



# COMMUNITY PROFILE REPORT

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# 2011

## **Disclaimer**

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The information in this Community Profile Report is based on the work of the Northern Indiana Affiliate of Susan G. Komen for the Cure® in conjunction with key community partners. The findings of the report are based on a needs assessment public health model but are not necessarily scientific and are provided "as is" for general information only and without warranties of any kind. Susan G. Komen for the Cure and its Affiliates do not recommend, endorse or make any warranties or representations of any kind with regard to the accuracy, completeness, timeliness, quality, efficacy or non-infringement of any of the programs, projects, materials, products or other information included or the companies or organizations referred to in the report.

## Acknowledgements

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To complete the 2011 Community Profile, a committee of individuals in varying professions was developed as the Planning Team: health care specialists, a fund development specialist, not for profit executives, assorted community volunteers, student interns from Saint Mary's College, the Regional Coordinator for the Indiana Breast and Cervical Cancer Program and the Affiliate Coordinator.

It was determined that the needs assessment surveys would be sent to the contacts that were listed in the Northern Indiana Affiliate Resource Guide and previous grantees. In addition to the Resource Guide contacts, community leaders including regional and local, state and federal elected officials and clergy were asked to complete the survey. The survey was posted on [Surveymonkey.com](http://Surveymonkey.com) for the convenience of those completing it and for ease in compiling the results.

Over 200 survey requests were sent allowing for determining a significant statistical analysis of the data gathered. The Planning Team reviewed the data and based on the responses, prioritized the results. In addition to the survey results, the breast health statistics and U.S. Census Bureau demographic data for the counties represented in the Northern Indiana Affiliate were compiled and evaluated.

Thank you to all who contributed to the planning process!

### **The Community Profile Planning Team**

Beth Brew, R.N., Elkhart General Hospital; Connie Guerra, R.N., Retired; Kari Gladieaux, Saint Mary's College, Intern; Mary Heck, United Health Services; Bridget Meade, Saint Mary's College, Intern; Pam Jarrett, Community Volunteer; Bonnie Raine, Aspera Consulting; Sandi Rousseve, Community Volunteer; Anita Selesky, Komen Northern Indiana Affiliate Coordinator

### **Expert Organizational Partners and Sources of Qualitative Data**

Cancer Legal Resource Center, Cancer Services of Northeast Indiana, Catherine McAuley Clinic, Community Cancer Research Foundation, Community Health Network, Congressman Donnelly's District Office, East Chicago Community Health Center, Elkhart General Hospital, Health Visions Midwest, Hope In A Handbag, Inc., Indiana Breast and Cervical Cancer Early Screening and Detection, Indiana State Dept of Health/BCCP, IU Health-Goshen, IU Health-LaPorte, Jay County Cancer Society, Journey Through Treatment, K21 Health Foundation, Logansport Regional Cancer Center, Lutheran Hospital Cancer Center, Memorial Home Care, Neighborhood Health Clinics, the physicians of Michiana Hematology Oncology, RiverBend Cancer Services, St. Anthony Medical Center, St. Joseph County Health Department, Saint Joseph Regional Medical Center, Saint Margaret Mercy Health Care Center, United Health Services, Young Survivors, the women of Curves - Rochester, the women of Dame Tu Mano, the women who prefer to be anonymous, YWCA of Greater Lafayette

## Table of Contents

<b>Executive Summary .....</b>	<b>5</b>
Introduction.....	5
Statistics and Demographic Review .....	5
Health Systems Analysis.....	7
Qualitative Data Overview .....	8
Conclusions.....	9
<b>Introduction.....</b>	<b>11</b>
Affiliate History .....	11
Organizational Structure .....	11
Description of Service Area.....	12
Purpose of the Report.....	14
<b>Breast Cancer Impact in Affiliate Service Area.....</b>	<b>15</b>
Methodology.....	15
Overview of the Affiliate Service Area .....	15
Communities of Interest.....	19
Conclusions.....	19
<b>Health Systems Analysis of Target Communities .....</b>	<b>21</b>
Overview of Continuum of Care.....	21
Methodology.....	21
Overview of Community Assets.....	22
Legislative Issues in Target Communities .....	24
Key Informant Findings.....	25
Conclusions.....	26
<b>Breast Cancer Perspectives in the Target Communities.....</b>	<b>27</b>
Methodology.....	27
Review of Qualitative Findings .....	28
Conclusions.....	30
<b>Conclusions: What We Learned, What We Will Do .....</b>	<b>32</b>
Review of the Findings .....	32
Conclusions.....	33
Action Plan.....	33
<b>References .....</b>	<b>36</b>

## Executive Summary

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### Introduction

The northern tier of the State of Indiana became acquainted with Susan G. Komen for the Cure® as its Ultimate Drive for the Cure wound its way over the highways and by-ways of the region. Three years later in 2006, breast health advocates and community leaders combined to bring the Susan G. Komen Northern Indiana Affiliate into existence.

The Affiliate supports 27 counties across northern Indiana stretching between the Ohio and Illinois borders - essentially the northern third of the state and home to fully 35.5 percent of its population in Adams, Allen, Benton, Carroll, Cass, DeKalb, Elkhart, Fulton, Huntington, Jasper, Kosciusko, LaGrange, Lake, LaPorte, Marshall, Miami, Newton, Noble, Porter, Pulaski, St. Joseph, Starke, Steuben, Wabash, Wells, White, and Whitley counties. To assure it would be most responsive to community needs, the Affiliate divided its 27 county Service Area into three main activity centers: the north central area including the South Bend, Mishawaka and Elkhart urban area; the north eastern area including Fort Wayne; and the north western region bordering on Chicago and including Gary, Hammond and Merrillville. It should be noted that while Indiana generally is minimally diverse racially and ethnically, pockets of diversity do exist, typically in the more urbanized portions of the Service Area. Age distributions in the Northern Indiana Affiliate Service Area roughly parallel those throughout the State of Indiana with women 65+ accounting for a slightly larger percentage, indicating a slightly older cohort than the state.

As a new Affiliate, one of the Board's first tasks was to engage a strategic planning process to focus the direction of long and short term activities it would complete in order to enhance its capacity to improve women's lives through living out the Komen mission. The Affiliate's main concern was to address the gaps in service that it had identified. Its vision is to be the premier resource in Northern Indiana for information/education on the prevention and treatment of breast cancer, outreach services to targeted populations, and funding for local breast cancer projects.

Since the time of its inception, the Northern Indiana Affiliate's major accomplishments include: the development of a comprehensive Breast Health Resource Guide; collaboration with other Komen Indiana Affiliates and breast health agencies to lobby the State of Indiana for improved breast health policy; distribution of educational material to partner agencies and health care providers; and, following its three successful Race for the Cure events, providing grants amounting just over \$406,000 to fund 36 programs in 17 organizations.

The overall purpose of the Komen Community Profile process is to assure that the Northern Indiana Affiliate has the tools it needs to meet its organizational mission throughout the Service Area. This Community Profile will assist the Affiliate in understanding the state of breast cancer in this Service Area and in targeting its efforts on gaps and needs. The Community Profile is a device to assist the Affiliate in being strategic and focused in its grant making, its educational efforts and its public policy priorities. The Profile also helps set the direction for strengthening partnerships and outreach. As the Affiliate's presence increases across northern Indiana, it is the goal that these strategic and targeted approaches will ultimately benefit the women and men throughout the 27 county Affiliate Service Area.

### Statistics and Demographic Review

A variety of data sources were used to prepare the Community Profile (CP). The Profile Team chose several important indicators of breast health for the Affiliate Service Area, primarily:

breast cancer incidence, breast cancer mortality, stage of diagnosis and mammogram participation. Its primary resource for quantitative data was the Indiana State Department of Health's Cancer Registry. Additional data were obtained from the U.S. Cancer Statistics Working Group web-based report through the National Cancer Institute/Centers for Disease Control and Prevention, Behavioral Risk Factor Surveillance System (BRFSS), and Surveillance Epidemiology and End Results (SEER) and the Indiana Breast and Cervical Cancer data. These data were compared to estimates prepared by Thomson Reuters and provided to, and by, Komen Headquarters. In most cases Thomson Reuters data were used only to confirm data from other sources or to amplify or supplement them where necessary. Because health disparities and disproportionality can exist among racial and ethnic groups, data were also parsed using demographic profiles for the Service Area. These additional data were compared to those obtained from the U.S. Census Bureau. Citations for the data sources can be found appended to this Community Profile. The data were analyzed by the Affiliate CP Planning Team.

The Team focused on three significant factors as indicators of the Affiliate Area's breast health: high mortality rates, high rates of late stage diagnosis, and low mammogram screening rates. While there are a number of counties that appear to be "outliers" on any given indicator, data suggest that there are six counties that have all three significant factors: (1) mortality rates >10percent above State and U.S. averages, (2) late stage diagnosis rates that exceed the State of Indiana average and (3) mammography percentages that are less than the State of Indiana percentage. These counties suggest themselves as "Communities of Interest" and include Fulton, Lake, Marshall, Miami, Pulaski and Starke. Fully 19 of the 27 counties in the Northern Indiana Affiliate Service Area have mammogram rates that are lower than the State of Indiana rate. Finally, there are racial and ethnic populations which raise questions for the Community Profile process. While nationally, late stage diagnosis and mortality rates for African Americans are higher than for white women, Lake County mortality rates and late stage diagnosis rates for African American women are also higher than State of Indiana mortality rates for African American women. Breast Cancer incidence rates for African American females in Elkhart County are higher than State incidence rates for African American females.

Of Fulton, Lake, Marshall, Miami, Pulaski and Starke counties mentioned above, it should be noted that all but Lake are sparsely populated, rural counties. This suggests that the Service Area might well consider a "rural strategy" in its planning. There are also racial and ethnic populations which raise questions for the Community Profile process. In key informant interviews, questions about the state of breast health among Latinas, especially in the counties with greater Hispanic populations, were constantly raised as well. Additional concerns were raised about the Burmese population of Allen County and the Amish women of six Affiliate Area counties. Poverty rates throughout the Affiliate Area are at the state average, with some outliers.

The Community Profile Team determined to focus where breast cancer mortality rates were high, the percentage of late stage diagnosis was high and mammography percentages were low as "Communities of Interest". With the exception of Lake County, the counties with all three significant factors, are rural. Lake County, on the other hand, presents a demographic profile that is very different. 5.5 times more densely populated than the State of Indiana as a whole, Lake County boasts a diversity which is uncharacteristic of the Hoosier state. Its African American population represents 25.9 percent of all its residents (compared to 9.1 percent in the State of Indiana) and a Hispanic population representing 16.7 percent of county residents (compared to

six percent in the State as a whole). There are racial and ethnic populations which raise questions for the Community Profile process outside of Lake County. St. Joseph and Elkhart counties have African American and Latina populations that are also significantly higher than the State. In key informant interviews, questions about survivors were constantly raised as well.

Although increasing mammogram rates for all women over 40 in the entire Service Area is critical, the following Target Communities emerged from the CP process: (1) Rural populations - while five counties in the Affiliate Service Area have all three significant factors, they are attributable to the population density and economic factors consistent with their rural nature. (2) Minority women - developing culturally responsive approaches to increase mammogram rates will go a long ways to reducing late stage diagnosis and mortality rates, especially among African American women. Specific focus on Lake County is vital because of its unique combination of population density, racial and ethnic diversity, socio-economic challenges and health outcomes. Amish women in the northeastern portion of the Affiliate Service Area need to be considered. (3) Survivors - qualitative data sections of key informant interviews indicated the importance of programs for survivors. Acknowledging the relevance of the mantra, “a ‘Survivor’ is an individual who has been diagnosed with breast cancer. Survivorship begins at the moment of diagnosis,” is important for understanding issues for women in the continuum of care.

