susan g. komen®

COMMUNITY PROFILE REPORT 2015

SUSAN G. KOMEN®
GREATER ATLANTA

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Executive Summary

Introduction to the Community Profile Report

Nancy G. Brinker promised her dying sister, Susan G. Komen, she would do everything in her power to end breast cancer forever. In 1982, that promise became Susan G. Komen®, which is the world's largest breast cancer organization and the largest source of nonprofit funds dedicated to the fight against breast cancer.

Susan G. Komen® Greater Atlanta was founded in 1991 by an all-volunteer board. Komen Greater Atlanta serves as a resource for those seeking opportunities for breast health education, screening, and treatment support and hosts several events and programs to raise awareness and educate the community about the benefits of early detection in the fight against breast cancer. Komen Greater Atlanta's thirteen-county service area includes more than 47 percent of the state's population and is comprised of more than 4.7 million people. The thirteen-county service area includes: Cherokee, Cobb, Clayton, Coweta, DeKalb, Douglas, Fayette, Forsyth, Fulton, Gwinnett, Henry, Newton, and Rockdale counties.

Through annual events including the Susan G. Komen Race for the Cure®, Bubbles & Bling and other fundraising, Komen Greater Atlanta raises funds that enable women and men to detect and survive breast cancer. Up to 75 percent of all funds raised by Komen Greater Atlanta stay in Atlanta to fund breast health programs for those who would not otherwise have access to screening and treatment support. Twenty-five percent of funds raised support the national Komen Foundation Award and Research Grant Program. Since its inception, Komen Greater Atlanta has raised over $41 million to provide breast health education, screenings, diagnostics, and support to breast cancer patients and their families and to support breast cancer research.

Purpose of the Community Profile Report

The purpose of the Susan G. Komen Greater Atlanta Community Profile is to provide current and comprehensive information about the status of breast health, breast cancer, and related services within the Komen Greater Atlanta 13-county service area. The 2015 Community Profile is meant to build upon previous editions of the report, and it provides an expanded overview of both quantitative and qualitative data.

The information contained in this report comes from a variety of local, state, and federal sources. It also includes information collected from a diverse group of individuals living and providing services within the service area. While preparing the report, Komen Greater Atlanta made a concerted effort to include varied data sources and community voices to ensure a well-rounded perspective of breast health and breast cancer services within the Komen Greater Atlanta community.

Findings from the 2015 Community Profile are instrumental in identifying specific strategies to address the gaps and barriers to accessing care, assessing the availability of breast health services and supporting Komen Greater Atlanta's mission to enable women and men to detect and survive breast cancer. Research contained in this document will help to:

- Shape the future direction for the organization's grant programs,
- Guide future public policy initiatives,
- Drive inclusion and access to care efforts in the community,
- Help expand community education and mobilization efforts and
- Develop strong collaborations and partnerships.

The completed Community Profile will be shared with stakeholders in the local breast cancer community via normal Komen Greater Atlanta public relations vehicles, including the organization's annual report and print, television, and online media efforts. Additionally, information sessions will be held for current and potential community partners, health care providers, and volunteers.

Quantitative Data: Measuring Breast Cancer Impact in Local Communities

Komen Greater Atlanta's service area as a whole has higher age-adjusted breast cancer incidence rates, death rates, and late-stage diagnosis rates than the state as a whole, and Georgia fares worse on these measures than does the general population in the United States. Komen Greater Atlanta endeavors to serve individuals throughout all 13 counties because the need is high throughout the service area. However, in order to focus the organization's resources and goals over the next four years, Komen Greater Atlanta has chosen five target communities within the service area. Target communities are those that are at the greatest risk for experiencing gaps in breast health services, barriers in access to care, or those that are home to populations most vulnerable to experiencing poor breast health outcomes.

The selection of Komen Greater Atlanta's target communities was based primarily on data from Healthy People 2020, a comprehensive United States federal government initiative that sets measurable objectives for improving community health outcomes. While Healthy People 2020 measures a variety of health outcomes, Komen Greater Atlanta reviewed goals relating to reducing late-stage breast cancer diagnosis (defined as regional and distant stages) and breast cancer deaths. Target communities were chosen based on the amount of time communities are anticipated to need in order to meet Healthy People 2020 breast cancer targets.

In addition to Healthy People 2020 data, Komen Greater Atlanta also reviewed the following county level data when selecting target communities:

- Incidence rates and trends
- Death rates and trends
- Late-stage rates and trends
- Breast cancer screening percentages
- Percentage of residents living below the federal poverty level
- Percentage of residents living without health insurance
- Unemployment levels
- Percentage of residents who are linguistically isolated and/or foreign born.

Based on these criteria, Komen Greater Atlanta has chosen the following target communities:

- Cherokee County
- Clayton County
- DeKalb County
- Fulton County
- Henry County

Health System and Public Policy Analysis

The Health Systems Analysis is intended to identify facilities and providers through which individuals in the service area may enter the breast health continuum of care, as well as to identify coverage gaps in the target communities. Data for the Health Systems Analysis was compiled from a wide variety of local, state, and federal resources listing breast health resources including:

- The Food and Drug Administration's list of certified mammography centers
- The National Association of County and City Health Official's list of health departments
- Lists of Health Centers and Free Clinics
- Lists of specially accredited or certified centers

Komen Greater Atlanta staff also used existing relationships with the local breast cancer community to identify facilities, in addition to conducting internet searches to locate any services and resources that may have previously been unknown to Komen Greater Atlanta. The Health Systems Analysis found that Cherokee, Clayton, and Henry counties lack adequate numbers of breast health care providers who see uninsured or underinsured women. While there are several providers in Fulton and DeKalb Counties, these counties continue to see high breast cancer death rates. This indicates that, while services are widely available within these areas, there still must be significant barriers preventing women from accessing them.

In addition to assessing the structure and availability of services in the target communities, Komen Greater Atlanta also conducted an assessment of local, state, and federal policies that impact access to breast health care in the service area. Based on this policy review, Komen Greater Atlanta's public policy priorities are:

- Expand Medicaid: Despite the restrictions placed on Medicaid expansion, Georgia would greatly benefit in expanding Medicaid to low-income, childless adults. Increased accessibility to insurance and health care would allow for thousands of women to receive recommended screenings, address risk factors, and receive necessary treatment for breast cancer. Additionally, by providing coverage to this population of women, funding for National Breast and Cervical Cancer Early Detection Program services can be redirected to reach additional populations not covered by insurance, especially immigrant women and women with language and literacy barriers that limit their utilization of screenings and services.

- Further reduce the cost of oral anticancer medication: Although the passage of the Cancer Fairness Treatment Act greatly improves upon the parity issue surrounding oral therapies, the cap on out-of-pocket costs to the patient remains too high for many low-income patients. Consequently, treatment compliance will be negatively affected within this population, hindering successful treatment and recovery.

Despite the many recent changes to preventative measures and access to care, gaps still exist among women in Komen Greater Atlanta's service area. Undocumented immigrants are exempt from receiving federal or state financed health coverage and represent a significant population that lacks proper access to screening and treatment services. Additionally, women with language and literacy barriers are often unaware of their screening options and providers. Consequently, Komen Greater Atlanta seeks to improve accessibility of services among this population with outreach efforts and by funding service providers within immigrant populations to facilitate communication and better use of offered services.

Qualitative Data: Ensuring Community Input

Since there is often a disconnect between provider suggestions and recommendations and what the community expresses that they want and need, the Affiliate sought to gain input from the community members themselves. This section of the Community Profile aimed to assess barriers to care that may not be captured by quantitative data.

Focus groups and key informant interviews were conducted to determine the breast health knowledge, screening behaviors, identified barriers and awareness of women living within the five target counties. Women in the target communities who had sought access to breast screenings in the last two years (whether or not the screening was completed) and breast cancer survivors were primarily involved in the focus groups. Breast health care providers participated in key informant interviews to explain barriers to care from an institutional perspective or those they have experienced as they navigate patients through the continuum of care.

Ten focus groups and forty key informant interviews were attempted; seven focus groups and 28 interviews were completed. The interviews and focus groups were designed to investigate three primary questions:

- To what extent are there barriers to accessing breast health services* in Clayton, Cherokee, Dekalb, Fulton, and Henry Counties?
- To what extent are there gaps in breast health continuum of care in Clayton, Cherokee, Dekalb, Fulton, and Henry Counties?
- To what extent are women satisfied with the breast health services they have received in Clayton, Cherokee, Dekalb, Fulton, and Henry Counties?
  *Breast health services include breast cancer screening, diagnosis, and treatment services

The focus groups explored what, if any, challenges prevent women from accessing breast cancer screening, diagnosis, and treatment services. Across counties, several common barriers emerged that prevent women from accessing breast health care services across the breast cancer care spectrum, from risk reduction to treatment including:

- Finances and the inability to pay for services
- Attitudes towards breast cancer, such as fear and stigma
- Factors related to culture and race/ethnicity, such as a lack of culturally appropriate information and providers
- Challenges navigating the health care system for services and resources
- Lack of prioritization of breast cancer as an urgent health issue affecting their community
- Lack of free or low cost transportation to health care facilities
- Lack of knowledge about breast cancer in the community at large

Key informant interviews largely supported the findings of the focus groups but also showed that providers lack knowledge about how and where to refer uninsured and underinsured patients for breast health services.

Mission Action Plan

Based on the findings of the Community Profile, Komen Greater Atlanta developed five problem statements to summarize the gaps in care in the target communities. Komen Greater Atlanta then developed the Mission Action Plan to guide the organization's mission work for the next two years. The Mission Action Plan will be updated biannually and rewritten with the Community Profile every four years so that Komen Greater Atlanta's mission work will remain focused on the populations in the service area who experience the most barriers in accessing high quality breast health care and achieving positive breast cancer outcomes.

Problem Statements

- According to the Quantitative Data, nine out of13 counties within the service area are 13 or more years away from meeting either the Healthy People 2020 breast cancer death rate target or the late-stage diagnosis target. Of these, four counties (Clayton, DeKalb, Fulton and Henry) are projected to need more than 13 years to meet both targets. Cherokee County is projected to need more than 13 years to meet the late-stage diagnosis target and more than seven years to meet the death rate target.
- According to the Quantitative Data, despite mammography rates at or above the national average, women in the service area experience high late-stage breast cancer diagnosis rates and high breast cancer death rates.
- According to the Qualitative Data, individuals in the service area have difficulty accessing affordable mammography and other breast health services.
- According to the Qualitative Data, culturally competent education and care are not widely available for all people seeking breast health services. Women of color, LGBT individuals, recent immigrants and individuals living below 250 percent of the federal poverty level may be disproportionately impacted and may delay or be denied care due to their socioeconomic status.
- According to the Qualitative Data, breast cancer survivors in the service area have limited access to navigation and support services after their active treatment phase is completed.

Health Systems Change

Priority 1: Increase the number of free or affordable breast health services available in the service area with a focus on Cherokee, Clayton, DeKalb, Fulton and Henry counties.

- *Objective 1:* By December 2015, recruit at least two new grant applicants focused on providing services in one or more of the target counties.
- *Objective 2:* Beginning with the FY2017 Community Grant Request for Application (RFA), programs that provide breast screenings serial and other as well as diagnostic services in the target counties will be a funding priority.
- *Objective 3:* Programs that offer co-pay assistance to under-insured women in the target communities will be a funding priority beginning with the FY2018 Community Grant Request for Application (RFA).

Priority 2: Reduce non-financial socioeconomic barriers to screening and diagnostic services in the target communities.

- *Objective 1*: By December 2015, host a conversation for grant applicants and grantees to discuss transportation and translation challenges.

- *Objective 2*: By the end of FY 2017, ensure that grantees in all counties have transportation and translation service plans in place as indicated by the Community Grant RFA.
- *Objective 3*: By the close of FY19, develop a strategy to build trust in the Black/African-American community to alleviate fear and increase the number of women screened from the highest need communities by 5%.

Education and Outreach

Priority 1: Provide only evidence based breast health education in target communities.

- *Objective 1:* By the end of FY 2016, eliminate broad education funding to other organizations and bring overall education funding to below ten percent of total grant expenses. Provide education grants only to grantees that show specific education needs in their target communities.
- *Objective 2:* By December 2015, through site visits and reporting confirm that all grantees are in compliance with Komen Breast Self-Awareness messages.
- *Objective 3:* By the end of FY 2017, hold at least three Komen Greater Atlanta survivorship events in different target communities in the service area.
- *Objective 4:* In cooperation with grantees or community partners, present ten educational programs to members of Black/African-American, Hispanic/Latina, LGBTQ or recent immigrant communities by December 2016.

Partnerships

Priority 1: Increase access to the breast health continuum of care through developing partnerships in the target communities.

- *Objective 1*: By the end of FY 2019, establish two partnerships outside of the grant making process to maximize the reach & expertise of each organization to increase the impact on target communities.

Public Policy

Priority 1: Develop and utilize partnerships to enhance public policy efforts in order to improve breast health outcomes in the service area.

- *Objective 1:* By December 2016, have five meetings or co-sponsored events with state and/or federal lawmakers in order to encourage policy that supports access to breast health services.
- *Objective 2:* By the end of FY 2016, partner with one other Komen or local organization to host an event highlighting Komen Greater Atlanta public policy efforts and priorities.
- *Objective 3:* By the end of FY 2019, collaborate with two organizations that have an established advocacy program that supports Komen's public policy priorities.

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

Affiliate History

Nancy G. Brinker promised her dying sister, Susan G. Komen, she would do everything in her power to end breast cancer forever. In 1982, that promise became Susan G. Komen®, which is the world's largest breast cancer organization and the largest source of nonprofit funds dedicated to the fight against breast cancer.

Susan G. Komen® Greater Atlanta was founded in 1991 by an all-volunteer board. Komen Greater Atlanta serves as a resource for those seeking opportunities for breast health education, screening, treatment and support and hosts several events and programs to raise awareness and educate the community about the benefits of early detection in the fight against breast cancer. Komen Greater Atlanta's thirteen-county service area includes more than 47 percent of the state's population, serving more than 4.6 million people. The thirteen-county service area includes: Cherokee, Cobb, Coweta, Clayton, DeKalb, Douglas, Fayette, Forsyth, Fulton, Gwinnett, Henry, Newton and Rockdale Counties.

Through annual events including the Race for the Cure®, Bubbles & Bling and other fundraising, Komen Greater Atlanta raises funds that enable women and men to detect and survive breast cancer. Up to 75 percent of all funds raised by Komen Greater Atlanta stay in Atlanta to fund breast health programs for those who would not otherwise have access to screening and treatment. Twenty-five percent of funds raised support the national Komen Foundation Award and Research Grant Program. Since its inception, Komen Greater Atlanta has raised over $38 million to provide breast health education, screenings, diagnostics, and support to breast cancer patients and their families and to support breast cancer research (Figure 1.1).

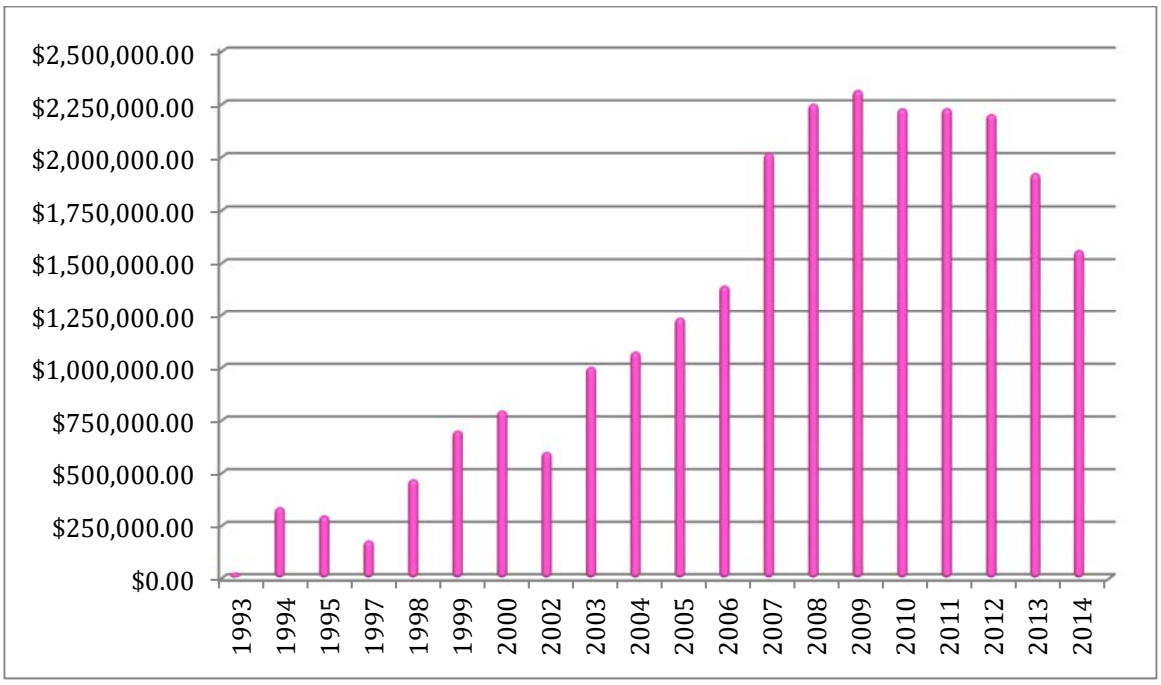


Figure 1.1. Amount of funding Komen Greater Atlanta has distributed to the local service area

The first Komen Greater Atlanta community grants were awarded in 1993 to three local organizations in the total amount of $22,000. Seventeen years later, Komen Greater Atlanta awarded 100 times that original amount, providing $2.2 million to 26 different grant programs in

2010. In 2014, Komen Greater Atlanta granted nearly $1.6 million to 18 screening, diagnostic, and treatment support initiatives serving the most medically underserved residents of metro Atlanta.

