COMMUNITY PROFILE REPORT

Susan G. Komen for the Cure®
Central New York Affiliate

2011

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EXECUTIVE SUMMARY

INTRODUCTION

Nancy G. Brinker promised her dying sister, Susan G. Komen, she would do everything in her power to end breast cancer forever. In 1982, that promise became Susan G. Komen for the Cure®. Today, Komen for the Cure is the largest network of breast cancer survivors and advocates in the world.

In the spring of 1991, the Central New York Affiliate of Susan G. Komen for the Cure® (Komen Central New York) was established. Four years later, on May 20, 1995, the first Komen Central New York Race for the Cure® was held in Syracuse, New York. Komen Central New York works throughout its 17-county service area to fulfill the promise – to save lives and end breast cancer forever by empowering people, ensuring quality care for all and energizing science to find the cures. This mission is based on the promise that Nancy made to her sister when little was known about the disease. Komen Central New York's work focuses on educating the community about breast health and breast cancer, working to ensure that screening and treatment are available to all residents in its 17-county service area, and raising money to fund breast cancer research. Since its inception, Komen Central New York has invested more than $3 million in grant funding for community breast health care programs in Central New York that focus on education, screening and treatment. In addition, Komen Central New York has invested more than $1 million, which together with funds raised in other Komen Affiliates around the world, has funded breast cancer research projects at major medical centers throughout the world.

Komen Central New York's promise to save lives and end breast cancer forever relies on information obtained through the Community Profile process. Every two years, Komen Central New York completes a comprehensive qualitative and quantitative analysis of Central New York's breast health needs. This report intends to describe the varied breast health needs that have been identified as well as potential areas in which Komen Central New York's programs and funding might help advance the network's promise of reducing breast cancer mortality. Potential opportunities and areas of interest have been drawn from analyses of breast cancer statistics, policies and programs in Central New York that may impact breast health and exploratory, primary data collection among providers and key informants throughout Central New York. After synthesizing data from various sources, this report presents data-driven priority areas from which Komen Central New York intends to develop funding decisions for the years 2012-2014.

DEMOGRAPHICS AND STATISTICS OVERVIEW

Komen Central New York's service area consists of seventeen rural and urban counties with a total estimated population in 2009 of 2,416,763. (Thomson Reuters, ©2009) The service area represents 12.4 percent of the total New York State population; however, the geographic area that Komen Central New York covers is approximately 34 percent of the state. Approximately 50 percent of the population in the 17-county service area lives in Monroe and Onondaga counties, which include the service area's two largest cities, Rochester and Syracuse, respectively.

Komen Central New York's population differs from the overall US population in several important ways. The percentage of adults age 65 and over is higher in Komen Central New York's service area (14.1 percent) than the US population (12.9 percent) and is expected to increase to 15.6 percent by the year 2014. (Thomson Reuters, ©2009) Given the association between breast cancer and age, this trend suggests a greater disease burden in the years to come.

In addition, the proportion of various race and ethnicity groups is different from the US as a whole. The ethnic background of Komen Central New York's service area is predominantly white at 96.6 percent. Minorities, particularly African Americans and Hispanics, are most concentrated in Monroe (14.8 percent) and Onondaga (10.3 percent) counties. (New York State Data Center, 2011) In all other counties in Komen Central New York's service area, the percent of African Americans and Hispanics ranges from 0.8 percent to 6.3 percent. (New York State Data Center, 2011) Although there are proportionally fewer African Americans and Latinas in Komen Central New York's service area compared to the total US population, there are significant concentrations of African-American and Latina women in Monroe and Onondaga counties.

Overall, 65.0 percent of women in Komen Central New York's service area are diagnosed at Stage I, 27.2 percent at stage II, 3.4 percent at stage III and 4.4 percent at stage IV. Since late stage diagnosis increases mortality from breast cancer, Komen Central New York's goal is to identify areas where late stage diagnosis is more common. Since rates of late stage diagnosis (stages III and IV) do not vary much by county, we took a more detailed look at late-stage diagnosis. Table 3 shows the areas with the highest rates of late stage (stages III and IV) diagnosis.

Table 3. Locations with Highest Proportions (95th percentile) of Late-stage Breast Cancer Diagnosis

County	Zip Code	Female Population	Percent Incidence at Stages III, IV	Percent White	Percent African-American	Percent Latina	Percent With No Insurance
Monroe	14608	5,882	**11.8**	17.2	64.3	12.3	40.4
Monroe	14611	9,540	**11.8**	16.4	70.6	7.8	37.4
Monroe	14619	7,480	**11.7**	19.3	72.8	3.6	18.6
Onondaga	13202	2,275	**11.3**	21.0	55.3	12.6	44.4
Monroe	14605	6,971	**11.2**	7.1	53.4	35.4	45.1
Monroe	14614	27	**10.4**	33.4	65.5	0.7	23.6
Onondaga	13205	9,874	**10.1**	35.0	53.0	3.6	35.5
Monroe	14621	17,887	**9.8**	21.7	43.5	28.8	38.9
Monroe	14604	964	**9.5**	41.4	33.7	14.4	34.7
Onondaga	13224	4,556	**9.4**	50.0	38.7	4.7	18.7
Monroe	14613	7,126	**9.3**	38.2	38.9	15.2	30.6
Onondaga	13207	7,337	**9.2**	49.6	38.7	6.0	19.1
Onondaga	13210	12,797	**9.0**	58.4	24.1	5.6	32.4
Monroe	14609	21,614	**8.8**	53.7	30.2	11.9	22.2
Onondaga	13204	10,214	**8.7**	51.8	24.9	16.3	35.9

These areas are broken down by county and further by zip code, and all are in the top 5 percent for late-stage diagnosis rate within Komen Central New York's service area. Again, the data is sorted so that the areas with the highest rates of late-stage diagnosis are at the top.