### **Health Systems Analysis**

While researching data about breast care in the Affiliate Service Area, if “outliers” with reference to State of Indiana or national trends emerged, the Community Profile Team did a “deeper dive” into the data through surveys and key informant interviews. A list of key informants for surveying was developed from a combination of health care providers, specialized services, support service providers and community leaders from throughout the Affiliate Service Area. The Profile Team monitored responses to assure that each region of the Affiliate Service Area was adequately represented and that diverse agencies and health care providers had responded. Follow up contacts were made to request the completed survey from those areas that were underrepresented. Over 30 responses were recorded. In addition to surveys, the Team executed interviews with specialty breast service providers. Some of the organizations that were of particular interest included grass roots service providers, medical clinics for low-income individuals, hospitals of large metropolitan areas, non-profit service organizations, government entities, and mammography facilities. The Team engaged in an asset mapping process as a method of visualizing important sites and services within the Northern Indiana Service Area’s target communities. This process gave the Team an understanding of existing resources and their locations throughout the Service Area, as well as a vision of where opportunities might exist for the development of community partnerships and the possibility for grants throughout the Service Area. An inventory of assets was taken from the Resource Guide developed by the Affiliate. In addition, resources initiated by grantees from 2007-2010 were added.

Despite robust assets throughout the Service Area, gaps and barriers to accessing the continuum of care abound. A comprehensive listing of all mammography and health care facilities, specialized health care assets and support service organizations within the three regions of the Affiliate Service Area largely shows a disconcerting, though obvious, trend. While each region has breast health resources which can serve women within the continuum of care, the accessibility of those resources is limited. Each region in the Area has both urban and rural areas with resources concentrated in its more densely populated locations. The Service Area has four

Regional Offices for the Indiana Breast and Cervical Cancer Program (BCCP) to serve low income women. All have committed to play an important role by encouraging the development of resources in the Target Communities; however the BCCP has received flat funding for the past five years allowing only 12 percent of eligible women in Indiana to enroll. Beyond that, additional financing options are a real need for women in the targeted communities. In order to improve outcomes in the Service Area and statewide, Komen needs to make health care access through insurance extension a real priority.

In analyzing the data on incidence, mortality, insured status, and disproportional representation overlaid on the geography and accessibility of resources throughout the Affiliate Service area, several conclusions were drawn by the Profile Team. Geographic remoteness from health care resources is an issue in the region. In rural areas, lack of proximity to resources is the concern; in urban areas, transportation to resources is the issue. Breast cancer mortality is disproportionately high among African American women in Lake and Allen Counties. While these populations live closer to facilities than their rural white counterparts, they are generally women of low income status. Surveys told us that all populations of women who are at or below certain economic thresholds struggle to make entering the continuum of care a priority due to: work and family obligations, the cost of insurance and co-pays, the cost of transportation and the fear of not having financial resources to address a positive diagnosis should one be given. The health system in the Affiliate Service Area could be more effective in assisting women to enter and complete the continuum of care if there were more financial assistance programs available, health care providers made outreach and cultural responsiveness a higher priority, there was a rural strategy to address women in less densely populated areas and that there were more consistent messages from highly trusted health care providers about the priority of screening mammograms for women in maintain their breast health.

### **Qualitative Data Overview**

To further refine its understanding of breast health indicators in the Affiliate Service Area, the Community Profile Team talked to women from the target communities themselves in order to understand their knowledge, attitudes and beliefs about breast cancer and breast cancer resources in their communities. A variety of methods was chosen to collect data from women in the community who were not service providers: key informant surveys, key informant interviews and focus groups. Some 240 questionnaires were distributed with a nearly 15 percent (original) response rate. Non-service providers responded to questions primarily related to areas of most need (treatment, screening materials, education materials), type of care provided in the community (screening, counseling, treatment), groups of women who are underserved, opinions about barriers to care, how to remove those barriers and what changes were needed in the communities to improve access to the continuum of care. Recipients were targeted across all areas but were particularly targeted if they represented minority or otherwise underserved women. Among communities of interest: women in specific rural communities, women over 40 who had not had a mammogram in the last 12 months, uninsured women, women who represent certain minority populations (African Americans, Latinas, Amish) and survivors. One focus group was conducted and a dozen additional key informants were interviewed/surveyed.

Several key themes emerged from the focus groups and key informant interviews about their capacity to access and sustain in the continuum of care:

- 1) Lack of access to the continuum of care was seen as a problem due to remote geography, transportation and, most importantly, lack of insurance.
- 2) The need to distinguish between the availability of assets for gaining access to the continuum of care through mammography and following up through diagnostic procedures and treatments is important. Co-pays for the un- and underinsured who do not qualify for programs for low income women, can be debilitating.
- 3) Lack of reliable and trusted, culturally competent information about the importance of mammography, and its safety, geared to the needs of specific populations written in a style that is meaningful, understandable and language-specific, needs to be part of overall outreach strategies. Personal feelings of well-being and being asymptomatic do not predispose women to seek out information or be attentive to it when available.
- 4) Responsiveness of health care professionals, specifically doctors can be a barrier. While valued for their opinions, recommendations and clinical care by most informants, representatives of minorities and survivor populations expressed concerns. Physicians are often not trusted in minority communities for a variety of reasons. In some populations, most often minorities though not exclusively, the gender of the physician matters with females being preferred. Also, survivors reported that receiving adequate information about treatment options, treatment side effects and ultimately living with cancer were not things that their physicians devoted an adequate amount of time to with them.
- 5) The existence of factors, well out of the purview of the health care system, and influencing women including those who struggle with low economic status is a critical concern. Competing priorities of finance, family obligations, and employment requirements do not allow breast health promotion to emerge as a priority. This requires a different sort of planning that takes into account motivation for behavioral change.

## **Conclusions**

The Susan G. Komen Northern Affiliate Community Profile Team analyzed these findings and drew four conclusions from them from which they developed an Action Plan.

- 1) Increasing mammogram participation rates for all women throughout the Affiliate Service Area is a priority. With 19 of the 27 counties falling below the state average, there is a lot of catching up to do. This is consistent with the Indiana Cancer Consortium goal to increase the percentage of women age 40 and older who receive annual breast screening from 62 percent to 67 percent. *Goal- Increase the rate of mammogram participation by: increasing the opportunities for women to have mammograms and promoting evidence based practices to assist women in making a decision to have a mammogram.*
- 2) Rural populations –Five rural counties in the Affiliate Service Area have particularly poor breast health indicators/outcomes. However, the vast majority of the Service Area is rural. Additional information gathering suggests that access to financial resources, access to health care resources and lack of reliable information about the importance of mammography as well as the power of certain myths about mammograms, are all factors worthy of planning. Developing a rural strategy that increases women’s access is vital. *Goal-Develop and disseminate an evidence supported rural strategy that will increase the mammogram participation rate in rural counties throughout the Affiliate Service Area.*
- 3) Minority women - Developing culturally responsive approaches to increase mammogram rates will go a long way toward reducing late stage diagnosis and mortality rates, especially among African American women. Programs that specifically focus on the needs of African Americans and Latinas, and address the concerns that informants raised on their inability and

unwillingness to enter the continuum of care, should be developed. Specific, though not exclusive, focus on Lake County is vital because of its unique combination of population density, racial and ethnic diversity, socio-economic challenges and health outcomes.

Continuing focus on Amish women in the northeastern portion of the Affiliate Service Area and the Burmese women of Allen County need to be considerations as well. *Goal-Develop and or disseminate culturally responsive programs geared toward increasing screening mammogram participation of African American and Hispanic women throughout the Affiliate Service Area.*

- 4) Survivors - Qualitative data sections of key informant interviews indicated the importance of programs for survivors. Acknowledging that survivorship begins at the moment of diagnosis is important for understanding issues which women in the continuum of care have before, during and after treatment. Developing strategies to assure that the continuum of care from diagnosis to “how to live with cancer” is not only a goal suggested by our key informants but is consistent with the literature, as well. *Goal-Develop and promote programs that focus on supporting survivors within the continuum of care.*

## Introduction

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### **Affiliate History**

The Susan G. Komen Northern Indiana Affiliate was incorporated in 2006 following two years of investigating the needs of the area, aligning key partnerships, and building support in the 27 counties and communities represented across northern Indiana. Recognizing that significant breast health concerns existed across the region both in needs for increased awareness and available resources, the regional office of the Indiana Breast and Cervical Cancer Program at United Health Services, RiverBend Cancer Services (an independent cancer services organization), and the Junior League of South Bend, united to apply for Komen Affiliation status. At the time of application, it was determined that incorporating the 27 counties of northern Indiana into one Affiliate Service Area would serve to cover most of the State of Indiana with Komen affiliates.

Whereas other Affiliates developed from a local Race for the Cure, the Northern Indiana Affiliate is unique in that there was not a considerable Komen presence in this region. The BMW Ultimate Drive for the Cure at three dealerships in Northern Indiana was its most visible presence.

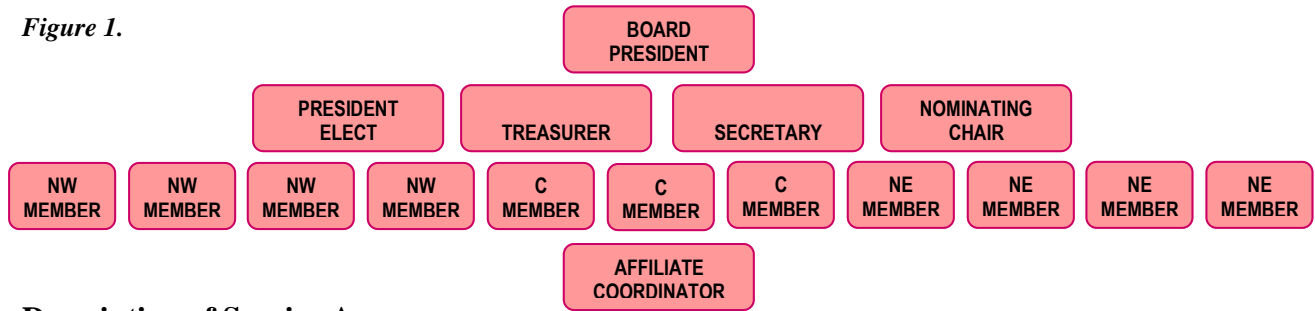
As a new Affiliate, one of the Board's first tasks was to complete a strategic planning process to focus the direction of long and short term activities that it would complete. The main concern was to address the gaps in service that were identified in the Affiliate application.

Since 2006, major accomplishments of the Northern Indiana Affiliate include: the development of a comprehensive Breast Health Resource Guide, collaboration with other breast health agencies to lobby the State of Indiana for improved breast health policy, distributing education material to partner agencies and health care providers, implementation of an October Awareness Campaign, providing grants amounting to just over \$406,000 to programs meeting Affiliate priorities, developing and holding the Affiliate's Race for the Cure, participation in several Komen branded events (e.g. BMW Ultimate Drive, the Yoplait lid program, "Rally for the Cure" events, Coldwater Creek's "Try It On for the Cure" and "Passionately Pink"), planning several local fundraisers, holding Annual Survivor Luncheons in all three areas of the Affiliate, and promoting the Affiliate profile so that it has become the beneficiary of numerous third party fund raising events.

### **Organizational Structure**

Considering the number of counties that were part of the Northern Indiana Affiliate, its diverse nature, and population hubs, it was determined that the Affiliate would be divided into 3 areas (Northwest, Central and Northeast). The Board of Directors is made up of representatives from each of the three areas that constitute the Northern Indiana Affiliate. The Governance structure is illustrated in Figure 1 below. With each geographic area having a specific set of goals unique to its particular needs, it convened its own Education Committee and developed its own Fund Development Plan (including marketing opportunities) within the area. A part time Coordinator was hired in 2008 which significantly improved the Affiliate's capacity to reach out to the communities it serves and raise awareness of the Komen mission.

