



COMMUNITY PROFILE REPORT

Susan G. Komen for the Cure®
Greater Atlanta Affiliate



2009

Acknowledgements

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The successful completion of this project would not have been possible without the participation and cooperation of the aforementioned. Thank you!

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2009 Komen Atlanta Community Profile Executive Summary

Introduction

Susan G. Komen for the Cure was born from a promise between Nancy G. Brinker and her dying sister, Susan G. Komen, to save lives and end breast cancer forever. This promise to find a cure has evolved and the people and resources behind it have grown tremendously.

Susan G. Komen for the Cure Greater Atlanta Affiliate was founded in 1991 by an all-volunteer board. The Affiliate is currently governed by a 15-member Board of Directors and maintains a staff of six full-time employees. Additionally, more than 500 survivors and activists volunteer their time and energy for the Affiliate and have made the promise to find a cure their own.

The Greater Atlanta Affiliate serves as a resource for those seeking opportunities for screening, treatment and support, and hosts several events and programs to raise awareness and educate the community about the benefits of early detection. 75% of all funds raised by the Affiliate remains in the local community to fund breast cancer screening, treatment and education programs for the medically underserved. 25% of funds raised supports the Komen Award and Research Grant Program.

The Affiliate raises funds by producing the annual Susan G. Komen Atlanta Race for the Cure and through individual, group, community and corporate donations. The Komen Atlanta Race for the Cure is the most successful education and fundraising event for breast cancer in Atlanta. Since its inception, the Affiliate has raised more than \$23.5 million for breast cancer research and local grassroots organizations to help provide assistance to breast cancer patients and their families.

To help empower the local community, the Affiliate hosts educational events, including Worship in Pink Weekend, participates in community health fairs and organizes a speakers bureau to spread the message of breast health and drive the breast cancer movement.

The 2009 Community Profile Report was conducted to find the needs and gaps in breast health services in the 10-county service area of the Greater Atlanta Affiliate of the Susan G. Komen for the Cure. It also serves as a guide for grantmaking and fundraising efforts, so as to not duplicate programs already in place and focus efforts on addressing unmet needs for breast health in the community.

Affiliate Service Area Key Demographics

The Affiliate's 10-county service area includes nearly 44% of the state's population, serving more than 4 million people and is comprised of Cherokee, Cobb, Clayton, DeKalb, Fayette, Forsyth, Fulton, Gwinnett, Henry and Rockdale counties. Figures 1.1 - 2.2 below display the wide range of demographic, as well as breast health indicator factors within the Greater Atlanta Affiliate area¹.

Figures 1.1 - 1.2: *Fulton County, followed by DeKalb and Gwinnett counties, has the largest population within the 10-county service area, while Clayton, DeKalb and Fulton have the lowest median family incomes.*

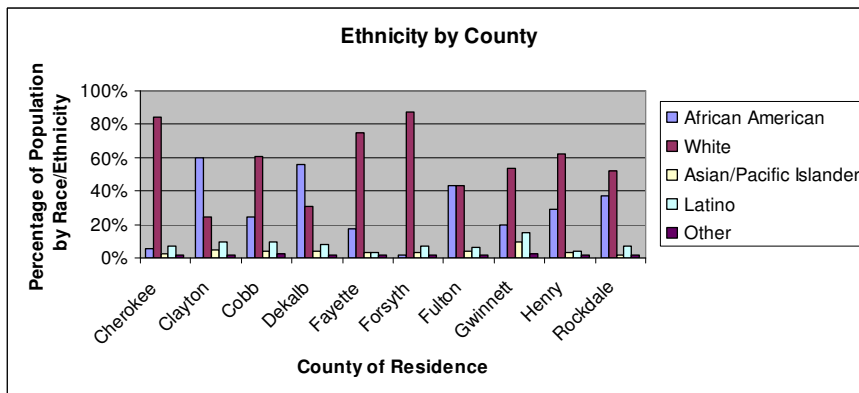
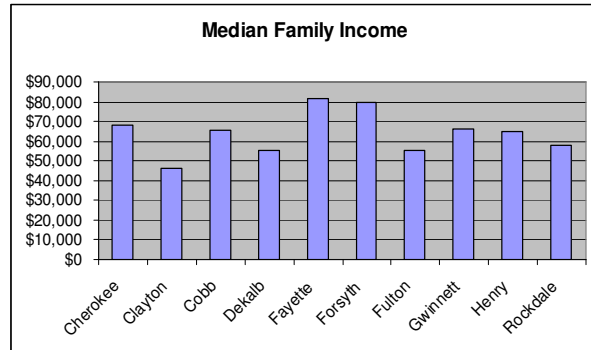
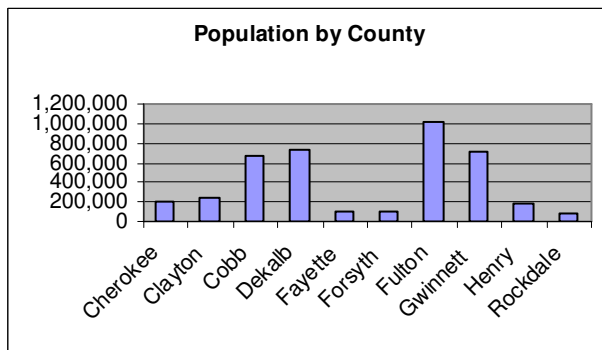


Figure 1.3: *Cherokee, Fayette and Forsyth have the largest population of residents who identify as White; Clayton, DeKalb and Fulton counties have the largest population of residents who identify as Black or African-American; Gwinnett has the largest population of Latino/Hispanic, as well as API residents.*

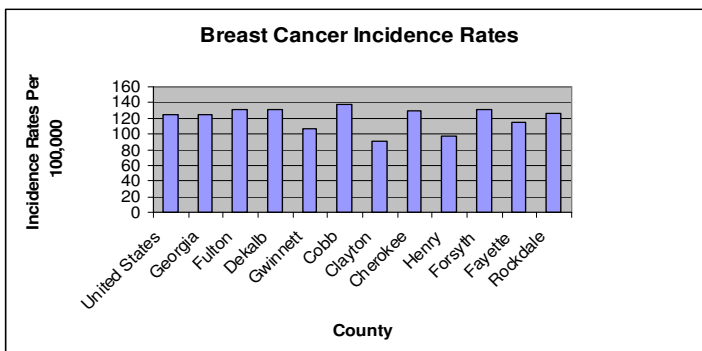


Figure 2.1: *Although the State's Breast Cancer incidence rate is very similar to the national rate, there are several counties within the Komen Atlanta service area that exceed both the national and state rates. These counties include Cobb, Fulton, Forsyth, Cherokee and Rockdale.*

¹ The Healthcare Business of Thomson Reuters © 2007. Greater Atlanta Demographic and Breast Cancer Data [Data file]. Retrieved August 1, 2008.

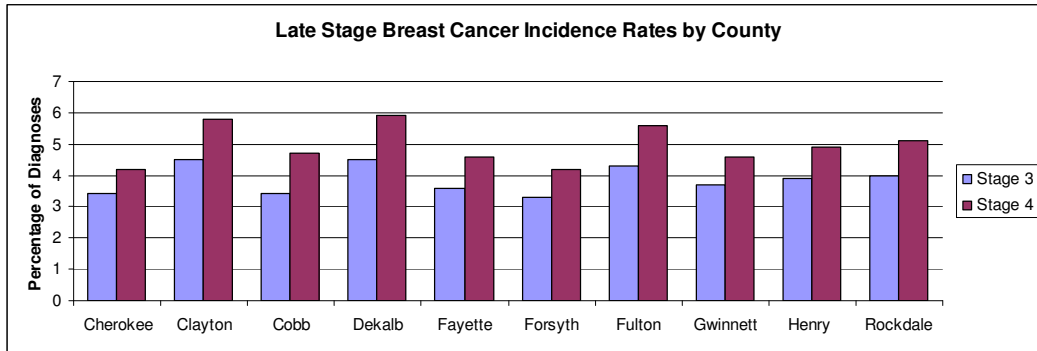


Figure 2.2: Late stage diagnosis is also used as a key indicator of community breast health. Figure 2.2 highlights the counties within the 10-county service area with the highest rates of late stage (stages 3 and 4) of breast cancer diagnosis. Based on the data provided above, Clayton, DeKalb and Fulton counties have the highest incidence rates for breast cancer diagnosed at stages 3 and 4.

Considering the previous statistics and the amount of overlap between several counties, the following 4 counties have been chosen as Affiliate areas of priority: Clayton, DeKalb, Fulton and Gwinnett.

Provider Survey Summary:

In an effort to gain additional detail about community resources and access and barriers to care, a provider survey was created. This instrument was posted on SurveyMonkey, an online survey tool. Providers from across the 10-county coverage area, including Komen Atlanta grantees, completed the survey resulting in 90 responses.