All of the areas listed are in the city of Rochester in Monroe County and the city of Syracuse in Onondaga County. The data in this table demonstrate that areas with the highest rates of late-stage diagnosis are also areas with high concentrations of minorities, including African-American and Latina women. In addition, many residents in these areas have incomes below the poverty level and are without insurance. All of these factors are known to impact the ability of women to access screening and diagnostic and treatment services for breast cancer. (American Cancer Society, 2011; Shavers and Brown, 2002)

HEALTH SYSTEMS ANALYSIS

Information on programs and services for this report was obtained from the New York State Department of Health, the New York State Cancer Consortium, and past and present Komen Central New York grantees. In addition, we sent a survey to providers within the service area. The survey asked about the age and ethnicities of the populations the providers served, what services they provided, what they thought were barriers to screening, how they were reimbursed for their services, and whether they offered financial assistance or partnered with other community agencies. We also asked providers to make open-ended comments and recommendations based on the breast health needs in their communities.

A number of organizations in Komen Central New York's 17-county service area provide breast health programs and services. The highest concentrations of diagnostic and treatment facilities occur around Rochester and Syracuse, both of which are home to medical schools and tertiary care hospitals as well as comprehensive clinics. Community hospitals and private practices provide the majority of services in the rural regions of the service area.

A crucial element in reducing breast cancer mortality rates is New York's statewide network of 54 community-based breast and cervical cancer screening projects called Cancer Services Program (CSP), which attempts to provide low-income, uninsured or under-insured women with annual comprehensive screening examinations and follow-up services. Each year, these Partnerships screen 60,000 women. Since first receiving federal funding in 1994, these Partnerships have detected more than 2,000 cases of breast cancer, 59 percent of which were detected at an early stage when treatment is the most effective.

We mailed the survey to 283 providers of breast health services in Komen Central New York's service area. Forty-four surveys were returned as of February 23, 2011. Key findings from this survey are presented below.

We asked the providers to estimate the percentages of women they served from various racial and ethnic groups. The vast majority of women they served were Caucasian (median = 93 percent), followed by African American (median = 3 percent), multi-ethnic (median = 2 percent), Latina (median = 2 percent), Asian/Pacific Islander (median = 1.5 percent), and Native American (median = 1 percent). These numbers are consistent with the known population percentages in Komen Central New York's service area. It is important to note, however, that 17 of the 44 (38.6 percent) respondents serve at least 10 percent minority (non-white) women, and 5 of the 44 (11.4 percent) respondents serve at least 25 percent minorities. Twenty-one (47.7 percent) of the respondents indicated that there are non-English speaking members of their communities who would benefit from breast health messages in other languages, most commonly, Spanish.

Providers also estimated the percentages of women they served in various age groups. Median percentages were 20 percent of women under age 40, 25 percent of women between ages 40 and 49, 30 percent of women between ages 50 and 64, and 25 percent of women 65 years and older.

The vast majority of respondents (93.2 percent) indicated that they provided breast health education materials and services. Ninety-one percent also provided screening and diagnostic services, of which 60 percent indicated that they could accommodate women with disabilities. A minority (37 percent) indicated that they provided breast cancer treatment services. Fifty-seven percent of respondents indicated that they provided outreach to women who did not typically

have access to screening services, while 73 percent indicated that they offered some type of financial assistance or discounted services for uninsured, underinsured and/or low income women. Many programs (70.5 percent) partnered with other organizations, for example Cancer Services Program Partnerships, to provide breast health services to women in their communities.

Many respondents understandably advocated for expanding services that low income women or women without insurance could access. They recommended “free screenings” or “no/low cost mammograms” or advocated for “mobile units (and) work site programs”.

Some noted the reluctance of poor women to access services and the need to assist them. Another common theme was the need to increase awareness of available services among women in poverty or with no insurance.

QUALITATIVE DATA OVERVIEW

Perspectives in target communities are derived from the qualitative component of Komen Central New York's Community Profile. The goal is to provide a better understanding about barriers to breast care, screening and treatment among urban populations in Komen Central New York's service area through in-depth interviews with key informants. To achieve this goal, one of our objectives was to reveal persistent and well as potential new and changing factors that could affect access to care and use of services in the target populations. We wanted to learn from providers and advocate experts. A further objective was to establish procedures for future focus groups involving at-risk women who do not use breast screening services – how to find, engage, and effectively lead such groups.

Qualitative findings can be used as the "formative" basis of new initiatives or research and to suggest changes to existing programs. Limitations of qualitative data include its lack of generalizability in using personalized accounts that may not apply to all members of a community and lack of empirical bases with non-scientific selection of key informants and non-significant numbers of interviews. Therefore, qualitative findings should be used only to inform and not to direct program changes. Yet, qualitative research is used extensively and successfully as a basis for finding new approaches and solutions to intractable problems.