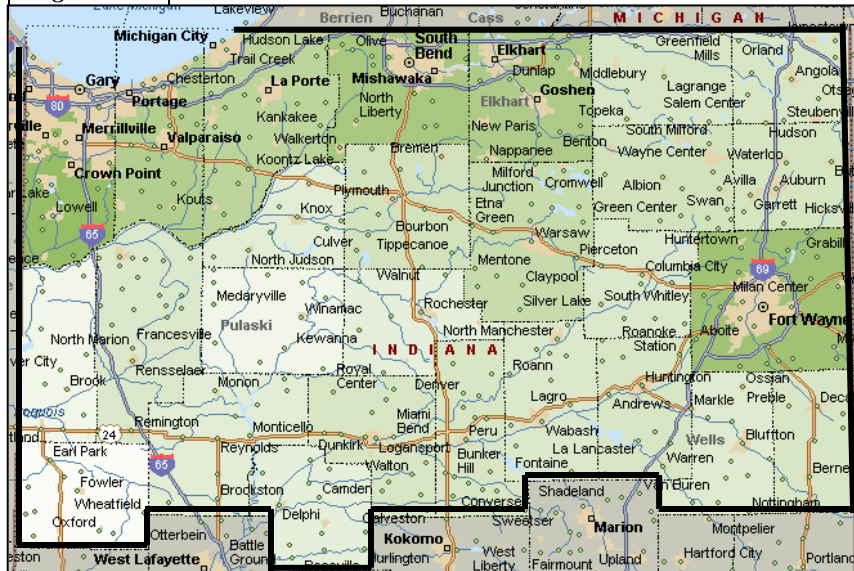
Figure 1.



**Description of Service Area**

In order to provide a context for our cancer data analysis it is important to understand a basic geographic and demographic profile of the Susan G. Komen Northern Indiana Affiliate.

Figure 2.



**Geography.** The service area encompasses the 27 counties of Northern Indiana, essentially the northern third of the state and home to fully 35.5 percent of its population: Adams, Allen, Benton, Carroll, Cass, DeKalb, Elkhart, Fulton, Huntington, Jasper, Kosciusko, LaGrange, Lake, LaPorte, Marshall, Miami, Newton, Noble, Porter, Pulaski, St. Joseph, Starke, Steuben, Wabash, Wells, White, and Whitley.

Figure 2 illustrates population density in counties with darker green representing higher levels of density (Lake, St. Joseph, Allen) and white less (Benton, Pulaski, Newton) with variations in between. Figure 2 also shows three densely populated metro regions in the Affiliate Area: Gary/Merrillville in the northwest, South Bend/Elkhart in the central area, and Fort Wayne in the northeast. Each of the three areas represents a regional economy as a center for employment, health care, education, retail commerce, and support services. In addition, there are commercial corridors on the perimeter of the Affiliate Service Area which extend outside the region and connect to Michigan, Chicago and Lafayette (Indiana). Taken as a whole, the region is not densely populated outside of these urban areas.

**Ethnicity.** Ethnicity is also important to our considerations. While Indiana generally is minimally diverse racially and ethnically, pockets of diversity do exist. Ethnic enclaves are prominent in the Northern Indiana Affiliate Service Area. The more urbanized portions of the Service Area, including Lake County, the city of Fort Wayne in Allen County, the city of South Bend in St. Joseph County and Elkhart city in Elkhart County, all account for a higher percentage of racial and ethnic diversity than in the Affiliate Service Area as a whole, or in the State of Indiana taken as a geographic unit. This is illustrated by the findings in Table 1, below.

Table 1. Northern Indiana Affiliate Area - Race/Ethnicity									
County	Total	White	% White	Black	% Black	Asian	% Asian	Hispanic	%Hispanic
Adams	34387	33642	97.8	190	0.6	119	0.3	1412	4.1
Allen	355329	291063	81.9	47666	13.4	11438	3.2	23093	6.5
Benton	8854	8586	97	78	0.9	22	0.2	431	4.9
Carroll	20155	19687	97.7	111	0.6	52	0.3	711	3.5
Cass	38966	34942	89.7	787	2	497	1.3	4897	12.6
DeKalb	42223	41392	98	298	0.7	264	0.6	1031	2.4
Elkhart	197559	168311	85.2	13745	7	2597	1.3	27886	14.1
Fulton	20836	20019	96.1	244	1.2	129	0.6	882	4.2
Huntington	37124	36463	98.2	295	0.8	243	0.7	631	1.7
Jasper	33478	32375	96.7	310	0.9	194	0.6	1823	5.4
Kosciusko	77358	73202	94.6	871	1.1	832	1.1	5634	7.3
LaGrange	37128	36168	97.4	182	0.5	196	0.5	1317	3.5
Lake	496005	329031	66.3	133434	26.9	7952	1.6	82663	16.7
LaPorte	111467	96128	86.2	13400	12	883	0.8	6093	5.5
Marshall	47051	44694	95	446	0.9	306	0.7	3971	8.4
Miami	36903	34512	93.5	1941	5.3	219	0.6	906	2.5
Newton	14244	13846	97.2	91	0.6	51	0.4	717	5
Noble	47536	44565	93.8	335	0.7	267	0.6	4567	9.6
Porter	164343	152894	93	5884	3.6	2690	1.6	13933	8.5
Pulaski	13402	13159	98.2	104	0.8	50	0.4	325	2.4
St. Joseph	266931	216802	81.2	38255	14.3	6342	2.4	19395	7.3
Starke	23363	22970	98.3	132	0.6	75	0.3	766	3.3
Steuben	34185	33400	97.7	275	0.8	248	0.7	982	2.9
Wabash	32888	32112	97.6	272	0.8	179	0.5	697	2.1
Wells	27636	27132	98.2	187	0.7	141	0.5	564	2
White	24643	23471	95.2	126	0.5	140	0.6	1746	7.1
Whitley	33292	32852	98.7	199	0.6	184	0.6	515	1.5

SOURCE: U.S. Census Bureau. (Updated June 7, 2011). State and County Quickfacts

Table 1 indicates that our service planning must account for the possibility of ethnic differences and health care disparities in certain portions of the Affiliate Service Area. Whites account for 84.3 percent of Indiana’s total population with an even higher proportion in the 27 counties of the Affiliate Service Area. Allen, Lake, and St. Joseph are the only counties in the Area with percentages of whites lower than the state average. The highest percentage of African Americans resides in those same three counties and Elkhart city.

Hispanics account for six percent of the total population in the State of Indiana and nine percent in the Affiliate Service Area. There are nine counties in the Service Area where the proportion of Hispanics relative to the total population is greater than the state: Lake (16.7), Elkhart (14.1), Cass (12.6), Noble (9.6), Porter (8.5), Marshall (8.4), Kosciusko (7.3), St. Joseph (7.3), White (7.1), and Allen (6.5) (U.S. Census Bureau, 2011).

It is worth noting that while the Asian population of Allen County is three percent, that represents a significant Burmese refugee population of over 8,000, the largest population of its type outside of Myanmar. Finally, the Affiliate Service Area is home to the third largest Amish population in the country with nearly 44,000 members residing in Adams, Allen, Elkhart, LaGrange, Miami, and Whitley counties (Young Center, 2010).

**Age.** Table 2 illustrates that women 40-49 years of age represent 13.4 percent of the total female population for the Affiliate Area which is comparable to state proportions (13.6). However, Benton, DeKalb, Newton, Porter, Pulaski, Steuben, and Whitley demonstrate slightly higher proportions. This has significance for consideration as BCCP screens only women age 50+. This

population has also received mixed messages in recent years about the efficacy of screening mammograms for their age group. Women 50-64 years of age account for 19.2 percent of the total female population for the State of Indiana and 19.5 percent for the Affiliate Service Area. Women 65+ account for 14.6 percent of the total female population for the State of Indiana and 15 percent of the total female population for Northern Indiana Affiliate Service Area, indicating a slightly older cohort than the state generally.

County	Female Population	40 to 49 years	Percent 40 to 49 years	50 to 64 years	65+ years
Adams	17388	2061	11.9%	2980	2765
Allen	182108	24117	13.2%	34002	24433
Benton	4469	648	14.5%	888	810
Carroll	10055	1358	13.5%	2147	1756
Cass	19488	2608	13.4%	3799	3401
DeKalb	21281	2988	14.0%	4177	3170
Elkhart	100101	13253	13.2%	17916	13719
Fulton	10477	1365	13.0%	2180	1944
Huntington	18885	2578	13.7%	3777	3171
Jasper	16812	2310	13.7%	3305	2578
Kosciusko	38892	5352	13.8%	7603	5827
LaGrange	18400	2162	11.8%	2990	2364
Lake	256622	34749	13.5%	51018	38413
LaPorte	53826	7430	13.8%	11499	9040
Marshall	23769	3236	13.6%	4556	3992
Miami	17216	2393	13.9%	3550	2849
Newton	7050	1015	14.4%	1516	1294
Noble	23751	3236	13.6%	4633	3398
Porter	83579	11965	14.3%	17571	11490
Pulaski	6635	956	14.4%	1389	1218
St. Joseph	137519	17726	12.9%	25862	20839
Starke	11827	1644	13.9%	2488	1916
Steuben	16935	2372	14.0%	3645	2764
Wabash	16914	2187	12.9%	3411	3459
Wells	14034	1934	13.8%	2871	2509
White	12523	1714	13.7%	2690	2370
Whitley	16739	2370	14.2%	3644	2674

SOURCE: U.S. Census Bureau. (Updated June 7, 2011). State and County Quickfacts

### **Purpose of the Report**

The overall purpose of the Komen Community Profile process is to assure that the Northern Indiana Affiliate has the tools to meet its organizational mission throughout the Service Area. This Community Profile will assist the Affiliate in understanding the state of breast cancer in this Area and targeting its efforts on gaps and needs. With the completion of the 2011 Community Profile, the Affiliate will embark on a strategic plan to guide its work for the next three years. The Community Profile is a device which challenges the Affiliate to be strategic and focused in its grant making, its educational efforts and its public policy priorities. The Community Profile also points the Affiliate in the direction of strengthening partnerships and outreach. As the Affiliate's presence increases across northern Indiana, it is the goal that these strategic and targeted approaches will ultimately benefit the women and men throughout its 27 county Service Area.

## Breast Cancer Impact in the Susan G. Komen for the Cure® Northern Indiana Affiliate Service Area

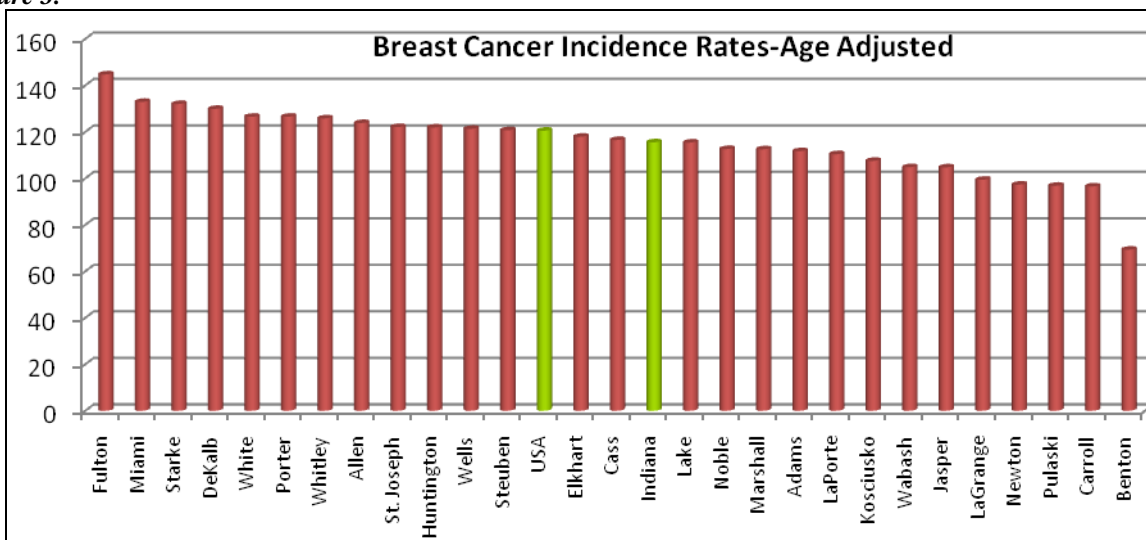
### Methodology

A variety of data sources were used to prepare the Komen Northern Indiana Affiliate Community Profile (CP). The Profile Team’s primary resource for quantitative data was the Indiana State Department of Health’s Cancer Registry. Additional data were obtained from the U.S. Cancer Statistics Working Group web-based report through the National Cancer Institute/Centers for Disease Control and Prevention, Behavioral Risk Factor Surveillance System (BRFSS), and Surveillance Epidemiology and End Results (SEER), and the Indiana Breast and Cervical Cancer data. It should be noted that most these data lag years. These data were compared to estimates prepared by Thomson Reuters and provided to, and by, Komen Headquarters. In most cases Thomson Reuters data were used only to confirm data from other sources or to amplify or supplement them where necessary. Additional data were obtained from the U.S. Census Bureau. Finally, where it made sense to do so, the quantitative data were compared to qualitative data available from key informant interviews, for the purpose of raising questions relative to target communities in order to set the stage for the Health Systems Analysis. The data were analyzed by the Affiliate CP Planning Team.

