susan g. komen®

COMMUNITY PROFILE REPORT 2015

SUSAN G. KOMEN® CENTRAL INDIANA

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Acknowledgments

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Executive Summary

Introduction to the Community Profile Report

Susan G. Komen® Central Indiana began its work in central Indiana in 1992 with the first Race for the Cure® under the auspices of the Junior League of Indianapolis. In 2001, leaders envisioned that this effort could be more than a Race and incorporated as an Affiliate of the Susan G. Komen organization. Led entirely by volunteers, the organization was raising more than one million dollars annually, before hiring its first paid staff member in 2003. In 2011, the Affiliate's name was changed from the Indianapolis Affiliate to Susan G. Komen Central Indiana to reflect the Affiliate's broader service area.

Komen Central Indiana reaches out to the community to educate breast cancer survivors, family and friends, caregivers and the public by organizing and attending local events, offering presentations, developing written communications and collaborating with other organizations serving the community.

The greatest part of the money received by Komen Central Indiana remains in the community as a source of help for Hoosiers in need. It goes to pay for services – including screenings, diagnostic testing, education and patient navigation – that benefit local women and men. Komen Central Indiana has granted more than $15 million to local nonprofit organizations carrying out these services. In the 2014-2015 grant cycle, $848,000 funded 11 local breast health programs that provided nearly 40,000 services to more than 25,000 unduplicated individuals.

Additionally, a meaningful portion of the money received by Komen Central Indiana funds Susan G. Komen Research Program endeavors to discover breast cancer causes, treatments and, ultimately, the cures. Susan G. Komen has funded, in part, many advancements in breast cancer research in the last 30 years.

Komen Central Indiana strives to be a local expert and leader in the breast cancer movement in central Indiana. The organization is an active member of the Indiana Cancer Consortium and received the 2013 award for Outstanding Contributions to Cancer Control. In 2014, Komen Central Indiana launched a coalition of local leaders committed to addressing the disparity in breast cancer deaths between Black/African-American and White women in Indianapolis. Representatives from the Komen Central Indiana staff and Board of Directors serve with numerous local agencies and organizations to advocate for and strengthen systems and resources for women, men and families who face breast cancer in the local community.

The Affiliate service area includes 21-counties in Central Indiana. Counties served include: Bartholomew, Boone, Brown, Clinton, Decatur, Delaware, Grant, Hamilton, Hancock, Hendricks, Henry, Howard, Johnson, Madison, Marion, Montgomery, Morgan, Rush, Shelby, Tippecanoe and Tipton (Figure 1).

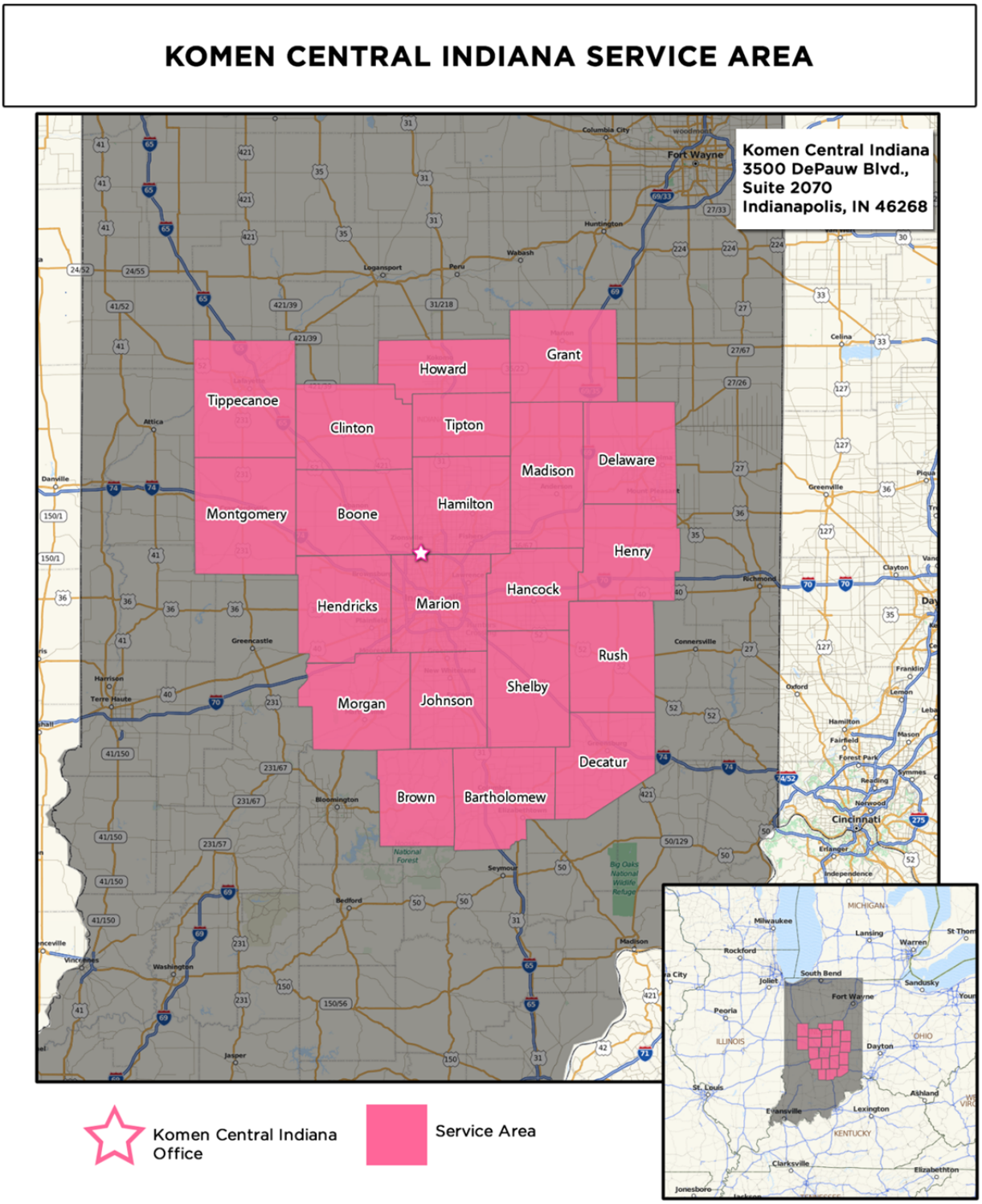

Figure 1. Susan G. Komen Central Indiana service area

The Affiliate service area includes the metropolitan areas of Indianapolis-Carmel, Lafayette, Anderson, Muncie, Kokomo and Columbus (in order of population). Indianapolis is the largest urban area in the services area, while those who live in rural areas comprise 16.4 percent of the population and 16.9 percent live in medically under-served areas.

Purpose of the Community Profile Report

The Community Profile is an assessment process completed every four years by Susan G. Komen Central Indiana, in order to understand the state of the breast cancer burden and needs in the service area. The information outlined in the report is vital to Komen Central Indiana for developing grant funding and programming priorities.

The Community Profile is actively used as a framework to identify the prevalence of breast cancer on a local level, recognize service gaps in breast health and breast cancer needs and develop priorities to address those needs. The Community Profile Report serves to:

- Align strategic and operational plans
- Drive inclusion efforts in the community
- Drive public policy efforts
- Establish focused granting priorities
- Establish focused education needs
- Establish directions for marketing and outreach
- Strengthen sponsorship and development efforts

The final Community Profile Report will be shared with the community through a press release and made available via the Susan G. Komen Central Indiana website.

Quantitative Data: Measuring Breast Cancer Impact in Local Communities

The purpose of the quantitative data report for Susan G. Komen Central Indiana is to combine evidence from many credible sources and use the data to identify the highest priority areas for evidence-based breast cancer programs.

The data provided in the report are used to identify priorities within the Affiliate's service area based on estimates of how long it would take an area to achieve Healthy People 2020 objectives for breast cancer late-stage diagnosis and death rates (http://www.healthypeople.gov/2020/default.aspx).

Breast Cancer Statistics

Incidence rates: The breast cancer incidence rate shows the frequency of new cases of breast cancer among women living in an area during a certain time period. The female breast cancer incidence rate is calculated as the number of females in an area who were diagnosed with breast cancer divided by the total number of females living in that area. To show trends (changes over time) in cancer incidence, data for the annual percent change in the incidence rate over a five-year period were used in the Community Profile Report

Overall, the breast cancer incidence rate in Komen Central Indiana's service area was slightly lower than that observed in the US as a whole and the incidence trend was higher than the US as a whole. The incidence rate and trend of the Affiliate service area were not significantly different than that observed for the State of Indiana.

The incidence rate was significantly lower in Brown, Clinton, and Decatur Counties. The rest of the counties had incidence rates and trends that were not significantly different than the Affiliate service area as a whole or did not have enough data available.

Death rates: The breast cancer death rate shows the frequency of death from breast cancer among women living in a given area during a certain time period. 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. To show trends in cancer incidence, data for the annual percent change in the incidence rate over a five-year period were used.

Overall, the breast cancer death rate in Komen Central Indiana's service area was slightly higher than that observed in the US as a whole. The death rate in the Affiliate service area was not significantly different than that observed for the State of Indiana. In the United States and in the Affiliate service area, breast cancer death rates in Blacks/African-Americans are substantially higher than in Whites overall.

None of the counties in the Affiliate service area had substantially different death rates than the Affiliate service area as a whole or did not have enough data available.

Late-stage diagnosis: The late-stage breast cancer incidence rate is calculated as the number of women with regional or distant breast cancer in a particular geographic area divided by the number of women living in that area. Trends are calculated by the annual percent change in late-state diagnosis rates between 2006 and 2010.

Overall, the breast cancer late-stage incidence rate in Komen Central Indiana's service area was slightly lower than that observed in the US as a whole and the late-stage incidence trend was slightly higher than the US as a whole. The late-stage incidence rate and trend of the Affiliate service area were not significantly different than that observed for the State of Indiana. For the Affiliate service area as a whole, the late-stage incidence rate was higher among Blacks/African-Americans than Whites and lower among APIs than Whites.

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

***Mammography Screening*:** Getting regular screening mammograms (and treatment if diagnosed) lowers the risk of dying from breast cancer. Screening mammography can find breast cancer early, when the chances of survival are highest. Mammography screening proportions show whether the women in an area are getting screening mammograms when they should.

The breast cancer screening proportion in Komen Central Indiana's service area was **significantly lower** than that observed in the US as a whole. The screening proportion of the Affiliate service area was not significantly different than the State of Indiana. For the Affiliate service area as a whole, the screening proportion was not significantly different among Blacks/African-Americans than Whites, and the screening proportion among Hispanics/Latinas was not significantly different than among Non-Hispanics/Latinas. None of the counties in the Affiliate service area had substantially different screening proportions than the Affiliate service area as a whole.

Population Characteristics. Demographic and socioeconomic data can be used to identify which groups of women are most in need of help and to figure out the best ways to help them. Marion County has a substantially larger Black/African-American female population percentage than that of the Affiliate service area as a whole, and Clinton County has a substantially larger Hispanic/Latina female population percentage, and substantially lower education levels. Delaware County has substantially lower income levels and lower employment than the Affiliate service area as a whole.

Healthy People 2020 forecasts: Healthy People 2020 (HP2020) is a major federal government initiative that provides specific health objectives for communities and for the country as a whole. In line with HP2020 cancer-related objectives, the report incorporates county breast cancer death rate and late-stage diagnosis data for years 2006 to 2010 and estimates for the trend (annual percent change) in county breast cancer death rates and late-stage diagnoses for years 2006 to 2010. Areas were compared and categorized from highest to lowest priority, based on a projection for how many years it will take for each county to meet the HP2020 objectives. .

Two counties in Komen Central Indiana's service area are in the highest priority category. Boone County is not likely to meet either the death rate or late-stage incidence rate HP2020 targets. Rush County is not likely to meet the late-stage incidence rate One county in Komen Central Indiana's service area is in the high priority category. Shelby County is not likely to meet the late-stage incidence rate HP2020 target.

Selection of Target Communities

The Community Profile Team examined the data provided by Komen Headquarters in the Quantitative Data Report with a special concentration on the Healthy People 2020 (HP2020) target for late-stage diagnosis and death rates. The Team also focused on counties that are likely to reach the HP2020 objectives but are shown to have higher minority populations that are at risk for experiencing barriers to accessing quality health care and completing the continuum of care.

The Community Profile Team analyzed the following for each county:

- incidence rate
- death rate
- late-stage diagnosis
- screening percentages
- residents have an income less than 250 percent of the poverty level
- residents (ages 40-64) living without health insurance
- unemployment percentages

The five selected target communities are:

- Boone County: Highest Priority
- Rush County: Highest Priority
- Shelby County: High Priority
- Marion County: Medium High Priority
- Clinton County: Low Priority

Boone County was selected as a target community because it is not likely to meet the HP2020 targets for death rate or late-stage incidence rate. The target to meet the female breast cancer death rate is 20.6 per 100,000. Boone County is at 31.8 and is expected to take 13 years or longer to meet this target. The target for late-stage incidence rate is 41.0 per 100,000; Boone is at 40.3 with an increasing trend. As a result, it is expected to take 13 years or longer to meet the target.

Rush County was selected as a target community because the predicted time to meet the HP2020 target for late-stage incidence rate is 13 years or longer. The target to meet the female breast cancer death rate is 20.6 per 100,000. Rush County is at 27.7 per 100,000. The predicted time to achieve the death rate target could not be suppressed as a result of small numbers. The HP2020 target for late-stage incidence rate is 41.0 per 100,000; Rush County is at 42.5 per 100,000 and is expected to take 13 years or longer to meet the target.

Shelby County was selected as a target community because the predicted time to meet the HP2020 late-stage incidence rate target is 13 years or longer, and the predicted time to achieve the death rate target is eight years. The target to meet the female breast cancer death rate is 20.6 per 100,000 and Shelby County is at 23.6. The target for late-stage incidence rate is 41.0 per 100,000. Shelby is at 45.6 and is expected to take 13 years or longer to meet the target. The trends for the late-stage incidence rate are 10.8 per 100,000, which indicates that the rates may be increasing.

Marion County was selected as a target community because the predicted time to meet the HP2020 death rate target is 13 years or longer. The target to meet the female breast cancer death rate is 20.6 per 100,000 and Marion County is at 26.1 per 100,000. Marion County was also selected due to its high percentage of minorities and the higher percentage of those living in poverty and without health insurance. According to Hunt et al., Marion County also ranked 10 of the 50 largest cities where non-Hispanic Black/African-American women face disparity in breast cancer deaths.

Clinton County was selected as a target community because of its Hispanic/Latina population. The percentage of Hispanics/Latinas is 12.6 percent, which is higher than the Indiana average of 5.8 percent and the Affiliate service area average of 5.3 percent. Furthermore, Clinton County has the highest percentage of Hispanics/Latinas among all Affiliate service area counties. The female population is 16,842 with 48.8 percent over the age of 40. The population in Clinton County consists of 17.7 percent having less than a high school education, which is the highest within the service area. In Clinton County, 36.2 percent of the population between the ages of 40 and 64 has an income less than 250 percent of the federal poverty level, and 18.1 percent of the population is living without health insurance.

Health System and Public Policy Analysis

Several resources were used to identify health care facilities that provide breast health services in the five target communities, including clinical breast exams, screening mammograms, diagnostic screenings, treatment, financial assistance and patient navigation. The analysis also

identified the scope and impact of national and state level public policy and programs on breast health services.

The Health Systems Analysis highlights several needs in target communities related to health systems and the Breast Cancer Continuum of Care (CoC).

Boone County: Potential barriers to care could result from the lack of public transportation available in Boone County. Parts of Boone County are rural in nature. Witham Hospital and the Boone County Community Clinic are the two providers of breast health services, and both are situated in the heart of Lebanon, making it difficult for individuals to access screenings. The hospital does not employ a patient navigator, so women in need of diagnostic imaging and further screening and treatment must navigate the health system independently. An additional barrier could be that there are no late evening or early morning screening options.

Rush County: Rush Memorial Hospital is the only medical provider for low income, under/uninsured women and the only medical provider in Rush County offering comprehensive breast health services. Women who are in need of breast reconstruction are referred to Indianapolis, over an hour drive, a potential barrier for some women. There are also no active IN-BCCP providers in Rush County.

Shelby County: One possible barrier is the lack of a dedicated patient navigator responsible for guiding women through breast health screenings at the diagnostic level.

Marion County: There are many options for women to access breast screenings in Marion County, but the systems are all quite large, which can be daunting for individuals who have no primary health care provider or health insurance.

Clinton County: The only hospital in the county does not provide onsite chemotherapy or radiation, and the only biopsies provided are ultrasound guided biopsies. Any patient who needs stereotactic, surgical or vacuum-assisted biopsies or is in need of treatment must travel 30 to 45 minutes to the nearest hospital. This can be a barrier for individuals who are living in poverty. The wait time for a clinical breast exam is several weeks, delaying access into the CoC.

The analysis highlights the need to have a stronger presence and collaborative relationships with partners in Boone, Shelby and Clinton Counties to ensure women are completing the CoC. Komen Central Indiana must also stay informed of the ever-changing health care environment following rollout of the ACA and the Healthy Indiana Plan 2.0.

Qualitative Data: Ensuring Community Input

Note: Qualitative data collection and analysis predate approval of the Healthy Indiana Plan 2.0.

To further assess the breast health and breast cancer issues highlighted by the quantitative data, Susan G. Komen Central Indiana conducted a qualitative data assessment in each of the five target communities.

Qualitative data collection lasted several months and involved key informant interviews and focus groups in each of the five target communities. In total, 33 key informant interviews, seven focus groups and one survey with 31 responses were conducted. The Team generated four categories of themes: 1) system barriers to receipt of breast health services; 2) individual barriers to receipt of breast health services; 3) facilitators for obtaining breast health services; and 4) specific vulnerable populations.

Variables, including breast cancer screening, occurrence, diagnosis, treatment, the completion of the COC and the presence of specific vulnerable populations in these counties, guided the selection of key assessment questions for the analysis.

The Qualitative Data Analysis highlighted specific system barriers to care, individual barriers to care, facilitators to care, and vulnerable populations in the five target communities.

Boone County: The most common system barrier found throughout the qualitative data from Boone County was related to a lack of or difficulty obtaining diagnostic services. The most common findings across all qualitative sources in Boone County related to individual barriers were fear of the unknown and perceived risk. Even though perceived risk is often a barrier, it can also act as a motivator to seeking screening services, as it was identified as a facilitator to care by both qualitative data sources in Boone County. Key informants noted several populations as vulnerable, including Black/African-American, Hispanic/Latina, post-menopausal/pre-Medicare, and women residing in rural areas of the county.

Rush County: Review of the qualitative data confirms that the community views the primary system barrier to seeking breast health services in Rush County to be lack of insurance. With the perception that services are only available at the one hospital in the county, women do not believe they have ample options for care in Rush County. Common individual barriers recited by qualitative data sources in Rush County included women's competing priorities, lack of education, lack of finances and fear of the unknown. Qualitative data sources indicated greater insurance coverage and an expansion of screening facilities would positively impact women's decisions to get screened. Key informants cited the county's Amish population, women with a family history, and young women as vulnerable groups in the community.

Shelby County: Key informants and community members cited lack of health insurance, the Affordable Care Act (those insured but unable to pay co-pays and deductible), lack of diagnostic services or lack of knowledge of diagnostic resources, and the failure of primary providers to screen routinely or inform patients of the importance of regular mammograms as system barriers to receiving breast health care. Key informants and focus group participants named competing priorities, income/finances, perceived risk and fear of inequities in care as individual barriers to obtaining breast health services.

Marion County: The complexity of the health insurance system is a critical barrier to receiving screening, diagnostic and treatment services. Thus, it is not only women without health insurance who face insurance-related issues when considering or seeking health care services. It is the perception of both providers and patients that, even with insurance, women face obstacles such as not understanding the coverage provided by their policy, prohibitive copays, deductibles and a lack of knowledge as to how to access services under the new Affordable Care Act. Individual barriers were rooted in a lack of resources, including both personal

finances and education/knowledge/awareness. Finances play a pivotal role in women's decisions to seek care. Low-income women may not be able to afford to take off work to seek breast health services, and are likely to have financial priorities above that of their breast health – such as money to care for their children, pay their utilities, etc.

The overwhelming majority of survey respondents (predominantly Black/African-American women) in Marion County indicated that there are no cultural barriers that prevent them from seeking care. However, the perspective of key informants was strikingly different, as they perceive that Black/African-American women in Marion County face more barriers to breast health care. Similarly, providers and nonprofit professionals indicate disparities in care between Black/African-American and White women.

Clinton County: Common findings among key informants and focus group participants (predominantly Hispanic/Latina women) in Clinton County related to system barriers, beginning with a lack of health insurance and confusion around the Affordable Care Act (ACA). Mistrust of the local health care system and providers was determined to be a barrier to care. Due to the high Hispanic/Latina population, language is also a barrier to care. Qualitative data showed individual barriers to care among Clinton County women relate primarily to finances - lack of insurance, transportation, and education. Cultural barriers, including language and somewhat of an acceptance that they will not be cared for, combined with a lack of financial resources is continuing to put this community at a high risk for low screening percentages.

The most common findings across the qualitative data in the target counties were inextricably linked to the key questions of **access and utilization of screening services**. A majority of the system and personal barriers to obtaining breast health care identified by the qualitative data in the five target counties are driven by a lack of income and finances. A second, widespread barrier revealed by the qualitative data is a lack of diagnostic services or a lack of knowledge of the available diagnostic services available within these communities. In particular, key informants and focus group participants made it clear that Komen Central Indiana needs to further its work in promoting *free* screening services in these communities in order to improve access to care and screening percentages.

An overarching conclusion is that Komen Central Indiana needs to develop more effective strategies, including enhanced partnerships, in these communities to not only ensure access to screening services, but ensure utilization of screening services and completion of the continuum of care.

Mission Action Plan

After completion of the Quantitative Data Report, the Health Systems and Public Policy Analysis, and the Qualitative Data Report, the Community Profile Team identified the most urgent challenges facing each of the target communities and connected these challenges to a specific problem expressed through a problem statement.

For each problem statement, priorities communicate the goals that will be achieved by Komen Central Indiana in order to effectively address the challenges and needs identified in problem statement.

Finally, under each priority falls a range of objectives that specify how the goals set in the priorities will be met. The objectives set forth the strategic actions that will be taken by Komen Central Indiana and are specific, measurable, attainable, realistic, and time bound. Note: The Susan G. Komen Central Indiana fiscal year begins on April 1 of the prior calendar year and concludes on March 31.

Together the problem statement, priorities, and objectives provide a road map to Komen Central Indiana for effective interventions for improving breast health in the target communities. The problem statement, priorities, and objectives for each target community are as follows:

Problem Statement: Women in **Boone County** have late-stage incidence and death rates higher than the Affiliate service area averages. Despite findings in the Health Systems Analysis that services are available in the county, screening percentages remain comparatively low. Qualitative and quantitative data indicate barriers that may affect access to care are especially high for people in rural areas, women with low income and education levels and women between ages 40-65.

