death Rate Reduction Target** | | 13 years or longer | 7-12 yrs. | 0 – 6 yrs. | Currently meets target | Unknown |
| | 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 Greater Fort Worth 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 |
|---|---|---|---|---|
| Johnson County - TX | Highest | 13 years or longer | 13 years or longer | Rural, medically underserved |
| Parker County - TX | Highest | 13 years or longer | 13 years or longer | Rural |
| Tarrant County - TX | Medium Low | 1 year | 1 year | |
| Hood County - TX | Lowest | Currently meets target | Currently meets target | Older, rural |

NA – data not available.
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.

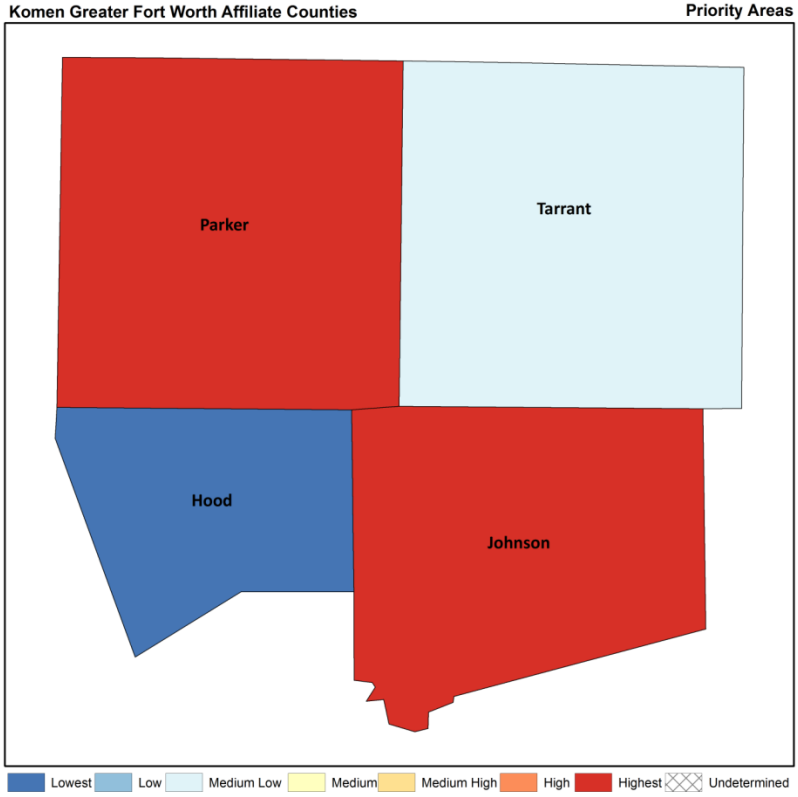


**Figure 2.1.** Intervention priorities

**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***

Two counties in the Komen Greater Fort Worth service area are in the highest priority category. Both of the two, Johnson County and Parker County, are not likely to meet either the death rate or late-stage incidence rate HP2020 targets.

The incidence rates in Parker County (130.6 per 100,000) appear to be higher than the Affiliate service area as a whole (122.3 per 100,000) although not significantly. The death rates in both Johnson County (26.4 per 100,000) and Parker County (26.6 per 100,000) appear to be higher than the Affiliate service area as a whole (21.7 per 100,000) although not significantly. The late-stage incidence trends in Parker County (7.2 percent per year) indicate that late-stage incidence rates may be increasing. Screening percentages in Parker County (70.0 percent) appear to be lower than the Affiliate service area as a whole (79.0 percent) although not significantly.

***Medium low priority areas***

One county in the Komen Greater Fort Worth service area is in the medium low priority category. Tarrant County is expected to take one year to reach both the death rate and late-stage incidence rate HP2020 targets.

The incidence rates in Tarrant County (122.9 per 100,000) are similar to those of the Affiliate service area but are higher than the rates in the State of Texas as a whole (114.4 per 100,000).

## Selection of Target Communities

Quantitative data collection and analysis are the first steps in the Community Profile process. Conclusions based on these analyses serve to guide the health system and public policy analysis and qualitative data collection. Based on the Quantitative Data Report provided by Komen Headquarters, Komen Greater Fort Worth has chosen to focus on one target community consisting of Parker County and Johnson County. Parker and Johnson Counties are combined into one target community because they share similar characteristics: both are largely rural, have similar demographics, and border Tarrant County, where the majority of breast health services in the Affiliate's service area are found. This target community, consisting of Parker and Johnson Counties, will be the focus of the Affiliate's strategic efforts over the next four years.

### Parker County

Parker County, with a population of 116,927, lies in the western portion of the Affiliate's service area. In a largely rural area, Weatherford, with a population of 25,250 as reflected in the 2010 census, serves as the county's seat. Parker County was chosen as a target community based on the data provided in the Quantitative Data Report.

Compared to the whole of the Affiliate service area and Texas, Parker County has the highest age-adjusted incidence rate of breast cancer at 130.6 (Table 2.1). Texas and the Affiliate service area represent incidence rates of 114.4 and 122.3, respectively. In addition, Parker County ranks the highest in death rate (26.6) when compared to the Affiliate service area (21.7) and Texas (21.8) (Table 2.1). Another key statistic is the age-adjusted late-stage diagnosis trend in which Parker ranks second within the Affiliate service area. Definitively, Parker County has the highest increasing trend in the service area for late-stage diagnosis at 7.2 percent.

Compared to all counties in the Affiliate service area, Parker County's women ages 50 to 74 represent the lowest percentage of women who report having a mammogram in the past two years (70.5 percent) compared to the Affiliate service area's average (79.2 percent) (Table 2.3). Parker County is almost exclusively White (96.5 percent) and more than half of the population lives in rural areas (56.1 percent) (Tables 2.4 and 2.5). This is the most rural population in the service area.

In assessing county trends of Healthy People 2020 breast cancer targets, Parker County demonstrates a delay in meeting breast cancer objectives. Healthy People 2020 is a major federal initiative providing specified health objectives aimed at reducing breast cancer death rates and late-stage diagnosis. Trends in Parker County reveal that county rates are not projected to meet the target for breast cancer late-stage incidence rates of 41.0 per 100,000 women (due to the increasing trend) or the breast cancer death rate of 20.6 per 100,000 women. Parker County will require a minimum of 13 years to meet both Healthy People 2020 targets, qualifying this county of highest priority (Table 2.7).

The Health Systems Analysis will evaluate the prevalence of providers and facilities available in this sparsely populated, rural community. While this community is not categorized as medically underserved, it is likely that breast screening resources will be available in more densely populated towns or cities such as Weatherford.

**Johnson County**

Johnson County lies Southwest in the service area with a population of 150,934. The largest populations are found in Cleburne and Burleson. Johnson County was chosen primarily due to its death rate, late-stage diagnosis trend, medically underserved status and Healthy People 2020 status.

When compared to counties in the service area and Texas, Johnson County has the lowest incidence rate. However, the low incidence rate may be due to Johnson County's status as medically underserved, which is probably linked to the low mammography usage rate (73.8 percent). While the incidence rate of breast cancer is comparatively low in Johnson County, Table 2.1 indicates this rate is rising.

Johnson County also experiences higher death rates than those of both the Affiliate area and of Texas. The county is ranked second only to Parker County, as shown in Table 2.1. Within the service area, Johnson County is ranked the second most rural population, with 37.9 percent of the population residing in rural settings (Table 2.5). Although the service area as a whole is likely to meet Healthy People 2020 targets, Johnson County is not expected to meet death rate and late-stage incidence objectives for a minimum of 13 years, causing the county to fall into the classification for highest needs (Table 2.7). Although Johnson County has a decreasing death rate trend (-0.2 percent), the decreasing trend does not reduce the county's death rate of 26.4 per 100,000 women to the HP2020 target of 20.6 by year 2020. While Johnson County's late-stage diagnosis rate (37.5 per 100,000) is lower than the HP2020 rate of 41.0, the county's increasing annual trend (0.8 percent) predicts that the rate will surpass the HP2020 target by year 2020.

Utilizing the Health Systems Analysis, a further exploration of Johnson County's status as medically underserved will be conducted. Currently, 17.7 percent of all residents in Johnson County live in areas considered to be medically underserved (Table 2.5). A study of what resources exist and why it may be difficult to utilize those resources, as well as what gaps in medical services exist, will be undertaken.

## Health Systems Analysis Data Sources

In order to obtain a comprehensive understanding of programs and services data, the Affiliate identified provider organizations by searching on websites such as the FDA's list of mammography centers, Medicare's list of hospitals, the National Association of County and Health Officials list of local health departments, the Health Resources and Services Administration's (HRSA) list of community health centers, and The National Association of Free and Charitable Clinics list of free clinics. The health systems analysis template, provided by Komen Headquarters, was completed for Parker County and Johnson County. Organizations were identified and contacted to inquire about breast health services offered.

## Health Systems Overview

Figure 3.1 shows the Breast Cancer Continuum of Care (CoC), a model that illustrates how a person moves through the health care system for breast care. Ideally, a woman would enter the CoC by getting a clinical breast exam or screening mammogram. If the screening results are negative or benign, the woman goes into the follow-up loop and returns for screening at the recommended interval. If a screening mammogram results in abnormal results, diagnostic exams such as mammograms, breast ultrasounds, or a biopsy may be needed. If breast cancer is diagnosed, the woman proceeds to treatment. Follow up and survivorship may occur simultaneously, and education is critical throughout the entire process. Sometimes there are delays in moving from one point of the continuum to another, and these delays can lead to poorer outcomes. Because of barriers a woman might face, she may not even enter into the CoC. Education can help address barriers such as misinformation, and as a result of breast health education, a woman may be able to proceed through the CoC more quickly.

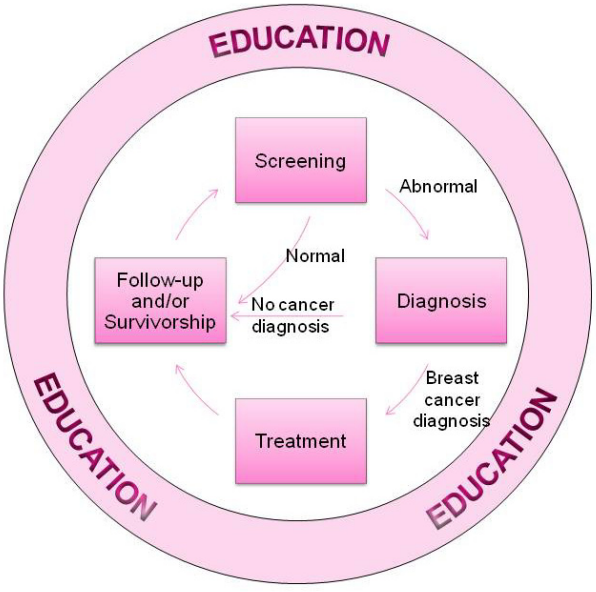


**Figure 3.1.** Breast Cancer Continuum of Care (CoC)

An examination of the Affiliate's target community, consisting of Parker County and Johnson County, reveals health systems strengths and weaknesses. In each county, there are potential new partnerships and collaboration opportunities.

Both Parker and Johnson Counties have hospitals that offer screening and diagnostic mammography, as well as cancer centers that offer oncology services. In both counties, the hospitals and cancer centers are located in the larger cities; individuals living in more rural areas of the counties must travel to the larger cities to obtain services.

**Parker County**

Parker County has a regional medical center, mammography imaging center, a hospital district center that serves as an administration office, and a cancer center (Figure 3.2). The hospital district center does not offer direct services, but it provides routes through which women can access mammography and other breast health services. The cancer center is certified through the Quality Oncology Practice Initiative, which is an oncologist-led, practice-based quality assessment and improvement program. Through these resources, women are able to get screening and diagnostic services, as well as treatment for breast cancer and survivorship support. However, all of these services are located in Weatherford, the county seat; women in more rural areas of the county have to travel to Weatherford to obtain services. The Affiliate has strong relationships with a hospital and cancer institute that serve individuals in Parker County, and in the future, the Affiliate plans to partner with a foundation that provides services for cancer patients in an oncology setting for low-income patients. Additionally, the Affiliate will seek to partner with the cancer center in Weatherford.

**Johnson County**

Johnson County has resources in two cities, Burleson and Cleburne (Figure 3.3). Each city has a hospital that offers screening services. The Cleburne hospital offers diagnostic exams, but the Burleson hospital does not. Each city has a cancer center where breast cancer patients are able to access treatment, including survivorship support. The cancer centers are part of the same group as the cancer center in Parker County; all centers are certified through the Quality Oncology Practice Initiative, which is an oncologist-led, practice-based quality assessment and improvement program. Although there are multiple breast health services offered in Burleson and Cleburne, other parts of the county do not have as many resources, and women in more rural areas of the county have to travel to Burleson and Cleburne to obtain services. The Affiliate has strong relationships with a hospital and cancer institute that serve individuals in Johnson County, and in the future, the Affiliate will seek to partner with the cancer centers in Burleson and Cleburne.

