

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



NORTHEAST REGION

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ABOUT SUSAN G. KOMEN®

In 1980, Nancy G. Brinker promised her dying sister, Susan, that she would do everything in her power to end breast cancer forever. In 1982, that promise became a global movement. What started with \$200 and a shoebox full of potential donor names has now grown into the world's largest nonprofit source of funding for the fight against breast cancer - the Susan G. Komen® organization.

Komen funds more breast cancer research than any other nonprofit organization outside of the US government while also providing real-time help to those facing the disease. Since 1982, Komen and its local Affiliates have funded more than \$920 million in research and provided more than \$2 billion for breast cancer screening, education and treatment programs serving millions of people in more than 30 countries worldwide.

Our efforts have contributed to advancements in early detection and treatment that have reduced death rates from breast cancer by 37 percent (between 1990 and 2013).

The image is a composite. On the left, a grayscale photograph shows a woman with long dark hair hugging a young child from behind. The child is smiling. On the right, a black rectangular box contains text in pink and white. The text reads: "KOMEN'S BOLD GOAL IS TO REDUCE THE CURRENT NUMBER OF BREAST CANCER DEATHS BY 50% IN THE U.S. BY 2026". At the bottom right of the black box is the Susan G. Komen logo.

A Bold Vision

Vision
A World Without Breast Cancer

Mission
To save lives by meeting the most critical needs of our communities and investing in breakthrough research to prevent and cure breast cancer.

KOMEN'S BOLD GOAL IS TO REDUCE THE CURRENT NUMBER OF BREAST CANCER DEATHS BY 50% IN THE U.S. BY 2026



COMMUNITY PROFILE INTRODUCTION

The Community Profile is a needs assessment completed by Susan G. Komen and its Affiliates to assess breast cancer burden within the US by identifying areas at highest risk of negative breast cancer outcomes. Through the Community Profile, populations most at-risk of dying from breast cancer can be identified. The Community Profile provides detailed information about these populations, including demographic and socioeconomic characteristics, as well as needs and disparities that exist in availability, access and utilization of quality care. This assessment allows Komen to make data-driven decisions in the development of collaborative opportunities, grant funding priorities and implementation of evidence-based community health programs that will meet the most urgent needs and address the most common barriers to breast cancer care in order to make the biggest impact.

This report contains data for Komen's Northeast Region. This region includes the states of Connecticut, Delaware, Maine, Maryland, Massachusetts, New Hampshire, New Jersey, New York, Pennsylvania, Rhode Island and Vermont.

As of August 2016, there were 14 Komen Affiliates located in the Northeast Region:

- Komen Central and South Jersey
- Komen Central New York
- Komen Greater New York City
- Komen Maine
- Komen Maryland
- Komen Northeastern New York
- Komen Northeastern Pennsylvania
- Komen North Jersey
- Komen Philadelphia
- Komen Pittsburgh
- Komen Southern New England
- Komen Twin Tiers Region
- Komen Vermont- New Hampshire
- Komen Western New York

ANALYSIS OF THE 2015 COMMUNITY PROFILE DATA

Purpose

From 2014-2016, Komen Affiliates completed Community Profiles of their local service areas while Komen Headquarters completed State Community Profiles.

While Komen Affiliates provide services at the community level, they are also grouped into seven regions that provide an opportunity for collaboration on a multi-state level. Although local and state level data are included in the Affiliate and State Community Profile Reports, regional data about breast cancer outcomes, needs and disparities are not. In addition, there is a lack of information regarding common strategies that Affiliates are implementing to address Community Profile findings.

Therefore, the Evaluation and Outcomes team at Komen Headquarters conducted an analysis of the local and state level Community Profiles in order to compile data and provide a broader perspective of the results found within the Komen Northeast Region. The data provided in this report are meant to aid Komen Headquarters and the Affiliates within the Northeast Region in identifying issues and barriers to care that are common in the region, and enable Affiliates to work together to address common goals, when appropriate.

Methods

Komen Headquarters Evaluation and Outcomes team reviewed data from the 11 State and 14 Affiliate Community Profile Reports representing the Komen Northeast Region and compiled the available data into this Komen Northeast Region Community Profile Report.

Quantitative Data

To determine which communities (e.g., counties, cities) in the Northeast Region bear the greatest burden of breast cancer, data representing all communities from the State Community Profiles were compared to Healthy People 2020 breast cancer targets, the benchmark for each community. Healthy People 2020 (HP2020) is a major federal government initiative that provides specific health objectives for communities and for the country as a whole. HP2020 has several cancer-related objectives, including the targets used in this report: reducing the number of breast cancers that are found at a late-stage and reducing women's death rate from breast cancer.

For this report, late-stage breast cancer is defined as regional (Stage III) or distant stage (Stage IV) using the Surveillance, Epidemiology and End Results (SEER) Summary Stage definitions (Young et al., 2001). The breast cancer late-stage diagnosis rate is calculated as the number of women with regional (Stage III) or

distant (Stage IV) breast cancer at the time of diagnosis in a particular geographic area divided by the number of women living in that area. Late-stage diagnosis rates are presented in terms of 100,000 women and have been adjusted for age. Late-stage diagnosis rates are important because medical experts agree that it's best for breast cancer to be detected early. Women whose breast cancers are found at an early stage (Stage I or Stage II) usually need less aggressive treatment and do better overall than those whose cancers are found at a later stage (US Preventive Services Task Force, 2016).

The breast cancer death rate shows the frequency of death from breast cancer among women living in a given area during a certain time period. The death rate is calculated as the number of women from a particular geographic area who died from breast cancer divided by the total number of women living in that area. Death rates are presented in terms of 100,000 women and have been adjusted for age.

The Evaluation and Outcomes team compiled breast cancer late-stage diagnosis and death rates and trends (changes over time) from the 11 State Community Profile Reports reflecting the Northeast Region. Communities that are predicted not to meet both the HP2020 breast cancer late-stage diagnosis rate and death rate benchmarks are referred to as "Highest Priority" communities, since they carry the highest burden of breast cancer within the region.

The Evaluation and Outcomes team also compiled key demographic and socioeconomic characteristics from the State Community Profile Reports including race, ethnicity, age, education level, poverty, unemployment, immigration (i.e., foreign born), use of English language (e.g., linguistically isolated), medically underserved, rural areas and uninsured. These population characteristics are known to impact health outcomes and may provide information on the types of services and interventions necessary to alleviate the burden of breast cancer in these areas (Adler and Rehkopf, 2008; American Cancer Society, 2015a; American Cancer Society, 2015c; Braveman, 2010; Danforth, 2013; Lurie and Dubowitz, 2007; Robert Wood Johnson Foundation, 2008).

The following sources were used for gathering the quantitative data:

- Death rate data: Centers for Disease Control and Prevention (CDC)- National Center for Health Statistics- Surveillance, Epidemiology and End Results (SEER)* Stat, 2006-2010
- Death trend data: National Cancer Institute (NCI) and CDC- State Cancer Profiles, 2006-2010
- Late-stage diagnosis and trends data: North American Association of Central Cancer Registries (NAACCR)-CINA Deluxe Analytic File, 2006-2010
- Race, ethnicity and age data: US Census Bureau- Population Estimates, 2011

- Education level, poverty, unemployment, immigration and use of English language data: US Census Bureau- American Community Survey, 2007-2011
- Rural population data: US Census Bureau- Census, 2010
- Medically underserved data: Health Resources and Services Administration, 2013
- Health insurance data: US Census Bureau- Small Area Health Insurance Estimates, 2011

Health Systems Analysis

The Evaluations and Outcomes team used a comprehensive internet search to identify and classify facilities offering breast cancer services including screening providers, diagnostic providers and treatment providers for each state.

The internet search included the following sites. For additional detail regarding the internet search please see Appendix A.

- Community Health Centers: <http://nachc.org/about-our-health-centers/find-a-health-center/>
- Title X: <http://www.hhs.gov/opa/title-x-family-planning/initiatives-and-resources/title-x-grantees-list/>
- Mammography Centers: <http://www.accessdata.fda.gov/scripts/cdrh/cfdocs/cfMQSA/mqsa.cfm>
- Hospitals: <https://data.medicare.gov/Hospital-Compare/Hospital-General-Information/v287-28n3>

The internet search consisted of locating the following types of facilities in the communities identified as having the greatest need (“Highest Priority” communities):

- Hospitals (e.g., public or private, for-profit or non-profit)
- Community health centers that provide care regardless of an individual’s ability to pay (e.g., Federally Qualified Health Centers (FQHCs) and FQHC look-alikes)
- Free and charitable clinics that utilize a volunteer staff model and restrict eligibility to individuals who are uninsured, underinsured and/or have limited to no access to primary health care
- Health departments (e.g., local county or city health department funded by a government entity)
- Title X providers that are usually family planning centers that also offer breast cancer screening services
- Facilities that provide breast cancer services, but do not fit under any of the other categories. (e.g., non-medical service providers)

Facilities were classified as screening if they provided clinical breast exams, screening mammograms and/or patient navigation into screening. Classification as a diagnostic service provider included locations that provide diagnostic mammography, ultrasound, biopsy, magnetic resonance imaging (MRI) scanning and/or patient navigation into diagnostic services. Classification as a treatment service provider included locations that provide chemotherapy, radiation therapy, surgery, reconstruction and/or patient navigation into treatment services. A facility may be classified under more than one classification depending on the breast cancer services provided.

The comprehensive internet search also included the identification of facilities that provide breast cancer services that are accredited by a national organization that monitors the facility to ensure that the quality of care being provided meets specific benchmarks. Each national organization's website was used to identify the accredited facilities in each state. For this report, the following national accreditations were used to measure the quality of care available:

- American College of Surgeons Commission on Cancer Certification (CoC) - <https://www.facs.org/quality-programs/cancer/coc>
- American College of Surgeons National Accreditation Program for Breast Centers (NAPBC)- <https://www.facs.org/quality-programs/napbc>
- American College of Radiology Breast Imaging Centers of Excellence (BICOE)- <http://www.acr.org/Quality-Safety/Accreditation/BICOE>
- National Cancer Institute's designated Cancer Centers - <http://www.cancer.gov/research/nci-role/cancer-centers>

Each State Community Profile Report contains the number, type and location of facilities that provide breast cancer services along with the number of accredited facilities that are available. The Evaluations and Outcomes team extracted from the State Community Profile Reports the number, type and location of facilities that provide breast cancer services in the Northeast Region's "Highest Priority" communities. In addition, the number and type of accredited facilities in the Northeast Region's "Highest Priority" communities were extracted and used in this report.

The following icons are used in the health systems analysis and discussion section to represent the different types of breast cancer services available in the "Highest Priority" communities.



Screening



Diagnostic



Treatment

Qualitative Data

The Evaluations and Outcomes team analyzed qualitative data from 14 Komen Affiliates in the Northeast Region, which were collected during the 2014-2015 Community Profile process. Data were gathered from health care providers, breast cancer survivors and community members who represented the target communities selected by the Affiliates. The methods used by Affiliates to collect an individual's attitude and beliefs about breast cancer care in the local community included:

- Surveys: open-ended questions to gather information in an online or paper format
- Focus groups: structured discussion used to obtain in-depth information from a group of people
- Key informant interviews: in-depth, structured discussions with people who are very familiar with the community
- Document review: review of published materials that used qualitative data collection methods

Using thematic analysis, the Evaluations and Outcomes team identified common themes from the qualitative data findings presented in the Affiliate Community Profile Reports. Themes were added, combined and revised as commonalities became more prevalent. The themes were tracked in a spreadsheet and were classified by Affiliate and community of interest. The most frequently cited themes are discussed in the qualitative data section of this report. A list of all themes and their corresponding definitions are located in Appendix B.