Komen Greater Atlanta also serves as a leader in breast health education and advocacy in metro Atlanta and the state of Georgia. Komen Greater Atlanta is regularly sought out to provide expertise and opinions on the state of breast health and access to breast health care and is a leader in coalitions to advocate for individuals with metastatic breast cancer and for oral chemotherapy parity in insurance coverage. Komen Greater Atlanta provides breast health education to more than 115,000 people annually, and its flagship education program, Worship in Pink, was awarded a Georgia Access to Care, Treatment, and Services (ACTS) Breast Cancer Grant in 2012 and in 2014 to expand its successful education programs into communities with high incidence of late-stage breast cancer diagnoses and high breast cancer death rates.

Affiliate Organizational Structure

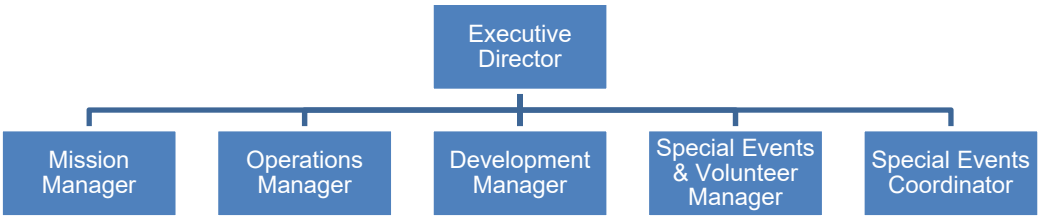


Figure 1.2. Komen Greater Atlanta organizational structure

Affiliate Service Area

According to 2013 US Census Bureau estimates, the population of the state of Georgia is approximately 9,992,167 people, and the thirteen-county Komen Greater Atlanta service area is home to 4,737,275 people in the northern and central portions of the state. This accounts for more than 47 percent of the state's general population and 46 percent of the state's female population.

At the core of Komen Greater Atlanta's service area (Figure 1.3) is the City of Atlanta, the state capitol and a large urban metropolitan area, located in Fulton and DeKalb Counties. Other counties in the service area are comprised of suburban, exurban, and rural areas.

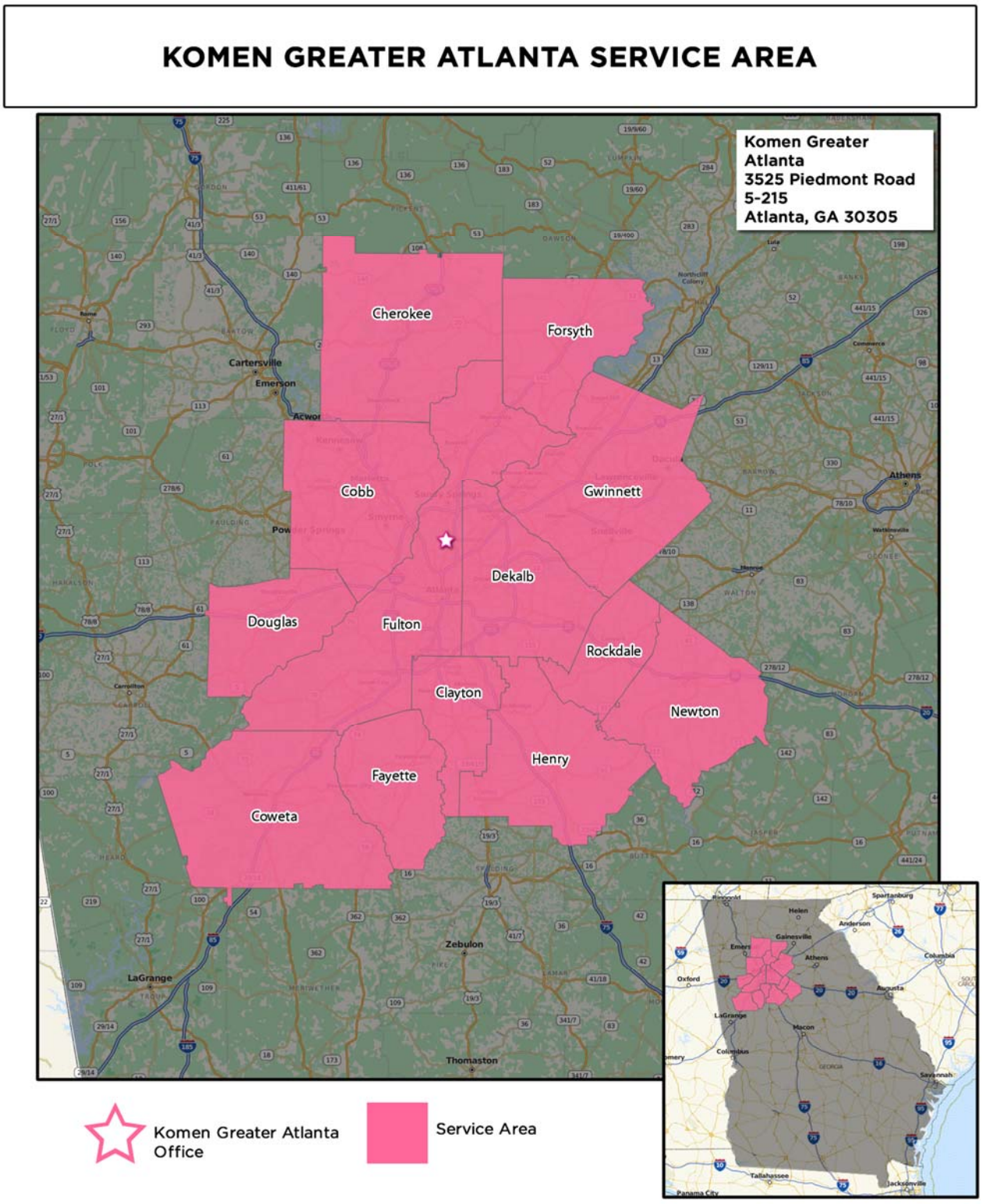


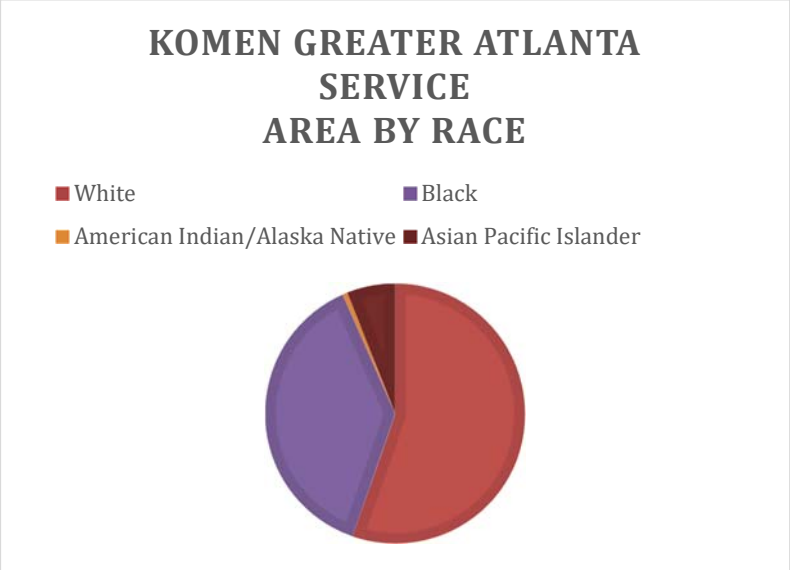
Figure 1.3. Susan G. Komen Greater Atlanta service area

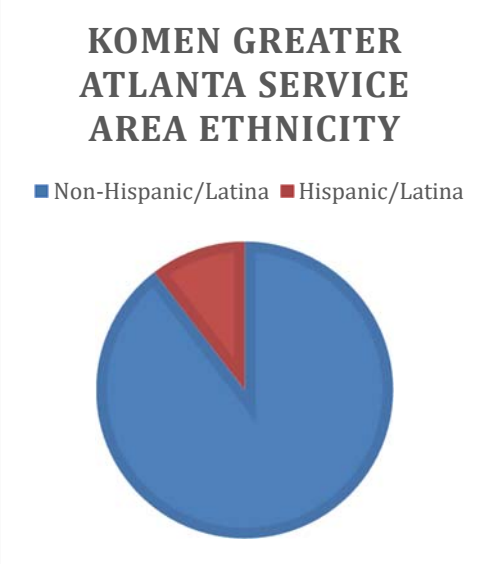
Availability of public services including public transit varies between counties with central counties having rail and bus service and peripheral counties having no public transit or taxi services.

The population of the Komen Greater Atlanta service area is racially and culturally diverse with 56 percent of the female population identifying as White and 44 percent identifying as non-White (Table 1.1 and Figure 1.4). Hispanic and/or Latina women comprise 9.5 percent of the population (Figure 1.5). More than 15 percent of people in the service area are foreign-born, and nearly five percent are linguistically isolated. The service area is also disproportionately comprised of medically underserved communities and communities in poverty. Approximately one in five people in the state and service area have no health insurance.

Table 1.1. Socioeconomic characteristics of the service area

	Income Below 100% Poverty	Income Below 250% Poverty	Unemployed	Foreign Born	Linguistically Isolated	Rural Areas	Medically Underserved Area	No Health Insurance
Komen Atlanta Service Area	13.3%	31.7%	10.0%	15.1%	4.8%	5.1%	17.8%	20.6%
Cherokee County	7.7%	24.4%	7.3%	8.5%	2.7%	17.1%	12.3%	18.1%
Clayton County	18.4%	48.1%	14.4%	14.7%	5.9%	90.0%	0.0%	25.3%
Cobb County	11.3%	26.2%	8.5%	15.2%	4.0%	20.0%	0.0%	18.2%
Coweta County	11.1%	28.7%	7.0%	5.7%	2.1%	32.9%	91.6%	16.6%
DeKalb County	17.1%	36.4%	12.5%	16.3%	5.6%	30.0%	9.0%	23.1%
Douglas County	12.7%	34.1%	12.3%	8.6%	2.3%	15.8%	0.0%	20.0%
Fayette County	5.9%	16.1%	7.0%	9.1%	1.6%	18.2%	0.1%	11.4%
Forsyth County	6.6%	16.8%	7.4%	13.2%	3.6%	9.9%	100.0%	14.6%
Fulton County	15.9%	34.8%	9.8%	12.8%	3.8%	1.1%	13.0%	22.1%
Gwinnett County	12.4%	31.6%	9.2%	25.5%	9.8%	50.0%	0.0%	22.3%
Henry County	9.5%	29.8%	9.6%	7.4%	1.5%	13.9%	100.0%	17.8%
Newton County	14.0%	40.2%	12.6%	6.5%	1.3%	31.2%	100.0%	22.1%
Rockdale County	12.9%	35.5%	12.6%	11.4%	3.0%	14.9%	0.0%	22.1%





Figures 1.4 and 1.5. Racial and ethnic characteristics of the service area

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The completed Community Profile will be shared with stakeholders in the local breast cancer community via normal Komen Greater Atlanta public relations vehicles including the organization's annual report and print, television, and online media efforts. Additionally, information sessions will be held for current and potential community partners, health care providers, and volunteers.

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 Atlanta 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 Atlanta'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*	-
Georgia	4,838,820	5,997	121.5	-0.3%	1,146	23.4	-1.4%	2,253	45.5	-0.4%
Komen Greater Atlanta Service Area	2,249,867	2,743	128.7	0.0%	490	24.4	NA	1,010	46.5	-0.5%
White	1,270,141	1,781	131.9	0.3%	290	21.9	NA	583	43.1	-0.1%
Black/African-American	841,707	874	127.7	-0.5%	193	31.7	NA	395	56.2	-0.8%
American Indian/Alaska Native (AIAN)	11,834	SN	SN	SN	SN	SN	SN	SN	SN	SN
Asian Pacific Islander (API)	126,185	73	71.8	-0.2%	7	8.6	NA	28	27.8	-8.2%
Non-Hispanic/ Latina	2,036,045	2,650	130.4	0.4%	484	25.1	NA	968	47.0	-0.3%
Hispanic/ Latina	213,822	93	94.2	-6.0%	5	7.1	NA	42	38.6	-5.8%
Cherokee County - GA	104,297	125	121.5	7.6%	21	21.7	-0.8%	42	39.9	7.9%
Clayton County - GA	135,658	135	117.0	-2.6%	28	26.9	0.9%	57	46.1	3.0%
Cobb County - GA	347,082	428	127.5	0.7%	70	22.3	-1.3%	149	43.7	-4.7%
Coweta County - GA	61,922	77	124.8	-4.2%	12	21.6	-3.3%	29	46.4	-8.1%
DeKalb County - GA	357,137	465	135.0	0.4%	87	26.1	-1.2%	183	51.8	0.2%
Douglas County - GA	66,109	76	124.0	-5.4%	15	25.1	-0.6%	30	46.9	-5.9%
Fayette County - GA	54,387	85	131.8	-3.8%	14	21.0	-2.4%	26	42.6	3.2%
Forsyth County - GA	82,179	99	125.0	5.3%	10	13.9	-2.3%	32	39.3	-1.0%
Fulton County - GA	453,948	590	135.1	-0.7%	124	29.2	-1.1%	218	49.6	-0.5%
Gwinnett County - GA	392,752	437	127.8	1.2%	67	21.9	-2.0%	163	46.1	2.5%
Henry County - GA	100,440	109	118.2	1.0%	22	25.1	-0.9%	43	45.6	5.1%
Newton County - GA	50,580	60	124.8	-7.3%	13	27.6	-0.5%	20	40.6	-4.7%
Rockdale County - GA	43,375	56	120.7	-0.4%	9	21.1	-2.3%	18	38.7	-9.8%

*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 in the Komen Greater Atlanta service area was higher than that observed in the US as a whole and the incidence trend was slightly higher than the US

as a whole. The incidence rate of the service area was **significantly higher** than that observed for the State of Georgia and the incidence trend was not significantly different than the State of Georgia.

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

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

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

Death rates and trends summary

Overall, the breast cancer death rate in the Komen Greater Atlanta service area was slightly higher than that observed in the US as a whole and the death rate trend was not available for comparison with the US as a whole. The death rate of the service area was not significantly different than that observed for the State of Georgia.

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 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 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.

The following county had a death rate **significantly higher** than the service area as a whole:

- Fulton County

The death rate was significantly lower in the following county:

- Forsyth County

Significantly less favorable trends in breast cancer death rates were observed in the following county:

- Clayton County

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

Late-stage incidence rates and trends summary

Overall, the breast cancer late-stage incidence rate in the Komen Greater Atlanta service area was slightly higher than that observed in the US as a whole and the late-stage incidence trend

was higher than the US as a whole. The late-stage incidence rate and trend of the service area were not significantly different than that observed for the State of Georgia.

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 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 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.