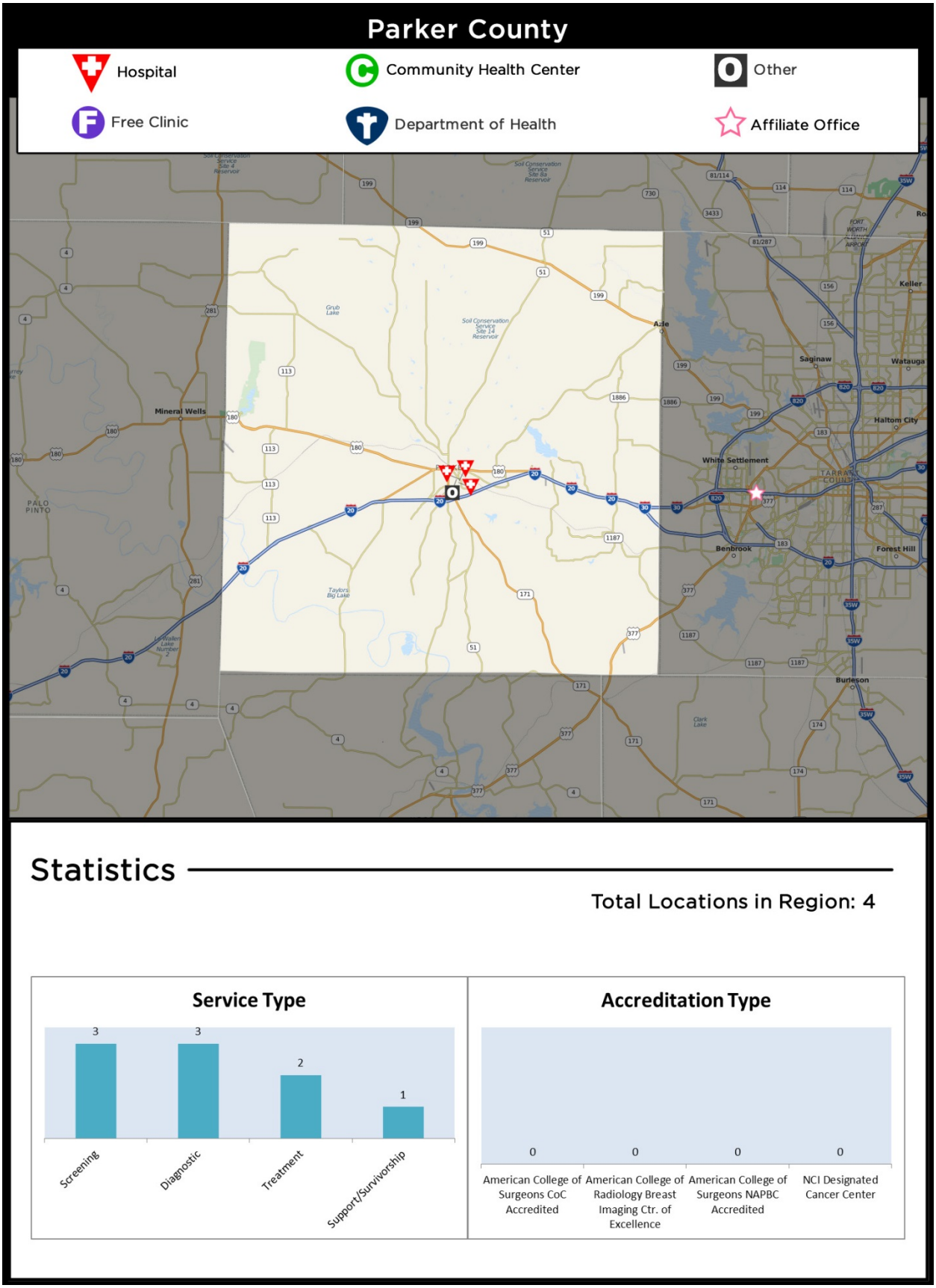


**Figure 3.2.** Breast cancer services available in Parker County

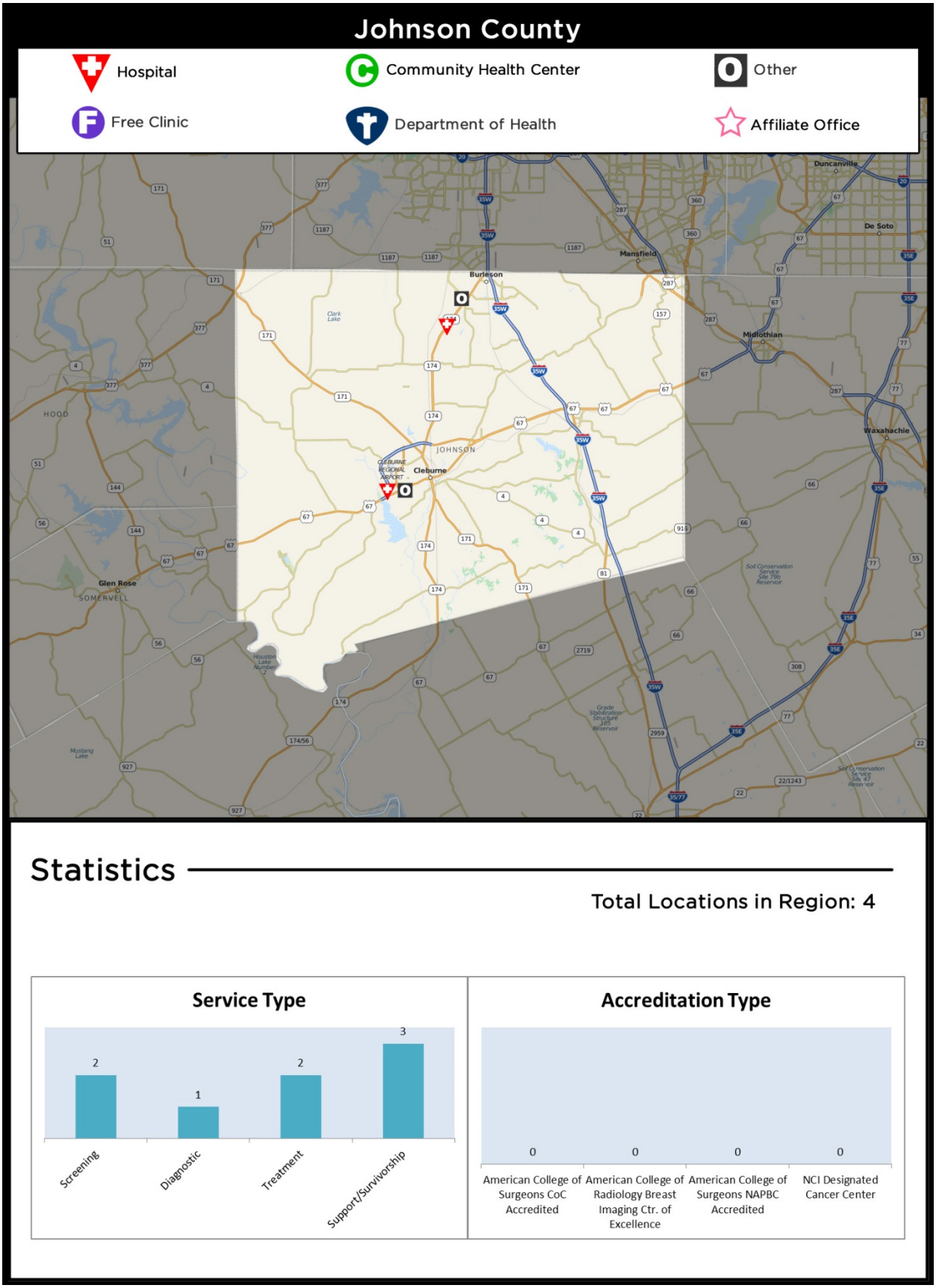


**Figure 3.3.** Breast cancer services available in Johnson County

## Public Policy Overview

The Affiliate works with the Komen Texas Advocacy Collaborative (KTAC), which maintains public policy communications and then reports back to the Texas Affiliates. Komen Greater Fort Worth receives emails from KTAC, and Affiliate staff members plan to attend conference calls and webinars that KTAC may host.

**National Breast and Cervical Cancer Early Detection Program (NBCCEDP)**
The Centers for Disease Control and Prevention (CDC) has a National Breast and Cervical Cancer Early Detection Program (NBCCEDP) that provides access to breast and cervical cancer screening services to underserved women in all 50 states, the District of Columbia, five US territories, and 11 tribes. For over 20 years, the NBCCEDP has provided no-cost and low-cost mammograms and Pap tests to uninsured and underinsured women. The Texas Department of State Health Services (DSHS) Breast and Cervical Cancer Services (BCCS) program helps fund clinic sites across Texas to provide quality, low-cost, and accessible breast and cervical cancer screening and diagnostic services to women.

The state BCCS program is funded by a mix of CDC funds, Title XX to Temporary Assistance for Needy Families (TANF) funds, and State General Revenue. CDC funds are for federal cancer prevention and control programs for state, territorial and tribal organizations. Texas has opted to convert a portion of its Title XX to TANF funds to Social Services Block Grant (Title XX) funds, which can be used for clinical women's health services. State General Revenue consists of state funds allocated by the Texas legislature.

BCCS program 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. 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

*High Priority Populations*

- Breast Cancer: Ages 50-64

BCCS contracted health clinics are the gateway to cancer treatment and determine a woman's eligibility for the Medicaid for Breast and Cervical Cancer (MBCC) program. BCCS contractors are required to: 1) collect the verifying documents for identity, income, and qualifying diagnosis; 2) complete the MBCC application; and 3) send all the documents to DSHS for review of the qualifying diagnosis.

To be eligible for MBCC, a woman must be:

- Diagnosed and in need of treatment for one of the following biopsy-confirmed 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; **and**
- Have family gross income at or below 200 percent of the Federal Poverty Income Guidelines, as defined by BCCS policy (Table at: www.dshs.state.tx.us/bcccs/eligibility.shtm#income); and
- Uninsured, that is, she must not otherwise have creditable coverage (including current enrollment in Medicaid); **and**
- Under age 65; **and**
- A Texas resident; **and**
- A US citizen or qualified alien.

For enrollment, people can contact a BCCS contractor in their area; visit the BCCS Clinic Locator at http://www.dshs.state.tx.us/bccscliniclocator.shtm. 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.

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.

The Collaborative relationship with BCCS is new. Susan G. Komen Headquarters managed the relationship in the past, but with recent advocacy program changes, KTAC is taking over responsibility of communicating and working with the agency to ensure advocacy interests are met.

Advocacy efforts for the next four years include more communication with Breast and Cervical Cancer Services and learning methods by which Komen Greater Fort Worth can be helpful in ensuring BCCS serves more of the working poor. The program currently serves only 6.0 percent of eligible women.

**State Comprehensive Cancer Control Coalition**
The state cancer coalition is the Cancer Alliance of Texas (CAT). The mission of the CAT is to engage organizations, agencies, institutions and individuals to work collaboratively to reduce the impact of cancer in Texas and promote the Texas Cancer Plan (Cancer Alliance of Texas, 2014). To address this issue, the most recent edition of the Texas Cancer Plan was published in 2012. The Plan identifies the challenges and issues that affect Texans and presents a comprehensive set of goals, objectives and strategic actions to inform and guide them in the fight against cancer. One of the goals of the Plan is to increase the proportion of early stage

diagnosis through screening and early detection to reduce deaths from breast cancer. This goal has two objectives:

1. Increase the proportion of women who receive breast cancer screening according to national guidelines.
2. 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 at http://www.canceralliance oftexas.org/storage/texas-cancer-plan2012.pdf .

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 Komen Austin, Dallas County, Houston and North Texas Affiliates, from the Komen Texas Advocacy Collaborative (KTAC), are members of the Cancer Alliance of Texas (CAT)—the state cancer coalition. Member Affiliates share responsibility of attending quarterly calls and updating KTAC on developments. Komen Greater Fort Worth has recently submitted an application to become a member of CAT.

Goals of The Komen Texas Advocacy Collaborative include:

1. Encouraging more Affiliates to become Cancer Alliance of Texas members
2. Integrating cancer policy objectives into the KTAC advocacy agenda.

With budget and staffing limitations, KTAC Affiliates will seek ways to collaborate with other CAT agencies for policy advocacy, especially those working on Medicaid Expansion and issues relating to increased access to care.

**Affordable Care Act**

Texas forfeited its option to run a state insurance exchange. As a result, consumers in the state can choose coverage from a federally run marketplace. Texas did not expand Medicaid coverage for those with incomes up to 133 percent of the poverty level. This would have increased access to health care for about 1,046,430 people in the state (Henry J. Kaiser Family Foundation, 2014b). Medicaid Expansion could also mean an overall increase in economic activity through the addition of federal funds for the program (Missed Opportunities, 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, 2014a). The Affordable Care Act (ACA) insurance mandate for the public went into effect January 2014; its impact on the current uninsured percentage is still being determined.

There has been minimal impact to the BCCS program by the implementation of the ACA as most BCCS clients do not qualify for marketplace subsidies because their incomes are too low.

The impact of health reform for health care providers varies among states, with some exchange plans offering a larger network of providers. Those with lower incomes tend to choose exchange plans with lower premiums, with higher deductibles resulting in problems affording care.

Texas has the highest rate of uninsured people in the nation. According to the Kaiser Family Foundation (2014c), 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, 2014b). Affordable Care Act provisions such as preventive services—including mammograms—without cost sharing, 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 in 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).

More community outreach efforts might be needed to connect the eligible uninsured to insurance access through the marketplace, especially with 31.0 percent of the uninsured reporting never having coverage in their lifetime (Henry J. Kaiser Family Foundation, 2014c).

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. In the meantime, thousands of women will still need breast cancer screening, treatment, education and aftercare services.

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 Affordable Care Act outreach collaborations, Komen might be able to use grant funding more efficiently, by ensuring those without insurance options receive resources.

**Affiliate's Public Policy Activities**

Komen Greater Fort Worth has relationships with local and federal elected officials, and the Mayor of Fort Worth serves on the Affiliate's Advisory Board. The Affiliate has met with elected officials in the past, and the Affiliate's relationships with elected officials may be strengthened through continued individual meetings and phone calls.

KTAC attends conference calls as needed while the Public Policy Committee conducts bi-monthly calls to discuss updates from state health agencies and advocacy organizations. The Committee is responsible for public policy planning and decides KTAC's role for local advocacy. With advocacy program changes at Komen Headquarters, KTAC is assuming more state level advocacy and public policy roles. Komen Greater Fort Worth plans to begin participating in these KTAC activities.

Future goals include working with more cancer and health coalitions to learn about patient issues and to develop Komen's advocacy presence.

## Health Systems and Public Policy Analysis Findings

The health systems analysis reveals that both Parker and Johnson Counties have large areas with no access to screening mammograms, diagnostic exams, and breast cancer treatment services. In order to enter the Continuum of Care, women have to travel to the largest cities in the counties so they can obtain breast health screening and diagnostic services. Potential new partners in Parker County include Weatherford Regional Medical Center and the Center for Cancer and Blood Disorders in Weatherford. Potential new partners in Johnson County include Texas Health hospitals in Burleson and Cleburne, as well as the Center for Cancer and Blood Disorders in Burleson and Cleburne.