The following icons were used to represent different data collection methods conducted by the Affiliates.



Survey



Focus Group



Key Informant Interview



Document Review

Mission Action Plan

Using the data collected during the Community Profile process, Komen Affiliates developed an action plan, referred to as the Mission Action Plan (MAP), to implement within a four-year time period to address the breast cancer needs identified for their target communities. All 14 Affiliates in Komen's Northeast Region completed a MAP. Each Affiliate's MAP consists of problem statements, priorities and objectives. The problem statements summarize the issues revealed during the Community Profile process in the communities of interest. Priorities represented the goals that the Affiliates expected to achieve within five years. Objectives are the activities that an Affiliate is going to do to reach the priorities.

The Evaluations and Outcomes team used descriptive analysis to identify commonalities within the problem statements, priorities and objectives in each Affiliate's Mission Action Plan. The problem statements, priorities and objectives were first classified into descriptive categories. The categories were then analyzed to identify commonalities. Commonalities identified from the Northeast Region Affiliates' MAPs are presented in the conclusions section of this report.

Challenges and Limitations

The various methods used to gather data for the 2015 Community Profile process resulted in challenges that limit the generalizability of the data collected.

Recent data

At the time of quantitative data collection for the State and Affiliate Community Profile Reports, the most recent data available were used but, for breast cancer late-stage diagnosis and death rates, these data are still several years behind. For example, the breast cancer late-stage diagnosis and death rates that were available in 2013, when data were being collected, were from 2010. For the US as a whole and for most states, breast cancer late-stage diagnosis and death rates do not often change rapidly. Rates in individual communities might change more rapidly. In particular, if a cancer control program has been implemented in 2011-2013, any impact of the program on death and late-stage diagnosis rates would not be reflected in this report.

As time passes, the data in this report will become more out-of-date. However, the trend data included in the report can help estimate current values. Also, the State Cancer Profiles Web site (<http://statecancerprofiles.cancer.gov/>) is updated annually with the latest cancer data for states and can be a valuable source of information about the latest breast cancer rates. However, it is unlikely that the data that is presented in this report will change significantly in the five years between Community Profile updates to result in changes to the "Highest Priority" communities.

The available breast cancer services (e.g., screening, diagnostic and treatment) and accredited facilities (e.g., CoC, BICOE, NAPBC, and NCI Cancer Centers) identified in the health system analysis section of this report were collected between September 2014 - March 2015. Therefore, local facilities that provide breast cancer services (e.g., screening, diagnostics and treatment) may have changed since March 2015 and may be either over-represented or under-represented in the community.

Data Availability

For some communities, data might not be available or might be of varying quality. Cancer surveillance programs vary from state to state in their level of funding and

this can impact the quality and completeness of the data in the cancer registries and the state programs for collecting death information. There are also differences in the legislative and administrative rules for the release of cancer statistics used for studies such as community needs assessments. These factors can result in missing data for some of the data categories in this report. Communities missing both death and late-stage diagnosis rate data were excluded from HP2020 priority classification. This does not mean that the community may not have high needs; it only means that sufficient data are not available to classify the community.

There are also many factors that impact breast cancer risk and survival for which quantitative data are not available. Some examples include family history, genetic markers like HER2 and BRCA, other medical conditions that can complicate treatment, and the level of family and community support available to the patient. Good quantitative data are not available on how factors such as these vary from place to place.

Qualitative Data

Qualitative methods (e.g., surveys, focus groups, key informant interviews) that were used during the Affiliate Community Profile process gathered information regarding an individual's attitude and beliefs about breast cancer care in their local community. The qualitative data used in this report have some specific limitations that were unable to be controlled for because the methods implemented and data collected were completed by 14 different Affiliates. These limitations include, but are not limited to:

- Small sample sizes limit the ability of the data to accurately represent everyone in the community
- Data collected by the Affiliates were not always from communities that were classified as "Highest Priority" in this report
- Bias of the facilitator and/or interviewer in which they give preference to their own view over others and recall information that favors their view only
- Response bias in which participants provide answers they believe the facilitator or interviewer wants to hear, even if untrue
- Poor wording of questions may have resulted in inaccurate, or unrelated responses that do not match the intent of the question
- Sampling bias in which attitudes and beliefs of those that participated in the different qualitative methods may be different than those that did not (e.g., those that participated may have less barriers than those that did not participate)

These limitations may result in the qualitative data in this report not being representative of the geographic areas that are not predicted to meet HP2020 targets for death and late-stage diagnosis rates, and may only represent the

perspectives of those that participated in the surveys, focus groups and key informant interviews.

DISCUSSION

In order to better understand the breast cancer issues and barriers to care that are common across the Komen Northeast Region and enable Affiliates within the region to work together to address common goals, Komen Headquarters Evaluation and Outcomes team compiled available quantitative, health systems and qualitative data within the Northeast Region. This section details the findings of this regional analysis.

Quantitative Data Analysis

Breast cancer late-stage diagnosis and death rates and trends were analyzed across the Komen Northeast Region in order to assess the burden of breast cancer within the region. These data were then compared to Healthy People 2020 targets for breast cancer to identify the areas of greatest need within the region. Table 1 shows both late-stage diagnosis and death rates and trends for the states within Komen's Northeast Region.

Table 1. Female breast cancer late-stage diagnosis and death rates and trends- Komen Northeast Region

Population Group	Female Population (Annual Average)	Late-Stage Diagnosis and Trends			Death Rates and Trends		
		# of New Late-stage Cases (Annual Average)	Age-adjusted Late-stage Diagnosis Rate /100,000	Late-stage Trend (Annual Percentage Change)	# of Deaths (Annual Average)	Age-adjusted Death Rate /100,000	Death Trend (Annual Percent Change)
US (states with available data)	145,332,861	70,218	43.7	-1.2%	40,736	22.6	-1.9%
Connecticut	1,820,737	958	44.6	0.0%	507	21.6	-2.3%
Delaware	454,255	222	42.6	0.3%	125	22.8	-2.9%
Maine	677,964	354	41.6	-1.9%	193	20.9	-2.5%
Maryland	2,942,268	1,521	46.4	-0.5%	818	24.5	-2.0%
Massachusetts	3,344,752	1,586	41.4	-2.6%	895	21.3	-3.2%
New Hampshire	665,676	326	41.6	1.1%	174	21.3	-3.1%
New Jersey	4,476,452	2,402	46.5	-1.6%	1,389	25.2	-2.4%
New York	9,929,239	5,026	44.6	-1.6%	2,704	22.3	-2.6%
Pennsylvania	6,474,106	3,566	45.4	-0.4%	2,103	23.8	-2.3%
Rhode Island	546,285	272	42.6	-4.8%	149	20.8	-3.3%
Vermont	316,866	148	38.5	1.9%	84	20.4	-2.7%

NA - data not available.

Late-stage diagnosis data are for years 2006-2010.

Death data are for years 2006-2010.

Rates are cases/deaths per 100,000.

Age-adjusted rates are adjusted to the 2000 US standard population.

Source of late-stage diagnosis rates and trend data: NAACCR - CINA Deluxe Analytic File.

Source of death rate data: CDC - NCHS mortality data in SEER*Stat.

Source of death trend data: NCI/CDC State Cancer Profiles.

Comparison to Healthy People 2020 Targets

Healthy People 2020 (HP2020) is a major federal government initiative that provides specific health objectives for communities and for the country as a whole. HP2020 targets for breast cancer death and late-stage diagnosis rates were used as a benchmark to determine which communities (e.g., county, city) in the Northeast Region have the highest breast cancer needs. In 2014, the HP2020 target for late-stage diagnosis rate was 41.0 per 100,000 females and the target for breast cancer death rate was 20.6 per 100,000 females.

Breast cancer late-stage diagnosis and death rates and trends (changes over time) were used to calculate whether each community in the Northeast Region would meet the HP2020 target, assuming that the trend seen in years 2006 to 2010 continue for 2011 and beyond. A negative trend means that the rates are predicted to decrease each year; while a positive trend indicates that rates are increasing each year. For breast cancer death and late-stage rate, a negative trend is desired.

Communities are classified as follows:

- Communities that are not likely to achieve either of the HP2020 targets for late-stage diagnosis or death rates are considered to have the highest needs.
- Communities that have already achieved both targets are considered to have the lowest needs.
- Other communities are classified based on the number of years needed to achieve the two targets.

Table 2 shows how communities are assigned to priority categories. There has not been any indication that either one of the two HP2020 targets is more important than the other. Therefore, the report considers them equally important.

Table 2. Priority classification based on the projected time to achieve HP2020 breast cancer targets

		Time to Achieve Late-stage Diagnosis Reduction Target				
		13 years or longer	7-12 yrs.	0 - 6 yrs.	Currently meets target	Unknown
Time to Achieve Death Rate Reduction Target	13 years or longer	Highest	High	Medium High	Medium	Highest
	7-12 yrs.	High	Medium High	Medium	Medium Low	Medium High
	0 - 6 yrs.	Medium High	Medium	Medium Low	Low	Medium Low
	Currently meets target	Medium	Medium Low	Low	Lowest	Lowest
	Unknown	Highest	Medium High	Medium Low	Lowest	Unknown

If the time to achieve the HP2020 target cannot be calculated for one of the HP2020 indicators (i.e., late-stage diagnosis rate or death rate), then the community is classified based on the other indicator. If both indicators are missing, then the

community is classified as “unknown”. This doesn’t mean that the community may not have high needs; it only means that sufficient data are not available to classify the community.

Table 3 represents communities in the Komen Northeast Region that have been designated “Highest Priority”. The “Highest Priority” designation means that they are not likely to meet the Healthy People 2020 targets for breast cancer late-stage diagnosis or deaths. In addition, key demographic and socioeconomic characteristics have been provided in Table 3 that may assist in identifying who in these communities may be most in need of help. For this report, demographic and socioeconomic characteristics are considered influential factors when the percentage is substantially higher than the state. Substantially higher is defined as three percentage points higher for a factor less than 10.0 percent and five percentage points higher for a factor equal to or greater than 10.0 percent. Detailed information regarding key population characteristics of each of the “Highest Priority” communities can be located in Appendix C.

Demographic characteristics include populations that have been found to have less favorable breast cancer outcomes:

- Black/African-American women: Breast cancer is the most common cancer among Black/African-American women. In 2013, breast cancer deaths were 39 percent higher in Black/African-American women than in white women (Howlader et al., 2016). Although breast cancer survival in Black/African-American women has increased over time, survival rates remain lower than among white women.
- Hispanic/Latina women: Breast cancer is the leading cause of cancer death in Hispanic/Latina women (American Cancer Society, 2015b).
- Asian and Pacific Islander (API) women: Breast cancer incidence among Asian-American, Native Hawaiian and Pacific Islander women have increased since 2005 (American Cancer Society, 2016). Breast cancer is the second leading cause of cancer death in Asian-American, Native Hawaiian and Pacific Islander women (American Cancer Society, 2016).
- American Indian and Alaska Native (AIAN) women: The last two decades have seen large increases in both incidence and death rates for American Indian and Alaska Native women (American Cancer Society, 2015a). Among AIAN women, those who live in Alaska and the Southern Plains have the highest death rates and women who live in the Southwest have the lowest mortality rates (White et al., 2014).
- Older women (65 and older): The risk of breast cancer increases as an individual becomes older. Most breast cancers and breast cancer deaths occur in women aged 50 and older (American Cancer Society, 2015a)

Socioeconomic characteristics include factors that have been identified as barriers that may prevent individuals from being able to access care, afford care and/or understand the care that their doctor recommends. For example, uninsured individuals that have an annual income below 200 percent Federal Poverty Level may not have the financial resources to pay for diagnostic services if they have an abnormal mammogram. Immigrants that do not speak English fluently may experience cultural and language barriers when receiving care. Individuals that reside in rural and/or medically underserved areas may have to travel outside of their community to access care which requires transportation resources as well as longer periods of time off work.