Priorities and Objectives

1. Increase the capacity of existing health providers (located centrally in the City of Lebanon) to reach the rural poor with increased access to screening services.
   a. In FY16 and FY17, hold a series of collaborative meetings (at least three) with health care providers and community based organizations to develop strategies to link women residing in rural areas to screening services.
   b. In FY16, hold a series of collaborative meetings (at least two) with a provider of charitable transportation services, local health care providers, and community-based organizations to provide free and low-cost transportation to low-income individuals living in rural areas.
   c. In FY16 and FY17, develop a collaboration among community organizations and breast health service providers in Boone County to provide screening services during evening and weekend hours.
   d. In the RFAs for FY16 through FY19, a funding priority will be to deliver early detection services, including screening and diagnostics, that may improve death rates and late-stage incidence rates in target communities.

2. Facilitate community awareness, education and mobilization efforts aimed at reaching women living in low-income, rural areas in Boone County.
   a. In FY16, FY17 and FY18, identify and develop cooperative relationships with local community organizations, churches, schools, etc. in rural, low-income areas to mobilize women not currently in the CoC through behavior change communications relating to screening services.
   b. In FY16 and FY17, establish a supply chain of Komen educational materials targeting low-income, low-education, rural women, delivered through local breast health service providers and community-based organizations in Boone County.
   c. In FY16 and FY17, lead a series of collaborative meetings (at least three) with local community-based organizations to develop strategies for targeting rural populations in Boone County with key messaging, linking them directly to resources and services in the county that are available but underutilized.

Problem Statement: Women in **Rush County** have a death rate and late-state diagnosis rate higher than the averages for the Affiliate service area and are not expected to reach the HP2020 guidelines for late stage diagnosis for 13 or more years. Quantitative and qualitative data indicate poverty, unemployment and lack of insurance as potential contributors to comparatively high late-stage diagnosis and death rates. Qualitative data and the Health Systems Analysis suggest a lack of breast health services, underutilization of breast health services and insufficient funding for breast health services are barriers that may impede receiving care.

Priorities and Objectives

1. Increase the capacity of existing health care systems to provide seamless transition for women who are screened to diagnostic and treatment services in Rush County and the surrounding counties.
   a. In FY16 and FY17, lead a series of collaborative meetings (at least three) with local cancer or health-related organizations and public agencies to develop a plan to identify and address gaps in the continuum of care; from screening to diagnostics, to treatment and beyond.
   b. In FY16 and FY17, assist local breast health service providers in Rush County with the process of seeking and obtaining additional resources from government and nonprofit funding sources and programs.
   c. In the RFAs for FY16 through FY19, a funding priority will be to deliver early detection services, including screening and diagnostics, that may improve death rates and late-stage incidence rates in target communities.

2. Facilitate community awareness, education and mobilization efforts aimed at reaching women living in low-income, rural areas in Rush County.
   a. In FY16 and FY17, identify and develop cooperative relationships with community-based organizations directly serving low-income individuals and families in Rush County, in an effort to reach more women with important information relating to screenings and programs for the un/underinsured.
   b. In FY16 and FY17, develop a supply chain for Komen breast cancer educational materials and resources, aimed at educating women and directing them to resources and services in Rush County.
   c. In FY16 and FY17, in partnership with community-based organizations and government agencies offering ACA and HIP 2.0 enrollment and navigation, develop education and awareness measures targeting the uninsured and directing them to enrollment and navigation services, in addition to screening services.

Problem Statement: The target area of **Shelby County** has a high late-stage incidence rate compared to the Affiliate service area average. Additionally, the late-stage incidence rate has increased more than the Affiliate service area trend, growing faster than any other county. Shelby County is not expected to reach the HP2020 targets for late-stage incidence rate for 13 years or longer and is not expected to reach the target for death rate for eight years. Qualitative and quantitative data and the Health Systems Analysis indicate lack of screening and diagnostic services and poor provider/patient communications are barriers that may be preventing women from entering the CoC, especially for women with low levels of income and education.

Priorities and Objectives

1. Increase the health care system's capacity to provide screening opportunities and keep women within the CoC through improved provider/patient communication, patient education and patient navigation.
   a. In FY17, develop an action plan for community entry into Shelby County (Komen currently has no grantee residing in Shelby County) in order to identify key contacts with existing health care providers, government agencies and community-based organizations and identify potential grantees.
   b. In FY17 and FY18, lead a series of at least three collaborative meetings with local breast health service providers to develop strategies for targeting rural populations in Shelby County with key messaging, linking them directly to resources and services in the county.
   c. In the RFAs for FY16 through FY19, a funding priority will be to deliver early detection services, including screening and diagnostics, that may improve death rates and late-stage incidence rates in target communities.

2. Facilitate community awareness, education and mobilization efforts aimed at reaching women living in low-income, rural areas in Shelby County.
   a. In FY17 and FY18, identify and develop cooperative relationships with local community organizations, churches, schools, etc., in rural, low-income areas to mobilize women not currently in the CoC through behavior-change communications relating to screening services.
   b. In FY17 and FY18, establish a supply chain of Komen educational materials targeting White, low-income, low-education, rural, women, delivered through local breast health service providers and community based organizations in Shelby County.
   c. In FY17 and FY18, facilitate a series of collaborative meetings with local breast health services providers, community-based organizations, government programs and current Komen grantees (serving, but not located in, Shelby County) aimed at improving patient navigation and increasing screening percentages.

Problem Statement: Despite a screening percentage higher than the Affiliate service area as a whole, **Marion County** has higher late-stage incidence and death rates. Additionally, Marion County is not expected to achieve the HP2020 target for late-stage incidence rate for 13 years or longer. Qualitative and quantitative data indicate high unemployment, a high uninsured population and low income levels may contribute to barriers to breast health services. Marion County has the largest populations of Black/African-American and Hispanic/Latina women (in real numbers) in the Affiliate service area, and barriers to services are especially prominent for these populations.

Priority and Objectives

1. Facilitate community awareness, education and mobilization efforts aimed at Black/African-American women, with an emphasis on reducing the disparity in breast cancer death rates between Black/African-American and White women, with specific messages and services relating to an increase in access to services and increased awareness within the community.

a. In FY16 and FY 17, using grant funding received by Komen Central Indiana for this purpose, work with collaborating organizations to develop and facilitate a series of quantitative and qualitative assessments aimed at identifying the factors contributing to late-stage incidence and death rates among Black/African-American women in Marion County.
b. In FY16 and FY17, participate in a series of collaborative meetings (at least 15) with predominantly Black/African-American churches to place at least 15 Breast Health Advocates in congregations to mobilize community members to enter and remain in the continuum of care, and create specific opportunities for Black/African-American women to receive breast health services.
c. In FY16 and FY17, in partnership with community-based organizations and government agencies offering ACA and HIP 2.0 enrollment and navigation, develop education and awareness measures targeting the uninsured within the Black/African-American population in Marion County, directing them to enrollment and navigation services, in addition to screening.
d. In the RFAs for FY16 through FY19 a funding priority will be to provide direct services to Black/African-American women with regard to breast health education and breast cancer navigation services.

Problem Statement: <u>Clinton County</u> has the highest percentage of Hispanic/Latina women of all counties in Komen Central Indiana's service area. Despite low late-stage diagnosis and death rates, both well below the Affiliate service area average, qualitative and quantitative data indicate Hispanic/Latina women face barriers to breast health services.

Priorities and Objective

1. Generate increased breast health awareness targeting the Hispanic/Latino, Spanish-speaking community through community-based education and mobilization.
   a. In FY18 and FY19, identify and develop cooperative relationships with community-based organizations currently engaged directly with the Latino community in Clinton County.
   b. In FY18 and FY19, develop a supply chain of Komen educational and promotion materials in the Spanish language to be used by community organizations and breast health service providers in Clinton County.
   c. In FY18 and FY19, apply the existing bilingual Breast Cancer Education Toolkit provided by Komen Headquarters for Hispanic and Latino Communities to provide training to local breast health service providers in Clinton County.

2. Increase the health care system's capacity to overcome system barriers preventing Hispanic/Latinos from seeking or receiving services and entering the Continuum of Care.
   a. In FY18 and FY19, facilitate a series of collaborative meetings (at least three) with community-based providers of breast health services in Clinton County, with an emphasis on the providing services targeting the Hispanic/Latino community in Clinton County.
   b. In FY18 and FY19, link community-based organizations serving the Hispanic/Latino community to transportation services provided by various nonprofit cancer organizations serving Clinton County.

c. In FY18 and FY19, coordinate with a mobile mammography unit to target Hispanic/Latino populations in Clinton County, increasing accessibility, reducing wait times and providing psychosocial support to Latino women, who often feel marginalized in Clinton County.
e. In the RFAs for FY16 through FY19 a funding priority will be provide direct services to Spanish speaking women with regard to breast health educationand breast cancer navigation services.

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

Affiliate History

In the fight to end breast cancer forever, Susan G. Komen® Central Indiana is the locally led and empowered Affiliate of Susan G. Komen, a global organization whose name is synonymous with its cause.

Susan G. Komen Central Indiana began its work in central Indiana in 1992 with the first Race for the Cure® under the auspices of the Junior League of Indianapolis. In 2001, leaders envisioned that this effort could be more than a Race and incorporated as an Affiliate of the Susan G. Komen organization. Led entirely by volunteers, the organization was raising more than one million dollars annually, before hiring its first paid staff member in 2003. In 2011, the Affiliate's name was changed from the Indianapolis Affiliate to Susan G. Komen Central Indiana to reflect the Affiliate's broader service area.

Komen Central Indiana reaches out to the community to educate breast cancer survivors, family and friends, caregivers and the public by organizing and attending local events, offering presentations, developing written communications and collaborating with other organizations serving the community.

The greatest part of the money received by Komen Central Indiana remains in the community as a source of help for Hoosiers in need. It goes to pay for services – including screenings, diagnostic tests, education and patient navigation – that benefit local women and men. Komen Central Indiana has granted more than $15 million to local nonprofit organizations carrying out these services. In the 2014-2015 grant cycle, $848,000 funded 11 local breast health programs that provided nearly 40,000 services to more than 25,000 unduplicated individuals.

Additionally, a meaningful portion of the money received by Komen Central Indiana funds Susan G. Komen Research Programs that endeavor to discover breast cancer causes, treatments and, ultimately, the cures. Susan G. Komen has funded, in part, many advancements in breast cancer research in the last 30 years.

Komen Central Indiana strives to be a local expert and leader in the breast cancer movement in central Indiana. The organization is an active member of the Indiana Cancer Consortium and received the 2013 award for Outstanding Contributions to Cancer Control. In 2014, Komen Central Indiana launched a coalition of local leaders committed to addressing the disparity in breast cancer deaths between Black/African-American and White women in Indianapolis. Representatives from the Komen Central Indiana staff and Board of Directors serve with numerous local agencies and organizations to advocate for and strengthen systems and resources for women, men and families who face breast cancer in the local community.

Affiliate Organizational Structure

The activities of Susan G. Komen Central Indiana are led by a local Board of Directors. Members are community leaders and representatives from diverse industries and professional fields. The Board governs the work of the organization and oversees the Executive Director, who supervises a staff of four full-time employees and one part-time employee to manage daily

operations. Staff members include the Executive Director, Mission Director, Development Director, Development and Volunteer Manager, Communications and Marketing Coordinator and part-time Finance Coordinator.

More than 500 volunteers are actively engaged in the organization's events and work. Among these volunteers are members of numerous committees that offer energy and expertise to carry out the work of Komen Central Indiana in the community. Committees and working groups convened at the time of this report include the Grant Review Panel, the Community Profile Team, the Race for the Cure Executive Committee and Committee, the Pink Tie Ball Committee, the Project Pink Fashion Show Committee and the Pink Ribbon Celebration Survivor Luncheon Committee.

Affiliate Service Area

The Affiliate service area includes 21-counties in Central Indiana. Counties served include: Bartholomew, Boone, Brown, Clinton, Decatur, Delaware, Grant, Hamilton, Hancock, Hendricks, Henry, Howard, Johnson, Madison, Marion, Montgomery, Morgan, Rush, Shelby, Tippecanoe and Tipton (Figure 1.1).

The Affiliate service area includes the metropolitan areas of Indianapolis-Carmel, Lafayette, Anderson, Muncie, Kokomo and Columbus (in order of population). Indianapolis is the largest urban area in the services area, while those who live in rural areas comprise 16.4 percent of the population, and 16.9 percent live in medically under-served areas.

The service area includes a population of more than 2.5 million and female population of nearly 1.3 million. The population is 83.8 percent White, 13.2 percent Black/African-American, 0.4 percent American Indian and Alaska Native and 2.5 percent Asian Pacific Islander. The population is 5.3 percent Hispanic/Latina and 94.7 percent Non-Hispanic/Latina.

In the service area, 12.3 percent of the population has less than a high school education, and 14.0 percent live at or below 100 percent of the federal poverty level with 31.4 percent at or below 250 percent of the federal poverty level. An average 1,628 new cases of breast cancer are diagnosed annually in the service area.

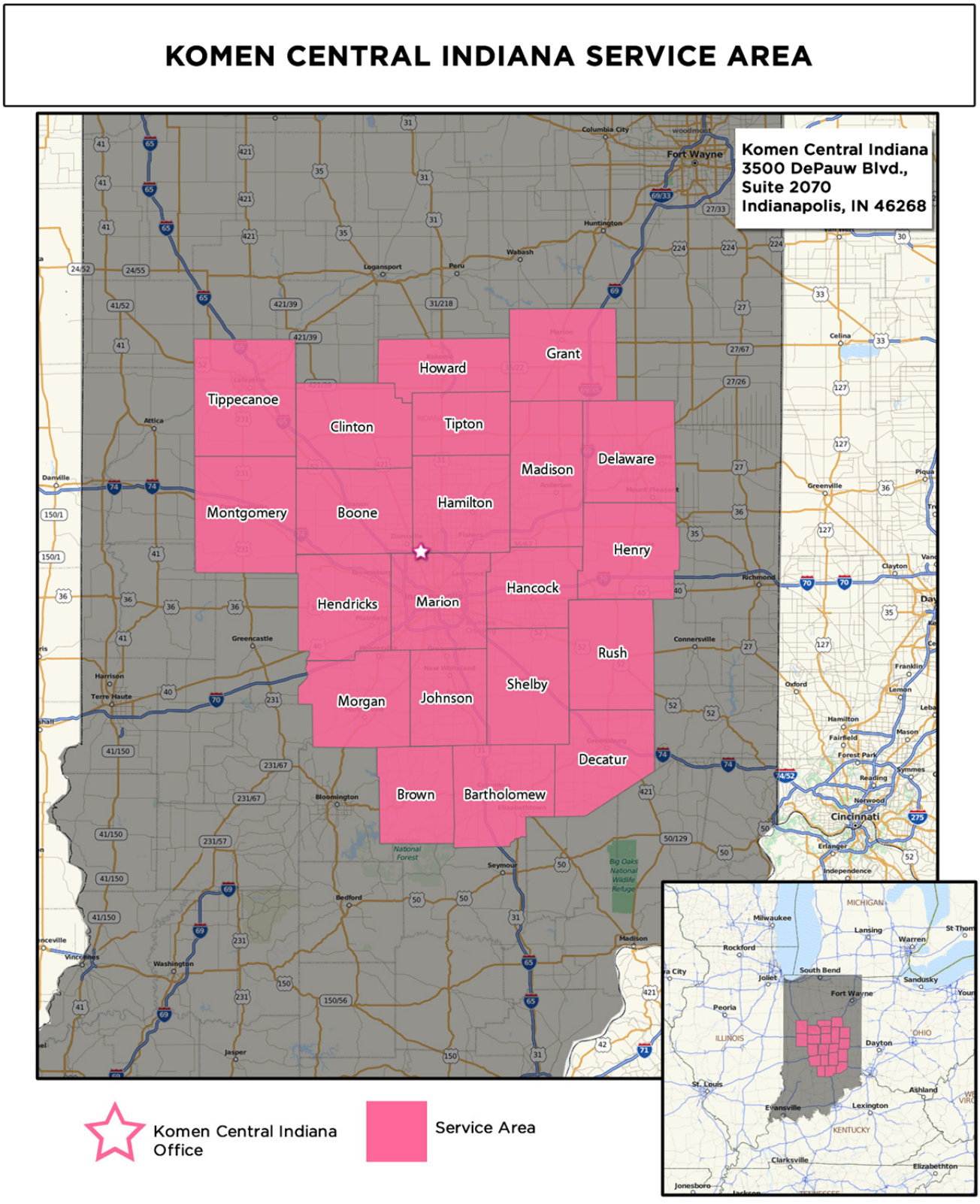

Figure 1.1. Susan G. Komen Central Indiana service area

Purpose of the Community Profile Report

The Community Profile is an assessment process completed every four years by Susan G. Komen Central Indiana, in order to understand the state of the breast cancer burden and needs in the service area. The information outlined in the report is vital to Komen Central Indiana for developing grant funding and programming priorities.

The Community Profile is actively used as a framework to identify the prevalence of breast cancer on a local level, recognize service gaps in breast health and breast cancer needs and develop priorities to address those needs. The Community Profile Report serves to:

- Align strategic and operational plans
- Drive inclusion efforts in the community
- Drive public policy efforts
- Establish focused granting priorities
- Establish focused education needs
- Establish directions for marketing and outreach
- Strengthen sponsorship and development efforts

The final Community Profile Report will be shared with the community through a press release and made available via the Susan G. Komen Central Indiana website. On an ongoing basis, Komen Central Indiana representatives will reference the report in media interviews, presentations, programs and partnerships with organizations and health care systems.

Quantitative Data: Measuring Breast Cancer Impact in Local Communities

Quantitative Data Report

Introduction

The purpose of the quantitative data report for Susan G. Komen® Central Indiana is to combine evidence from many credible sources and use the data to identify the highest priority areas for evidence-based breast cancer programs.

The data provided in the report are used to identify priorities within the Affiliate's service area based on estimates of how long it would take an area to achieve Healthy People 2020 objectives for breast cancer late-stage diagnosis and death rates (http://www.healthypeople.gov/2020/default.aspx).

The following is a summary of Komen Central Indiana's Quantitative Data Report. For a full report please contact the Komen Central Indiana.

Breast Cancer Statistics

Incidence rates

The breast cancer incidence rate shows the frequency of new cases of breast cancer among women living in an area during a certain time period (Table 2.1). Incidence rates may be calculated for all women or for specific groups of women (e.g. for Asian/Pacific Islander women living in the area).

The female breast cancer incidence rate is calculated as the number of females in an area who were diagnosed with breast cancer divided by the total number of females living in that area.

Incidence rates are usually expressed in terms of 100,000 people. For example, suppose there are 50,000 females living in an area and 60 of them are diagnosed with breast cancer during a certain time period. Sixty out of 50,000 is the same as 120 out of 100,000. So the female breast cancer incidence rate would be reported as 120 per 100,000 for that time period.

When comparing breast cancer rates for an area where many older people live to rates for an area where younger people live, it's hard to know whether the differences are due to age or whether other factors might also be involved. To account for age, breast cancer rates are usually adjusted to a common standard age distribution. Using age-adjusted rates makes it possible to spot differences in breast cancer rates caused by factors other than differences in age between groups of women.

To show trends (changes over time) in cancer incidence, data for the annual percent change in the incidence rate over a five-year period were included in the report. The annual percent change is the average year-to-year change of the incidence rate. It may be either a positive or negative number.

- A negative value means that the rates are getting lower.
- A positive value means that the rates are getting higher.
- A positive value (rates getting higher) may seem undesirable—and it generally is. However, it's important to remember that an increase in breast cancer incidence could also mean that more breast cancers are being found because more women are getting mammograms. So higher rates don't necessarily mean that there has been an increase in the occurrence of breast cancer.

Death rates

The breast cancer death rate shows the frequency of death from breast cancer among women living in a given area during a certain time period (Table 2.1). Like incidence rates, death rates may be calculated for all women or for specific groups of women (e.g. Black/African-American women).

The death rate is calculated as the number of women from a particular geographic area who died from breast cancer divided by the total number of women living in that area. Death rates are shown in terms of 100,000 women and adjusted for age.

Data are included for the annual percent change in the death rate over a five-year period.

The meanings of these data are the same as for incidence rates, with one exception. Changes in screening don't affect death rates in the way that they affect incidence rates. So a negative value, which means that death rates are getting lower, is always desirable. A positive value, which means that death rates are getting higher, is always undesirable.

Late-stage incidence rates

For this report, late-stage breast cancer is defined as regional or distant stage using the Surveillance, Epidemiology and End Results (SEER) Summary Stage definitions (http://seer.cancer.gov/tools/ssm/). State and national reporting usually uses the SEER Summary Stage. It provides a consistent set of definitions of stages for historical comparisons.

The late-stage breast cancer incidence rate is calculated as the number of women with regional or distant breast cancer in a particular geographic area divided by the number of women living in that area (Table 2.1). Late-stage incidence rates are shown in terms of 100,000 women and adjusted for age.

Table 2.1. Female breast cancer incidence rates and trends, death rates and trends, and late-stage rates and trends

		Incidence Rates and Trends			Death Rates and Trends			Late-stage Rates and Trends		
Population Group	Female Population (Annual Average)	# of New Cases (Annual Average)	Age-adjusted Rate/ 100,000	Trend (Annual Percent Change)	# of Deaths (Annual Average)	Age-adjusted Rate/ 100,000	Trend (Annual Percent Change)	# of New Cases (Annual Average)	Age-adjusted Rate/ 100,000	Trend (Annual Percent Change)
US	154,540,194	182,234	122.1	-0.2%	40,736	22.6	-1.9%	64,590	43.8	-1.2%
HP2020	.	-	-	-	-	20.6*	-	-	41.0*	-
Indiana	3,260,368	4,287	117.4	-0.3%	909	23.9	-1.9%	1,488	41.1	-0.6%
Komen Central Indiana Service Area	1,278,423	1,628	119.2	0.4%	333	23.8	NA	541	40.0	-1.0%
White	1,079,993	1,439	119.5	0.7%	288	23.1	NA	466	39.2	-1.2%
Black/African-American	163,969	168	122.8	-2.5%	42	32.3	NA	67	48.8	-0.5%
American Indian/Alaska Native (AIAN)	5,072	SN	SN	SN	SN	SN	SN	SN	SN	SN
Asian Pacific Islander (API)	29,389	13	59.7	13.0%	SN	SN	SN	6	28.7	14.0%
Non-Hispanic/ Latina	1,219,282	1,613	120.3	0.3%	331	24.1	NA	536	40.4	-1.0%
Hispanic/ Latina	59,142	15	55.4	21.7%	SN	SN	SN	6	18.3	4.5%
Bartholomew County - IN	38,387	50	110.3	2.1%	10	21.0	-2.9%	17	36.8	2.6%
Boone County - IN	27,834	41	133.8	5.9%	10	31.8	-0.1%	13	40.3	10.5%
Brown County - IN	7,679	9	81.9	-17.3%	SN	SN	SN	4	35.1	-27.2%
Clinton County - IN	16,842	18	94.1	-6.7%	4	16.8	-4.0%	6	35.7	-21.6%
Decatur County - IN	12,940	13	84.8	0.6%	5	27.4	-0.3%	4	26.0	-8.2%
Delaware County - IN	60,910	87	129.9	-0.3%	16	23.0	-1.4%	28	43.0	-2.0%
Grant County - IN	36,459	57	123.5	2.7%	11	21.9	-3.9%	16	37.8	-7.7%
Hamilton County - IN	133,552	158	124.1	-0.7%	27	23.4	-2.3%	50	39.1	-0.3%
Hancock County - IN	34,608	51	131.1	-2.7%	9	22.7	-2.9%	18	45.6	1.1%
Hendricks County - IN	70,202	81	110.9	0.7%	15	21.2	-1.7%	25	34.2	2.5%
Henry County - IN	24,390	36	110.9	0.0%	8	24.0	-0.1%	9	29.1	-2.4%
Howard County - IN	43,251	63	117.0	-8.6%	13	22.7	-1.7%	20	38.5	-3.2%
Johnson County - IN	69,202	86	115.0	4.0%	18	22.5	-2.3%	29	39.3	9.8%
Madison County - IN	65,827	94	112.6	3.5%	19	21.2	-2.3%	27	32.7	8.1%
Marion County - IN	461,040	572	122.1	0.4%	123	26.1	-1.6%	201	43.2	-2.8%
Montgomery County - IN	18,949	24	99.0	-13.4%	4	17.9	-3.0%	8	36.1	-9.3%
Morgan County - IN	34,558	51	127.7	-4.4%	9	22.8	0.7%	19	47.9	-5.3%
Rush County - IN	8,882	10	94.4	1.3%	3	27.7	NA	4	42.5	1.3%
Shelby County - IN	22,245	30	115.6	10.8%	6	23.6	-1.8%	11	45.6	10.7%
Tippecanoe County - IN	82,470	86	119.8	5.4%	17	23.0	-3.1%	29	40.9	-3.1%
Tipton County - IN	8,198	10	93.1	20.1%	SN	SN	SN	SN	SN	SN

*Target as of the writing of this report.
NA – data not available.
SN – data suppressed due to small numbers (15 cases or fewer for the 5-year data period).
Data are for years 2006-2010.
Rates are in cases or deaths per 100,000.
Age-adjusted rates are adjusted to the 2000 US standard population.
Source of incidence and late-stage data: North American Association of Central Cancer Registries (NAACCR) – Cancer in North America (CINA) Deluxe Analytic File.
Source of death rate data: Centers for Disease Control and Prevention (CDC) – National Center for Health Statistics (NCHS) mortality data in SEER*Stat.
Source of death trend data: National Cancer Institute (NCI)/CDC State Cancer Profiles.