We interviewed key informants in Syracuse and Rochester and made observations of survivors who were reaching out to other women. Key informants are community members who know about the breast care needs of underserved women in their communities. They are also long-time community advocates, cancer services employees, and providers of breast health services for breast cancer patients and at-risk populations. We also attended and took notes at an outreach event of Syracuse's Witness Project, at which survivor advocates spoke to the local chapter of the National Council of Negro Women to inform, encourage, and support its members through the continuum of care for breast cancer screening, treatment, and recovery.

We interviewed five key informants, four in Syracuse and one in Rochester, all of whom current Komen grantees recommended. All interviews were in-person, and interview locations were the workplaces of each informant. All but one of the interviews lasted approximately one to two hours; the one exception was limited to twenty minutes due to scheduling. We provided key informants with a series of open-ended questions to which they replied. We also encouraged them to offer their opinions about barriers to care among underserved women in their communities. We did not provide any incentives to key informants or to survivor advocates from the Witness Project for their participation.

We began by showing the key informants a data summary of breast cancer diagnosis stages in Central New York displayed by zip code, racial mix, and insurance status. (Thomson Reuters, ©2009) The data showed that the highest levels of late stage (III and IV) diagnoses were in urban neighborhoods of Syracuse and Rochester that had high proportions of African Americans and uninsured persons. These groups were identified as the at-risk population. We then asked the key informants open-ended questions that covered the following topics:

A. Description of at-risk populations and how these groups may be changing
B. How low-income and underserved urban women learn about breast care services
C. How this population obtains mammograms and treatment when necessary
D. Barriers to screening among the underserved
E. The nature of breast health services for underserved women in each city

F. Constraints that providers experience in delivering breast health services to underserved women
G. Outreach and educational services and their perceived effectiveness
H. Thoughts on needs and improvements for outreach, screening, and treatment services.

Among other things, our key informants described various barriers to breast cancer screening that underserved urban women in Syracuse and Rochester experience. These barriers fall into six categories: knowledge; communication; fear; expense (including insurance); belief systems; and "life situations."

CONCLUSIONS

The Community Profile Team created Komen Central New York's priorities to present to the Board of Directors. The Team selected the priorities after reviewing the findings in the report. "Komen Central New York's Board of Directors was presented with the priorities as recommended and ranked by the Community Profile Team and voted to approve them." The priorities and recommendations will influence Komen Central New York's strategic plan for FY 2012 and FY 2013 requests for proposals and all other mission initiatives.

Priority 1: Promote breast health awareness and the importance of screening and early detection among women in Central New York.

Objective 1: Conduct targeted outreach to solicit grant applications from not-for-profit organizations with knowledge of, and experience in, underserved minority communities located in Monroe and Onondaga counties, particularly in the cities of Rochester and Syracuse.

Objective 2: Partner with local not-for-profit organizations in underserved communities and create "train the trainer" programs to help these organizations draft appropriate RFAs and continue to follow up with the organizations that receive grants to ensure the success of their programs to reach underserved women to increase knowledge of, and access to, free and reduced-cost screening and diagnostic services.

Objective 3: Facilitate partnerships among agencies in an affirmative fashion, i.e., between providers or provider agencies and non-traditional breast health organizations like faith-based organizations, social and cultural organizations, etc. to extend the reach and penetration of breast health messaging.

Priority 2: Promote breast health awareness and the importance of screening and early detection among women in Central New York.

Objective 1: Through grant efforts, improve consumer awareness about screening programs and services in targeted communities throughout Central New York including increasing awareness about free or low-cost breast health programs and services.

Objective 2: Brain storm with identified organizations to create programs through media that appeal to underserved populations.

Objective 3: Find ways to incentivize women to take advantage of free and reduced-cost services.

Priority 3: Develop partnerships with community organizations that can assist women to navigate through the continuum of care

Objective 1: Partner with local providers to develop and sustain programs to train patient navigators who will be available to underserved minority populations to ensure that these populations have the resources, e.g., translation services and culturally-sensitive materials, that they need to ensure proper care.

Objective 2: Facilitate access for racial and ethnic minority populations in the identified geographic areas by supporting culturally-appropriate, creative outreach strategies and partnerships.

ACKNOWLEDGEMENTS

Volunteers are the core foundation of any organization, its activities, community involvement and success. The individuals who volunteered to join the Komen Central New York Community Profile Team demonstrated this core, and we appreciate their commitment.

A special thank you to Gary S. Brooks, PT, DrPH, CCS, Associate Professor, CHP-Physical Therapy, Upstate Medical University, and Mary Ann Sandiford-Day, Graduate Student, MPH Program, Upstate Medical University, without whom the completion of this Community Profile would not have been possible.

Komen Central New York and the Community Profile team are indebted to all those who shared their experiences and stories, particularly Colleen Henderson, Assistant Director, Clinical Services – Women's Imaging, University Health Care Center, Syracuse, New York; Christopher P. Morley, Assistant Professor, Family Medicine, CNYMPH Program, Upstate Medical Center; *The Witness Project Spokespersons*, Emma Owen-Richardson, Cancer Services Partnership of Onondaga County; Sue Swift, Anthony L. Jordan Health Center & Board of Directors, Komen Central New York; and Sheila Walker, Women's Health Outreach, Onondaga County Health Department. The knowledge we gained allowed us to understand the challenges faced by women and families impacted by breast cancer. The recommendations in this report are a result of their stories; it is our hope that they will have a positive impact on breast education, screening and treatment in Central New York.