Table 3. Healthy People 2020 “Highest Priority” communities in the Komen Northeast Region

State	Community	Affiliate Coverage	Late-Stage Diagnosis Rate per 100,000 (trend)	Death Rate per 100,000 (trend)	Key Population Characteristics
Healthy People 2020 Target			41.0*	20.6*	
United States (states with available data)			43.7 (-1.2%)	22.6 (-1.9%)	
Delaware	Kent County	Komen Philadelphia	45.4 (+3.0%)	27.7 (-1.7%)	Rural
Maine	Knox County	Komen Maine	50.5 (+8.9%)	26.8 (-1.4%)	Rural
Maine	Piscataquis County	Komen Maine	44.7 (+26.2%)	SN	Rural, medically underserved
Maryland	Baltimore City	Komen Maryland	51.9 (+7.1%)	27.9 (-0.2%)	%Black/African-American, education, poverty, employment, medically underserved
Maryland	Calvert County	Komen Maryland	52.6 (+1.7%)	27.6 (-1.5%)	Rural, medically underserved
Maryland	Charles County	Komen Maryland	45.4 (0.0%)	24.4 (-0.8%)	%Black/African-American, rural
Maryland	Worcester County	Komen Maryland	49.3 (+6.1%)	27.9 (-0.2%)	Older, rural, medically underserved
Massachusetts	Dukes County	Komen Southern New England	SN	26.5 (-0.9%)	Rural
Massachusetts	Nantucket County	Komen Southern New England	72.9 (+12.3%)	SN	Rural
New Jersey	Atlantic County	Komen Central and South Jersey	45.2 (+2.2%)	26.7 (-1.7%)	Rural, medically underserved
New Jersey	Camden County	Komen Central and South Jersey / Komen Philadelphia	53.3 (-0.9%)	28.3 (-2.3%)	%Black/African-American
New Jersey	Gloucester County	Komen Central and South Jersey	50.5 (+0.4%)	27.8 (-1.5%)	
New Jersey	Sussex County	Komen North Jersey	52.8 (-2.0%)	29.5 (-1.2%)	Rural
New York	Monroe County	Komen Central New York	43.4 (+0.2%)	22.8 (+2.4%)	
New York	Seneca County	Komen Central New York	38.4 (+3.7%)**	23.6 (+21.4%)	Rural
New York	Wyoming County	Komen Western New York	55.1 (+18.6%)	24.7 (-0.5%)	Rural, medically underserved
Pennsylvania	Delaware County	Komen Philadelphia	46.3 (-0.1%)	27.5 (-2.1%)	%Black/African-American
Pennsylvania	Fayette County	Komen Pittsburgh	44.7 (+2.9%)	25.9 (-1.7%)	Poverty, rural, medically underserved
Pennsylvania	Jefferson County	Komen Pittsburgh	44.8 (+5.8%)	28.2 (-1.5%)	Rural, medically underserved



State	Community	Affiliate Coverage	Late-Stage Diagnosis Rate per 100,000 (trend)	Death Rate per 100,000 (trend)	Key Population Characteristics
Pennsylvania	Mercer County	Komen Pittsburgh	46.3 (+9.3%)	27.3 (-1.1%)	Rural
Pennsylvania	Mifflin County	Komen Pittsburgh	50.2 (+3.0%)	24.9 (-0.3%)	Education, rural, medically underserved
Pennsylvania	Montour County	Komen Northeastern Pennsylvania	36.9 (+17.0%)**	SN	Rural
Pennsylvania	Philadelphia County	Komen Philadelphia	51.6 (-0.6%)	29.0 (-2.2%)	%Black/African-American, %API, %Hispanic/Latina, education, poverty, employment, foreign born, language, insurance, medically underserved
Pennsylvania	Pike County	Komen Northeastern Pennsylvania	49.8 (+7.7%)	27.7 (+9.8%)	Employment, rural
Pennsylvania	Schuylkill County	Komen Northeastern Pennsylvania	46.9 (+4.9%)	28.6 (-0.2%)	Rural, medically underserved
Vermont	Addison County	Komen Vermont New Hampshire	38.5 (15.3%)**	24.8 (+24.1%)	Rural
Vermont	Bennington County	Komen Vermont New Hampshire	40.8 (+4.1%)**	23.6 (-.09%)	

*Target as of the writing of this report.

** While this community currently meets the HP2020 target, because the trend is increasing it should be treated the same as a community that will not meet the HP2020 target.

NA - data not available.

SN - data suppressed due to small numbers (15 deaths or fewer for the 5-year data period).

Late-stage diagnosis data are for years 2006-2010.

Death data are for years 2006-2010.

Rates are in cases/deaths per 100,000.

Age-adjusted rates are adjusted to the 2000 US standard population.

Source of late-stage diagnosis rate and trend data: NAACCR - CINA Deluxe Analytic File.

Source of death rate data: CDC - NCHS mortality data in SEER*Stat.

Source of death trend data: NCI/CDC State Cancer Profiles

In the Komen Northeast Region, there are 27 communities that are not projected to meet HP2020 breast cancer targets and are, thus, considered “Highest Priority”. All 27 communities are located within a Komen Affiliate service area. When viewing the region as a whole, 20 of the 27 “Highest Priority” communities have a substantially higher percentage of individuals residing in rural areas (Table 4).

Table 4. HP2020 “Highest Priority” communities in the Northeast Region with a substantially higher percentage of individuals living in rural areas

Komen Affiliate	Community	Key Demographic/ Socioeconomic factors
Komen Southern New England	Dukes County, MA	Rural
	Nantucket County, MA	Rural
Komen Maine	Knox County, ME	Rural
	Piscataquis County, ME	Rural, Medically Underserved
Komen Maryland	Charles County, MD	%Black/African-American, Rural
	Calvert County, MD	Rural, Medically Underserved
	Worcester County, MD	Older, Rural, Medically Underserved
Komen Central and South Jersey	Atlantic County, NJ	Rural, Medically Underserved
Komen North Jersey	Sussex County, NJ	Rural
Komen Central New York	Seneca County, NY	Rural
Komen Western New York	Wyoming County, NY	Rural, Medically Underserved
Komen Philadelphia	Kent County, DE	Rural
Komen Pittsburgh	Fayette, County PA	Poverty, Rural, Medically Underserved
	Jefferson County, PA	Rural, Medically Underserved
	Mercer County, PA	Rural
	Mifflin County, PA	Education, Rural, Medically Underserved
Komen Northeastern Pennsylvania	Schuylkill County, PA	Rural, Medically Underserved
	Montour County, PA	Rural
	Pike County, PA	Employment, Rural
Komen Vermont New Hampshire	Addison County, VT	Rural

Collaboration among Komen Affiliates in the Northeast Region that have a higher percentage of individuals residing in rural areas would allow sharing of best practices on what has worked and what has not worked in reaching rural populations and addressing the barriers they have in accessing care.

In addition, 11 of 27 communities have a substantially larger percentage of individuals living in medically underserved areas (Table 5). According to the US Department of Health and Human Services, areas are designated as medically underserved when they have too few primary care providers to serve the area residents, a high percentage of residents with incomes below the poverty level and/or a high percentage of the population being over the age of 65. These factors have been linked to barriers associated with accessing quality and timely care. Two of the

“Highest Priority” communities in Komen’s Northeast Region are considered to be medically underserved despite being urban areas: Baltimore City, MD and Philadelphia County, PA.

Table 5. HP2020 “Highest Priority” communities in the Northeast Region with a substantially higher percentage of individuals living in medically underserved areas

Komen Affiliate	Community	Key Demographic/ Socioeconomic factors
Komen Maine	Piscataquis County, ME	Rural, Medically Underserved
Komen Maryland	Baltimore City, MD	%Black/African-American, education, poverty, employment, medically underserved
	Calvert County, MD	Rural, Medically Underserved
	Worcester County, MD	Older, Rural, Medically Underserved
Komen Central and South Jersey	Atlantic County, NJ	Rural, Medically Underserved
Komen Western New York	Wyoming County, NY	Rural, Medically Underserved
Komen Philadelphia	Philadelphia County, PA	%Black/African-American, %API, %Hispanic/Latina, education, poverty, employment, foreign born, language, insurance, medically underserved
Komen Pittsburgh	Fayette, County PA	Poverty, Rural, Medically Underserved
	Jefferson County, PA	Rural, Medically Underserved
	Mifflin County, PA	Education, Rural, Medically Underserved
Komen Northeastern Pennsylvania	Schuylkill County, PA	Rural, Medically Underserved

Of the 11 communities considered medically underserved, nine of the communities are also rural including:

Komen Central and South Jersey

- Atlantic County, NJ

Komen Western New York

- Wyoming County, NY

Komen Maine

- Piscataquis County, ME

Komen Pittsburgh

- Fayette County, PA
- Jefferson County, PA
- Mifflin County, PA

Komen Maryland

- Calvert County, MD
- Worcester County, MD

Komen Northeastern Pennsylvania

- Schuylkill County, PA

Black/African-American women are often diagnosed with late-stage breast cancer when treatment options are limited, and the prognosis is poor. Black/African-American women also have a 39 percent higher breast cancer death rate than White women (Howlander et al., 2016). In the Komen Northeast Region, five of the “Highest



Priority” communities have a substantially larger Black/African-American female population than their respective state as a whole:

Komen Central and South Jersey/Komen Philadelphia

- Camden County, NJ

Komen Maryland

- Baltimore City, MD
- Charles County, MD

Komen Philadelphia

- Delaware County, PA
- Philadelphia County, PA

Within Komen’s Northeast Region, there are “Highest Priority” communities that are adjacent to each other. Individuals residing in areas where two or more “High Priority” communities are adjacent to each other may experience additional barriers compared to a “Highest Priority” community that is adjacent to lower priority communities. These additional barriers (e.g., transportation, acceptance of health insurance) may lead individuals to forgo doctor recommended screening and/or follow up, thus resulting in the possibility that breast cancer is found and treated at a later stage when prognosis is poorer.

Additional geographical complexities in accessing care occur when “Highest Priority” communities are located on a state border and the closest breast cancer care facility is across the state border. When individuals cross state borders, the individual’s health insurance may not be accepted. For example, Medicaid coverage is a state health insurance and therefore coverage varies by state. An individual with Medicaid coverage may not be able to access the closest breast cancer services if those services are in another state because their Medicaid health insurance is only accepted within their state of residency.

In the Northeast Region, there are two clusters of two or more ‘Highest Priority’ communities that may indicate greater needs than a single “Highest Priority” community bordered by lower priority communities. Both of these clusters cross state borders which may add additional barriers to someone seeking breast cancer care (e.g., insurance coverages change between states, transportation). The two community clusters are:

- Atlantic County (NJ), Camden County (NJ), Gloucester County (NJ), Delaware County (PA) and Philadelphia County (PA) served by Komen Central and South Jersey and Komen Philadelphia.