Incidence rates and trends summary

Overall, the breast cancer incidence rate in the Komen Central Indiana service area was slightly lower than that observed in the US as a whole and the incidence trend was higher than the US as a whole. The incidence rate and trend of the Affiliate service area were not significantly different than that observed for the State of Indiana.

For the United States, breast cancer incidence in Blacks/African-Americans is lower than in Whites overall. The most recent estimated breast cancer incidence rates for Asians and Pacific Islanders (APIs) and American Indians and Alaska Natives (AIANs) were lower than for Non-Hispanic Whites and Blacks/African-Americans. The most recent estimated incidence rates for Hispanics/Latinas were lower than for Non-Hispanic Whites and Blacks/African-Americans. For the Affiliate service area as a whole, the incidence rate was slightly higher among Blacks/African-Americans than Whites and lower among APIs than Whites. There were not enough data available within the Affiliate service area to report on AIANs so comparisons cannot be made for this racial group. The incidence rate among Hispanics/Latinas was lower than among Non-Hispanics/Latinas.

The incidence rate was significantly lower in the following counties:

- Brown County
- Clinton County
- Decatur County

The rest of the counties had incidence rates and trends that were not significantly different than the Affiliate service area as a whole or did not have enough data available.

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

Death rates and trends summary

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

For the United States, breast cancer death rates in Blacks/African-Americans are substantially higher than in Whites overall. The most recent estimated breast cancer death rates for APIs and AIANs were lower than for Non-Hispanic Whites and Blacks/African-Americans. The most recent estimated death rates for Hispanics/Latinas were lower than for Non-Hispanic Whites and Blacks/African-Americans. For the Affiliate service area as a whole, the death rate was higher among Blacks/African-Americans than Whites. There were not enough data available within the Affiliate service area to report on APIs and AIANs so comparisons cannot be made for these racial groups. Also, there were not enough data available within the Affiliate service area to report on Hispanics/Latinas so comparisons cannot be made for this group.

None of the counties in the Affiliate service area had substantially different death rates than the Affiliate service area as a whole or did not have enough data available.

Late-stage incidence rates and trends summary

Overall, the breast cancer late-stage incidence rate in the Komen Central Indiana service area was slightly lower than that observed in the US as a whole and the late-stage incidence trend was slightly higher than the US as a whole. The late-stage incidence rate and trend of the Affiliate service area were not significantly different than that observed for the State of Indiana.

For the United States, late-stage incidence rates in Blacks/African-Americans are higher than among Whites. Hispanics/Latinas tend to be diagnosed with late-stage breast cancers more often than Whites. For the Affiliate service area as a whole, the late-stage incidence rate was higher among Blacks/African-Americans than Whites and lower among APIs than Whites. There were not enough data available within the Affiliate service area to report on AIANs so comparisons cannot be made for this racial group. The late-stage incidence rate among Hispanics/Latinas was lower than among Non-Hispanics/Latinas.

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

Mammography Screening

Getting regular screening mammograms (and treatment if diagnosed) lowers the risk of dying from breast cancer. Screening mammography can find breast cancer early, when the chances of survival are highest. Table 2.2 shows some screening recommendations among major organizations for women at average risk.

Table 2.2. Breast cancer screening recommendations for women at average risk

American Cancer Society	National Cancer Institute	National Comprehensive Cancer Network	US Preventive Services Task Force
Mammography every year starting at age 40	Mammography every 1-2 years starting at age 40	Mammography every year starting at age 40	Informed decision-making with a health care provider ages 40-49 Mammography every 2 years ages 50-74

Because having mammograms lowers the chances of dying from breast cancer, it's important to know whether women are having mammograms when they should. This information can be used to identify groups of women who should be screened who need help in meeting the current recommendations for screening mammography. The Centers for Disease Control and Prevention's (CDC) Behavioral Risk Factors Surveillance System (BRFSS) collected the data on mammograms that are used in this report. The data come from interviews with women age 50 to 74 from across the United States. During the interviews, each woman was asked how long it has been since she has had a mammogram. BRFSS is the best and most widely used source available for information on mammography usage among women in the United States, although it does not collect data matching Komen screening recommendations (i.e. from women

age 40 and older). The proportions in Table 2.3 are based on the number of women age 50 to 74 who reported in 2012 having had a mammogram in the last two years.

The data have been weighted to account for differences between the women who were interviewed and all the women in the area. For example, if 20.0 percent of the women interviewed are Latina, but only 10.0 percent of the total women in the area are Latina, weighting is used to account for this difference.

The report uses the mammography screening proportion to show whether the women in an area are getting screening mammograms when they should. Mammography screening proportion is calculated from two pieces of information:

- The number of women living in an area whom the BRFSS determines should have mammograms (i.e. women age 50 to 74).
- The number of these women who actually had a mammogram during the past two years.

The number of women who had a mammogram is divided by the number who should have had one. For example, if there are 500 women in an area who should have had mammograms and 250 of those women actually had a mammogram in the past two years, the mammography screening proportion is 50.0 percent.

Because the screening proportions come from samples of women in an area and are not exact, Table 2.3 includes confidence intervals. A confidence interval is a range of values that gives an idea of how uncertain a value may be. It's shown as two numbers—a lower value and a higher one. It is very unlikely that the true rate is less than the lower value or more than the higher value.

For example, if screening proportion was reported as 50.0 percent, with a confidence interval of 35.0 to 65.0 percent, the real rate might not be exactly 50.0 percent, but it's very unlikely that it's less than 35.0 or more than 65.0 percent.

In general, screening proportions at the county level have fairly wide confidence intervals. The confidence interval should always be considered before concluding that the screening proportion in one county is higher or lower than that in another county.

Table 2.3. Proportion of women ages 50-74 with screening mammography in the last two years, self-report

Population Group	# of Women Interviewed (Sample Size)	# w/ Self-Reported Mammogram	Proportion Screened (Weighted Average)	Confidence Interval of Proportion Screened
US	174,796	133,399	77.5%	77.2%-77.7%
Indiana	3,249	2,306	69.5%	67.5%-71.5%
Komen Central Indiana Service Area	1,057	791	73.8%	70.3%-77.1%
White	885	658	74.0%	70.2%-77.5%
Black/African-American	147	116	74.1%	61.8%-83.5%
AIAN	SN	SN	SN	SN
API	SN	SN	SN	SN
Hispanic/ Latina	13	10	66.5%	31.5%-89.5%
Non-Hispanic/ Latina	1,037	776	73.9%	70.3%-77.2%
Bartholomew County - IN	30	22	73.7%	50.3%-88.6%
Boone County - IN	23	17	67.1%	40.3%-86.1%
Brown County - IN	SN	SN	SN	SN
Clinton County - IN	16	10	54.7%	28.2%-78.8%
Decatur County - IN	11	9	76.8%	41.5%-93.9%
Delaware County - IN	48	35	72.2%	54.4%-85.0%
Grant County - IN	38	30	82.1%	62.6%-92.6%
Hamilton County - IN	58	44	77.0%	61.0%-87.8%
Hancock County - IN	14	11	72.9%	40.0%-91.6%
Hendricks County - IN	34	26	73.8%	51.5%-88.2%
Henry County - IN	27	24	91.0%	70.1%-97.7%
Howard County - IN	44	32	78.1%	59.0%-89.9%
Johnson County - IN	47	34	73.7%	55.9%-86.0%
Madison County - IN	60	38	60.0%	43.9%-74.1%
Marion County - IN	450	342	75.4%	69.8%-80.3%
Montgomery County - IN	16	12	78.4%	48.7%-93.3%
Morgan County - IN	27	21	71.8%	50.2%-86.6%
Rush County - IN	28	21	76.8%	53.9%-90.4%
Shelby County - IN	19	12	67.9%	42.3%-85.9%
Tippecanoe County - IN	52	41	73.6%	55.4%-86.3%
Tipton County - IN	SN	SN	SN	SN

SN – data suppressed due to small numbers (fewer than 10 samples).
Data are for 2012.
Source: CDC – Behavioral Risk Factor Surveillance System (BRFSS).

Breast cancer screening proportions summary

The breast cancer screening proportion in the Komen Central Indiana service area was **significantly lower** than that observed in the US as a whole. The screening proportion of the Affiliate service area was not significantly different than the State of Indiana.

For the United States, breast cancer screening proportions among Blacks/African-Americans are similar to those among Whites overall. APIs have somewhat lower screening proportions than Whites and Blacks/African-Americans. Although data are limited, screening proportions among AIANs are similar to those among Whites. Screening proportions among Hispanics/Latinas are similar to those among Non-Hispanic Whites and Blacks/African-Americans. For the Affiliate service area as a whole, the screening proportion was not significantly different among Blacks/African-Americans than Whites. There were not enough data available within the Affiliate service area to report on APIs and AIANs so comparisons cannot be made for these racial groups. The screening proportion among Hispanics/Latinas was not significantly different than among Non-Hispanics/Latinas.

None of the counties in the Affiliate service area had substantially different screening proportions than the Affiliate service area as a whole.

Population Characteristics

The report includes basic information about the women in each area (demographic measures) and about factors like education, income, and unemployment (socioeconomic measures) in the areas where they live (Tables 2.4 and 2.5). Demographic and socioeconomic data can be used to identify which groups of women are most in need of help and to figure out the best ways to help them.

It is important to note that the report uses the race and ethnicity categories used by the US Census Bureau, and that race and ethnicity are separate and independent categories. This means that everyone is classified as both a member of one of the four race groups as well as either Hispanic/Latina or Non-Hispanic/Latina.

The demographic and socioeconomic data in this report are the most recent data available for US counties. All the data are shown as percentages. However, the percentages weren't all calculated in the same way.

- The race, ethnicity, and age data are based on the total female population in the area (e.g. the percent of females over the age of 40).
- The socioeconomic data are based on all the people in the area, not just women.
- Income, education and unemployment data don't include children. They're based on people age 15 and older for income and unemployment and age 25 and older for education.
- The data on the use of English, called "linguistic isolation", are based on the total number of households in the area. The Census Bureau defines a linguistically isolated household as one in which all the adults have difficulty with English.

Table 2.4. Population characteristics – demographics

Population Group	White	Black/African-American /African-American	AIAN	API	Non-Hispanic /Latina	Hispanic /Latina	Female Age 40 Plus	Female Age 50 Plus	Female Age 65 Plus
US	78.8 %	14.1 %	1.4 %	5.8 %	83.8 %	16.2 %	48.3 %	34.5 %	14.8 %
Indiana	87.4 %	10.2 %	0.4 %	1.9 %	94.2 %	5.8 %	48.0 %	34.6 %	14.8 %
Komen Central Indiana Service Area	83.8 %	13.2 %	0.4 %	2.5 %	94.7 %	5.3 %	46.3 %	32.6 %	13.6 %
Bartholomew County - IN	93.4 %	2.5 %	0.5 %	3.7 %	94.6 %	5.4 %	49.3 %	35.8 %	15.9 %
Boone County - IN	96.4 %	1.4 %	0.2 %	2.1 %	97.7 %	2.3 %	49.4 %	33.1 %	12.8 %
Brown County - IN	98.2 %	0.9 %	0.4 %	0.6 %	98.8 %	1.2 %	60.9 %	47.2 %	18.4 %
Clinton County - IN	98.6 %	0.7 %	0.4 %	0.3 %	87.4 %	12.6 %	48.8 %	36.1 %	16.6 %
Decatur County - IN	98.1 %	0.6 %	0.3 %	1.0 %	98.6 %	1.4 %	50.4 %	36.9 %	16.7 %
Delaware County - IN	90.4 %	7.8 %	0.3 %	1.4 %	98.2 %	1.8 %	45.7 %	34.4 %	16.4 %
Grant County - IN	91.1 %	7.7 %	0.5 %	0.8 %	96.7 %	3.3 %	50.6 %	38.4 %	18.1 %
Hamilton County - IN	90.1 %	4.2 %	0.3 %	5.4 %	96.5 %	3.5 %	44.5 %	27.6 %	9.8 %
Hancock County - IN	96.0 %	2.5 %	0.3 %	1.2 %	98.1 %	1.9 %	50.6 %	35.0 %	14.0 %
Hendricks County - IN	92.0 %	5.0 %	0.4 %	2.6 %	97.0 %	3.0 %	46.9 %	31.4 %	12.4 %
Henry County - IN	98.0 %	1.3 %	0.2 %	0.5 %	98.7 %	1.3 %	54.4 %	40.6 %	19.2 %
Howard County - IN	90.5 %	7.8 %	0.4 %	1.2 %	97.5 %	2.5 %	53.0 %	40.0 %	18.5 %
Johnson County - IN	95.7 %	1.6 %	0.3 %	2.4 %	97.1 %	2.9 %	47.5 %	33.2 %	14.0 %
Madison County - IN	91.0 %	7.9 %	0.4 %	0.7 %	96.9 %	3.1 %	51.7 %	38.5 %	17.8 %
Marion County - IN	67.7 %	29.3 %	0.6 %	2.4 %	91.4 %	8.6 %	43.7 %	30.7 %	12.3 %
Montgomery County - IN	97.8 %	1.1 %	0.4 %	0.6 %	95.8 %	4.2 %	51.9 %	38.2 %	17.9 %
Morgan County - IN	98.4 %	0.6 %	0.3 %	0.7 %	98.8 %	1.2 %	51.8 %	36.5 %	14.7 %
Rush County - IN	98.1 %	1.2 %	0.3 %	0.4 %	98.9 %	1.1 %	53.1 %	38.9 %	17.8 %
Shelby County - IN	97.5 %	1.4 %	0.3 %	0.8 %	96.5 %	3.5 %	52.0 %	37.1 %	16.0 %
Tippecanoe County - IN	88.8 %	5.1 %	0.4 %	5.7 %	92.5 %	7.5 %	37.5 %	27.0 %	11.2 %
Tipton County - IN	98.7 %	0.6 %	0.3 %	0.5 %	98.0 %	2.0 %	56.3 %	41.8 %	19.7 %

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

Table 2.5. Population characteristics – socioeconomics.

Population Group	Less than HS Education	Income Below 100% Poverty	Income Below 250% Poverty (Age: 40-64)	Un-employed	Foreign Born	Linguistic-ally Isolated	In Rural Areas	In Medically Under-served Areas	No Health Insurance (Age: 40-64)
US	14.6 %	14.3 %	33.3 %	8.7 %	12.8 %	4.7 %	19.3 %	23.3 %	16.6 %
Indiana	13.4 %	14.1 %	32.9 %	9.0 %	4.5 %	1.8 %	27.6 %	14.7 %	15.6 %
Komen Central Indiana Service Area	12.3 %	14.0 %	31.4 %	8.9 %	5.6 %	2.1 %	16.4 %	16.9 %	14.8 %
Bartholomew County - IN	11.0 %	11.4 %	30.7 %	6.9 %	6.8 %	3.2 %	33.7 %	0.0 %	14.3 %
Boone County - IN	6.7 %	7.9 %	18.1 %	4.6 %	3.1 %	0.3 %	34.4 %	0.0 %	9.3 %
Brown County - IN	11.5 %	11.2 %	33.0 %	8.8 %	1.6 %	0.6 %	100.0 %	100.0 %	17.0 %
Clinton County - IN	17.7 %	13.9 %	36.2 %	9.2 %	6.7 %	3.2 %	49.8 %	12.4 %	18.1 %
Decatur County - IN	15.2 %	12.5 %	35.4 %	9.0 %	2.3 %	0.8 %	53.8 %	6.9 %	14.7 %
Delaware County - IN	14.9 %	20.6 %	38.9 %	12.9 %	2.0 %	0.7 %	22.8 %	0.0 %	15.4 %
Grant County - IN	16.0 %	17.8 %	41.2 %	11.2 %	1.6 %	0.4 %	28.9 %	0.0 %	16.2 %
Hamilton County - IN	4.0 %	4.7 %	13.7 %	4.6 %	6.7 %	1.2 %	5.6 %	0.0 %	9.2 %
Hancock County - IN	8.3 %	7.3 %	24.3 %	6.3 %	1.5 %	0.6 %	30.4 %	0.0 %	12.2 %
Hendricks County - IN	6.6 %	5.1 %	19.4 %	5.1 %	3.8 %	1.0 %	17.8 %	0.0 %	10.8 %
Henry County - IN	15.5 %	14.6 %	39.0 %	11.4 %	0.8 %	0.2 %	42.9 %	0.0 %	16.7 %
Howard County - IN	12.9 %	15.3 %	33.8 %	11.2 %	1.7 %	0.4 %	21.5 %	33.0 %	13.2 %
Johnson County - IN	9.3 %	8.5 %	23.1 %	6.0 %	3.4 %	0.6 %	13.9 %	14.6 %	11.7 %
Madison County - IN	13.2 %	16.1 %	36.2 %	10.9 %	1.9 %	0.5 %	23.1 %	0.0 %	15.7 %
Marion County - IN	15.8 %	18.3 %	39.3 %	10.7 %	8.2 %	3.6 %	0.6 %	21.0 %	17.9 %
Montgomery County - IN	12.6 %	13.1 %	33.6 %	8.0 %	3.1 %	1.5 %	52.8 %	0.0 %	16.2 %
Morgan County - IN	14.5 %	9.6 %	29.6 %	9.1 %	1.2 %	0.1 %	49.1 %	0.0 %	14.2 %
Rush County - IN	14.7 %	14.2 %	36.3 %	9.4 %	0.3 %	0.5 %	61.2 %	0.0 %	15.8 %
Shelby County - IN	14.2 %	11.1 %	31.2 %	8.0 %	2.7 %	0.8 %	52.0 %	0.0 %	15.5 %
Tippecanoe County - IN	9.5 %	20.8 %	29.5 %	7.8 %	10.3 %	3.7 %	14.5 %	100.0 %	15.4 %
Tipton County - IN	10.9 %	7.0 %	28.8 %	7.1 %	1.4 %	0.5 %	61.6 %	0.0 %	14.1 %

Data are in the percentage of people (men and women) in the population.
Source of health insurance data: US Census Bureau – Small Area Health Insurance Estimates (SAHIE) for 2011.
Source of rural population data: US Census Bureau – Census 2010.
Source of medically underserved data: Health Resources and Services Administration (HRSA) for 2013.
Source of other data: US Census Bureau – American Community Survey (ACS) for 2007-2011.

Population characteristics summary

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

The following county has a substantially larger Black/African-American female population percentage than that of the Affiliate service area as a whole:

- Marion County

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

- Tippecanoe County

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

- Clinton County

The following counties have substantially older female population percentages than that of the Affiliate service area as a whole:

- Henry County
- Tipton County

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

- Clinton County

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

- Delaware County

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

- Delaware County

Priority Areas

Healthy People 2020 forecasts

Healthy People 2020 (HP2020) is a major federal government initiative that provides specific health objectives for communities and for the country as a whole. Many national health organizations use HP2020 targets to monitor progress in reducing the burden of disease and improve the health of the nation. Likewise, Komen believes it is important to refer to HP2020 to see how areas across the country are progressing towards reducing the burden of breast cancer.

HP2020 has several cancer-related objectives, including:

- Reducing women's death rate from breast cancer (Target as of the writing of this report: 41.0 cases per 100,000 women).
- Reducing the number of breast cancers that are found at a late-stage (Target as of the writing of this report: 41.0 cases per 100,000 women).

To see how well counties in the Komen Central Indiana service area are progressing toward these targets, the report uses the following information:

- County breast cancer death rate and late-stage diagnosis data for years 2006 to 2010.
- Estimates for the trend (annual percent change) in county breast cancer death rates and late-stage diagnoses for years 2006 to 2010.
- Both the data and the HP2020 target are age-adjusted.

These data are used to estimate how many years it will take for each county to meet the HP2020 objectives. Because the target date for meeting the objective is 2020, and 2008 (the middle of the 2006-2010 period) was used as a starting point, a county has 12 years to meet the target.

Death rate and late-stage diagnosis data and trends are used to calculate whether an area will meet the HP2020 target, assuming that the trend seen in years 2006 to 2010 continues for 2011 and beyond.

Identification of priority areas

The purpose of this report is to combine evidence from many credible sources and use the data to identify the highest priority areas for breast cancer programs (i.e. the areas of greatest need).

Classification of priority areas are based on the time needed to achieve HP2020 targets in each area. These time projections depend on both the starting point and the trends in death rates and late-stage incidence.

Late-stage incidence reflects both the overall breast cancer incidence rate in the population and the mammography screening coverage. The breast cancer death rate reflects the access to care and the quality of care in the health care delivery area, as well as cancer stage at diagnosis.

There has not been any indication that either one of the two HP2020 targets is more important than the other. Therefore, the report considers them equally important.

Counties are classified as follows (Table 2.6):

- Counties that are not likely to achieve either of the HP2020 targets are considered to have the highest needs.
- Counties that have already achieved both targets are considered to have the lowest needs.
- Other counties are classified based on the number of years needed to achieve the two targets.