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Introduction

Komen Central New York – History

In the early fall of 1990, a small group of women led by Nancy Dunigan, a breast cancer survivor, gathered in the office of local plastic surgeon, Dr. Hadley Falk, to discuss the possibility of creating an organization designed to support the growing numbers of breast cancer survivors in the community. Nancy's energy, enthusiasm, and dedication, not to mention her relentless pursuit of information and people, gave birth to the organization. Dr. Falk's belief that one patient's experience should help the next patient was a strong motivating factor. The group felt that no one should feel alone, and they combined their efforts, time and finances to insure the success of the project.

Searching for an affiliation yielded nothing until Nancy watched *The Home Show*, starring Gary Collins. Gary was interviewing a representative from Susan G. Komen for the Cure in Dallas, Texas. Nancy was so impressed that she flew to Dallas and visited the Susan G. Komen for the Cure headquarters. She reported back, and the group decided to start an affiliate in Central New York.

The first meeting of the chapter was held on March 26, 1991, with fifteen people in attendance. Those in attendance appointed officers, and legal and financial volunteers helped with the charter documents. Komen Central New York became the thirteenth Komen Affiliate to be organized.

In the beginning, Komen Central New York's major focus was education and support. Starting in early summer 1991, Komen Central New York presented Breast Health Awareness programs in many and varied settings, including programs at universities, colleges, businesses, health fairs, community centers, and government agencies from Syracuse to Rochester, Buffalo, Oswego, Utica, Binghamton and surrounding areas. It was evident that there was a definite need for increasing awareness and supplying information. Survivors developed the education program with the assistance of Dr. Falk. At that time, Susan G. Komen for the Cure had no specific education materials to share with its affiliates. There was no commercial display, just photocopied handouts, overheads and enthusiastic presenters.

The dream of "having a RACE" became a reality on May 20, 1995. Nancy Dunigan was Chair of the first CNY Komen Race for the Cure. Crouse Irving Memorial Hospital was the first major sponsor. The 1995 Race for the Cure allowed Komen Central New York to award its first grant. The recipient of this first grant was University Hospital, which used the grant monies to purchase a refrigerator for its breast cancer research program.

Komen Central New York's goals are to raise money, to award annual grants to not-for-profit breast health care organizations and programs, and, together with other Komen affiliates worldwide, to fund breast cancer research projects in major medical centers around the world. Since its inception, Komen Central New York has provided more than $3 million in grant funding for community breast health care programs.

Organizational Structure

Figure 1 displays the organizational structure of Komen Central New York.

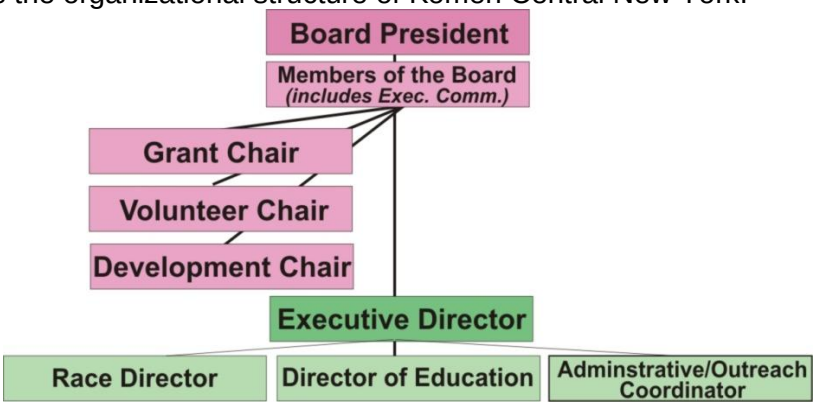

Figure 1. Organizational Structure of Komen Central New York

Description of Service Area

Komen Central New York's service area includes the following counties, representing almost one-third of New York State: Cayuga, Chenango, Cortland, Herkimer, Jefferson, Lewis, Livingston, Madison, Monroe, Oneida, Onondaga, Ontario, Oswego, St. Lawrence, Seneca, Wayne and Yates (figure 2). These counties cover a broad geographical area and include several larger metropolitan centers as well as large rural expanses.

Figure 2. Komen Central New York's 17-County Service Area

Purpose of Report

Komen Central New York's promise to save lives and end breast cancer forever relies on information obtained through the Community Profile process. Every two years, Komen Central New York completes a comprehensive qualitative and quantitative analysis of Central New York's breast health needs. This report intends to describe the varied breast health needs that have been identified as well as potential areas in which Komen Central New York's programs and funding might help advance the network's promise of reducing breast cancer mortality. Potential opportunities and areas of interest have been drawn from analyses of breast cancer statistics, policies and programs in Central New York that may impact breast health and exploratory, primary data collection among providers and key informants throughout Central New York. After synthesizing data from various sources, this

report presents data-driven priority areas from which Komen Central New York intends to develop funding decision for the years 2012-2014.

Quantitative Data: Measuring Breast Cancer Impact in Central New York

Methodology

Susan G. Komen for the Cure® contracted with the Healthcare Business of Thomson Reuters, ©2009 to compile data for every Komen affiliate, providing breast cancer statistics and demographic data for the counties within each affiliate's service area. The data that Thomson Reuters, © 2009 supplied was based on 2009 population studies. A portion of the data supplied for individuals was based on statistics derived from national-level data.