- Sussex County (NJ) and Pike County (PA) served by Komen North Jersey and Komen Northeastern Pennsylvania.

Figure 1 shows each community within Komen’s Northeast Region according to their priority classification based on HP2020 targets in Table 2. When both of the indicators used to establish a priority for a community are not available, the priority is shown as “undetermined” on the map.

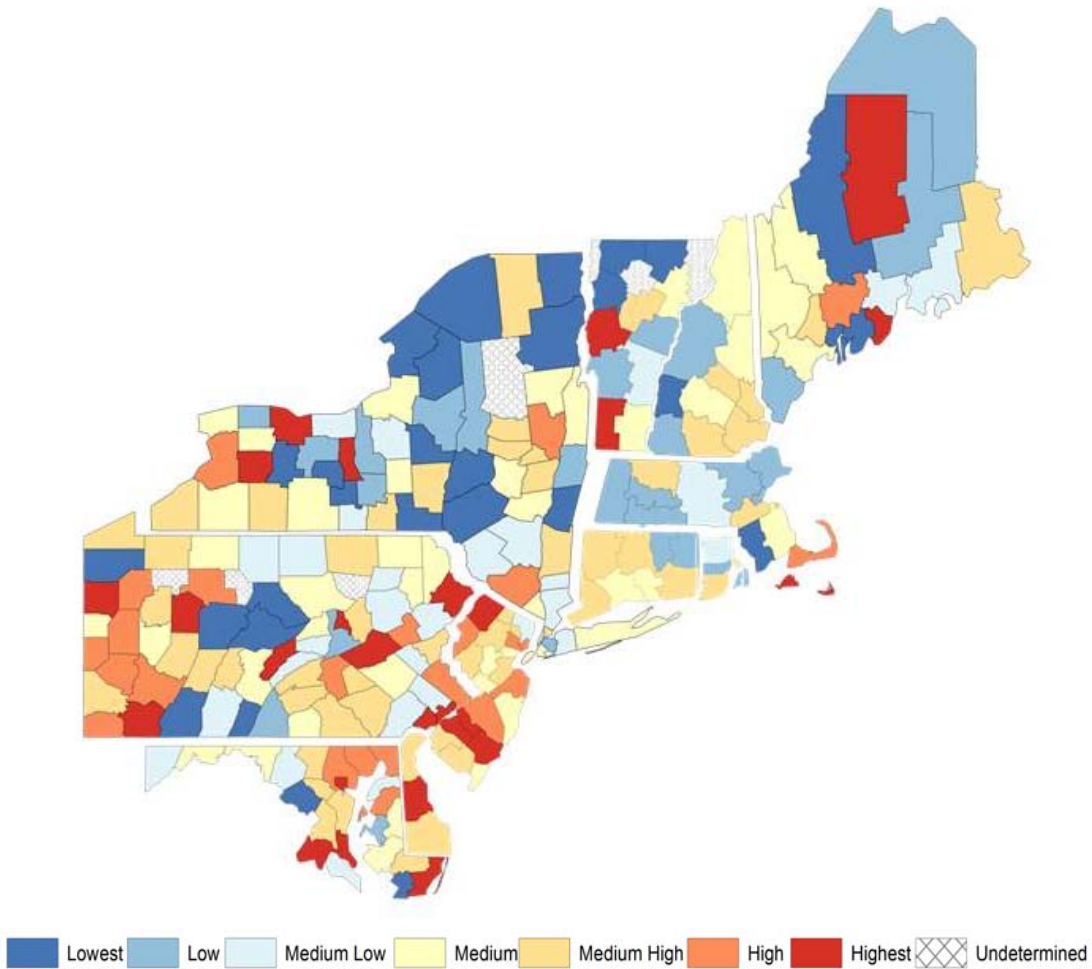


Figure 1. Healthy People 2020 priority classifications- Komen Northeast Region

Health System Analysis

An inventory of breast cancer programs and services in the Komen Northeast Region was collected by Komen Headquarters Evaluation and Outcomes team through a comprehensive internet search (Appendix A) to identify the following types of health care facilities or community organizations that may provide breast cancer related services: hospitals, community health centers, free clinics, health departments, Title X providers, and additional facilities that provide breast cancer services (e.g., non-medical service providers).



In Komen's Northeast Region, there are 3,244 facilities that provide screening services (i.e. clinical breast exam, screening mammography and/or patient navigation into screening services). Of those facilities that provide screening services, 374 are located in a "Highest Priority" community.



In Komen's Northeast Region, there are 1,550 facilities that provide diagnostic services (i.e. diagnostic mammography, ultrasound, biopsy, magnetic resonance imaging (MRI) scanning and/or patient navigation into diagnostic services). Of those facilities that provide diagnostic services, 132 are located in a "Highest Priority" community.



In Komen's Northeast Region, there are 526 facilities that provide treatment services (i.e. chemotherapy, radiation, surgery, reconstruction and/or patient navigation into treatment services). Of those facilities that provide treatment services, 57 are located in a "Highest Priority" community.

A facility may be classified under more than one classification depending on the services provided. Appendix D provides the total number of screening, diagnostic and treatment facilities for the Northeast Region's "Highest Priority" communities and states.

These numbers, however, do not tell the whole story about the availability of services for individuals that are residing in a "Highest Priority" community. An individual residing in a "Highest Priority" community may only have only one or two of the services available within a short distance from their residence and may have to travel a greater distance within the community, or to another community, to receive additional care. A lack of local services increases the likelihood that an individual will have difficulty accessing initial screening services and follow-up care after an abnormal screening. This, in turn, may contribute to breast cancer being diagnosed at a later stage when treatment options are limited, and prognosis is poor, or may result in delays in treatment after diagnosis, which contribute to poorer outcomes.



The following Northeast Region HP2020 “Highest Priority” rural community in Komen Northeastern Pennsylvania’s service area has in-community screening services, but does not have any facilities that provide diagnostic and treatment services:

- Pike County, PA

In the Komen Northeast Region, four HP2020 “Highest Priority” communities have in-community screening and diagnostic services, but do not have any facilities that provide treatment services:

Komen Central New York

- Seneca County, NY

Komen Pittsburgh

- Fayette County, PA

Komen Maine

- Piscataquis County, ME

Komen Southern New England

- Dukes County, MA

The remaining communities have breast cancer screening, diagnostics and treatment services available locally.

Although these communities may have services, this doesn’t account for quality of care that may be provided at these facilities. The Institute of Medicine defines quality of care as “providing patients with appropriate services in a technically competent manner, with good communication, shared decision-making and cultural sensitivity” (Hewitt and Simone, 1999). Hospitals and medical centers that provide quality care tend to have up-to-date facilities and equipment, follow current breast cancer screening, diagnostic and treatment guidelines, and have doctors with appropriate credentials and experience in treating breast cancer. Overall, quality of care is about the process of care, outcomes of care, and patient satisfaction levels from a particular program and/or organization.

Komen Headquarters Evaluation and Outcomes team collected data on the number of facilities in the Northeast Region that were accredited by standard quality programs for breast cancer care in the United States. The specific breast cancer related accreditations considered for this report include American College of Radiology Breast Imaging Centers of Excellence, American College of Surgeons Accreditation Program for Breast Centers, American College of Surgeons Commission on Cancer Certification and the National Cancer Institute’s designated Cancer Centers.

While screening, diagnostic and treatment services are available through facilities located in HP2020 “Highest Priority” communities, the services provided may not follow recommended guidelines and lack care coordination to diagnostic and

treatment services. This may result in the individual having to coordinate their own care within a complex health care system. Confusion and frustration of navigating a complex health care system may lead to individuals forgoing care, not being aware that additional tests are needed, or taking longer to be diagnosed leading to potential delays in beginning recommended breast cancer treatment. Additionally, patients may not be made aware of breast cancer clinical trials that they may be eligible to participate in, and planning and coordination of care may be “siloed” (e.g., each medical provider focused one isolated part of care and not how that care functions within a larger treatment plan).

American College of Radiology Breast Imaging Centers of Excellence (BICOE)

<http://www.acr.org/Quality-Safety/Accreditation/BICOE>

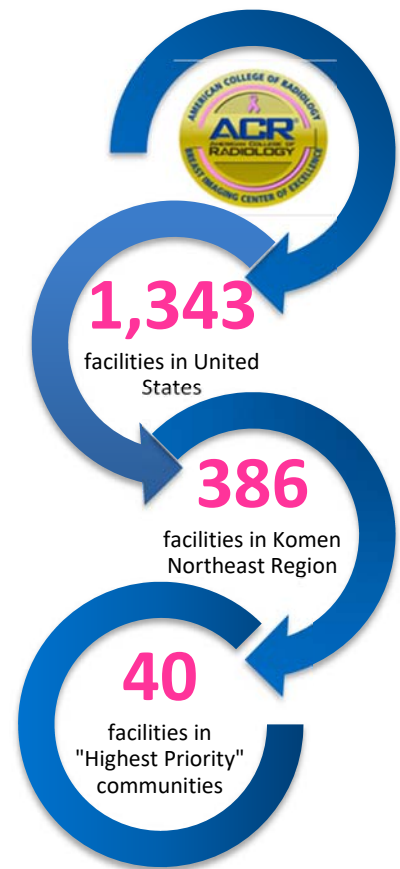
The American College of Radiology (ACR) BICOE “designation is awarded to breast imaging centers that achieve excellence” in providing effective, safe and quality breast imaging care to patients (American College of Radiology, n.d.).

In order for a facility to receive designation as a BICOE, the facility must meet quality breast imaging screening and diagnostic performance measures for mammography, stereotactic breast biopsy, breast ultrasound and breast MRI.

In the US, there are 8,283 facilities that provide breast cancer screening and diagnostic services; of those facilities, 1,343 (16.2%) are accredited as an ACR BICOE facility.

In Komen’s Northeast Region, there are 1,510 facilities that provide breast cancer screening and diagnostic services; of those facilities, 386 (25.6%) are accredited as an ACR BICOE facility.

Within the Northeast Region’s “Highest Priority” communities, there are 140 facilities that provide breast cancer screening and diagnostic services; of those facilities, 40 (28.6%) are accredited as an ACR BICOE facility (Table 6). Individuals that reside in communities that have accredited screening and diagnostic facilities have access to services that meet quality breast imaging performance measures. However, in the



Northeast Region, there are 100 facilities located in 12 communities that are not ACR BICOE accredited and the services provided to individuals seeking care may not meet quality breast imaging performance measures (Table 7).

Table 6. HP2020 “Highest Priority” communities in the Northeast Region with ACR BICOE accredited facilities

Komen Affiliate	Community	Total number of facilities in the community*	Number of BICOE accredited facilities in the community	Key demographic/ socioeconomic factors
Komen Central New York	Monroe County, NY	22	6	
Komen Central and South Jersey	Atlantic County, NJ	4	1	Rural, Medically Underserved
	Gloucester County, NJ	6	4	
Komen Central and South Jersey/Komen Philadelphia	Camden County, NJ	13	9	%Black/African-American
Komen Maryland	Baltimore City, MD	30	2	%Black/African American, education, poverty employment, medically underserved
	Calvert County, MD	3	2	Rural, medically-underserved
	Worcester County, MD	1	1	Older, rural, medically underserved
Komen Northeastern Pennsylvania	Montour County, PA	1	1	Rural
Komen Philadelphia	Kent County, DE	7	2	Rural
	Delaware County, PA	7	3	%Black/African-American
	Philadelphia County, PA	21	5	%Black/African-American, %API, %Hispanic/Latina, education, poverty, employment, foreign born, language, insurance, medically underserved
Komen Pittsburgh	Mercer County, PA	4	2	Rural
Komen Vermont New Hampshire	Bennington County, VT	1	1	Rural
Komen Western New York	Wyoming County, NY	2	1	Rural, Medically Underserved

* Note: Facilities that provide screening and diagnostic services in the HP2020 “Highest Priority” communities with a least one BICOE accredited facility. These numbers do not represent the number of facilities that provide screening and diagnostic services in all HP2020 “Highest Priority” communities.

