

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



**SUSAN G. KOMEN®**  
**CENTRAL INDIANA**  
**EXECUTIVE SUMMARY**

# 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. In 2015, the Affiliate merged with the Susan G. Komen Wabash Valley Affiliate, broadening its reach even further throughout the State of Indiana.

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 \$16 million to local nonprofit organization 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.

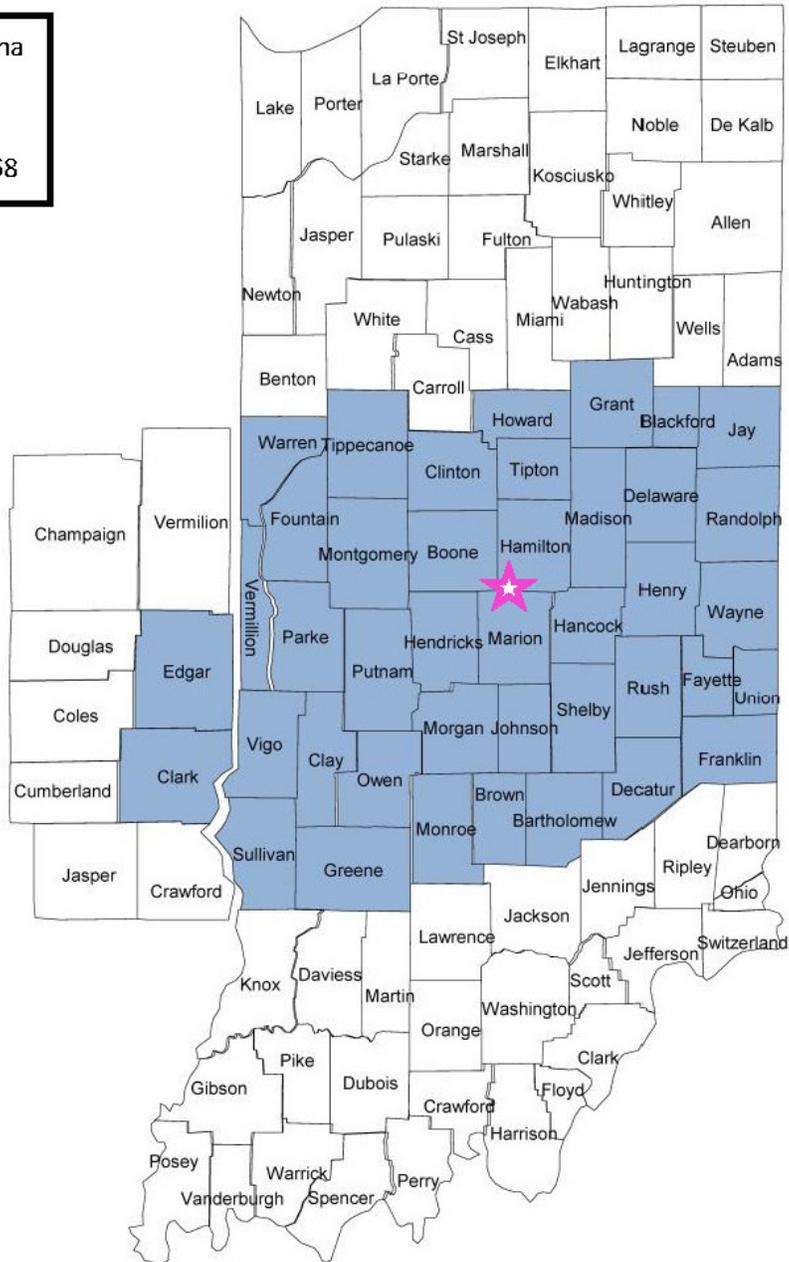
Additionally, a meaningful portion of the money received by Komen Central Indiana funds Susan G. Komen Research Program endeavors to discover breast cancer causes, treatments, and, ultimately, the cures. Susan G. Komen has funded, in part, many advancements in breast cancer research in the last 30 years.

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 41 counties across Indiana and Illinois. Counties served include: Bartholomew, Blackford, Boone, Brown, Clay, Clinton, Decatur, Delaware, Fayette, Fountain, Franklin, Grant, Greene, Hamilton, Hancock, Hendricks, Henry, Howard, Jay, Johnson, Madison, Marion, Monroe, Montgomery, Morgan, Owen, Parke, Putnam, Randolph, Rush, Shelby, Sullivan, Tippecanoe, Tipton, Union, Vermillion, Vigo, Warren, and Wayne Counties in Indiana and Clark and Edgar Counties in Illinois (Figure 1).