The following county had a late-stage incidence rate **significantly higher** than the service area as a whole:

- DeKalb County

The rest of the counties had late-stage incidence rates and trends that were not significantly different than the 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 Mammography every year starting at age 45 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 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%
Georgia	2,341	1,874	81.0%	78.8%-83.1%
Komen Greater Atlanta Service Area	733	595	83.7%	79.9%-86.9%
White	485	383	80.9%	76.2%-84.9%
Black/African-American	223	193	88.8%	81.9%-93.3%
AIAN	SN	SN	SN	SN
API	SN	SN	SN	SN
Hispanic/ Latina	15	14	93.8%	65.5%-99.2%
Non-Hispanic/ Latina	715	578	83.1%	79.2%-86.4%
Cherokee County - GA	41	29	77.5%	57.2%-89.9%
Clayton County - GA	93	79	88.4%	75.6%-94.9%
Cobb County - GA	85	67	80.0%	67.3%-88.6%
Coweta County - GA	27	22	79.5%	54.1%-92.8%
DeKalb County - GA	137	113	85.4%	75.9%-91.6%
Douglas County - GA	27	20	83.5%	60.7%-94.4%
Fayette County - GA	19	14	89.0%	66.8%-97.0%
Forsyth County - GA	23	18	79.6%	56.7%-92.0%
Fulton County - GA	137	117	86.4%	76.4%-92.6%
Gwinnett County - GA	76	61	83.7%	70.8%-91.6%
Henry County - GA	32	29	87.7%	66.1%-96.3%
Newton County - GA	19	15	79.2%	51.7%-93.1%
Rockdale County - GA	17	11	80.8%	56.3%-93.2%

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 Atlanta service area was significantly higher than that observed in the US as a whole. The screening proportion of the service area was not significantly different than the State of Georgia.

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 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 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 service area had substantially different screening proportions than the service area as a whole.

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 %
Georgia	62.8 %	32.9 %	0.5 %	3.7 %	91.8 %	8.2 %	45.5 %	31.0 %	12.3 %
Komen Greater Atlanta Service Area	55.3 %	38.1 %	0.6 %	6.0 %	89.6 %	10.4 %	43.9 %	28.2 %	10.0 %
Cherokee County - GA	90.3 %	6.9 %	0.6 %	2.3 %	90.9 %	9.1 %	46.0 %	29.7 %	10.7 %
Clayton County - GA	24.7 %	69.3 %	0.7 %	5.3 %	88.2 %	11.8 %	39.8 %	24.8 %	7.7 %
Cobb County - GA	66.5 %	27.9 %	0.5 %	5.1 %	88.4 %	11.6 %	45.0 %	29.0 %	10.0 %
Coweta County - GA	78.2 %	19.3 %	0.4 %	2.1 %	93.8 %	6.2 %	46.7 %	30.8 %	11.8 %
DeKalb County - GA	36.6 %	57.5 %	0.6 %	5.4 %	91.8 %	8.2 %	44.0 %	29.4 %	10.7 %
Douglas County - GA	55.1 %	42.4 %	0.5 %	2.0 %	92.0 %	8.0 %	44.2 %	27.7 %	9.9 %
Fayette County - GA	73.2 %	21.7 %	0.4 %	4.7 %	93.7 %	6.3 %	56.4 %	39.0 %	14.8 %
Forsyth County - GA	88.8 %	3.5 %	0.5 %	7.1 %	91.0 %	9.0 %	46.0 %	27.3 %	10.1 %
Fulton County - GA	46.2 %	47.5 %	0.4 %	5.8 %	92.7 %	7.3 %	42.7 %	28.3 %	10.6 %
Gwinnett County - GA	60.8 %	26.8 %	0.9 %	11.4 %	81.0 %	19.0 %	42.1 %	25.5 %	8.1 %
Henry County - GA	56.2 %	39.8 %	0.4 %	3.6 %	94.2 %	5.8 %	44.4 %	27.1 %	9.5 %
Newton County - GA	55.0 %	43.4 %	0.3 %	1.2 %	95.5 %	4.5 %	44.6 %	29.0 %	11.3 %
Rockdale County - GA	48.3 %	49.1 %	0.4 %	2.2 %	91.5 %	8.5 %	48.1 %	32.3 %	12.2 %

Data are for 2011.
Data are in the percentage of women in the population.
Source: US Census Bureau – Population Estimates

Table 2.5. Population characteristics – socioeconomics

Population Group	Less than HS Education	Income Below 100% Poverty	Income Below 250% Poverty (Age: 40-64)	Un-employed	Foreign Born	Linguistic-ally Isolated	In Rural Areas	In Medically Under-served Areas	No Health Insurance (Age: 40-64)
US	14.6 %	14.3 %	33.3 %	8.7 %	12.8 %	4.7 %	19.3 %	23.3 %	16.6 %
Georgia	16.0 %	16.5 %	37.6 %	9.9 %	9.7 %	3.3 %	24.9 %	37.3 %	20.7 %
Komen Greater Atlanta Service Area	11.5 %	13.3 %	31.7 %	10.0 %	15.1 %	4.8 %	5.1 %	17.8 %	20.6 %
Cherokee County - GA	11.0 %	7.7 %	24.4 %	7.3 %	8.5 %	2.7 %	17.1 %	12.3 %	18.1 %
Clayton County - GA	17.9 %	18.4 %	48.1 %	14.4 %	14.7 %	5.9 %	0.9 %	0.0 %	25.3 %
Cobb County - GA	9.5 %	11.3 %	26.2 %	8.5 %	15.2 %	4.0 %	0.2 %	0.0 %	18.2 %
Coweta County - GA	12.8 %	11.1 %	28.7 %	7.0 %	5.7 %	2.1 %	32.9 %	91.6 %	16.6 %
DeKalb County - GA	11.7 %	17.1 %	36.4 %	12.5 %	16.3 %	5.6 %	0.3 %	9.0 %	23.1 %
Douglas County - GA	13.7 %	12.7 %	34.1 %	12.3 %	8.6 %	2.3 %	15.8 %	0.0 %	20.0 %
Fayette County - GA	6.5 %	5.9 %	16.1 %	7.0 %	9.1 %	1.6 %	18.2 %	0.1 %	11.4 %
Forsyth County - GA	9.4 %	6.6 %	16.8 %	7.4 %	13.2 %	3.6 %	9.9 %	100.0 %	14.6 %
Fulton County - GA	9.9 %	15.9 %	34.8 %	9.8 %	12.8 %	3.8 %	1.1 %	13.0 %	22.1 %
Gwinnett County - GA	12.9 %	12.4 %	31.6 %	9.2 %	25.5 %	9.8 %	0.5 %	0.0 %	22.3 %
Henry County - GA	10.3 %	9.5 %	29.8 %	9.6 %	7.4 %	1.5 %	13.9 %	100.0 %	17.8 %
Newton County - GA	16.4 %	14.0 %	40.2 %	12.6 %	6.5 %	1.3 %	31.2 %	100.0 %	22.1 %
Rockdale County - GA	14.9 %	12.9 %	35.5 %	12.6 %	11.4 %	3.0 %	14.9 %	0.0 %	22.1 %

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

The following counties have substantially larger Black/African-American female population percentages than that of the service area as a whole:

- Clayton County
- DeKalb County
- Fulton County
- Newton County
- Rockdale County

The following county has a substantially larger API female population percentage than that of the service area as a whole:

- Gwinnett County

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

- Gwinnett County

The following county has a substantially lower education level than that of the service area as a whole:

- Clayton County

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

- Clayton County

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

- Clayton County

The county with a substantial foreign born and linguistically isolated population is:

- Gwinnett 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 Atlanta 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.

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 Atlanta 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
Clayton County - GA	Highest	13 years or longer	13 years or longer	%Black/African-American, education, poverty, employment
DeKalb County - GA	Highest	13 years or longer	13 years or longer	%Black/African-American
Fulton County - GA	Highest	13 years or longer	13 years or longer	%Black/African-American
Henry County - GA	Highest	13 years or longer	13 years or longer	Rural, medically underserved
Cherokee County - GA	High	7 years	13 years or longer	Rural
Douglas County - GA	Medium High	13 years or longer	3 years	Rural
Fayette County - GA	Medium High	1 year	13 years or longer	Rural
Gwinnett County - GA	Medium High	4 years	13 years or longer	%API, %Hispanic/Latina, foreign, language
Cobb County - GA	Medium	7 years	2 years	
Newton County - GA	Medium	13 years or longer	Currently meets target	%Black/African-American, rural, medically underserved
Coweta County - GA	Medium Low	2 years	2 years	Rural, medically underserved
Rockdale County - GA	Low	2 years	Currently meets target	%Black/African-American, rural
Forsyth County - GA	Lowest	Currently meets target	Currently meets target	Medically underserved

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 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.

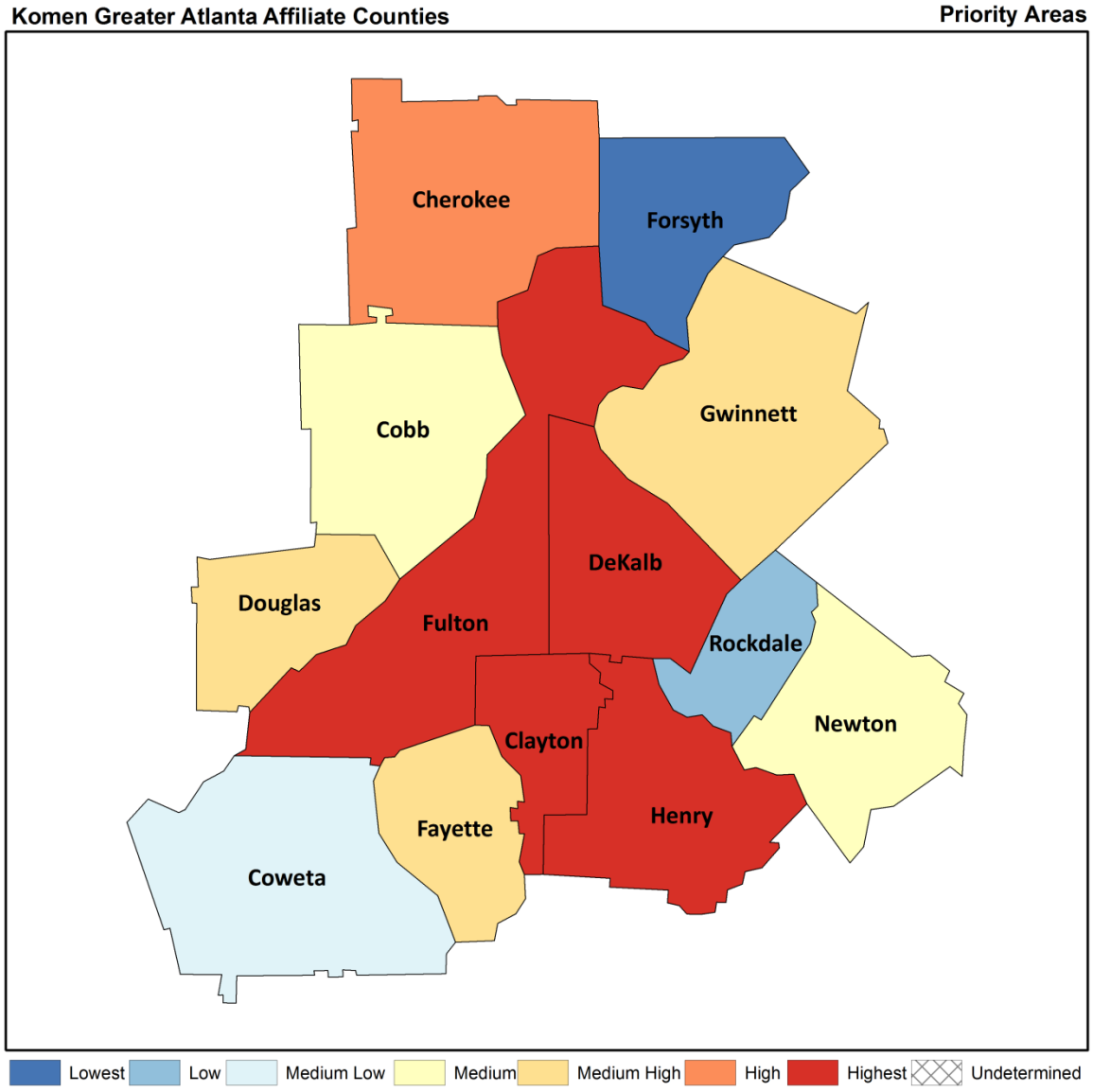

Figure 2.1. Intervention priorities

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

Four counties in the Komen Greater Atlanta service area are in the highest priority category. All of the four, Clayton County, DeKalb County, Fulton County and Henry County, are not likely to meet either the death rate or late-stage incidence rate HP2020 targets.

The death rates in Fulton County (29.2 per 100,000) are significantly higher than the service area as a whole (24.4 per 100,000). The late-stage incidence rates in DeKalb County (51.8 per 100,000) are significantly higher than the service area as a whole (46.5 per 100,000).

Clayton County has a relatively large Black/African-American population, low education levels, high poverty percentages and high unemployment. DeKalb County has a relatively large Black/African-American population. Fulton County has a relatively large Black/African-American population.

High priority areas

One county in the Komen Greater Atlanta service area is in the high priority category. Cherokee County is not likely to meet the late-stage incidence rate HP2020 target.

Selection of Target Communities

Susan G. Komen Greater Atlanta is comprised of a 13 county service area, encompassing more than 46 percent of the State of Georgia's population. Counties within the service area are Cherokee, Clayton, Cobb, Coweta, DeKalb, Douglas, Fayette, Forsyth, Fulton, Gwinnett, Henry, Newton, and Rockdale. Komen Greater Atlanta's service area as a whole has higher age-adjusted breast cancer incidence rates, death rates, and late-stage diagnosis rates than the state as a whole, and Georgia fares worse on these measures than does the general population in the United States (Table 2.1). Komen Greater Atlanta endeavors to serve individuals throughout all 13 counties because the need is high throughout the service area. However, in order to focus the organization's resources and goals over the next four years, Komen Greater Atlanta has chosen five target communities within the service area. Target communities are those that are at the greatest risk for experiencing gaps in breast health services, barriers in access to care, or those that are home to populations most vulnerable to experiencing poor breast health outcomes.

The selection of Komen Greater Atlanta's target communities was based primarily on data from Healthy People 2020, a comprehensive United States federal government initiative that sets measurable objectives for improving community health outcomes. While Healthy People 2020 measures a variety of health outcomes, Komen Greater Atlanta reviewed goals relating to reducing late-stage breast cancer diagnosis (defined as Stage 3 or Stage 4) and breast cancer deaths. Target communities were chosen based on the amount of time communities are anticipated to need in order to meet Healthy People 2020 breast cancer targets.

In addition to Healthy People 2020 data, Komen Greater Atlanta also reviewed data including but not limited to county level when selecting target communities:

- Incidence rates and trends
- Death rates and trends
- Late-stage rates and trends
- Breast cancer screening percentages
- Percentage of residents living below the federal poverty level
- Percentage of residents living without health insurance
- Unemployment levels
- Percentage of residents who are linguistically isolated and/or foreign born.

Based on these criteria, Komen Greater Atlanta has chosen the following target communities:

- Cherokee County
- Clayton County
- DeKalb County
- Fulton County
- Henry County

Cherokee County

Cherokee County is primarily a rural county in the northern portion of the Komen Greater Atlanta service area. The county is a high priority county based on Healthy People 2020 measures and is anticipated to need 13 or more years to meet the late-stage incidence target and seven years to meet the death rate target (Table 2.7). Cherokee County has the highest annual percentage increase in both breast cancer incidence and late-stage diagnosis in the service area at 7.6 percent and 7.9 percent, respectively. The Komen Greater Atlanta service area as a whole has a 0.0 percent change in incidence rate and a -0.5 percent change in late-stage diagnosis, meaning that Cherokee County is an extreme outlier on these measures and is moving away from rather than towards Healthy People 2020 targets (Table 2.1).

Breast cancer screening percentages are also a concern in Cherokee County. While 77.5 percent of women (CI 57.2 percent - 89.9 percent) age 50 to 74 reported receiving a screening mammogram within the last two years, this percentage is the lowest in the service area (Table 2.3).

The health systems analysis will examine access to and barriers to breast health care in Cherokee County along with investigating what changes have been or are taking place in the County for breast cancer incidence and late-stage diagnosis to have risen so rapidly in recent years.