The public policy analysis reveals the impact of public policy on breast health. The Texas Breast and Cervical Cancer Services program offers low-income women, ages 18-64, access to screening and diagnostic services for breast and cervical cancer. The overall impact of the Affordable Care Act in Texas on the uninsured will take time to unfold. Thousands of Texas women will still be in need of breast cancer screening, treatment, education and aftercare services. Komen Greater Fort Worth will continue to serve high volumes of uninsured and underserved women through community-based grants and partnerships with local hospitals, cancer centers, and other agencies. The Affiliate will continue working with KTAC and will begin membership with CAT. The Affiliate will also begin strengthening relationships with local elected officials in an effort to promote breast cancer awareness and secure support for Susan G. Komen.

## Qualitative Data Sources and Methodology Overview

### Methodology

Researchers from the University of North Texas Health Science Center (UNTHSC) conducted the qualitative study for the Community Profile. The UNTHSC Office of Research Compliance Institutional Review Board reviewed and approved the study protocol on October 14, 2014. Based on issues raised from the Quantitative Data Report and Health Systems and Public Policy Analysis, Komen staff and UNTHSC researchers sought to find answers to key assessment questions about what factors impact access and utilization of breast health care in Parker and Johnson Counties, what factors serve as barriers to breast health care in these counties, and how to best assist breast cancer survivors. Researchers also asked key questions about breast health outreach and education in Parker and Johnson Counties.

This research consisted of a focus group study and an online survey study. Focus groups were utilized for their ability to elicit detailed responses during discussion, and the online survey was utilized to obtain responses from participants who may otherwise have difficulty attending a focus group or interview. For the focus groups and online survey, participants included breast cancer survivors, breast cancer co-survivors, and health care professionals. These groups were surveyed because of their unique perspectives on breast health care in Parker and Johnson Counties, as well as their ability to offer insight into the key questions assessed by the researchers.

Susan G. Komen Greater Fort Worth staff members recruited focus group and/or survey participants via email and paper flyers, contacting Race for the Cure participants, Komen volunteers, and organizations serving women residing in Parker and Johnson Counties. Focus group participants had to be individuals (both men and women) 18 years or older who work and/or reside in Parker or Johnson Counties. Staff members emailed potential participants up to five times, approximately once per week, and answered all questions from potential study participants. Once a potential participant arrived to a focus group, the consenting process was explained by a UNTHSC research team member, and all subsequent questions addressed by UNTHSC researchers.

The online survey included both quantitative (demographic information) and qualitative questions (access, barriers utilization, and survivorship). The qualitative questions elicit authentic responses from participants because of the anonymity of the online survey.
The focus groups were semi-structured; that is, the UNTHSC interviewer asked specific and general questions (Appendix A), re-phrased questions as needed, and asked probing questions related to the participants' unique circumstances. The semi-structured format promoted engagement and authenticity of responses, by allowing conversation to occur naturally between the interviewer and the respondents. The focus group questions consisted of general and group-specific questions. The general questions were asked in each focus group, whereas the specific questions related to the type of group (i.e., survivors, co-survivors and health care professionals).

**Sampling**

Affiliate staff recruited breast cancer survivors, breast cancer co-survivors, and health care professionals. Breast cancer survivors are individuals who have been diagnosed with breast cancer and are currently in treatment or post-treatment survivorship. Breast cancer co-survivors are individuals who lend support from diagnosis through treatment and beyond; co-survivors include family members, spouses or partners, friends, and colleagues. Health care professionals are individuals whose jobs are health-related, including but not limited to doctors, nurses, and technicians. The researchers conducted six focus groups; three groups in Johnson County and three groups in Parker County (Table 4.1).

**Table 4.1.** Susan G. Komen Greater Fort Worth 2015 assessment: Focus group study

| Date | Location | Group (Number of Participants) |
|---|---|---|
| 12/1/2014 | **Parker County**<br>Weatherford Regional Medical Center | Survivors (4) |
| 12/4/2014 | **Johnson County**<br>Texas Health Huguley | Health care Professionals (8) |
| 12/9/2014 | **Johnson County**<br>Cleburne Community Center | Survivors (3) |
| 1/5/2015 | **Parker County**<br>Weatherford Regional Medical Center | Survivors (3) |
| 1/6/2015 | **Johnson County**<br>Cleburne OBGYN | Health care Professionals (5) |
| 1/8/2015 | **Parker County**<br>Weatherford Regional Medical Center | Co-Survivors (2) |

Focus groups were facilitated by UNTHSC research staff only. A UNTHSC research staff person introduced the study and informed consent process using a script. UNTHSC research staff obtained informed consent prior to commencing the interview. The focus groups were audio recorded. Focus group participants were informed when the audio recording started and stopped. The audio recordings were later transcribed, coded and summarized. No demographic information or any identifiers were collected from the participants during the focus groups.
Using the same study subject recruitment methods as in the focus groups, Affiliate staff members recruited survey participants via email and flyers, contacting Race for the Cure participants, Komen volunteers, and organizations serving women residing in Parker and Johnson Counties. Recruitment was limited to persons (both men and women) 18 years or older who reside and/or work in Parker and Johnson Counties. The targeted study group included breast cancer survivors, breast cancer co-survivors, health care professionals, and women who are in the breast cancer continuum of care.

In the online survey, some respondents did not indicate their county, but the Affiliate is confident that all respondents live and/or work in the target community because the recruitment flyer explicitly stated that participants should reside or work in Parker or Johnson Counties.
The recruitment flyer (paper and email version are identical) identified a hyperlink to the anonymous online Qualtrics survey. The first page of the online survey is the research information sheet. The survey instrument consists of seven demographic questions (closed-ended) and four open-ended questions regarding access, barriers and utilization of breast health care, and support for breast cancer survivors. The characteristics of the survey sample respondents are summarized in Table 4.2.

**Table 4.2.** Susan G. Komen Greater Fort Worth 2015 assessment: Characteristics of 150 online survey respondents

| Sample Characteristic | Number of Respondents | Percent Respondents or Mean (Range) |
|---|---|---|
| **County Affiliation** | | |
| Johnson | 54 | 36 |
| Parker | 50 | 33 |
| Not Specified | 46 | 31 |
| **Respondent Type** | | |
| Survivor | 66 | 44 |
| Co-Survivor | 14 | 9 |
| Health care Provider | 37 | 25 |
| Not Specified | 33 | 22 |
| **Gender** | | |
| Female | 116 | 77 |
| Male | 3 | 2 |
| Not Specified | 31 | 21 |
| **Ethnicity** | | |
| Hispanic/Latina | 10 | 7 |
| Non-Hispanic/Latina | 110 | 73 |
| Not Specified | 30 | 20 |
| **Race** | | |
| White | 111 | 74 |
| Black/African-American | 5 | 3 |
| American Indian | 2 | 1 |
| Not Specified | 32 | 21 |
| **Age (Years)** | 120 | 53 (27-75) |
| | | |
| **Highest Level of Education** | | |
| None | 1 | 1 |
| < High School | 1 | 1 |
| High school or GED | 9 | 6 |
| Some college, no degree | 12 | 8 |
| Associates Degree | 17 | 11 |
| Bachelor's Degree | 13 | 9 |
| Master's Degree | 43 | 29 |
| Professional Degree (MD, JD, etc.) | 20 | 13 |
| Doctoral Degree (PhD, EdD) | 1 | 1 |
| Not Specified | 33 | 22 |

## Ethics

Before beginning the focus group discussion, the UNTHSC interviewer introduced the purpose of the focus group, explained participation, and asked each potential participant if s/he wanted to consent to join the discussion. UNTHSC interviewers followed the prepared script in the Focus Group Discussion Guide. The focus groups were conducted by the UNTHSC evaluation team at locations arranged by Susan G. Komen® Greater Fort Worth in Parker and Johnson Counties. During data collection and analysis, audio recordings and electronic meeting notes were collected and stored on password protected electronic devices (laptop or iPad). UNTHSC research staff transferred these recordings to Dropbox, an online password protected data storage system. Digital recordings, paper and electronic notes taken on iPads or laptops, were secured during transport, transferred to UNTHSC computers, and uploaded. Hard copy or electronic form (CDs, DVDs, digital or magnetic tape, hard-drives, flash-memory drives, etc.) will

continue to be stored and managed in a secure manner following NIH guidelines and according to state and institutional policies and practices. Research documents including electronic documents containing focus group data from subjects and anonymous survey data will be securely stored in locked containers (file cabinets, lockers, drawers, etc.) in accordance with the standard document management practices at UNTHSC.

Only listed key personnel specifically designated and authorized by the Principal Investigator has access to any research-related documents at all times. All such personnel were properly trained and supervised regarding the management and handling of confidential materials. The Principal Investigator assumes full responsibility for such training, supervision, and conduct. Names and other contact information of the participants were not collected (except on the Informed Consent), and therefore will not be included in any of the results or reports of the study, or study transcripts. Audio recordings and summaries of those recordings that are maintained in electronic documents (such as MS Word and Excel) will be kept in secure online Dropbox storage system. The audio recordings will be destroyed by the end of the study, no later than March 31, 2015.

For the survey, after reading the research information, respondents chose whether or not to take the survey. Thus, individuals who wished to participate in the online survey were provided with a research statement to review in lieu of a traditional consent form. No identifiers were collected using the survey tool. Researchers used the anonymous survey option in Qualtrics (no email addresses recorded).

The data from these surveys were collected by the evaluation team at UNTHSC via the Qualtrics online survey tool. Only non-identifying information was collected, stored and used for analysis. Research data, in hard copy or electronic form (flash-memory drives or Dropbox.) continue to be stored and managed in a secure manner following NIH guidelines and according to state and institutional policies and practices. Further, research documents including electronic documents containing subject data (no identifiers or linked data were used in this study) continue to be securely stored in locked containers (file cabinets, lockers, drawers, etc.) in accordance with the standard document management practices. As with the focus groups, only key personnel (listed on IRB application) were specifically designated and authorized by the Principal Investigator to have access to any research-related documents. All such personnel were properly trained and supervised regarding the management and handling of confidential materials. The Principal Investigator assumes full responsibility for such training, supervision, and conduct. All study data continues to be stored using Dropbox, an online password protected data storage system. Names and other contact information of the participants were not collected, and therefore not included in any of the results or reports of the study.

## Qualitative Data Overview

The focus groups were audio recorded, summarized into electronic documents, and coded using three stages of content analysis: open (line-by-line) coding, axial coding (categorical tree structures), and selective coding (thematic analysis).

The quantitative (epidemiologic) data analysis informed the priority areas for the qualitative research that was conducted. Two counties in Komen Greater Fort Worth's service area were identified as high priority areas: Johnson County and Parker County. Based on the

epidemiologic findings, there was evidence that these two counties were not likely to meet either the death rate or late-stage incidence rate Healthy People 2020 targets. The qualitative research centered on the experiences of survivors, co-survivors and health care providers in Johnson and Parker Counties. The qualitative research sought to deepen the Affiliate's understanding of the issues individuals in these counties face with regard to breast health care access, barriers to utilization, as well as the identification of geographic, racial, ethnic, cultural, or linguistic groups in these counties that may not get needed services. The qualitative research also sought to identify types of outreach and breast health education available in each of these counties, as well as what is needed.

Researchers collected qualitative data collection for the two studies: (1) key informant interviewing through six focus groups with survivors, co-survivors and health care providers (focus group study); and (2) Qualtrics online survey (survey study). The original qualitative data consisted of verbatim audio recordings transcribed into text documents (focus group study), interviewer notes and flip chart pages (focus group study), online Qualtrics de-identified survey data, exported as Excel and SPSS data files (survey study).

Survey demographic characteristics were reported using descriptive statistics. The responses to open-ended questions in both the focus groups and in the survey were coded and analyzed for themes. The thematic analysis was conducted separately for the focus group study and the survey study.

Researchers followed a protocol for the data management and analyses of the qualitative data from the focus group study and the survey study. First, researchers created verbatim text files of all respondent information. Next, researchers populated Microsoft Excel worksheets with individual "ideas" or "thoughts." From the focus groups, researchers identified 157 distinct "ideas" or "thoughts" from the 10 survivors, and 177 distinct "ideas" or "thoughts" from the 13 health care providers. Because there was only one co-survivor focus group, with only two study participants, researchers did not summarize the co-survivors so as to maintain confidentiality. For the survey study, researchers identified 463 distinct "ideas" or "thoughts" from the 150 respondents (only 104 of the 150 respondents typed responses to the qualitative questions).

The third step of the protocol involved coding the qualitative responses. The first stage of coding involved line-by-line coding of each distinct idea or thought; there were between one and four codes assigned to each response. As a result of open coding, researchers classified the 157 distinct "thoughts" of the 10 survivors (3 focus groups) into 350 coded responses; the 177 distinct "thoughts" of the 13 health care providers (2 focus groups) into 216 coded responses; and the 463 survey participant responses into 876 coded responses. The second stage of coding involved axial coding, in which researchers categorized open codes into axial themes. The final stage of coding involved the identification of themes and patterns among open and axial codes using selective coding. During this stage, researchers distinguished between the identification of needs and concerns, versus proposed solutions. Researchers also used pivot tables to cross-tabulate and aggregate codes across subgroups and counties, and examined variations in perceptions of survivors and health care providers.

**Detailed Analysis of Themes**

Twelve primary themes were selected to (1) correspond to the emergent issues unique to the focus group and survey data sets; and (2) and align with the goals of the Susan G. Komen® Community Profile process. Table 4.3 lists these themes and their descriptions, along with the distribution of coded responses of survivors (three focus groups), health care providers (two focus groups), and survey respondents (150 participants).

It is important to note that these themes only reflect the views of those surveyed (breast cancer survivors, co-survivors, and health care professionals), and cannot be generalized to the general community.