Table 2.6. Needs/priority classification based on the projected time to achieve HP2020 breast cancer targets

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

If the time to achieve a target cannot be calculated for one of the HP2020 indicators, then the county is classified based on the other indicator. If both indicators are missing, then the county is not classified. This doesn't mean that the county may not have high needs; it only means that sufficient data are not available to classify the county.

Affiliate Service Area Healthy People 2020 Forecasts and Priority Areas

The results presented in Table 2.7 help identify which counties have the greatest needs when it comes to meeting the HP2020 breast cancer targets.

- For counties in the "13 years or longer" category, current trends would need to change to achieve the target.
- Some counties may currently meet the target but their rates are increasing and they could fail to meet the target if the trend is not reversed.

Trends can change for a number of reasons, including:

- Improved screening programs could lead to breast cancers being diagnosed earlier, resulting in a decrease in both late-stage incidence rates and death rates.
- Improved socioeconomic conditions, such as reductions in poverty and linguistic isolation could lead to more timely treatment of breast cancer, causing a decrease in death rates.

The data in this table should be considered together with other information on factors that affect breast cancer death rates such as screening percentages and key breast cancer death determinants such as poverty and linguistic isolation.

Table 2.7. Intervention priorities for Komen Central Indiana service area with predicted time to achieve the HP2020 breast cancer targets and key population characteristics.

County	Priority	Predicted Time to Achieve Death Rate Target	Predicted Time to Achieve Late-stage Incidence Target	Key Population Characteristics
Boone County - IN	Highest	13 years or longer	13 years or longer	Rural
Rush County - IN	Highest	SN	13 years or longer	Rural
Shelby County - IN	High	8 years	13 years or longer	Rural
Bartholomew County - IN	Medium High	1 year	13 years or longer	Rural
Hancock County - IN	Medium High	4 years	13 years or longer	Rural
Hendricks County - IN	Medium High	2 years	13 years or longer	
Johnson County - IN	Medium High	4 years	13 years or longer	
Madison County - IN	Medium High	2 years	13 years or longer	Rural
Marion County - IN	Medium High	13 years or longer	2 years	%Black/African-American, %Hispanic/Latina
Morgan County - IN	Medium High	13 years or longer	3 years	Rural
Decatur County - IN	Medium	13 years or longer	Currently meets target	Rural
Delaware County - IN	Medium	8 years	3 years	Poverty, employment, rural
Henry County - IN	Medium	13 years or longer	Currently meets target	Older, rural
Grant County - IN	Low	2 years	Currently meets target	Rural
Hamilton County - IN	Low	6 years	Currently meets target	
Howard County - IN	Low	6 years	Currently meets target	Rural, medically underserved
Tippecanoe County - IN	Low	4 years	Currently meets target	%API, medically underserved
Brown County - IN	Lowest	SN	Currently meets target	Rural, medically underserved
Clinton County - IN	Lowest	Currently meets target	Currently meets target	%Hispanic/Latina, education, rural
Montgomery County - IN	Lowest	Currently meets target	Currently meets target	Rural
Tipton County - IN	Undetermined	SN	SN	Older, rural

NA – data not available.
SN – data suppressed due to small numbers (15 cases or fewer for the 5-year data period).

Map of Intervention Priority Areas

Figure 2.1 shows a map of the intervention priorities for the counties in the Affiliate service area. When both of the indicators used to establish a priority for a county are not available, the priority is shown as “undetermined” on the map.

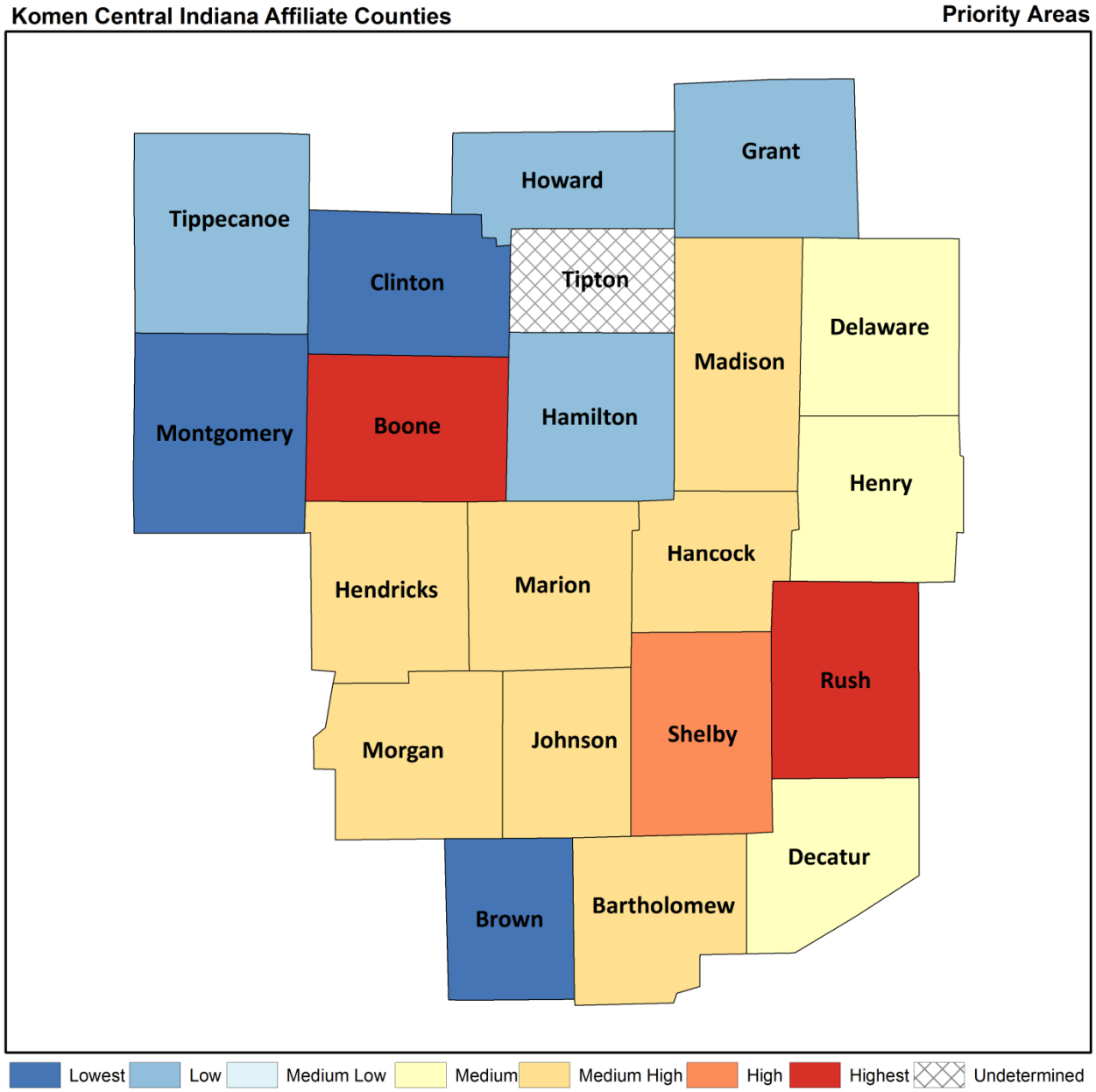

Figure 2.1. Intervention priorities.

Data Limitations

The following data limitations need to be considered when utilizing the data of the Quantitative Data Report:

- The most recent data available were used but, for cancer incidence and deaths, these data are still several years behind.
- For some areas, data might not be available or might be of varying quality.

- Areas with small populations might not have enough breast cancer cases or breast cancer deaths each year to support the generation of reliable statistics.
- There are often several sources of cancer statistics for a given population and geographic area; therefore, other sources of cancer data may result in minor differences in the values even in the same time period.
- Data on cancer rates for specific racial and ethnic subgroups such as Somali, Hmong, or Ethiopian are not generally available.
- The various types of breast cancer data in this report are inter-dependent.
- There are many factors that impact breast cancer risk and survival for which quantitative data are not available. Some examples include family history, genetic markers like HER2 and BRCA, other medical conditions that can complicate treatment, and the level of family and community support available to the patient.
- The calculation of the years needed to meet the HP2020 objectives assume that the current trends will continue until 2020. However, the trends can change for a number of reasons.
- Not all breast cancer cases have a stage indication.

Quantitative Data Report Conclusions

Highest priority areas

Two counties in the Komen Central Indiana service area are in the highest priority category. One of the two, Boone County is not likely to meet either the death rate or late-stage incidence rate HP2020 targets. The other, Rush County is not likely to meet the late-stage incidence rate HP2020 target.

The incidence rates in Boone County (133.8 per 100,000) appear to be higher than the Affiliate service area as a whole (119.2 per 100,000) although not significantly. The death rates in Boone County (31.8 per 100,000) appear to be higher than the Affiliate service area as a whole (23.8 per 100,000) although not significantly. The late-stage incidence trends in both Boone County (10.5 percent per year) and Rush County (1.3 percent per year) indicate that late-stage incidence rates may be increasing.

High priority areas

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

The late-stage incidence rates in Shelby County (45.6 per 100,000) appear to be higher than the Affiliate service area as a whole (40.0 per 100,000) although not significantly. The late-stage incidence trends in Shelby County (10.7 percent per year) indicate that late-stage incidence rates may be increasing.

Selection of Target Communities

The Community Profile Team examined the data provided by Komen Headquarters in the Quantitative Data Report with a special concentration on the Healthy People 2020 (HP2020) target for late-stage diagnosis and deaths. Areas were compared and categorized from highest to lowest priority. HP2020 has several cancer-related objectives, which include reducing women's death rate from breast cancer and reducing the number of breast cancers that are

found at late-stage. There are several Central Indiana counties not expected to reach either the predicted time to achieve death rate target or the predicted time to achieve the late-stage incidence target. The team also focused on counties that are likely to reach the HP2020 objective but are shown to have higher minority populations that are at risk for experiencing barriers to accessing quality health care and completing the continuum of care. The five selected counties are highlighted and explained in detail in this section.

The Community Profile Team analyzed the following for each county:

- incidence rate
- death rate
- late-stage diagnosis
- screening percentages
- residents have an income less than 250 percent of the poverty level
- residents (ages 40-64) living without health insurance
- unemployment percentages

The five selected target counties are:

- Boone County: Highest Priority
- Rush County: Highest Priority
- Shelby County: High Priority
- Marion County: Medium High Priority
- Clinton County: Low Priority

Boone County:

Boone County, which includes the cities of Lebanon and Zionsville, is primarily rural with 96.4 percent of the population being White (Table 2.4). The county has a female population of 27,834 with 49.4 percent of the female population over the age of 40 (Table 2.4). Individuals with incomes below 250 percent of the federal poverty level account for 18.1 percent of the total population in Boone County (Table 2.5). The national average of individuals living at 250 percent of poverty is 33.3 percent compared to Indiana's average at 32.9 percent (Table 2.5). Of the residents living in Boone County, 6.7 percent have less than a high-school education, and 9.3 percent are living without health insurance (Table 2.5).

Boone County was selected as a target community because it is not likely to meet the HP2020 targets for death rate or late-stage incidence rate. The target to meet the female breast cancer death rate is 20.6 per 100,000. Boone County is at 31.8 and is expected to take 13 years or longer to meet this target (Tables 2.1 and 2.7). The target for late-stage incidence rate is 41.0 per 100,000; Boone County is at 40.3 with an increasing trend. As a result, it is expected to take 13 years or longer to meet the target (Tables 2.1 and 2.7).

The incidence and death rates in Boone County are higher than the Affiliate service area, state and national rates (Table 2.8). Additionally, both incidence rate and death rates in Boone County are among the top four in the Affiliate service area. The death rate in Boone County is higher than the Affiliate service area, national and state averages and is the highest of all counties in the service area. The late-stage incidence rate is the eighth highest of the 21 counties in the service area with an annual 10.5 percent change in trend, which indicates that the late-stage incidence rates may be increasing.

Table 2.8. Boone County breast cancer statistics

	Boone County	United States	Indiana	Komen Central IN Service Area
Incidence Rate*	133.8	122.1	117.4	119.2
Death Rate*	31.8	22.6	23.9	23.8
Late-Stage Incidence Rate*	40.3	43.8	41.1	40.0

*rates are age-adjusted per 100,000 women

The screening percentages are the third lowest in the service area (Table 2.3), yet are not significantly different than the rest of the service area. The screening percentage for Boone County is 67.1 percent for women between the ages of 50 and 74. Further assessment will provide a clearer understanding of the screening percentage and insight as to why the county is not likely to meet either of the HP2020 objectives.

Rush County:

Rush County, whose largest city is Rushville, is primarily a rural community with 98.1 percent of the population being White (Table 2.4). The female population is 8,882 with 53.1 percent over the age of 40 (Table 2.4). The population in Rush County consists of 14.7 percent having less than a high school education, and 36.3 percent of the population between the ages 40 and 64 have an income that is less than 250 percent of the federal poverty level (Table 2.5). This is higher than the national, state and Affiliate service area averages. In Rush County, 15.8 percent of the population is living without health insurance, which is slightly lower than the national average, comparable to the state average and higher than the Affiliate service area average (Table 2.5). Rush County also has a high poverty level of 36.3 percent, compared to 33.3 percent for the United States and 32.9 percent for Indiana (Table 2.5). Rush County has a higher than average population of women over the age of 65, with a percentage of 17.8 percent, compared to 14.8 percent in both the United States and Indiana (Table 2.4).

Rush County was selected as a priority area because the predicted time to meet the HP2020 target for late-stage incidence rate is 13 years or longer (Table 2.7). The target to meet the female breast cancer death rate is 20.6 per 100,000. Rush County is at 27.7 per 100,000 (Tables 2.1 and 2.7). The predicted time to achieve the death rate target could not be suppressed as a result of small numbers. The HP2020 target for late-stage incidence rate is 41.0 per 100,000; Rush County is at 42.5 per 100,000 and is expected to take 13 years or longer to meet the target (Tables 2.1 and 2.7).

The incidence rates in Rush County are the fifth lowest in the Affiliate service area and lower than the national and state averages (Table 2.9). Alarmingly, the death rate is higher than the national, state, and Affiliate service area averages and is the second highest in the Affiliate service area. The late-stage incidence rate is higher than the national, state and Affiliate service area averages and appears to be increasing.

Table 2.9. Rush County breast cancer statistics

	Rush County	United States	Indiana	Komen Central IN Service Area
Incidence Rate*	94.4	122.1	117.4	119.2
Death Rate*	27.7	22.6	23.9	23.8
Late-Stage Incidence Rate*	42.5	43.8	41.1	40.0

*rates are age-adjusted per 100,000 women

The screening percentages for Rush County are of the sixth highest in the service area with 76.8 percent of the female population between the ages 50 and 74 reported having a mammogram in the last two years (Table 2.3). This is intriguing when compared to the death and late-stage rates being much higher than the national and state averages. Further assessment will help Komen Central Indiana understand why Rush County is not likely to meet the HP2020 objectives. Komen Central Indiana is also interested in understanding why the screening percentages are one of the highest within the service area, the incidence rate is lower, yet the death and late-stage diagnosis rates are higher.

Shelby County:
Shelby County, whose largest city is Shelbyville, is primarily rural with 97.5 percent of the population being White (Table 2.4). The female population is 8,882, with 52.0 percent over the age of 40 (Table 2.4). The population of Shelby County consists of 14.2 percent having less than a high school education, and 31.2 percent of the population between the ages of 40 and 64 have an income that is less than 250 percent of the federal poverty level (Table 2.5). This is higher than the national, state and Affiliate service area averages. In Shelby County, 15.5 percent of the population is living without health insurance, which is slightly lower than the national average, comparable to the state average, and higher than the Affiliate service area average (Table 2.5). Shelby County has a population of females over the age of 65 at 16.0 percent, which is higher than the national, state and Affiliate averages (Table 2.4).

Shelby County was selected as a priority area because the predicted time to meet the HP2020 late-stage incidence rate target is 13 years or longer, and the predicted time to achieve the death rate target is eight years (Tables 2.1 and 2.7). The target to meet the female breast cancer death rate is 20.6 per 100,000 and Shelby County is at 23.6 (Table 2.1). The target for late-stage incidence rate is 41.0 per 100,000. Shelby is at 45.6 and is expected to take 13 years or longer to meet the target (Tables 2.1 and 2.7). The trends for the late-stage incidence rate are 10.8 per 100,000, which indicates that the rates may be increasing (Table 2.1).

The incidence rates in Shelby County are slightly lower than the national, state and Affiliate averages (Table 2.10). The late-stage rate is slightly higher than the national average and higher than the state and Affiliate service area averages. Surprisingly, Shelby County is among the three highest late-stage incidence rates in the Affiliate service area.

Table 2.10. Shelby County breast cancer statistics

	Shelby County	United States	Indiana	Komen Central IN Service Area
Incidence Rate*	115.6	122.1	117.4	119.2
Death Rate*	23.6	22.6	23.9	23.8
Late-Stage Incidence Rate*	45.6	43.8	41.1	40.0

*rates are age-adjusted per 100,000 women

The screening percentages for Shelby County are the fourth lowest in the service area with 67.9 percent of the female population between the ages of 50 and 74 reported having a mammogram in the last two years (Table 2.3). When comparing this to the late-stage rate, which is higher than the national and state averages, it is intriguing. A deeper analysis will help Komen Central Indiana understand why the late-stage diagnosis rate is higher and what barriers are preventing women from obtaining screening mammograms.

Marion County:
Marion County, whose largest city is Indianapolis, is the largest county in the state of Indiana and the Affiliate service area in terms of population. Marion County has the highest percentage of Black/African-American women and the largest population of Hispanic/Latina and Black/African American women (in real numbers) in the Affiliate service area (Table 2.4). In Marion County, 29.3 percent of the population is Black/African-American, which is higher than the national average at 14.1 percent and the Indiana average at 10.2 percent. The population of Hispanics/Latinas in Marion County is at 8.6 percent which is lower than the national average at 16.2 percent but higher than the Indiana average of 5.8 percent (Table 2.4).

Marion County's female population is 461,040 with 43.7 percent being over the age of 40 (Table 2.3). The population in Marion County consists of 15.8 percent having less than a high school education (Table 2.5). Those with income below 250 percent of the federal poverty level account for 39.3 percent of the population (Table 2.5). Marion County residents living without health insurance comprise 17.9 percent of the population (Table 2.5). The rates for those living below the federal poverty level and without health insurance are higher than the national, state and Affiliate service area averages. Marion County also has a higher percentage of foreign-born individuals at 8.2 percent, which is lower than the national average of 12.8 percent but higher than the state average of 4.5 percent and the Affiliate service area average of 8.9 percent (Table 2.5).

Marion County was selected as a priority area because the predicted time to meet the HP2020 death rate target is 13 years or longer (Tables 2.1 and 2.7). The target to meet the female breast cancer death rate is 20.6 per 100,000 and Marion County is at 26.1 per 100,000 (Tables 2.1 and 2.7). Marion County was also selected due to its high percentage of minorities and the higher percentage of those living in poverty and without health insurance. According to Hunt et al., Marion County also ranked 10 of the 50 largest cities where non-Hispanic Black/African-American women face disparity in breast cancer deaths.

The incidence rates in Marion County are comparable to the national average and slightly higher than the state and Affiliate service area averages (Table 2.11). Marion County has the fourth highest death rate within the Affiliate service area, which is higher than the national and

state rates. Additionally, the county's late-stage incidence rate is the fourth highest within the Affiliate service area and higher than the state and Affiliate averages, but comparable to the national rate.

Table 2.11. Marion County breast cancer statistics

	Marion County	United States	Indiana	Komen Central IN Service Area
Incidence Rate*	122.1	122.1	117.4	119.2
Death Rate*	26.1	22.6	23.9	23.8
Late-Stage Incidence Rate*	43.2	43.8	41.1	40.0

*rates are age-adjusted per 100,000 women

In Marion County, 75.4 percent of the female population between the ages 50 and 74, reported having a mammogram in the last two years (Table 2.3). This is slightly lower than the United States percentage of 77.5 percent, higher than the percentage of 69.5 percent for Indiana, and higher than the percentage of 73.8 percent of the Affiliate service area. This is intriguing when comparing to the death rate, which is higher than the national and state averages. The primary focus will be to gain a better understanding of why the death rate is higher than the national and state averages. Studying Marion County will also offer insight to the barriers Black/African-American women face as they navigate the health care system.

Clinton County:

Clinton County, whose largest city is Frankfort, is primarily rural and stands out because of its large Hispanic/Latina population. The percentage of Hispanics/Latinas is 12.6 percent, which is higher than the Indiana average of 5.8 percent and the Affiliate service area average of 5.3 percent (Table 2.4). Furthermore, Clinton County has the highest percentage of Hispanics/Latinas among all Affiliate service area counties (Table 2.12). The female population is 16,842 with 48.8 percent over the age of 40 (Table 2.4). The population in Clinton County consists of 17.7 percent having less than a high school education, which is the highest within the service area (Table 2.5). In Clinton County, 36.2 percent of the population between the ages of 40 and 64 has an income less than 250 percent of the federal poverty level. Clinton County has the highest percentage of the population living without health insurance in the service area at 18.1 percent (Table 2.5). This is higher than the national, state and Affiliate service area percentages.

Table 2.12. Clinton County population statistics

	Clinton County	United States	Indiana	Komen Central IN Service Area
White	98.6%	78.8%	87.4%	83.8%
Black/African-American	0.7%	14.1%	10.2%	13.2%
Hispanic/Latina	12.6%	16.2%	5.8%	5.3%

Clinton County was selected as a target community because of its Hispanic/Latina population, which is the highest in the service area. Clinton County was also selected because of the percentage of the population with less than a high school education and the percentage of the population living without health insurance (Table 2.5). Furthermore, 3.2 percent of the

population of Clinton County is linguistically isolated, which is among the four highest in the service area (Table 2.5). However, Clinton County currently meets the Healthy People 2020 goals.

The screening percentages for Clinton County are the lowest in the service area at 54.7 percent which is lower than the National average of 77.5 percent, the state average of 69.5 percent and the Affiliate service area at 54.7 percent (Table 2.3). This is interesting to the team, and one of the reasons Clinton County was chosen for further exploration. Further analysis will help Komen Central Indiana understand the barriers individuals are facing as they obtain screening mammograms and why the screening percentage appears to be low in this county.

Health Systems Analysis Data Sources

Several resources were used to identify health care facilities that provide breast health services including clinical breast exams, screening mammograms, diagnostic screenings, treatment, financial assistance and patient navigation. The following resources enabled the team to have a comprehensive understanding of the programs and services that exist in priority areas:

- Mammography centers
- Federally qualified health centers (FQHCs)
- Hospitals
- Local health departments
- Free clinics
- American College of Surgeons Commission on Cancer
- American College of Radiology Centers of Excellence
- American College of Surgeons National Accreditation Program for Breast Centers (NAPBC)
- National Cancer Institute Designated Cancer Centers

For a list of the resource websites, please visit the reference page at the conclusion of the Community Profile.

In addition to these resources, the Team also contacted providers within the target communities to provide a clearer understanding of the services that are provided. Komen Central Indiana also worked with the Indiana Breast & Cervical Cancer Program (IN-BCCP) to identify IN-BCCP providers in the priority areas.