Table 7. HP2020 “Highest Priority” communities in the Northeast Region without ACR BICOE accredited facilities

Komen Affiliate	Community	Key demographic/socioeconomic factors
Komen Central New York	Seneca County, NY	Rural
Komen Maine	Knox County, ME	Rural
	Piscataquis County, ME	Rural, Medically Underserved
Komen Maryland	Charles County, MD	%Black/African-American, Rural
Komen North Jersey	Sussex County, NJ	Rural
Komen Northeastern Pennsylvania	Schuylkill County, PA	Rural, Medically Underserved
Komen Pittsburgh	Fayette, County, PA	Poverty, Rural, Medically Underserved
	Jefferson County, PA	Rural, Medically Underserved
	Mifflin County, PA	Education, Rural, Medically Underserved
Komen Southern New England	Dukes County, MA	Rural
	Nantucket County, MA	Rural
Komen Vermont New Hampshire	Addison County, VT	Rural

American College of Surgeons National Accreditation Program for Breast Centers (NAPBC)

<https://www.facs.org/quality-programs/napbc>

The American College of Surgeons’ (ACS) NAPBC is focused on improving quality of care and outcomes for patients with diseases of the breast (American College of Surgeons, 2014b). The NAPBC utilizes evidence-based standards, patient and provider education, and encourages leaders from major disciplines to work together to diagnose and treat breast disease.

In order to be an ACS NAPBC programs, the breast center must demonstrate a multidisciplinary, integrated and comprehensive model for providing breast care services and meet high-quality breast cancer care performance measures. NAPBC facilities must meet performance standards in providing screening, diagnostic and treatment services, employing medical providers with specialized knowledge and skills in diseases of the breast, participation in clinical trials, and implementation of education, support and survivorship programs.





In the US, there are 2,925 facilities that provide breast cancer screening, diagnostic and treatment services; of those facilities, 541 (18.5%) are accredited as an ACS NAPBC facility.

In Komen’s Northeast Region, there are 520 facilities that provide breast cancer screening, diagnostic and treatment services; of those facilities, 140 (26.9%) are accredited as an ACS NAPBC facility.

Within the Northeast Region’s “Highest Priority” communities there are 57 facilities that provide the full continuum of breast cancer care services (e.g., screening, diagnostic and treatment); of those facilities, 18 (31.5%) are accredited as an ACS NAPBC facility (Table 8). Individuals that reside in communities that have NAPBC facilities have access to services that meet high-quality breast cancer care performance measures. However, in the Northeast Region, there are 39 facilities located in 13 communities that are not ACS NAPBC accredited and the services provided to individuals seeking care may not meet high-quality breast cancer care performance measures (Table 9).

Table 8. HP2020 “Highest Priority” communities in the Northeast Region with ACS NAPBC accredited facilities

Komen Affiliate	Community	Total number of facilities in the community*	Number of NAPBC accredited facilities in the community	Key demographic/ socioeconomic factors
Komen Central and South Jersey	Atlantic County, NJ	2	1	Rural, Medically Underserved
	Gloucester County, NJ	1	1	
Komen Central and South Jersey/ Komen Northeastern Pennsylvania	Camden County, NJ	2	1	%Black/African-American
Komen Maryland	Baltimore City, MD	16	4	Black/African-American, Education, Poverty, Employment, Medically Underserved
Komen Northeastern Pennsylvania	Montour County, PA	1	1	Rural
Komen Philadelphia	Delaware County, PA	4	3	%Black/African-American
	Philadelphia County, PA	15	6	%Black/African-American, %API, %Hispanic/Latina, Education, Poverty, Employment, Foreign born, Language, Insurance, Medically Underserved
Komen Vermont/New Hampshire	Bennington County, VT	1	1	Rural

* Note: Facilities that provide screening, diagnostic and treatment services in the HP2020 “Highest Priority” communities with a least one NAPBC accredited facility. These numbers do not represent the number of facilities that provide screening, diagnostic and treatment services in all HP2020 “Highest Priority” communities.

Table 9. HP2020 “Highest Priority” communities in the Northeast Region without an ACS NAPBC accredited facility

Komen Affiliate	Community	Key demographic/socioeconomic factors
Komen Central New York	Monroe County, NY	
Komen Maine	Knox County, ME	Rural
Komen Maryland	Calvert County, MD	Rural, Medically Underserved
	Charles County, MD	%Black/African-American, Rural
	Worcester County, MD	Older, Rural, Medically Underserved
Komen North Jersey	Sussex County, NJ	Rural
Komen Northeastern Pennsylvania	Schuylkill County, PA	Rural, Medically Underserved
Komen Philadelphia	Kent County, PA	Rural
Komen Pittsburgh	Mercer County, PA	Rural
	Mifflin County, PA	Education, Rural, Medically Underserved
Komen Southern New England	Nantucket County, MA	Rural
Komen Vermont New Hampshire	Addison County, VT	Rural
Komen Western New York	Wyoming County, NY	Rural, Medically Underserved

American College of Surgeons Commission on Cancer (CoC)

<https://www.facs.org/quality-programs/cancer/coc>

The American College of Surgeons (ACS) CoC “recognizes cancer care programs for their commitment to providing comprehensive, high-quality and multidisciplinary patient centered care” (American College of Surgeons, 2014a).

Throughout the cancer continuum of care, accredited programs are at the forefront of improving survival and quality of life for those diagnosed with cancer by setting care standards, research, prevention, education and monitoring to ensure comprehensive quality care is being provided (American College of Surgeons, 2014a).

The benefits of having an ACS CoC accredited facility in the local community include (American College of Surgeons, 2014a):

- Dedicated resources to ensure quality treatment and supportive care services are provided



- Community-based cancer prevention and screening events
- Guarantee that patients have access to treatment recommended by Health and Medicine Division (formerly the Institute of Medicine), National Cancer Comprehensive Network and American Society of Clinical Oncology
- Patients’ care is coordinated through a multidisciplinary oncology team
- Patients are informed about clinical trials
- Patients are provided a standard of care verified by a national organization
- Patients have access to quality cancer care that is close to home

In the US, there are 2,997 facilities that provide breast cancer treatment services; of those facilities, 1,422 (47.5%) are accredited as an ACS CoC facility.

In Komen’s Northeast Region, there are 526 facilities that provide breast cancer treatment services; of those facilities, 339 (64.5%) are accredited as an ACS CoC facility.

Within the Northeast Region’s “Highest Priority” communities, there are 57 facilities that provide breast cancer treatment services; of those facilities, 43 (75.4%) are accredited as an ACS CoC facility (Table 10). Individuals that reside in communities with ACS CoC accredited facilities have access to comprehensive, quality breast cancer treatment close to home. However, in the Northeast Region, there are 20 facilities located in six communities that are not ACS CoC accredited and the service provided to individual seeking care may not meet ACS cancer care standards (Table 11).

Table 10. HP2020 “Highest Priority” Communities in the Northeast Region with ACS CoC accredited facilities

Komen Affiliate	Community	Total number of facilities in the community*	Number of CoC accredited facilities in the community	Key demographic/ socioeconomic factors
Komen Central and South Jersey	Atlantic County, NJ	2	2	Rural, Medically Underserved
	Gloucester County, NJ	1	1	
Komen Central and South Jersey/ Komen Philadelphia	Camden County, NJ	2	2	%Black/African-American
Komen North Jersey	Sussex County, NJ	1	1	Rural
Komen Central New York	Monroe County, NY	5	2	
Komen Western New York	Wyoming County, NY	1	1	Rural, Medically Underserved
Komen Maryland	Charles County, MD	1	1	%Black/African-American, Rural
	Baltimore City, MD	16	12	Black/African-American, Education, Poverty, Employment, Medically Underserved

Komen Affiliate	Community	Total number of facilities in the community*	Number of CoC accredited facilities in the community	Key demographic/ socioeconomic factors
Komen Maine	Knox County, ME	1	1	Rural
Komen Northeastern Pennsylvania	Montour County, PA	1	1	Rural
Komen Philadelphia	Kent County, DE	2	2	Rural
	Delaware County, PA	4	4	%Black/African-American
	Philadelphia County, PA	15	10	%Black/African-American, %API, %Hispanic/Latina, Education, Poverty, Employment, Foreign born, Language, Insurance, Medically Underserved
Komen Pittsburgh	Mercer County, PA	1	1	Rural
	Mifflin County, PA	1	1	Education, Rural, Medically Underserved
Komen Vermont/New Hampshire	Bennington County, VT	1	1	Rural

* Note: Facilities that provide screening, diagnostic and treatment services in the HP2020 “Highest Priority” communities with a least one CoC accredited facility. These numbers do not represent the number of facilities that provide screening, diagnostic and treatment services in all HP2020 “Highest Priority” communities.

Table 11. HP2020 “Highest Priority” communities in the Northeast Region without an ACS CoC accredited facility

Komen Affiliate	Community	Key demographic/socioeconomic factors
Komen Maryland	Calvert County, MD	Rural, Medically Underserved
	Worcester County, MD	Older, Rural, Medically Underserved
Komen Northeastern Pennsylvania	Schuylkill County, PA	Rural, Medically Underserved
Komen Pittsburgh	Jefferson County, PA	Rural, Medically Underserved
Komen Southern New England	Nantucket County, MA	Rural
Komen Vermont New Hampshire	Addison County, VT	Rural

National Cancer Institute Designated Cancer Centers

<http://www.cancer.gov/research/nci-role/cancer-centers>

A National Cancer Institute (NCI) designated Cancer Center is an institution dedicated to researching the development of more effective approaches to the prevention, diagnosis, and treatment of cancer (National Cancer Institute, 2012). A NCI-designated Cancer Center conducts cancer research that is multidisciplinary and incorporates collaboration between institutions and university medical centers. This collaboration also provides training for scientists, physicians, and other professionals

interested in specialized training or board certification in cancer-related disciplines. NCI-designated Cancer Centers also provide clinical programs that offer the most current forms of treatment for various types of cancer and typically incorporate access to clinical trials of experimental treatments.

There are 69 NCI-designated Cancer Centers in the United States with 19 centers located in Komen’s Northeast Region. Of those 19 NCI-designated Cancer Centers located in the Northeast Region, there are three centers located in Philadelphia County, PA, a “Highest Priority” community. The other 16 NCI-designated Cancer Centers in the Komen Northeast Region are located in communities that are not considered “Highest Priority”.

In summary, each of the 27 HP2020 “Highest Priority” communities in the Northeast Region has facilities that offer screening services. In the Northeast Region, one HP2020 “Highest Priority” community only have access to in-community screening services; four “Highest Priority” communities have in-community screening and diagnostic services; and 22 “Highest Priority” communities have in-community access to screening, diagnostic and treatment services. While services may be available within the community, the number of available facilities may be too few to service the population in need, facilities may not accept an individual’s health insurance plan, individuals can become “lost in the system” after an abnormal screening mammogram and/or the care received does not meet any quality-based standards. In the Northeast Region, there are nine HP2020 “Highest Priority” communities that do not have any of the listed quality-based accredited breast cancer services (Table 12).