The Thomson Reuters, ©2009 data is the primary source of demographic and breast cancer statistics used in this report. By comparing local data with published national data as well as various breast cancer studies, Komen Central New York identified counties and segments of the population that showed the greatest need for breast cancer-related resources and funding, thus forming the basis of its action plan and priorities. Other sources of national data and breast cancer data include the United States Census Bureau, Centers for Disease Control and Prevention – Behavioral Risk Factor Surveillance System (BRFSS), New York State Department of Health, New York State Data Center and the American Cancer Society, as well as articles published in professional journals.

Overview of Komen Central New York's Service Area

Komen Central New York's service area consists of seventeen rural and urban counties with a total estimated population in 2009 of 2,416,763. (Thomson Reuters, ©2009) See Figure 1 for a map of Komen Central New York's 17-county service area. The service area represents 12.4 percent of the total New York State population; however the geographic area that Komen Central New York covers is approximately 34 percent of the state. Approximately 50 percent of the population in the 17-county service area lives in Monroe and Onondaga counties, which include the service area's two largest cities, Rochester and Syracuse, respectively.

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In addition, the proportion of various race and ethnicity groups is different from the US as a whole. The ethnic background of Komen Central New York's service area is predominantly white at 96.6 percent. Minorities, particularly African Americans and Latinas, are most concentrated in Monroe (14.8 percent) and Onondaga (10.3 percent) counties. (New York State Data Center, 2011) In all other counties in Komen Central New York's service area, the percent of African Americans and Hispanics ranges from 0.8 percent to 6.3 percent. (New York State Data Center, 2011) Although there are proportionally fewer African Americans and Latinas in Komen Central New York's service area compared to the total US population, there are significant concentrations of African-American and Latina women in Monroe and Onondaga counties.

Breast Cancer Prevalence, Incidence and Mortality

Table 1 displays the 2009 female population, as well as prevalence, incidence, number of deaths and mortality rate for female breast cancer in Komen Central New York's service area during the year 2009. Prevalence indicates the number of breast cancer cases in each county. Incidence represents new cases of breast cancer during the year and mortality represents the number of deaths from the disease. Rather than showing percentages (i.e. per 100), incidence and mortality rates are per 100,000 women so that the numbers are easier to understand. The numbers are sorted by the prevalence (in **bold** font) so that the counties with the highest prevalence appear at the top of the table, and those with the lowest prevalence appear at the bottom. Prevalence indicates the "burden" of breast cancer in the counties that Komen Central New York serves.

Table 1. Overview of Breast Cancer in Komen Central New York's Service Area

County	2009 Female Population	Breast Cancer Cases	Breast Cancer Incidence (per 100k)	Breast Cancer Deaths	Breast Cancer Mortality (per100k)
Onondaga	234,702	**1,252**	142.16	48	20.62
Monroe	374,868	**1,172**	83.27	77	20.55
Oneida	118,484	**720**	161.64	29	24.47
Jefferson	59,062	**284**	128.68	11	19.35
Oswego	61,330	**282**	122.90	10	16.94
St. Lawrence	53,192	**242**	121.41	9	17.70
Madison	37,453	**208**	148.35	9	23.01
Herkimer	30,631	**186**	161.78	7	22.58
Cayuga	38,155	**179**	124.85	6	16.16
Ontario	52,775	**172**	86.77	12	22.09
Wayne	47,472	**151**	84.57	11	23.25
Chenango	26,144	**143**	145.28	6	21.32
Cortland	24,767	**112**	121.14	4	15.28
Livingston	30,829	**95**	82.17	7	22.44
Lewis	12,211	**70**	152.18	2	17.47
Seneca	14,844	**58**	103.24	3	22.78
Yates	13,232	**44**	88.21	3	19.83
Total CNY	1,230,151	5,370	116.32	254	20.68
NY State total	9,949,743	46,332	124.2	N/A	20.44

Thomson Reuters, ©2009

It should also be noted that the incidence and mortality rates are not adjusted for age. As older women have higher rates of breast cancer occurrence, counties with older populations would be expected to have higher rates of cancer. According to the New York State Department of Health, female breast cancer incidence in New York is rising, while mortality is falling. (New York State Department of Health, 2011)

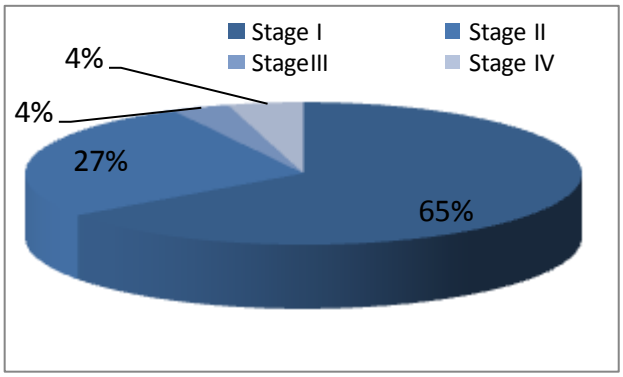

Figure 3. Stage at Diagnosis in Komen Central New York's service area

Late Stage Diagnosis

Stage at diagnosis is determined by how large the tumor is and how much it has spread. The stages range from stage I (small and localized) to stage IV (larger and more widespread). Figure 3 shows the percentages of breast cancer cases in Komen Central New York's service area diagnosed in 2009 at each of the four stages. Since later stage diagnosis of breast cancer decreases five year survival, (American Cancer Society, 2011) it is important to consider how many women are being diagnosed at later stages.