Based on provider responses, there are numerous services being offered to women in a wide array of communities. However, access to these services remains a challenge. Providers’ responses allude to women not knowing about the availability of breast health resources, being inadequately informed about the need and importance of these services, not having adequate access to the services - including transportation - and not being able to afford the services. Additionally, providers may not be as well informed about additional community resources. When asked about community resources, 95% of respondents named metro-area hospitals only. Less than half were aware of resources for financial assistance or clinical trials enrollment.

Community Member Survey Summary:

A total of 152 responses were collected from women throughout the Komen Atlanta service area. The majority of respondents to the survey were African-American or White, between the ages of 40 - 64, with an income range of \$0 - \$27,000 annually, at least one degree, and private insurance. Fulton, DeKalb and Gwinnett were the primary counties of residence.

The survey results confirmed that women are generally informed about mammography and breast cancer. However, a large majority of the respondents – regardless of education or socioeconomic status – associate family history with a breast cancer diagnosis and death as a common outcome. Based on responses assessing knowledge of breast health outcomes, there may be a correlation between the number of women who do not regularly schedule their routine mammograms and fear that if diagnosed with breast cancer, death is the most common outcome of that diagnosis. It must also be noted that while all women reported relying heavily on information from their primary provider first, African-American and White women listed the media and family/friends/neighbors (respectively) as secondary sources, but Asian/Pacific Islander and Latina women listed community-based/non-profit organizations and family/friends/neighbors as their secondary sources. When asked about barriers to care, insurance was the most frequently reported answer among eligible women who did not schedule their routine mammogram. Community respondents listed fear as the second greatest barrier to care, followed by transportation.

The following areas were highlighted based on provider and community level responses:

A. Education

Both provider and community level data highlighted access and barriers to care concerns. Fear was one of the leading indicators of why women do not routinely seek care and community members across all demographic sectors also appear to be misinformed about the key risk factors associated with developing breast cancer, as well as the range of options available for women who have been diagnosed. These two findings highlight the need for continued breast health education as a critical component to eliminating myths associated with breast cancer.

Providers also weighed in heavily on the need for additional community education. Suggestions included general breast health information delivered via television and radio media, specific advertising that informs community members of the availability of free and reduced-cost services and culturally appropriate educational information.

Both providers and community members listed providers as their key sources of health information. Therefore, efforts must not only address educating community members, but providers as well. Provider education efforts must focus on developing positive patient-provider relationships, in addition to continued efforts to keep providers informed of key community resources. As providers are seen as a major resource, their ability to adequately inform clients of their options and refer them to the appropriate venues is a critical piece in the continuum of care.

B. Financial Resources

When women are adequately informed of the need to regularly schedule their routine exams, they are often met with other challenges including transportation and the ability to pay for these services. Along with the provision of additional funding for screening and diagnostic programs, providers reported that lack of ability to pay for services is a major barrier to care. Community members echoed this fact by reporting insurance as the number one barrier to care.

C. Transportation and Other Support Services

It is known that when providing a continuum of care people must not only be informed about their health care options, but complete the required steps to ensure proper screening, diagnosis and treatment (when applicable). Qualitative data from providers strongly suggested the need for transportation and mobile mammography services. Community members replied with a similar request, listing transportation as another leading barrier to care.

Providers also suggested additional support services for women seeking to access care. This includes incentivizing women who complete their screening appointments and funding patient navigators/peer counselors.

While there were several highlighted areas of need provided by both the patient and community level respondents, Komen Atlanta seeks to support community initiatives in a subset of these areas. In addition to identifying the key areas that the Affiliate will focus on, the primary objectives within these areas are included below.

Affiliate Action Plan

Through the completion of a strategic planning process lead by an external consultant and the completion of this Community Needs Assessment, the Greater Atlanta Affiliate of Susan G. Komen for the Cure has chosen the following areas and supporting action items as the critical steps in its action plan.

Education: Address myths about the causes of breast cancer, as well as treatment options; provide health education through a wide range of media and community resources; educate providers on the importance of patient-provider relationships and availability of key community resources

A. Focus the efforts of the organization on one “priority program” of the organization, including focusing a marketing campaign on this program.

1. Develop Worship in Pink to a widespread educational initiative that provides general breast health education through religious

organizations in the 10-county service area and serves as a quality resource for women seeking breast health services

2. Incorporate culturally relevant education in Worship in Pink

Grants: Fund programs in areas that are currently underserved and have a disproportionate number of health disparities; increase support for screening and diagnostic programs; increase support for education programs; support programs that create a linkage to care

A. Provide funding to grantees through a lens of enabling women to detect and survive breast cancer

1. Fund screening and diagnostic programs that ultimately lead to a reduction in late-stage diagnosis of breast cancer
2. Continue to provide funding for low and reduced-cost services
3. Continue focus on south-metro area
4. Provide funding for culturally relevant programs
5. Begin considering application of chosen evidence-based outcomes to the grantmaking program

Advocacy: Advocate for increased BCCP funding; advocate for additional coverage for those who are underinsured and uninsured; support initiatives that allocate additional resources for public transit systems and vouchers for medically underserved populations

A. Maintain or increase Georgia's budget and policy initiatives that impact detection and access to care for breast cancer

1. Preserve and enhance the *BreasTEST and More* program by encouraging the movement of the program to the Georgia Department of Community Health
2. Expand screening activities in partnership with DCH/DHR programs
3. Maintain or increase Georgia's budget and policy initiatives that impact detection and access to care for breast cancer
4. Ensure that the three Care Management Organizations (CMOs) and other private health plans provide optimal coverage for prevention, diagnosis and management of breast cancer

Limitations of Findings

The 2009 - 2010 Community Profile Report will be used as a tool to guide the Affiliate in a number of areas, including Education, Grants and Advocacy. While a variety of primary and secondary data were used and collected, it must be noted that there are limitations to this Community Profile Report. They are included below:

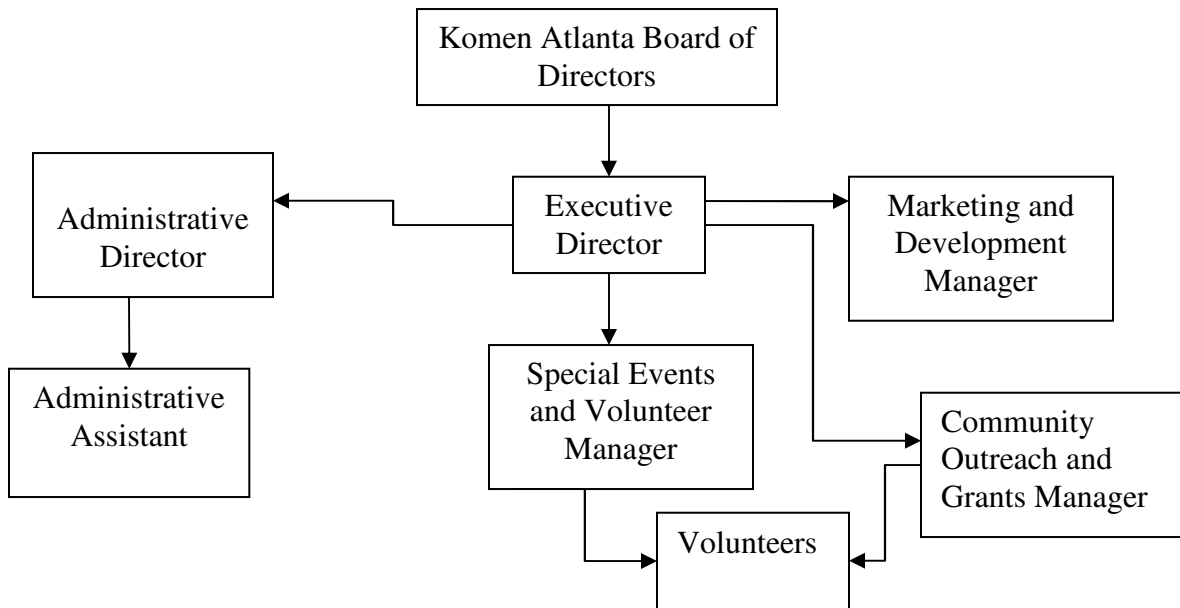
- Surveillance data sources used information from 2000 - 2007, including estimates from the Center for Disease Control and Thompson Reuters
- There were no provisions made to eliminate biases during the distribution of the face-to-face surveys
- Respondents to the electronic surveys did not have to log on to a secure website or provide any personal identifier information
- Respondents to the electronic survey were able to skip questions if they were not comfortable providing an answer
- Respondents could gain access to the survey multiple times

2009 Komen Atlanta Community Profile Full Report

Introduction

Susan G. Komen for the Cure was born from a promise between Nancy G. Brinker and her dying sister, Susan G. Komen, to save lives and end breast cancer forever. This promise to find a cure has evolved and the people and resources behind it have grown.