Health Systems Overview

The Breast Cancer Continuum of Care (CoC) (Figure 3.1) is a model that shows how a woman typically moves through the health care system for breast care. A woman would ideally move through the CoC quickly and seamlessly, receiving timely, quality care in order to have the best outcomes. Education can play an important role throughout the entire CoC.

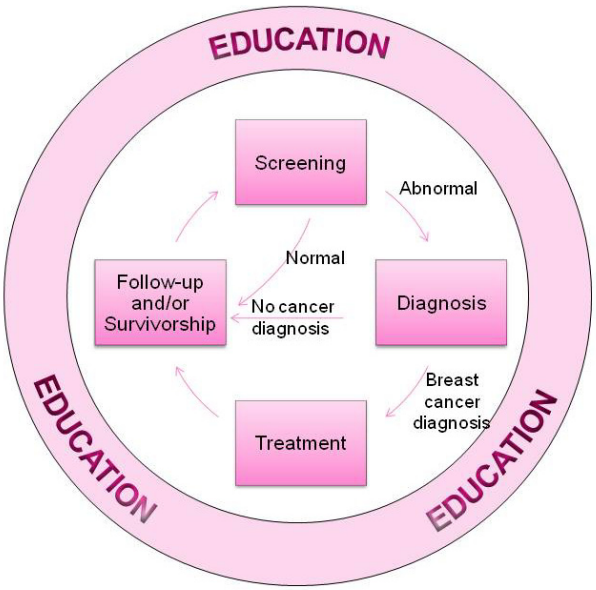

Figure 3.1. Breast Cancer Continuum of Care (CoC)

While a woman may enter the continuum at any point, ideally, a woman would enter the CoC by getting screened for breast cancer with a clinical breast exam or a screening mammogram. If the screening test results are normal, she would loop back into follow-up care, where she would get another screening exam at the recommended

interval. Education plays a role in both encouraging women to get screened and reinforcing the need to continue screening routinely thereafter.

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

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

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

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

Boone County:
Boone County Community Clinic (BCCC) is a state-funded, nurse-managed, independent, 501c(3) Community Health Center (Figure 3.2). The clinic provides access to basic medical services, including clinical breast exams and genetic testing for residents who are under/uninsured and have limited financial resources. BCCC works closely with Witham Medical Imaging services to provide the majority of screening and diagnostic services with financial support from IN-BCCP, the YWCA of Greater Lafayette and Susan G. Komen Central Indiana. These partnerships ensure women who are in need of breast health care have the financial resources to complete the CoC.

Boone County has one hospital, Witham Hospital, located in Lebanon, Indiana. Imaging services include digital mammography, ultrasounds, MRI, ultrasound guided biopsies, traditional wire biopsies and stereotactic needle biopsies. Women diagnosed with breast cancer can receive treatment at the Cancer Institute located at Witham Hospital and in partnership with St. Vincent Hospital. The Cancer Institute provides oncology and radiation oncology. The Hospital has received accreditation from the American College of Radiology Center of Excellence. The Women's Center is a Breast Center of Excellence. Witham Health Services also provides monthly support groups for patients, survivors, family members and friends. Witham Hospice Care is provided to patients who are terminal, and is coordinated with local hospice care providers. Witham Hospital is an IN-BCCP site. The hospital does not employ a patient navigator, so women in need of diagnostic imaging and further screening and treatment must navigate the health system independently.

Potential barriers to care could result from the lack of public transportation available in Boone County. There is no transit system, nor is there a cab service for those individuals who are without reliable transportation. Boone County has remote and rural areas, and Witham Hospital and the Boone County Community Clinic are both situated in the heart of Lebanon making it difficult for individuals to access screenings. An additional barrier could be that there are no late evening or early morning screening options. The latest screening appointment is 6:00 p.m. and the earliest is 7:30 a.m. which can make it difficult for women who are working full time or have limited child care.

While Komen Central Indiana has a strong relationship with BCCC, the relationship with Witham Hospital could be developed to ensure timely care and opportunities for future collaborative initiatives. An enhanced partnership is needed to reduce the death rates and late-stage diagnosis rates and to increase survivorship with a special focus on HP2020 objectives.

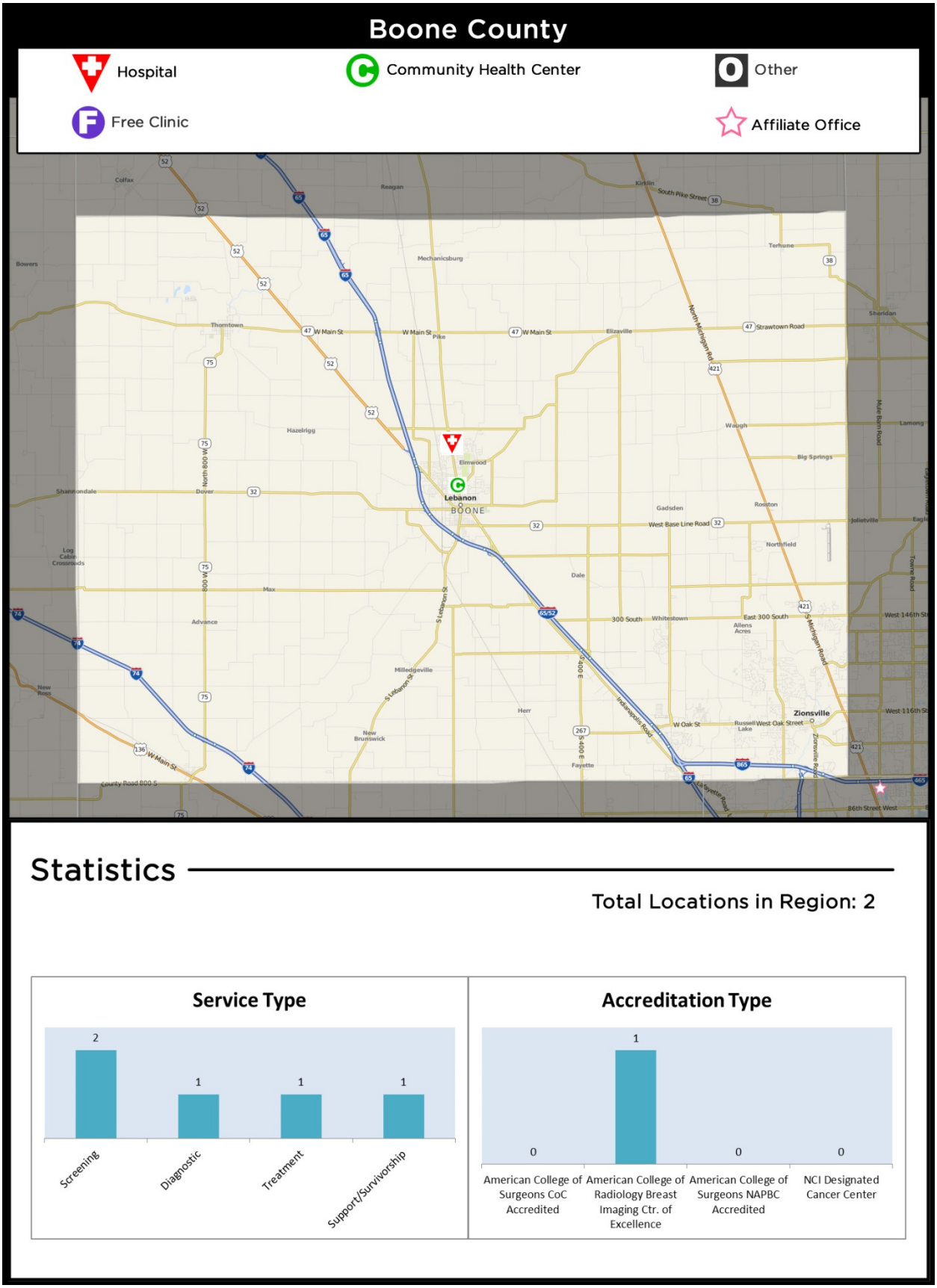

Figure 3.2. Breast cancer services available in Boone County

Rush County:
Rush County has one hospital, Rush Memorial Hospital, located in Rushville, Indiana (Figure 3.3). Rush Memorial Hospital is the only medical provider for low income, under/uninsured women and is a Susan G. Komen Central Indiana grant recipient. The Hospital provides digital mammography, ultrasounds, MRI and breast biopsies. The Sheehan Cancer Center offers surgical oncology, radiology and medical oncology. Through the Komen grant, Rush Memorial Hospital receives funding for breast health services and has a full-time navigator working with women who enter the continuum of care and are under/uninsured to ensure the completion of the CoC. The Rush Memorial Hospital Foundation has a fund called "Brian's Cause," which is a cancer treatment relief fund. The Rush Memorial Hospital Patient Financial Assistance program offers charity care for those individuals who qualify. For individuals who have limited income, are living without insurance or are underinsured, clinical breast exams are provided at a sliding scale at Meridian Health Services.

Rush Memorial Hospital is the only medical provider in Rush County offering comprehensive breast health services. Women who are in need of breast reconstruction are referred to Indianapolis, which is over an hour drive. This can be a serious barrier for women who are interested in completing the CoC into survivorship. There are also no active IN-BCCP providers in Rush County. The only funding available for screening for those without health insurance is through the Komen Central Indiana grant. Grant funding from Komen is never a guarantee, and individuals who are under/uninsured may have difficulty accessing affordable breast screenings should Komen dollars no longer exist within the community. It is important that local providers diversify their funding sources to ensure women within their community who are in need of affordable screenings have assistance.

Future partnerships could be developed with local food pantries to conduct outreach and education regarding the importance of breast self-awareness. In addition to the food pantries, developing a relationship with the Meridian Health Clinic will help to ensure that women enter the continuum of care with clinical breast exams and complete all necessary preventative and diagnostic screening.

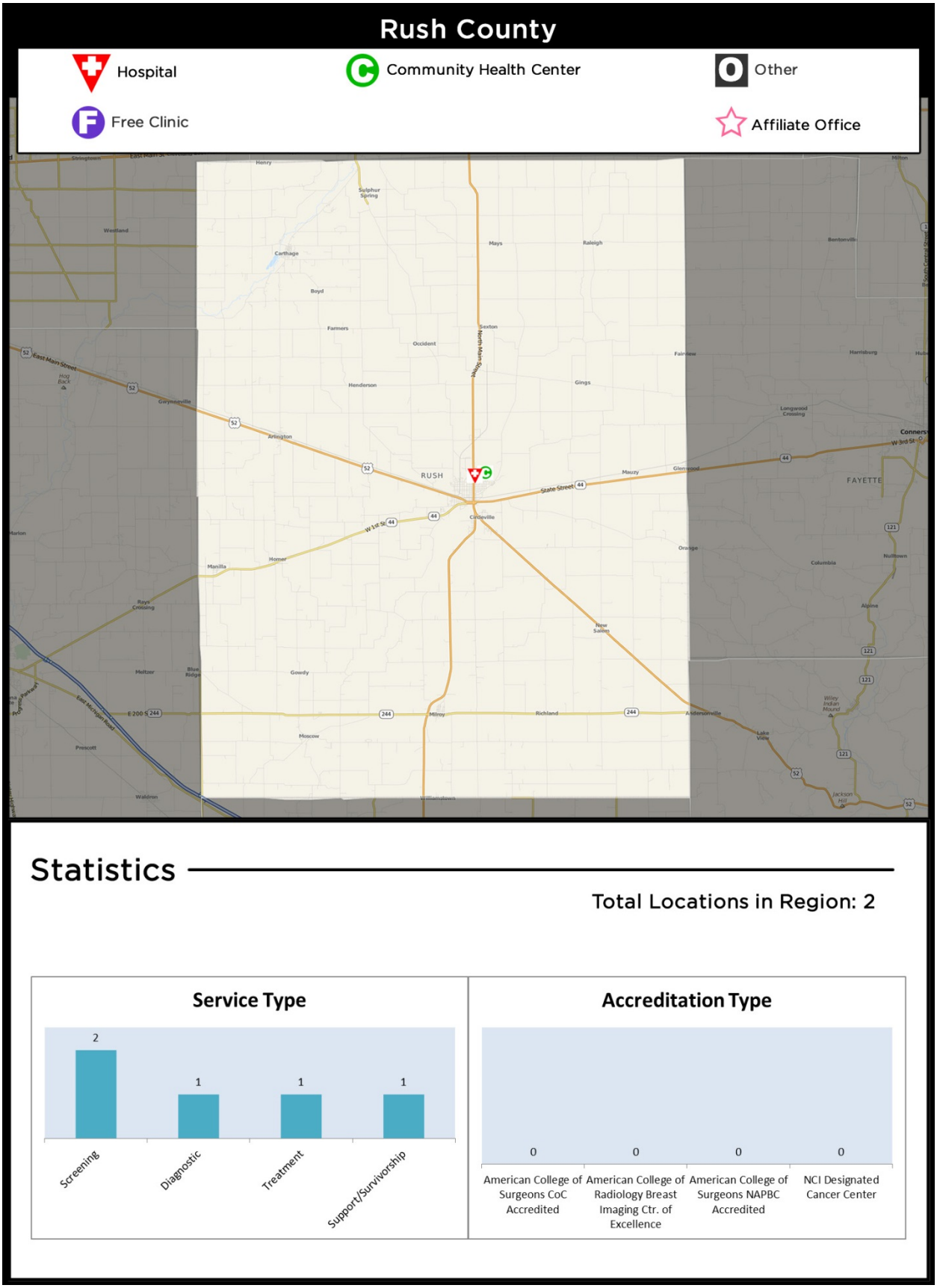

Figure 3.3. Breast cancer services available in Rush County

Shelby County:
Shelby County has one hospital, Major Hospital, located in Shelbyville, Indiana (Figure 3.4). The hospital provides screening and diagnostic digital mammography, as well as MRI, ultrasounds and stereotactic biopsies. Breast surgeries, including mastectomy and lumpectomy, are performed onsite with reconstructive breast procedures. The Beneese Oncology Center, located at Major Hospital, provides treatment. The hospital contracts with Little Red Door, a Komen Central Indiana grantee, and IN-BCCP to pay for breast screenings for women who meet eligibility guidelines.

The Shelby Community Clinic is a free clinic staffed by a women's health nurse practitioner. Free clinical breast exams are provided for any woman who doesn't have health insurance. For women under the age of 40, the clinic works with Little Red Door to fund clinical breast exams.

A deeper exploration will occur through key informant interviews and focus groups to help identify gaps in care and barriers to completion of the CoC. One possible issue is the lack of a dedicated patient navigator responsible for guiding women through breast health screenings at the diagnostic level. Organizations in Shelby County also lack an outreach educator, responsible for raising awareness about the importance of breast health screenings, and how to access affordable and low cost imaging.

Little Red Door, which is located in Indianapolis, is the only current grantee of Komen Central Indiana providing services in Shelby County. Future collaborative opportunities with Shelby Community Clinic and Major Hospital are imperative as Komen Central Indiana continues to explore problems and solutions to increase the survival rate in Shelby County.

Figure 3.4. Breast cancer services available in Shelby County

Marion County:
Marion County has four hospital systems, including Community Health Network, St. Vincent Health, St. Francis Hospital and Indiana University Health. Indiana University Health includes Eskenazi Health, Indiana University Melvin & Bren Simon Cancer Center and Methodist Hospital (Figure 3.5). All of the health systems provide mammography screening, diagnostic imaging, breast biopsies, breast surgery, radiation, chemotherapy, hospice and survivor support. The health institutions provide patient navigation at the point of diagnostic services, with the exception of Eskenazi Health, which begins navigation at screening mammograms for all patients referred from the Eskenazi Health clinics. Indiana University Health and Methodist Hospital have received accreditation from the American College of Surgeons CoC and American College of Radiology Breast Imaging Center of Excellence. Community Health Network has received accreditation from the American College of Surgeons CoC and American College of Surgeons NAPBC. St. Francis and St. Vincent Hospitals have received accreditation from American College of Surgeons CoC, American College of Radiology Breast Imaging Center of Excellence and the American College of Surgeons NAPBC. Eskenazi Health has received accreditation from the American College of Radiology Breast Imaging Center of Excellence. There are also several stand-alone imaging centers that provide mammography and diagnostic screening.

There are 21 community health centers and four free health clinics in Marion County. These organizations provide health care regardless of the patient's ability to pay, but are restricted to those who are under/uninsured and have limited or no access to primary health care.

There are many options for women to access breast screenings in Marion County, but the systems are all quite large, which can be daunting for individuals who have no primary health care provider or health insurance. Komen Central Indiana has strong collaborative relationships with health care providers and clinics within Marion County. Komen Central Indiana works closely with the Indiana University Health and Community Health Network hospital systems. Komen Central Indiana maintains working relationships with providers in all of the hospital systems. Komen Central Indiana grantees offering services in Marion County include Gennesaret Free Clinic, the Eskenazi Health Embrace Program and Little Red Door Cancer Agency.

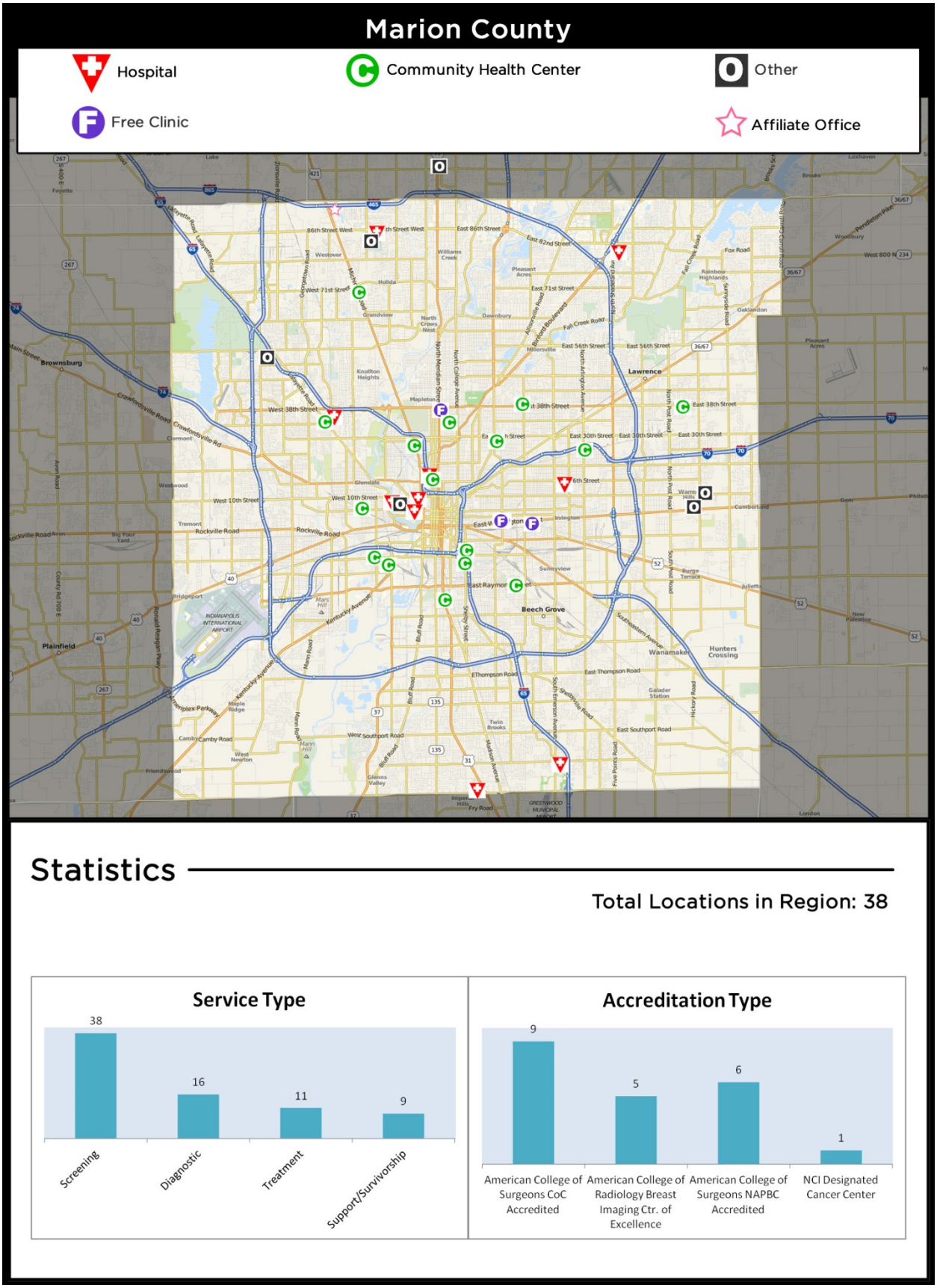

Figure 3.5. Breast cancer services available in Marion County

Clinton County:
Clinton County has one hospital, St. Vincent Frankfort, located in Frankfort, Indiana (Figure 3.6). The hospital provides screening and diagnostic mammograms. St. Vincent Frankfort is an IN-BCCP provider, along with Open Door Health Clinic, which provides clinical breast exams. Arnett Clinic, also located in Frankfort, provides clinical breast exams for individuals who do not have the ability to pay or are underinsured. The hospital does not provide onsite chemotherapy or radiation, and the only biopsies provided are ultrasound guided biopsies. Any patient who needs stereotactic, surgical or vacuum-assisted biopsies or is in need of treatment must travel 30 to 45 minutes to the nearest hospital. This can be a barrier for individuals who are living in poverty. The wait time for a clinical breast exam is several weeks, delaying access into the health CoC.

Komen Central Indiana does not currently have relationships with St. Vincent Frankfort Hospital, Open Door Health Clinic or Arnett Clinic and must explore partnerships with these health systems to ensure timely care is obtained for screening, treatment and access to the CoC.

The Purdue Extension, which provides education to Hispanic/Latina women regarding breast health, is a Komen Central Indiana grantee. The Extension office partners with the YWCA of Greater Lafayette, another Komen Central Indiana grantee, to provide screening mammograms, diagnostic services and patient navigation, as some in this population may be undocumented and not eligible for IN-BCCP.