### Overview of Key Demographic and Breast Cancer Statistics for the Komen Northern Indiana Affiliate Service Area

#### Affiliate Area Breast Cancer Diagnosis

Figure 3.



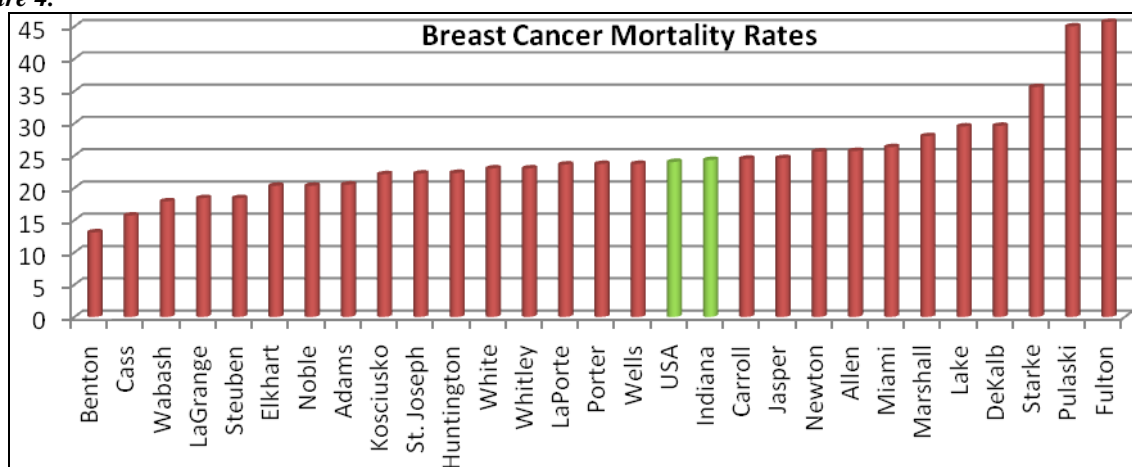
SOURCE: Breast cancer incidence rates per 100,000 – age adjusted 2004-2008. Indiana State Department of Health, Indiana State Cancer Registry

Data show (Figure 3) U.S. age adjusted breast cancer incidence rates at 121, with State of Indiana averages at 116 per 100,000. The incidence rate for the Northern Indiana Affiliate Service Area taken as a whole is 123. Within the Service Area counties higher than national rates include Fulton (145), Miami (133), Starke (132), DeKalb (130), Porter (127), White (127), Whitley (125), and Allen (124). It should be noted that while these incidence rates are higher, they are indicated, with the exception of Allen, in rural counties with smaller populations representing a much smaller population of women.

Health disparities can be discerned by comparing incidence rates among racial, ethnic or economic sub-groups. Eliminating data where rates were unstable for non-white groups, incidence rates higher than State incidence rates include breast cancer in African American females in Elkhart County. While the Indiana State Department of Health Tumor Registry does not break out Hispanic women as a separate category, we do know that in its 2007 data, the National Program of Cancer Registries shows that Hispanic women in Indiana have a higher incidence rate (101.3) than Hispanic women nationally (88.2).

Over 300 women in the Northern Indiana Affiliate Service area die each year with breast cancer. Adequate screening can often be a factor influencing incidence rates, so these data should be correlated with mortality rates. Northern Indiana Affiliate Area mortality rates are illustrated in Figure 4. Counties in the Northern Indiana Affiliate Area that had mortality rates >10 percent above State of Indiana (24.3) and U.S. (24) averages include Fulton (45.7), Pulaski (45), Starke (35.6), DeKalb (29.9), Lake (29.5), Marshall (28), and Miami (26.3). With the exception of Allen and Lake Counties, these areas are rural representing small numbers of women

**Figure 4.**



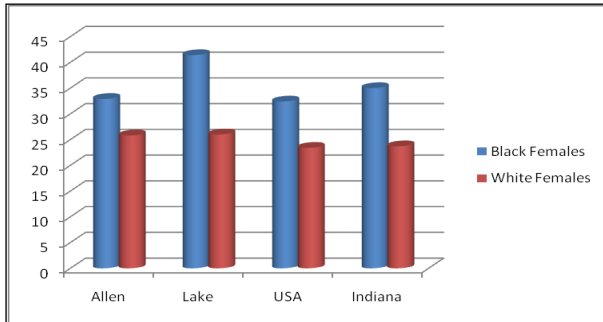
SOURCE: Breast mortality rates per 100,000 – age adjusted 2003-2007. Indiana State Department of Health, Indiana State Cancer Registry

When adjusted to eliminate rates with unstable data, Allen and Lake Counties show mortality rates for African American women that are significantly higher than for white women (cf. Figure 5). Lake County rates are also higher than State of Indiana or U.S. mortality rates. It is worth noting that 2007 data from the National Program of Cancer Registries within the NCI show that African American females in Indiana have a higher mortality rate (36.9) than white females (23.3) and a higher mortality rate than African American females across the U.S. (32.4).

Mortality taken together with stage of diagnosis is also a useful indicator. The average mortality rate for late stage diagnosis in the state of Indiana is 6.6. Counties in the Affiliate exceeding the state average (Figure 6) include Fulton (10.4), Newton (10.2), Miami (10.1), Starke (10), Lake (9.1), Steuben (8.5), Marshall (8.5), White (8.4), Kosciusko (8.3), Wabash (8.2), Pulaski (8), St. Joseph (7.2), Noble (7.1), Carroll (6.7), and Allen (6.7).

While this is illustrative, when these rates are analyzed for statistical significance (i.e., eliminating counties with rates based on fewer than 20 cases, therefore considered unstable), Lake and St. Joseph Counties were the only counties with late stage diagnosis rates higher than the State of Indiana. Lake County (12.2) late stage diagnosis rates for African American

**Figure 5. Breast Cancer Mortality Rates Black and White Females Compared Selected Counties**

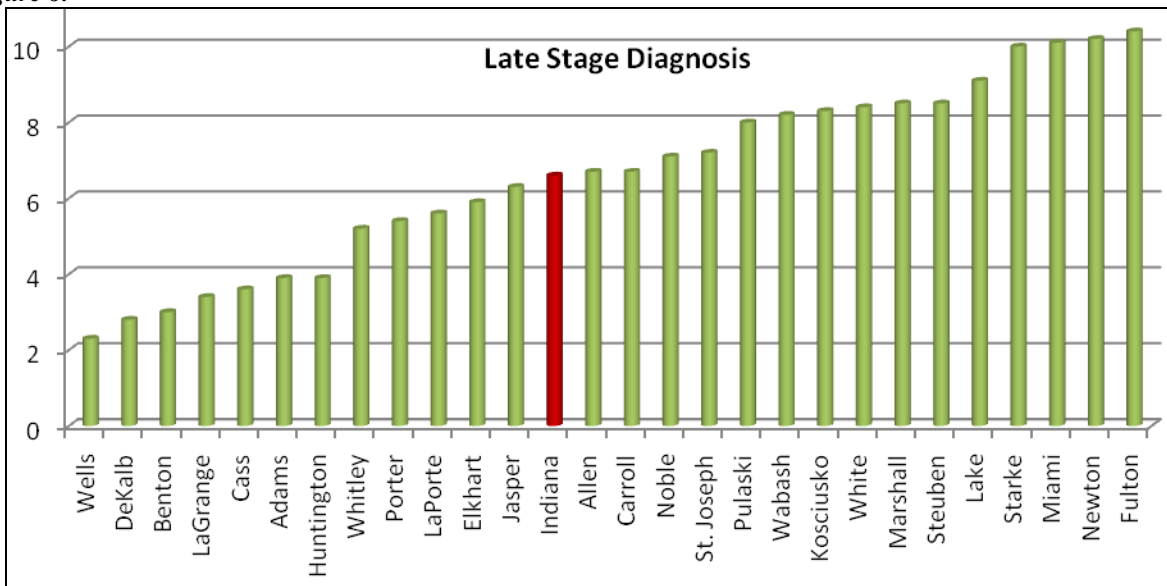


women are also 20 percent higher than the average State rate (10.1) for African American women.

Late stage diagnosis taken together with mortality and mammogram rates can be another indicator of a community’s breast cancer profile. Mammography is considered the best screening tool used today to detect breast

SOURCE: Breast mortality rates per 100,000 – age adjusted 2003-2007. Indiana State Department of Health, Indiana State Cancer Registry

**Figure 6.**



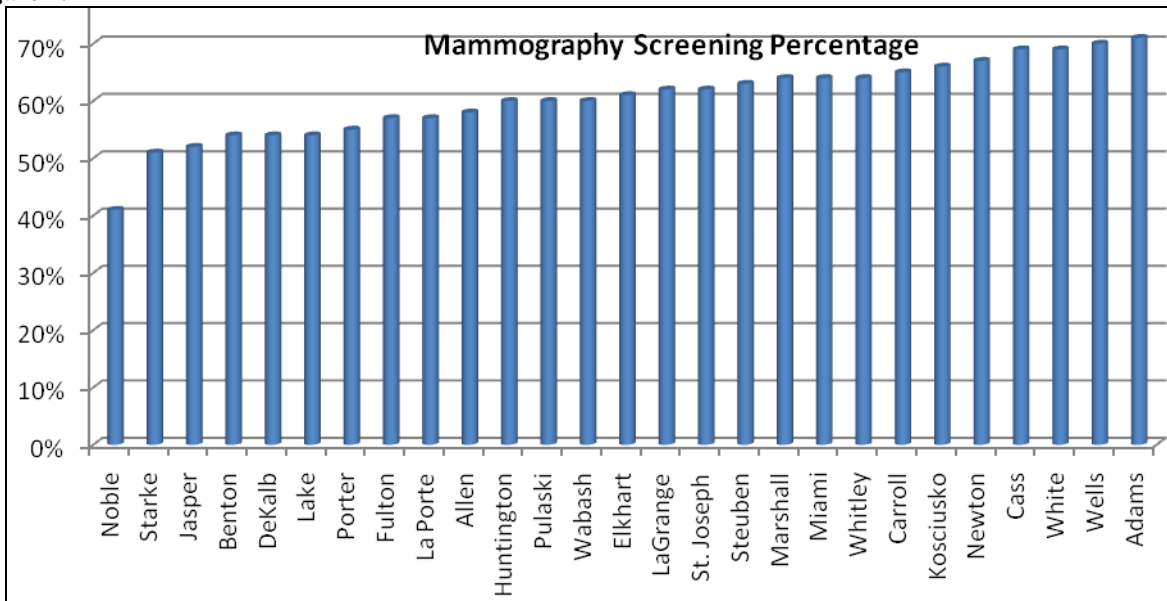
SOURCE: Breast cancer mortality rates stage of diagnosis-age adjusted 2004-2008. ISDH, Indiana State Cancer Registry

cancer at its earliest, most treatable stages since it has the ability to detect breast cancers before they can be felt. For women at average risk for breast cancer, Komen recommends having a mammogram every year starting at age 40. In fact, the recent release of the 29 year Umeå University-directed national SCRY Study in Sweden, the largest study of its kind ever performed anywhere in the world, demonstrates that mammography examinations of women aged 40-49 reduce breast cancer mortality by 29 percent, a statistically significant reduction. Hence, examining the Affiliate Area’s rate of mammogram utilization contributes to a more complete understanding of the community’s breast cancer profile. The mammogram screening rate national benchmark is 74 percent while the State of Indiana’s average is 61 percent.