Susan G. Komen for the Cure Greater Atlanta Affiliate was founded in 1991 by an all-volunteer board. The Affiliate is currently governed by a 15-member Board of Directors and maintains a staff of six full-time employees. Additionally, more than 500 survivors and activists volunteer their time and energy for the Affiliate, and have made the promise to find a cure their own.

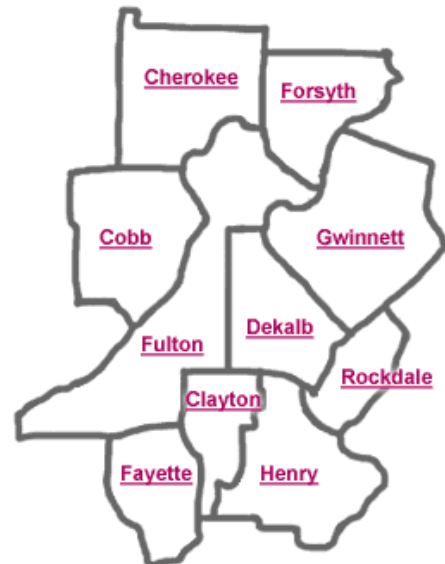


The Greater Atlanta Affiliate serves as a resource for those seeking opportunities for screening, treatment and support, and hosts several events and programs to raise awareness and educate the community about the benefits of early detection in the fight against breast cancer (www.komenatlanta.org). Seventy-five percent of all funds raised by the Affiliate remains in the local community to fund breast cancer screening, treatment and education programs for the medically underserved. Twenty-five percent of funds raised supports the Komen Award and Research Grant Program.

The Affiliate raises funds by producing the annual Susan G. Komen Greater Atlanta Race for the Cure and through individual, community group and corporate donations. The Komen Atlanta Race for the Cure is the most successful education and fundraising event for breast cancer in Atlanta. Since its inception, the Affiliate has raised more than \$23.5 million for breast cancer research, local grassroots organizations, community agencies and support groups to help provide assistance to breast cancer patients and their families. In 2008, the Affiliate reached a record in giving, investing \$2.25 million in the local community to 38 grant programs. In addition, the Affiliate also awarded more than \$650,000 to the Komen Award and Research Grant Program.

To help empower the local community, the Affiliate hosts annual educational events, including Worship in Pink Weekend, participates in community health fairs and organizes a speakers bureau to spread the message of breast health and drive the breast cancer movement.

The Affiliate's 10-county service area includes nearly 44% of the state's population, serving more than 4 million people and is comprised of Cherokee, Cobb, Clayton, DeKalb, Fayette, Forsyth, Fulton, Gwinnett, Henry and Rockdale counties.



The 2009 Community Profile Report was conducted to find the needs and gaps in breast health services in the 10-county service area of the Greater Atlanta Affiliate of the Susan G. Komen for the Cure. It also serves as a guide for grantmaking and fundraising efforts, so as to not duplicate programs already in place and focus efforts on addressing unmet needs for breast health in the community.

Demographic and Breast Cancer Statistics

Data Source and Methodology Overview

The Greater Atlanta Affiliate of Susan G. Komen for the Cure used a number of quantitative and qualitative data collection methods. Preliminary quantitative data, including demographic information and breast cancer incidence mortality rates were collected using The Healthcare Business of Thomson Reuters © 2007, *Greater Atlanta Demographic and Breast Cancer Data* [Data file]. Supplemental quantitative data was then collected from The American Cancer Society, the National Institute of Health, Georgia Department of Human Resources and the Georgia Cancer Coalition. Graduate students from Rollins School of Public Health at Emory University piloted the community based survey in a low-income community in Fulton County before full release. Provider and community surveys were then posted on SurveyMonkey to gain additional quantitative and qualitative data from the local community.

Komen Atlanta used quantitative data as the foundation for the Community Profile Report. This section outlines key national and statewide statistics. It also provides a thorough look at the Komen Atlanta Affiliate in comparison to national and statewide breast health trends.

Overview of Key Demographic & Breast Cancer Statistics at State and County Level

The US Census Bureau² estimated the population of Georgia to equal 9,339,947 residents in 2007. The demographics of the population include 60% of the population identifying as White/Non-Hispanic; 29% Black/Non-Hispanic; 7% Hispanic; 3% Asian/Pacific Islander; and 1% Other/Multi-Race/Non-Hispanic. Figure 1.0 displays the demographic breakdown by ethnicity for the state of Georgia.

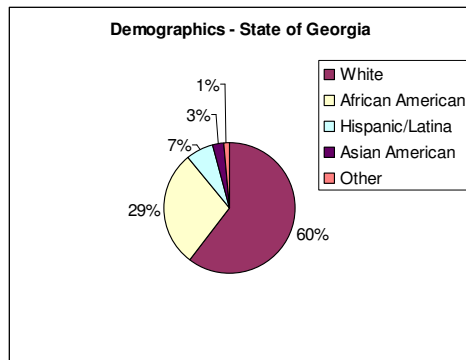


FIGURE 1.0

² U.S. Census Bureau. 2005-2007 American Community Survey. Retrieved November 1, 2008 from http://factfinder.census.gov/servlet/ADPTable?_bm=y&-qr_name=ACS_2007_3YR_G00_DP3YR5&-geo_id=04000US13&-gc_url=null&-ds_name=ACS_2007_3YR_G00_-lang=en

The Greater Atlanta Affiliate of Susan G. Komen for the Cure’s service area includes nearly 44% of the state’s population, with an estimated combined population of 4,078,944 people. The following charts exhibit the combined demographics of the Greater Atlanta 10-county service area, including Cherokee, Cobb, Clayton, DeKalb, Fayette, Forsyth, Fulton, Gwinnett, Henry and Rockdale counties³.

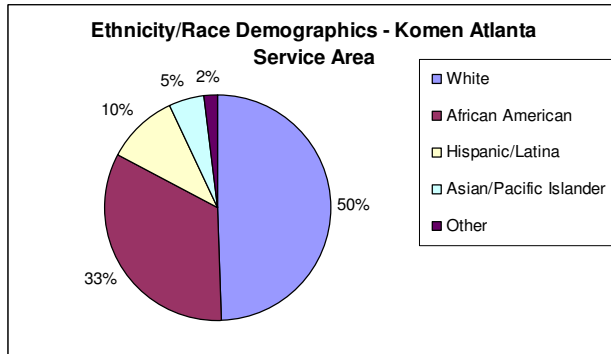


FIGURE 2.1

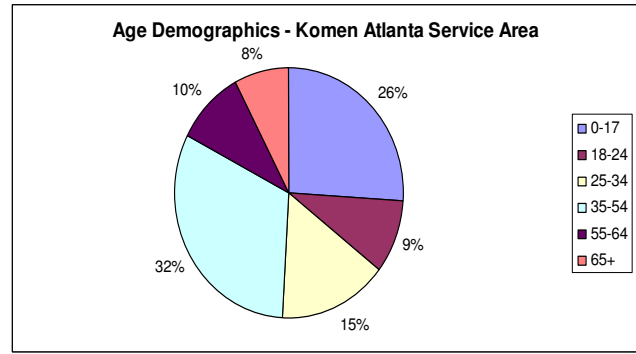


FIGURE 2.2

Figures 2.1 and 2.2: The Komen Atlanta service area race/ethnicity demographics closely resemble those of the statewide demographics: 50% of the population identifies as White; over 25% as Black or African-American; 10% identifying as Latino or Hispanic; 5% identifying as Asian or Pacific Islander; and 2% identifying as Other, including American Indian. The majority of the population of the 10 counties falls within 3 age groups: 0-17, 25-34 and 35-54.