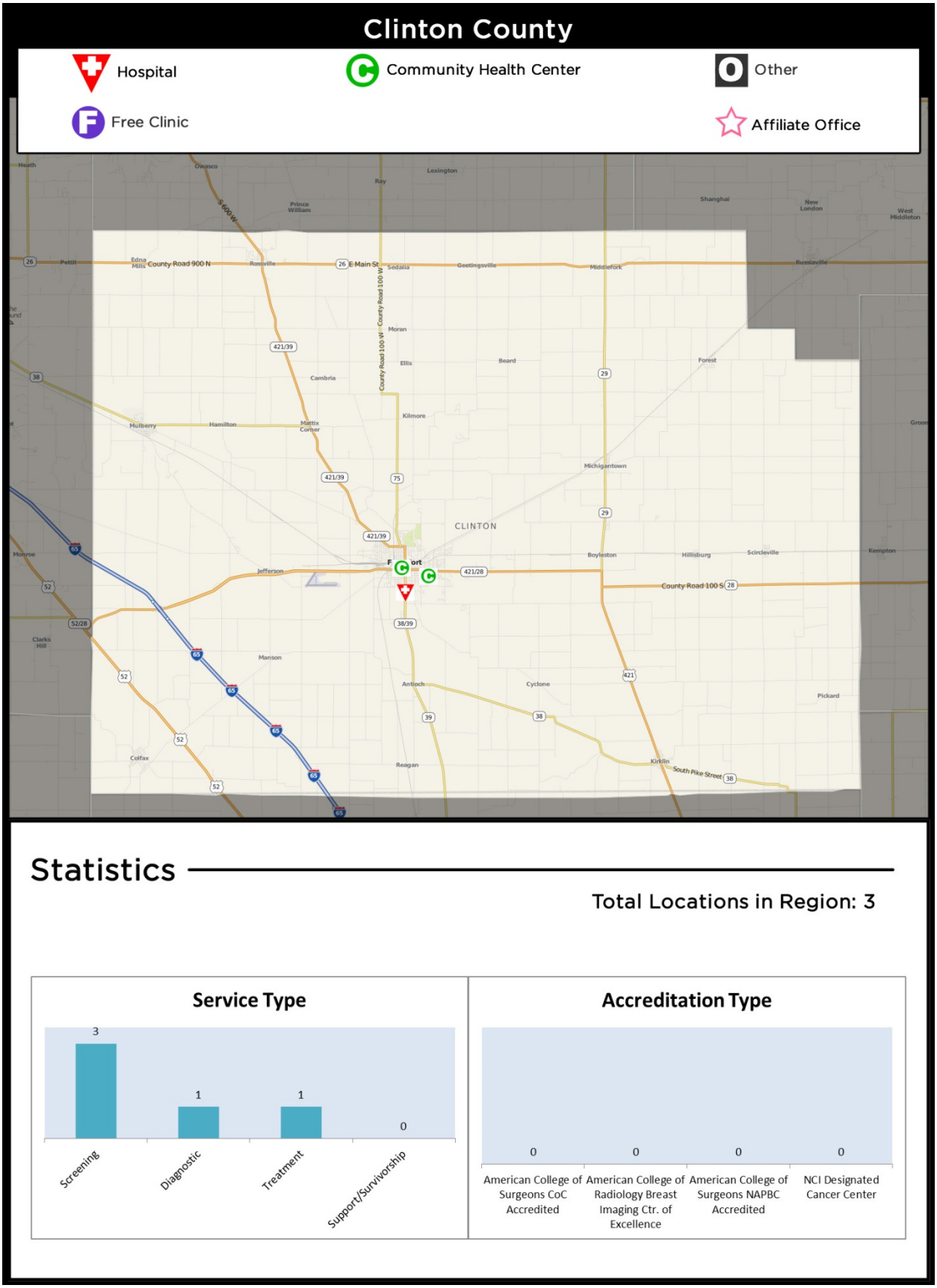

Figure 3.6. Breast cancer services available in Clinton County

Public Policy Overview

National Breast & Cervical Cancer Early Detection Program (NBCCEDP)

The Indiana Breast and Cervical Cancer Program (IN-BCCP) is funded through the Centers for Disease Control (CDC) and state funding. The IN-BCCP provides access to breast and cervical cancer screening and diagnostic services to women between the ages of 40 and 64 with no creditable insurance, who fall at 200 percent of the federal poverty level or below. Women are recruited through regional coordinators or enrolled at the offices of providers who participate in the program. Women are tracked via a data management system, and providers are reimbursed at Medicare rates. Women are matched with a case manager if an abnormal result is found to ensure timely and appropriate follow up and diagnosis. If women are diagnosed with breast or cervical cancer, they are enrolled into Medicaid and receive full coverage for the duration of treatment. Individuals who are diagnosed with triple negative breast cancer are restricted from the Medicaid treatment program as soon as they have completed radiation. This is an issue, as many with triple negative breast cancer face reoccurrence and need to be followed closely by an oncologist.

IN-BCCP patient navigators transition women enrolled in IN-BCCP into the Medicaid Treatment Program if diagnosed with breast or cervical cancer. The Indiana State Department of Health (ISDH) supports a full-time position to coordinate the Option 3 Treatment Program application process with the Medicaid Office for women diagnosed with breast or cervical cancer outside of the IN-BCCP.

IN-BCCP has a Memorandum of Understanding with the Family and Social Services Administration (FSSA), including the Office of Medicaid Policy and Planning and the Division of Family Resources, to implement the provisions of the Breast and Cervical Cancer Prevention and Treatment Act of 2000, Public Law 106-354, to ensure eligible women diagnosed with breast or cervical cancer through IN-BCCP or by another provider receive Medicaid to cover treatment. ISDH ensures that women meet the eligibility requirements, and FSSA provides final eligibility determination and coverage.

Recently, the ISDH Cancer Early Detection Section was awarded funds through the National Association of Chronic Disease Directors (NACDD) to partner with the Office of Medicaid Policy and Planning (OMPP) to plan collaborative approaches to cancer screening through aggressive outreach to targeted, high-burden populations. Roadmaps have been developed to:

- increase cancer screening among never or rarely screened populations;
- sustain appropriate cancer screening and follow-up for current Indiana Breast and Cervical Cancer Program (IN-BCCP) enrollees transitioning into Medicaid; and
- enhance or combine existing data systems to support population-based education, outreach, screening registries, diagnosis and follow up.

Susan G. Komen Central Indiana has a collaborative working relationship with IN-BCCP. The Director of IN-BCCP and the former Komen Central Indiana Grants and Outreach Manager served together as Co-Chairs of the Indiana Cancer Consortium (ICC) Breast & Cervical Cancer Committee. Under their leadership, this Committee developed a provider flow chart to ensure that limited funds are used appropriately and a state map highlighting the providers for IN-BCCP, the Indiana Breast Cancer Awareness Trust, Susan G. Komen grantees in Indiana and federally qualified health clinics. The two organizations have also partnered in developing

webinars for providers, nurse practitioners and patient navigators and collaborated on presentations and programs to measure outcomes and increased survivorship.

Susan G. Komen Central Indiana will continue to partner with IN-BCCP, focusing on increasing access to care and reducing deaths from breast cancer.

State Comprehensive Cancer Control Coalition

Komen Central Indiana has a collaborative relationship with the Indiana Cancer Consortium (ICC). A representative from Komen Central Indiana was a subject matter expert in developing the breast cancer objectives for the 2010-2015 Indiana Cancer Control Plan. Susan G. Komen Central Indiana received the 2013 ICC Outstanding Contributions to Cancer Control Organization Award. A representative from Komen Central Indiana authored and served as a subject matter expert for the 2015 Indiana Cancer Facts & Figures breast cancer section.

This collaborative relationship will continue to focus on the Cancer Control Plan's breast cancer and early detection objectives. ICC has developed a provider flow chart and asset map, which identifies Komen Grantees, IN-BCCP providers, Indiana Breast Cancer Awareness Trust grantees and Affordable Care Act navigators, clearly identifying free or reduced-cost breast screenings. In addition to the asset map, the Employer Gold Standard will provide accreditation to employers that implement best practice policies, encouraging employees to obtain breast health screenings.

Komen Central Indiana supports the collaborative nature and systematic approach of the ICC and intends to continue partnering with the group.

Affordable Care Act (ACA) and Healthy Indiana Program 2.0 (HIP 2.0)

The ACA has the potential to provide health care coverage for uninsured Hoosiers, potentially reaching over 800,000 individuals, who were living without insurance prior to the rollout. Indiana is currently operating a federal health exchange model. There are 229,815 individuals who are eligible to enroll in a marketplace plan and 155,961 who can receive financial assistance to enroll in a marketplace plan. As of April, 2014 132,423 Indiana residents had enrolled in marketplace coverage.

The expansion of Medicaid was included as an option for each state in the 2011 Affordable Care Act, and this option was intended to provide health care coverage to individuals who fall in the gap between receiving ACA subsidies and those eligible for traditional Medicaid. While individuals earning above 138% federal poverty level may receive financial assistance in the form of subsidies for marketplace coverage through the Affordable Care Act, individuals this income threshold are not entitled to subsidies. Prior to Medicaid expansion in Indiana, adults ages 19-64 who earn 138% of the federal poverty level or less and did not qualify for Medicaid fell into a coverage gap.

Beginning in 2008 Indiana used the Section 1115 Medicaid Demonstration Waiver to expand Medicaid coverage to some adults in the state. The Healthy Indiana Plan (HIP) expanded coverage to parents with dependent children with incomes above the state's eligibility limit for full Medicaid coverage (22% of the federal poverty level) and below 200% of the federal poverty level, and other adults with incomes between 0% and 200% of the federal poverty level. There was no enrollment cap for parents, but other childless adults were subject to an enrollment cap

of 34,000. At the end of 2008, 37,568 adults were enrolled in HIP, and prior to expansion of the HIP in December 2014, 52,400 were enrolled.

In January 2015, the Indiana Executive Branch in Indiana and the Centers for Medicare and Medicaid Services reached an agreement to expand Medicaid coverage in Indiana by expanding and further developing HIP. HIP 2.0 was developed from the existing Medicaid Waver program, and expands eligibility to residents 19 to 64 years old who are earning up to 138% of the federal poverty level. The state estimates 350,000 potential beneficiaries in the first year, including approximately 182,000 who would have fallen in into the coverage gap. As of July, 2015 approximately 279,000 people had enrolled in HIP 2.0.

Differing from traditional Medicaid, HIP 2.0 is a consumer-driven model, which resembles that of a health savings account and requires participants to make financial contributions into their POWER accounts. POWER account contributions are based on a sliding scale fee, reflecting two percent of household income, and will be used to pay deductible expenses. Employers will be allowed to contribute up to 50 percent of a participant's required POWER account contribution. Mammograms and preventative screenings are covered by the plan up to $500.00.

The Indiana State Department of Health hired a consultant to assess the impact of ACA and HIP 2.0 on IN-BCCP, as well as any other program that provides direct services. While IN-BCCP eligibility, which currently serves women ages 40 to 64, under or uninsured and at or below 200 percent of the federal poverty level, has not changed, new eligibility guidelines are being developed in response to the impact of HIP 2.0.

For many in the coverage gap, accessibility to preventative screenings, diagnostic services and treatment is unattainable without the assistance from Komen Central Indiana, IN-BCCP and other foundations. Komen Central Indiana remains focused on removing the barriers which stop women from entering into and completing the CoC. Komen Central Indiana is acutely aware of the fact that, while individuals may purchase health care through the ACA marketplace or enroll in HIP 2.0, new barriers might emerge, ranging from providers not accepting the health plan to diagnostic screenings not being covered until very high premiums and out–of-pocket costs are met. Komen Central Indiana will actively educate collaborative partners, grantees and community members regarding the limitations and barriers newly insured individuals will face. Komen Central Indiana will monitor the ever changing health care landscape, and will amend funding priorities as needed over time to ensure all women have access to timely and quality breast health care. Komen Central Indiana will encourage its grantees to remain up-to-date on knowledge regarding the ACA and to be flexible in providing assistance to individuals in need of assistance.

Providers are finding that the ACA gives back their power in treating patients, rather than the insurance deciding what treatments are appropriate and reimbursable. The ACA encourages preventative screenings and also recognizes the current shortage of doctors and nurses by providing incentives.

Public Policy Activities

Susan G. Komen announced the following Advocacy Priorities in 2014, and this is the platform Komen Central Indiana has been presenting when working with policymakers:

- Protecting federal and state funding for the National Breast and Cervical Cancer Early Detection Program (NBCCEDP), to ensure all women have access to potentially lifesaving breast cancer screening
- Ensuring continued federal investment in cancer research through the National Institutes of Health (NIH),National Cancer Institute (NCI) and Department of Defense (DOD), to discover and deliver the cures
- Requiring insurance companies provide coverage for oral anti-cancer drugs on a basis that is no less favorable than what's already provided for intravenously-administered chemotherapy, to protect patients from high out of pocket costs; and
- Expanding Medicaid coverage to ensure the availability of the full-range of breast health services to low-income women, including cancer screening, diagnostics and treatment.

Komen Central Indiana has met with representatives from local government, including state representatives, and members of Congress to encourage them to support these priorities. Komen Central Indiana will continue to support these initiatives and will partner with local officials to ensure the success of the priorities.

Komen Central Indiana will partner with the ICC to encourage health systems to develop a system which automatically orders mammography screening reminders within primary care settings. With the ICC, Komen Central Indiana will advocate for a policy change that would require providers to report on dates between screening to diagnostic to diagnosis and ultimately treatment. Komen Central Indiana will meet with the Senator who originally authored the MA-12 treatment bill to encourage an amendment to the current language to allow women who have been diagnosed with triple negative breast cancer to remain enrolled in Medicaid until a physician determines treatment is completed. The law currently states that survivors are to remain on Medicaid until all treatment is completed. This excludes triple negative women as treatment is considered "complete", upon finishing radiation.

Health Systems and Public Policy Analysis Findings

The Health Systems Analysis highlights several needs in target communities related to health systems and the CoC. First, patient navigation is imperative to the completion of the CoC in Boone and Shelby Counties. Having a dedicated individual working with low income/under/uninsured women within the health system will ensure women who enter the CoC, complete all necessary screenings. Second, despite other available resources, a current grant from Komen Central Indiana provides the only coverage for health services to under/uninsured women in Rush County. Third, in Marion County women have multiple options for care but can easily fall out of the CoC resulting from the presence of many different health institutions and the absence of a single provider monitoring care. Komen Central Indiana will focus on solutions to ensure monitored care and timely treatment. Furthermore, Komen Central Indiana will identify reasons Black/African-American women are facing a disparity in death rate compared to White women and work collaboratively to identify solutions and decrease disparities. Finally, as it stands, women in need of treatment in Clinton County must travel to a nearby county, which can be a barrier for those with limited incomes and/or without reliable

transportation. It is a priority to ensure that women living in Clinton County receive timely and accessible treatment.

While Komen Central Indiana partnerships are strong in communities with existing Komen Central Indiana grantees and in Marion County where the Komen Central Indiana office is located, relationships in the smaller, rural counties need to be strengthened. The analysis highlights the need to have a stronger presence and collaborative relationships with partners in Boone, Shelby and Clinton Counties to ensure women are completing the CoC. Specifically, Komen Central Indiana will seek to build a relationship with Witham Hospital in Boone County. Komen Central Indiana will continue to partner with Rush Memorial Hospital in Rush County to ensure that women access timely screenings and breast cancer care and are aware of the importance of early detection and financial resources. Komen Central Indiana will explore partnerships with Shelby Community Clinic and Major Hospital in Shelby County. In Marion County, Komen Central Indiana will work to maintain existing partnerships and to build new relationships. Developing collaborative partnerships with the hospital systems and the free health clinic in Clinton County will deepen Komen Central Indiana's understanding of gaps in care and will enable Komen Central Indiana to support or partner on interventions to further efficient and timely completion of the CoC.

Komen Central Indiana must also stay informed of the ever-changing health care environment following rollout of the ACA and HIP 2.0. Komen Central Indiana will represent the voice of those served by Komen's mission to ensure adequate, timely and affordable health care. While the ACA and HIP 2.0 may increase availability to screening and care, Komen Central Indiana will stay vigilant of other issues, like provider shortage and new barriers as a result of high-deductible insurance plans. This will be accomplished through continued partnerships with ICC, IN-BCCP, grantees, community partners, navigators and communications with federal and state representatives.

Qualitative Data: Ensuring Community Input

Qualitative Data Sources and Methodology Overview

Note: Qualitative data collection and analysis predate approval of the Healthy Indiana Plan 2.0.

To further study the breast health and breast cancer issues highlighted by the quantitative data, Susan G. Komen® Central Indiana conducted a qualitative data assessment. Equally important to the quantitative data, this exploration into the observations and opinions of health care providers and lay community members helped the Community Profile Team to more deeply understand the needs of the communities it serves.

Following completion of thorough quantitative data analysis, Komen Central Indiana selected five priority counties for qualitative data collection and review: Boone, Rush, Shelby, Marion and Clinton Counties. Variables, including breast cancer screening, occurrence, diagnosis, treatment, the completion of the Breast Cancer Continuum of Care (CoC) and the presence of specific vulnerable populations in these counties, guided the selection of the target communities and the key assessment questions for the analysis.

Because quantitative data revealed that the Affiliate service area has a significantly lower breast cancer screening percentage than that observed in the United States as a whole, the Community Profile Team identified **access and utilization of screening services** as key topics for its qualitative studies. Key assessment questions related to these two variables were intended to help Komen Central Indiana pinpoint the **barriers to breast health services** (both system-level and individual), as well as **facilitators for obtaining breast health services** – ultimately revealing observations that could improve Komen Central Indiana's ability to increase the number of women seeking preventive care, diagnostic and treatment services.

In addition, Komen Central Indiana identified the **quality and quantity of its relationships with local partners serving women in priority areas** as a key variable impacting women's ability to complete the CoC, with a particular need for bolstering these relationships in Boone, Rush, Shelby and Clinton Counties. Key assessment questions related to this aim were intended to guide Komen Central Indiana as to how to most effectively build a stronger presence and greater collaborative partnerships outside its home base of Marion County.

Komen Central Indiana also sought to better understand its service area's **especially vulnerable populations** through this analysis by targeting high priority populations in two of the five target areas.

Komen Central Indiana used (1) key informant interviews and (2) focus groups to collect qualitative data from its five target communities. In addition, surveys were used as a tactical response to overcome limitations of focus group data in Marion County. The Community Profile Team, which included staff members of Komen Central Indiana, a professor from Butler University, a local cancer policy and research director, a local cancer prevention and evaluation specialist, as well as a Butler University student, led key informant interviews, moderated the patient/consumer focus groups and developed the survey.

The selected collection methods were intended to encompass a broad range of community perspectives, from those who work in women's health to those who make up central Indiana's underserved populations.

Qualitative, in-depth key informant interviews with women's health professionals in each target area were chosen as a data collection method for the ability to deliver critical insight from the viewpoint of health care providers and nonprofit professionals with an interest in breast health. Key informants provided valuable observations, not just from their own perspectives, but also from the perspectives of the women they serve. Key informant interviews were executed through a script created by the Community Profile Team and encompassed questions relating to the identified key variables. The interviews were intended to evoke thoughtful, critical information from those most capable of identifying barriers to breast health and breast cancer services in central Indiana.

The Community Profile Team selected focus groups as a complementary method of qualitative data collection in order to elicit critical information from the other side of the care equation, i.e. the consumer/lay community member. Focus groups were designed to provide qualitative assessment through analysis of the target populations' perceptions, opinions, beliefs and attitudes towards breast health and breast cancer.

Drafted with the viewpoint of health care providers, administrators or those who deliver support services in mind, the Community Profile Team developed a script for key informant interviews. Every key informant interviewer used the written script ("interview guide") to guide their conversation with interviewees. Each interview assessed the key informant's:

- Length of involvement in the breast cancer field;
- Observations as to changes in breast cancer occurrence, diagnosis or treatment in their community;
- Reasoning for working in their locale;
- Thoughts as to why their community is experiencing low screening percentages and/or higher late-state diagnosis or death rates;
- Perceived obstacles that slow down the progress made between screening, diagnostic services and treatment for women in their community;
- Thoughts on why women in their service area do not follow recommended screening guidelines;
- Insight as to why women do not use available screening facilities;
- Insight as to community members' feelings toward the health care system;
- Observations as to specific populations that seem left out of screening and diagnosis in their community;
- Opinion as to what factors impact the affordability of care in their community/county (including the impact of insurance);
- Opinion as to what factors impact access to care in their community/county;
- Observations as to particular populations who have poorer survival and why;
- Observations as to language being a barrier to care;
- Observations as to physician insensitivity and its impact on care; and
- Observations as to gaps in resources within the Continuum of Care in their community/county.

All interviews were recorded and transcribed verbatim. The transcripts were then analyzed and coded by members of the Community Profile Team.

Similarly, the Community Profile Team developed a script to lead the focus groups into a meaningful discussion about breast health and breast cancer. A Community Profile Team member acted as a moderator in each of the focus groups, utilizing the prepared script ("focus group moderator's guide") to evoke participants' perceptions, opinions, beliefs, and attitudes as to:

- The most important health problems for women in their community;
- The meaning of breast cancer;
- The rank of breast cancer as a daily concern in their lives;
- The availability and convenience of breast health services in their community;
- The cultural barriers to seeking breast health services;
- Changes that could be made in their community to ensure breast health messaging and services get to those who need them;
- Where women in their community get health information and where they can get credible health information;
- What motivates women to seek screening services and annual screening services thereafter;
- What hinders women from seeking screening services;
- Barriers within their community that prevent women from seeking or receiving screening services;
- The role of their support network in influencing them to seek breast health screenings;
- Experiences related to barriers to follow-up care following an abnormal mammogram result;
- The advantages and disadvantages of getting a mammogram;
- Whether providers are respected and valued in their community; and
- The trustworthiness of the health care system and physicians.

All focus group discussions were recorded and transcribed verbatim. The transcripts were then analyzed and coded by members of the Community Profile Team.

The use of multiple data sources and collection methods allowed for a systematic review that revealed patterns and conclusions that can assist Komen Central Indiana in better serving the women of central Indiana. The data collection methods were not only meant to propel such triangulation of the various types of qualitative data itself, but also to support triangulation of the Quantitative Data Report, Health System and Public Policy Analysis and Qualitative Data Report collectively. It is only by bringing all of this data together that Komen Central Indiana can determine the gaps to access, utilization and quality of care in its service area.

Specifically, verbatim transcripts from key informant interviews and focus groups, as well as responses to written surveys, allowed the Community Profile Team to code the data and extract recurrent or related themes.

In an effort to understand barriers to access, screening, diagnosis and treatment, the Community Profile Team selected health care providers, as well as public health and nonprofit professionals, as key informant data sources because these community experts have first-hand

knowledge of the communities they serve and the problems they face. These key informants were recruited through Komen Central Indiana's relationships with hospitals, health clinics, state/county departments of health and community-based organizations. Key informants included individuals representing both Komen Central Indiana grant recipients and non-grantees. The Community Profile Team believed it was important to include not only perspectives of grantees, but also representatives of organizations who are less intimately familiar with Komen Central Indiana's work or involvement in the community.

Specifically, the Community Profile Team interviewed 33 central figures in the breast cancer community throughout the five target counties for key informant interviews. Examples of the key informants' roles and positions include physicians, nurses and administrators in hospitals and community clinics, administrators and program staff in government agencies, such as the county or state departments of health, and nonprofit agencies that serve cancer patients, special populations or the communities in general. Members of the Community Profile Team personally arranged the interviews, which were conducted by telephone or in person.

With the intention of gleaning insight from women who were not breast cancer survivors and not closely tied to Komen's mission, the Community Profile Team targeted women reflective of the general population, age 40 and over who would fall into recommended screening guidelines, for its focus groups. Specifically, since quantitative data revealed that the Affiliate service area has significantly lower breast cancer screening percentages than that observed in the United States as a whole; Komen Central Indiana was interested in reaching "everyday" women of the general population to help answer key questions related to access and utilization of breast cancer screening services.

However, certain demographics – based on quantitative data pointing to high priority populations – were also targeted in two target communities. Specifically, Black/African-American women in Marion County are a population of interest. Marion County has the largest Black/African-American population in the Affiliate service area, and Black/African-American women in the Affiliate service area have higher rates of death and late-stage incidence than White women. In Clinton County, Hispanic/Latina women are a population of interest. Clinton County's Hispanic/Latina population is higher than any other county in the Affiliate service area and higher than the Affiliate service area as a whole. This correlates with a low breast cancer screening percentage (54.7 percent) in Clinton County. Focus groups in these two counties answered key questions related to these especially vulnerable populations.