# KOMEN CENTRAL INDIANA SERVICE AREA

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★ Komen Central Indiana Office

■ Service Area

**Figure 1.** Susan G. Komen Central Indiana service area

The Affiliate service area includes the metropolitan areas of Indianapolis-Carmel, Lafayette, Anderson, Terre Haute, Bloomington, Muncie, Kokomo, and Columbus (in order of population). Indianapolis is the largest urban area in the service area, while those who live in rural areas comprise 16.4 percent of the population and 16.89 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 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 Komen Central Indiana'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 the State of Illinois was slightly higher than that observed in the US as a whole and the incidence trend was similar to the US as a whole. The

breast cancer incidence rate in the State of Indiana was slightly lower than that observed in the US as a whole and the incidence trend was similar to the US as a whole.

The incidence rate was significantly lower in Brown, Decatur, Fayette, Franklin, and Wayne Counties in Indiana. The incidence rate was significantly higher in Fountain and Jay Counties in Indiana. Tipton County in Indiana had an incidence rate trend that was significantly less favorable relative to the State of Indiana. The rest of the counties had incidence rates and trends that were not significantly different than their respective states 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 deaths, data for the annual percent change in the death rate over a five-year period were used.

Overall the breast cancer death rate in the State of Illinois was similar to that observed in the US as a whole and the death rate trend was lower than the US as a whole. The breast cancer death rate in the State of Indiana was slightly higher than that observed in the US as a whole and the death rate trend was similar to the US as a whole.

None of the counties in Komen Central Indiana's service area had substantially different death rates than their respective state 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-stage diagnosis rates between 2006 and 2010.

Overall, the breast cancer late-stage incidence rate in the State of Illinois was significantly higher than that observed in the US as a whole and the late-stage incidence trend was higher than the US as a whole. The breast cancer late-stage incidence rate in the State of Indiana was significantly lower than that observed in the US as a whole and the late-stage incidence trend was higher than the US as a whole.

The late-stage incidence rate was significantly lower in Henry, Madison, and Wayne Counties in Indiana. The rest of the counties in Komen Central Indiana's service area had late-stage incidence rates and trends that were not significantly different than their respective state as a whole or did not have enough data available.

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

None of the counties in Komen Central Indiana's service area had substantially different screening proportions than their respective states 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 State of Indiana as a whole. Clinton County has a substantially larger Hispanic/Latina female population percentage than Indiana as a whole. Fayette and Parke Counties have substantially lower education levels than Indiana as a whole. Delaware and Fayette Counties have substantially lower income levels than Indiana as a whole, and together with Blackford County, they have substantially lower employment levels than Indiana 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 diagnoses 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.

Four counties in Komen Central Indiana's service area are in the highest priority category. Boone and Vigo Counties are not likely to meet either the death rate or late-stage incidence rate HP2020 targets. Rush and Vermillion Counties are not likely to meet the late-stage incidence rate. Two counties in Komen Central Indiana's service area are in the high priority category. Shelby and Wayne Counties are not likely to meet the late-stage incidence rate HP202 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 proportions
- Residents having an income less than 250 percent of the poverty level
- residents (ages 40-64) living without health insurance
- Unemployment percentages

The three selected target communities are:

- Boone, Rush, Shelby, and Vermillion Counties
- Vigo and Wayne Counties
- Marion County

**Boone, Rush, Shelby, and Vermillion Counties** were selected as a target community because they are not predicted to meet the HP2020 targets for late-stage incidence rates. The target for late-stage incidence rate is 41.0 per 100,000; each of these counties is predicted to take 13 years or longer to reach this target. Boone and Shelby Counties are also not predicted to meet the HP2020 targets for death rates. Rush and Vermillion Counties' data around death rates were suppressed due to small numbers. The target for death rate is 20.6 per 100,000. Boone County is predicted to take 13 years or longer to reach this target, and Shelby County is predicted to take eight years or longer.