Although the percentages of women diagnosed in late stages (stages III and IV) are relatively small, they represent large numbers of women within the populations. In addition, these figures do not include important information about breast cancer staging in women of color and women at different income levels who do not have health insurance. This information will be presented in the next section.

Screening Rates

Screening rates are based on the mammography participation within Komen Central New York's service area. Table 2 (right) shows the percentage of women over 40 who reported not having a mammogram within the past 12 months. The table shows the counties with the highest rates at the top and the lowest rates at the bottom. Size of the female population 40 years and older is also shown. Note that the two most populous counties, Monroe and Onondaga, have the lowest rates of non-participation in mammography screening. However, because mammography participation is related to income level, (BRFSS, 2011) these numbers likely do not reflect the true non-participation rates of low income women in these counties.

Table 2. Percentage of women over 40 who reported not having a mammogram within the past 12 months.

County	Female Population age 40 and Higher	Percent No Mammogram in the Past Year
St. Lawrence	25,848	41.2
Chenango	13,512	40.9
Lewis	6,559	40.6
Herkimer	16,677	40.4
Seneca	8,376	40.3
Oswego	29,105	40.0
Cortland	11,219	39.3
Jefferson	24,372	39.0
Livingston	15,058	38.5
Yates	6,269	38.5
Wayne	23,802	38.2
Cayuga	20,495	37.8
Madison	17,372	37.6
Oneida	60,860	37.5
Ontario	27,600	35.9
Onondaga	116,211	35.6
Monroe	188,724	34.8
Total	612,059	36.9

Thomson Reuters, ©2009

Communities of Interest

Although breast cancer mortality rates per 100,000 women are higher in other counties, the number of breast cancer deaths is highest in Monroe and Onondaga counties. In addition the screening data noted above may not reflect lower screening rates in the low-income communities that are concentrated in these counties. Stage at which breast cancer is diagnosed offers further insight into the needs of women in Komen Central New York's service area.

Overall, 65.0 percent of women in Komen Central New York's service area are diagnosed at Stage I, 27.2 percent at stage II, 3.4 percent at stage III and 4.4 percent at stage IV. Since late stage diagnosis increases mortality from breast cancer, Komen Central New York's goal is to identify areas where late stage diagnosis is more common. Since rates of late stage diagnosis do not vary much by county, we took a more detailed look at late stage diagnosis. Table 3 shows the areas with the highest rates of late stage diagnosis. These areas are broken down by county and further by zip code, and all are in the top 5 percent for late-stage diagnosis in Komen Central New York's service area. Again, the data is sorted so that the areas with the highest rates of late-stage diagnosis are at the top.

Table 3. Locations with Highest Proportions (95th percentile) of Late-stage Breast Cancer Diagnosis

County	Zip Code	Female Population	Percent Incidence at Stages III, IV	Percent White	Percent African-American	Percent Latina	Percent With No Insurance	Percent with Income Below Poverty Level
Monroe	14608	5,882	**11.8**	17.2	64.3	12.3	40.4	37.1
Monroe	14611	9,540	**11.8**	16.4	70.6	7.8	37.4	28.0
Monroe	14619	7,480	**11.7**	19.3	72.8	3.6	18.6	13.5
Onondaga	13202	2,275	**11.3**	21.0	55.3	12.6	44.4	45.3
Monroe	14605	6,971	**11.2**	7.1	53.4	35.4	45.1	43.8
Monroe	14614	27	**10.4**	33.4	65.5	0.7	23.6	66.7
Onondaga	13205	9,874	**10.1**	35.0	53.0	3.6	35.5	22.8
Monroe	14621	17,887	**9.8**	21.7	43.5	28.8	38.9	29.3
Monroe	14604	964	**9.5**	41.4	33.7	14.4	34.7	43.9
Onondaga	13224	4,556	**9.4**	50.0	38.7	4.7	18.7	13.6
Monroe	14613	7,126	**9.3**	38.2	38.9	15.2	30.6	23.8
Onondaga	13207	7,337	**9.2**	49.6	38.7	6.0	19.1	16.2
Onondaga	13210	12,797	**9.0**	58.4	24.1	5.6	32.4	23.4
Monroe	14609	21,614	**8.8**	53.7	30.2	11.9	22.2	14.9
Onondaga	13204	10,214	**8.7**	51.8	24.9	16.3	35.9	31.4

All of the areas listed are in the city of Rochester in Monroe County or in the city of Syracuse in Onondaga County. The data in this table demonstrate that areas with the highest rates of late-

stage diagnosis are also areas with high concentrations of minorities, including African-American and Latina women. In addition, many residents in these areas have incomes below the poverty level and are without insurance. All of these factors are known to impact the ability of women to access screening and diagnostic and treatment services for breast cancer. (American Cancer Society, 2011; Shavers and Brown, 2002)

Despite the higher breast cancer mortality *rate* in other counties, the high number of breast cancer deaths in Monroe and Onondaga counties and the higher rate of late-stage diagnosis in low-income communities within these counties suggest the need to focus resources in these predominantly urban areas. In addition, low screening rates among low income women as noted by BRFSS data further argue for the need to provide services in these urban communities.