Boone, Rush and Shelby Counties were selected due to the predictive time to meet the HP2020 guidelines for late-stage incidence and/or death rates. In addition, the screening percentages for Shelby County are in the bottom four of the Affiliate's 21-county service area. Furthermore, the Health Systems Analysis revealed a need to have a more palpable presence and an increased number of collaborative relationships in these counties. As such, the Community Profile Team determined both key informant interviews and focus groups would help Komen Central Indiana identify specific needs and avenues to improve access to screening, diagnosis and treatment in these counties.

To recruit focus group members, the Community Profile Team posted flyers in several sites throughout each target county, including churches, community organizations, hospitals and clinics. Komen Central Indiana issued a press release specific to each county and promoted

the opportunity to participate in focus groups via social media. The team created a focus group script which explained the participants' voluntary participation, their privacy rights and the purpose of the focus groups.

Ultimately, 22 women ages 28 to 60 participated in focus groups in Clinton, Boone, Rush, and Shelby Counties, with a majority of the women being over the age of 40. Members of the Community Profile Team moderated the focus groups.

As a result of poor focus group turnout in Marion County (explained in more detail later in this section), the Community Profile Team developed an electronic survey consisting of 18 substantive questions related to women's health, breast cancer and access to care. This survey was conducted in lieu of focus groups but intended to gather the same perspective as the planned focus groups. This electronic survey was distributed to female members of churches with predominantly Black/African-American congregations, and there were 31 respondents.

The sample of sources for key informant interviews, focus groups and written surveys were selected primarily by convenience. Key informant and focus group participants were those who responded to requests by Komen Central Indiana, promotion for focus groups or subsequent surveys. Key informants were recruited through Komen Central Indiana's relationships with hospitals, health clinics, state/county departments of health, and community-based health organizations – making them a convenient and effective source. Members of the Community Profile Team personally arranged the interviews, which were conducted by telephone and in person.

Sample size for both key informant interviews and focus groups varied from county to county and was determined by ease of scheduling (willingness of key informants to participate) and turnout rate (how many community members reported to focus groups).

Scripts for both key informant interviews and focus groups, as well as the introduction to the written survey, explained the participants' voluntary participation, their privacy rights and the purpose of the interview/focus group. Emphasis was placed on the fact that all answers would be kept confidential and that no actual names or organizations would be identified or used in the coding process or subsequent publications. Focus group participants completed a consent form that outlined the voluntary and confidential nature of participation.

Qualitative Data Overview

Qualitative data collection lasted several months and involved 33 key informant interviews, seven focus groups and one survey with 31 responses across the five-county target area. The raw data from key informant interviews and focus groups was in the form of verbatim transcripts (transcribed after voice recording). The raw data from written surveys was submitted via Survey Monkey and contained respondents' verbatim answers to 18 questions.

The Community Profile Team met in person to compile notes and conduct a detailed review of transcripts from key informant interviews and focus groups. The team generated four categories of themes: 1) system barriers to receipt of breast health services; 2) individual

barriers to receipt of breast health services; 3) facilitators for obtaining breast health services; and 4) specific vulnerable populations.

Findings within the qualitative data are summarized in Table 4.1 in relation to the four identified themes, from which common findings are then discussed in detail.

Table 4.1. Findings within qualitative data

System Barriers	Individual Barriers	Facilitators	Vulnerable Populations
• Lack of health insurance or inadequate insurance • Uncertainty with the Affordable Care Act • Medicaid limitations • Lack of diagnostic services • Inability to provide timely breast health services • Lack of transportation • Lack of care coordination across the continuum • Location of screening facilities • Appearance of facilities • Disparities in services from location to locations • Barriers to effective patient-provider communication • Prohibitive guidelines • Restrictive hours for services • Conflicting health messages/information as to guidelines and curability • Navigation issues • Language barriers • Conflicting health messaging • Lack of primary care providers or failure to make referrals • Quality of care	• Competing priorities in patients' lives (family, work) • Lack of financial resources (income) • Emotional barriers/assumptions concerning breast cancer • Lack of education • Lack of knowledge of diagnostic resources • Transportation • Mistrust of health care system and providers • Fear of the unknown • Perceived risk • Perception that one is invincible / denial • Anticipated discomfort • Perceived lack of quality of care	• Health insurance • Optimism • Perceived risk if there is a family history • Income • Education • Faith • Appearance of facilities • Sufficient locations • Effective patient-provider communication • Psychosocial support • Medical home (primary care provider) • Access all through the Continuum of Care • Improved treatments / medical advancements • Awareness through consistent national-level messaging • Targeted community approaches to vulnerable populations	• Black/African-American women • Triple negative diagnosis • Hispanic/Latina women • Post-menopausal, pre-Medicare women • Language minorities • Immigrants (undocumented) • Rural women • Those with a family history or genetic propensity

Several themes from the qualitative data cut across all target communities, and from both health care providers and community lay persons alike, particularly when it comes to barriers to screening, diagnosis and treatment.

Boone County

Common findings within the qualitative data collected from Boone County (eight key informants interviewed and one focus group participant) included the following:

System Barriers: The most common system barrier found throughout the qualitative data from Boone County was related to a lack of or difficulty obtaining diagnostic services. Specific rationales for this difficulty varied across sources, from complaints about higher quality providers being located outside Boone County to trouble getting preventive care services covered for the uninsured (even under the Indiana Breast and Cervical Cancer Program). That said, review of the qualitative data also indicated conflicting perceptions of the quality of local care, revealing somewhat of an identity crisis for breast health providers in Boone County. Contingent to Marion County and inclusive of a large Indianapolis suburb, the perception is that a large number of Boone County women seek follow-up services in Marion County; on the other hand, lower-income women in the more rural parts of the county are more likely to seek care through the local hospital. Some women are more satisfied and comfortable with the care received locally, while others perceive Marion County as a source of higher quality services.

Individual Barriers: The most common findings across all qualitative sources in Boone County related to individual barriers were fear of the unknown and perceived risk. Women know once they take the leap to their first mammogram that they are opening themselves up to potentially undesirable news about their health. As summarized by one key informant, “No news is good news” to many women. Both key informants and focus group members also pointed to lack of education as an individual barrier to seeking care.

Facilitators: Even though perceived risk is often a barrier, it can also act as a motivator to seeking screening services, as it was identified as a facilitator to care by both qualitative data sources in Boone County. Likewise, as previously mentioned some women were very satisfied with the care choices and the care itself among Boone County providers and viewed the location of available resources as a facilitator to care.

Vulnerable Populations: Unfortunately, focus groups did not shed any light on perceptions related to vulnerable populations in Boone County. However, key informants noted several populations as vulnerable, including Black/African-American, Hispanic/Latina, post-menopausal/pre-Medicare, and women residing in rural areas of the county.

Rush County

Common findings within the qualitative data collected from Rush County (three key informants interviewed and two focus groups) included the following.

System Barriers: Despite other possible resources, a current grant from Komen Central Indiana provides the only coverage for health services to under/uninsured women in Rush County. Review of the qualitative data confirms that the community views the primary system barrier to seeking breast health services in Rush County to be lack of insurance. With the perception that

services are only available at the one hospital in the county, women do not believe they have ample options for care in Rush County.

Individual Barriers: Common individual barriers recited by qualitative data sources in Rush County included women's competing priorities, lack of education, lack of finances and fear of the unknown. Both key informants and focus group participants observed that women put everyone else in their lives before themselves. Women with financial constraints, especially single mothers, will choose to spend their limited resources on their children and necessities. As stated by one key informant, "If it's either buying food for her kids or getting a mammogram, then she's going to buy the food."

Some women are so busy in their roles as caregiver to children, parents and/or siblings that the thought of getting a mammogram has never crossed their mind – they don't have enough awareness of breast cancer for screening to make their list of priorities. It was also observed that even if a woman made the time to try to schedule a screening appointment, her competing priorities would limit her availability and she may not be able to find a screening facility to accommodate her schedule. The bottom line is that it is difficult for many women to put their health first.

The qualitative evidence also suggests a strong lack of knowledge of screening and diagnostic resources in Rush County. Thus, despite the local hospital's promotion of free mammograms through the Komen program, the under- and uninsured are either unaware of the program's existence or still believe there will be a cost to them. One focus group participant shared that she had gone without a mammogram for 12 years because she was not aware of any free services in the county. Key informants believe they have observed a great number of women with late-stage diagnoses, as a result of these barriers.

Additionally, it is perceived that the women of Rush County are not educated as to the risk of breast cancer or aware of free programs that will screen them for breast cancer. Furthermore, many of the uninsured women face financial barriers that make transportation to a screening facility difficult.

All of these barriers are compounded by the overwhelming qualitative evidence that women have substantial fear of the unknown. With so many others depending on them, as well as the stress of limited financial resources, low-income women are often too scared to find out if something is wrong with them. They fear there will be no one to provide for or take care of their loved ones if something happens to them. On the other hand, providers in Rush County also believe there is a perceived lack of risk among many women in the service area, suggesting they are not aware that breast cancer should be a concern.

Facilitators: Taking into consideration the findings related to barriers to screening and diagnosis in Rush County, the qualitative evidence reveals that greater insurance coverage and an expansion of screening facilities would positively impact women's decisions to get screened. In addition, perceived risk was seen as a motivator to obtaining breast health care and the perception that a lot of women in the area have breast cancer was a cross-finding among data sources. In particular, key informants perceive there to be a greater incidence of breast cancer among younger women in their community and they believe this perceived risk is motivating

women to talk about breast cancer. Specifically, one key informant noted, “Now talking isn’t going and getting screening, but talking may lead to that.”

Vulnerable Populations: While focus group participants did not elaborate on vulnerable populations within Rush County outside of the uninsured, key informants cited three groups of women as seemingly vulnerable to breast cancer: 1) the county’s Amish population; 2) women with a family history; and 3) young women.

Shelby County

Common findings within the qualitative data collected from Shelby County (five key informants interviewed and two focus groups) included the following.

System Barriers: Shelby County key informants and community members cited the following as system barriers to receiving breast health care: health insurance, the Affordable Care Act, lack of diagnostic services or lack of knowledge of diagnostic resources, and the failure of primary providers to screen routinely or inform patients of the importance of regular mammograms.

Specifically, focus group participants noted that lack of insurance keeps them from seeking regular screenings, and key informants stressed the difficulty experienced by those low-income women who fall in the insurance gap – they don’t qualify for indigent care, but they cannot afford the co-pays or deductibles associated with insurance. There was also a perception among both groups that the Affordable Care Act has caused great barriers to health care, with focus groups citing immense frustration with enrollment and key informants perceiving that the ACA is actually making mammograms less affordable. Thus, it was noted that “health insurance doesn’t mean access to care.”

In addition, qualitative sources revealed that knowledge as to screening and diagnostic resources in Shelby County is low. Many low-income women are not aware of existing free breast health services. Key informants were equally aware that breast health providers in Shelby County are not reaching the women who need their services. Key informants were also particularly concerned with the lack of diagnostic services available following an abnormal mammogram result – not only are community resources low to perform these services, but women’s finances are often too low to support completion of the CoC following a questionable exam or mammogram.

A more unique system barrier exposed by the qualitative data in Shelby County is the failure of primary health care providers to inform patients as to screening guidelines and free resources. Key informants noted that providers are not stressing the importance of mammograms to their patients, are not ordering annual mammograms for patients, and are not checking in with patients to be sure they adhere to a regular screening plan. Focus group participants noted that everything seems to cost more when they go through a primary care provider, so they have stopped using these providers for their basic care.

Individual Barriers: Key informants and focus group participants named competing priorities, income/finances, perceived risk and fear of inequities in care as individual barriers to obtaining breast health services. Specifically, focus groups highlighted the difficulty of working women to take time off to receive health care services. “Is there somewhere that is going to be open at 7:00 at night?” quoted one participant. Directly related, another common personal barrier to

care discussed was lack of income among Shelby County residents who many perceived as "unemployable."

In addition, the community is seen as older - not just age-wise, but also in that they are stuck in old health habits which have resulted in high rates of obesity and smoking. Residents are perceived to not be in a mindset of healthiness and thus are not in tune with the importance of preventive care. This mindset is once again attributed to low incomes, education and socioeconomic status.

Perceived risk was also noted as an individual barrier to obtaining breast health services. Women in Shelby County perceive their risk of having breast cancer as very low; thus, it isn't worth expending their limited time and resources to get screened. Fear of the unknown was also cited by both groups as a deterrent. As stated by one focus group participant, "ignorance is bliss."

Some issues concerning the perception of quality of care in the area were also raised by qualitative data sources in Shelby County. Key informants lack confidence in the area's ability to see women through the CoC, believing that the community lacks a referral "hub" and patient navigation services. On the community side, low-income women do not believe they will be offered the same treatment as a woman with more financial resources.

Facilitators: There were no common findings across the two groups of qualitative sources in Shelby County related to facilitators to obtaining breast health services. Key informants suggested better access along the CoC and primary care provider education as ways to improve breast health care and screening percentages in the community. Community members cited both perceived risk and psychosocial support as positive influences to seeking breast screenings. Specifically, it was noted by focus groups that as women get older they become more cautious of their health and are prompted to seek care because they believe their risk is increasing as they age. It was also noted that women's spouses could be a motivator to seeking care if men were more educated about breast cancer.

Vulnerable Populations: There were also no common findings related to vulnerable populations in Shelby County, however key informants identified language minorities and rural women as particularly vulnerable.

Marion County

Common findings within the qualitative data collected from Marion County (13 key informants interviewed and a survey with 31 respondents) included the following.

System barriers: The complexity of the health insurance system is a critical barrier to receiving screening, diagnostic and treatment services. Thus, it is not only women without health insurance who face insurance-related issues when considering or seeking health care services. It is the perception of both providers and patients that, even with insurance, women face obstacles such as not understanding the coverage provided by their policy, prohibitive copays, deductibles and a lack of knowledge as to how to access services under the new Affordable Care Act. In addition, Indiana's decision to not expand Medicaid (prior to or at the time of the interviews) and insurance age guidelines for screening services are leading to diminished availability and eligibility for breast health services.

Transportation is also linked to the convenience of locations of breast health services. The distance to a screening facility is an initial hurdle, but even after completing a screening, the CoC can be delayed or broken if a follow-up service (i.e. biopsy, referral to a specialist) is provided in yet another location.

Patient-provider communication was also identified as a common barrier to receiving services. Patients want to be provided consistent information they can understand, and just as importantly, they want the information delivered in a caring manner. From physician to physician, there are differences in the way breast health and breast health services are communicated. Time constraints can lead physicians and their staff to not thoroughly explain a patient's options. As a result, some patients are turned off by confusion or insensitivity and do not follow through with receiving complete breast health care.

Individual Barriers: Individual barriers were rooted in a lack of resources, including both personal finances and education/knowledge/awareness. Finances play a pivotal role in women's decisions to seek care. Low-income women may not be able to afford to take off work to seek breast health services, and are likely to have financial priorities above that of their breast health – such as money to care for their children, pay their utilities, etc. And despite enactment of the Affordable Care Act, finances are still a determinant of insurance status and health care expenses are still a deterrent to receiving care.

Related to finances, transportation was identified as a personal barrier to care by both key informants and survey respondents in Marion County. Women may have a desire to be screened, but cannot get there. In addition, women in treatment may reach a point where transporting themselves is problematic, creating a gap in the Breast Cancer Continuum of Care (CoC).

Additional individual barriers included lack of education/knowledge/awareness. Women are not educated as to the factors that can lead to breast cancer and are often not knowledgeable enough to be proactive about their own health. Neither their community nor their employers are educating them as to the importance of breast health. Thus, they are missing the foundational blocks that would prepare them to ask the right questions about breast health and are particularly lacking the knowledge of where to obtain information and services. These gaps in knowledge exist all along the CoC, as women also do not understand the importance of follow-up services even if initial screening services are obtained.

Another common individual barrier noted throughout the qualitative data in Marion County was fear of the unknown. Surveys indicated that women have great anxiety and fear attached to the issue of breast cancer – fears that they have breast cancer, may get breast cancer and may not be able to access quality care for breast cancer. From the provider perspective, women's fear drives their resistance to completing the CoC. Similar to fear, fatalistic ideation and women's perceived risk of getting breast cancer - particularly if they have a family history of breast cancer – act as personal barriers to seeking screening services. On the flip side, providers noted that perceived risk by some women that breast cancer is no longer a deadly disease has made women less concerned with their breast health and more likely to delay the beginning of a healthy breast monitoring routine.

In addition, while identified as a facilitator by Black/African-American lay women in Marion County, providers actually noted that a woman's faith can be an obstacle to following recommended breast health services. Black/African-American women may be more likely to trust in their deep faith in God than in their health care providers or medicine. Survey responses supported this notion, as social support and prayer came in as a very close second most common response when Marion County women were asked what a friend's diagnosis would mean to them. While 10 women responded that a friend's diagnosis would prompt them to be screened themselves, eight women responded that a friend's diagnosis would prompt them to support her and pray for her.

Facilitators to Obtaining Breast Health Services: Qualitative data sources from Marion County, whether health care providers or lay community members, indicated that survivor strength is a facilitator to obtaining care. Survivors are a valuable resource to women in any stage of the CoC and are an effective marketing and awareness vehicle for breast health.

In addition, both groups of qualitative respondents (key informants and survey respondents) highlighted the importance of a woman's support network - one survey respondent referring to psychosocial support as her "lifeline" and her "everything." It was also noted that psychological support can help women overcome other barriers, including financial. Despite the cost, having psychosocial and emotional support from a strong network of family, friends, and community can increase a woman's adherence to a diagnostic or treatment plan. Providers particularly recognize that traditional treatment alongside psychosocial support improves treatment adherence.

And while perceived risk was noted as a barrier in some instances, it was also identified as a motivator to seeking screening services. A woman's strong family history or having a friend diagnosed with breast cancer may make her more proactive in educating herself as to guidelines, symptoms and early detection methods.

Vulnerable Populations: The overwhelming majority of survey respondents (predominantly Black/African-American women) in Marion County indicated that there are no cultural barriers that prevent them from seeking care. However, the perspective of key informants was strikingly different, as they perceive that Black/African-American women in Marion County face more barriers to breast health care. Similarly, providers and nonprofit professionals indicate disparities in care between Black/African-American and White women. Many key informants emphasized the impact of cultural differences, including a higher prevalence of mistrust of the medical community by Blacks/African-Americans and a greater need for clear messaging that breast cancer does exist among Black/African-American women.

Another polar response between key informants and Black/African-American women in Marion County concerned the importance Black/African-American women place on breast cancer as an issue within their community. While more than half of survey respondents indicated breast cancer, or cancer in general, as the most important health problem for women in their community, key informants perceived that a lack of knowledge of the prevalence and importance of familial basis of breast cancer among Black/African-American women contributes to a cultural de-prioritization of the issue. In addition, key informants believe that due to unique biological and physiological differences, as well as high-risk health behaviors, Black/African-American women have a greater propensity for breast cancer. While this is perception, as the

quantitative data does not support this, the data does support disparities in late-stage incidence and death rates.

Thus, a conclusion could be drawn that while Black/African-American women are keenly aware of breast cancer, they are delaying screening or not following through with regular screenings. Key informants seem to believe that even though Black/African-American women are a high priority population, they get lost in the campaign against breast cancer by messaging that only speaks to White women. One key informant recalled hearing a Black/African-American woman say, “Well, this is probably just another program for White people.”

Clinton County

Common findings within the qualitative data collected from Clinton County (four key informants interviewed and two focus groups) included the following.

System Barriers: Several common findings among key informants and focus group participants (predominantly Hispanic/Latina women) in Clinton County related to system barriers, beginning with a lack of health insurance and the Affordable Care Act (ACA). Respondents believe health care is not affordable without insurance and that the ACA has caused so much confusion that women (1) do not know how to enroll or (2) do not understand what services are covered if they have enrolled. Thus, they are avoiding health care services. In addition, many low-income women in Clinton County fall in a gap because they make too much money to qualify for Medicaid but not enough money to afford insurance through the ACA marketplace.

Mistrust of the local health care system and providers was also noted as a barrier among qualitative data sources. This mistrust and lack of confidence is felt by providers and patients alike, with the common perception that women would rather receive their health care in a different county.

Due to the high Hispanic/Latina population, language is a serious barrier to care in Clinton County. While women are aware that translators are available, they noted that the wait can be extremely long. This is supported by key informants’ observations that there are only one or two interpreters for all the doctors in the community. It was suggested that there is a need for an interpreter in nearly every health care provider location in the county.

Qualitative data also indicates there is up to a six-month wait for screening appointments in Clinton County; and while grant funds have been provided for screening efforts, no effort has been put into actually educating Hispanic/Latina women on the available resources or assisting them in getting to the screening sites. Focus group respondents confirm this perceived lack of knowledge of screening and diagnosis resources, as some were not aware the county provided any free breast health services. Others believe the free services are only available in Indianapolis for Marion County residents. In other words, Hispanic/Latina women do not believe there are any health care providers with their interests in mind. As stated by one focus group participant, “We’re not the priority as far as too many illnesses or cancers.”

For those women who have had preventive services, they believe provider-patient communication is poor which causes them to not complete subsequent screenings. It was also noted that there is a lack of physicians who are comfortable with caring for Hispanic/Latina women.

In summary, the system barriers in Clinton County related to a lack of insurance, lack of timeliness in treatment and concerns over the quality of care available in the county.

Individual Barriers: Qualitative data showed individual barriers to care among Clinton County women relate primarily to finances - lack of insurance, transportation, and education. Transportation becomes an especially strong barrier in completing the CoC, as most diagnostic and treatment services are located outside the county. As previously discussed, Clinton County residents also seem to grapple with trust in their local health care system and providers, along with perceptions that the quality of care available in their county is lesser than the care they would receive elsewhere.

Similar to qualitative data sources in other counties, Clinton County women are also deterred to seeking health care services by a fear of the unknown and their perceived risk. In general, the perception is that the Hispanic/Latina population does not seek health care services until they are too sick to work. This is backed up by a focus group finding that Hispanic/Latina women fear that because they are already behind on their health care they may not learn of their cancer until it is in a later stage. One focus group member commented that she "wouldn't die of cancer, but [she] would just die of being worried about it…stressed out." In addition, Hispanic/Latina women are afraid to learn they have breast cancer and are resistant to further diagnostic services because they feel they won't be able to afford treatment once they are diagnosed.

Facilitators: Both key informants and women at large in Clinton County believe a facilitator to obtaining breast health services would be a different community approach to reaching Hispanic/Latina women. Many women do not have access to a cell phone or the internet, but do have access to television and do regularly attend church. Therefore, new avenues to educating Hispanic/Latinas must be explored, and health care providers need cultural training to be better able to communicate and more confident in caring for this vulnerable population.

Vulnerable Populations: As shown through the discussion above, the qualitative data strongly points to the vulnerability of Hispanic/Latina women in Clinton County. Cultural barriers, including language and somewhat of an acceptance that they will not be cared for, combined with a lack of financial resources is continuing to put this community at a high risk for low screening percentages and high death rates from breast cancer.