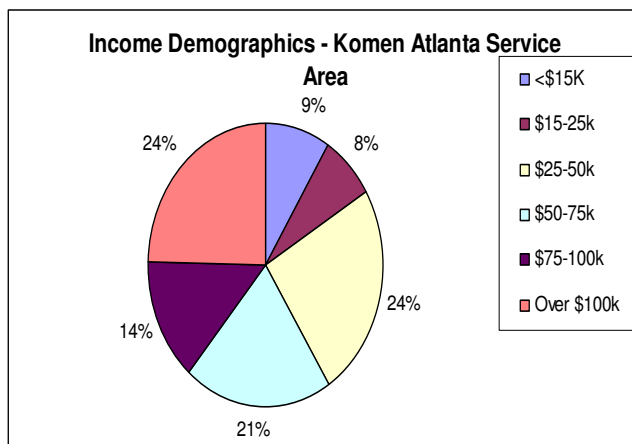


FIGURE 2.3

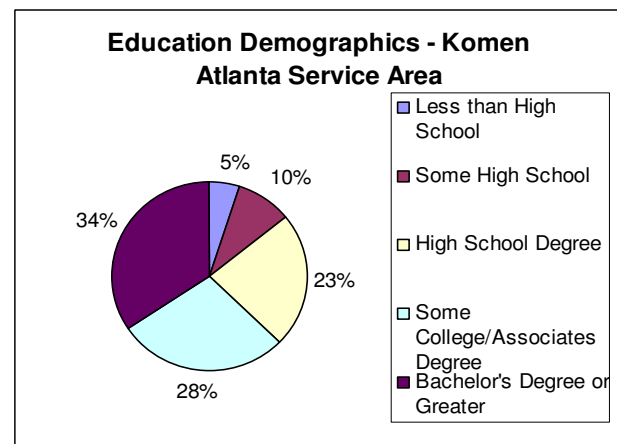


FIGURE 2.4

Figures 2.3 and 2.4: There is an even split in the population between families with a median income over \$100,000 and those with an income between \$25,000 and \$50,000. The third leading category is families with incomes between \$50,000 and \$75,000. The Greater Atlanta service area is also comprised of a highly educated population with almost two-thirds of the population estimated to have at least some college/associates degree, a bachelor’s degree or greater.

³ The Healthcare Business of Thomson Reuters © 2007. Greater Atlanta Demographic and Breast Cancer Data [Data file]. Retrieved August 1, 2008.

Within Komen Atlanta's 10-county service area, there is a great deal of diversity, including income, ethnicity and education. Figures 3.1 - 3.4 below display the wide range of other demographic factors that are considered during program and service delivery to the Greater Atlanta Affiliate area.

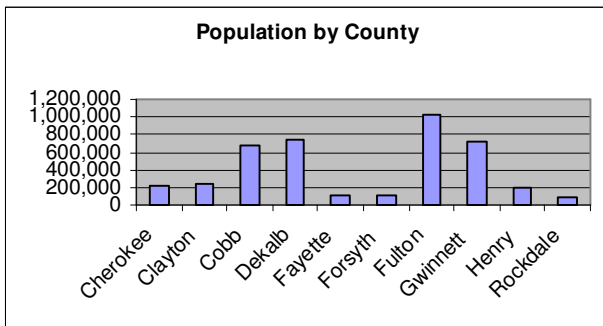


Figure 3.1

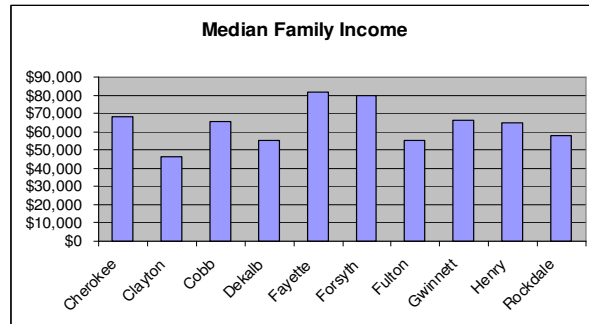


Figure 3.2

Figures 3.1 - 3.2: Fulton County, followed by DeKalb and Gwinnett counties, has the largest population within the 10-county service area, while Clayton, DeKalb and Fulton have the lowest median family incomes.

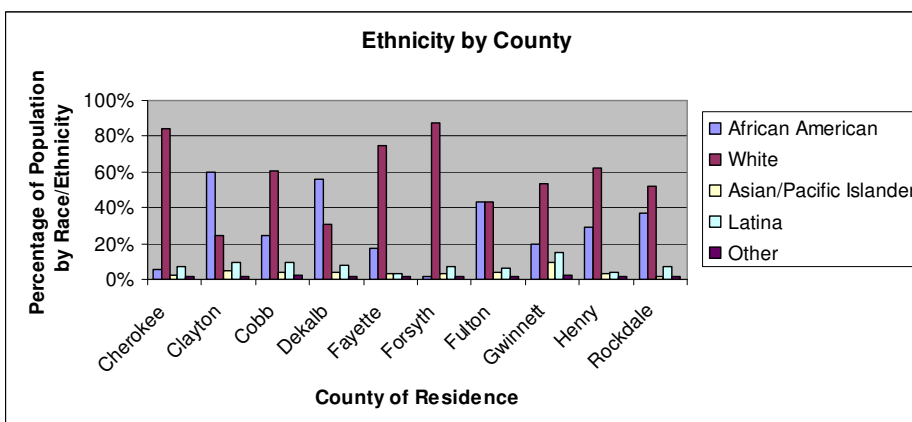


Figure 3.3:

Cherokee, Fayette and Forsyth have the largest population of residents who identify as White, while Clayton, DeKalb and Fulton counties have the largest population of residents who identify as Black or African-American.

Gwinnett has the largest population of Latino/Hispanic, as well as Asian/Pacific Islander residents.

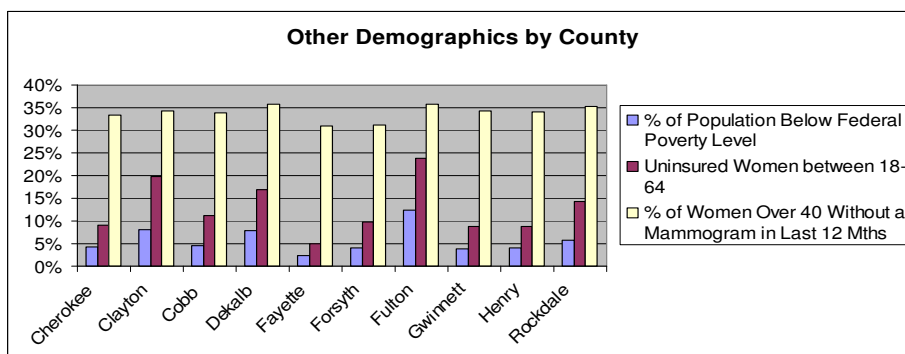


Figure 3.4: Fulton, DeKalb and Clayton counties have the largest number of residents living below the federal poverty level and have the largest number of women the between ages of 18 and 64 who are uninsured. Fulton, DeKalb and Rockdale counties have the largest number of eligible women over 40 who have not received a mammogram in the last 12 months.

Key Breast Cancer Indicators: According to the American Cancer Society (ACS), there was an estimated 178,480 new cases of breast cancer in 2007. Of

those diagnosed, 40,910 women were expected to lose their lives to this life-altering disease⁴. In the state of Georgia, 4,520 new cases of breast cancer were expected to be diagnosed in 2007⁵. Surveillance data from the National Cancer Institute's State Cancer Profiles reported that between 2001 and 2005, the annual death rate for Georgia was 24.7 (per 100,000), with an average of 1,069 deaths per year. This is in comparison to an annual death rate of 25.0 (per 100,000) and an average of 41,319 deaths per year for the United States⁶.

The breast cancer incidence rate* for the state of Georgia is 123.8. Figure 4.1 below details the breast cancer incidence rates within the Komen Atlanta 10-county coverage area in comparison to the state and national average. Figure 4.2 details the projected breast cancer deaths in the service area. *For graphs 4.1-4.3, all state and national averages are based on NCI State Cancer Profiles data for the 2001-2004 rate periods; all county data is based on Thomson Reuters © 2007.*

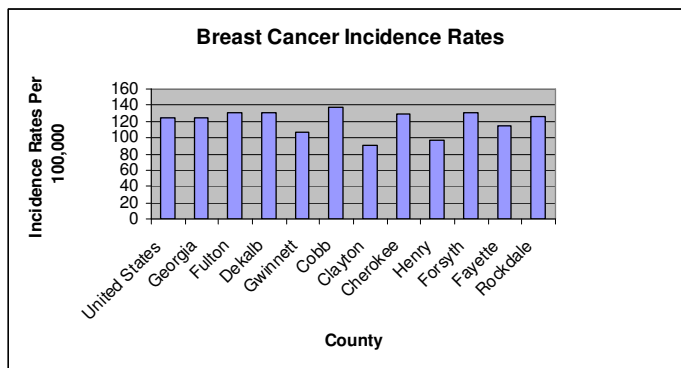


Figure 4.1

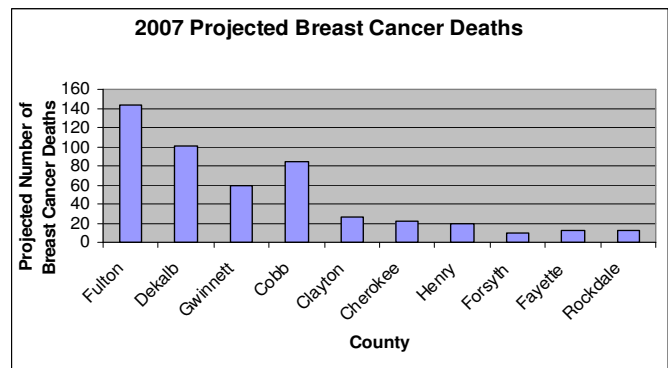


Figure 4.2

Although the state of Georgia's breast cancer incidence rate is very similar to the national rate, there are several counties within the Komen Atlanta service area that exceed both the national and state rates: 123.8 and 123.9 respectively (see Figure 4.1). These counties include Cobb, Fulton, Forsyth, Cherokee and Rockdale. Due to increased availability of screening services, higher incidence rates exclusively are not cause for alarm, however breast cancer mortality rates* are. As Figure 4.2 exhibits, Fulton, DeKalb, Cobb and Gwinnett counties have the highest projected breast cancer deaths for 2007. While the projected number of mortality cases for the aforementioned counties range between 144 and 84 deaths per year, the rates for the remaining six counties within the Komen Atlanta service area range between 26 and 12 projected deaths per year - a significant difference.