**Table 4.3.** Key themes of responses from focus group and survey respondents

| **Theme** (Axial Code) | **Description** | **Percent of 350 Coded Responses of Survivors** (3 Focus Groups; 10 Participants) | **Percent of 216 Coded Responses of Health care Providers** (2 Focus Groups; 13 Participants) | **Percent of 875 Coded Responses of Survey Respondents** (150 Surveyed) |
|---|---|---|---|---|
| **Communication and Knowledge** | Communication and knowledge codes were assigned to comments about the need for information, education, marketing, better communication, and outreach. | 34 | 36 | 25 |
| **Affordability** | Affordability codes were assigned to comments regarding the cost of services, variations in insurance coverage and copays, general socioeconomic disadvantage, and the need for free or low-cost services. | 6 | 14 | 24 |
| **Survivor Supports** | Survivors support codes were attached to feedback regarding auxiliary services sought or needed by survivors (e.g., prosthetics, wellness activities, nutrition, social support, counseling, etc). | 14 | 2 | 12 |
| **Accessibility** | Accessibility refers to dimensions of services that may be available in the community but are difficult to obtain due to other factors such as scheduling, eligibility requirements, and convenience. | 7 | 5 | 10 |
| **Availability and Location** | Availability and location codes were assigned to comments regarding the lack of certain services in each county, or the location of the desirable facilities and provider expertise. | 5 | 3 | 9 |
| **Personal factors** | Personal factors include respondent comments about fear, denial, motivation, and mental health. | 17 | 13 | 5 |
| **Adequacy** | Adequacy codes were assigned to passages that described services that were available, but perceived as being insufficient in some way or of lesser quality. | 11 | 8 | 4 |
| **Community Resources** | Community Resource codes were assigned to descriptions of existing organizations or programs perceived as being important for breast health. | 6 | 19 | 3 |
| **Service Coordination and Navigation** | Service coordination and navigation codes were assigned to comments regarding the need for health navigation and coordination of care/treatment. | 0 | 0 | 3 |
| **Subpopulations** | Subpopulation codes were assigned to descriptions of groups of people in particular need of services, outreach or education. These included racial/ethnic groups and age groups. | 0 | 0 | 3 |
| **No Problems or Concerns** | In some instances, respondents mentioned a lack of concern or perceived problems in the county. | 0 | 0 | 2 |

***Communication and Knowledge***

Communication and knowledge development was a primary focus of feedback obtained from focus group and survey participants. This theme addressed the key questions of access, utilization, and barriers to breast health care. While many respondents simply identified the need for basic "education," others stressed the importance of making the link between early detection and survival, advertising screening and treatment services, and raising general awareness of breast cancer and its impacts. Understanding the needs of breast cancer survivors was also perceived as important, particularly for health care providers and co-surviving family members. The targets of potential educational, awareness and outreach efforts included the general community, health care providers, and underserved populations such as those living in poverty, the uninsured and those experiencing language barriers. Figure 4.1 summarizes these key issues and Appendix Tables B.1 and B.2 include respondents' quotes associated with communication and knowledge.

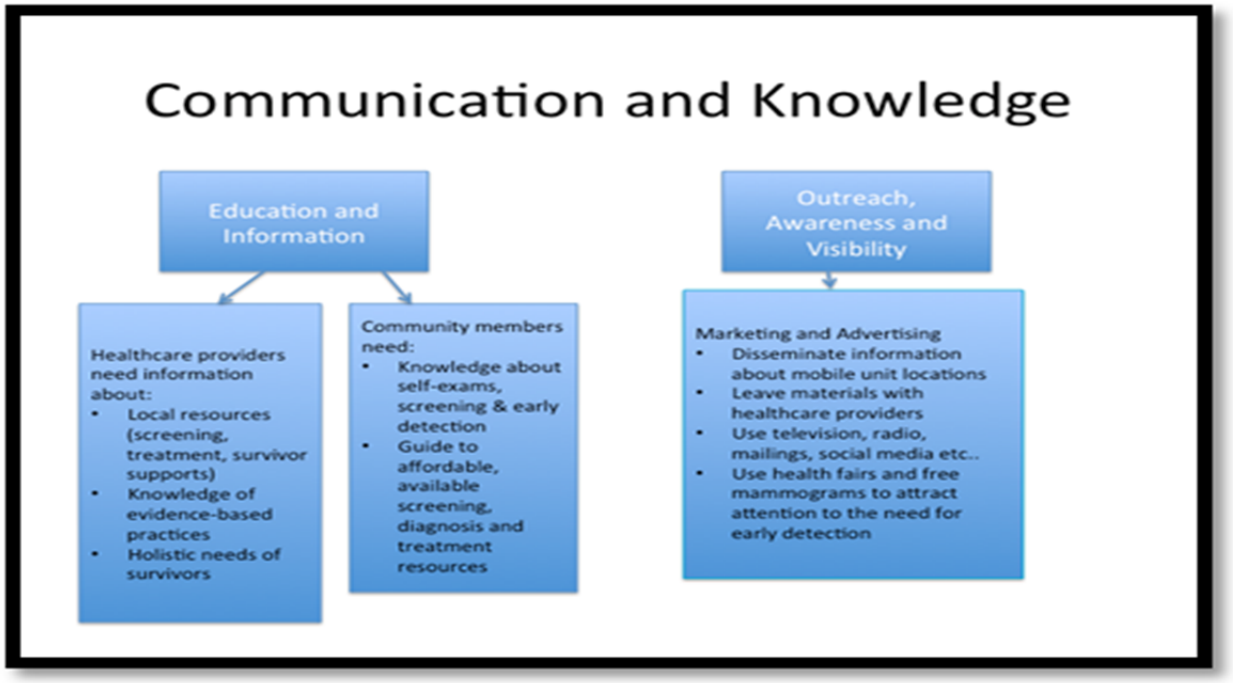


**Figure 4.1.** Dimensions of the communication and knowledge theme

***Affordability***

The affordability theme, which addressed the key question of barriers to breast health care, was split between two primary dimensions. The first addressed insurance coverage, lack of insurance and being uninsured. Some respondents mentioned barriers associated with high copays/fees and challenges in finding health care providers in their region who are covered by their insurance plan.

*"Cancer drains your bank account."*
*– Parker County Survivor*

The second dimension of affordability addressed the general issue of local poverty and socioeconomic disadvantage. The life struggles faced by people in poverty (e.g., obtaining basic needs such as food) were perceived to reduce the likelihood that they will participate in

preventive health care. These comments sometimes included discussion of the cost of transportation in addition to the cost of screening, diagnostic and treatment care. Often mentioned in conjunction with lack of coverage was the fear of what the costs may be incurred in the future. Figure 4.2 summarizes these key issues.

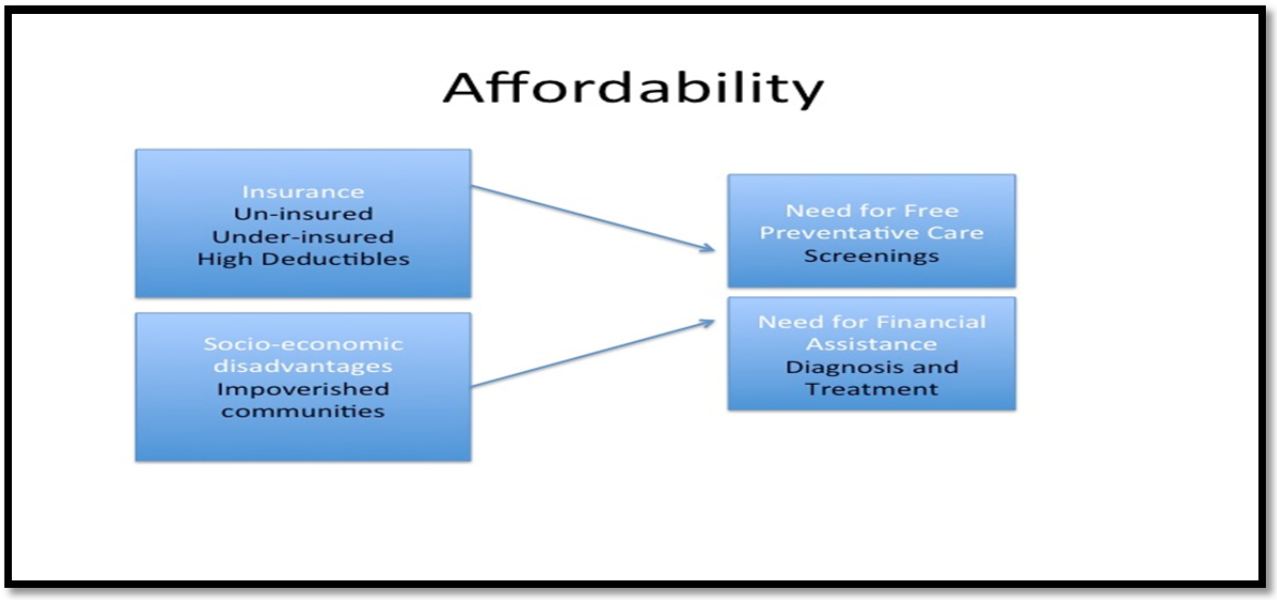


**Figure 4.2.** Dimensions of the affordability theme

***Survivor Supports***

The most rich and detailed data gathered from the online key informant survey were associated with survivor supports. This theme addressed the key question of methods to best identify and assist breast cancer survivors. In these passages, survivors, co-survivors and health care professionals shared their perceptions about what survivors need and how to meet these needs. Subthemes associated with survivor supports include:

- The need for support groups (comprising 24.0 percent of this theme);
- The importance of holistic services (health, nutrition, wellness, mental health, social support, navigation, prosthetics, etc.);
- The need for coordination treatment and aftercare services with physicians;
- Supportive services and involvement of caregivers; and
- Better preparation for the post-treatment health concerns and physical effects of treatment.

*"We need after care services: to handle related issues after treatment: nutrition, exercise, lymphatic issues, fear of recurrence, recurrence."*

*"We also need a way to give back to newly diagnosed."*
*- Parker County Survivor*

Focus group survivors echoed these themes and also touched on the importance of services that deal directly with the health effects of cancer treatment, as well as doctors who understand what it is like to be a cancer survivor.

*"There's just a lot of things going on because of the chemo, which they don't tell you. You know, they put the chemo in your body and this is gonna kill the cancer but it's also gonna destroy this and maybe cause other cancers."*

*– Parker County Survivor*

Co-survivors spoke of needing support groups specific to caregivers and loved ones. Figure 4.3 summarizes these key issues.


**Figure 4.3.** Dimensions of the social supports theme

***Accessibility***

If a particular service, such as screening, was perceived to be available in the community but difficult to access due to other factors, it was assigned to the theme of accessibility, which was one of the key questions. The majority of comments associated with accessibility related to scheduling (i.e., need for Saturday screenings), lack of time (e.g., being busy and having parental/work obligations), convenience, lack of public or other transportation, and the combination thereof (time and resources needed to travel through rural areas). The remaining accessibility codes included suggestions for mobile services.

*"The area where I work has very few health resources even though we do have a JPS clinic available. Many of the families also have one car, which prevents them from going to the doctor during the day."*

*– Survivor*

***Availability and Location***

Closely related to the key question of accessibility is availability and location. Numerous individuals mentioned obtaining care, particular treatment, in Metroplex cities such as Fort Worth, Arlington and Dallas. While some respondents appeared to perceive this distance as acceptable, others perceived it as a barrier. Numerous respondents simply listed "location" as a barrier or factor affecting access to breast health care. Of the survivors who participated in the focus groups, 60.0 percent received their care in either Tarrant or Dallas Counties.

*"There is a travel barrier because most of the treatments are in Fort Worth or the Mid-Cities."*

*– Parker County Survivor*

***Personal factors***

Personal factors perceived as affecting access to breast health care included fear, denial and motivation – these factors were related to the key question of barriers to breast health care. Dimensions of fear included fear of pain during the procedures as well as fear of being diagnosed with cancer. Knowing someone with breast cancer was perceived as increasing motivation to get screened and/or treated.

*"In the past, I have known women who put off getting mammograms either because of fear of pain during the process, fear of possible "bad news," denial, and cost."*

*- Johnson County Health Care Provider*

***Adequacy***

Survivors in both Johnson and Parker Counties mentioned perceived quality of care, which addresses the key question of utilization of care. Several commented that they chose to travel outside of their county because they perceived physicians and other health services to be better in the metroplex. Another dimension of adequacy related to the perceived compassion, or lack thereof, exhibited by physicians. Figure 4.4 displays the overlapping relationships between health care adequacy, accessibility and availability.

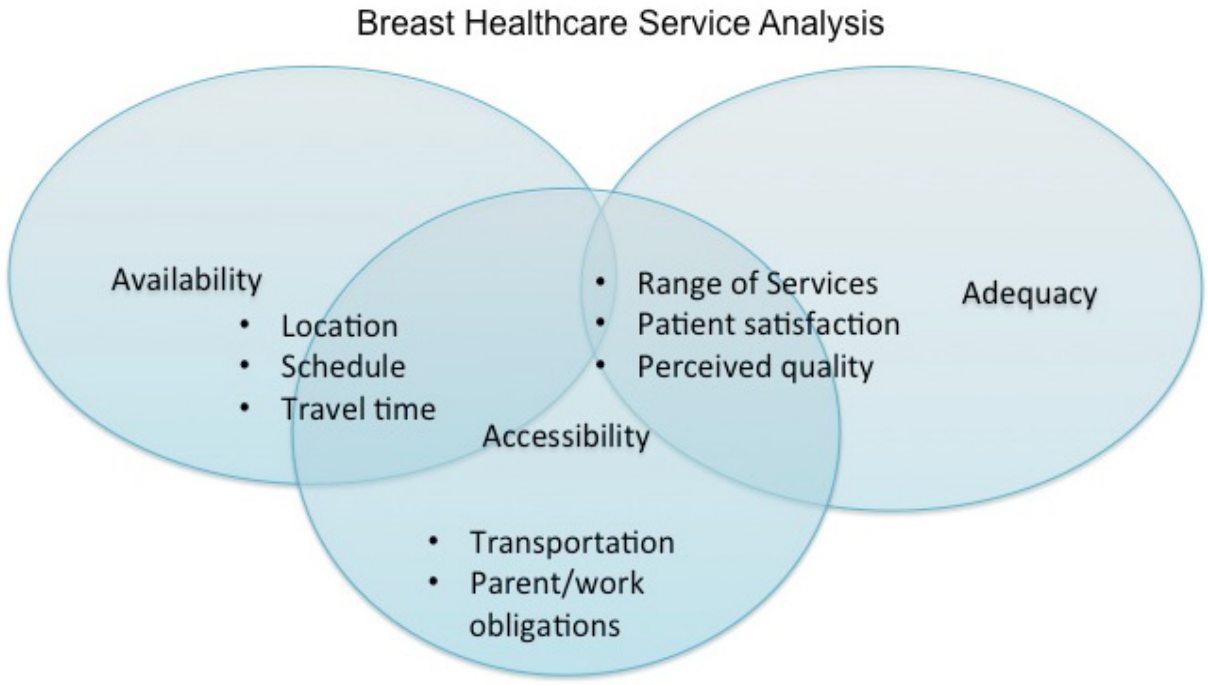


**Figure 4.4.** Overlapping Dimensions of Availability, Access and Adequacy of Breast Health care Services

***Community Resources***

Several community resources were identified as being valuable or promising to promote breast health care in Johnson and Parker Counties. These included suggestions to maximizing the networks of church attenders, the value of Pink Sunday programs, and the utility of services such as 211, and other cancer-specific programs/organizations. These community resources are linked to access and utilization of care.