Clayton County

Clayton County is an urban county in the southern portion of the Komen Greater Atlanta service area, just south of the City of Atlanta. Clayton County is designated as a Healthy People 2020

highest priority county, anticipated to need more than 13 years to meet both the death rate and late-stage incidence targets (Table 2.8). Clayton County's breast cancer incidence rate is slightly lower than rates throughout the service area, state, and country, but both the county's death rate and late-stage incidence rate are higher than all three comparison groups with the exception of the county's late-stage diagnosis rate being just below the service area rate.

Table 2.8. Clayton County breast cancer statistics

	Clayton County	Komen Greater Atlanta Service Area	Georgia	United States
Incidence Rate	117.0	128.7	121.5	122.1
Death Rate	26.9	24.4	23.4	22.6
Late-stage Rate	46.1	46.5	45.5	43.8

* All rates are age-adjusted rates per 100,000 women

Socioeconomic factors indicate individuals living in Clayton County may have difficulty accessing affordable breast health care. Nearly half of Clayton County residents live below 250 percent of the federal poverty level, and more than a quarter do not have health insurance (Table 2.9). These rates are the highest in the Komen Greater Atlanta service area. The county also has a low high school completion rate along with a high unemployment level and slightly elevated linguistic isolation percentage.

Table 2.9. Clayton County socioeconomic indicators

	Less than HS Education	Below 250% Poverty	Unemployed	Linguistically Isolated	No Health Insurance
Clayton County	17.9%	48.1%	14.4%	5.9%	25.3%
Komen Greater Atlanta	11.5%	31.7%	10.0%	4.8%	20.6%
Georgia	16.0%	37.6%	9.9%	3.3%	20.7%
United States	14.6%	33.3%	8.7%	4.7%	16.6%

* Data in the percentage of people in the population

Additionally, Clayton County has a significantly higher percentage of women who identify as Black/African-American at 69.3 percent than does the service area at 38.1 percent (Table 2.4). This is significant because of the comparatively high breast cancer morbidity rate among Black/African-American women as compared to White women and the general population.

While Clayton County is located in close proximity to the metropolitan center of the service area, the county lacks any public transportation creating a barrier that keeps women from accessing breast health services in a nearby county. The health systems analysis will look deeper at this and other structural or cultural barriers that exist for the women of Clayton County in addition to surveying the breast health resources that are available for women in this area.

DeKalb County

DeKalb County is the second most populous county in metro Greater Atlanta and in the Komen Greater Atlanta service area. Based on Healthy People 2020 targets, it is a highest priority county that will likely need more than 13 years to meet both death rate and late-stage incidence targets (Table 2.7). The age-adjusted incidence rate, age-adjusted death rate, and late-stage diagnosis rate for DeKalb County all exceed the Komen Greater Atlanta, Georgia, and US

population rates, and DeKalb's late-stage diagnosis rate is the highest in the service area (Table 2.10).

Table 2.10. DeKalb County breast cancer statistics

	DeKalb County	Komen Greater Atlanta Service Area	Georgia	United States
Incidence Rate	135.0	128.7	121.5	122.1
Death Rate	26.1	24.4	23.4	22.6
Late-stage Rate	51.8	46.5	45.5	43.8

* All rates are age-adjusted rates per 100,000 women

DeKalb County's high breast cancer incidence rate could be related to the fact that 85.4 percent (CI = 75.9 percent - 91.6 percent) of women in the county report receiving a mammogram in the last two years, meaning that fewer cancers go undetected in DeKalb County than is the case in counties with lower screening percentages (Table 2.3). If this is the case, however, it is particularly concerning given the elevated late-stage diagnosis. Either women are not getting mammograms early enough to detect cancer early, or the mammograms are not effectively detecting cancer.

DeKalb County is one of the service area's most racially and ethnically diverse counties. White women comprise 36.6 percent of women in the county, Black/African-American women 57.5 percent, and Asian/Pacific Islanders 5.4 percent (Table 2.4). Additionally, 8.2 percent of women in the county are Hispanic/Latina, and 16.3 percent are foreign born (Table 2.4, Table 2.5). Because the county is so diverse, finding culturally competent care may be difficult for all women in the area. Low health insurance rates may also serve as a barrier to breast health care in DeKalb County; 23.1 percent of people age 40-64 in the county do not have health insurance (Table 2.5).

Given both high screening percentages and high late-stage diagnosis rates in DeKalb County, the health systems review will analyze the availability and accessibility of breast health services for all women. Cultural competence of breast health services will also be reviewed to ensure that available breast health service providers are equipped to serve the county's diverse population.

Fulton County

Fulton County is the largest county in the Komen Greater Atlanta service area based both on geography and population. One in five women in the Komen Greater Atlanta service area lives in Fulton County (Table 2.1). The county is a highest priority county based on Healthy People 2020 data and is anticipated to need more than thirteen years to meet target rates for both death rate and late-stage incidence (Table 2.7). The age-adjusted incidence rate, age-adjusted death rate, and late-stage diagnosis rate for Fulton County all exceed the Komen Greater Atlanta, Georgia, and US population rates, and the death rate is the highest in the service area (Table 2.11).

Table 2.11. Fulton County breast cancer statistics

	Fulton County	Komen Greater Atlanta Service Area	Georgia	United States
Incidence Rate	135.1	128.7	121.5	122.1
Death Rate	29.2	24.4	23.4	22.6
Late-stage Rate	49.6	46.5	45.5	43.8

* All rates are age-adjusted rates per 100,000 women

Minority race and ethnicity women comprise the majority of the female population in Fulton County with 46.2 percent of women identifying as White, 47.5 percent identifying as Black/African-American, 5.8 percent identifying as Asian/Pacific Islanders, and 7.3 percent of women of Hispanic/Latina decent (Table 2.4). Similar to DeKalb County, this means that cultural competency among breast health care providers is of the utmost importance in Fulton County. The racial and ethnic composition of the county is also important because, despite lower breast cancer incidence, non-White women may have poorer breast cancer outcomes than White women.

Many women in Fulton County may also experience barriers to breast health care for socioeconomic reasons as 34.8 percent of adults age 40-64 live on less than 250 percent of the federal poverty level (Table 2.5).

One of the most important tasks of the health systems analysis will be to examine the distribution of breast health services in Fulton County to understand whether or not they are available to all individuals in the county given the geographic and demographic diversity of the county. The analysis may also help to explain why, despite higher rates of mammography than the service area average, state, and U.S. population, Fulton County has the highest death rate in the service area.

Henry County

Henry County is a mixed urban and rural county in the southern part of the Komen Greater Atlanta service area, just outside of the Atlanta metropolitan center. Henry County has the smallest population of the target communities with 4.5 percent of the service area's population (Table 2.1). The entire county is designated as a medically underserved area (Table 2.5).

Henry County is a highest priority county with regard to the Healthy People 2020 targets and will likely need more than 13 years to meet the initiative's death rate and late-stage incidence goals (Table 2.7). Breast cancer incidence in Henry County is slightly lower than the service area, state, and country, but the death rate and late-stage diagnosis rates are elevated (Table 2.12).

Table 2.12. Henry County breast cancer statistics

	Henry County	Komen Greater Atlanta Service Area	Georgia	United States
Incidence Rate	118.2	128.7	121.5	122.1
Death Rate	25.1	24.4	23.4	22.6
Late-stage Rate	45.6	46.5	45.5	43.8

* All rates are age-adjusted rates per 100,000 women

The late-stage diagnosis rate particularly concerning in that Henry County is experiencing a 5.1 percent annual increase in late-stage diagnosis (Table 2.1). Given that Henry has a high rate of screening mammography with 87.7 percent (CI = 66.1 percent - 96.3 percent) of women age 50 – 74 reporting a mammogram within the last two years, it is possible that some of the late-stage diagnoses are due to an increase in screening mammography in the county.

Because Henry County is just outside of the metropolitan center where many low cost and no-cost breast health services are located and the county itself is in a medically underserved area, it may be difficult for all women in Henry County who need mammograms to access affordable services. One of the tasks of the health systems analysis will be to investigate how women in the county can access breast health care as needed.

Health Systems Analysis Data Sources

Data for the Health Systems Analysis was compiled from a wide variety of local, state, and federal resources listing breast health resources including:

- The Food and Drug Administration's list of certified mammography centers
- The National Association of County and City Health Official's list of health departments
- Lists of Health Centers and Free Clinics
- Lists of specially accredited or certified centers

Komen Greater Atlanta staff also used existing relationships with grantees and the local breast cancer community to identify facilities in addition to conducting internet searches to locate any services and resources that may have previously been unknown to Komen Greater Atlanta. Once facilities and organizations were located, the services provided at each location in the target counties were verified either by the organization's website or a phone call to the organization.

Komen Greater Atlanta staff and Community Profile Committee members reviewed the resources for each county by assembling the information collected into a spreadsheet with a separate worksheet for each target community. Organizations were listed in the county where they operate, regardless of the counties from which their constituents come. Collecting all of the services providers for a target area on one sheet allowed Komen Greater Atlanta staff to view the strengths and weaknesses of each area with regards to the availability of services in the area.

In addition to assessing the structure and availability of services in the target communities, Komen Greater Atlanta also conducted an assessment of local, state, and federal policies that impact access to breast health care in the service area. The Public Policy Analysis follows the Health Systems Analysis and helps to provide a more thorough explanation of barriers to education, screening, and care in the target communities.

Health Systems Overview

The Breast Cancer Continuum of Care (CoC) is a model that shows how a person typically moves through the health care system for breast care (Figure 3.1). An individual would ideally move through the CoC quickly and seamlessly, receiving timely, quality care in order to have the best outcomes. Education can play an important role throughout the entire CoC. While a person may enter the continuum at any point, ideally, a person would enter the CoC by getting screened for breast cancer – with a clinical breast exam or a screening mammogram. If the screening test results are normal, she would loop back into follow-up care, where she would get another screening exam at the recommended interval. Education plays a role in both providing education to encourage people to get screened and

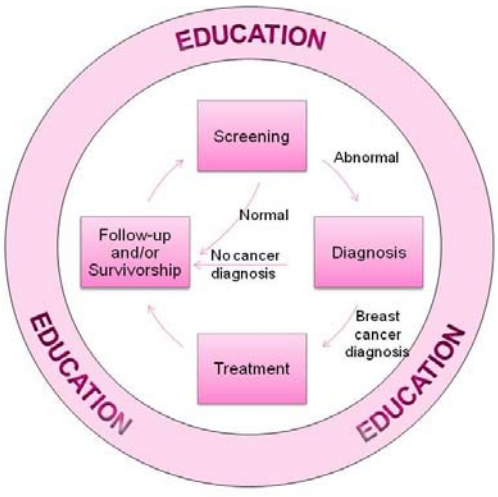

Figure 3.1. Breast Cancer Continuum of Care (CoC)

reinforcing the need to continue to get screened routinely thereafter.

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

If breast cancer is diagnosed, she would proceed to treatment. Education can cover such topics as treatment options, how a pathology reports determines the best options for treatment, understanding side effects and how to manage them, and helping to formulate questions a person may have for her providers.

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

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

Mission Related Partnerships and Opportunities

Cherokee County

Komen Greater Atlanta's primary partners in Cherokee County are Northside Hospital and WellStar hospitals along with their offices (Figure 3.2). Northside is a longtime Komen Greater Atlanta grantee and serving uninsured and underinsured people throughout the service area. Northside's recent expansion into Cherokee County provides more breast health resources in the area than were previously available, but Northside's free and low-cost screening resources are limited given the demand for their services. WellStar also receives Komen Greater Atlanta screening and diagnostic funding, though the majority of their funds are spent screening individuals in other counties.

The county health department is also an important point of access in the county, but the health department primarily screens women age 50-64 through clinical breast exams and refers out for mammograms when necessary. Women who do not fall within these guidelines or who are undocumented immigrants may not be able to be screened within the county if they cannot pay for services. Northside and WellStar hospitals are the primary providers of treatment and

support services for breast cancer patients, but individuals may need to drive to neighboring counties for ancillary services. Survivorship resources and non-medical support including legal aid, financial assistance, and counseling are limited in the area.

In order to better meet the needs of individuals in Cherokee County, Komen Greater Atlanta needs to seek out relationships with the county health department and community clinics in the area – particularly those that can serve Spanish-speaking individuals. Throughout the service area, Komen Greater Atlanta will also begin to invest in survivorship programs given their scarcity in and for the target populations identified.

Clayton County

Clayton County has one health department office that provides clinical breast exams and mammography referrals and one hospital that provides for the full continuum of breast health care, and they are supplemented by a few community health centers and free clinics that can provide clinical breast exams and referrals (Figure 3.3). The county is geographically close to many providers in Fulton County and the City of Atlanta, but there is no public transportation in Clayton County, and transportation assistance is scarce.

Komen Greater Atlanta partners with the Clayton County Health Department and the Women's Center at Spivey Station to pay for breast screenings, diagnostics, and lymphedema care. Komen Greater Atlanta grants increase the number of individuals who can be screened through the programs, but additional partnerships are needed to reduce transportation and other economic barriers to screening. Mobile mammography is one potential solution to this challenge, but there are no mobile mammography providers serving the area regularly at this time.

DeKalb County

DeKalb County is metro Atlanta's second most populous county. It is home to Emory University Hospital, a large private research institution and Georgia's only NCI designated cancer center, and DeKalb Medical Center, a public hospital (Figure 3.4). Grady Hospital, the metro area's largest indigent care facility, serves DeKalb County residents but is located in neighboring Fulton County. These hospitals provide services along the entire continuum of breast health care. Several free clinics and community health centers are also located in DeKalb County, but these clinics typically perform clinical breast exams only and provide referrals to the hospitals for additional services.

Though there are a number of high quality breast health services in DeKalb County, the resources are not enough to meet the needs of the entire population, especially the uninsured and immigrant populations in the northern part of the county. This is particularly true since the closing of DeKalb Medical Foundation's Wellness on Wheels (WoW) in 2013. WoW formerly provided mobile mammography services for a large portion of the uninsured and underinsured population in the area. There is no other organization providing such a high volume of free or low-cost screenings in the county, so people must cross into a neighboring county for services. Because of a large recent immigrant population in the county, language is also a significant barrier to education, screening, diagnostics, and treatment for much of the population.

Since the closing of WoW, Komen Greater Atlanta does not have a large volume breast screening partner in DeKalb County. Komen Greater Atlanta partners with and provides grants to a number of smaller organizations who provide clinical breast exams and refer out for mammography, but there are not sufficient hospitals and screening facilities conducting low cost mammograms in the county to serve all of the population in need. Komen Greater Atlanta

should seek out partners to fill this need and continue to invest in culturally competent breast health education and services for the diverse population in the county.

Fulton County

Fulton County has the largest population in the metro Atlanta area and is home to branches of five hospital systems, including the region's largest public hospital (Figure 3.5). These hospitals provide the majority of free and low cost mammography, diagnostics, and treatment not only for individuals who enter the CoC via the hospitals but also the majority of free or low-cost mammography, diagnostics and treatment for individuals referred from more than thirty health departments, community health centers, and free clinics in the area. Many people also travel to Fulton County from neighboring counties with less medical resources, so the resources within the county are strained.

Komen Greater Atlanta funds three of the hospital systems located in Fulton County (Northside, Grady, and Piedmont) along with nonprofit organizations who outreach to specific populations in need including Black/African-American women, Hispanic/Latinas, Asian Americans, new immigrant and/or transient populations, and LGBTQ individuals. Komen Greater Atlanta also has a long time partnership with the Fulton County health department. Opportunities for the future include developing greater infrastructure within Fulton County to serve both the county residents and those who travel to the area while also maintaining smaller and highly competent outreach and screening programs that are best at educating hard to reach or highly underserved populations.

Henry County

Henry County has few breast health providers (Figure 3.6). Piedmont Henry Hospital is the only organization providing at least one service in each part of the continuum of care. Some services, such as breast MRI, are not available in the county because Piedmont Henry refers to their main campus in Fulton County for those services. Henry County does have one health department location and a handful of community clinics providing free or low-cost clinical breast exams, but those organizations must refer patients to another facility for imaging or treatment.

Piedmont Henry is Komen Greater Atlanta's only current partner in Henry County. Komen Greater Atlanta should work to develop additional partnerships in the area to increase access to screening and other resources. As a semi-rural county with few medical facilities, Henry County would also benefit from mobile mammography services. Komen Greater Atlanta will continue to work to make mobile mammography more accessible in target areas.