* **Incidence Rate:** number of new cases; **Mortality Rate:** number of deaths

⁴ American Cancer Society (2007). Cancer Facts and Figures. Retrieved November 1, 2008 from <http://www.cancer.org/downloads/STT/caff2007PWSecured.pdf>.

⁵ Division of Public Health. 2007 Georgia Program and Data Summary: Cancer. Retrieved November 1, 2008 from http://health.state.ga.us/pdfs/epi/cdiee/CDIEE%20Data%20Summaries%202007/2007_Cancer_Program_Data_Summary.pdf.

⁶ National Cancer Institute's Surveillance, Epidemiology and End Results (SEER) Program. State Cancer Profiles. Retrieved November 1, 2008 from <http://statecancerprofiles.cancer.gov/cgi-bin/quickprofiles/profile.pl?13&055>.

Late stage diagnosis is also used as a key indicator of community breast health. Figure 4.3 highlights the areas within the 10-county service area with the highest rates of late stage (stages 3 and 4) of breast cancer diagnosis.

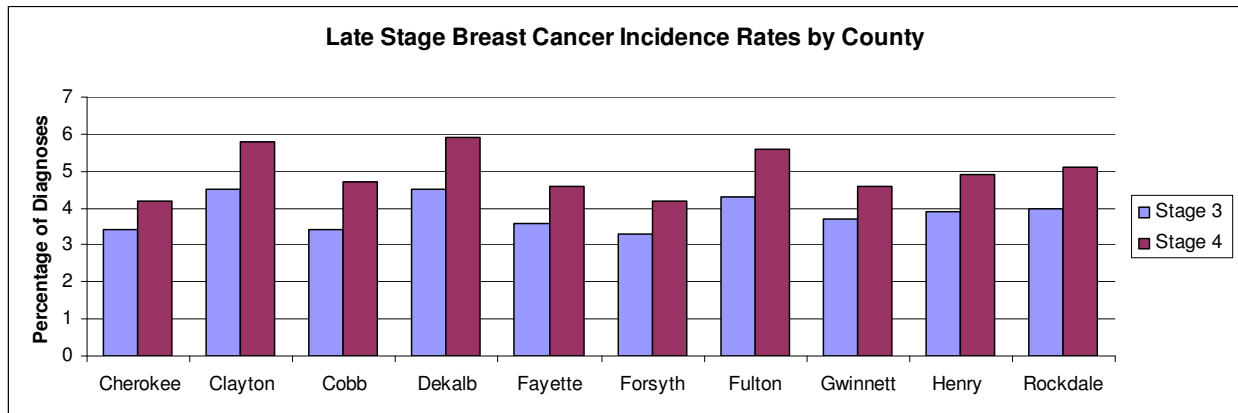


Figure 4.3

Based on the data provided above, Clayton, DeKalb and Fulton counties have the highest breast cancer incidence rates diagnosed at stages 3 and 4.

Summary: The information provided in this section highlighted key breast health indicators at the national and state levels, as well as within the Komen Atlanta 10-county service area. While there is no statistic that can exclusively determine breast health outcomes, there are several factors that – when combined with others – present reason for alarm and targeted outreach. These factors include race/ethnicity, socioeconomic status, breast cancer incidence and mortality rates, and late stage diagnosis. Other key indicators include insurance status and frequency of mammograms.

ACS reported that the cancer death rate for White and Hispanic/Latina women fell by 2.4% between 1995 and 2004, but only by 1.6% for African-American women. During the same time period, no change was seen in cancer death rates of Asian Americans/Pacific Islanders⁷. In addition to having the largest populations of the 10-county service area, Clayton, DeKalb and Fulton have the largest African-American population, while Gwinnett has the largest population of Latina/Hispanic and Asian/Pacific Islander residents. Clayton, DeKalb and Fulton have the lowest family median incomes, the largest number of residents living below the federal poverty level and the largest number of uninsured women between the ages of 18 and 64. DeKalb and Fulton have the largest number of women over 40 who did not have a mammogram within the last twelve months.

⁷ American Cancer Society (2007). Facts & Figures: A Statistical Snapshot of Breast Cancer Today. Retrieved November 1, 2008 from http://www.cancer.org/docroot/NWS/content/NWS_1_1x_Breast_Cancer_Report_Death_Rate_Incidence_Continue_to_Drop.asp.

Considering the aforementioned, the following 4 counties have been chosen for further analysis: Clayton, DeKalb, Fulton and Gwinnett. Further research indicated key cities and zip codes within the counties of interest that have higher incidence and mortality rates when compared to other cities within the county.

- The cities and corresponding zip codes with the highest incidence and mortality rates of breast cancer within Clayton County are Morrow and Jonesboro (30260 and 30236).
- The city and zip code with the highest incidence and mortality rates of breast cancer in DeKalb is within the city of Decatur (30033).
- The city and zip code with the highest breast cancer incidence and mortality rates in Fulton County is Atlanta (30326).
- The cities and corresponding zip codes with the highest incidence and mortality rates in Gwinnett County are Lilburn (30047) and Snellville (30078).

The highlighted counties of interest identify high priority geographic areas within the 10-county service area. While data discussed in the *Exploratory Data* section asserts that health disparities exist in all counties within the Affiliate coverage area, having specific counties and areas of interest allow for additional targeted and tailored health promotion programming.

Programs and Services



The previous sections of the Community Profile provided a detailed analysis of the Komen Atlanta service area based on quantitative epidemiological data. To assist with further interpretation of this data, local providers were contacted to assess what services they currently provide, determine what they consider to be major barriers to care, and what the priority areas are for service delivery and funding.

Data Source and Methodology Overview

The data for this segment of the Community Profile Report was collected in a variety of ways. Based on Komen Atlanta's 2005 Community Profile, the need for additional tools detailing community resources was identified. Therefore, Komen Atlanta created an online Breast Cancer Resource Directory. This directory lists agencies across the 10-county service area that provides education, screening, diagnostic, navigation and support services to women. This Resource Guide was used as one of the resources to help identify current community assets.

A provider survey was also created and posted on SurveyMonkey, an online survey tool. Providers from across the 10-county coverage area were invited to complete the survey. The survey collected information on provider office location, services provided and perceptions about barriers to breast cancer education and care, as well as suggestions for increasing breast cancer screenings. The survey was released at the beginning of November and remained online for three months. Providers, including Komen Atlanta grantees, from across the Komen Atlanta service area participated resulting in 90 completed provider surveys.

Additional data identifying FDA approved mammography sites was collected from the Department of Health and Human Services.

Programs and Services Overview

The Greater Atlanta service area is comprised of a wide variety of organizations that provide a range of breast health services. A number of these services are offered in the metro Atlanta area, including Fulton, DeKalb, Cobb and Gwinnett counties. Fewer services are offered in Clayton, Rockdale, Henry, Fayette, Forsyth and Cherokee counties.

At the time of data collection, there were 249 FDA approved mammography sites in the state of Georgia. Eighty-three of these sites are located within the 10-county service area. However, only 16 of them are located within the southern region (Clayton, Henry, Fayette, and Rockdale) and only 4 in the extreme northern region (Cherokee and Forsyth) of the Komen Atlanta service area⁸.



Although services are provided to women across the 10-county coverage area, of the 38 grantees in the Komen Atlanta service area, over 90% of them are located within Fulton and DeKalb counties.

Provider Survey Summary:

I. Demographics:

- Of those surveyed, 50% have offices in Fulton County, 19% in DeKalb, 10% in Gwinnett and 9% in Clayton. Representation from the other 6 counties was less than 8% each.
- 58% of the women they provide services for are from Fulton County; 35% from DeKalb County; 24% from Gwinnett County; and 19% from Clayton County.
- Over 90% of the providers have clients who are African-American or Latina. 84% reported providing services to White women; 76%

⁸ U.S. Food and Drug Administration. *Mammography*. Retrieved November 1, 2008 from <http://www.accessdata.fda.gov/scripts/cdrh/cfdocs/cfMQSA/mqsa.cfm>.

to Asian/Pacific Islanders; and over 60% provide services to women with disabilities or who partner with other women.

