



COMMUNITY PROFILE REPORT

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2011

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While we cannot name each person who contributed to this process, we would like to thank all of the community members, survivors, and healthcare professionals who recruited individuals and groups to participate in the surveys, focus groups, and all other aspects of the data collection and assessment process.

Executive Summary

Introduction

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 for the Cure®, the world's largest breast cancer organization and the largest source of non-profit funds dedicated to the fight against breast cancer with more than \$1.9 billion invested to date.

The Northeast Ohio Affiliate of Susan G. Komen for the Cure was initiated in 1994 and raised \$150,000 through its first Race for the Cure®. In 2010, the Northeast Ohio Affiliate raised more than \$2.4 million and granted nearly \$1.5 million to 24 organizations, impacting close to 46,000 people. The Northeast Ohio Affiliate was also named Affiliate of the Year by Komen National in 2010.

The Affiliate service area covers 22 highly diverse counties across Northeast Ohio. The largest urban area is the city of Cleveland in Cuyahoga County. In addition to other major cities (Lorain and Elyria in Lorain County, Youngstown in Mahoning County, Akron in Summit County, Canton in Stark County, and Mansfield in Richland County), the Affiliate serves a large rural population. Half of the counties within the service area are part of Appalachia, and Millersburg, OH, located in Holmes County, is home to the world's largest Amish settlement.

A vital first step in fulfilling our promise to end breast cancer forever is to understand the state of breast health in our service area. The Komen Community Profile is a community needs assessment conducted every two years that assists the Affiliate in identifying needs related to breast health and cancer education, screening, treatment and survivorship. The Community Profile includes an overview of demographic and breast cancer statistics highlighting target areas, groups or issues. This data helps identify regions, communities and populations where our efforts are most needed. To ensure these efforts are effective and non-duplicative, an inventory of programs and services is also conducted. A more in-depth analysis within communities of interest provides further insight into the statistics.

Statistics and Demographic Review

Data provided by Thompson Reuters was reviewed by the Community Profile Team and led by key staff at the Prevention Research Center for Healthy Neighborhoods at Case Western Reserve University in Cleveland. This data was collected from multiple sources including: insurance estimates, the Claritas Demographics, the National Health Interview Survey (NHIS), the Surveillance, Epidemiology, and End Results (SEER) Database, and information collected from the US Census Bureau.

Because of the immense differences throughout the region, data was broken down to the county level, and further to a zip code level where the data allowed. The Community Profile team looked at the following seven categories to determine areas "in need": high percentage of women over the age of 40, high percentage of non-white females, high

percentage of uninsured females ages 18-64, high percentage of females age 40 and older with no mammogram in the past year, a high incidence rate, a high percentage of late stage diagnosis (Stages 2-3-4), and a high mortality rate. The following counties were selected as communities of interest based on their high rates in all seven categories when compared with every county in the service area.

Counties/Communities of Interest

County	Female Population 40+	% Non-white	% Uninsured Females 18-64	% Females 40+ with no Mammography in Last 12 Months	Incidence in Female Population per 100K	% Late-Stage Diagnosis (2-3-4)	Mortality in Female Population per 100k
Cuyahoga	354,500	37.1	18.6	36	135.9	36.5	32.21
Lorain	76,556	18.9	12.4	35.7	122.73	35.2	29.00
Mahoning	67,633	22.3	19.2	37	106.41	35	34.92
Richland	32,389	12.9	14.7	38.3	138.17	34.7	31.84
Harrison/Jefferson/Belmont	43,946	6.4	20.4	40.0	144.81	34.1	37.60
22 County Average		19.1	15.2	36.6	119.58	35.4	29.77
US Average					118.69	35.8	23.61
Ohio Average					116.2	35.5	27.87

Table 1. 2011 Komen Northeast Ohio communities of interest.

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Each community of interest has a unique grouping of characteristics that place it higher than others on the list of potential need. Cuyahoga County was selected for its high rates in nearly all seven categories across the board, but specifically for its high rates of uninsured (18.6%), late-stage diagnosis (36.5%) and mortality (32.2/100k women). Lorain County was chosen for its high rates of incidence (122.7), mortality (29.0) and, in particular, low screening rates for women over 40 (35.7%). Mahoning County was selected for its relatively low rate of incidence (106.4) coupled with an above average mortality rate (34.9), as well as a high non-white population (22.3%) and uninsured women (19.2%). Richland County was picked for high rates of incidence (138.2) and mortality (31.84). The combination community of Harrison/Jefferson/Belmont was chosen for its unique combination of high incidence rates (144.8) and mortality (37.6).

It is important to note that within the larger counties, as in Cuyahoga County, there are diverse sub-sections that need to be treated differently. Therefore, within each community of interest, information was broken down to the zip-code level to determine specific “hotspot” areas, or areas in need of further investigation.

Health Systems Analysis

The continuum of care (see *Figure 1*) provides the framework for the analysis in this section and highlights the many factors within the healthcare system influencing the statistics in our communities of interest. An inventory of programs and services was conducted on screening and treatment facilities, education and outreach programs, and survivor support programs within Northeast Ohio. Data from the Ohio Department of Health, the Affiliate’s grantee network, the Ohio Hospital Association and a variety of internet sources was also utilized. The physical location of these resources was then plotted on an asset map to further illustrate the needs in the communities of interest.