> *"I think partnering with faith community organizations can fill in the gaps when it comes to prevention of health. Offering screenings in conjunction with faith communities in the rural settings seem to bring a lot more people in to these offerings."*
>
> *– Parker County Health Care Provider*

***Service Coordination and Navigation***

Both survivors and health care professionals in Parker and Johnson Counties mentioned the importance of offering health navigation services and coordination of care, which addresses all factors related to the key questions: access, utilization, barriers, and survivorship. The process of transitioning from screening and diagnosis through treatment is complex and can be made less stressful with the support of a navigator.

> *"I was sent to get a mammogram by my gynecologist and then was told I needed a biopsy which was done by someone I didn't know. After I was diagnosed I didn't know where to go or what the diagnosis meant. The facility that did the biopsy/mammogram just told me to ask my gynecologist what to do. I wish there was a better way to handle that. I wish I'd been assigned a navigator who would have helped me with questions and helped me know where I could turn, etc."*
>
> *- Parker County Survivor*

***Subpopulations***

Numerous respondents mentioned populations who are in particular need of outreach, education, screening and other health care services. These include cultural groups (Black/African-American and Hispanic/Latino), women under the age of 40 who may have other risk factors, and non-English speaking immigrants.

> *"I believe we need more education for our minority population. The numbers of Hispanics or Black ladies who come in for mammograms is noticeably less."*
>
> *- Johnson County Health Care Professional*

***No Problems or Concerns***

A small group of respondents expressed their belief that either no barriers or problems regarding breast health care exist in their region, or that they had excellent experiences with their own breast cancer treatment.

> *"Didn't have any barriers. I had a very pleasant experience, as pleasant as this experience could possibly be, and can't think of anything that could have been done differently."*
>
> *– Parker County Survivor*

The free online word analysis program, *Wordle*, was used to examine all of the responses written in the online key informant survey. The Affiliate used the response frequencies to produce a graphic image (Figure 2.5) with the larger words representing those that were used the most. Many of these words reflect the themes that have been identified, such as cost, insurance, services, information and support.


**Figure 2.5.** *Wordle* Diagram of Online Survey Responses

## Qualitative Data Findings

The aim of the qualitative data collection was threefold: (1) ensure community input through a learning experience and relationship-building process; (2) capture community members' insights with greater depth and specificity about the situation and context for breast health care in target regions than feasible using quantitative methods; and (3) identify patterns, themes and stories that demonstrate a synergy with the epidemiologic (quantitative) and health systems analyses conducted as part of the Community Profile.

The qualitative study accomplished each of these dimensions. The focus groups were lively and engaging. Participants shared stories and insights, built on one another's comments and shared a sense of common purpose. The quotes (Appendix B) illustrate the genuine, open and thoughtful engagement of the focus group participants. Similarly, the number of online survey responses was high (150 responses), particularly given the short time frame (less than one month) of advertising and collecting survey data.

The researchers conducted the qualitative focus group study and survey study in accord with the 2015 Community Profile process as detailed in the Susan G. Komen® Community Profile

Guidebook (October 2013), Module 4: Qualitative Data: Ensuring the Community Input. The researchers used open-ended questions (Appendix A) for both the focus group and survey studies.

The qualitative data collection findings are linked to the key questions formed after the analysis of the Quantitative Data Report and Health Systems and Public Policy Analysis. The findings relate to the questions of access and utilization of breast health care, barriers to health care, and survivorship support.

There are three primary limitations of the qualitative data collection: (1) the small number of focus groups and participants in the focus groups; (2) the use of broad open-ended questions in an online survey; (3) only the perspectives of breast cancer survivors, co-survivors, and health care professionals were collected, and therefore the data cannot be generalized to the target community as a whole.

Using open-ended questions likely explains the high rate of respondents who did not answer all questions and/or only answered the closed-ended demographic questions. Further, the open-ended survey questions were broadly stated, often resulting in answers that were generic (e.g., lack of adequate insurance and high costs) rather than specific (e.g., it was too expensive for me to continue with COBRA when I needed to quit my job during my treatment).

An additional limitation is that there may have been duplication of individuals who completed the online survey and individuals who participated in focus groups; that is, some people may have completed the survey as well as participated in a focus group.

Overall, the qualitative data revealed that increased communication and knowledge is needed, affordability of care is an issue, various forms of survivor support are needed, lack of desirable and adequate facilities is an issue, there is a need for service coordination and patient navigation, and several subpopulations are in particular need of services, outreach, and education; these subpopulations include uninsured individuals and minority racial/ethnic groups.

**Breast Health and Breast Cancer Findings of the Target Communities**

Findings from the Quantitative Data Report shed light on the state of breast health in the Affiliate's service area. The Quantitative Data report revealed that both Parker and Johnson Counties will be delayed in meeting Healthy People 2020 breast cancer targets. Compared to the State of Texas and the rest of the Affiliate service area, Parker County has the highest age-adjusted incidence rate of breast cancer. Additionally, out of all four counties in the service area, Parker County ranks highest in death rates from breast cancer and has the highest increasing trend for late-stage diagnosis. Parker County has the most rural population out of all the counties in the service area, as well as the lowest percentage of women who report having a mammogram in the past two years. Like Parker County, Johnson County is also projected to be delayed in meeting Healthy People 2020 breast cancer targets. While Johnson County has the lowest breast cancer incidence rate in the service area, it experiences a higher death rate than the overall Affiliate service area, second only to Parker County. Furthermore, Johnson County is classified as being medically underserved. Due to these quantitative findings, the Affiliate chose to focus on Parker and Johnson Counties. The counties are combined into one target community because they share similar characteristics: both are largely rural, have similar demographics, and border Tarrant County, where the majority of breast health services in the Affiliate's service area are found.

After selecting the target community consisting of Parker County and Johnson County, the Affiliate conducted the Health Systems and Public Policy Analysis. Through the Health Systems Analysis, the Affiliate learned that Parker County has a regional medical center, mammography imaging center, a hospital district center that serves as an administration office, and a cancer center. However, most services are located in Weatherford, the county seat; individuals who live in more rural areas of Parker County often have to travel to larger cities in order to obtain services. The Health Systems Analysis showed that Johnson County's resources are primarily in the cities of Burleson and Cleburne. As with Parker County, individuals who live in more rural areas of Johnson County often have to travel long distances to obtain services in these larger towns.

Examining the quantitative and health systems analysis findings led the Affiliate to ask several questions about the target communities: What factors impact access to breast health care? What are the barriers to care and how can they be decreased? What factors impact utilization of breast health care? How can the Affiliate identify the best ways to assist breast cancer survivors? What obstacles are encountered by breast cancer co-survivors? What types of outreach and breast health education are taking place in each target community? How can more women enter in and progress through the continuum of care? To seek answers to all these questions, the Affiliate used an online qualitative survey and focus groups.

Three focus groups were conducted in Parker County, three focus groups in Johnson County, and 150 individuals participated in the online survey. Several key themes were identified through qualitative data analysis. Participants made comments about the need for information, education, marketing, and improved communication and outreach. Many participants indicated that affordability of care is a barrier, especially for those without insurance. Accessibility of services was also identified as a barrier, with participants indicating that services may be difficult

to obtain because of scheduling, travel requirements, and location. Many participants identified survivor needs such as wellness activities, nutrition, and social support. They also indicated that the need for social support also extends to co-survivors. Some participants expressed that services in the target communities are available but not deemed to be adequate, and some individuals preferred to travel to other counties for services. Several subpopulations were identified as needing extra navigation support, such as non-English-speaking populations and uninsured residents.

Together, the findings from the Quantitative Data Report, Health Systems and Public Policy Analysis, and Qualitative Data revealed several areas of need that the Affiliate may address.

## Mission Action Plan

The Affiliate identified three main need statements for the target communities and developed corresponding priorities and objectives to address the identified problems.

Need statement: As indicated in the Quantitative Data Report, Parker and Johnson Counties have higher breast cancer death rates than the rest of the Affiliate service area and the State of Texas, and are projected to be delayed in meeting Healthy People 2020 breast cancer targets.

Priority 1: Increase potential availability and access to breast health services for individuals in Parker and Johnson Counties.

Objective 1.1: By November 2015, Community Grant RFA will include programs that provide mammograms and treatment services in Parker and Johnson Counties as a funding priority.

Objective 1.2: By November 2015, hold at least one grantwriting workshop targeting organizations that serve individuals in Parker County to encourage grant applications.

Objective 1.3: By November 2016, hold at least one grantwriting workshop targeting organizations that serve individuals in Johnson County to encourage grant applications.

Need statement: Residents in Parker and Johnson Counties indicated that individuals sometimes have to travel long distances to obtain services, which may delay care.

Priority 2: Increase potential availability and access to transportation assistance for individuals in Parker and Johnson Counties to obtain breast health services.

Objective 2.1: By December 2015, participate in at least one meeting to discuss transportation initiatives in Parker and Johnson Counties.

Objective 2.2: By December 2017, apply for at least one grant that addresses transportation issues in Parker and Johnson Counties.

Need statement: In Parker and Johnson Counties, residents indicated there is a need to develop partnerships to improve community outreach and collaboration.

Priority 3: Increase community outreach and breast health partnerships in Parker and Johnson Counties.

Objective 3.1: By December 2016, participate in or host at least one educational health event in Parker County.

Objective 3.2: By December 2016, participate in or host at least one educational health event in Johnson County.

Objective 3.3: By December 2017, meet with at least two organizations or providers in Parker County to form partnerships and explore how to reach rural residents to provide breast health education and increase awareness.

Objective 3.4: By December 2018, meet with at least two organizations or providers in Johnson County to form partnerships and explore how to reach rural residents to provide breast health education and increase awareness.

Objective 3.5: By December 2018, meet with at least two legislators or government officials who serve Parker and Johnson Counties to discuss public policy and Komen's breast health priorities.

Need statement: Focus group and survey participants indicated that there are several subpopulations in Parker and Johnson Counties need increased access to breast cancer education and services. These subpopulations include non-English-speaking residents and uninsured individuals.

Priority 4: Increase access to culturally competent breast health education among non-English-speaking residents in Parker and Johnson Counties.

Objective 4.1: By December 2016, participate in at least one health education event that reaches non-English speaking residents in Parker County.

Objective 4.2: By December 2017, participate in at least one health education event that reaches non-English speaking residents in Johnson County.

Priority 5: Increase access to breast health services for uninsured individuals in Parker and Johnson Counties.

Objective 5.1: By December 2018, participate in at least three health events which target attendees who are uninsured or underserved in Parker and Johnson Counties to increase awareness of available no-cost and reduced cost services.

Objective 5.2: By December 2017, meet with at least one elected State of Texas official to advocate for Medicaid Expansion and/or continued funding of the Breast and Cervical Cancer Services program which would increase access to services for uninsured individuals.

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# Appendices

**Appendix A.** Focus group questions

**General Questions (all survivor, co-survivor, and health care professional groups)**

1. **Access to care:** What factors impact access to breast health care in the county?
   What factors impact the affordability of care in the county?
   How far are people willing to travel for health care services?
2. **Barriers:** What are barriers to breast health care in the county?
   What can be done differently in your county to make sure that breast health messages and services get to the women that need them?
3. **Utilization of care:** What factors impact utilization of breast health care?
   Why are women not following recommended screening guidelines?
   Why is the rate of late-stage diagnosis high?
   Why might community members have negative feelings towards the health care system?
   What motivates women to seek breast screening services?
   What can local providers do to encourage women to seek breast health services?
   How would you describe the women in your community who are least likely to be getting regular breast cancer screening?
4. **Survivorship:** How do we identify the best ways to assist breast cancer survivors?
   How do we identify survivors?
   How do we identify what services survivors need?
   How do we educate providers about the needs of survivors?

**Specific Questions**

***Survivors***

1. What barriers did you experience when getting your mammogram, diagnosis, treatment, and/or follow-up care?
   Did anything get in the way of receiving your diagnosis?
   What support or assistance do you wish had been available to you when going through treatment?
   What information, support, or resources have been lacking during your survivorship years?

***Co-survivors***

1. What obstacles did you encounter as your loved one progressed through treatment?
   What support or assistance do you wish had been available for your loved one when going through treatment?

***Health Care Professionals***

1. **Access and utilization:** What issues do patients in your county face with regard to access and utilization of care?
   Are there certain types of patients that have problems accessing services at your organization?
   Are there specific racial, ethnic, cultural, or linguistic groups in the county that you believe do not get the services they need?
   Are there geographical areas where women are not getting the services they need?
2. **Outreach and education:** What types of outreach and breast health education are taking place in the county?
   Do you think that current outreach attempts are encouraging people to get screened? Why or why not?
   In your experience, what is the most effective way to educate women in your community about breast health issues?
3. **Continuum of care:** How can more women enter in and progress through the continuum of care?
   What new services, programs, and policies are needed in your area to deliver breast health services?