**Vigo and Wayne Counties** were selected as a target community because neither is predicted to meet the HP2020 late-stage incidence rate or death rate. The target for late-stage incidence rate is 41.0 per 100,000, and both of these counties are predicted to take 13 years or longer to reach this target. The target to meet the female breast cancer death rate is 20.6 per 100,000. Vigo County is expected to take 13 years or longer to reach this target; Wayne County is expected to take eight years or longer. Interestingly, both counties currently meet the target for late-stage diagnosis rate, but with increasing trends, both counties are not expected to meet the target. Both counties have screening proportions lower than state and national levels.

**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 tenth of the 50 largest cities where non-Hispanic Black/African-American women face disparity in breast cancer deaths.

### **Health System and Public Policy Analysis**

Several resources were used to identify health care facilities that provide breast health services in the three 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, Rush, Shelby, and Vermillion Counties:** Potential barriers to care could result from the lack of public transportation available in these mostly rural counties. Additional barriers to care include few medical providers for low income, under/uninsured women and lack of dedicated patient navigators responsible for guiding women through breast health screenings at the diagnostic level.

**Vigo and Wayne Counties:** There are several options for women to access breast health services in these counties. However, Komen Central Indiana needs to develop relationships in these counties to further understand what barriers may be facing women living here.

The analysis highlights the need to have a stronger presence and collaborative relationships with partners in these 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.

**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.

### **Qualitative Data: Ensuring Community Input**

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 three target communities.

Qualitative data collection lasted several months and involved key informant interviews, focus groups, surveys, and a literature review. In total, 33 key informant interviews, six focus groups, one survey with 31 responses, and a literature review 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 three target communities.

**Boone, Rush Shelby, and Vermillion Counties:** Commonly cited system barriers for these counties include difficulty obtaining diagnostic services (including accessibility of these services), lack of insurance or lack of understanding of insurance benefits, and failure of primary care physicians to provide or refer to routine screenings. Commonly cited individual barriers to care for these counties included fear of the unknown, perceived risk, competing priorities, lack of education, underinsurance, and lack of understanding of available community resources. Facilitators to care for this target community include location of available resources, perceived risk, access to education about breast cancer risk, and an increase in comfortable medical facilities. Vulnerable populations identified through the focus groups and key informant interviews in this target community include Black/African-American, Hispanic/Latina, post-menopausal/pre-Medicare, rural women, young women, women with a family history of breast cancer, Amish women, language minorities and un/underinsured women.

**Vigo and Wayne Counties:** In Wayne County, system barriers included lack of physician referral for screening, lack of insurance, and lack of access to care. Individual barriers to care include lack of understanding of insurance benefits, prohibitive out-of-pocket expenses, and competing priorities in women's lives. The only facilitator to care mentioned for this county was translation services that are available to language minorities. Minority populations, rural women, and women who use illegal drugs were identified as particularly vulnerable populations in this community.

Despite repeated efforts, the Community Profile Team was unable to gather community input in Vigo County. As such, a literature review of relevant issues, including breast cancer and survivorship, access to care, and uninsured populations, was conducted. This review revealed common system and individual barriers, including access to care in more rural areas of these counties, competing priorities, and lack of quality insurance.

**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 Affordable Care Act and the Healthy Indiana Plan 2.0. 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 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 women and White women.

The most common findings across the qualitative data in the target communities were inextricably linked to the key questions of knowledge of, access to, and utilization of screening services as well as ability to navigate through the complexities of the Continuum of Care following a diagnosis. A majority of the system and personal barriers to obtaining breast health care identified by the qualitative data in the seven 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, focus group participants, and survey respondents made it clear that Komen Central Indiana needs to further its work in promoting available 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 to 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, 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 the 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.

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.

**Problem Statement:** **Boone, Rush, Shelby, and Vermillion Counties** are highest and high priority counties due to the fact that they are not predicted to meet Healthy People 2020 targets related to late-stage incidence and death rates. These counties share the key population characteristic of being primarily rural; hence, they were grouped together as one target community. Quantitative and qualitative data indicate poverty, unemployment, and lack of insurance as potential contributors to comparatively high late-stage incidence 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 as potential barriers that may impede receiving care.

### ***Priorities and Objectives***

1. Facilitate community awareness, education, and mobilization efforts aimed at reaching women living in low-income, rural areas.
  - a. In the RFAs for FY17 through FY19, in order to improve late-stage incidence rates, a funding priority will be to provide evidence-based education guiding women to the screening and diagnostic services most appropriate for them based on their payer (private insurance, HIP 2.0, uninsured safety nets, etc.).
  - b. In FY18, 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 these counties.
  - c. In FY18 through FY19, provide a series (at least one session per county) of educational sessions for employers, encouraging these employers to participate in initiatives that will make it easier for their employees to take time away from work to receive appropriate screening tests.