Table 12. HP2020 “Highest Priority” Communities in the Northeast Region without ACR BICOE, ACS CoC, ACS NAPBC or NCI accredited screening, diagnostic and treatment services

Komen Affiliate	Community	Key demographic/socioeconomic factors
Komen Central New York	Seneca County, NY	
Komen Maine	Piscataquis County, ME	Rural, Medically Underserved
Komen Northeastern Pennsylvania	Pike County, PA	Employment, Rural
	Schuylkill County, PA	Rural, Medically Underserved
Komen Pittsburgh	Fayette County, PA	Poverty, Rural, Medically Underserved
	Jefferson County, PA	Rural, Medically Underserved
Komen Southern New England	Dukes County, MA	Rural
	Nantucket County, MA	Rural
Komen Vermont New Hampshire	Addison County, VT	Rural

Qualitative Data Analysis

In order to gain a better understanding of the key barriers to breast cancer care in the local communities, Komen Headquarters Evaluation and Outcomes team analyzed qualitative data collected by Komen Affiliates. This analysis includes the review of qualitative data reports for all Affiliates within the Northeast Region and the coding of central themes that were cited most frequently by survey, interview and focus group participants and published qualitative documents (Figure 2).

During 2014-2015, Affiliates conducted qualitative data collection in communities of interest (e.g., HP2020 “Highest Priority” communities and/or non-“Highest Priority” communities) within their service area to “hear” from local health care providers and/or community members the challenges local residents have in accessing breast cancer care; as well as potential solutions that may assist individuals in receiving physician recommended breast cancer screening, diagnostic and treatment services.

In the Northeast Region, 14 Komen Affiliates collected qualitative data from 50 communities of interest during the Community Profile process. Of the 50 communities of interest, 44 are designated as a HP2020 “Highest Priority” community. The common barriers to breast cancer care identified were cited by interview, focus groups and survey participants with varying demographics and socioeconomic factors and in published qualitative literature in each Affiliate’s qualitative data



Figure 2. Komen Northeast Region qualitative data collection methods and number of participants/documents

report; but may not have been a barrier in each community of interest. Therefore, the qualitative data collected may not be representative of the specific HP2020 “Highest Priority” communities, but only the perspective of those that participated in the qualitative data collection process.

According to the qualitative data analysis, the five most commonly cited barriers that may prevent an individual from getting breast cancer services in the Komen Northeast Region are:

1. Fear

- Anticipation of pain and discomfort during breast cancer screening, diagnostic and treatment procedures
- Legal or immigration status concerns
- Denial of being diagnosed with breast cancer
- Worry about one’s declining health if diagnosed with breast cancer
- Stigma of being diagnosed with cancer
- Distrust of the health care system

“The first thing they think of at diagnosis is their family and the fear of losing their dreams.” -Health care provider

2. Availability of Services

- Lack of available facilities and/or providers that provide breast cancer screening, diagnostic and treatment services
- Facilities and/or providers have limited hours and/or days open
- Lack of (quality) accredited breast cancer services

3. Insurance Barriers

- Lack of private or federal (e.g., Medicaid, Medicare) insurance (uninsured)
- Co-pays/deductibles too high (underinsured)
- Physicians who do not accept patients with Medicaid or Medicare

4. Transportation Barriers

- Lack of available public transportation methods, ride-sharing or personal vehicle
- Time, frequency and/or availability of public transportation or ride-sharing were not in alignment with appointments
- Lack of resources (e.g., time off work, money to pay for gas/public transportation, childcare/adult care) to be able to travel the distance required to receive care.

5. Lack of Appropriate Breast Cancer Education

- Need for culturally appropriate education and outreach.
 - One participant mentioned the effects of culture and breast health, “Patients are more apt to listening and receiving information from those they think they relate to and who understand their background, which maybe come from the same cultural background as they do.”
- Lack of awareness and confusion regarding breast cancer screening guidelines
- Lack of breast cancer education including personal risk of breast cancer

“[We] need to educate [the community] on how to get linked to some of the services that are available, [promote] general breast self-awareness that extends from just finding a lump and refocus education to the people that are most at-risk and need to get proactive about being screened. We also need to tell young folks what they need to be aware of.” – Key informant

Other barriers that were less frequently mentioned by community members were lack of financial resources, cultural and/or language concerns, and other health conditions that take precedence (e.g., diabetes, asthma and weight management). In addition, within the Komen Northeast Region, community members indicated that Blacks/African-Americans and Hispanics/Latinas may experience greater barriers to care than others. For a list of all qualitative data themes identified with corresponding definitions please see Appendix B.

CONCLUSIONS

The Komen Northeast Region consists of eight states and 14 Affiliates. Within the Komen Northeast Region states, three states (Maryland, New Jersey and Pennsylvania) have late-stage diagnosis and death rates higher than the US as a whole. While the Komen Northeast Region states may have better breast cancer outcomes than the US as a whole, communities within each state may face disparate outcomes.

Healthy People 2020 breast cancer targets were used as the benchmark for all communities in the Komen Northeast Region. Communities that are predicted not to meet the benchmarks by 2020 are classified as “Highest Priority” since these communities are of greater need for breast cancer interventions than other areas within the region. Within the Komen Northeast Region, there are 27 communities that are considered “Highest Priority” and all are served by a Komen Affiliate. Even though the 27 “Highest Priority” communities are located in several states, there are demographic and socioeconomic commonalities between the communities that

suggest that they may share similar barriers to accessing care that could be addressed through the implementation of evidence-based and/or best practice interventions.

Within the 27 HP2020 "Highest Priority" communities there are 374 screening facilities, 132 diagnostic and 57 treatment facilities. In 14 of the 27 "Highest Priority" communities there are 40 American College of Radiology BICOE accredited sites. There are 57 facilities that provide screening, diagnostic and treatment services in the HP2020 "Highest Priority" communities; however, only 18 facilities located in eight "Highest Priority" communities are recognized as meeting the American College of Surgeons NAPBC performance measures. When reviewing the accreditations for quality treatment in Komen's Northeast Region, there are 43 American College of Surgeon CoC facilities located in 16 of the 27 "Highest Priority" communities. In addition, there are three NCI-designated Cancer Centers located in Philadelphia County, PA, a "Highest Priority" community. The communities that do not have facilities that are accredited by the American College of Radiology, American College of Surgeons or the National Cancer Institute tend to be rural and classified as medically underserved by the US Department of Health and Human Services.

In Komen's Northeast Region, 20 of the 27 "Highest Priority" communities have a substantially higher percentage of individuals residing in rural areas. Within these rural communities, breast cancer screening, diagnostic and treatment services are limited. For example, Pike County, PA has breast cancer screening services within the community but none of the facilities are accredited by the American College of Radiology, American College of Surgeons or the National Cancer Institute. If an individual from Pike County needs diagnostic and treatment services, they would have to travel outside of the community to receive care. Furthermore, individuals residing in the rural communities of Dukes County, MA; Piscataquis County, ME; Seneca County, NY and Fayette County, PA that are diagnosed with breast cancer have to travel to a neighboring community for breast cancer treatment. Having to travel outside of one's community to receive quality care may result in a delay in diagnosis and/or treatment and can result in a poorer outcome.

Through review of focus groups, interviews and surveys conducted by Komen Affiliates, residents in the Northeast Region had various concerns about availability of services. For example, Seneca County, NY and Fayette County, PA indicated a lack of services within these communities resulting in the need to travel to more populous communities to access breast cancer care. As indicated by participants in the qualitative data process and document review, transportation is one of the top barriers identified that may prevent individuals from seeking care. A need for breast cancer education was also frequently cited by residents, as many were uncertain of

breast screening mammography guidelines and felt they lacked knowledge of general breast care health. Other frequently cited barriers included fear (e.g., pain from the procedure, immigration status and health care system distrust, insurance coverage (e.g., uninsured or underinsured), and confusion regarding personal risk of breast cancer and screening recommendations.

Collaboration among Komen Affiliates in the Northeast Region that have a higher percentage of individuals residing in rural areas would allow sharing of best practices on what has worked and what has not worked in reaching rural populations and addressing the barriers they have in accessing breast cancer care. The 20 rural “Highest Priority” communities are located in the following service areas: Komen Central New York, Komen Maine, Komen Northeastern Pennsylvania, Komen Pittsburg, Komen Southern New England and Komen Vermont New Hampshire.

Eleven of the 27 “Highest Priority” communities have a substantially larger percentage of individuals living in medically underserved areas which may result in delays in obtaining breast cancer screening, diagnostic and treatment services. Medically underserved areas may be areas where there are too few primary care providers to provide adequate care for the community’s population, have a high percentage of individuals with incomes below poverty level and/or an older population (65 years and older). Adding to the barriers associated with residing in a medically underserved area, nine of the “Highest Priority” communities also have a high percentage of residents residing in rural areas: Calvert County, MD; Worcester County, MD; Piscataquis County, ME; Atlantic County, NJ; Wyoming County, NY; Fayette County, PA; Jefferson County, PA; Mifflin County, PA and Schuylkill County, PA. Seven of the nine medically underserved and rural communities have breast cancer screening, diagnostic and treatment services available within the local community; Piscataquis County, ME and Fayette County, PA only have screening and diagnostic services available. These communities also have varying numbers of accreditations with many lacking accreditations listed in the Health Systems Analysis.

From interviews, surveys, focus groups and document reviews conducted in eight of nine (qualitative data was not collected in Piscataquis County, ME) “Highest Priority” rural and medically underserved communities, individuals that reside in or provide services to residents of these communities indicated that a lack of financial resources and education regarding breast screening guidelines, available breast cancer resources, and breast cancer risk were all barriers to breast cancer care. Lack of transportation, including inadequate public transportation and lengthy travel times were also cited. Rural populations cited transportation, in general, as a barrier to accessing care during the winter months. Many rural communities mentioned varying cultural beliefs from groups including the Amish, Mennonite and other smaller populations regarding barriers to seeking breast cancer services.

The other two medically underserved communities (Baltimore City, MD and Philadelphia County, PA) are urban and have several facilities that offer accredited and non-accredited breast cancer screening, diagnostic and treatment services; however, the facilities may not be accessible to those in greatest need in the community (e.g., minorities, low-income, unemployed and uninsured). Individuals from these two medically underserved and urban communities indicated that a lack of health care insurance is a critical barrier to accessing breast health services leading to delays in breast cancer screening, diagnosis and treatment. The financial burden of breast cancer care was also frequently cited as a barrier. Other frequently cited barriers to receiving breast cancer care included language barriers, logistical issues such as childcare and lack of awareness of available resources.

While barriers are similar between medically underserved rural and urban communities, the interventions that could be implemented to address these barriers may be slightly different. For example, transportation assistance was identified as a barrier to care for both rural and urban individuals in the “Highest Priority” communities. Transportation for rural individuals to receive breast cancer care may include providing gas cards; whereas, in an urban setting the assistance may be public transportation and/or taxi vouchers. Collaboration among the following Affiliates may reveal interventions that have been successful in reaching medically underserved individuals that reside in rural areas: Komen Central and South Jersey, Komen Maine, Komen Maryland, Komen Pittsburg, Komen Northeastern Pennsylvania and Komen Western New York. Collaboration between Komen Maryland and Komen Philadelphia may identify best practices for urban residents.