II. Services Provided:

- 78% of respondents provide low-cost or free breast health services, 20% of providers’ patients were Medicaid or Medicare recipients, and 44% of those patients qualified for free services through the state BCCP or other voucher programs. Only 17% of their clients were insured.
- Providers offered a wide range of services along the continuum of care. Education services included providing general educational material and/or providing one-on-one education sessions. Support services included transportation, support groups, wigs/prosthesis and Lymphedema care. Services included in the “Other” category are interpretation, referrals or linkages to care and case management.

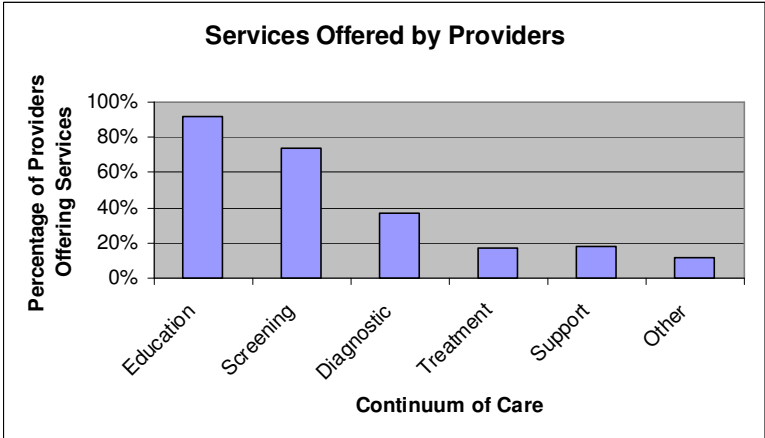


Figure 5.1

III. Barriers to Care:

- Insurance, fear and other financial obligations were listed by providers as the top three barriers to care. When asked to list other barriers to care, the greatest responses were language barriers and cultural barriers.

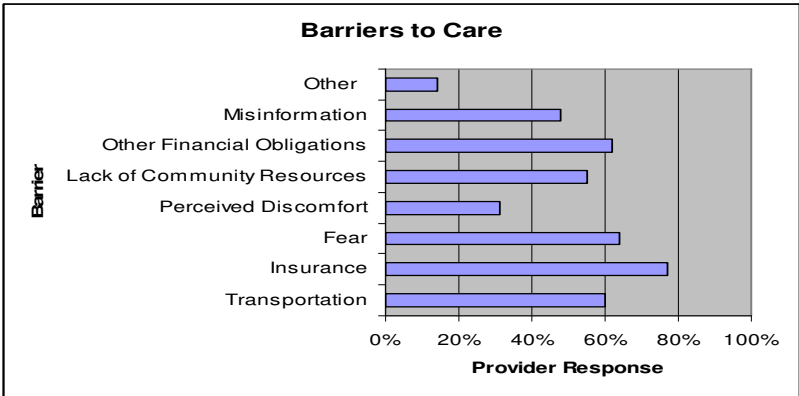


Figure 5.2

- IV. **Provider Referrals:** Providers rated themselves as the largest resource for breast health information, followed by community-based/non-profit organizations and friends/relatives and neighbors. However, only 49% of providers knew of places to refer their clients if they needed additional financial assistance and over 60% of respondents were not aware of clinical trials in their area, provided no information regarding clinical trials and provided no direct access to clinical trials.
- V. **Provider Recommendations:** When asked what can be done to increase screening rates, the following were common themes: culturally relevant and low-literacy education material; increased funding for breast health screening; increased marketing for community resources; transportation and mobile mammography units; and services for women under 40 years of age.
- VI. **Other:** Just over half of respondents (51%) offered incentives to motivate women to seek screening and diagnostic services.

Partnerships and Grant Opportunities

Komen Atlanta has current funding relationships with many of the major hospitals and cancer centers in the service area. Additionally, included in the grantee network are also numerous organizations that provide services to minority populations such as Latina, African-American and Asian/Pacific Islander women. By funding the state BCCP, these services are further extended to parts of the service area that Komen Atlanta may not be able to access as easily, including counties such as Rockdale and Henry.

Komen Atlanta's reach is extensive, but there are still communities in need where extensive services are not provided, such as those in the southern metro part of the service area. New funding opportunities that exist in geographic areas outside of the metro Atlanta area and programs that provide additional financial assistance and cover transportation were recommendations gathered from the provider data. Breast health education, including education on the availability of community resources, screening guidelines and general breast care was also highly recommended.

Promising Practices and Evidence-Based Programs

The Affiliate has made contact with the National Cancer Institute's Cancer Information Service and other resources to transition our grants and education programs to evidence-based program planning and evaluation.

Public Policy Perspectives

The Cancer Screening Program, formerly known as the Georgia Breast and Cervical Cancer Program (BCCP), was established in 1992 with funding from the Centers of Disease Control and Prevention and the State of Georgia. The Cancer Screening Program is a statewide breast and cervical cancer early

detection program accessible through more than 200 public health clinics and selected nonprofit agencies to low-income, uninsured women.

These services include Clinical Breast Examinations, pelvic exams, Pap tests and screening mammograms for women ages 40-64 and may be accessed by a woman going to the Public Health Department in her county of residence to determine her eligibility. Women detected to have abnormal screening results are referred to participating health care providers for evaluation and diagnostic services. Diagnostic services and care management are provided for free or at a low cost to eligible women. If treatment is necessary, low-income women who are eligible through the state BCCP will receive treatment services through the Women's Health Medicaid Program (WHMP).

Women are presumed eligible for coverage under the WHMP if they are: eligible for the Georgia Breast and Cervical Cancer Program; were diagnosed with breast (or cervical) cancer; are under 65 years of age; have no health insurance coverage and not eligible for Medicare or Medicaid; a Georgia resident who is a US Citizen or qualified alien⁹.

Georgia currently receives funds from state and federal sources to provide approximately 16,000 women age 40 and older with breast and cervical cancer early detection services.

In 2007, Komen Atlanta recognized that in spite of the state's efforts, there were many women who were unable to receive care at their local health department due to the unavailability of services. The primary cause for this is lack of funds to meet the demands of women needing medical attention. Therefore, Komen contacted the state BCCP Coordinator, Cathy Broom, to begin what has become an extremely beneficial partnership. To date, Komen Atlanta has awarded more than \$600,000 to the state BCCP.

In 2008, a statewide health care lobbyist joined the Komen Atlanta Board of Directors. This was a key addition for Komen Atlanta as the Board of Directors and Advocacy Committee continue to work on building key relationships with representatives from the city of Atlanta, surrounding communities and the state of Georgia. One of the goals of this partnership is to encourage increased financial support for BCCP.

⁹ Georgia Cancer Coalition. Cancer Screening Program. Retrieved January 1, 2009 from: <http://www.georgiacancer.org/treat-screening.php>.

Key Programs and Service Findings

Based on provider responses, there are numerous services being offered to women in a wide array of communities. However, access to these services remains a challenge. Providers' responses allude to women not knowing about breast health services, being inadequately informed about the need and importance of these services, not having proper access to the services - including transportation - and not being able to afford the services. Additionally, providers may not be as well informed about additional community resources. When asked about community resources, 95% of respondents named metro-area hospitals only. As previously mentioned, less than half were aware of resources for financial assistance or clinical trials enrollment.

Komen Atlanta also continues to seek relationships at the legislative level; based on provider responses that insurance serves as a large barrier to care, the Affiliate recognizes that structural change at the state and federal levels must occur to support additional programs that give women access to affordable healthcare.

Programming Areas of Emphasis Based on Responses

- **General breast health education**
- **Continued education on the availability of breast health resources**
- **Increased provider education on community resources**
- **Increased provider education on clinical trials (when applicable)**
- **Increased funding for transportation resources**
- **Increased funding for free/reduced-cost screening programs**
- **Advocacy for increased financial support of BCCP**

Exploratory Data



There is often a disconnect between provider suggestions and recommendations and what the community expresses that they want and need. Therefore, the Affiliate also sought the input of Komen Atlanta community members; this portion of the Community Profile used community members as the advisors. Surveys were administered to capture knowledge of community resources and access to care challenges. The data gathered proved beneficial in gauging current community-level knowledge, as well as barriers to care.