Health Systems Analysis

Data Source and Methodology Overview

Information on programs and services for this report was obtained from the New York State Department of Health, the New York State Cancer Consortium, and past and present Komen Central New York grantees. In addition, we sent a survey to providers within the service area. The survey asked about the age and ethnicities of the populations the providers served, what services they provided, what they thought were barriers to screening, how they were reimbursed for their services, and whether they offered financial assistance or partnered with other community agencies. We also asked providers to make open-ended comments and recommendations based on the breast health needs in their communities.

Overview of the Continuum of Care

A number of organizations in Komen Central New York's 17-county service area provide breast health programs and services. The highest concentrations of diagnostic and treatment facilities occur around Rochester and Syracuse, both of which are home to medical schools and tertiary care hospitals as well as comprehensive clinics. Community hospitals and private practices provide the majority of services in the rural regions of the service area. Figure 4 illustrates the continuum of care in Komen Central New York's service area.

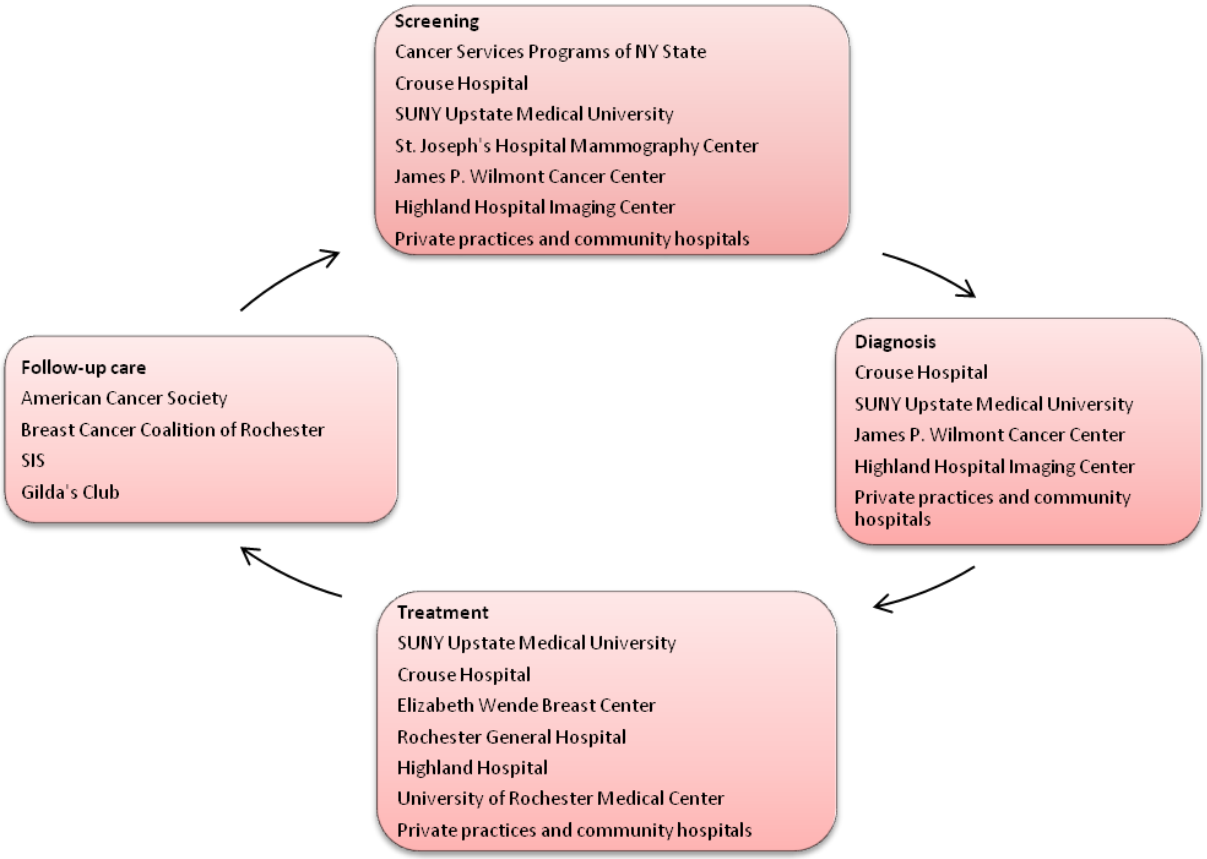

Figure 4. Diagram of the Continuum of Care

A crucial element in reducing breast cancer mortality rates is New York's statewide network of 54 community-based breast and cervical cancer screening projects called Cancer Services Program (CSP), which attempts to provide low-income, uninsured or under-insured women with annual comprehensive screening examinations and follow-up services. Each year, these Partnerships screen 60,000 women. Since first receiving federal funding in 1994, these Partnerships have detected more than 2,000 cases of breast cancer, 59 percent of which were detected at an early stage when treatment is the most effective.

Overview of Community Assets

The following organizations provide key breast cancer services to Central New York residents. This list does not reflect all program and service providers in the region.

- **American Cancer Society (ACS):** ACS provides a variety of supports, resources and information to persons affected by cancer. One-on-one support to persons with breast cancer is available through *Look Good…Feel Better,* which provides a free make-up and skin care kit to women going through treatment. *Road to Recovery* is a program offering transportation for cancer patients to their treatment appointments and is based on volunteer driver availability. Financial assistance is also available.