Black/African-American women, who have a 39 percent higher breast cancer death rate than White women, are often diagnosed with late-stage breast cancer when treatment options are limited and the prognosis is poor (Howlader et al., 2016). In Komen’s Northeast Region, five of the “Highest Priority” communities have a substantially larger Black/African-American female population than their respective state as a whole: Baltimore City, MD; Charles County, MD; Delaware County, PA; Philadelphia County, PA and Camden County, NJ. Individuals in these five communities indicated that due to other health issues and family concerns, combined with lack of health care insurance and financial resources, breast cancer care is a low priority. Additionally, lack of trust for the healthcare system, fear of breast cancer diagnosis, and cultural and language barriers within diverse populations were frequently cited as barriers. Collaboration among Komen Central and South New Jersey, Komen Maryland and Komen Philadelphia may identify interventions that have been successful in assisting Black/African-American women in accessing care and addressing specific barriers identified by community members.

Analysis also found there are clusters of “Highest Priority” communities that expand beyond state borders. Collaboration between Komen Central Virginia and Komen Maryland may identify how to increase access to breast cancer services within the seven HP2020 “Highest Priority” communities that are located on the Maryland and Virginia border: Calvert County, MD; Charles County, MD; Caroline County, VA; Orange County, VA; Spotsylvania County, VA and Stafford County, VA. Individuals in Calvert County and Charles County, MD indicated barriers to accessing care which included long wait times and limited availability of appointments. Other frequently cited barriers included transportation, lack of awareness of available resources, and financial barriers.

Komen Central and South Jersey and Komen Philadelphia could collaborate on addressing the barriers of individuals in five of the HP2020 “Highest Priority” communities: Atlantic County, NJ; Camden County, NJ; Gloucester County, NJ; Delaware County, PA and Philadelphia County, PA. Individuals in these five communities indicated that there was a lack of education about breast cancer, screening guidelines, available resources and program availability. Other frequently cited barriers included fear of breast cancer diagnosis, availability of services, transportation, lack of health insurance and financial concerns.

Collaboration between Komen North Jersey and Komen Northeastern Pennsylvania may be able to address the high late-diagnosis and death rates in Sussex County, NJ and Pike County, PA. Individuals that participated in focus groups, interviews and surveys in these two communities indicated that there was a lack of knowledge regarding federal health care insurance regulations, breast cancer screening guidelines and available health care services. Residents also indicated that they believe there is a shortage of providers in this area and that many individuals must travel to other communities to receive breast cancer care. Additional barriers included time constraints and financial burdens.

To address the identified barriers in accessing quality breast cancer care, Komen Northeast Region Affiliates have identified priorities within their local service area that share commonalities with all Affiliates in the region. There are five common priorities that Komen Northeast Region Affiliates intend to focus on to reduce breast cancer late-stage diagnosis and deaths over the next five years:

- Support programs that reduce or eliminate barriers that have been identified as interfering with an individual being able to access breast cancer screening, diagnostic and treatment services. Client-oriented programs to reduce barriers include, but are not limited to, free or low-cost breast cancer services, transportation assistance, mobile mammography, extended clinic hours/locations and interpreter services.

- Support patient navigation programs. Patient navigation is a process by which a trained individual- the patient navigator- guides patients through and around barriers in the complex breast cancer care system. The primary focus of a patient navigator is on the individual patient, with responsibilities centered on coordinating and improving access to timely screening, diagnostic and treatment services tailored to individual needs. Patient navigators offer interventions that may vary from patient to patient along the continuum of care and include a combination of informational, emotional, and practical support (e.g., breast cancer education, counseling, care coordination, health system navigation, and access to transportation, language services and financial resources).
- Provide and/or support breast cancer education programs in local communities that provide accurate, evidence-based information.
- Develop community partnerships to address concerns raised by community members regarding lack of breast cancer education, lack of available services and language and cultural barriers.
- Advocate for increasing availability of and access to affordable, high quality breast cancer care.

In the Northeast Region, Affiliates identified that Black/African-American women, Hispanic/Latina women, Asian and Pacific Islander women, women over 65, and medically underserved women may have a greater challenge in overcoming barriers to care. Northeast Region Affiliates intend to focus efforts to reduce the breast cancer disparities that these individuals may be experiencing.

In conclusion, community members who participated in focus groups, interviews and surveys from the HP2020 “Highest Priority” communities identified a lack of available breast cancer services within their local community as a barrier to receiving care. While all the “Highest Priority” communities have at least one local facility that provides breast cancer screening, there are several communities that have no local facilities that provide breast cancer diagnostic and/or treatment services. This requires an individual to navigate between health care systems and have resources to travel to other communities to receive care. These results align with the HP2020 socioeconomic data showing a majority of the “Highest Priority” communities are classified as rural and medically underserved. Although breast cancer services are available, the services in nine of the 27 “Highest Priority” communities lack quality accreditations.

Each of the Northeast Region’s “Highest Priority” communities is located in a Komen Affiliate service. The local Komen Affiliate is a breast cancer resource for each “Highest Priority” community that can assist with addressing the identified barriers to care, convene stakeholders to develop solutions to increase access of available



breast cancer services, and provide “real-time” assistance to areas of greatest need through funding of local community grants. Collaboration across service areas and state borders provide an opportunity for the Komen Northeast Region to share resources and best-practices, provide consistent messaging and address similar barriers to care, all in an effort to reduce the number of breast cancer deaths by 50.0 percent over the next ten years.

REFERENCES

Adler, N. and Rehkopf, D. 2008. US disparities in health: descriptions, causes, and mechanisms. *Annu Rev Public Health*, 29, 235-52.

American Cancer Society. 2015a. Breast cancer facts and figures, 2015-2016. Atlanta, GA: American Cancer Society .

American Cancer Society. 2015b. Cancer facts and figures for Hispanics/Latinos, 2015-2017. Atlanta, GA: American Cancer Society.

American Cancer Society. 2015c. Cancer prevention & early detection facts & figures, 2015-2016. Atlanta, GA: American Cancer Society.

American Cancer Society. 2016. Cancer facts and figures, 2016. Atlanta, GA: American Cancer Society.

American College of Radiology. n.d. Mammography accreditation. Accessed on 07/11/2014 from <http://www.acraccreditation.org/-/media/ACRAccreditation/Documents/Mammography/Requirements.pdf?la=en>

American College of Surgeons. 2014a. Commission on Cancer. Accessed on 7/11/2014 at <https://www.facs.org/quality-programs/cancer/coc>.

American College of Surgeons. 2014b. National accreditation program from breast centers. Accessed on 07/11/2014 from <http://napbc-breast.org/>.

Braveman, E.A. 2010. Health disparities and health equity. *Am J Public Health*, 101(Suppl 1), S149-S155.

Danforth, D.N., Jr. 2013. Disparities in breast cancer outcomes between Caucasian and African-American women: A model for describing the relationship of biological and nonbiological factors. *Breast Cancer Research*, 15, 208.

Hewitt, M. and Simone, J.V. (eds). 1999. Ensuring quality cancer care. Washington, DC: Institute of Medicine and Commission on Life Sciences.

Howlader, N., Noone, A.M., Krapcho, M., et al. (eds). 2016. SEER cancer statistics Review, 1975-2013: Fast stats. Bethesda, MD: National Cancer Institute. Accessed from http://seer.cancer.gov/csr/1975_2013/.



Lurie, N. and Dubowitz, T. 2007. Health disparities and access to health. *JAMA*, 297(10), 1118-1121.

National Cancer Institute. NCI-Designated cancer centers, 2012. Accessed on 07/11/2014 from <http://www.cancer.gov/researchandfunding/extramural/cancercenters/about>.

Robert Wood Johnson Foundation. Overcoming Obstacles to Health. Commission to Build a Healthier America, 2008. Available from <http://www.rwjf.org/content/dam/farm/reports/reports/2008/rwjf22441>.

US Preventive Services Task Force. 2016. Final update summary: Breast cancer screening. Accessed from <http://www.uspreventiveservicestaskforce.org/Page/Document/UpdateSummaryFinal/breast-cancer-screening>.

White, A., Richardson, L.C., Li, C., Ekwueme, D.U., and Kaur, J.S. 2014. Breast cancer mortality among American Indian and Alaska Native women, 1990-2009. *Am J Public Health*. 104 (Suppl 3), S432-8.

Young, J.L. Jr., Roffers, S.D., Ries, L.A.G., Fritz, A.G., and Hurlbut, A.A. (eds). 2001. SEER summary staging manual - 2000: Codes and coding instructions, Pub. No. 01-4969, Bethesda, MD: National Cancer Institute. Accessed from <http://seer.cancer.gov/tools/ssm/>.

APPENDICES

Appendix A. Health System Analysis Internet Search

The Evaluations and Outcomes team developed a tracking template for the Health Systems Analysis section to capture resources in target communities. The following sites were used to capture data.

Community Health Centers (CHC's) <http://nachc.org/about-our-health-centers/find-a-health-center/>

The team used the “Download Health Centers and Look-Alikes Report by State (PDF)”. Select the state you are working on and click “Generate Report”. Behavioral, Dental, Teen, Children’s, Shelters, Nursing homes, Jails, Schools and Administrative facilities were not be included in the information collected.

Title X <http://www.hhs.gov/opa/title-x-family-planning/initiatives-and-resources/title-x-grantees-list/>

The team used the facilities in the Title X list on the page. If the facility found matches the name and address information from CHC, the team retained the CHC. Behavioral, Dental, Teen and Children’s facilities should not be included in the information collected. The records are all listed by states that are applicable.

Mammography Centers

<http://www.accessdata.fda.gov/scripts/cdrh/cfdocs/cfMQSA/mqsa.cfm>

This site provides a listing by zip code or state, of all mammography facilities certified by the FDA or Certifying State as meeting baseline quality standards for equipment, personnel and practices under the Mammography Quality Standards Act of 1992 (MQSA) and subsequent Mammography Quality Standards Reauthorization Act (MQSRA) amendments. To legally perform mammography, a facility must be FDA certified. This list of Food and Drug Administration (FDA) Certified Mammography Facilities is updated weekly according to the website. The team searched by state and list accordingly.

Hospitals <https://data.medicare.gov/Hospital-Compare/Hospital-General-Information/v287-28n3>

This site is a list of all hospitals that have been registered with Medicare. The team did not include psychiatric and children’s hospitals. The team verified what services are offered across the Continuum of Care by visiting the hospital’s website.

Appendix B. Qualitative Data Themes- Komen Northeast Region

Availability of Services – Lack of health services in community, limited number of health professionals in community

Awareness/Education – Lack of awareness of available services, lack of awareness of screening guidelines and confusion of screening guidelines

Cultural/Language – Lack of interpreter services, education materials that are not translated, lack of physicians who resemble patient’s culture, lack of programs that are culturally appropriate

Fear –Pain and discomfort during screening, diagnosis and treatment, legal or immigration status concerns if treatment is obtained, denial of diagnosis, afraid of breast cancer stigma

Financial Barriers- Lack of funds necessary to pay for the breast cancer services during the continuum of care

Insurance Lack of insurance, lack of adequate insurance coverage (underinsured)

Lack of Awareness of Resources – Lack of awareness of available resources that may or may not be free or reduced cost including screening, diagnostic, treatment and support services as well as Komen Affiliate activities

Lack of Childcare/Adult Care – Lack of assistance to watch or take care of children or other adult family members during appointment

Lack of Social Support -Lack of counseling, family support, difficulty shopping, cooking and caring for family, lack of emotional support or psychological services

Navigation – Lack of direction by health system, lack of appointment verification or scheduling, lack of connectivity through continuum of care

No Symptoms – Patients feels/has no symptoms or health concerns so feels there is no need to be screened or treated

Other Health Priorities – Health concerns that are immediate including weight management, asthma, diabetes etc.