While the *Healthy People 2010* objective of 70 percent participation in mammography within the prior 2 years is an important benchmark, the 61 percent State average was used here. Using two data sources we can get a more adequate picture of mammogram screening rates in the Affiliate Area’s 27 counties. Figure 7 illustrates Medicare data for the Affiliate Area’s counties with several counties mammogram screening rate of *less than 60 percent*: Allen (58), LaPorte (57), Fulton (57), Porter (55), Lake (54), DeKalb (54), Benton (54), Jasper (52), Starke (51) and Noble (41). Thomson Reuters estimates of the percentage of women 40+ with “*No* Mammogram in the

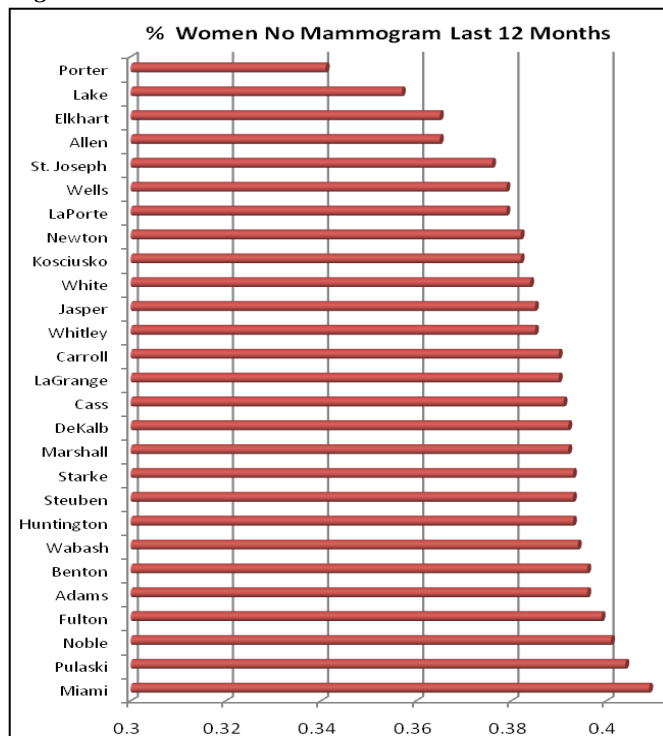
Last 12 Months” at rates *over 39 percent* that correlate with the Medicare data, include Noble (40.1), Fulton (39.9), Benton (39.6), Starke (39.3) and DeKalb (39.2) counties. Additional counties suggested by the Thomson Reuters estimates include Miami (40.9), Pulaski (40.4), Adams (39.6), Wabash (39.4), Huntington (39.3), Steuben (39.3), Marshall (39.2), and Cass (39.1) (Figure 8). Using the Medicaid mammogram screening rate together with Thompson Reuters estimates suggest that 18 of the Area’s 27 counties do not meet the state of Indiana average.

Figure 7.



SOURCE: Percent of female Medicare enrollees that receive mammogram screenings 2006-2007. University of Wisconsin Population Health Institute. *County Health Rankings 2011*.

Figure 8.



SOURCE: The Healthcare Business of Thomson Reuters (2010)

The Behavioral Risk Factor Surveillance System (BRFSS) is a state-based system of health surveys that collects information on health risk behaviors, preventive health practices, and health care access primarily related to chronic disease and injury. For many states, the BRFSS is the only available source of timely, accurate data on health-related behaviors. The Indiana Cancer Consortium (ICC) uses BRFSS data to set goals for cancer prevention and early detection and recently reported that the number one reason that women do not get mammograms is that it is not a priority; this crosses all ages, incomes and ethnicity.

**Communities of Interest**

Communities of Interest emerge when mortality is high, percent of late stage diagnosis is high and mammography

percentages are low.

**Review of Communities.** Data suggest that in the Affiliate Area there are six counties that have all three significant factors: (1) mortality rates >10 percent above State and U.S. averages, (2) late stage diagnosis rates that exceed the State of Indiana average and (3) mammography percentages that are less than the State of Indiana percentage. The counties that suggest themselves as Communities of Interest include Fulton, Lake, Marshall, Miami, Pulaski and Starke. In addition, 19 of the 27 counties in the Northern Indiana Affiliate Service Area have mammogram rates that are lower than the State of Indiana rate. Finally, there are racial and ethnic populations which raise questions for the Community Profile process. Lake County mortality rates and late stage diagnosis rates for African American women are also higher than State of Indiana mortality rates for African American women. Breast Cancer incidence rates for African American females in Elkhart County are higher than State incidence rates for African American females. In key informant interviews, questions about the state of breast health among Latinas, especially in the counties with greater Hispanic populations, were also raised.

**Key Demographic Variables.** With the exception of Lake County, the counties with all three significant factors (mortality rates, late stage diagnosis rates, and mammography percentages) are rural. Fulton, Marshall, Miami, Pulaski and Starke have a combined female population of 71,910 a meager 28 percent of the female population of Lake County. They are not very densely populated with a mere 73.4 persons/square mile as compared with the State of Indiana average of 180.8. They are predominantly white with 13.9 percent of the families living below the poverty level as compared with the State of Indiana average of 14.4 percent. One of the six, Starke County, (University of Wisconsin, 2011) ranks ninety-first out of Indiana's 92 counties in health outcomes. Three of the six have the lowest median family income in the Service Area (Fulton, Miami, Starke) and one (Miami) has the highest poverty level (U.S. Census, 2011). In addition, Thompson Reuters estimates suggest that 12.5 percent of the female population age 18-64 is uninsured.

Lake County presents a demographic profile that is very different from these five counties. 5.5 times more densely populated than the State of Indiana as a whole, Lake County boasts a diversity which is uncharacteristic of the Hoosier state. Its African American population represents 25.9 percent of all its residents (compared to 9.1 percent in the State of Indiana) and a Hispanic population representing 16.7 percent of county residents (compared to six percent in the State as a whole). Lake County is challenged to plan its services with racial/ethnic diversity in mind. Its poverty level is 16.4 (U.S. Census Bureau, 2011).

Culturally appropriate approaches are also important for the nine other counties in the Service Area where the proportion of Hispanics relative to the total population is greater than the state: Allen, Cass, Elkhart, Kosciusko, Marshall, Noble, Porter, St. Joseph, and White (U.S. Census Bureau, 2011). Allen County must also develop culturally responsive approaches to its Burmese population of over 8,000 which is the largest population of its kind outside of Myanmar. Counties throughout the Area must also account for culturally responsive approaches to women in the Amish community.

## **Conclusions**

While increasing mammogram rates for all women over 40 in the Service Area is critical, the following target communities are Communities of Interest for the Community Profile:

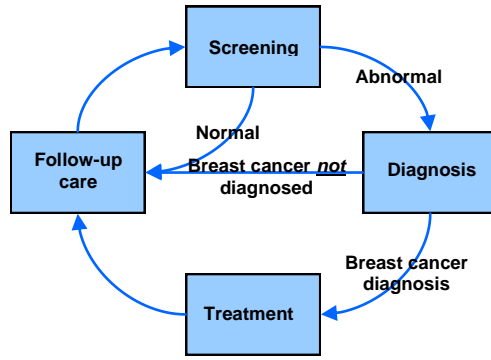
- 1) Developing a Rural Strategy. While five counties in the Affiliate Service Area have all three significant factors (mortality rates, late stage diagnosis rates, and mammography percentages), they are attributable to the population density and economic factors consistent with their rural nature. Increasing mammogram rates among women 40+ will be an important part of this strategy.
- 2) Addressing the Needs of Minority Women. Developing culturally responsive approaches to increase mammogram rates will go a long way toward reducing late stage diagnosis and mortality rates, especially among African American women. While disaggregated State data on Latinas or the Burmese refugee population are not available, best practices in early intervention suggest their importance. Increasing mammogram rates among women 40+ will be an important part of this strategy. Specific focus on Lake County is vital because of its unique combination of population density, racial and ethnic diversity, socio-economic challenges and health outcomes. Amish women in the northeastern portion of the Affiliate Service Area need to be a consideration as well.
- 3) While not based on the quantitative data study of this section, later qualitative data sections of key informant interviews will indicate the importance of programs for survivors.

## Health Systems Analysis of Target Communities

### Overview of Continuum of Care

The continuum of care is a vital tool for analyzing how the health system in the Affiliate Service area is working for our Target Communities relative to promoting and maintaining breast health.

*Figure 8. The Continuum of Care*



Screening is the ideal entry point into the continuum of care. In general, we noted that in 19 out of the 27 counties in the Affiliate Area, women are less likely to enter the continuum of care at the Screening point than in the State generally. Understanding barriers that may account for that phenomenon (e.g., Accessibility? Transportation? Cultural Acceptance? Financing?), is important in making the system more functional for women in the Affiliate Service Area. Delaying entry into the continuum of care or leaving it prematurely may

be the difference between “beating” a breast cancer diagnosis and failing to survive it. While our analysis is not laid out using a “phase by phase” organizational structure, we will regularly reference our findings to issues relative to the continuum of care framework.

### Methodology

As mentioned in the previous chapter, the Community Profile Team in its data gathering phase analyzed breast cancer statistics from various sources and demographic data from the most recent posts of the U.S. Census Bureau to develop a profile of Target Communities within the Affiliate Service Area that tended to be “outliers” with reference to State of Indiana or national trends. In summary, the need for a rural strategy emerged as well as more aggressive and effective outreach to certain minority populations within the Affiliate Service Area. Finally, in key informant interviews described below, there was repeated concern expressed about the survivor community.

The Team engaged in an asset mapping process to visualize important sites and services within the Service Area’s target communities. This process gave the Team an understanding of existing resources and their locations throughout the Service Area as well as a vision of where opportunities might exist for the development of community partnerships and the possibility for grants. An inventory of assets was taken from the Resource Guide developed by the Affiliate. This was updated through additional research and the input of community partners. In addition, resources initiated by grantees from 2007-2010 were added.

A list of key informants was developed from a combination of health care providers, specialized services, support service providers and community leaders from throughout the Affiliate Service Area. The Planning Team monitored responses to assure that each region of the Service Area was adequately represented and that diverse agencies and health care providers had responded. Follow up contacts were made to request the completed survey from those areas that were underrepresented. Over 30 responses were recorded.

In addition to surveys, the Team executed interviews with specialty breast service providers. Some of the organizations that were of particular interest included grass roots service providers,

medical clinics for low-income individuals, hospitals of large metropolitan areas, nonprofit service organizations, government entities, and mammography facilities.

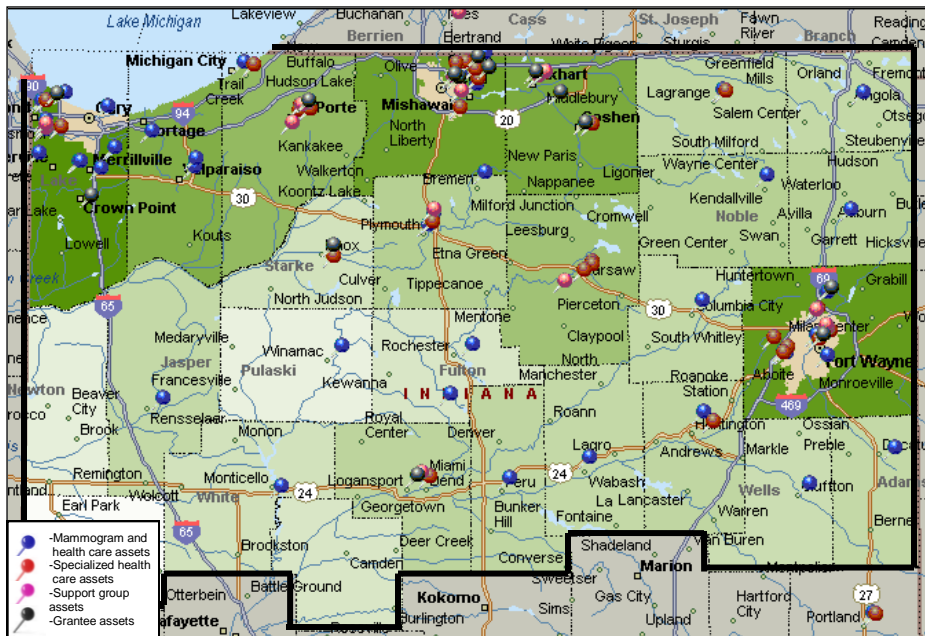
### Overview of Community Assets

The Northern Indiana Affiliate, since its inception, has fostered relationships with breast health organizations by looking for collaborative opportunities while avoiding duplication of services. Many new relationships were formed between the Affiliate and breast cancer service providers during the development of the Resource Guide.