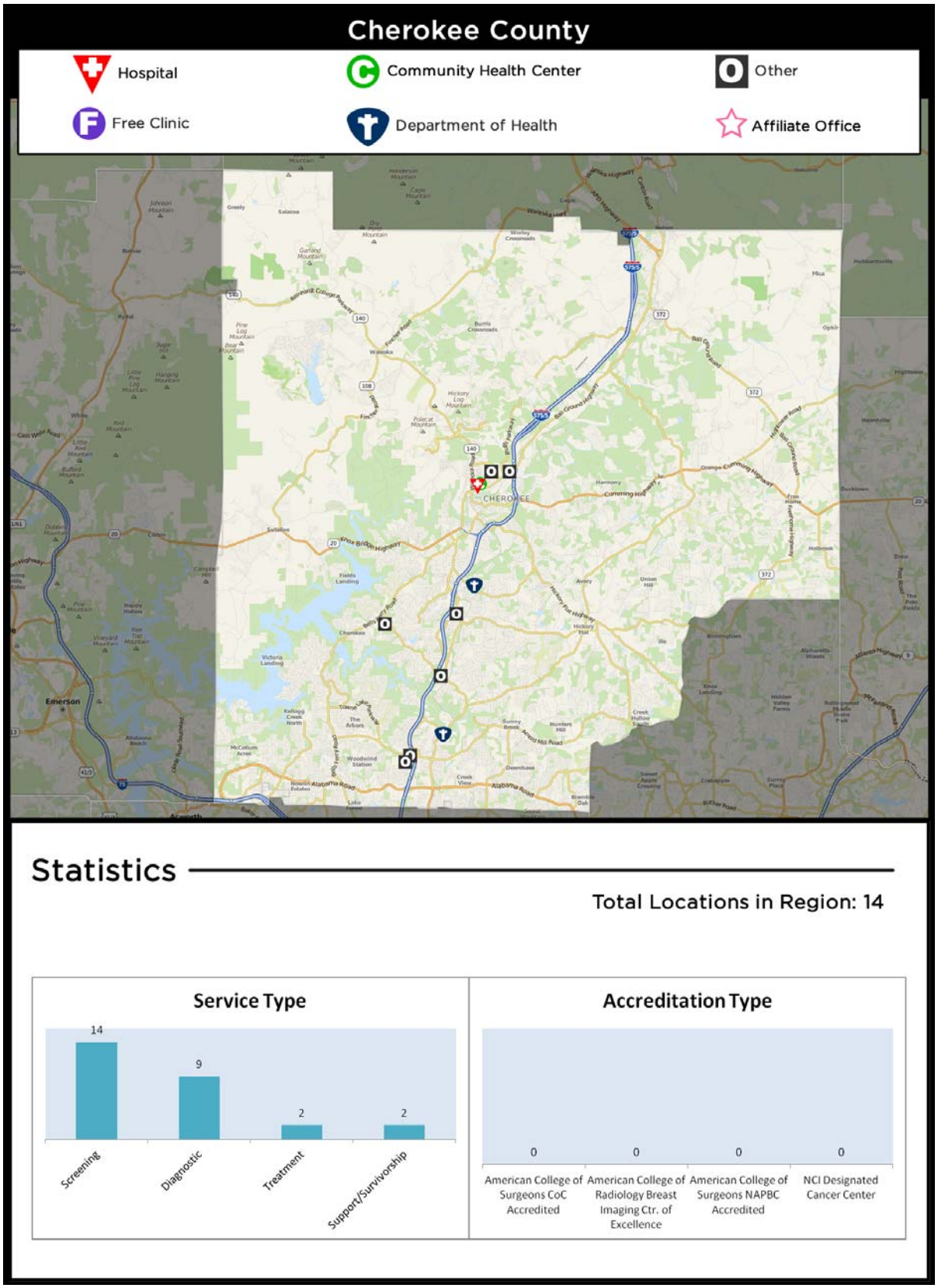

Figure 3.2. Breast cancer services available in Cherokee County

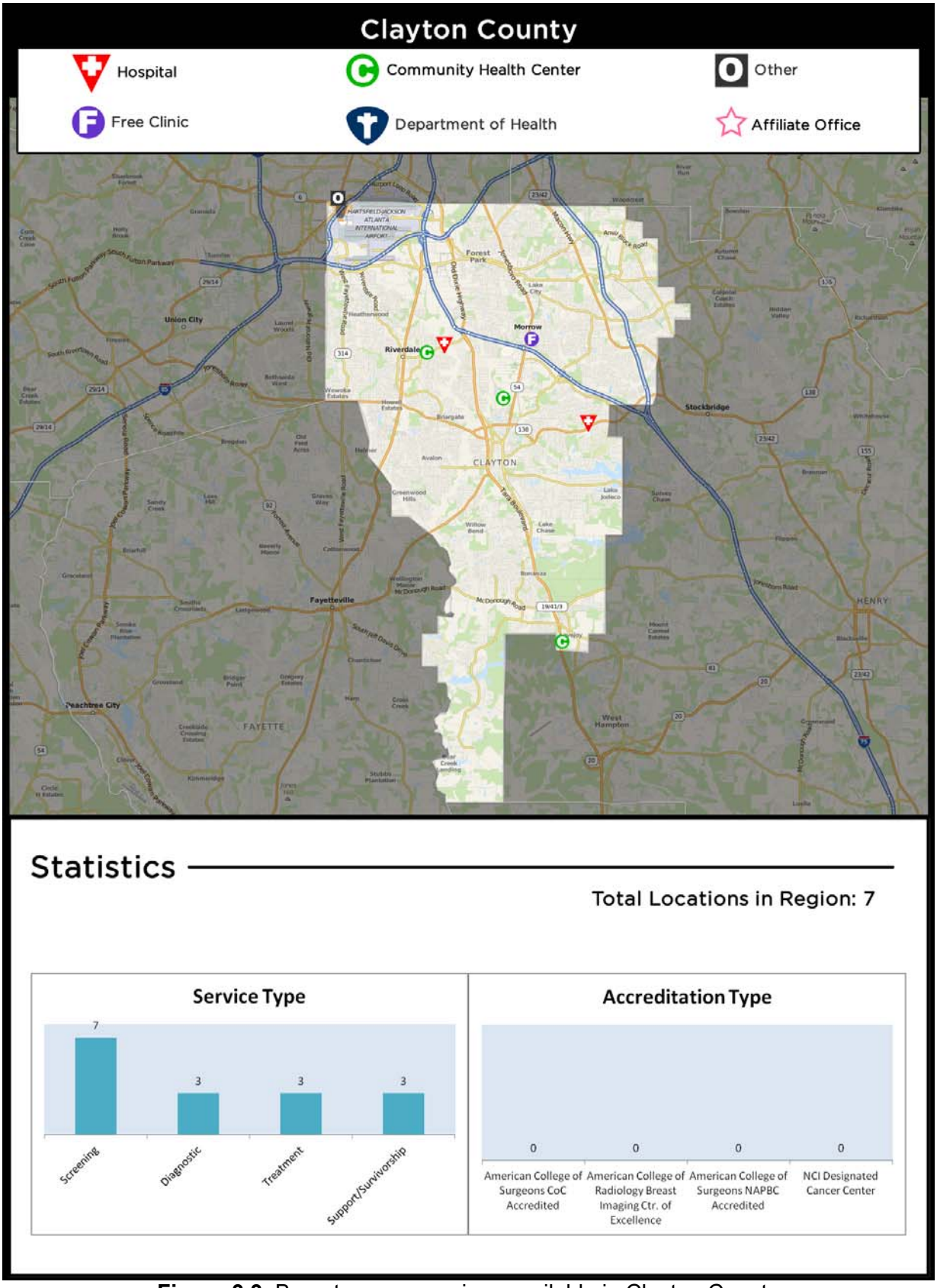

Figure 3.3. Breast cancer services available in Clayton County

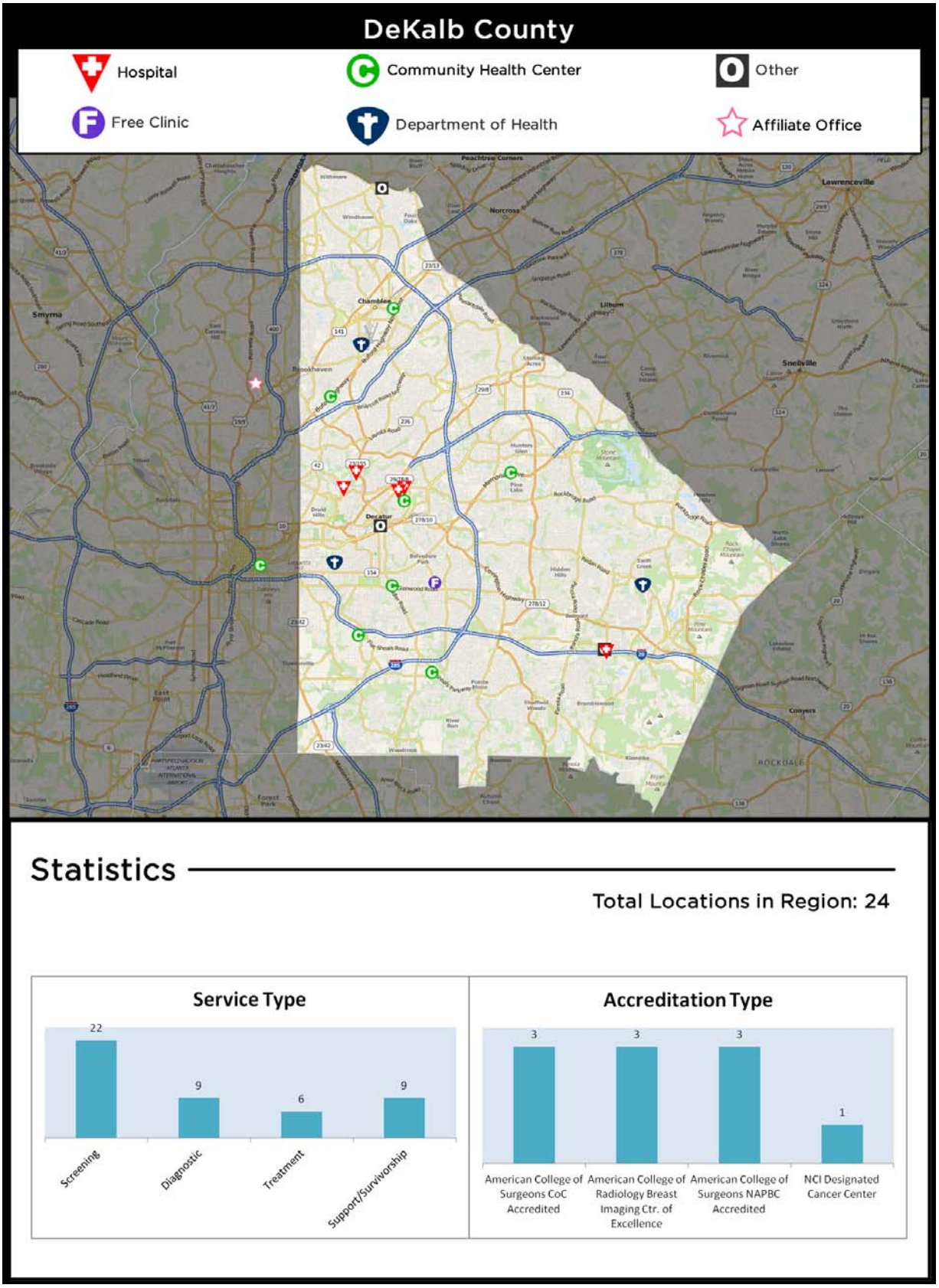

Figure 3.4. Breast cancer services available in DeKalb County

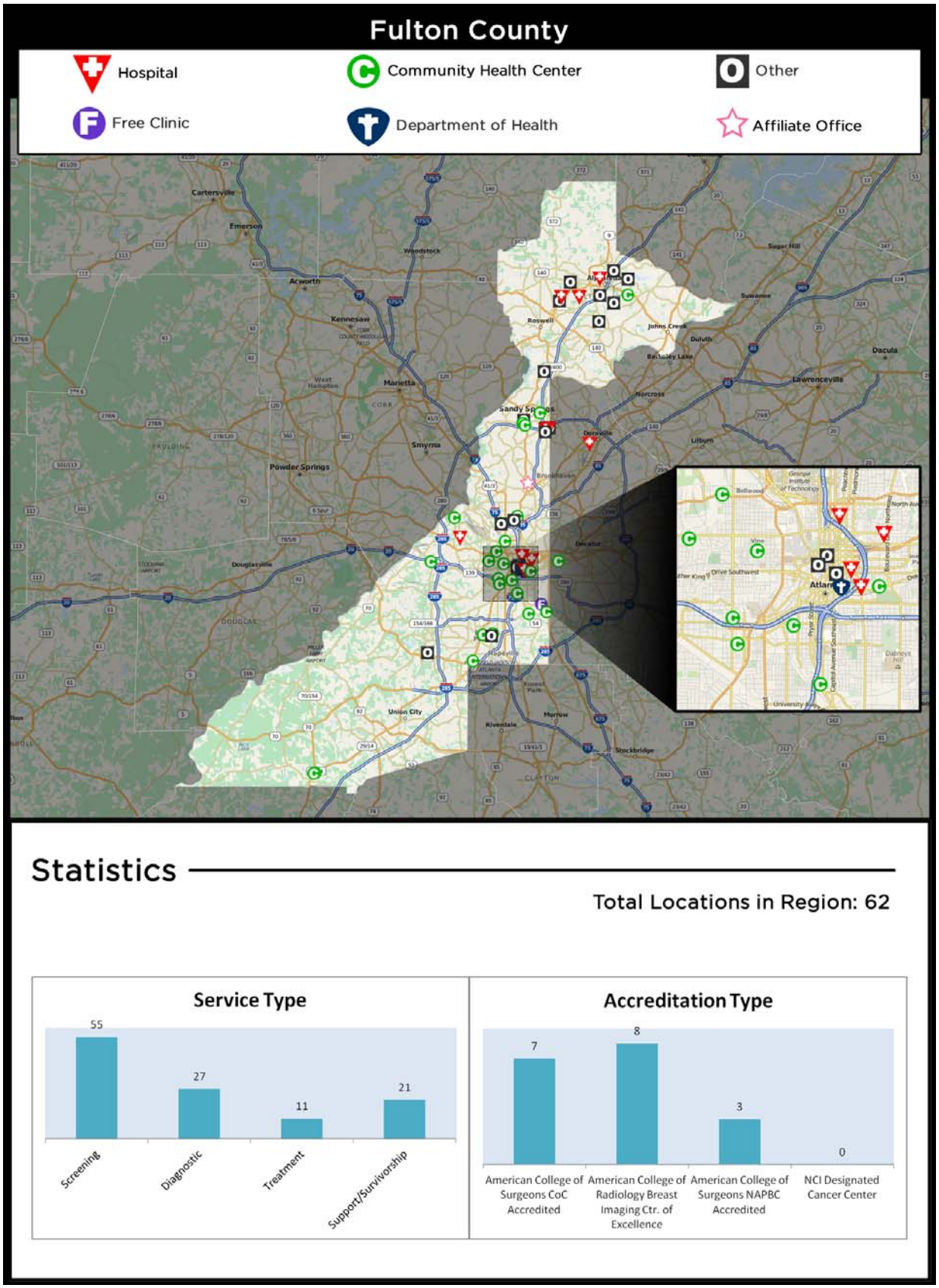

Figure 3.5. Breast cancer services available in Fulton County

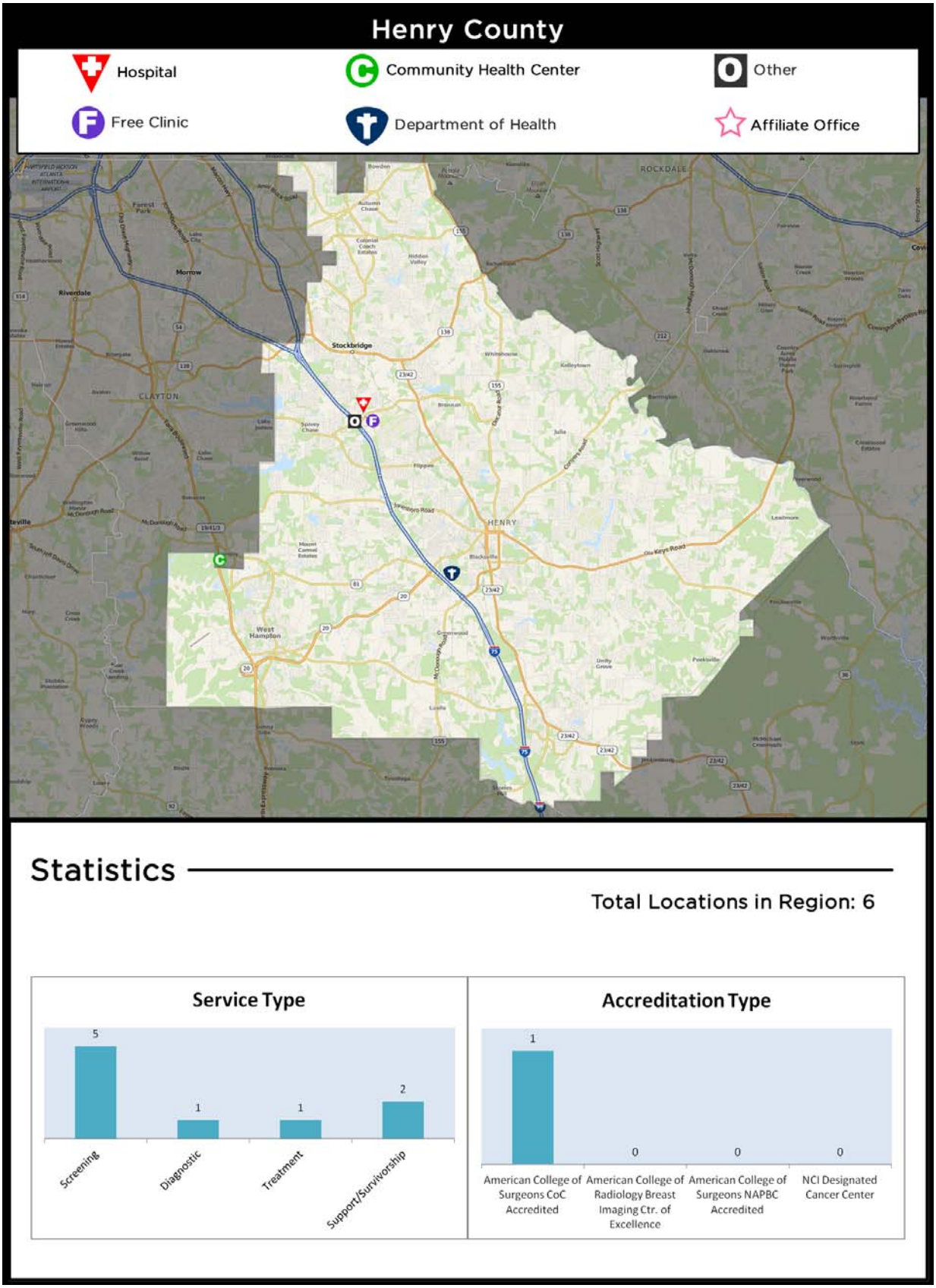

Figure 3.6. Breast cancer services available in Henry County

Public Policy Overview

National Breast and Cervical Cancer Early Detection Program

Overview

The National Breast and Cervical Cancer Early Detection Program (NBCCEDP) strives to provide low-income uninsured and underinsured women with access to cancer screenings for breast and cervical cancer. NBCCEDP was established in 1991 through the Breast and Cervical Cancer Death Prevention Act of 1991 and is implemented through the Centers for Disease Control and Prevention (CDC). Within Georgia, approximately 35,000 women were provided with mammography services through the NBCCEDP between 2008 and 2012 (CDC NBCCEDP 2014).

State Policy

In Georgia, the state's public health department runs the Georgia Breast and Cervical Cancer program (BCCP), funded by both federal and state revenues through the NBCCEDP, the Master Settlement Agreement, and state resources. Despite its funding sources, the state only receives enough funding to provide breast cancer services to 16,000 women (Cobb & Douglas 2014), covering less than 15 percent of the program's eligible population (CDC Georgia 2014).

To be eligible for the BCCP, women must be a resident of the state, between the ages of 40 and 64, low-income (less than 200 percent of the federal poverty level), and uninsured. Through the BCCP, eligible women will receive clinical breast examinations, mammograms, and diagnostic evaluation in case of abnormal results. Should results be conclusive of breast cancer, women will be referred to treatment options through Georgia's Women's Health Medicaid Program. In order to enroll in the program or find a BCCP provider, women can contact their local county public health department (Georgia Department of Public Health 2014).

Treatment Options

Once diagnosed with breast cancer, women are eligible for Georgia's Women's Health Medicaid program, provided that they meet the same low-income requirements of the BCCP program, are younger than 65 years old, and do not have insurance or coverage for cancer treatment. In comparison to other states, Georgia has a less restrictive treatment option – women eligible for Medicaid are not required to have been diagnosed through the BCCP program. If her provider receives NBCCEDP funding and the administered service was within the scope of the state's program, a diagnosed woman can enroll in Georgia's Medicaid program (ACS 2010). Consequently, Georgia's less restrictive treatment option allows for a greater number of low-income and uninsured women to receive proper medical attention for her diagnosis, as well as any other medical needs throughout the course of her disease.

The effects of the BCCP and subsequent Medicaid treatment have been significant within Georgia. Studies have shown that through the passage of the BCCPTA and extension of the Women's Health Medicaid program, women are more likely to enroll in Medicaid earlier – the time between diagnosis and enrollment decreased by seven to eight months (Adams, Chien, Florence, & Raskind-Hood, 2009). In comparison to other traditional Medicaid eligible groups, women enrolled through the BCCPTA were more likely to receive treatment (Adams, Chien, Gabram-Mendola, 2012), demonstrating that the program has become a path for greater access to services within the state.

Komen Greater Atlanta and the NBCCEDP

In order to support the NBCCEDP program, which remains significantly underfunded through its current sources, Komen Greater Atlanta provides grants to health programs and providers that

administer NBCCEDP services through its competitive community grants program. Due to the support of Komen Greater Atlanta, these providers are able to screen more women and refer them to appropriate medical treatment if diagnosed. Komen Greater Atlanta will continue to monitor the state of NBCCEDP funding and the availability of providers in the service area, funding providers through the grants program when possible and appropriate. Komen Greater Atlanta will also advocate for continued or expanded funding for the NBCCEDP in keeping with Komen advocacy priorities.

Georgia Comprehensive Cancer Control Program

Overview

In 1998, the CDC established the National Comprehensive Cancer Control Program in an effort to reduce cancer-related morbidity and death through the creation of coalitions, assessment of burden and priorities, and development of tailored plans within each state (CDC NCCCP, 2013). Consequently, the Georgia Comprehensive Cancer Control Program (GCCCP) was created as part of the CDC's national initiative. The GCCCP is run by the Georgia Department of Public Health and aligns its goals and efforts with those of the Healthy People 2020 National Objectives. The GCCCP brings together various stakeholders from the Georgia Cancer Control Consortium to develop the Georgia Cancer plan, in which priority cancer conditions are highlighted and plans of action are determined to help reduce rates of morbidity and death (Georgia Department of Public Health, 2013).

GCCCP Breast Cancer Objectives

In the 2014-2019 Georgia Cancer Plan, the GCCCP has outlined several priority areas to focus its attention, including breast cancer. The GCCCP acknowledges that breast cancer remains a leading cause of death within the state, and that if certain efforts, including increased screening percentages, are undertaken, prevalence and death rates can be greatly reduced.

The breast cancer specific objectives outlined in the plan seek to ensure that all women have access to high quality screening, genetic screening, counseling, and preventative services. In order to meet their objectives, the GCCCP strives to sustain current community-based screening programs that focus on racial and ethnic minority groups, with the goal of reducing disparities in screening percentages by 10 percent by 2019. Additionally, the GCCCP aims to promote genetic screening in an effort to increase the proportion of high-risk individuals receiving genetic risk assessment and appropriate screening by 25 percent. Furthermore, the GCCCP seeks Medicaid and state insurance reimbursement for genetic testing and counseling, as well as preventative procedures such as mastectomies in high-risk individuals. Additional preventative measures, such as educational campaigns focused on screening, the promotion of breastfeeding (which is linked to reducing the risk of breast cancer), as well as reduction in obesity, are also initiatives supported by the GCCCP (Georgia Cancer Control Consortium, 2013).

Komen Greater Atlanta and the GCCCP

Komen Greater Atlanta works with the Georgia Center for Oncology Research and Education (CORE) and other members of the GCCCP to increase screening in medically underserved communities. Komen Greater Atlanta has limited coordination in advocacy efforts with the GCCCP at the present time, but Komen Greater Atlanta will work over the next four years to partner with the GCCCP to promote legislation and policies that are mutually beneficial.

The Affordable Care Act

Overview

In 2009, the Affordable Care Act (ACA) was signed to improve access to health care and transform the American health care system. The provisions of the ACA are particularly beneficial to the risk reduction and treatment of breast cancer. Through the individual mandate and expansion of Medicaid, the law ensures that more people will receive insurance, consequently improving their access to health care and treatment. Additionally, women with already diagnosed breast cancer cannot be prevented from receiving insurance due to pre-existing conditions, or dropped from their existing plans due to their health state (ACS, 2013). Prior to the implementation of the ACA, many private insurance plans enforced gender rating, in which women were required to pay higher premiums for the same coverage as men – however, with the ACA, private plans are no longer allowed to charge women more than men (National Women's Law Center, 2013).