**Appendix B.** Selected quotes

| Table B.1. Selected Quotes Exemplifying Axial Themes from the Online Survey | | |
|---|---|---|
| **Location** | **Type of Respondent** | **Quotation *(slightly edited for spelling)*** |
| **Communication and Knowledge - Outreach, Awareness and Visibility** | | |
| **Parker** | **Survivor** | I've used the mobile mammography unit before; however I found out it was going to be in my community by accident. I don't think that the word gets out very well. |
| **Parker** | **Survivor** | We need to somehow, get the word out that there is funding for mammograms for the insured and even help if diagnosed. All doctors' offices ought to furnish info on free mammograms and maybe even a billboard on South Main. |
| **Parker** | **HCP** | There are always pockets of individuals that fall through the cracks of health care. I do not believe that there is a tried and true answer for these individuals, but I do believe reaching out to the community liaison and leaders would pave the way for some individuals seeking/needing screening services to find them. Most often the resources are available but unknown or feared within a given community. |
| **Johnson** | **Co-Survivor** | I know it can be very emotional. There needs to be more awareness of this illness. It not only changes the person's life but also the life of family members. |
| **Johnson** | **Survivor** | More advertising, even from smaller organizations like Careity and Athena, etc. |
| **Parker** | **Co-Survivor** | The best doctor I met who understood what a cancer survivor goes through was a cancer survivor. Does that mean all providers should have cancer, no... But it does mean that providers need to look beyond the disease and see the person. A provider should not get their feelings hurt when a survivor sees the aftermath of their mastectomy for the first time, or even the hundredth time. It is a devastating moment in a person's life. |
| **Johnson** | **Survivor** | Facts of early discovery and treatment, need to be on posters, and other promotional materials. |
| **Johnson** | **Survivor** | Women need to be informed how important mammograms are and that it is important also to do self exams and HOW to do self exams because many people including myself found their "lump" themselves. I passed out info from Komen on Pink Sunday at my church. |
| **Parker** | **HCP** | I believe that women are not educated enough on the need for routine breast screenings and the overall success rate if treatment is needed. / I believe more community outreach with survivors giving testimonies, medical provider outreach and education, and overall blanket marketing would reach individuals that otherwise hide their heads in the sand regarding medical screenings until it is too late. |
| **Johnson** | **Co-Survivor** | Although it has become more common to speak about, there still is more to be done in getting the message out to the public regarding the need to have regular check-ups in order to be on top of anything that might arise. |
| **Parker** | **Co-Survivor** | Not enough information and being talked to like an idiot when asking questions. Dumb it down a little for those who don't have a medical degree. |

| Affordability | | |
|---|---|---|
| **Johnson** | **Co-Survivor** | Cost would be the greatest impact. Insurance companies are not providing mammograms unless you have a problem or if you have a family history. Age 50 is too long to wait. |
| **Parker** | **HCP** | Cost of services and the funding for financial assistance only goes to those hardly making anything. |
| **Parker** | **HCP** | For most with no insurance is the cost of things. What good does it do to get a mammogram and find something but you can't afford treatment so why find something out. |
| **Parker** | **HCP** | People either do not qualify because they are out of the particular county and/or they are middle class who make too much money to qualify for free or reduced price even though they don't really make a lot of money. For those that are on fixed incomes, the once a year screenings offered in rural areas are not as often or accessible to them even though they may qualify. Also, for any provider it would be very beneficial to have a contact person at the breast health arena to find out regularly what programs are offered so they can plan accordingly to refer their unfunded patients to the screening during those times. I think there is a lack of communication as to what is available in the rural areas. |
| **Parker** | **HCP** | I understand that health care costs money, without it no doctor could continue to practice, but for the ones that do not have insurance and barely survive, added cost are too much. Careity does an awesome job of helping the women of Parker County in these areas. |
| **Johnson** | **Survivor** | My greatest barrier was money. |
| **Parker** | **HCP** | In my opinion, it boils down to whether or not you have money/insurance. If you have insurance, the doors are wide open but without insurance you don't make it through the doors without a HUGE down payment. Most women know they have a problem but without funds, they won't do anything. The local doctors do encourage women of age to get the necessary screenings. I get my mammogram done because I know I need it, but I've always had insurance. The uninsured are not going to get it done. |
| **Parker** | **Co-Survivor** | Women without insurance are least likely to get regular breast cancer screenings. Providers can make women aware of free services that are available to women without health care insurance. |
| **Parker** | **Survivor** | Being uninsured at the time of diagnosis, the financial burden was the biggest concern. The day I heard I had cancer, I knew I could beat it if I was given a chance, but when I realized I couldn't afford it, I almost gave up. My surgeon found the Medicaid Breast and Cervical Cancer Program and that's what saved my life. I know because of [HIPPA] laws, it's hard for someone else to make phone calls on the patient's behalf seeking assistance but the hardest thing for me was repeating "I've been diagnosed with Breast Cancer and I need help" over and over and over. I am pretty persistent and believe in "You can't get turned down if you don't ask" but asking for help is one of the hardest things I've ever had to do. |
| **Unknown** | **Survivor** | Those without insurance should get a voucher to get a screening. |
| **Johnson** | **Survivor** | These free [mammogram] screening programs are great programs, I work at a facility that benefits from programs like [these], and [the] ladies [who] come in are so grateful, some actually cry, when [they] realize that these programs take care of all that they do. |
| **Johnson** | **Survivor** | I do not know if Johnson County offers free mammograms. If not, |

| | | |
|---|---|---|
| | | this should be available free of charge. |
| **Parker** | **Survivor** | Those least likely to get care are struggling to buy food and pay utilities. |
| | | **Survivor Supports** |
| **Parker** | **Survivor** | During treatment you do not feel like cooking but you need to eat healthy. Help with meals would be great. You need counseling....mentorship with a survivor would help. |
| **Parker** | **Survivor** | We need after care services: to handle related issues after treatment: nutrition, exercise, lymphatic issues, fear of recurrence, recurrence. We also need a way to give back to newly diagnosed. I do this informally all the time. |
| **Johnson** | **Survivor** | Needs of survivors are what to eat, how to identify depression and what to do once it is identified, side effects of the Prolia shot, chemo may be an option and radiation may be something we choose not to have. I would have loved to have prevented lymphedema rather that treating it. And with all the medications provided, it is good to know that you can take all your [prescriptions] to a pharmacy and they will put the list in order. |
| **Johnson** | **Survivor** | I did not experience any barriers. I had excellent health insurance that covered all my expenses. I had moral support from my husband and children. I went to a few of the survivor meetings, found I really did not have the energy to attend, and saw people that were in far worse shape than myself, which was discouraging. I kept wondering if that was the next step for myself. It would have been nice to have a SURVIVOR BUDDY during the recovery/treatment time. Someone trained to say the right things, help me stay focused on the positive side of the treatments, and help me realize they really did understand and care. |
| **Johnson** | **Survivor** | I had a great support system, so I have to answer for my ladies that did not have that, and that would be, they needed more help with the kids, cooking their meals, picking them up and taking back and forth to school, transportation back & forth to the treatments, helping the kids with homework, everyday things. The side effects from these treatments might not show up for a few days after the treatment, and people do not realize that, I have had several ladies tell me that as soon as their help left, that's when the side effects would start, so after discussing this with their support, and making them aware, they would continue to give support until the side effects would come & go..all parties involved needs to communicate |
| **Parker** | **Survivor** | Find local support groups and help them organize in the community. They/we could then get word out of services or help that can be provided. |
| **Johnson** | **Survivor** | I feel we need support, I did not have support from my spouse during or after my treatment. Led to depression and low self-esteem. A site or blog so we can chat or vent to others in the same situation. |
| **Parker** | **Survivor** | No barriers. But would love to have more exercise options for survivors in east Parker County. |
| **Johnson** | **Survivor** | Identifying ways to assist breast cancer survivors depends on the individual. Some need extra support, and others need less. … Every woman has had different diagnosis, surgeries, treatments, medications, so it's individualistic. |
| **Johnson** | **Survivor** | A sponsorship or "buddy" system would have been helpful |
| **Johnson** | **Survivor** | Patient education...didn't know what to expect....during treatment. A |

| | | |
|---|---|---|
| | | sponsorship or "buddy" system would have been helpful |
| **Johnson** | **Survivor** | I wish there was some sort of survivor support system. Chemo induced menopause for me, but I there seems to be nothing I can do to alleviate some of the more problematic effects of menopause since I cannot have any sort of hormone therapy. Also, my body changed…. and sometimes it still doesn't feel or seem right to me. If the center where I received treatment would have survivors take surveys periodically, maybe that would help, but I would love some sort of group meetings of survivors who understand my issues and concerns. |
| **Johnson** | **Co-Survivor** | My mom's doctors were great. Sometimes we needed more information about treatment and the long term side effects she would encounter. I feel like the patients and their families have to do a lot of research on their own and hope that what they find is accurate. There needs to be a better way to get the latest info to people in a timely manner. |
| **Unknown** | **HCP** | Barriers include lack of time, people work and are not always able to get to needed appointments when facilities are open. Screenings are put off until a problem presents itself. This leads to delays in treatment. |
| **Johnson** | **HCP** | Most people are too busy to think about another test they need to have, I would say they only seek a screening when they feel there might be an issue. I would suggest having access to a screening on the same day as your annual exam is scheduled. (2 appointments on the same day) |
| **Johnson** | **HCP** | I think women are so busy taking care of others that they rarely spend time on themselves. |
| **Accessibility – Transportation & Travel** | | |
| **Johnson** | **HCP** | Better transportation services to treatment and low cost health examinations. |
| **Unknown** | **Survivor** | I know there are survivors that may need transportation services to go to doctor appointments, radiation and or chemo treatments. I was lucky and only needed radiation so I could manage my care. However, my daughter needed chemo and she lived in Plano so it was necessary for my husband or I to take off work in order to help her during and after her treatments. I'm sure there are many survivors that don't have that kind of support system. Support systems need to be identified when someone is diagnosed with breast cancer. If there isn't support there, then services need to be identified that could help them. |
| **Parker** | **Survivor** | There is a travel barrier because most of the treatments are in Fort Worth or the Mid-Cities. I am fortunate to work in the mid-cities a little over a mile from treatment facilities. Most patients have to take off a lot of time at work to go to appointments or treatments and they cannot afford that time off. |
| **Availability – Lack of Services** | | |
| **Johnson** | **Survivor** | [There is a] lack of free standing mammography sites. [People] have to go to the hospital or out of town |
| **Johnson** | **Survivor** | I lived in Tarrant County when I was diagnosed. I've lived in Johnson County for 4 years. It is appalling to me there is not a facility - except for the hospital in Cleburne - where one can get a mammogram. I go back to Arlington. |
| **Johnson** | **HCP** | NOT ENOUGH PROVIDERS |

| | | |
|---|---|---|
| **Johnson** | **Survivor** | My opinion would [be] the lack of known professional breast care teams in Johnson county. |
| **Johnson** | **Survivor** | There seems to be very few locations in this area for information or treatment in our area. |
| **Unknown** | **HCP** | I believe more mobile mammography units would be of great value, especially if they could be sent to places of employment during working hours. This would enable more people to be screened. |
| | | **Adequacy – Quality of Care** |
| **Parker** | **Survivor** | It starts with your OB/GYN and there were no female doctors in the county when I moved here. I think there might be one, but there are very few quality OB/GYN Dr.'s in the area. |
| **Parker** | **Survivor** | Quality of care. I don't trust the resources here. I go to Dallas |
| | | **Coordination- Navigating Care** |
| **Parker** | **Survivor** | I was sent to get a mammogram by my gynecologist and then was told I needed a biopsy which was done by someone I didn't know. After I was diagnosed I didn't know where to go or what the diagnosis meant. The facility that did the biopsy/mammogram just told me to ask my gynecologist what to do. I wish there was a better way to handle that. I wish I'd been assigned a navigator who would have helped me with questions and helped me know where I could turn, etc. |
| **Johnson** | **HCP** | We need someone to help these ladies navigate their care. Educational, nutritional, life coaching would all be beneficial to our ladies. |
| **Johnson** | **Survivor** | Don't even get me started!! My sister was recently also [diagnosed] with breast cancer, the nurse navigators she had contact with were knowledgeable and kind. Witnessing her journey has been dramatically different from mine. No support system in place,[the] doctor [and] staff [were] not helpful. |
| | | **Demographics** |
| **Johnson** | **HCP** | I believe we need more education for our minority population. The numbers of Hispanics or Black ladies who come in for mammograms is noticeably less. |
| **Johnson** | **Survivor** | Immigrants who are scared of deportation, cultural fears, no insurance, lack of funds, language barriers. |
| **Johnson** | **HCP** | Unfortunately, I have met a number of people who express having a negative, even hostile, attitude toward western medicine. Their objections seem to stem from distrust and/or having one or more "bad" experiences (directly or vicariously) with a traditional health care provider. Common denominators seem to be lower socioeconomic status, limited education level, limited ability to engage in critical thinking, mental health issues, and possibly a lack of self-esteem. |
| | | **No Barriers** |
| **Unknown** | **Survivor** | nothing, there is plenty of information out there, billboards, pamphlets in health care providers offices, Komen provides assistance, i think there is all opportunities available for mammograms |
| **Parker** | **Survivor** | No barriers and excellent follow-up care. After diagnosis and surgery, it was helpful to talk with other survivors who were familiar with what you were feeling. |

| Community Partnerships | | |
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| **Parker** | **HCP** | I think partnering with faith community organizations can fill in the gaps when it comes to prevention of health. Offering screenings in conjunction with faith communities in the rural settings seem to bring a lot more people in to these offerings. Currently, we utilize an indigent care clinic and discuss preventive services and for those that never have screenings we try to connect them with the available service and follow up that it gets done. |