Planning Team members made personal contacts with mammography sites, oncology practices, support group leaders, and ancillary service providers to garner the information for the Guide and the Community Profile. Through this process, the Affiliate was able to develop lasting partnerships with breast health resources throughout the Affiliate Service Area.

However, a comprehensive listing of all mammography and health care facilities, specialized health care assets and support service organizations within the three regions of the Affiliate Service Area largely shows a disconcerting, though obvious, trend. While each region within the Area has breast health resources which can serve women within the continuum of care, the accessibility of those resources is limited. Each region in the Area has both urban and rural areas with resources concentrated in its more densely populated locations. This trend is illustrated in Figure 9 which shows the distribution of breast health assets throughout the Northern Indiana Affiliate Area. These assets include health care facilities, mammography sites, specialized services (e.g., financial assistance enrollment sites, counseling, cosmetic and prosthetics suppliers) and education and support groups.

**Figure 9.** Breast health assets in Northern Indiana Affiliate Service Area



It is important to be reminded that the data analysis above suggests that six counties in the Service Area have three significant factors influencing effectiveness of the continuum of care: mortality rates, late stage diagnosis rates and mammography percentages less than the State of Indiana average.

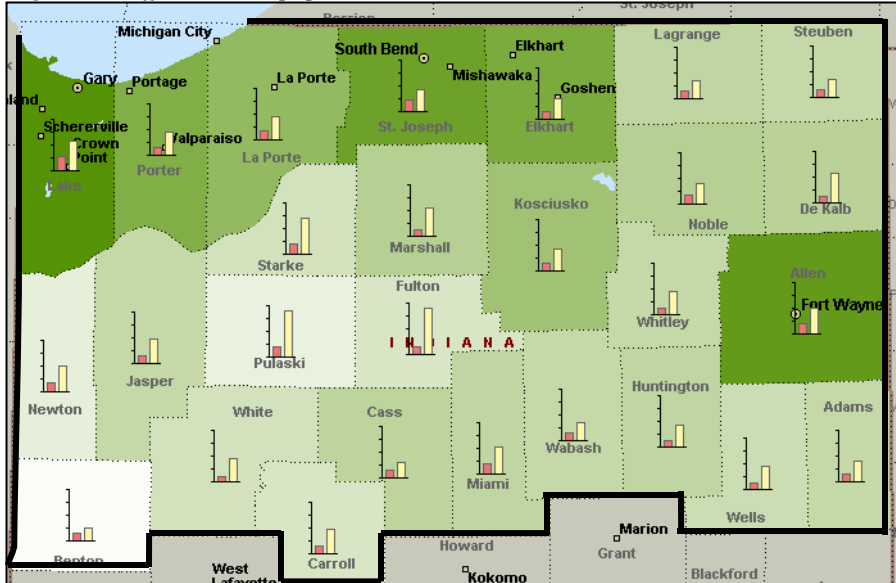
SOURCE: Susan G. Komen Northern Indiana Affiliate Resource Guide

Those Communities of Interest include Fulton, Lake, Marshall, Miami, Pulaski and Starke. With the exception of Lake County, there is a dearth of resources in these counties which will cause

the Team to inquire what sort of rural strategy can be developed to improve women’s access to the continuum of care in the Area.

Figure 10 illustrates population density (the darker the green, the more dense the population) in the Affiliate Area overlaid with the percentage of uninsured women (pink column to the left) and breast cancer mortality rates (tan column to the right representing deaths per 100,000). There appears to be a level of correlation to varying and disproportional degrees in several counties with no clear emerging trend. While not addressing mortality, the BRFSS indicated in 2008 the difference in mammography rates between women with and without health insurance was 27.5%.

**Figure 10.** Affiliate Area population with uninsured women and breast cancer mortality rates

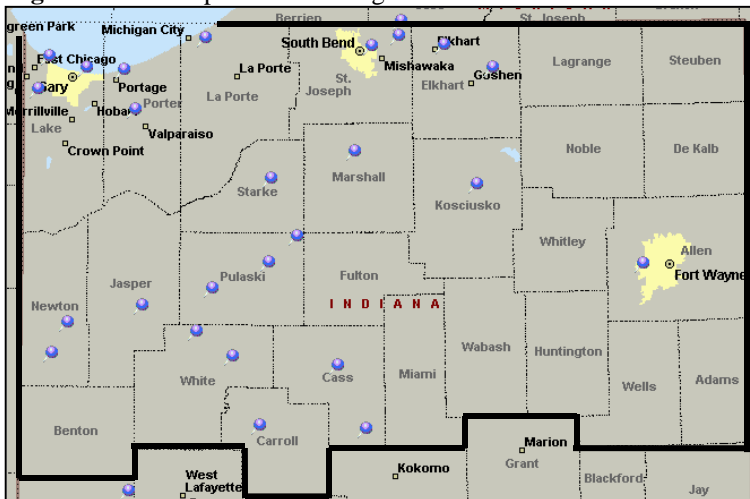


Lake County, with a large percentage of African American and Latina women, has its own set of concerns which will cause the Team to ask qualitative questions around access of minority populations to the continuum of care.

The Service Area’s four Indiana Breast and Cervical Cancer Program (BCCP) Regional Offices all

SOURCE: U.S. Census Bureau; Thompson Reuters©; ISDH, Indiana State Cancer Registry

**Figure 11.** BCCP provider coverage in the Affiliate Service Area



have committed to play an important role by encouraging the development of resources in the target communities. BCCP is administered through the Indiana State Department of Health and funded through the Centers for Disease Control.

Figure 11 represents the location of BCCP service providers in the Service Area. The BCCP sites are excellent sources of information concerning available services in their respective areas. Each

SOURCE: Indiana State Department of Health

Regional Office screens women for eligibility, schedules appointments, collects reports and bills, maintains extensive data bases and filing systems, and provides care management services. In Calendar Year 2010, BCCP funded screening mammograms for 1,700 women in 14 of the 27

Affiliate Service Area Counties (Table 3 below). 39 cancers were diagnosed meaning 1 out of every 43 women having screening mammograms was found to have breast cancer. It should be noted that in Indiana the BCCP only screens women over the age of 50, while other states screen women 40 and older. Despite the fact that the BCCP is a “mission critical” program, many community leaders and health care providers report that they will not become BCCP providers in the Service Area since consumers go to other locations to get their health care. With slightly more than 50 percent of the Service Area covered, accessibility to the continuum of care remains an issue for women of economic disadvantage.

**Table 3. BCCP Services SFY2010**

Activity	Allen	Benton	Carroll	Cass	Elkhart	Jasper	Lake	Marshall	Newton	Porter	Pulaski	St. Joseph	Starke	White	TOTALS
Area	NE	NW	NW	NE	NC	NC	NW	NC	NW	NW	NC	NC	NC	NW	
Screening Mammogram	256	68	103	6	340	7	383	19	10	80	17	349	6	56	1700
Diagnostic	32	1		1	84	7	49	73		16	3	73		6	273
Biopsy	17	4	4		19	7	18	1	4	8	2	27	1	5	117
Cancers Diagnosed	6		1		6	3	5		1	3	2	9		3	39

SOURCE: Indiana State Department of Health-Maxtrac Data

However, BCCP provider coverage is not as significant an accessibility issue for low income women as is the reduced financial resources provided to the program by the State of Indiana. The BCCP has received flat funding for the past five years, causing only 12 percent of the eligible women in Indiana to be able to enroll. In August of 2010, the CDC representatives met with the six BCCP Regional Coordinators with the purpose of assessing the impact of the program statewide. Through this discussion, it was found that all six BCCP regions are leveraging this federal program with Komen grant dollars and other community funding to insure that women are receiving the breast health services that they need, including for women between 40 and 50. This fact has helped the Indiana BCCP request additional federal funding to increase the number of women to be screened in 2011/2012 fiscal year. Finally, without funding for outreach, marketing, support groups or transportation subsidies, BCCP will not reach its targeted populations completely.

### **Legislative Issues in Target Communities**

Data concerning the state of breast health and the availability in our target communities (i.e., rural areas of the Affiliate Service Area, minority communities and survivors) suggest several legislative priorities. Already, there has been some legislative impact on extending access to low income women, including rural women. Indiana has adopted the “MA 12” Medicaid status for women enrolled in BCCP who are diagnosed with breast or cervical cancer. Comprehensive Medicaid is available within two weeks of their diagnosis. In 2009, Indiana also enacted “Option 3” Medicaid for women who meet the income guideline based on 200 percent of poverty, regardless of their age. This is comprehensive Medicaid coverage for as long as treatment is required. As discussed above, with state funding limitations for the BCCP, expanding state commitment to that program is a clear priority. Beyond that, additional financing options are a real need for women in the targeted communities. 13.9 percent of women in the Affiliate Service Area live below the poverty level while 12.5 percent are uninsured. In order to improve outcomes in the Service Area and statewide, Komen needs to make health care access through insurance extension a real priority. The State of Indiana has shown reluctance to support the Patient Protection and Affordable Care Act. It is clear that whatever one’s politics, poor and otherwise economically disadvantaged, uninsured women need access to health care in order to assure timely entry into the continuum of care. Expansion of funding for the BCCP in Indiana

should be a priority as well, not only to more adequately cover qualifying women, but to expand the qualifying age to women between 40 and 50 years of age.

### **Key Informant Findings**

While it was clear from responses that key informants in the Affiliate Service Area have poured a great deal of resource into meeting women's breast health needs, in order to ascertain respondents' concerns about access to the continuum of care certain questions were asked about barriers through surveys, direct interviews and focus groups. Responses fell into three categories: financing, accessibility and cultural barriers. 75.9 percent of respondents to the Planning Team's survey indicated they think most women in their community do NOT have regular breast health screenings (mammograms or clinical breast exams). The number one reason cited for this phenomenon was lack of sufficient financial resources to enter the continuum of care.

When asked if there was a specific group of women (racial, ethnic, cultural, age, etc.) that had a particular need for breast health and breast cancer services, key informant responses were varied but indicative of both broad and specific needs within the Service Area. Among the categories of responses: minority populations including African Americans, Latinas, Burmese, Amish and immigrants; low income populations, including the working poor; un- or underinsured women (including women with high deductible plans), specifically those who need follow-up in the continuum of care following screening; women without a medical home; women under 40; certain women ineligible for BCCP, specifically women ages 35-49.

When asked what financial resources were available to assist women to obtain screenings, these key informants revealed a patchwork of programs which might help, everything from the BCCP, to Komen to programs which select individual providers sponsored. All these programs have one set of characteristics in common: they are not uniform county-to-county, they have limited resources and may be difficult to identify for those who are not "in-the-know." That being said, key informant surveys indicated that fully 86 percent did provide services for the medically underserved. Informants frequently mentioned the need to coordinate often disparate service providers into a single visible network. They also cited Medicaid, Medicare and the Hoosier Insurance Plan (HIP-Indiana's program for the uninsured) as important. These publicly financed programs serve defined populations and, in the case of HIP, close enrollment almost as quickly as it opens. Community Health Centers were also cited for the work they do among those who are uninsured. Respondents mentioned that while screening for the uninsured was often available, the vital post screening diagnostic and treatment phases of the continuum of care had very few funding sources outside of Medicaid, insurance and the BCCP. The need for more providers (particularly physicians) to accept Medicaid was also referenced.

Accessibility is a theme which refers to geography, demography and awareness. In some less densely populated locations, mammography facilities simply do not exist. Key informants mentioned the two mobile mammography units with which the Area is blessed. However, because of travel restrictions, neither of these units goes to counties on the west side of the Affiliate Service Area where no facilities exist (please see Figure 10, above). When asked about who among the medically underserved they targeted though, fully nine informants indicated rural women. Even in urban areas where services are more readily available, the lack of transportation can be a barrier to a woman's access. In key informant surveys, of those who provided services in the continuum of care, fully 75 percent did not provide transportation. In terms of demographics, programs that assist women financially are governed by age and income level.