Qualitative Data Findings

The most common findings across the qualitative data in the target counties were inextricably linked to the key questions of **access and utilization of screening services** identified by Komen Central Indiana in the Quantitative Data and Health Systems and Public Policy Analysis. The qualitative data were particularly helpful in identifying system barriers and facilitators to obtaining breast health care.

As such, qualitative sources repeatedly identified a lack of income and finances as impediments to accessing breast health care services in their communities. Whether they are uninsured, underinsured or even insured, women do not believe they have the resources to afford routine

breast care. In addition, they perceive that they especially do not have the resources to complete the Breast Cancer Continuum of Care should they be diagnosed with breast cancer.

The qualitative data also made it apparent that access and utilization of screening services are hindered by women's perception that their communities lack ample and affordable screening resources. Many women lack knowledge as to any free screening opportunities in their area.

The qualitative data also shows that women are being held back from seeking screening services by their own fear of the unknown and their perceived risk of getting breast cancer. Whether they perceive their risk as low or high, women find reasons to not be screened that are driven by fear, or oppositely, a lack of knowledge as to any risk of breast cancer.

Perceived risk, while sometimes referenced as a barrier, was commonly mentioned as a facilitator for women to seek screening and breast health services. Both key informants and focus group participants in all geographic areas acknowledged an increased awareness of breast cancer in recent years, whether due to national awareness campaigns or due to the diagnosis of one or more individuals nearby. Data sources believed this awareness and the resulting perceived risk translates into women being more likely to seek services.

While qualitative data sources may not have made specific references to the **quality and quantity of relationships with Komen Central Indiana partners**, the data overwhelmingly revealed gaps in care that can be filled by enhancing these relationships. The data not only shows the need for these relationships to be enhanced in order to increase access and utilization of screening services, but in particular, to increase the likelihood of women completing the Breast Cancer Continuum of Care. Aside from Marion County, follow-up care in these target communities is often fragmented and inconvenient due to additional diagnostic resources being located outside the county.

In addition, the qualitative data shed light on the issues concerning the **vulnerable populations** within these five counties. In Marion County, there is a discrepancy between what Black/African-American women believe they are doing to stay on top of their breast health and the outcomes they actually face according to the quantitative data. In Clinton County, Hispanic/Latina women are not inclined to seek health care services until a symptom prohibits their ability to work. They also do not feel they are a priority to health care providers in the area and they experience long wait times due to language barriers when they do seek care.

The Community Profile Team experienced both quantitative and qualitative limitations in its data sources and methods. Quantitative limitations included small sample sizes in four of the five counties for the key informant interviews, with five or less key informant interviews in Clinton, Rush and Shelby Counties (13 key informants were interviewed in Marion County and eight in Boone County).

Likewise, small sample sizes were a weakness within the focus groups, as the Community Profile Team faced unexpected low turnouts at a majority of the planned groups. Accordingly, data from Boone and Shelby Counties encompassed two or less focus groups comprised of two or less persons (only one individual reported to one focus group in Boone County). In Rush County, two focus groups were held, each comprised of two to three women. The strongest

focus group data were yielded from Clinton County, wherein two focus groups were held, each comprised of five to ten women.

In Marion County, no participants were recruited to any of the scheduled focus groups; thus, alternatively, the Community Profile Team sent an electronic written survey through Survey Monkey to churches with high Black/African-American membership. Thirty-one surveys were returned through this effort.

In reviewing verbatim transcripts from the key informant interviews and the focus groups, the Community Profile Team also noted qualitative limitations due to stylistic differences between the interviewers and focus group moderators. Questions were not framed identically by the interviewers or focus group moderators. Rather, different techniques set different tones for key informant responses and focus group feedback.

Due to the limitations of the data, the perspectives provided represent only those that participated in the focus groups, surveys and interviews and do not represent the general population of the community or providers as a whole.

Despite these seemingly critical weaknesses in qualitative data, the Community Profile Team uncovered evident themes across the five counties using the various methodologies. Ultimately, a majority of the system and personal barriers to obtaining breast health care identified by the qualitative data in the five target counties turn on a lack of income and finances. Low-income women are under- or uninsured and face competing priorities that lead them to put their jobs and families first. With their limited resources, low-income women in these communities are not choosing their health as a spending priority.

A second, widespread barrier revealed by the qualitative data are a lack of diagnostic services or a lack of knowledge of the available diagnostic services available within these communities. In particular, key informants and focus group participants made it clear that Komen Central Indiana needs to further its work in promoting *free* screening services in these communities in order to improve access to care and screening percentages.

On an individual level, whether they perceive their risk as low or high, women are finding reasons to not be screened. The conclusion is that women in these high priority areas need to be provided health messaging that will alleviate their fears related to breast cancer, emphasizing that early detection can take substantial fear and anxiety out of the process.

An overarching conclusion is that Komen Central Indiana needs to develop more effective strategies, including enhanced partnerships, in these communities to not only ensure access to screening services, but ensure utilization of screening services and completion of the Continuum of Care.

Breast Health and Breast Cancer Findings of the Target Communities

Communities with the most pressing needs for breast health interventions were identified and targeted through the findings in the Quantitative Data Report for the 21 counties served by Komen Central Indiana. The Community Profile Team collected data from a variety of credible sources and tracked indicators measuring breast cancer rates, indicators measuring breast health services and indicators contributing to, or directly related to, breast cancer rates. Each county was compared to state and national averages, and to the Affiliate service area as a whole.

After the target communities were identified, the Community Profile Team dug deeper into the challenges facing these specific communities through a Health Systems and Public Policy Analysis and Qualitative Data Report. The Health Systems and Public Policy Analysis identifies existing health care providers currently providing services and resources for breast health services and public programs affecting breast health services. The Qualitative Data Report allowed Komen Central Indiana to hear directly from health care providers and lay people in the community and identify common themes relating to the trends highlighted through the Quantitative Data Report and key issues identified in the Health Systems Analysis and Public Policy Analysis.

Quantitative Data Report

While a range of indicators were tracked and included in the Quantitative Data Report, the Community Profile Team placed an emphasis on the counties with the longest predicted time to reach the HP 2020 targets for death rates and late-stage incidence rates, and actual death, late-stage incidence and incidence rates, as well as the four-year trends for each. Emphasis was also placed on screening percentages, residents (40-60) living without health insurance, residents with income less than 250 percent of the poverty level, unemployment percentages and percentages of the population that are Black/African-American and Hispanic/Latino. This analysis allowed Komen Central Indiana to highlight problem areas geographically and target counties with the highest level of need.

Of the 21 counties in the Affiliate service area, five counties were identified as Target Communities.

1. Boone County (Highest Priority)
2. Rush County (Highest Priority)
3. Shelby County (Highest Priority)
4. Marion County (Medium Priority)
5. Clinton County (Low Priority)

Health Systems and Public Policy Analysis

The Health Systems and Public Policy Analysis connected the problem areas identified in the Quantitative Data Report to the availability of services and resources in each of the target communities. The Community Profile Team identified health care facilities in the targeted communities that provide breast health services, including clinical breast exams, screening mammograms, diagnostic screenings, treatment, financial assistance and patient navigation.

In addition to these resources, the Community Profile Team also contacted providers within the targeted communities to gain a clearer understanding of the services that are provided. Komen Central Indiana also worked with the Indiana Breast & Cervical Cancer Program (IN-BCCP) to identify IN-BCCP providers in the priority areas. This analysis helped the Community Profile Team to determine if problem areas in the Quantitative Data Report were related to a lack of services or resources, gaps in services or resources, or other barriers preventing women from entering the CoC.

The team also analyzed the impact of the Affordable Care Act and the Healthy Indiana Plan 2.0, and the changing health care environment, taking into account the potential for an increase in individuals with health insurance, the gaps that will continue to prevent women from entering the CoC despite having insurance and challenges relating to patient navigation.

Through the Health Systems and Public Policy Analysis Komen Central Indiana determined:

1. Patient Navigation is imperative to the completion of the CoC.
2. Komen is the only funding source for services to low-income/under/uninsured women in Rush County.
3. Marion County women have many options for health care services and providers but easily fall out of the CoC.
4. Women in need of treatment in Clinton County must travel to a nearby county.
5. There is a need for a stronger presence and collaborative relationships in Boone, Shelby, and Clinton Counties.
6. There is a need for Komen Central Indiana to stay informed of the ever-changing health care environment following the rollout of the ACA and HIP 2.0.

Qualitative Data Report

Equally important to the quantitative data, this exploration into the observations and opinions of health care providers and lay community members helped Komen Central Indiana to more deeply understand the needs of the communities it serves.

Because quantitative data revealed that the Affiliate service area has a significantly lower breast cancer screening percentage than that observed in the United States as a whole, the Community Profile Team identified access and utilization of screening services as key topics for its qualitative studies. Key assessment questions related to these two variables were intended to help Komen Central Indiana pinpoint the barriers to breast health services (both system-level and individual), as well as facilitators for obtaining breast health services – ultimately revealing observations that could improve Komen Central Indiana's ability to increase the number of women seeking preventive care, diagnostic and treatment services.

In addition, Komen Central Indiana identified the quality and quantity of its relationships with local partners serving women in priority areas as a key variable impacting women's ability to complete the CoC, with a particular need for bolstering these relationships in Boone, Rush, Shelby and Clinton Counties. Key assessment questions related to this aim were intended to guide Komen Central Indiana as to how to most effectively build a stronger presence and greater collaborative partnerships outside its home base of Marion County.

Komen Central Indiana also sought to better understand its service area's especially vulnerable populations through this analysis by targeting high priority populations in two of the five target areas.

Komen Central Indiana used key informant interviews and focus groups to collect qualitative data from its five target communities. In addition, surveys were used as a tactical response to overcome limitations of focus group data in Marion County.

The selected collection methods were intended to encompass a broad range of community perspectives, from those who work in women's health to those who make up central Indiana's underserved populations.

The most common findings across the qualitative data in the target counties were inextricably linked to the key questions of access and utilization of screening services identified by Komen Central Indiana in the Quantitative Data and Health Systems and Public Policy Analysis. Qualitative sources repeatedly identified a lack of income and finances as impediments to accessing breast health care services in their communities. The data also shows that women are being held back from seeking screening services by their own fear of the unknown and their perceived risk of getting breast cancer.

Mission Action Plan

After completion of the Quantitative Data Report, the Health Systems and Public Policy Analysis, and the Qualitative Data Report, Komen Central Indiana identified the most urgent challenges facing each of the target communities and connected these challenges to a specific problem expressed through a problem statement.

For each problem statement, priorities communicate the goals that will be achieved by Komen Central Indiana in order to effectively address the challenges and needs identified in problem statement.

Finally, under each priority falls a range of objectives that specify how the goals set in the priorities will be met. The objectives set forth the strategic actions that will be taken by Komen Central Indiana and are specific, measurable, attainable, realistic, and time bound. Note: The Susan G. Komen Central Indiana fiscal year begins on April 1 of the prior calendar year and concludes on March 31.

Together the problem statement, priorities, and objectives provide a road map to Komen Central Indiana for effective interventions for improving breast health in the target communities.

Boone County

Problem Statement

Women in **Boone County** have late-stage incidence and death rates higher than the Affiliate service area averages. Despite findings in the Health Systems Analysis that services are available in the county, screening percentages remain comparatively low. Qualitative and quantitative data indicate barriers that may affect access to care are especially high for people in rural areas, women with low income and education levels and women between ages 40-65.

Priorities and Objectives

1. Increase the capacity of existing health providers (located centrally in the City of Lebanon) to reach the rural poor with increased access to screening services.
   a. In FY16 and FY17, hold a series of collaborative meetings (at least three) with Witham Hospital, Boone County Community Clinic, other health care providers and community-based organizations to develop strategies to link women residing in rural areas to screening services. The result of these meetings will be a local action plan for increased access to services for rural women, created by at least two breast health care providers, and at least one community-based organization.
   b. In FY16, hold a series of collaborative meetings (at least two) with a provider of charitable transportation services, local health care providers, and community-based organizations to provide free and low-cost transportation to low-income individuals living in rural areas. These meetings will result in a scheduling and appointment process for patients and at least 30 available free or low cost rides. (Transportation provided through Boone Area Transit or a volunteer-based nonprofit.)
   c. In FY16 and FY17, develop a collaboration among community organizations and breast health service providers in Boone County to provide screening services during evening and weekend hours to serve those who are not able to visit a screening location during regular business hours. The result of this collaboration will be at least one medical facility providing screening in evening or weekend hours once per month.
   d. In the RFAs for FY16 through FY19, a funding priority will be to deliver early detection services, including screening and diagnostics, that may improve death rates and late-stage incidence rates in target communities.

2. Facilitate community awareness, education and mobilization efforts aimed at reaching women living in low-income, rural areas in Boone County.
   a. In FY16, FY17 and FY18, identify and develop cooperative relationships with local community organizations, churches, schools, etc. in rural, low-income areas to mobilize women not currently in the CoC through behavior change communications relating to screening services. This effort will result in contact with at least 10 community-based organizations in Boone County, an ongoing collaboration with at least three organizations, and at least one event.
   b. In FY16 and FY17, establish a supply chain of Komen educational materials targeting low-income, low-education, rural women, delivered through local breast health service providers and community-based organizations in Boone County. This will result in consistent availability of education materials to at least five community-based organizations and health care facilities for distribution to their constituents.
   c. In FY16 and FY17, lead a series of collaborative meetings (at least three) with local community-based organizations to develop strategies for targeting rural populations in Boone County with key messaging, linking them directly to resources and services in the county that are available but underutilized. The result of this effort will be a local action plan for community mobilization created by at least two community-based organizations and one health care provider.

Rush County

Problem Statement

Women in **Rush County** have a death rate and late-state diagnosis rate higher than the averages for the Affiliate service area and are not expected to reach the HP2020 guidelines for late stage diagnosis for 13 or more years. Despite high screening percentages and low incidence rates compared to the Affiliate service area, quantitative and qualitative data indicate poverty, unemployment and lack of insurance as potential contributors to comparatively high late-stage diagnosis and death rates. Qualitative data and the Health Systems Analysis suggest a lack of breast health services, underutilization of breast health services and insufficient funding for breast health services are barriers that may impede receiving care.

Priorities and Objectives

1. Increase the capacity of existing health care systems to provide seamless transition for women who are screened to diagnostic and treatment services in Rush County and the surrounding counties.
    a. In FY16 and FY17, lead a series of collaborative meetings (at least three) with Rush Memorial Hospital, Meridian Clinic, Indiana State Department of Health and other local cancer or health-related organizations to develop a plan to identify and address gaps in the continuum of care; from screening to diagnostics, to treatment and beyond. These meetings will result in a document mapping the availability of services and a referral plan for screening and diagnostic providers.
    b. In FY16 and FY17, assist local breast health service providers in Rush County with the process of seeking and obtaining additional resources from government and nonprofit funding sources and programs (Komen Central Indiana is currently the sole funding source to Rush Memorial Hospital for screening and breast cancer services). This effort will result in at least one agreement between a Rush County breast health service provider and the IN-BCCP program or another funder of breast cancer screenings.
    c. In the RFAs for FY16 through FY19, a funding priority will be to deliver early detection services, including screening and diagnostics, that may improve death rates and late-stage incidence rates in target communities.

2. Facilitate community awareness, education and mobilization efforts aimed at reaching women living in low-income, rural areas in Rush County.
    a. In FY16 and FY17, identify and develop cooperative relationships with community-based organizations directly serving low-income individuals and families in Rush County, in an effort to reach more women with important information relating to screenings and programs for the un/underinsured. This effort will result in a local action plan for community mobilization, developed by at least one breast health care provider and at least three community-based organizations.
    b. In FY16 and FY17, develop a supply chain for Komen breast cancer educational materials and resources, aimed at educating women and directing them to resources and services in Rush County, using local collaborating organizations to disseminate information. This will result in consistent availability of education materials to at least 10 community-based organizations and health care facilities for distribution to local constituents.

c. In FY16 and FY17, in partnership with community-based organizations and government agencies offering ACA and HIP 2.0 enrollment and navigation, develop education and awareness measures targeting the uninsured and directing them to enrollment and navigation services, in addition to screening services. This effort will result in contact with at least 10 community-based organizations in Rush County and at least one event intended to inform the public on health care coverage options and available navigation services.

Shelby County

Problem Statement

The target area of **Shelby County** has a high late-stage incidence rate compared to the Affiliate service area average. Additionally, the late-stage incidence rate has increased more than the Affiliate service area trend, growing faster than any other county. Shelby County is not expected to reach the HP2020 targets for late-stage incidence rate for 13 years or longer and is not expected to reach the target for death rate for eight years. Qualitative and quantitative data and the Health Systems Analysis indicate lack of screening and diagnostic services and poor provider/patient communications are barriers that may be preventing women from entering the CoC, especially for women with low levels of income and education.

Priorities and Objectives

1. Increase the health care system's capacity to provide screening opportunities and keep women within the CoC through improved provider/patient communication, patient education and patient navigation.
   a. In FY17, develop an action plan for community entry into Shelby County (Komen currently has no grantee residing in Shelby County) in order to identify key contacts with existing health care providers, government agencies and community-based organizations and identify potential grantees. This plan will result in contact with at least 10 local organizations.
   b. In FY17 and FY18, lead a series of at least three collaborative meetings with local breast health service providers to develop strategies for targeting rural populations in Shelby County with key messaging, linking them directly to resources and services in the county. These meetings will result in a local action plan for increased services created by at least two health care providers serving Shelby County and at least one community-based organization.
   c. In the RFAs for FY16 through FY19, a funding priority will be to deliver early detection services, including screening and diagnostics, that may improve death rates and late-stage incidence rates in target communities.

2. Facilitate community awareness, education and mobilization efforts aimed at reaching women living in low-income, rural areas in Shelby County.
   a. In FY17 and FY18, identify and develop cooperative relationships with local community organizations, churches, schools, etc., in rural, low-income areas to mobilize women not currently in the CoC through behavior-change communications relating to screening services. This effort will resulting in a local action plan for community mobilization created by at least three community organizations, and at least one health care provider serving Shelby County.

b. In FY17 and FY18, establish a supply chain of Komen educational materials targeting white, low-income, low-education, rural, women, delivered through local breast health service providers and community based organizations in Shelby County. This will result in the consistent availability of education materials to at least 10 community-based organizations and health care facilities for distribution to local constituents.
c. In FY17 and FY18, facilitate a series of collaborative meetings with local breast health services providers, community-based organizations, government programs and current Komen grantees (serving, but not located in, Shelby County) aimed at improving patient navigation and increasing screening percentages. The result of this effort will be contact with at least 10 community based organizations in Shelby County and at least one event intended to inform the public of health care coverage options and available navigation services.

Marion County

Problem Statement

Despite a screening percentage higher than the Affiliate service area as a whole, **Marion County** has higher late-stage incidence and death rates. Additionally, Marion County is not expected to achieve the HP2020 target for late-stage incidence rate for 13 years or longer. Qualitative and quantitative data indicate high unemployment, a high uninsured population and low income levels may contribute to barriers to breast health services. The Health Systems Analysis indicates a high level of complexity to the health care system and payment processes, highlighting the importance of patient navigation. Marion County has the highest populations of Black/African-American and Hispanic/Latina women in the Affiliate service area, and barriers to services are especially prominent for these populations.

Priority and Objectives

1. Facilitate community awareness, education and mobilization efforts aimed at Black/African-American women, with an emphasis on reducing the disparity in breast cancer death rates between Black/African-American and White women, with specific messages and services relating to an increase in access to services and increased awareness within the community.
   a. In FY16 and FY 17, using grant funding received by Komen Central Indiana for this purpose, work with collaborating organizations to develop and facilitate a series of quantitative and qualitative assessments aimed at identifying the factors contributing to late-stage incidence and death rates among Black/African-American women in Marion County. The result of this effort will be an analysis of breast health related behaviors, perceptions among Black/African-American women in various areas in Marion County, and a strategy for reaching Black/African-American women through community level engagement.
   b. In FY16 and FY17, participate in a series of collaborative meetings (at least 15) with Black/African-American churches to place at least 15 Breast Health Advocates in congregations to mobilize community members to enter and remain in the continuum of care, and create specific opportunities for Black/African-American women to receive breast health services. The meetings will result in contact with at least 15 predominantly Black/African-American places of worship in Marion County, and at

least five events intended to inform the public on health care coverage options and available navigation services.

c. In FY16 and FY17, in partnership with community-based organizations and government agencies offering ACA and HIP 2.0 enrollment and navigation, develop education and awareness measures targeting the uninsured within the Black/African-American population in Marion County, directing individuals to enrollment and navigation services, in addition to screening. This partnership will result in contact with at least five community-based organizations in Marion County and at least one event intended to inform the public on health care coverage options, available navigation services and breast health services.
d. In the RFAs for FY16 through FY19, a funding priority will be to provide direct services to Black/African-American women with regard to breast health educationand breast cancer navigation services.

Clinton County

Problem Statement

Clinton County has the highest percentage of Hispanic/Latina women of all counties in the Komen Central Indiana's service area. Despite low late-stage diagnosis and death rates, both well below the Affiliate service area average, qualitative and quantitative data indicate Hispanic/Latina women face barriers to breast health services.

Priorities and Objectives

1. Generate increased breast health awareness targeting the Hispanic/Latino, Spanish-speaking community through community-based education and mobilization.
   a. In FY18 and FY19, identify and develop cooperative relationships with community-based organizations currently engaged directly with the Latino community in Clinton County. The result of this effort will be a local action plan for mobilization of the Latino population in Clinton County, created by at least two community-based organizations and at least one local health care provider.
   b. In FY18 and FY19, develop a supply chain of Komen educational and promotion materials in the Spanish language to be used by community organizations and breast health service providers in Clinton County. This will result in consistent availability of education materials to at least five community-based organizations and health care facilities for distribution to local constituents.
   c. In FY18 and FY19, apply the existing bilingual Breast Cancer Education Toolkit provided by Komen Headquarters for Hispanic and Latino Communities to provide training to local breast health service providers in Clinton County. This will result in at least one Komen-facilitated training event.

2. Increase the health care system's capacity to overcome system barriers preventing Hispanic/Latinos from seeking or receiving services and entering the Continuum of Care.
   a. In FY18 and FY19, facilitate a series of collaborative meetings (at least three) with community-based providers of breast health services in Clinton County, with an emphasis on the providing services targeting the Hispanic/Latino community in Clinton County. The result of these meetings will be a local action plan for increased

access to services for Hispanic/Latino individuals in Clinton County, created by at least two health care providers and at least one community-based organization.

b. In FY18 and FY19, link community-based organizations serving the Hispanic/Latino community to transportation services provided by various nonprofit cancer organizations serving Clinton County. The result of this effort will be a collaborative relationship with at least one service organization providing charitable transportation services.
c. In FY18 and FY19, coordinate with a mobile mammography unit to target Hispanic/Latino populations in Clinton County, increasing accessibility, reducing wait times and providing psychosocial support to Latino women, who often feel marginalized in Clinton County. This will result in at least two visits by a mobile unit to predominantly Hispanic/Latino neighborhoods in Clinton County.
d. In the RFAs for FY16 through FY19 a funding priority will be provide direct services to Spanish speaking women with regard to breast health education breast cancer navigation services.

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