**Table B.2. Selected Quotes Exemplifying Axial Themes from the Focus Group Study**

| Location | Type of Respondent | Quotation |
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| **Accessibility – Time, Travel & Limited Services** | | |
| **Parker** | **Survivor** | "Well, and the other thing with women is you've got kids, you've got work, […inaudible…] you know, taking care of everybody else but yourself." |
| **Johnson** | **HCP** | "They just do not have time for themselves." |
| **Parker** | **Survivor** | "My general surgeon that did the mastectomy works with a plastic surgeon in Fort Worth, and she practices in Fort Worth, too, but I didn't want to be far from home. […] I didn't want to have my breast removed and then have to drive 45 minutes to get back home. When I was released from the hospital, I wanted to be at home. That's why I chose to do my treatment in Weatherford." |
| **Johnson** | **Survivor** | "And it [free mammograms] shouldn't be just when they have the breast cancer push in October." |
| **Johnson** | **Survivor** | "I wasn't given the option of other doctors. I was told, 'Okay, this surgeon will take care of this'." |
| **Parker** | **Co-Survivor** | As well as another barrier may be […] for lack of a better term here […] variety. We have got this one hospital here whereas if you go to Fort Worth, there is not just hospitals but there is Margaret Cancer Center, Cancer Care Services […] there is just a variety of options." |
| **Adequacy – Quality of Care, Lack of Follow-Up, Coordination of Care** | | |
| **Parker** | **Survivor** | "So I had two diagnoses. The first one was when I lived in [...inaudible...] so I accessed all Dallas doctors at that point. And then, I moved here eight years ago, and I was re-diagnosed, it's been four years now, and, quite frankly, I just wouldn't have come to Parker County. I just went back to Dallas and drove all that way because I don't know if I, well, first of all, I was comfortable with my doctors in Dallas, but secondly, my perception is that it's not as sophisticated here, and that's based on feedback I've received from other people. [...] That's been a barrier for me. And, you know, I did have a colonoscopy cause I'm BRCA 2 so I have a lot of history of cancer and have colon cancer in my family, as well, and I did access a doctor in Weatherford for that, and I was so disappointed that I was just like, 'No, I'm gonna go back to Dallas.' And it concerns me because, of cause as I get older, you know, we live in Azle, too, we live in Parker County, and I'd like to be able to access but I'm fearful, and maybe that's just perception, it could be total perception. But, so, that's just my experience." |
| **Parker** | **Survivor** | "Well, and I've personally just heard a lot of stories from people, cause I'm very connected, I do a lot of mentoring of breast cancer patients and people who have been newly diagnosed, and sometimes you hear the stories of, from the outlying areas, that you just want to say, 'Get to a major city, a major cancer [...incomplete thought...].' And then, I mean, you've got to be comfortable with your team and your doctors, but, I don't know, I've just heard too many stories of misdiagnoses, they told me it was nothing, to watch it for a year, and it was something. Those stories tend to come from outlying areas." |
| **Johnson** | **Survivor** | "I have a big thought on that, and it doesn't just include this part of |

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| | | the world. There needs to be more primary care doctors that understand breast cancer survivors or cancer survivors in general. I have had several, I finally have one now that understands when you have a pain somewhere [...] that the first thing that comes into your mind is the cancer has come back. And they can tell you well it's probably nothing but considering your history we need to check it out. And also, because of the medications, and I don't know about the rest of you, but I'm on several medications that Dr. Young prescribed but I don't think I need to take. Now I'm eight years out, I don't need to be taking up her time, but I need a doctor that understands what, why I need these medicines and they need to be refilled. And I, after several doctors, I found one, but she's in Fort Worth. But that is an issue that a lot of primary care doctors don't understand what, why you're on a medicine you're on and the first thing they want to do is try to wean you off of it when it's been working for eight years, I think I need it." |
| **Johnson** | **Survivor** | "Well, we shouldn't be the ones walking in there telling the doctors what kind of medications we need. They should be aware, they should be well aware, of what it is we need when we tell them we're having that issue, or this issue, or whatever." |
| **Parker** | **Survivor** | "The only barrier that I can think of when I got my diagnosis, cause I already had a sister who was 35 who was diagnosed so I knew a little bit more and I was 40, and I asked so many questions, and I sought lots of opinions, I interviewed doctors cause I thought, this is my life, my deal, right. And there was a lot of doctors in particular that didn't like you questioning, didn't like you asking about, doing the research and finding out about the different kind of mastectomies you could have and asking which one they, you know, asking the questions after you did your research. I found that barrier, then I found doctors who, you know, that my personality meshed with, but I felt like there was a lot of that, like, from doctors like you should just listen to what they say. What they say is 'cause they've got the MD after their name, right." |
| **Parker** | **Survivor** | "Everything is so compartmentalized today. You go to one doctor for this and one doctor for that, and they don't seem to interact that much. Nobody knows, like, he sends you to get chemo or he sends you to get radiation and that's it, and then that doctor takes over. But I don't think they interact like they should. I think you're the one that does the interacting." |
| **Parker** | **Survivor** | "The whole holistic approach. Like, okay, you're done with chemo and radiation and your surgery and you're getting your checkups and everything, but what are the things that you can do that will keep you healthy, I mean, to keep your stress level down, to keep your eating properly, to keep, you know, all those kinds of things going. I think that more, yeah, I'm done giving you chemo, but, you know, I care about you as a person, keeping you healthy and all those kinds of things." |
| **Johnson** | **HCP** | "After they all have their surgery they are pretty much done with us." |
| **Parker** | **Survivor** | "I remember that kind of being at the end, you know, once I completed treatment and stuff, who do I go to now? From here on out, who do I see, you know? And mine, you know, kind of everybody led me to my oncologist so I still call her for some things, you know. And I'm like, at what point do you, I can just go see a |

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| | | Primary if I want. So I think a lot of times there's confusion, you know, who takes care of me now?" |
| **Affordability** | | |
| **Johnson** | **HCP** | "The women who do not have insurance. Not having insurance and the cost involved but because they do not have insurance. I mean that is a huge factor in not seeking out any kind of care." |
| **Johnson** | **HCP** | "Or some of us, even I, have been guilty of stretching screenings because I have to figure out where to put my health care dollars. You know, if it is always negative then I think 'Okay, well, I have this issue or that issue and I have only so much money'." |
| **Parker** | **Co-Survivor** | "I have a feeling a lot of women cannot afford to get care for themselves because they have to for their children." |
| **Johnson** | **HCP** | "I really think follow up is […] I mean I think it is the cost […]. But I mean a very close friend of mine said, 'Well I think it is something but I do not have my deductible so high and so there is no use in finding out anything so what can I do about it.' And if they do not have any insurance and you try to get them into county services, the wait is prohibitive to get in so they get frustrated." |
| **Parker** | **Survivor** | "I was very fortunate with my insurance, but I remember the fear of thinking when I even got the diagnosis, you know, when we went in, my husband said the first thing you need to let her know is we're not gonna lose our home, we're not gonna go bankrupt. Because at that point, I still didn't have any idea that we had a maximum out-of-pocket on our insurance or things like that. I just knew we had insurance, but I still figured it was gonna cost hundreds of thousands of dollars, you know, I didn't, I wasn't educated enough." |
| **Parker** | **Survivor** | "I ended up with the Medicaid breast and cervical program. It's what paid for all of my treatment, which is a [sic] awesome program. […] a lot of women don't know about it. With indigent care, you have pay, there's quite a bit you have to pay every time you go to the doctor [...]. If you're not able to work, that 10 dollars might as well be a thousand. But the breast and cervical cancer program, that's what saved my life." |
| **Johnson** | **Survivor** | "I think the free mammograms, and I think that Komen kind of contributes to that. The ones they do in October, those are just for uninsured women. [...] I think if there were more of those and people knew about those [...]." |
| **Johnson** | **Survivor** | "I think probably because there's, you know, maybe a lot of poverty and lack of insurance and so women don't [incomplete thought]. You know, I have always had a yearly appointment with a gynecologist forever, you know. I've always gotten a mammogram every year. But I think there are women who don't have insurance." |
| **Johnson** | **Survivor** | "I think Cleburne's probably more along that line [no insurance] than people that live in Burleson. [...] Cleburne is just a whole different world than Burleson. [...] Burleson's more like Fort Worth and Mansfield and stuff, but Cleburne's just very backwoods-ey I was gonna say red-neck cause I don't know how else to explain it. And I can see how that can somehow even lead people that have insurance not to go regularly because it's just inconvenient." |
| **Parker** | **Survivor** | "When I was first diagnosed, I didn't have insurance. That was […] scary." |
| **Availability – Lack of Services & Location** | | |
| **Parker** | **Survivor** | "But you're [Komen] not in our community, you're not in our face." |
| **Parker** | **Survivor** | "Careity is a local, well known, charitable organization, but they |

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| | | could be more than they are. Right now, to me, they weren't really a resource. I thought they were more about mammograms for low-income. But we need some sort of entity here that can be that contact." |
| **Johnson** | **Survivor** | "There was no option. Until I started coming to the group [support group], I had no idea [...inaudible...]" |
| **Parker** | **Survivor** | "And the more rural, I think, because when you're in a bigger city, you have access to more people and more experiences, but the more rural you get, and I just noticed that from moving out this way from being in the bigger city, it's just less connectivity so there's less information it seems to me." |
| **Johnson** | **HCP** | "But I mean why does it have to all be in a county, why can't we all be partners? Why can't there be a certain number of cases that we follow through even if they come to our facility? Why do we always have to kick them out of the door? What are the options there? I mean I know we are not a charity facility, but a certain percentage. Certainly we do not want to just diagnose people always and send them out to nowhere or to 5-6-7 months waiting list on a county facility that is taxed. Cause we do not know the resource, I mean if you gave her a list of everywhere they could go and there was one place that they could go to, I mean that is the end goal." |
| **Johnson** | **HCP** | "We do not see Komen as a One Stop Shop. You see them in screening that is it. You know where do you go from there? There is not [...] any interaction at all with 'We are going to help with this follow up, we are going to help this patient get surgery,' and I do not know if Komen is just structured that way. I do not know." |
| **Johnson** | **HCP** | “If they live here, work here and send their kids to school here but the services that they need that are available […] through the Affiliates or through other foundations are available in Fort Worth, they are not going to go to Fort Worth.” |
| **Parker** | **Survivor** | “I love my doctor here, she's a breast specialist, and [...] I like here a lot. She has an office here and in Fort Worth, and [...] she just said, 'If you go to Fort Worth, we can get you in sooner, we can do the treatment sooner.' [...] I don't mind going to Fort Worth because it's close enough, you know. I don't know that I'd want to drive all the way to Dallas, though, that's a long way. For diagnosing and for just seeing her once a year for a check-up, I'm very happy with my doctor." |
| **Parker** | **Survivor** | "I think the facilities in Fort Worth are better than here. [...] They seem to have more equipment, more diagnostic tools. They diagnose here, but then a lot of times will maybe send you to Fort Worth for the procedure so I don't think we're quite set-up to do everything here like a larger city is." |
| **Johnson** | **Survivor** | "It's a whole different thing than Fort Worth and Arlington and even Mansfield. Cleburne's totally different. You might as well be in West Texas or something." |
| **Communication – Advertising, Outreach & Visibility** | | |
| **Johnson** | **Survivor** | "I think if you were talking about this area of the world, that new technology is not what you're looking at. I think more along the lines of newspaper, billboard ads or something along that line. Like I said, this more, to me, more of a rural." |
| **Parker** | **Survivor** | "We've got all the Fort Worth media. It's not like there's a lot of marketing to even make people in the community aware." |
| **Parker** | **Survivor** | "I'd like to say something that they're [Komen] doing right in my |

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| | | opinion, and that is, I use Facebook, and there's, Komen has pages on Facebook, I don't know how many or what there are, but I 'like' that page and then lots of my other friends 'like' them, and they will post something about it, and I post it, and it makes awareness. It causes awareness out there, and three of my friends through Facebook, one is my sister-in-law in Florida, through that and through me posting my journey not explicitly, but 'hey, chemo today, people are praying today' that helped. And I think the Komen postings that they do, the ribbons and different things. I think that's good awareness." |
| **Johnson** | **HCP** | "The small towns they have [..] they have yearly events, fairs and things like that. I have gone a few times to the October fest with a food to promote CPR and those sorts of things, give flu shots and there is big crowds there and any information that you made available to facilities that go to community events or put on a mobile bus that at least could direct people to where they could go. That could be useful too." |
| **Parker** | **Survivor** | "I think it's important, what you said, I think other women sharing their stories is the most powerful thing that there is out there because at the bottom line, it's your life, you have to advocate for yourself, and when we share stories, which long ago people didn't, they didn't talk about it, and, you know, now, largely thanks to Komen, [...] people do talk about those things, and I think real women sharing their stories, you know, I was forty years old or I was 35 years old and this happened to me. That's the most powerful thing that we can do for breast education, I think, because I don't think we can rely on our doctors." |
| **Johnson** | **HCP** | "The thing is how are they going to know about it? If they do not go to the doctor, they do not leave their house, they go to shop at the HEB, you know the grocery store. If there was something in the grocery stores and other places that they actually have to go […] to give them information on free services." |
| **Communication and Knowledge - Education and Information** | | |
| **Johnson** | **HCP** | "That is when we do our teaching too […] we do a lot of you know teaching when they are pregnant. Not only about their pregnancies but about their ... about health, about their women's health. You know a lot of women have no idea that you are supposed to get your first screening mammography at age 40. They go, 'Age 40! That is young,' you know." |
| **Johnson** | **HCP** | "Having little luncheons, you know, where we feed the community, when there is food people will show up. I have spoken at luncheons here at the hospital, it was a great turn out, you know. But you really, you know, you want to reach more than just the hospital staffs, you want to reach those community members. Cause there is […] every time I have done one of these talks, I used to do a lot of talks in luncheons, so many people from the community come out, and there is so much misconception, there is so much misinformation, misunderstanding of information, and if you really bring it to their level and educate them they are very receptive." |
| **Parker** | **Co-Survivor** | "I was thinking if they could put some kind of information like in the WIC offices. I mean I know there are WIC offices here. I thought they could maybe put some in the court house next door information about services that are available to women in Parker County. I know there is got to be lots of women in this county they |