Women with extremely limited income <40 with a risk history generally have no obvious options; likewise women > than 150 percent of FPL. Most often in comments, “Awareness” referred not to women’s lack of awareness of breast health importance (though over half the key informants indicated that educating the public in preventive health care was important in overcoming barriers to getting routine health care) but to their lack of awareness about how to access services. Comments were made about programs that have excellent care navigator aspects once a woman enters the continuum of care but concern was expressed about having care navigation to get there in the first place.

Several cultural barriers were cited by informants relative to Latinas and African American women. The primary barrier was lack of trust in the medical community with all its accoutrements. Again fully half the key informants indicated that educating health care providers to be more culturally sensitive was critical to bring women in to the continuum of care. In addition, there are deeply held cultural values that respect modesty and the privacy of a woman’s body; hence, mammography and clinical breast exams are considered invasive. Other cultural characteristics involve a long history of women with responsibility for caring for multi-generational families; they simply don’t place a priority on care for themselves. For many, routine physical exams are not part of their family history due to economic and cultural factors. Of course, language barriers are a factor for recent immigrant populations, as is fear among those who are undocumented. Key informants did indicate that fully 76 percent of them had Spanish language services available. Burmese language availability was also noted in that enclave. Targeted marketing, education and outreach activities to diverse populations must be supported because it is not funded anywhere else.

Additional important information garnered from key informants included the fact that when asked what other specific breast cancer services besides support groups they provided over half indicated specialized services for African Americans and Hispanics. One specifically mentioned the Burmese refugee population. Four mentioned long-tem survivors. Patients appear to be more comfortable sharing their feelings of feeling forsaken when treatment is over. No one is systematically addressing the "how to live with cancer."

## **Conclusions**

In analyzing the data on incidence, mortality, insured status, and disproportional representation overlaid on the geography and accessibility of resources within the health care system throughout the Affiliate Service area, several conclusions were drawn by the Profile Team.

- 1) Geographic remoteness from health care resources is an issue in the region.
  - (a) In rural areas, lack of proximity to resources is the concern.
  - (b) In urban areas, transportation to resources is the concern.
- 2) Breast cancer mortality is disproportionately high among African American women in Lake and Allen Counties. While these populations live closer to facilities than their rural white counterparts, they are generally women of low income status.
- 3) Surveys told us that all populations of women who are at or below certain economic thresholds struggle to make entering the continuum of care a priority due to: work and family obligations, the cost of insurance and co-pays, the cost of transportation and the fear of not having financial resources to address a positive diagnosis should one be given.

## Breast Cancer Perspectives in the Target Communities

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### Methodology

An integral part of the Community Profile development process was to talk to women from the target communities themselves in order to understand their knowledge, attitudes and beliefs about breast cancer and breast cancer resources in their communities. It was important to the process to know if current education and outreach is effective and what recommendations they have to reach women like themselves. A variety of methods were chosen to collect data from women in the community who were not service providers: key informant surveys, key informant interviews and focus groups.

The surveys were parsed into sets of informants: those who were service providers and those who were not. Some 240 questionnaires were distributed with a nearly 15 percent (original) response rate. Non-service providers responded to questions primarily related to areas of most need (treatment, screening materials, education materials), type of care provided in the community (screening, counseling, treatment), groups of women who are underserved, opinions about barriers to care, how to remove those barriers and what changes were needed in the communities to improve access to the continuum of care. Recipients were targeted across all areas but were particularly targeted if they represented minority or those otherwise underserved.

The Team understood that qualitative data has some inherent limitations. Surveys as a research tool are particularly good for producing descriptions of large populations and allow for the collection of a great deal of data from a large number of people, but they may also suffer from being somewhat artificial, setting up responses based only on the questions that were asked. The Affiliate Area survey had some open-ended questions which, in many ways, were the most informative and useful. When the data from the surveys were analyzed, it was determined that gaps existed. New questions arose which needed to be answered and so field research in the form of focus groups and focused interviews were scheduled.

The Planning Team prioritized representative groups it wanted to access for a deeper dive into the meaning of the data compiled. Among communities of interest: women in specific rural communities, women over 40 who had not had a mammogram in the last 12 months, uninsured women, women who represent certain minority populations (African Americans, Latinas, Amish) and survivors. Informants were recruited using a variety of strategies, including: flyers in community settings, presentations at support groups, e-mails from partner organizations and *ad hoc* requests to available clients. As participants were selected using convenience sampling methods, it is clear that while informative, the data are not necessarily representative. Specifically, the Profile Team received recommendations from appropriate community leaders for the formation of focus groups or the use individual of key informant interviews based on women's actual experience or their broader insight into the community or experience they represented in the continuum of care. Key informants for interviews were identified as follows, women: over forty, underinsured and had not had a mammogram in the past 12 months, survivors, and representing minority communities.

One focus group was convened representing women over 65 from a rural community. We attempted others with African American and Hispanic women, but ended up doing key informant interviews instead because of difficulty recruiting and scheduling groups. The group of eight rural seniors signed up at Curves in the heart of Fulton County and participated in a group

moderated by Profile Team members using the Susan G. Komen® Community Profile focus group questions. As a thank you they received Komen gear. 12 additional key informant interviews were conducted to get insight regarding African American, Latina, Amish women, underinsured women and survivors. Focus groups utilized the questions devised by Komen. Other key informant interviews, with exception of survivors, were structured around questions of the Komen survey with enhanced questions targeted at the community of interest. Interviews with survivors were crafted around the Komen co-sponsored *El Paso Breast Cancer Survivor Survey* and the NCI's *Health Information National Trends Survey*.

Generally focus groups can gather useful information from multiple individuals with an array of knowledge and experience. They can also contribute to, complement and support findings of other methods such as surveys. However, the sheer limitation of number or sample size can serve to inappropriately focus on one set of data and may suffer from bias emerging through interaction between participants and facilitator. That being said, it was determined that the Team needed more insight on the limitations of rural populations' access to the continuum of care, as well as understanding the needs of survivors. Focus groups and key informant interviews have the capacity to get information in ways that no other methods do: how else does one find out, for example, that a community only got its first ob-gyn practice two years ago or that there is a tiny out-of-the-way clinic that "flies under the radar"? Responses were recorded and analyzed for the insight they provided. It was important to know if what the Profile Team learned through the interviews or focus groups diverged from analysis of the quantitative data and the surveys with key informants or actually provided the additional information it was hoping for.

### **Review of Qualitative Findings**

Research has shown that low-income and minority women are less likely to be screened for breast cancer and less likely than others to be diagnosed at early stages. Previous studies conducted to understand how social, economic, and health care environments affect screening among African American, Amish, and Latina women, have identified barriers women face: not always following recommendations; feeling intimidated during appointments; having incorrect information about risks, screening guidelines, and programs; and receiving information in ways they cannot understand or accept. In those studies, women indicated a strong desire for accurate information and, identified strategies for reducing barriers to screening. The surveys, focus groups and key informant interviews that were part of this Community Profile study revealed surprising consonance with national studies. Information gleaned, in addition to that reported in the chapter above, is summarized as follows.

Several key themes emerged from the focus groups and key informant interviews. Among the women over 40 of the rural focus group, several themes emerged. Lack of access was seen as a problem due to: remote geography (women in their community traveled 22 miles one way to a healthcare center for screenings and cancer care) and lack of insurance (one in three people in their county lack sufficient health care coverage).

Virtually all informants referenced lack of financial resources as the key barrier to accessing routine breast health care in the community. This is consistent with the survey data outlined in the third chapter above. The women in the rural focus group also discussed how lack of information about the importance of mammography, or how to get subsidized services, was a problem. Referencing the mixed messages in the media about the efficacy of mammography for women 40-50 years of age, they universally opined that this was a significant detriment to

participation. They shared women's reticence to participate either because it didn't seem to be a priority (even when touched by a family member's breast cancer) or fear of discomfort inherent in the procedure. "Can you believe it?" one woman remarked, "Even when I was diagnosed, she (her relative) would not get a mammogram!" Unlike African American and Latina women, they were universally positive about the impact of their doctor's recommendation that they get screening mammograms.

In addition to the information provided in the surveys, key informants among African American women reported that the top barriers for their peers entering the continuum of care included fear, lack of education, transportation, economic factors and life issues in general and specifically, lack of insurance. Informants reported that most African American women are reluctant to talk about their experience with breast cancer. Their instinct is to hide their disease and treatment from friends. Therefore, the perception that African American women have when there is a breast cancer diagnosis is that it is a death sentence since they don't know survivors. "We would rather avoid mammograms and not worry about receiving bad news," said a candid informant. There is not an emphasis on preventative health among African American women. Education is key for women to think of taking preventative measures, informants told us, but with the African American community this kind of education must be done one on one, or on a very personal level, over and over again to be effective. Culturally competent outreach is vital but almost not existent. They reported that most women go to community health clinics for their health care.

Respondents who were or served Latinas indicated several barriers as well. Language is an obvious barrier. For example, when 30 health care providers in the Affiliate Service Area were asked if they had staff who spoke Spanish, 76.7 percent indicated that Spanish was available, while fully 56.7 percent said they had staff who spoke English only. There is a sense among informants that the Hispanic population may not yet have had a sufficient number of messages geared to them to realize the importance of mammograms and other early intervention strategies in supporting their health. Among many Latinas, health information is often passed from mother to daughter, so looking outside this primary source of information is not an obvious source. The Hispanic radio outreach in one county reportedly has become a good alternative source of health information including information on breast health screening. Like Amish women and African American women and others, not having mammograms is often related to lack of symptomology. Cost of the mammogram and needing to take time off work is barrier as well as perceived pain of the procedure. Fear of finding breast cancer was also mentioned as a barrier to screening. Finally, there is a significant undocumented population in the Service Area so fear of deportation is always a concern.

With regard to the Amish minority in the Service Area, key informants reported that a health care provider has established clinics in two rural communities specifically providing outreach to the women. Barriers to access peculiar to the Amish community include transportation and their unique shunning of traditional insurance models. These are addressed by both locating clinics in areas that don't require motorized transportation and by bringing in a mobile medical unit. A payment schedule specifically for the Amish community has been established by two regional health care providers, as well as some trusted primary care physician practices. Another unique program that reaches out to the Amish and Mennonite communities is the "Simple Guidance" program. Held annually since 2005, the program provides health education and free cancer screenings for women. While outreach to Amish women needs continual effort, it is clear that

some strategies devised by providers are outstanding examples of how culturally responsive strategies tailored to the unique needs of specific populations can be developed.

Key informant interviews with underinsured women who had not received a mammogram in the last 12 months indicated financial constraints as virtually the sole barrier. They reported that while a screening mammogram might be accessed at no charge, follow up services would be their own expense due to the high deductible nature of their plans. One key informant without a mammogram in the last 12 months who needed costly diagnostic procedures in the past, reported being on the verge of medical bankruptcy because of those costs.

There is a mantra among survivors that goes, “A ‘Survivor’ is an individual who has been diagnosed with breast cancer. Survivorship begins at the moment of diagnosis.” This perspective on survivorship causes us to examine all the experiences that women have from diagnosis throughout the journey of treatment. Key informants among survivors had different themes about services within the continuum of care than providers or other women who did not receive a positive diagnosis. Their concerns were less about access and more about process. None of the survivors interviewed indicated any issues accessing the continuum of care. Once within the continuum of care, however, they experienced delays in treatment, unpredictable amounts of responsiveness to their social-emotional needs throughout treatment, and inconsistent availability of information about treatment options. An informant remarked, “Survivors should not have to go to websites to find answers to questions that their medical providers should be providing.” Informants supported the idea of networks to support women in treatment and post-treatment to address its long-term effects. Survivors universally reported that no one in the continuum of care addressed the topic “how to live with cancer” after treatment was completed.