The ACA also requires health plans, both private and public, to cover the cost of recommended preventative services. Mammograms will be provided at no cost to the patient, beginning at age 40 (based on the 2002 U.S. Preventative Services Task Force guidelines) for all insured women, in addition to BRCA1 and BRCA2 testing and counseling for high-risk women.

Medicaid Expansion in Georgia

When initially signed, the ACA stipulated that states must expand their Medicaid eligibility to include individuals up to 138 percent of the federal poverty line. To cover the costs of the expansion, the federal government would fund 100 percent of the expenditures for the newly eligible population until 2016 and gradually decrease its contribution to 90 percent by 2020. However, in the case of *National Federation of Individual Business v. Sebelius*, the Supreme Court found the Medicaid mandate unconstitutional and instead left the decision to expand Medicaid to each state's discretion.

As a result of the Supreme Court's decision, Georgia decided not to expand its Medicaid eligibility. Consequently, Medicaid is limited to parents below 38 percent of the federal poverty line, resulting in a gap in which childless adults and those between 38 and 138 percent are not eligible for Medicaid. Prior to the implementation of the ACA, an estimated 2,107,000 individuals were uninsured within Georgia (Holahan, Buettgens, Carroll, & Dorn, 2012). As of April 2014, this number was reduced to 1,849,000 (Henry Kaiser Foundation, 2014). Conversely, if Georgia decided to expand Medicaid, the percentage of uninsured would have been reduced by 51.3 percent (Holahan, Buettgens, Carroll, & Dorn, 2012).

Effects of the ACA on the NBCCEDP

Due to Georgia's decision not to expand Medicaid, more than 266,000 women will not have access to health insurance (ACS, 2013), indicating that the need for screenings through the NBCCEDP and coverage through Women's Health Medicaid remains significant within the state. However, due to the individual mandate and the essential benefits covered through the ACA, women who are able to purchase individual plans through the market with the aid of tax credits and subsidies, or women who were previously underinsured, will now have access to no-cost screenings and will not be prevented from enrolling in insurance due to their gender or pre-existing conditions. With this decrease in the population in need of NBCCEDP services, more women can be screened through the program.

Conversely, the provisions of the ACA do not cover diagnostic tests after the initial screening. Follow-up or secondary testing such as biopsies and other imaging may be subject to deductibles or copayments; consequently, low-income women may not be able to afford the

additional costs and may further delay treatment. NBCCEDP funding covers additional diagnostic tests and can provide coverage to women in need. Nevertheless, the program remains underfunded and requires continued and increased funding to support its services and provide screenings and testing for all women in need.

Effects of the ACA on Providers

By improving access to health insurance, as well as guaranteeing coverage of essential benefits, the ACA allows for the reduction of uncompensated care that many providers had to face, as well as increases the number of patients that will be seen by providers. Furthermore, insurance companies will be held more accountable for their payments to providers and cannot deny or rescind patient coverage. Stronger integration of care across providers will also facilitate better communication between different providers in the care of their patient and decrease administrative burden that often hinders effective care.

Effects of the ACA on Komen Greater Atlanta

As a result of the ACA, the number of uninsured women who require access to breast cancer screenings and treatment will decrease slightly in Komen Greater Atlanta's service area. However, Georgia's decision not to expand Medicaid ensures that a significant portion of the population continues to require assistance through NBCCEDP and community health centers aided by Komen Greater Atlanta. In particular, undocumented immigrants, who are excluded from federally funded insurance as well as subsidies in the insurance marketplace, remain a noteworthy population that requires assistance in accessing breast cancer screenings and treatment.

Komen Greater Atlanta's Public Policy Activities

Oral Chemotherapy Advocacy

Komen Greater Atlanta was a supporter of Georgia's House Bill 943, the Cancer Treatment Fairness Act (16). HB 943 addresses the issue of oral chemotherapy parity by amending state law to allow for a reduction in the patient's cost-sharing requirements for oral therapies. Oral anticancer medications have become increasingly popular, as they eliminate barriers to treatment accessibility such as transportation and time costs associated with intravenous chemotherapy. Prior to the passage of HB 943, intravenous and oral anticancer medications were considered as separate benefits – intravenous chemotherapies were covered under health plans, while oral chemotherapies under prescription plans. Consequently, oral drugs often cost patients significantly higher payments compared to intravenous drugs, resulting in patients' failure to fill prescriptions due to high costs.

To eliminate the discrepancy between intravenous and oral drugs, HB 943 requires private health plans to cover oral cancer treatments, shifting coverage away from prescription plans and eliminating its cost-barriers. Furthermore, a limit of $200 per month is placed on patients' copayments, coinsurance, or deductibles. Although Komen Greater Atlanta supports the legislation, the success of the bill is not complete; Komen Atlanta was advocating for a $50 per month cap on patients' out-of-pocket costs. While $200 is an improvement to the previous cost structure, studies have shown that 10 percent of patients tend to forego treatment if out-of-pocket costs are greater than $100. Therefore, Komen Greater Atlanta continues to advocate for the further reduction of patients' costs.

Metastatic Breast Cancer Awareness Forum

In October 2013, in recognition of Breast Cancer Awareness month, Komen Greater Atlanta sponsored the Breast Cancer Awareness Forum at the Georgia State Capitol, in conjunction with the Georgia Women's Legislative Caucus and the Center for Black Women's Wellness. The

event brought together legislatures, advocates, and survivors for a policy briefing that highlighted the need for risk reduction in Georgia, as well as increase awareness of the issue.

Georgia State Laws- Medicaid Limitations

In addition to addressing the issue of oral chemotherapy parity, HB 943 includes a clause that prevents any state agency from using funds in activities deemed to advocate or influence citizens in supporting Medicaid expansion. Through this restriction, the bill essentially limits the advocacy surrounding expansion and allowing citizens to become informed of its merits.

Similarly, HB 990 constrains the power of future governors and leaders from expanding Medicaid without prior legislative approval (HB 990, 2014). As the ACA left the decision of Medicaid expansion to the discretion of state governors, HB 990 represents a severe limitation on the power of future governors. Given Georgia's history, expansion of Medicaid in the near future seems unlikely through the passage of this bill.

As previously discussed, Georgia's expansion of Medicaid would allow for thousands of women to access regular screenings and ensure healthier outcomes. Georgia's decision not to expand has resulted in a gap between women who have insurance and those who cannot afford it, further constraining the limited resources provided by the NBCCEDP.