Data Sources and Methodology Overview

Data for this segment of the Community Profile Report was collected from the U.S. Census Bureau, Thomson Reuters © 2007 and by the administration of two surveys. A community member survey was piloted at a health fair in Fulton County, one of the key counties of interest. The data was analyzed using SPSS 16.0 and conducting univariate, as well as bivariate analysis. An amended version of this survey was then posted on SurveyMonkey and released to other community members. After reviewing the demographics of respondents, the survey was translated into Spanish and reposted. Hardcopies were also mailed to a Pan Asian community organization for distribution to women in the Asian/Pacific Islander community who may not have access to the internet. The survey instrument included both quantitative and qualitative measures.

Exploratory Data Overview

Using a variety of survey administration methods allowed the Affiliate to collect data from women that may not have otherwise been accessible. The next section will explore the key finding more in depth, while this section serves as an overview of the demographics of the group.

A total of 152 responses were collected from women throughout the Komen Atlanta service area. The demographics of the group are as follows:

- *Race/Ethnicity*: 51% of respondents were African-American; 9% Asian/Pacific Islander; 9% Latina; 31% White
- *Age*: 28% of respondents were younger than 40 years old; 34% were between 40 and 49; 30% between 50 and 64; and 8% over 65 years of age
- *Income*: 25% of respondents reporting having an income from 0-\$9,000 per year; 33% from \$9,012 - 27,000; 20% from \$27,012 - \$45,000; and 22% with an income over \$45,001 per year
- *Education*: 48% of respondents completed college or received some other advanced degree; 23% completed some college; 18% completed high school; 10% completed some high school; and 2% completed middle school only
- *Insurance Status*: 63% of respondents had private insurance; 23% had no insurance; 14% were covered by Medicare or Medicaid
- *Residence*: 40% of respondents resided in Fulton County; 17% were from DeKalb and Gwinnett Counties; 11% from Cobb County; Representation from the remaining six counties was less than 5% per county.

In summary, the majority of respondents to the survey were African-American or White, between the ages of 40 and 64, with an income range of \$0-\$27,000 annually, at least one degree and private insurance. Fulton, DeKalb and Gwinnett were the primary counties of residence.

Exploratory Data Findings

- In spite of the education and income ranges, the overwhelming majority of women were generally familiar with the terms mammogram and breast cancer.
- In response to a question assessing risk factors associated with breast cancer, genetics was listed more than any other option. Other commonly listed factors included age, weight/obesity, diet and smoking.

- When asked to list the possible outcomes of a breast cancer diagnosis, death was listed as a possible outcome more than any other option, including treatment, breast removal and survival. Other frequently listed outcomes included hair loss and hormonal therapy.
- While African-American and White women were more likely to rely on information provided by their health care provider, followed by the media and family/friends/neighbors, Latina and Asian/Pacific Islander women relied more heavily on information from a health care provider, followed by community based/non-profit organization and family/friends/relatives.
- For women who were eligible for a mammogram, but did not receive one, insurance was listed as the greatest barrier to care. Fear and transportation were other commonly listed barriers to care.

Key Findings and Observations

The community research or exploratory data was not intended to answer all questions about why women do not routinely seek breast health services or what factors in their lives serve as barriers to care. Instead, it has provided a substantive basis for guiding the Affiliate in its major outreach initiatives and leading further research in key areas of interest.

Key observations in the following areas can be made based on what has been found to date: genetics and breast cancer; outcomes of a breast cancer diagnosis; provider-patient relationships; and barriers to care. The narrative below briefly describes each of these variables.

Genetics and Breast Cancer

The survey results confirm that women are generally informed about mammography and breast cancer. However, a large majority of the respondents - regardless of education or socioeconomic status - associates family history with a breast cancer diagnosis and death as a common outcome.

While family history is a risk factor for a breast cancer diagnosis, current research has found that genetics or family history accounts for only 5-10% of all breast cancer cases¹⁰. The balance that must be created in educational outreach has to consider that too much emphasis on genetics can lead a woman to not seek routine screening under the false pretense that not having a family history significantly reduces or eliminates her risk. However, on the opposite end of the spectrum, women who do have a family history may make uninformed assumptions that family history always leads to a breast cancer diagnosis, thereby avoiding screening due to fear.

¹⁰ Breastcancer.org. Retrieved January 4, 2009 from <http://www.breastcancer.org/risk/genetic/>.

While respondents seemed to have a general knowledge of breast cancer, all communities must continue to be provided with the most recent facts regarding risk factors and treatment options. Women must be informed that while there are several risk factors that increase their chances of a breast cancer diagnosis, it remains unclear as to what the specific causes of this disease are.

It must be noted that while more women reported genetics as a risk factor, other risk factors were also listed including, but not limited to, age, weight/obesity, diet and smoking.

Breast Cancer Diagnosis Outcomes

When considering possible outcomes of a breast cancer diagnosis, women have many more treatment options today than in previous decades. ACS reports that when found early, the 5-year survival rate is 97%¹¹. Less than 5% of respondents listed survival as an option. Based on the survey responses, there may be a correlation between the number of women who do not regularly schedule their routine mammograms and fear that if diagnosed with breast cancer, death is the most common outcome.

Women must be made aware of the plethora of options now available to them if diagnosed with breast cancer. While some women do lose their lives to this life-altering disease, the number of women who survive far outweighs the numbers who do not. The local Affiliate plays a key role in this information sharing. Through quality grants programs and intentional educational initiatives, women can continue to receive the education they need to make informed decisions, with consideration given to all available options.

Provider - Patient Relationships

Survey results showed that while all women rely on their primary care physician for information first, African-American and White were more likely to rely on the media and family/friends/neighbors (respectively) as secondary resources. However, Asian/Pacific Islander and Latina women rely heavily on information from community-based/non-profit organizations and family/friends/neighbors as secondary resources. As recent research has stated, patient-provider relationships are critical to positive health outcomes. It is also important to acknowledge that different cultural groups may often receive health messages from varying sources. This is an important factor when considering avenues for health education, but also when determining where to market available health programs.

¹¹ American Cancer Society (ACS). Facts and Figures 2003-2004. Retrieved November 1, 2008 from http://www.cancer.org/docroot/STT/content/STT_1x_Breast_Cancer_Facts_Figures_2003-2004.asp.

Barriers to Care

When asked about barriers to care, insurance was the most frequently reported answer among eligible women who did not schedule their routine mammogram. This response is in alignment with provider responses that listed insurance as the greatest barrier to patients receiving quality care. Providers also rated fear, other financial obligations and transportation (in that order) as large barriers to care. Community respondents listed fear as the second greatest barrier to care, followed by transportation.

Insurance challenges continue to plague communities across the nation. Advocacy efforts and funding of viable grants programs that provide financial assistance to women seeking screening and diagnostic services continue to remain a priority for the Affiliate.

Atlanta is a major metropolitan city with a public transportation system that is still developing and expanding to less accessible areas. With this in mind, transportation concerns can be addressed by the Affiliate at the policy level, as well as the grants level. Advocating for initiatives such as transportation assistance programs for cancer patients is an option for the Affiliate. Additionally, encouraging grant recipients to include transportation reimbursement or voucher programs in their overall screening, diagnostic and support programs may also prove to be beneficial.

The collection of data at the community level provided additional insight to selecting key priorities for the Affiliate. There were also several overlapping responses between provider and community responses addressing barriers to care. The following section will address more specifically key finding and priority areas, including specific action items, for the Affiliate based on the findings of all previously mentioned data sources.

Programming Areas of Emphasis Based on Responses

- **General breast health education, including risk factors and treatment options**
- **Diversified health education, including using a variety of media outlets**
- **Increased provider education**
- **Increased funding for transportation assistance programs**
- **Advocacy for increased funding of BCCP**

Conclusion

The Komen Atlanta Community Profile used a number of data sources to compile this completed project. Statistical data provided the foundation for a more in depth look at our service area and breast health disparities. The provider data informed the Affiliate of the professional outlook of breast health services, gaps and barriers to care, while the community data added the personal element. Collectively, these mechanisms will serve as a guiding tool for the Affiliate in the areas of Advocacy, Education and Grantmaking.

Target Area Findings

There was a great deal of overlap in the data collected. Based on the primary and secondary data sources, four counties were highlighted as specific areas of interest. These counties are: Clayton, DeKalb, Fulton and Gwinnett.