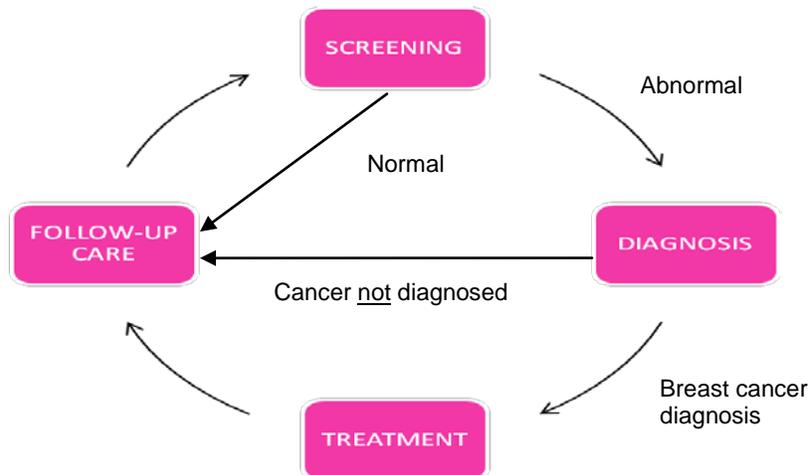


Figure 1. The continuum of care.

Overall, nearly 600 organizations are currently providing breast health services in Northeast Ohio. This includes 246 screening services, 92 treatment facilities, 104 education and outreach programs, and 176 survivor programs. Cuyahoga County has the greatest concentration of resources, followed by Harrison/Jefferson/Belmont, Mahoning, and Lorain Counties. Richland County had the least amount of services available to residents. It is important to note, however, that taken on their own the counties of Harrison, Jefferson, and Belmont have the least amount of services available to their residents.

The Ohio Breast and Cervical Cancer Project (BCCP) is a state-wide, high-quality breast and cervical cancer program offered at no cost to eligible women. Each county in the Affiliate service area is supported by a regional BCCP office. The program is funded by the Center for Disease Control and Prevention (CDC) with supplemental funding provided by the state. Eligible women who are diagnosed with breast cancer through this program qualify for BCCP Medicaid, which covers all costs of treatment. The Northeast Ohio Affiliate has a strong working relationship with the Ohio BCCP program. However, with the recent national and state budget crisis, the program's ability to screen eligible women, and its future stability, is in jeopardy.

To gather more information related to services and needs, survivors, healthcare providers and community leaders in the communities of interest completed 319 online surveys. The respondents answered questions related to access, quality of care, and personal opinions of the current healthcare system. 15 key informant interviews were completed with select survey respondents. This data indicated that the populations least likely to get mammograms were under/uninsured (85.1%), those living in poverty (87.2%), and those with low literacy rates (65.2%). Minority populations (46.8%) and populations with other health problems (37.8%) were also identified. 81.3% of those not accessing screening services were reported to have a combination of all those factors.

Major areas where women fall out of the continuum of care were also identified. There is a strong need for more culturally competent evidence-based education and

awareness programs specifically targeted to priority populations (under/uninsured, minority women). Provider education related to the BCCP and screening guidelines were also indicated. The main area of concern identified was the need for financial assistance programs related to mammography screening services.

Qualitative Data Overview

Exploratory data was collected via surveys, key informant interviews and focus groups. 319 online surveys were completed by three targeted groups in the identified communities of interest: survivors, healthcare providers and community leaders. 15 key informant interviews were conducted over the phone with select provider survey respondents to gather more detailed information related to their answers. One survivor focus group was conducted in Cuyahoga County and included eight Latina women. Because a survivor focus group could not be conducted in Richland County, one was completed in neighboring Ashland County and included 14 Caucasian women, some of whom were from Richland. A provider focus group was completed in Jefferson County with eight healthcare professionals. A PhotoVoice (PV) project, including four under/uninsured African American women and two Latina women, was also completed in Cuyahoga County.

Several key themes emerged during the data collection process and reinforced the findings from the previous two sections. First is the need for more education and awareness around breast cancer and screenings to break down barriers to care related to fear or not knowing about screening recommendations. Second is the need for more education, awareness, services and support for younger women so they can begin looking for breast cancer sooner, thus increasing their chances of survival. And finally, as reported earlier, financial assistance programs are a major concern for many of the participants, including advocacy efforts for insurance during treatment, financial assistance for screening, transportation, childcare, gas money, and prosthesis.

Conclusions

A review of demographic and breast cancer data, programs and services, and information collected from target populations in priority communities revealed many populations and areas adversely affected by breast cancer. Based on this data, the following priorities and objectives were created as the action plan to address the disparities related to breast cancer in the Northeast Ohio service area.

Priority 1: Systemic Issues - Develop and strengthen relationships with stakeholders and non-traditional partners along the continuum of care to increase access and reduce systemic barriers.

Priority 2: Education/Awareness - Increase breast health awareness and education programs, including early detection and screening information, for women most in need of services, with a focus on minority populations.

Priority 3: Access – Increase access to screening and treatment services for the low-income, under/uninsured, working poor and minority populations.