## **Conclusions**

Several key themes emerged from the focus group and key informant interviews about their capacity to access and sustain in the continuum of care:

- 1) Lack of access to the continuum of care was seen as a problem due to remote geography, transportation and, most importantly, lack of insurance.
- 2) The need to distinguish between the availability of assets for gaining access to the continuum of care through mammography and following up through diagnostic procedures and treatments is important. Co-pays for the un- and underinsured who do not qualify for programs for low income women, can be debilitating.
- 3) Lack of reliable and trusted, culturally competent information about the importance of mammography, and its safety, geared to the needs of specific populations written in a style that is meaningful, understandable and language specific needs to be part of overall outreach strategies. Personal feelings of well-being and being asymptomatic do not predispose women to seek out information or be attentive to it when available.
- 4) Responsiveness of health care professionals, specifically doctors can be a barrier. While valued for their opinions, recommendations and clinical care by most informants, representatives of minorities and survivor populations expressed concerns. Physicians are often not trusted in minority communities for a variety of reasons. In some populations, most often minorities though not exclusively, the gender of the physician matters with females being preferred. Also, survivors reported that receiving adequate information about treatment options, treatment side effects and ultimately living with cancer were not things that their physicians devoted an adequate amount of time to with them.

- 5) The existence of factors, well out of the purview of the health care system, and influencing women including those who struggle with low economic status is a critical concern. Women have competing priorities of finance, family obligations, employment requirements, etc., that do not allow breast health promotion to emerge as a priority. This requires a different sort of planning taking into account motivation for behavioral change.

These findings are consistent with data about breast health indicators and other information about these “Communities of Interest”. Most key informants discussed barriers to accessing the continuum of care and clearly that inability is a contributing factor to rates of high breast cancer mortality, late stage diagnosis and low mammography participation that exists in pockets throughout the Affiliate Service Area. The conclusions 1-5 above amplify details outlined in other areas of this study.

Previously the CP Team identified six counties that have all three significant factors (high breast cancer mortality, late stage diagnosis and low mammography participation). With the exception of one county, Lake County, the counties are rural. Lake County, being densely populated and ethnically and racially diverse, demonstrates additional needs that are replicatable in St. Joseph, Elkhart and Allen counties, which are also more diverse. In addition, the CP study determined that 19 of the 27 counties in the Northern Indiana Affiliate Service Area have mammogram rates that are lower than the State of Indiana rate. All informants, of whatever type, reported that financial resources, specifically the lack of them, created the greatest single detriment in women’s ability to access the continuum of care. Geographic remoteness from health care resources is also an issue in the region. In rural areas, lack of proximity to resources is the concern; in urban areas, transportation to resources is the issue. Breast cancer mortality is also disproportionately high among African American women in Lake and Allen counties. Surveys told us that all populations of women who are at or below certain economic thresholds struggle to make entering the continuum of care a priority due to a variety of factors.

While increasing mammogram rates for all women over 40 in the entire Service Area is critical, the Community Profile process suggests the following priorities:

- 1) Rural populations –five rural counties in the Service Area have particularly poor outcomes. Additional information gathering suggests that access to financial resources, access to health care resources and lack of reliable information about the importance of mammography as well as the power of certain myths about mammograms, are all factors worthy of planning.
- 2) Minority women - developing culturally responsive approaches to increase mammogram rates will go a long ways to reducing late stage diagnosis and mortality rates, especially among African American women. Programs that specifically focus on the needs of African Americans and Latinas, and address the concerns that informants raised on their inability and unwillingness to enter the continuum of care, should be developed. Specific, though not exclusive, focus on Lake County is vital because of its unique combination of population density, racial and ethnic diversity, socio-economic challenges and health outcomes. Continuing focus on Amish women in the northeastern portion of the Affiliate Service Area and the Burmese women of Allen County need to be considerations as well.
- 3) Survivors - qualitative data sections of key informant interviews indicated the importance of programs for survivors. Acknowledging that survivorship begins at the moment of diagnosis is important for understanding issues which women in the continuum of care have before, during and after treatment.

## Conclusions: What We Learned, What We Will Do

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### Review of the Findings

When breast cancer mortality and the percentage of late stage breast cancer diagnoses are high, and this is coupled with a percentage of low mammography participation among women in targeted age groups, breast health indicators are troubling. In the course of its study, the Community Profile Team identified six counties in the Northern Affiliate Service Area (Fulton, Lake, Marshall, Miami, Pulaski and Starke) that have all three of these significant factors. With the exception of one county, Lake County, these counties are rural. One of the six, Starke County, ranks ninety-first out of Indiana's 92 counties in health outcomes (University of Wisconsin, 2011). Three of the six have the lowest median family income in the Affiliate Service Area (Fulton, Miami, Starke) and one (Miami) has the highest poverty level (U.S. Census, 2011). Lake County, being densely populated and ethnically and racially diverse, demonstrates additional needs that are replicatable in St. Joseph, Elkhart and Allen counties, which are also more diverse. Breast cancer mortality is also disproportionately high among African American women in Lake and Allen counties. While demography is not destiny, one must ask about the correlation between these outcomes and the rural nature of certain counties on the one hand, and the racial/ethnic diversity and socio-economic status on the other.

In addition, the Community Profile study determined that fully 19 of the 27 counties in the Northern Indiana Affiliate Service Area have mammogram rates that are lower than the State of Indiana rate. Indiana Cancer Consortium (ICC) reports using Indiana Behavioral Risk Factor Surveillance System data suggest that across age, income and ethnicity mammogram participation is not a priority. Throughout the process, all informants, of whatever type, reported that financial resources, specifically the lack of them, created the greatest single detriment in women's ability to access the continuum of care. Geographic remoteness from health care resources is also an issue in the region: lack of proximity to resources the concern rural areas, while transportation to them is the concern in urban areas. Fortunately, there are evidence-based practices that suggest new roles for health providers and advocates to improve screening participation. Among them are increased education of women and providers, and additional targeted outreach to under-screened groups including women of lower socio-economic status, uninsured and select minority groups. The CDC's *Guide to Community Preventive Services* outlines interventions including, engaging and personal client reminders to women, using small media (e.g., videos, letters, flyers, and brochures), and reducing structural barriers (e.g., providing more convenient hours and increasing attention to language, health literacy, and cultural factors) (CDC July, 2008). In some communities (e.g., Lake County) the Breast and Cervical Cancer Program is the *sole* source of free mammograms for women with limited income.

When studying the continuum of care, the Community Profile Team looked at more than entry points. Acknowledging that survivorship begins at the moment of diagnosis is important for understanding issues which women in the continuum of care have before, during and after treatment. Both health care providers and survivors shared concerns related to treatment and "living with cancer." Once in the continuum of care, survivors reported experiencing delays in treatment, unpredictable amounts of responsiveness to their social-emotional needs throughout treatment, and inconsistent availability of information about treatment options. Not only did

informants support the idea of networks of support for women in treatment and post-treatment, this is an idea (patient navigators) that has some evidence to support the approach.

### **Conclusions**

The Susan G. Komen Northern Affiliate Community Profile Team drew four conclusions from these findings about the state of breast cancer indicators in the Affiliate Service Area.

- 1) Increasing mammogram participation rates for all women throughout the Affiliate Service Area is a priority. With 19 of the 27 counties falling below the state average, there is a lot of catching up to do. This is consistent with the Indiana Cancer Consortium goal to increase the percentage of women age 40 and older who receive annual breast screening from 62 percent to 67 percent.
- 2) Rural populations –Five rural counties in the Affiliate Service Area have particularly poor breast health indicators/outcomes. However, the vast majority of the Service Area is rural. Additional information gathering suggests that access to financial resources, access to health care resources and lack of reliable information about the importance of mammography as well as the power of certain myths about mammograms, are all factors worthy of planning. Developing a rural strategy that increases women’s access is vital
- 3) Minority women - Developing culturally responsive approaches to increase mammogram rates will go a long way toward reducing late stage diagnosis and mortality rates, especially among African American women. Programs that specifically focus on the needs of African Americans and Latinas, and address the concerns that informants raised on their inability and unwillingness to enter the continuum of care, should be developed. Specific, though not exclusive, focus on Lake County is vital because of its unique combination of population density, racial and ethnic diversity, socio-economic challenges and health outcomes. Continuing focus on Amish women in the northeastern portion of the Affiliate Service Area and the Burmese women of Allen County need to be considerations as well.
- 4) Survivors - Qualitative data sections of key informant interviews indicated the importance of programs for survivors. Acknowledging that survivorship begins at the moment of diagnosis is important for understanding issues which women in the continuum of care have before, during and after treatment. Developing strategies to assure that the continuum of care from diagnosis to “how to live with cancer” is not only a goal suggested by our key informants but is consistent with the literature, as well.

### **Action Plan**

The Action Plan that the Community Profile Team developed based on Affiliate Area needs will influence its strategic planning process. The Team also developed some organizational strategies to enhance its capacity to implement its Action Plan and Strategic Plan, suggesting:

- 1) Recruiting a public health professional to the Board.
- 2) Creating a strategic grant program to fund the Affiliate Service Areas goals.
- 3) Informing State officials of our findings and coordinating strategies with other providers/advocates in the state.

The following Action Plan was developed by the Community Profile Team.

**PROBLEM STATEMENT 1:**  
19 of the 27 counties in the Affiliate Service Area have percentages of mammogram participation falling below the state average (61-2%)

**PRIORITY ONE:**  
Increase the rate of mammogram participation by: increasing the number of opportunities for women to have mammograms and promoting evidence based practices to assist women in making a decision to have a mammogram.

By the end of FY12, to develop competitive funding opportunities for organizations in counties to provide an additional 250 low cost mammograms to underserved women.

By the end of FY12, to develop and disseminate Komen branded information on evidence based practices for increasing mammogram participation to health care organizations throughout the Affiliate Service Area.

By the end of FY13, to develop and implement a process for partnering with providers to target Fulton, Lake, Marshall, Miami, Pulaski and Starke with expanded mammogram access.

**PROBLEM STATEMENT 2:**  
Five rural counties in the Affiliate Service Area have particularly poor breast health indicators/outcomes. However, the vast majority of the Service Area is rural.

**PRIORITY TWO:**  
Develop and disseminate an evidence supported rural strategy that will increase the mammogram participation rate of women in rural counties throughout the Affiliate Services Area.

By the end of FY12, to develop three partnerships with mobile medical units to access underserved communities in Fulton, Marshall, Miami, Pulaski and Starke counties.

By the end of FY12, to reach out to five existing health care providers in Fulton, Lake, Marshall, Miami, Pulaski and Starke counties to develop a plan to reach underserved women.

By the end of FY13, to develop partnerships with providers throughout the Service Area to utilize the Komen branded information based on evidence and geared to rural women.

**PROBLEM STATEMENT 3:**  
Minority women, especially African Americans throughout the Affiliate Service Area have poor breast health indicators/outcomes.

**PRIORITY THREE:**  
Develop and/or disseminate culturally responsive programs geared toward increasing screening mammogram participation of African American and Hispanic women throughout the Affiliate Services Area.

By the end of FY12, to develop three partnerships with faith based ministries in each region of the Affiliate Service Area that will specifically promote screening mammogram participation of African American women.

By the end of FY12, to develop three partnerships in each region of the Affiliate Service Area with informal or formal groups of Hispanic women that will each host one educational workshop on breast health for Latinas.

By the end of FY13, to identify partners and develop one "Circle of Promise" program in each region of the Affiliate Service Area.

**PROBLEM STATEMENT 4:**  
Breast cancer survivors report challenges within the continuum of care with delays in treatment, varying amounts of responsiveness to their social-emotional needs, inconsistent availability of information about treatment options and little input on “how to live with cancer”.

**PRIORITY FOUR:**  
Develop and promote programs that focus on supporting survivors within the continuum of care.

By the end of FY12, to procure Komen booklets, “How to Talk to Your Doctor” and disseminate them to groups throughout the Affiliate Service Area that give packets/bags to women who are newly diagnosed.

By the end of FY12, to do an inventory of breast cancer providers to determine which ones have patient navigator programs, devise descriptions of those programs and publish and disseminate them in the Affiliate Resource Guide.

By the end of FY14, to provide a workshop teaching participants to develop the skills that would allow them to be lay patient navigators.

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