Key Points about Counties Chosen as Priority Areas

- DeKalb , Fulton and Gwinnett have the largest populations in the service area while Clayton, DeKalb , and Fulton have the largest populations of African-Americans and Gwinnett has the largest population of Latino and Asian/Pacific Islander residents
- Clayton, DeKalb and Fulton are the counties with the lowest median family income; Fulton, DeKalb and Clayton counties have the largest percentage of residents living below the federal poverty level.
- Clayton, DeKalb and Fulton have the largest percentage of women the between ages of 18 and 64 who are uninsured.
- DeKalb and Fulton counties have the largest percentage of eligible women over 40 who have not received a mammogram in the last 12 months.
- Fulton and DeKalb have the 2nd and 3rd highest breast cancer incidence rate, exceeding both the state and national rate, and have the leading number of projected breast cancer deaths
- Clayton, DeKalb and Fulton have the largest rates of late stage breast cancer diagnosis
- There are only 16 FDA approved mammography sites serving the southern metro-area
- Of the providers surveyed, the majority of services were offered in Fulton and DeKalb counties

Based on the aforementioned, it can be concluded that there are a number of overlapping disparities that exist within 3 of the 4 counties of interest. These include Clayton, DeKalb and Fulton. In alignment with Komen's mission to

continue targeted minority outreach, Gwinnett County was also added due to its large population of Latina and Asian/Pacific Islander residents.

While Clayton, DeKalb, Fulton and Gwinnett counties were chosen as priority areas, this does not omit the fact that several other counties were leading in some key indicators. These highlights are provided below.

Other Counties within 10-County Service Area

- Cherokee, Fayette and Forsyth are the counties with the largest population of residents who identify as White and report the largest median family incomes.
- Henry, Gwinnett, Cherokee and Forsyth are estimated to have a 4% rate of the population below the federal poverty level.
- Additionally, while Fayette has the lowest percentage of women who are uninsured, 9% of women in Cherokee, Gwinnett and Henry counties are uninsured.
- Cobb County ranked 1st in breast cancer incidence rates and 3rd in projected breast cancer deaths
- Rockdale ranked in the top 5 for percentage of the population living below the federal poverty level, the number of uninsured women between the ages of 18 and 64 and the percentage of women over 40 who have not had a mammogram in the last 12 months
- Rockdale and Henry counties ranked in the top 5 for counties with the highest incidence rates of late-stage diagnosis

When looking at the other counties within Komen Atlanta's service area, it is imperative to note that, as listed above, Cobb, Henry and Rockdale also have disproportionate rates of adverse demographic factors including breast cancer incidence rates and late stage diagnosis. The information provided on the other counties validates that in spite of education and socioeconomic differences, health disparities exist across the Komen Atlanta service area and all counties warrant access to quality care.

The combination of data provided and researched proved valuable in identifying key challenges regarding the community's health outcomes. One critical factor is access to care. Improving access to care begins with education, followed by the provision of support mechanisms to ensure that a women seeking health care can fully utilize all options available. These steps assist women in fluidly moving through a healthcare continuum of care - a system that links all needed healthcare resources together to ensure the best health outcomes. The next section details the survey responses in relation to access to care and the creation of a continuum of care.

Access to Care

A. Education

Both provider and community level data highlighted access and barriers to care concerns. Fear was one of the leading indicators of why women do not routinely seek care and community members across all demographic sectors also appear to be misinformed about the key risk factors associated with developing breast cancer, as well as the range of options available for women who have been diagnosed. These two findings highlight the need for continued breast health education as a critical component to eliminating myths associated with breast cancer.

Providers also weighed in heavily on the need for additional community education. Suggestions included general breast health information delivered via television and radio media, specific advertising that informs community members of the availability of free and reduced-cost services and culturally appropriate educational information.

Both providers and community members listed providers as their key sources of health information. Therefore, efforts must not only address educating community members, but providers as well. Provider education efforts must focus on developing positive patient-provider relationships, in addition to continued efforts to keep providers informed of key community resources. As providers are seen as a major resource, their ability to adequately inform clients of their options and refer them to the appropriate venues is a critical piece in the continuum of care.

B. Financial Resources

When women are adequately informed of the need to regularly schedule their routine exams, they are often met with other challenges including transportation and the ability to pay for these services. Along with the provision of additional funding for screening and diagnostic programs, providers reported that lack of ability to pay for services is a major barrier to care. Community members echoed this fact by reporting insurance as the number one barrier to care.

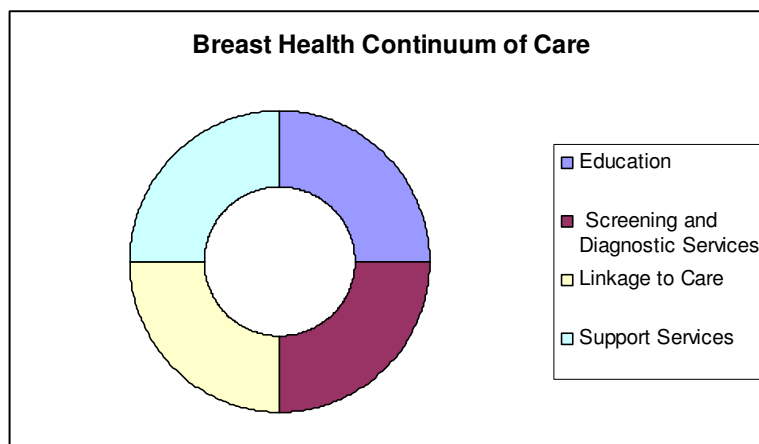
C. Transportation and Other Support Services

It is known that when providing a continuum of care people must not only be informed about their health care options, but complete the required steps to ensure proper screening, diagnosis and treatment - when required. Qualitative data from providers strongly suggested the need for transportation and mobile mammography services. Community members replied with a similar request, listing transportation as another leading barrier to care.

Providers also suggested additional support services for women seeking to access care. This includes incentivizing women who complete their screening appointments and funding patient navigators/peer counselors.

Selecting Affiliate Priorities

Through Komen Atlanta’s mission of *enabling women to detect and survive breast cancer*, the Affiliate understands the importance of providing resources along the continuum of care. The illustration below exhibits that Komen Atlanta seeks to support ongoing care, whereby women never completely lose access to the network. Instead, they fluidly move through the continuum first by being educated, followed by seeking the necessary screening and diagnostic services, being linked to care and moving on to receive the necessary support mechanisms. If and when necessary, the woman can easily regain access to resources at any point on the continuum.



While there were several highlighted areas of need provided by both the patient and community level respondents, Komen Atlanta seeks to support community initiatives in a subset of these areas. In addition to identifying the key areas that the Affiliate will focus on, the primary objectives within these areas are included below.

Affiliate Action Plan

Through the completion of a strategic planning process led by an external consultant and the completion of this Community Profile Report, the Greater Atlanta Affiliate of Susan G. Komen for the Cure has chosen the following areas and supporting action items as the critical steps in the action plan.

Education

Address myths about the causes of breast cancer, as well as treatment options; provide health education through a wide range of media and community resources; educate providers on the importance of patient-provider relationships and availability of key community resources

- A. Focus the efforts of the organization on one “priority program” of the organization, including focusing a marketing campaign on this program.*
 - 1. Develop Worship in Pink to a widespread educational initiative that provides general breast health education through religious organizations in the 10-county service area and serves as a quality resource for women seeking breast health services
 - 2. Incorporate culturally relevant education in Worship in Pink

Grants

Fund programs in areas that are currently underserved and have a disproportionate number of health disparities; increase support for screening and diagnostic programs; increase support for education programs; support programs that create a linkage to care

- A. Provide funding to grantees through a lens of enabling women to detect and survive breast cancer*
 - 1. Fund screening and diagnostic programs that ultimately lead to a reduction in late-stage diagnosis of breast cancer
 - 2. Continue to provide funding for low and reduced-cost services
 - 3. Continue focus on south-metro area
 - 4. Provide funding for culturally relevant programs
 - 5. Begin considering application of chosen evidence-based outcomes to the grantmaking program

Advocacy

Advocate for increased BCCP funding; advocate for additional coverage for those who are underinsured and uninsured; support initiatives that allocate additional resources for public transit systems and vouchers for medically underserved populations

A. Maintain or increase Georgia's budget and policy initiatives that impact detection and access to care for breast cancer

1. Preserve and enhance the *BreasTEST and More* program by encouraging the movement of the program to the Georgia Department of Community Health
2. Expand screening activities in partnership with DCH/DHR programs
3. Maintain or increase Georgia's budget and policy initiatives that impact detection and access to care for breast cancer
4. Ensure that the three Care Management Organizations (CMOs) and other private health plans provide optimal coverage for prevention, diagnosis and management of breast cancer

Limitations of Findings

The 2009 - 2010 Community Profile Report will be used as a tool to guide the Affiliate in a number of areas, including Education, Grants and Advocacy. While a variety of primary and secondary data were used and collected, it must be noted that there are limitations to this Community Profile. They are included below:

- Surveillance data sources used information from 2000 - 2007, including estimates from the Center for Disease Control and Thompson Reuters
- There were no provisions made to eliminate biases during the distribution of the face-to-face surveys
- Respondents to the electronic surveys did not have to log on to a secure website or provide any personal identifier information
- Respondents to the electronic survey were able to skip questions if they were not comfortable providing an answer
- Respondents could gain access to the survey multiple times