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| | | don't have insurance. I feel like there are some low income areas and people do not have insurance and they need any kind of services they can get." |
| **Parker** | **Survivor** | "I don't know, maybe education can start way younger […] in the schools somewhere or something." |
| **Parker** | **Survivor** | "I think the more uneducated you are, the less likely [you are to get screened]. I think that's all it is." |
| **Johnson** | **Survivor** | "The information is not, it's definitely not out there." |
| **Parker** | **Survivor** | "Well, my diagnosis was 27 years ago, I'm a 27-year survivor, and things were different then. I was in my early forties, and I'd never had a mammogram, no one had ever mentioned having a mammogram, so it was a complete shock to me. [...] Like they were saying, my doctor never mentioned it, you know that I should start. But even now I they don't recommend it so much for under forty. [...] I've read that even forty-year-olds they don't think it's worth it sometimes. Komen does, but other groups, doctors, [...] they say, 'No, it might save one life.' Well, that's one life as far as I'm thinking." |
| **Johnson** | **Survivor** | "I think there needs to be consistency as far as how the information is put out there." |
| **Parker** | **Survivor** | "They [mammography technicians] should be offering more information." |
| | | **Coordination – Navigating Care** |
| **Parker** | **Survivor** | "I had that [nurse navigator] at Baylor. A friend of mine […] a friend of mine has received all of her treatments here in Weatherford, and she didn't have the same support that I got from that service." |
| **Parker** | **Survivor** | "You're just looking for that one person that can just tell you, you know, if you can tell me who's supposed to take care of me then I'll go there." |
| **Parker** | **Survivor** | "When I was first diagnosed, I had a navigator contact me from Harris Methodist in downtown Fort Worth and, you know, talk to me and tell me she was gonna be there every step of the way and, you know, she's just, if I need to talk anytime and all this, and I got a little notebook to take notes in the mail, and then, from that point, I saw her the day she brought to my room, which was probably the day after my mastectomy, my little [...] camisole thing, you know, to hold the drains, that I had to pay for. She delivered that, and then that was it. I didn't hear from her anymore, I didn't see from her anymore. [...] I mean, in the beginning, that first conversation, that was so comforting, I mean, she was somebody for me to grasp onto and feel like, okay, she's gonna have answers when I have questions and stuff that my husband's not gonna know, that was the feeling I got from that phone call, you know, was she's gonna be my person, and that didn't " |
| | | **Community Resources** |
| **Parker** | **Survivor** | "People know the name Komen, but they don't know the resources." |
| **Parker** | **Survivor** | "I knew Komen, but I thought they were only research." |
| **Parker** | **Survivor** | "Komen just doesn't provide resources […] but they can direct you." |
| **Parker** | **Survivor** | "I know there's a group here called Careity. [...] I've heard they've done wonderful things for people who don't have funds, that they help you, they help pay for your treatments, so perhaps that's the best way, to go through a group like that and just pay for people |

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| | | that cannot afford it." |
| **Johnson** | **Survivor** | "You mentioned the American Cancer Society, and I just now remembered this. A co-survivor who introduced herself to me at work when I was diagnosed. […] I was still doing chemo, but I wasn't losing my hair anymore, and my hair was growing back, and I didn't have a need for this particularly because I didn't lose my eyebrows or eyelashes or any of that, but she told me to go online to the American Cancer Society, and I don't know if Komen offers this or not, but it's a class or something like that, and you can go and take your wig with you and they have name brand cosmetics. [...] Look Good, Feel Good program. And they will help you put on your makeup. They'll help you style your wig on your head. They'll tell you how to wear your hats. And I think that's a good thing. It's not a financial issue [...] but it's a good thing that I think would help a survivor or someone going through it feel a little better." |
| **Johnson** | **Survivor** | "And one of the things, while we're on the subject of this, one of the ways of information [sic] to be spread is Pink Sunday. And our church, which is a big church - First Methodist in Mansfield, has always participated in Pink Sunday. We've always gotten, well before this year, like five hundred packets, and, like, at least a hundred in Spanish. But this year you had to print them off yourself. And I think, I can't imagine some of these small churches would have been able to participate. Fortunately, our church did print off, I don't know how many, but they were just the one page flyer that talked about risk factors on one side and then the other side showed how to do breast exams. And I got credit for missing church in the past because I went to church three times that weekend to make sure there was someone there cause we passed out the pink bracelets [...]. We wanted someone from the support group to be at every service to pass out those brochures in case someone asked about the support group because we all agree the support group is a very important, you know, somebody could come up and say, 'I have a cousin that has breast cancer' and we could send them to the support group. [...] But I'm just thinking some of the smaller churches that used to participate in that might not have had funding. I didn't realize our support group had funding [...] to pay for those brochures to be printed." |
| | | **Insurance Limitations** |
| **Johnson** | **HCP** | “The other thing, too, also Medicaid. I am not being biased, but Medicaid does not cover Well Women exams. It does not. I have to discuss contraception so that I can […] which I would but if a patient is coming to me for a well woman and she has zero problem I have to […] talk about something so that Medicaid would pay for the Well Women exams. I would think preventative medicine is something that Medicaid would cover and birth control is something that it would be a little more ‘iffy' about. It is completely opposite and it makes it very difficult when you do get that Medicaid patient and they do not know.” |
| **Johnson** | **HCP** | "We have a lot of healthier patients too. If we went to more preventative care coverage you know I mean come on not everybody is sick, not everybody has issues. I agree when somebody is really being proactive with their health and they want to come and get their breast exam and they want to come and get their pap smears but nothing else is really going on and their |

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| | | Medicaid […] but they are Medicaid, we cannot circle a well exam." |
| **Johnson** | **HCP** | "I get girls who are postpartum. […] That is when we do our breast cancer […] I mean our breast exams, and that is when we do our education, and they will […] you know their Medicaid runs […] out in two weeks." |
| **Personal Factors – Fear, Denial & Risk Factors** | | |
| **Johnson** | **HCP** | "I think it is also they do not want to believe it is anything. They are afraid of what the treatment might be even if they can afford it. They do not want to get chemo they do not want to lose their hair, they do not want to be sick, they … ignore it for a while hoping it is something else." |
| **Parker** | **Survivor** | "When we were talking about getting mammograms and why people don't, my daughter-in-law said she didn't want to get one because she heard it hurt. She was really afraid, I mean, not just a little afraid, she said, 'It's just so painful.' And I said, 'That's silly.' I said, 'You know, it takes about a second,' and I said, 'It's not bad at all,' but that's, I think, a myth. Well, I mean, it's not pleasant, but it's not something you can't put up with, you know, for the length of time. I think a lot of women have that opinion that it's too painful, I don't want to do it. [...] This was just recently that she said, 'I don't want to cause it hurts.' I said, 'Well, you've never had one so you don't know if it hurts.' But you know, it's just such a minor thing, but finally I talked her into it. |
| **Parker** | **Survivor** | "I think everybody, or a lot of people believe it's not gonna happen to me. You know, what are the odds? It's not gonna happen." |
| **Johnson** | **Survivor** | "A lot of women think, 'There's no one in my family.' When I was diagnosed [...] my cousin said, 'We don't have breast cancer in our family.' Well, you do now. [...] Just because it's not in your family doesn't mean a thing in the world. It only increases your risk like very minimally, doesn't it?" |
| **Parker** | **Survivor** | "The media and all the perception is that it's just the BRCA gene that becomes this big deal so if you have no family history, you're walking around thinking this is not something that I'm gonna have to deal with when in fact the numbers are quite high for those who don't have the gene." |
| **Parker** | **Survivor** | "I felt that since I did have family history - I had a sister who had breast cancer when she was 35, a younger sister - so once I had that history, my doctor was much more willing and able to push me to, not only just regular mammograms, but [...] the diagnostic ones based on family history. But I do find that in talking to a lot of people that don't have that, especially if you're under 40, getting blown off, like, 'Eh, don't worry about that, you know, that lump, don't worry, you're young' or whatever, and so you have to be more of an advocate, when you don't have family history, you have to be more of an advocate for yourself because otherwise [...incomplete thought...]. That's how it feels." |
| **Johnson** | **Survivor** | "I don't think family history is a deciding factor." |
| **Parker** | **Survivor** | "And you don't feel sick, that's another thing. Like when you have a cold you know something's wrong, but when you have breast cancer you don't feel anything, and it's internal so you don't see it. It's tricky." |
| **Sensitivity** | | |
| **Johnson** | **Survivor** | "You need a doctor that understands. I went through two others before the one I have now. [...] She understands that I have |

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| | | questions that a normal person going in for a physical is not gonna have. And there needs to be more doctors like that. Maybe doctors that are primary care but they specialize in people who've had cancer." |
| **Parker** | **Survivor** | "I didn't feel like he [colonoscopy doctor] listened to my cancer history enough. [...] I was referred to him, and I just felt like he didn't know enough about cancer. I didn't have any cancer problems, it was just time to have a colonoscopy, but I have huge family history of lots of kinds of cancer, and I just felt like there wasn't that emphasis placed on looking at that. I mean, I had a colonoscopy, it was fine, whatever, but I didn't have that level of expertise. I feel like I would go back to Dallas again." |
| **Johnson** | **Survivor** | "If one of the doctors, because I had several - the surgeon, the plastic surgeon, the oncologist, the radiation oncologist, and then eventually a wound care doctor - if any of them had ever [...] had something that they handed me or the chemo nurses or any of the people that I was seeing, that would have been great support." |
| **Johnson** | **HCP** | "Culture of not realizing that if we say a certain time that is what we mean and not just whenever you can get here. If you can't get here then someone needs to call us and let us know that you are not going to get here but there is that language barrier too. However, a lot of the ladies that come in for mammogram bring their little granddaughters to translate." |
| | | **Survivor & Co-Survivor Supports** |
| **Parker** | **Co-Survivor** | "I have a suggestion which would be just to get them involved to things that survivors are a part of outside of treatment and care. You know may be it is race for the cure where they can just see what survivors and their families do with survivors outside of the hospital and the treatments." |
| **Johnson** | **HCP** | "Just complete support so that they do not have to worry. You know if they need transportation, fine. I know there is a […] I was part of a group and it still exists, it's in Tarrant County where they provide healthful all natural meals for people with cancer." |
| **Johnson** | **Survivor** | "More support groups would be helpful." |
| **Parker** | **Survivor** | "I think [...] if doctor's offices had some type of support groups. You know, you see, we're here for a reason, we're here to try to help, you know, if we can help one person that may go through it or answer one question for them or, you know, keep them from having one side effect. [...] I remember, like, when I went to my oncologist, that evening we went to a class talking about what to expect from chemo, so, you know, something like that about the after, you know, [...] cause you know there are people out there that would love to engage in that education and be somebody that would oversee that type of group or something like that, you know, so I just think there needs to be more." |
| **Parker** | **Survivor** | "You know, talking, having other survivors talk to you. I remember when I had my mastectomy, in the hospital, she wasn't a nurse, she was with a group, just a support group, and she came and sat down and talked to me and somehow I felt so much better cause I guess you feel all alone or, after that kind of surgery, you just don't know what's gonna happen, and when somebody who's gone through it talks to you, it makes you feel better. That helped a lot. I remember that." |
| **Parker** | **Survivor** | "And what about having some sort of guidelines? Like, you might |

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| | | experience this or you might experience that. Maybe just as a handout or something as you're finishing your treatments so you're not just caught off guard when something happens and no one's told you about it and you don't know what it is. I think any kind of information like that would help. [...] Give it to the survivors and say, 'This is what we've found.' Not a book, I think that's probably too much, but, you know, just some facts like you might experience this or that." |
| **Parker** | **Survivor** | "I think [teaching survivors] how to take care of yourself." |
| **Parker** | **Survivor** | "Exercise is key to keeping it from coming back, but you're so tired and the chemo's caused […] chronic kidney disease and there's just a lot of things going on because of the chemo, which they don't tell you. You know, they put the chemo in your body and this is gonna kill the cancer but it's also gonna destroy this and maybe cause other cancers." |
| **Johnson** | **Survivor** | "There's stuff at Moncrief, there's an exercise class that I went to for a while at Moncrief. It's on a brochure, but that's all the way in Fort Worth. If they had something like that here. [...] The one that's done at Moncrief is done by someone who knows [cancer]. It's not just breast cancer, it's women with cancer. [...] But she [the instructor] knows whatever kind of cancer you have, like if you're not supposed to put weight on your shoulder [...], whereas, somebody in a regular fitness center wouldn't." |
| **Johnson** | **Survivor** | "I hadn't gone through menopause until I started chemo. [...] And then there's just things, like my hair is still not, and it's been five years, well, four and a half, and it still is not right. There are thin spots there. And the issues with menopause, and I can't have anything to help, hormones or anything like that, because of breast cancer, and it's like, there are things I'm just having to live with cause I had breast cancer. It has an effect on my quality of life, not major, but still." |
| **Johnson** | **Survivor** | "It kills me what it [chemo] does to your brain. I used to could remember things." |
| **Parker** | **Survivor** | "Well, I think, [...] I guess I'm a twice survivor now. [...] I'm a huge advocate, I try to do a lot of mentoring and everything, but I think afterwards, I think, I sought this on my own, I think there's a need to know about nutrition, exercise, lymphatic drainage massage. I mean, there's a lot of things that I found on my own to help me in my health afterwards that I couldn't get answers from my doctor. [...] Like how do you take care of yourself to try to avoid breast cancer, cause there's a lot of things coming out about that, too, so I feel like, like I go searching for that all the time on my own, but it would be nice again if a doctor would say, 'Hey, you have a lot of fluid build up. Lymphatic drainage massage therapy could really work, and here's three people that do that kind of thing,' instead of experiencing that, trying to figure it out on your own. [...] For me, with survivorship, there's a lot of issues afterwards. There was a lot of weight gain after [...], but after all the chemotherapy cocktails, you go to the doctor, and they're like, well, you need to be on a diet. Well, there's a reason for all that, right. Then you seek it yourself, you find the answers. [...] It's kind of like you all said, you're done, and it's like, 'Okay, you're done. Bye.'" |
| **Parker** | **Co-Survivor** | "I think it might be helpful ...you know we have so many 5ks, we have got the 'Race for a Cure 5k', we have got the 'Relay for Life' |

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| | | and we have got all these things that really focus […] may be not 'Relay for Life' but a lot of these 5k's and events that focus on a cure. And that's may be little tangents that spun off of that that have to do with celebrations of a survivors. We can take those avenues if you will and use that opportunity to say okay we are still here to try to find a cure, we are going to raise money to try to find a cure but to really emphasize a support for co-survivors you know to say […] anything […] if someone is really looking for that support they could probably find especially today with google. But a lot of folks do not think they need it or won't take the time to find that but if someone found them I think they can be an asset that would just be invaluable. That would be kind of a neat deal to have." |
| **Parker** | **Co-Survivor** | "I just keep going back to that having some sort of not committee but team that they focus on just that […] not the cure […] not survivors […] just the co-survivors and learning what their needs are whether it is information, whether it is someone to go to for a cup of coffee with them... so something to keep them solid so they could be that co-survivor. And then afterwards if it does not […] if the patient does not make it you know then you go down that path. But if they do that is another path as well but you still need someone there to kind a say 'okay, you need to be [….] it's not going to be all roses and pile of sky even though they survived. You are still going to have these battles and these battles or these roadblocks or whatever may be' and have someone here that has been through that kind of coach them along and help them." |
| **Johnson** | **Survivor** | "I don't think it should necessarily be limited to just the breast cancer [...inaudible...] [...] but whoever is their basic care giver. That was one of the things that my ex through in my face [...inaudible...] [no support groups for caregivers, family members]." |