Health Systems and Public Policy Analysis Findings

Future Policy Improvements

1. ***Expand Medicaid*:** Despite the restrictions placed on Medicaid expansion through house bills 943 and 990, Georgia would greatly benefit in expanding Medicaid to low-income, childless adults. Increased accessibility to insurance and health care would allow for thousands of women to receive recommended screenings, address risk factors, and receive necessary treatment for breast cancer. Additionally, by providing coverage to this population of women, funding for NBCCEDP services can be redirected to reach additional populations not covered by insurance, especially immigrant women and women with language and literacy barriers that limit their utilization of screenings and services.
2. ***Further reduce the cost of oral anticancer medication*:** Although the passage of the Cancer Fairness Treatment Act greatly improves upon the parity issue surrounding oral therapies, the cap on out-of-pocket costs to the patient remains too high for many low-income patients. Consequently, treatment compliance will be negatively affected within this population, hindering successful treatment and recovery. Komen Greater Atlanta continues to advocate for a reduction in out-of-pocket costs from $200 to $50 per month.
3. ***Expansion of Women's Health Medicaid*:** Currently, Georgia employs treatment option 2, in which women who are screened by providers who receive NBCCEDP funding are eligible for Women's Health Medicaid. However, when the BCCPTA was initially enacted within the state, Georgia opted for treatment option 3. During this period, all eligible uninsured and underinsured women, regardless of provider, were able to enroll in Women's Health Medicaid in the event of positive diagnosis. If Georgia reverts back to option 3, the gap in treatment and insurance coverage for diagnosed breast cancer patients will be greatly minimized.

Additional Goals

Despite the many recent changes (both improvements and limitations) to preventative measures and access to care, gaps still exist among women in Komen Greater Atlanta's service area. Undocumented immigrants are exempt from receiving federal or state financed health coverage,

and represent a significant population that lacks proper access to screening and treatment services. Additionally, women with language and literacy barriers are often unaware of their screening options and providers. Consequently, Komen Greater Atlanta seeks to improve accessibility of services among this population with outreach efforts and funding providers within immigrant populations to facilitate communication and better use of offered services. Furthermore, additional funding should be provided to support BCCP programs, as the program covers only a minimal portion of the eligible population, and Georgia's decision not to expand Medicaid retains a substantial population in need of BCCP services.

Qualitative Data: Ensuring Community Input

Qualitative Data Sources and Methodology Overview

Since there is often a disconnect between provider suggestions and recommendations and what the community expresses that they want and need, the Affiliate sought to gain input from the community members themselves. This section of the Community Profile aimed to assess barriers to care that may not be captured by quantitative data.

Focus groups and key informant interviews were conducted to determine the breast health knowledge, screening behaviors, identified barriers and awareness of women living within the five target counties. Women in the target communities who had sought access to breast screenings in the last two years (whether or not the screening was completed) and breast cancer survivors were primarily involved in the focus groups. Breast health care providers participated in key informant interviews to explain barriers to care from an institutional perspective or that they have experienced as they navigate patients through the continuum of care.

Focus groups were conducted by Louise Palmer, a consultant for Southern Research and Evaluation Institute. The Consultant attempted to recruit participants for two focus groups in each target community through leveraging existing Komen Greater Atlanta partnerships and conducting new outreach in each community. She then moderated each focus group with the assistance of a volunteer note taker and prepared a report summarizing the findings. Key informant interview questions were asked at regular site visits to current grantees serving the target communities, and additional key informant interviews with breast health care providers were conducted by the Komen Greater Atlanta Community Outreach and Grants Manager. Ten focus groups and 40 key informant interviews were attempted; seven focus groups and 28 interviews were completed. The interviews and focus groups were designed to investigate three primary questions:

- To what extent are there barriers to accessing breast health services* in Clayton, Cherokee, Dekalb, Fulton, and Henry Counties?
- To what extent are there gaps in the breast health continuum of care in Clayton, Cherokee, Dekalb, Fulton, and Henry Counties?
- To what extent are women satisfied with the breast health services they have received in Clayton, Cherokee, Dekalb, Fulton, and Henry Counties?
  *Breast health services include breast cancer screening, diagnosis, and treatment services

A variety of non-random sampling techniques were used to recruit focus group and key informants. Community partners were identified that had the ability to identify women that met the sampling criteria. These partners were then able to invite women to participate in the focus groups. Recruitment flyers were also posted in community service agencies in the target communities. Key informants were chosen by beginning with Komen Greater Atlanta grantees and using a snowball sampling technique, asking interviewees and community contacts for other providers in the target communities. It is important to note that there are some limitations to data collected using convenience sampling, particularly in that it may decrease generalizability. This means that these results may not be fully generalizable to the larger public, as respondents were not chosen at random, and thus, the sample may not be fully representative of the target population.

In both the focus groups and key informant interviews a trained volunteer, intern, or Komen Greater Atlanta staff person took notes during the interviews, and the interviewer also made

process notes immediately after the sessions. After all data were collected, notes were coded and analyzed for significant themes. The emergent themes are outlined in this report.

All focus group participants were informed about the goal of the focus groups and were asked to sign a consent form. Individuals were not identified by name in the Consultant's report, so all comments remain anonymous. Each focus group participant was compensated with a $10 gift card, and those participants who needed transportation assistance were provided with transportation reimbursement. Key informants were briefed on the purpose of the interviews, and neither their names nor specific affiliations are released, maintaining informant anonymity.

Qualitative Data Overview

Focus groups

Focus group participant numbers and demographics

A total of 49 women participated in the focus groups and interviews. Of these, 15 were breast cancer survivors. In terms of socioeconomic demographics, the majority of participants identified as Black/African-American (73 percent). Of the remainder, 13 percent of women identified as White, nine percent as Hispanic/Latino, and two percent as American Indian/Alaskan Native.

The education status of participants varied. Eleven percent of participants did not graduate high school. For 18 percent of participants, the highest level of educational attainment was high school graduation. Nine percent of participants graduated college with a bachelor's degree and 11 percent with a graduate degree. Almost half of participants (49 percent) had between a vocational certificate and some college education. While the education status of participants varied somewhat, the majority of participants can be described as low-income. Although 27 percent of women declined to provide their annual household income, of those who did, fully 61 percent reported a household annual income less than $20,000. In terms of age, 33 percent of participants were between the ages 40-49 years, 31 percent 50-59, and 33 percent 60-69.

Qualitative Data Findings

Barriers to accessing breast health care

The focus groups explored what, if any, challenges prevent women from accessing breast cancer screening, diagnosis, and treatment services. Across counties, several common barriers emerged that prevent women from accessing breast health care services across the breast cancer care spectrum, from risk reduction to treatment including:

- Finances and the inability to pay for services
- Attitudes towards breast cancer, such as fear and stigma
- Factors related to culture and race/ethnicity, such as a lack of culturally appropriate information and providers
- Challenges navigating the health care system for services and resources
- Lack of prioritization of breast cancer as an urgent health issue affecting their community
- Lack of free or low cost transportation to health care facilities
- Lack of knowledge about breast cancer in the community at large

Below are details on each of these topics.

Financial barriers: A uniform finding across all focus groups is the lack of affordable health care options for low income women in Georgia, which directly affected participants' ability to

access breast health care services. Most participants in the mammogram focus group series were ineligible for Medicaid because they did not meet the income thresholds. However, participants stated that health insurance options provided through the Federal Health Insurance Exchange were too expensive to purchase. For example, participants cited health insurance plans costing $70/month for a single policy and $160/week for a family policy as too expensive for their budgets. Many of these participants thought that they would have been eligible for Medicaid had Georgia opted into the expansion. Fully 40 percent of women in the focus groups were uninsured. Of the remaining 60 percent, 40 percent received government-funded health insurance, and 20 percent had private health insurance plans. Of those participants receiving government-funded health insurance, 47 percent were breast cancer survivors.

Uninsured participants described a situation in which they cannot access health care and preventive services during the critical years for early detection of breast cancer. Participants reported finding it stressful to find affordable health care and cited finances as a reason for not having mammograms or clinical breast exams. Instead of paying for preventive health services, participants instead opt to pay bills, buy gas for their cars to get to work, or purchase other family members' prescriptions.

"Health and finance go hand-in-hand…." "The class divide in Georgia is huge…."
"The working poor are ignored…."
"Without health insurance you don't go to the doctor…."
– Focus group participants from the mammogram screening series

Participants also cited finances as a reason they might delay seeing a doctor if they noticed a change in their breasts. Unmet need is a critical measure of access to health care, which is defined as a time in the past 12 months when a person needed to see a doctor but did not. Fully 58 percent of focus group participants reported one or more unmet health care needs in the last 12 months. Excluding women with Medicaid or Medicare, this percentage increases to 88 percent. Thus, Medicaid may provide some buffer against unmet needs and increase access to health care.

Many participants in the mammogram focus group series received their mammograms for free either through the state-funded Breast and Cervical Cancer Program (BCCP) or through the Komen-funded mammogram program. Several women reported years in which they did not receive mammograms when these programs had met their annual quota. Furthermore, several women who had recently learned about the free mammogram programs had gone many years—over ten in some instances—without a mammogram.

The exception to these findings is Cherokee County in which all the women had health insurance and stated that finances were not a barrier to accessing breast health services. Indeed, these women stated that Cherokee County is affluent compared to other Metro Atlanta counties. However, Cherokee County participants also stated that there are pockets where low-income families live, such as around Teasley Middle School and further north in the county.

For breast cancer survivors, "breast cancer is very, very, very expensive."
- Breast Cancer Survivor

Sixty-seven percent of the breast cancer survivors in the study had Medicaid or Medicare during treatment. Several participants reported they were uninsured at the time of diagnosis and subsequently received Medicaid. Despite health care coverage, breast cancer survivors described the difficulties of paying out-of-pocket expenses, such as $2000 deductibles, 15

percent coinsurance amounts, and $45 copays. Making these payments was especially hard for breast cancer survivors during the many months they were out of work and receiving only 60 percent of their salary through disability payments. Even with insurance, survivors report scrambling for sparse grants from local nonprofits to pay for daily expenses such as household bills and gas for their cars. One participant depleted her 401K account to pay for treatment. Further, participants report knowing women who turn down treatment because they cannot afford the copay amount.

"I don't know what I would have done without insurance. I shudder [at] the thought. It (cancer) probably would have gone unattended…."
– Breast cancer survivor

Attitudinal barriers: Among all focus groups, participants identified societal attitudes towards breast cancer as a reason why either they, or women in their communities, might not seek breast screening services. Chief among these attitudes, fear of a breast cancer diagnosis remains prevalent. Participants stated that women in their communities adopt an "out of sight, out of mind" approach, whereby avoiding mammograms also avoids a potential cancer diagnosis. A breast cancer survivor who delayed seeing a doctor even though she had health insurance and experienced symptoms explained: "People who don't go, it's got to be fear, fear of the unknown. The big C word. If I don't know about it, I don't have to worry about it. I was busy but it wouldn't have taken long to get it checked out. It had to be an element of fear. "What you don't know don't [sic] hurt you"—it's a lie, but that's the mentality..."

There may also remain an element of stigma and taboo in discussing female health issues. One participant felt that women in her community (Henry County) do not have the information they need about breast health screenings because "women are still ashamed to talk about women's health." Indeed, breast cancer survivors agreed that a diagnosis of breast cancer remains stigmatizing to the extent that they avoided telling people about their diagnosis.

"People's reaction to breast cancer is stigmatizing; it's (telling people) a coming out process…."
– Breast cancer survivor

Culture and race/ethnicity: The findings indicate that current education and outreach efforts to Hispanic/Latino and Black/African-American communities need improvement to better reach and resonate with these groups of women. Hispanic/Latina participants stated that breast cancer is not a topic of conversation at all in the Hispanic/Latino community because of fear, stigma, and a general knowledge deficit about the disease, its cause, and prognosis. Participants explained that many Hispanic/Latinos still regard breast cancer as a death sentence, and subsequently there is a belief that early detection through screenings provides no benefit. Similarly, one participant explained that in the

Hispanic/Latino culture, "the focus is on healing, not sickness," and as such there is rarely dialogue about disease risk reduction. In addition to possible language barriers, participants also suggested that it is especially hard for undocumented immigrants to receive screening services because they are ineligible for government-funded programs.

Some Black/African-American participants indicated that breast cancer is not generally perceived as a topic of concern for their community. Rather, other diseases such as HIV, diabetes, and heart disease are considered more pressing health issues for Black/African-Americans. Indeed, one participant stated that even doctors do not emphasize breast cancer as a high priority for Black/African-Americans, but instead screen for other diseases with high

prevalence rates in the Black/African-American community. Another participant said that, until she knew of a Black/African-American friend with breast cancer, she considered it "not a Black/African-American issue. It's a white disease." Other participants explained that women think breast cancer is "an old woman's disease." Therefore, education and outreach initiatives in both Hispanic/Latino and Black/African-American communities should emphasize that breast cancer is a disease that can and does affect women of all ages in their communities.

" Make it known that it (breast cancer) is an issue that affects the Black/African-American and Hispanic/Latino communities…."
– Hispanic/Latina participant from the mammogram focus group series

Other Black/African-American participants discussed how there is a historical and cultural unspoken rule not to discuss health issues, and that this creates a culture of secrecy around illnesses like breast cancer.

"We were taught as children what goes on in the home, stays in the home. We were taught that health and illness is a secret… you don't want to be ostracized (by talking about it). It's still that way. It's part of our culture. We don't talk about it...."
– Black/African-American breast cancer survivor

Black/African-American participants strongly urged Susan G. Komen to work with their communities to develop health education messaging and outreach campaigns that are culturally appropriate. Participants stated current breast cancer education materials are missing their mark among Black/African-American women because "they do not use our language."

"Talk our language. Be direct. Speak to us the way we talk to each other. Don't make it too medical."
– Black/African-American breast cancer survivor

To resonate culturally with Black/African-Americans, participants suggested placing messaging on beauty products used by Black/African-American women. Also, to overcome the "this won't happen to me" mentality, participants recommended identifying local role models of all ages from the Black/African-American community who have had breast cancer to talk to other women.

In addition to comments about health promotion messaging missing its mark, several Black/African-American participants expressed the importance of finding an Black/African-American breast health provider who they could relate to and with whom they could feel comfortable.

Health care system navigation: In most focus groups, participants expressed frustration navigating the health care system for services and resources, a concern especially heightened for women lacking health insurance and most breast cancer survivors. Low-income women in the mammogram screening groups expressed difficulty navigating the health care system to find free health care services. Across groups, women did not know free breast screening services were available until they discovered about either BCCP or the Komen mammogram program by happenstance. For example, several women stated that they went to the Health Department for another reason and while there, the nurse asked if they had had a mammogram recently. Indeed, participants explained that the Health Department is widely known as the community location for WIC services and not as a place to get preventive screenings. Therefore, better advertising of available services at the Health Departments may increase the number of women

who receive breast screening services. However, participants who use the Health Department applauded the staff there for making the appointment at the mammography imaging center on their behalf and giving women the paperwork they need for the mammogram.

Low-income, Black/African-American participants explained that what services are available in their communities tend to be disjointed from other health care services. For example, while there may be occasional mobile health screening trucks in their neighborhoods, they are disconnected from primary care providers or breast health specialists if a woman needs to be referred.
Breast cancer survivors expressed frustration in finding resources to help them pay for treatment.

Several Black/African-American breast cancer survivors noted the need to train Black/African-American women from their communities as patient navigators to assist women in their neighborhoods with accessing the breast health services they need, especially after a diagnosis. Survivors also suggested a "virtual" navigator program, with simple step-wise advice on what women needed to do after a diagnosis.

Participants also suggested an online clearing house listing free health services for women that they could search and find health resources to meet their needs.

Breast cancer as priority for women: In most focus groups, participants described women as caregivers who put their health needs last, and that this mentality is a barrier to accessing breast health services in a timely manner. As one participant stated, "women are advocates for others first" and themselves last. Most women worked or had families to take care of, and stated that they were too busy with each day's challenges to prioritize their health needs, let alone breast health. Participants strongly agreed that the message to women should be to put their health needs first so that they can be healthy to effectively look after their families. Several participants cited that they decided to get a mammogram when they made the determination to live a long life for their significant others.

"I don't know what it's going to take to have people say "I see about me." Commercials are great but it's just an individual thing. Had it not been for the pain, I would never have gone to see about it (a lump she felt). I don't know what it would take. Just be persistent "let's take care of you. Check yourself."
—Breast cancer survivor

With age, women's feelings towards both prioritizing their health needs and breast cancer appeared to change. As one participant said, "as you get older, you take it (breast cancer) more seriously." With the exception of Cherokee County, participants generally perceived breast cancer messages to be visible in their communities, especially in October. However, unanimously across groups, participants stated that breast cancer does not become a high health priority until you either know someone affected by breast cancer, you have a scare or symptoms yourself, or you have made the mental shift to put your health before others whom you care for. Participants therefore emphasized that breast cancer messaging should focus on the fact that this really could happen to you.

