

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



SUSAN G. KOMEN®
GREATER ATLANTA
EXECUTIVE SUMMARY

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Michael Cohen, MD

Director, Division of Breast Imaging
Emory Health Care
Professor, Department of Radiology
Emory University School of Medicine

Kim Hartsock

Partner
Warren Averett, LLC
Board President
Susan G. Komen Greater Atlanta

Lila L. Hertz

Grants Committee Chairperson
Susan G. Komen Greater Atlanta

Meredith Sidewater

Senior Vice President and General Counsel
LexisNexis

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Report Prepared by:

Susan G. Komen® Greater Atlanta

3525 Piedmont Road
Building 5, Suite 215
Atlanta, Georgia 30305
404.814.0052
www.komenatlanta.org

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 Officials' 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 of 13 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.