2. Increase the capacity of existing health care systems to provide seamless transition for women who are screened to diagnostic and treatment services.
  - a. In the RFAs for FY17 through FY19, in order to improve death rates, a funding priority will be to provide evidence-based patient navigation from the point a patient enters the continuum of care through their cancer journey by ensuring the patient has the resources necessary to overcome barriers to receiving care.
  - b. In FY18, hold a series of collaborative meetings (at least one per county) among local community organizations, churches, schools, etc. in rural, low-income areas to identify and develop cooperative relationships to better map available resources for reducing barriers to care in each community.

**Problem Statement:** Despite a screening percentage higher than Komen Central Indiana's 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 Komen Central Indiana's service area, and barriers to services are especially prominent for these populations.

### ***Priorities 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 women and White women, with specific messages and services relating to an increase in access to services and increased awareness within the community.
  - a. In FY18 through FY19, in partnership with community-based organizations, government agencies, churches, schools, etc. develop culturally relevant awareness, education, and outreach resources targeting the uninsured within the Black/African-American population in Marion County, guiding them to insurance enrollment and screening services.
  - b. In the RFAs for FY17 through FY19, in order to improve late-stage diagnosis rates, a funding priority will be to provide evidence-based education guiding women to the screening and diagnostic services most appropriate for them based on payment method (private insurance, HIP 2.0, uninsured safety nets, etc.).
  - c. In FY18, establish a supply chain of Komen educational materials targeting low-income, low-education, Black/African-American, and/or Hispanic/Latina women, delivered through local breast health service providers and community-based organizations in Marion County.
2. Increase the capacity of existing health care systems to provide seamless transition for women who are screened to diagnostic and treatment services.
  - a. In the RFAs for FY17 through FY19, in order to improve death rates, a funding priority will be to provide evidence-based patient navigation from the point a patient enters the continuum of care through their cancer journey by ensuring the patient has the resources necessary to overcome barriers to receiving care.

- b. In FY18, hold a series of collaborative meetings (at least three) among local community organizations, churches, schools, etc. in Marion County to identify and develop cooperative relationships to better map available resources for reducing barriers to care.

**Problem Statement: Vigo and Wayne Counties** are not expected to reach HP2020 targets related to death and late-stage incidence rates for eight to 13 years or longer. These two counties are new to the Komen Central Indiana service area, and as such, qualitative data was weaker than other target communities. However, lack of insurance, lack of physician referrals for annual mammograms, and competing priorities were identified as possible barriers to care. Additionally, through the Health Systems Analysis, the Community Profile team learned that there is a lack of breast health services in these counties outside the cities of Terre Haute and Richmond.

### ***Priorities and Objectives***

1. Facilitate community awareness, education, and mobilization efforts aimed at reaching women living in low-income and possibly rural areas of these counties.
  - a. In the RFAs for FY17 through FY19, in order to improve late-stage incidence rates, a funding priority will be to provide evidence-based education guiding women to the screening and diagnostic services most appropriate for them based on their payer (private insurance, HIP 2.0, uninsured safety nets, etc.).
  - b. In FY18, establish a supply chain of Komen educational materials targeting low-income, low-education, older women delivered through local breast health service providers and community-based organizations in these counties.
  - c. In FY18 and FY19, hold a series of educational sessions (at least one per county) to share Community Profile data with health care providers and educate providers on available resources for free and reduced cost screening for their patients.
  - d. In FY18 through FY19, determine what resources are available for specialized populations within these counties (i.e., Amish) to receive screening services and meet with resource providers to learn how Komen Central Indiana can enhance their work.
  
2. Increase the capacity of existing health care systems to provide seamless transition for women who are screened to diagnostic and treatment services.
  - a. In the RFAs for FY17 through FY19, in order to improve death rates, a funding priority will be to provide evidence-based patient navigation from the point a patient enters the continuum of care through their cancer journey by ensuring the patient has the resources necessary to overcome barriers to receiving care.
  - b. In FY18 and FY19, hold a series of collaborative meetings (at least one per county) among local community organizations, churches, schools, etc. in these counties to identify and develop cooperative relationships in order to better map available resources for reducing barriers to care in each community and create a referral pipeline to these resources.

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