Pride/Modesty – Lack of female physicians in community and unwillingness to be seen by male physician, unwillingness to accept cancer diagnosis, unwillingness to ask for help

Quality of Care – Lack of accredited health services in community, patients distrust in the health system due to experiences, lack of provider education and expertise, lack of facility technology, poor provider-patient interaction

Religious Perspectives – Fatalistic attitudes, belief that God will take care of it, delay of treatment due to religious beliefs

Transportation – Lack of personal transportation available, inadequate public transportation, access to public transportation, distance to services, availability of ride-share opportunities, and public transportation limited hours.

Time –Amount of time it takes for screening, diagnosis and appointments, lack of time off work, school or away from family, work conflicts

Appendix C. Population characteristics, Komen Northeast Region Healthy People 2020 “Highest Priority” communities

Population Group	Black/ African- American (females)	AIAN (females)	API (females)	Hispanic/ Latina (females)	Age 65 Plus (females)	Less than HS Education (females and males)	Income Below 100% Poverty (females and males)	Income Below 250% Poverty (Age: 40-64) (females and males)	Un- employed (females and males)	Foreign Born (females and males)	Linguis- tically Isolated (females and males)	In Rural Areas (females and males)	In Medically Under- served Areas (females and males)	No Health Insurance (Age: 40-64) (females and males)
US	14.1 %	1.4 %	5.8 %	16.2 %	14.8 %	14.6 %	14.3 %	33.3 %	8.7 %	12.8 %	4.7 %	19.3 %	23.3 %	16.6 %
Delaware	23.4 %	0.7 %	3.7 %	7.8 %	16.0 %	12.6 %	11.2 %	28.5 %	7.7 %	8.3 %	2.3 %	16.7 %	25.4 %	10.4 %
Kent County	26.6 %	0.8 %	2.9 %	5.9 %	15.1 %	15.1 %	12.4 %	33.9 %	8.2 %	4.9 %	1.6 %	27.0 %	0.0 %	10.6 %
Maine	1.4 %	0.8 %	1.3 %	1.3 %	17.8 %	9.8 %	12.8 %	33.5 %	7.1 %	3.3 %	1.1 %	61.3 %	12.0 %	13.3 %
Knox County	0.5 %	0.4 %	0.7 %	1.0 %	21.6 %	9.7 %	11.4 %	35.1 %	4.9 %	2.2 %	0.3 %	67.9 %	9.3 %	14.0 %
Piscataquis County	0.5 %	0.6 %	0.9 %	0.9 %	21.8 %	12.1 %	16.9 %	46.0 %	7.1 %	1.6 %	0.4 %	100.0	47.8 %	16.4 %
Maryland	32.0 %	0.6 %	6.4 %	7.8 %	13.9 %	11.8 %	9.0 %	22.8 %	7.3 %	13.5 %	3.2 %	12.8 %	17.4 %	11.1 %
Baltimore City	66.5 %	0.5 %	2.6 %	3.7 %	13.5 %	21.5 %	22.4 %	48.9 %	12.6 %	7.2 %	2.3 %	0.0 %	70.2 %	15.1 %
Calvert County	14.7 %	0.4 %	2.3 %	3.0 %	12.4 %	7.9 %	4.6 %	15.2 %	5.3 %	3.5 %	0.1 %	38.7 %	100.0 %	7.9 %
Charles County	44.0 %	0.9 %	4.0 %	4.4 %	10.7 %	9.4 %	5.6 %	15.9 %	6.8 %	5.4 %	0.8 %	29.5 %	16.4 %	8.5 %
Worcester County	15.0 %	0.3 %	1.3 %	3.0 %	25.1 %	11.3 %	10.6 %	28.5 %	7.9 %	4.3 %	1.3 %	35.5 %	100.0 %	13.8 %
Massachusetts	8.4 %	0.5 %	6.0 %	9.7 %	15.7 %	11.1 %	10.7 %	24.0 %	8.1 %	14.7 %	5.7 %	8.0 %	15.7 %	4.4 %
Dukes County	4.5 %	1.4 %	1.5 %	2.3 %	18.3 %	7.3 %	10.2 %	26.3 %	5.0 %	7.5 %	1.3 %	39.0 %	0.0 %	6.8 %
Nantucket County	7.6 %	0.1 %	1.4 %	8.5 %	14.3 %	6.9 %	8.8 %	20.7 %	2.8 %	14.0 %	1.7 %	18.9 %	0.0 %	6.3 %
New Jersey	15.7 %	0.6 %	9.1 %	17.5 %	15.5 %	12.4 %	9.4 %	23.6 %	8.7 %	20.6 %	7.3 %	5.3 %	12.6 %	14.5 %
Atlantic County	18.7 %	0.8 %	8.2 %	16.6 %	16.0 %	15.8 %	12.5 %	32.5 %	10.7 %	15.5 %	5.9 %	12.7 %	40.9 %	16.2 %
Camden County	22.5 %	0.7 %	5.7 %	14.1 %	14.7 %	14.1 %	11.8 %	27.4 %	10.4 %	10.2 %	4.4 %	1.6 %	11.0 %	13.9 %
Gloucester County	11.4 %	0.3 %	3.1 %	4.8 %	14.2 %	10.0 %	7.3 %	20.2 %	9.5 %	5.0 %	1.2 %	8.3 %	0.0 %	11.0 %
Sussex County	2.2 %	0.2 %	2.3 %	6.7 %	13.5 %	6.6 %	4.9 %	16.6 %	8.4 %	7.0 %	1.3 %	39.8 %	0.0 %	10.6 %
New York	19.0 %	1.1 %	8.3 %	17.6 %	15.5 %	15.4 %	14.5 %	32.3 %	8.2 %	21.8 %	8.3 %	12.1 %	20.3 %	12.1 %
Monroe County	17.2 %	0.5 %	3.6 %	7.4 %	15.9 %	11.4 %	14.4 %	30.1 %	7.5 %	8.3 %	3.0 %	6.4 %	13.8 %	9.1 %
Seneca County	1.6 %	0.2 %	0.9 %	2.0 %	17.8 %	17.0 %	11.7 %	32.9 %	5.9 %	1.7 %	0.8 %	58.7 %	5.4 %	10.5 %
Wyoming County	0.5 %	0.3 %	0.6 %	1.4 %	16.6 %	13.8 %	10.1 %	31.2 %	6.8 %	2.4 %	0.3 %	64.1 %	44.5 %	10.6 %
Pennsylvania	12.1 %	0.4 %	3.1 %	5.6 %	17.6 %	12.1 %	12.6 %	30.3 %	7.9 %	5.7 %	2.2 %	21.3 %	15.2 %	11.0 %
Delaware County	21.5 %	0.2 %	5.1 %	2.9 %	16.4 %	9.0 %	9.5 %	23.8 %	7.9 %	8.7 %	2.1 %	0.5 %	3.8 %	9.8 %
Fayette County	4.4 %	0.2 %	0.5 %	0.7 %	20.6 %	16.7 %	19.2 %	45.0 %	9.8 %	1.1 %	0.1 %	47.9 %	100.0 %	13.2 %
Jefferson County	0.7 %	0.2 %	0.3 %	0.7 %	20.6 %	13.5 %	14.1 %	40.8 %	7.3 %	0.5 %	0.2 %	61.5 %	56.0 %	13.0 %
Mercer County	5.8 %	0.2 %	0.9 %	1.0 %	21.2 %	12.2 %	12.8 %	35.4 %	8.8 %	1.7 %	0.5 %	44.5 %	7.7 %	11.3 %
Mifflin County	0.9 %	0.1 %	0.5 %	1.1 %	20.7 %	19.1 %	15.2 %	42.4 %	9.0 %	0.6 %	1.1 %	50.5 %	34.9 %	13.8 %
Montour County	1.6 %	0.1 %	1.9 %	2.0 %	21.8 %	10.9 %	10.4 %	29.6 %	5.7 %	3.7 %	1.3 %	53.8 %	0.0 %	8.8 %

Population Group	Black/ African- American (females)	AIAN (females)	API (females)	Hispanic/ Latina (females)	Age 65 Plus (females)	Less than HS Education (females and males)	Income Below 100% Poverty (females and males)	Income Below 250% Poverty (Age: 40-64) (females and males)	Un- employed (females and males)	Foreign Born (females and males)	Linguis- tically Isolated (females and males)	In Rural Areas (females and males)	In Medically Under- served Areas (females and males)	No Health Insurance (Age: 40-64) (females and males)
Philadelphia County	47.1 %	1.0 %	6.8 %	12.0 %	14.0 %	20.0 %	25.6 %	49.7 %	13.4 %	11.6 %	6.6 %	0.0 %	40.0 %	16.3 %
Pike County	6.9 %	0.4 %	1.4 %	9.4 %	17.2 %	7.8 %	9.3 %	29.0 %	11.3 %	6.7 %	1.3 %	70.8 %	14.4 %	13.5 %
Schuylkill County	1.4 %	0.2 %	0.7 %	2.3 %	21.3 %	15.0 %	11.8 %	34.6 %	8.0 %	1.8 %	0.7 %	36.5 %	37.5 %	10.9 %
Vermont	1.3 %	0.5 %	1.6 %	1.5 %	16.4 %	9.0 %	11.3 %	28.4 %	6.3 %	3.9 %	0.8 %	61.1 %	14.5 %	7.6 %
Addison County	1.0 %	0.3 %	1.8 %	1.6 %	15.5 %	9.2 %	10.7 %	26.7 %	6.2 %	4.1 %	0.9 %	78.4 %	7.5 %	7.9 %
Bennington County	1.1 %	0.3 %	0.9 %	1.6 %	21.1 %	10.2 %	12.3 %	32.5 %	6.7 %	3.1 %	0.4 %	64.5 %	0.0 %	8.4 %

*The data in red represent at least a 3.0 (if <10.0%) or 5.0% (if ≥ 10.0%) percentage point difference than the state average.

Source of race, ethnicity and age data: Source: US Census Bureau - Population Estimates, 2011.

Source of health insurance data: US Census Bureau - Small Area Health Insurance Estimates (SAHIE), 2011.

Source of rural population data: US Census Bureau - Census 2010.

Source of medically underserved data: Health Resources and Services Administration (HRSA), 2013.

Source of other data: US Census Bureau - American Community Survey (ACS), 2007-2011.

Appendix D. Breast cancer services available within HP2020 “Highest Priority” communities and the states in the Komen Northeast Region*



	“Highest Priority”	State	“Highest Priority”	State	“Highest Priority”	State
Connecticut	NA	225	NA	115	NA	30
Delaware	13	64	7	35	2	7
Maine	5	107	1	39	0	20
Maryland**	96	237	38	110	20	38
Massachusetts	2	345	1	199	0	62
New Hampshire	NA	71	NA	30	NA	24
New Jersey	54	260	24	107	6	63
New York	57	1060	25	576	6	145
Pennsylvania	140	719	34	280	21	112
Rhode Island	NA	76	NA	43	NA	12
Vermont	7	80	2	16	2	13

* Data represents information gathered through an internet search in 2014. Therefore not all services in a community may be represented.

** Data excludes Montgomery County, MD and Prince George’s County, MD which are located in the National Capital Region.

NA- Not applicable- State did not have any “Highest Priority” communities.