"Until breast cancer happens in your community, you don't think about it...."
"You don't hear about it unless someone's sick with it...."
– Participants from the mammogram focus group series

Transportation: The availability of public transportation and the extent to which it contributes as a barrier to accessing breast health services varies by county. In Henry and Clayton Counties, participants expressed that transportation could be a barrier to seeking breast health services for women who do not own cars. Clayton County currently has no public transportation, although a recent transit referendum voted to fund reinstatement of a county bus service and future rail service. Therefore, to access health providers, residents must pay for taxis (generally at $2 per mile), get a ride from a friend, or own a car. However, breast cancer survivors pointed out that many women must sell their cars to pay for treatment.

The situation in Henry County is only marginally better. The county transit service is a reservation only service, whereby residents must call ahead to make an appointment and pay $4.00 per stop. Participants complained that sometimes when you call to make an appointment, there are no drivers available to run the service. Further, one breast cancer survivor was unable to take the county transit service to her appointments because her breast health specialist was located over the county line and out of the jurisdiction of the transit service.

In North Fulton, participants felt the transportation difficulty would affect seniors the most because of potential mobility limitations. Otherwise, participants reported no difficulties in traveling to breast health providers, other than distance to providers. In Dekalb County, participants felt there were many transportation options available and they also reported no problems getting to appointments. Participants in Cherokee County felt that most people had cars and would not move to the county otherwise. However, they did acknowledge transportation to health services may be a challenge for some people.

Knowledge: Participants across all focus groups were well informed about breast cancer screening recommendations. Indeed, 74 percent of participants who answered the question “at what age should women have annual mammograms” answered correctly. Further, the majority of participants had had a mammogram in the last 12 months. Therefore, at least among this sample, lack of knowledge about screening advice is not a major barrier to accessing care. However, participants suggested that other women in their communities might not seek routine breast health screening services if they were asymptomatic, but rather only if they experienced breast pain or identified a lump. As one participant explained, “they feel well and so are not going to get a mammogram.” A few participants also said that people in their communities believe there’s a breast cancer cure and that survival rates are good, therefore there is no need for early detection. This belief is in direct contradiction to the perception among Hispanic/Latinos that breast cancer is a death sentence.

Several participants across focus groups expressed a desire to know the cause of breast cancer and how they could prevent it. For breast cancer survivors, this knowledge gap extended to a wish to participate in long-term research studies collecting data from survivors. Further, when asked what they would do if they noticed a change in their breasts, several women said they would go to the emergency room, rather than to their primary care provider.

Therefore, the findings regarding knowledge gaps in the sample are conflicting. Participants expressed good levels of understanding about annual screening requirements, but their knowledge on causes and risk reduction strategies was mostly absent. Additionally, participants described misunderstandings in the community at large about breast cancer and what they should do were they to experience breast changes.

Provider attitude: It is possible that some women are discouraged from accessing breast health services because of real or perceived negative provider attitudes. Women expressed that

they have experienced negativity from health care providers in general because of their uninsured health status and feel that compared to insured women, they receive "the bare minimum treatment." Participants also stated that they often feel rushed at breast health appointments and expressed a desire for doctors to slow down, be more attentive, and provide more details about the screening test and any findings. However, many women also reported they felt satisfied with the care they received from their breast health provider.

Breast health providers
Participants in North Fulton, Henry, and Clayton Counties feel strongly that their communities lack general health care options for low-income people – both in terms of health care providers and resource centers that can advise them on available free or low-cost services.

In Henry and Clayton Counties, the Health Departments are critical safety net service providers to the un/underinsured. However, some participants were unable to get free wellness visits at the Health Departments unless they had symptoms or could not afford the sliding scale fee offered. Even a sliding scale of $30 for annual tests was cited as too much by one participant, who as a consequence is past due a checkup for several chronic conditions. This participant was able to get her mammogram through the Komen program. Therefore, while a critical health care resource in low-income communities, Health Departments are limited in the services they provide and offer only a "Band-Aid solution" to the un/underinsured.

For participants undergoing treatment for breast cancer in Clayton and Henry Counties, there were limited options for imaging, treatment centers, and support groups. However, there is a new breast health center in Henry County and as a result, participants expect to see improvement in the services at the hospital.

Breast cancer survivors in Dekalb and Fulton Counties did not have any problems finding a breast health specialist, but some participants felt their doctor choice was limited by the insurance they had. Participants in Cherokee County felt there are plenty of convenient breast health options for women seeking screening and treatment services and that providers in the area are well respected.

Outreach gaps and suggestions
Participants felt that more outreach and education in their communities is necessary across all age groups. Participants in Cherokee County in particular said they see very little in the county in terms of breast cancer messaging. Participants in all groups emphasized that outreach and education on breast cancer should be yearlong and not just in October. Participants felt that breast cancer awareness organizations were not engaging certain communities – in particular, poor neighborhoods, Hispanic/Latina and immigrant communities, seniors, and women under the age of 40.

"In October you see the pink ribbons everywhere, but the outreach people don't go in the poor neighborhoods…."
"Make yourself visible…." "You can't start too young…."
– Participants from the mammogram focus group series

The role of church in health
The role of religion and faith in women's health were dominant themes in all the focus groups. For some women, the lack of a safety net is compensated for by faith. Indeed, participants shared a deeply held belief that their faith in God would assist their health care struggles. Many

breast cancer survivors discussed their diagnosis in terms of their symptoms being a sign from God. In one instance, a participant ignored her symptoms until she received this "signal."

"For a couple of months I just ignored it. I'm a woman of extreme faith and that is what got me through it. At the end of June, I started to have pain and it was God's way of saying it's time to make a decision (about her course of treatment). God allows everything to happen for a reason."
– Breast cancer survivor discussing her two month delay in getting breast cancer treated after diagnosis

"The information was overwhelming. I had to pray . . . I didn't want to deal with it for awhile…."
– Breast cancer survivor

"We (the Black/African-American community) put a lot into our faith…."
– Breast cancer survivor

The experience of breast cancer survivors
Breast cancer diagnosis: Breast cancer survivor group participants discovered that they had breast cancer either because they experienced symptoms or through a routine mammogram. A few women delayed seeking medical advice after experiencing symptoms. One survivor experienced symptoms on and off for eight years before she went to her primary care provider. After visiting a health care provider, most participants experienced a swift diagnosis, and their providers helped them with the next steps – from referring them to an imaging center, discussing the mammogram findings, referring them to a biopsy surgeon, discussing the results, and referring them to an oncologist and treatment facility.

The survivors advocated for this seamless system, which is not always the experience. Indeed, one survivor in Henry County had a very different and difficult diagnosis experience. After the lump was discovered, the imaging center gave the survivor two biopsy provider options, and only one of these options was local (the other being in Cobb County). The local biopsy option was a thoracic surgeon who was unable to answer the survivor's questions when the cancer diagnosis was returned. The surgeon was also unable to provide the survivor with referrals to a breast specialist. A friend referred the participant to a local breast health specialist, but she was unable to get an appointment for several weeks.

The participants strongly agreed that standalone imaging centers require training on how to give diagnoses to women and provide the information they need for the next steps. The participants suggested that all imaging centers should be integrated into a system of breast health care with clear protocols on the steps to take upon a diagnosis. Survivors complained that imaging centers feel "like a cattle chute" and "like a business."

Breast cancer treatment: After diagnosis, women had to wait up to one month for treatment, which they said was too long. During the waiting period, the women did not sleep and worried greatly about if the cancer was growing during this time. One survivor discussed how she had a difficult time deciding on her course of treatment after being given two different options to consider: "I didn't like either option (total mastectomy, or partial with radiation). I couldn't wrap my head around losing my breast."

Most of the survivors were prescribed Tamoxifen for four years post radiation. The women expressed feelings of frustration that they had to take more drugs after finishing radiation, especially one that causes side effects, including the chance for uterine cancer. Consequently,

several survivors commented that they inconsistently take Tamoxifen. Survivors also discussed how they now have other co-morbidities as a result of breast cancer treatment. Participants expressed the difficulty of working through treatment and suggested legislation changes so that women do not have to do so.

Breast cancer support: All the survivors stated that they received the most amount of support from their church and their breast cancer survivor support group. However, survivors agreed that there should be more support groups and that they should be highly visible, as "you only hear about them by word of mouth." Not all survivors went to a survivor group because they preferred to handle it by themselves. Furthermore, participants said some women do not like to go to survivor groups because they are depressing.

The general consensus was that breast cancer continues to be stigmatizing in the community at large, and even if they had a great support group of friends and family, only at a survivor group could they access the level of empathy and support that made them no longer feel alone. However, participants pointed out that there are financial barriers to accessing support groups when women do not have transportation. Also, when women are really sick, they are unable to leave the house to go to a support group.

"I didn't feel like I needed a survivor specific group because I had so much support from church. But it was the best thing in the world. I didn't know I needed it until I went. They get it…."
– Breast cancer survivor.

Additional sources of support came from hospital-based breast cancer patient navigators. Patient navigators, in the cases mentioned, were breast cancer survivors and greeted women as they signed in for their treatment appointments, stayed with them if needed, provided them information, and answered their questions. Survivors who did not receive help from a navigator thought that it would have been helpful.

Women wished there was meals delivery assistance and education on the types of foods to eat to promote recovery. Finally, breast cancer survivors said that the co-survival model of support had been helpful to them and their friends or family and that there need to be more spousal support groups. In all, survivors advocated for greater levels of visible support in their communities both for women with breast cancer and their families.

Survivorship years: Despite side-effects from cancer medications and the financial burden of cancer treatment, survivors are looking for ways to stay healthy, have fun, and help other women in their communities who have breast cancer. Survivors are especially looking for low impact exercise classes that are appropriate for their physical condition, for example, chair yoga. Survivors asked that classes also have options for women working full-time.

Key Informant Interview Data
Key informant interviews generally supported the observations made by focus group members but elucidated a few additional themes:

1. Breast health care providers were generally aware of some free and low cost screening programs but feel that demand far exceeds the available resources. This perceived or actual deficit in available services may keep providers from referring asymptomatic women who may need a breast exam.
2. Providers noted that many of their patients with insurance had difficulty with diagnostic or treatment copays and out of pocket expenses.

3. Providers, with the exception of nurse navigators, often had little to no resources to offer patients regarding financial assistance and transportation during diagnostics and treatment. Most providers stated that they could connect patients with language translation services, if needed.
4. Providers in Fulton and DeKalb Counties stated that they knew of wellness resources for breast cancer survivors. Providers in Cherokee, Clayton, and Henry Counties did not know of survivorship programs in their home counties.

Breast Health and Breast Cancer Findings of the Target Communities

In order to focus the organization's resources and goals over the next four years, Komen Greater Atlanta has chosen five target communities within the service area. Target communities are those that are at the greatest risk for experiencing gaps in breast health services, barriers in access to care, or those that are home to populations most vulnerable to experiencing poor breast health outcomes.

The selection of Komen Greater Atlanta's target communities was based primarily on data from Healthy People 2020, a comprehensive United States federal government initiative that sets measurable objectives for improving community health outcomes, which showed that all of the five target counties would need 13 or more years to meet the Healthy People 2020 standards relating to breast cancer incidence and death. While Healthy People 2020 measures a variety of health outcomes, Komen Greater Atlanta reviewed goals relating to reducing late-stage breast cancer diagnosis (defined as regional and distant stages) and breast cancer deaths. Target communities were chosen based on the amount of time communities are anticipated to need in order to meet Healthy People 2020 breast cancer targets.

Based on these criteria, Komen Greater Atlanta has chosen the following target communities:

- Cherokee County
- Clayton County
- DeKalb County
- Fulton County
- Henry County

The Health Systems Analysis found that Cherokee, Clayton and Henry counties lack adequate numbers of breast health care providers who see uninsured or underinsured women. While there are several providers in Fulton and DeKalb Counties, these counties continue to see high breast cancer death rates. While services are widely available within these areas, structural and social barriers are preventing women from accessing available services.

The qualitative data gathered from focus groups and key informant interviews in all of the target counties highlighted several key problems in accessing quality care throughout the breast cancer continuum of care including:

- Finances and the inability to pay for services
- Attitudes towards breast cancer, such as fear and stigma
- Factors related to culture and race/ethnicity, such as a lack of culturally appropriate information and providers
- Challenges navigating the health care system for services and resources
- Lack of prioritization of breast cancer as an urgent health issue affecting their community
- Lack of free or low cost transportation to health care facilities

Based on the findings of the three investigative sections in the Community Profile, the Mission Action Plan was developed in order to guide Komen Greater Atlanta's mission work over the next two years. The Mission Action Plan seeks to address the greatest deficits in access to high quality breast health care in the service area and is comprised of problem statements, priorities and measurable program goals to address each priority.

Mission Action Plan

Problem Statements

- According to the Quantitative Data, nine out of13 counties within the service area are 13 or more years away from meeting either the Healthy People 2020 breast cancer death rate target or the late-stage diagnosis target. Of these, four counties (Clayton, DeKalb, Fulton and Henry) are projected to need more than 13 years to meet both targets. Cherokee County is projected to need more than 13 years to meet the late-stage diagnosis target and more than seven years to meet the death rate target.
- According to the Quantitative Data, despite mammography rates at or above the national average, women in the service area experience high late-stage breast cancer diagnosis rates and high breast cancer death rates.
- According to the Qualitative Data, individuals in the service area have difficulty accessing affordable mammography and other breast health services.
- According to the Qualitative Data, culturally competent education and care are not widely available for all people seeking breast health services. Women of color, LGBT individuals, recent immigrants and individuals living below 250 percent of the federal poverty level may be disproportionately impacted and may delay or be denied care due to their socioeconomic status.
- According to the Qualitative Data, breast cancer survivors in the service area have limited access to navigation and support services after their active treatment phase is completed.

Health Systems Change

Priority 1: Increase the number of free or affordable breast health services available in the service area with a focus on Cherokee, Clayton, DeKalb, Fulton and Henry counties.

- *Objective 1:* By December 2015, recruit at least two new grant applicants focused on providing services in one or more of the target counties.
- *Objective 2:* Beginning with the FY2017 Community Grant Request for Application (RFA), programs that provide breast screenings serial and other as well as diagnostic services in the target counties will be a funding priority.
- *Objective 3:* Programs that offer co-pay assistance to under-insured women in the target communities will be a funding priority beginning with the FY2018 Community Grant Request for Application (RFA).

Priority 2: Reduce non-financial socioeconomic barriers to screening and diagnostic services in the target communities.

- *Objective 1*: By December 2015, host a conversation for grant applicants and grantees to discuss transportation and translation challenges.
- *Objective 2*: By the end of FY 2017, ensure that grantees in all counties have transportation and translation service plans in place as indicated by the Community Grant RFA.
- *Objective 3*: By the close of FY19, develop a strategy to build trust in the Black/African-American community to alleviate fear and increase the number of women screened from the highest need communities by 5%.

Education and Outreach

Priority 1: Provide only evidence based breast health education in target communities.

- *Objective 1:* By the end of FY 2016, eliminate broad education funding to other organizations and bring overall education funding to below ten percent of total grant expenses. Provide education grants only to grantees that show specific education needs in their target communities.
- *Objective 2:* By December 2015, through site visits and reporting confirm that all grantees are in compliance with Komen Breast Self-Awareness messages.
- *Objective 3:* By the end of FY 2017, hold at least three Komen Greater Atlanta survivorship events in different target communities in the service area.
- *Objective 4:* In cooperation with grantees or community partners, present ten educational programs to members of Black/African-American, Hispanic/Latina, LGBTQ or recent immigrant communities by December 2016.

Partnerships

Priority 1: Increase access to the breast health continuum of care through developing partnerships in the target communities.

- *Objective 1*: By the end of FY 2019, establish two partnerships outside of the grant making process to maximize the reach & expertise of each organization to increase the impact on target communities.

Public Policy

Priority 1: Develop and utilize partnerships to enhance public policy efforts in order to improve breast health outcomes in the service area.

- *Objective 1:* By December 2016, have five meetings or co-sponsored events with state and/or federal lawmakers in order to encourage policy that supports access to breast health services.
- *Objective 2:* By the end of FY 2016, partner with one other Komen or local organization to host an event highlighting Komen Greater Atlanta public policy efforts and priorities.
- *Objective 3:* By the end of FY 2019, collaborate with two organizations that have an established advocacy program that supports Komen's public policy priorities.

References

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