- **Breast Cancer Coalition of Rochester (BCC):** BCC provides support to those touched by a diagnosis of breast cancer, to make access to information and care a priority through education and advocacy, and to empower women and men to participate fully in decisions relating to breast cancer.

- **SIS:** SIS provides financial grants and quality of life enhancements to those in need as a result of their breast cancer treatment.

- **Gilda's Club of Rochester**: Gilda's Club provides a meeting place for men, women and children living with cancer, along with their family and friends. They join with others to build social and emotional support as a supplement to medical care. Free of charge and non-profit, Gilda's Club offers support and networking groups, lectures, workshops and social events in a non-residential, homelike setting. Gilda's Club is funded through the generosity of private individuals, corporations, foundations, and grants.

- **SUNY Upstate Medical University Breast Cancer Program**: University Hospital has more than 20 years of experience providing state-of-the-art comprehensive breast care. As part of its commitment to the treatment of breast disease, SUNY Upstate Medical Center has CNY's first Multi-Disciplinary Breast Cancer Program. The Program is designed to provide prompt, comprehensive, compassionate, and coordinated care with an integrated team of medical oncologists, breast surgeons, radiation oncologists, pathologists and support staff.

- **Crouse Hospital**: A central New York leader in women's healthcare, Crouse Hospital in Syracuse, NY, places a strong emphasis on breast cancer intervention, treatment and education. The Mammography Program has long been a leader in providing the latest in high-quality screening and diagnostic breast imaging services and pioneered use of a non-surgical breast biopsy procedure. The dedicated breast-care professionals at Crouse Hospital offer a full range of screening, diagnostic and interventional breast imaging services.

- **St. Joseph's Hospital Mammography Center:** Staffed by female technologists and nurses specifically trained in women's health, the Center, located in Syracuse, NY, is equipped with state-of-the-art mammography equipment that has improved image quality and is able to detect smaller tumors.

- **Highland Hospital Imaging Center:** The Highland Breast Imaging Center in Rochester, NY, is one of the few all-digital, full-service breast imaging and diagnostic centers in the area. It is committed to providing highly personalized quality service to all women.

- **James P. Wilmot Cancer Center**: The Wilmot Cancer Center, in Rochester, NY, provides comprehensive services, including Breast Imaging Services, Screening mammography, Diagnostic breast imaging, Diagnostic and therapeutic breast ultrasound, Stereotactic and ultrasound directed breast biopsy, and Wire localization

Partnerships

New York's statewide network of 54 community-based breast and cervical cancer screening projects, called the Cancer Services Program, currently provides low-income, uninsured or under-insured women with annual comprehensive screening examinations and follow-up services. Each year, 60,000 women are screened through the Program. The priority population for this Program is women ages 40 and older who are at or below 250 percent of the federal poverty guideline and who have no health insurance or whose insurance does not cover screening or diagnostic services. Of special concern are ethnic and racial minority groups and women who are medically under-served because they live in isolated, rural communities. More than 2,000 cases of breast cancer have been detected in women screened through the Program. Approximately 59 percent of the cases of breast cancer detected through the Program were diagnosed at an early stage when treatment is most successful. In 2001, the New York State Health Department added a case management component to assist the approximately 6,000 women who require diagnostic follow-up after their initial screening exams. The Program helps women navigate the health care system, obtain transportation, childcare or translation services and overcome other personal and cultural barriers. **A list of these programs is included in Appendix 1.**

Grant Opportunities

Komen Central New York has granted funds to groups across a broad spectrum of interests. From 2005-2010, more than 110 non-profits have been grant recipients of Komen Central New York. **A list of the 2010 grantees can be found in Appendix 2.** As previously demonstrated, Onondaga and Monroe counties have the greatest needs for screening, education and treatment as they are population and minority dense as well as environmentally urban and account for much of the counties' poverty.

The remaining counties in the service area pose different problems, although they are still based around Komen's goals of education, screening and treatment. Financial access to care and assistance with transportation and childcare are needs that must be addressed. Often, even after diagnosis, women need funds for everyday living expenses and to compensate for loss of pay due to sick leave. There is an ever-increasing need to fund educational outreach and screening programs in order to disseminate the early detection message to these women.

Challenges in the Current Fiscal Environment

One of the biggest problems facing all Komen affiliates in New York State is the looming national and state budget cuts that have arisen in the current financial atmosphere. Two of the three mobile mammography units, both of which Komen Central New York had funded in the past, are no longer in service due to government budget cuts. The counties with the largest rural populations are suffering greatly due to this lack of mammography services. Komen Central New York needs to fill in the gaps that reduced government spending has created. As of October 2009, New York state budget cuts totaled $3.74 billion and included a three-percent reduction in the state budget, a state payroll lag and a state workforce furlough. In December 2009, the NYS Department of Health informed all counties that all state-funded programs would be cut 12.5 percent. The state is currently redesigning its Medicaid program and plans to cut more than $900 million from the program. Komen Central New York no longer has the luxury to pick and choose to which programs it can award grants; it must fill in the gaps just to maintain current levels of education, screening and treatment. As the deficit grows each day, Komen Central New York will not be able to cover basic needs.

Quantitative Results of the Provider Survey

We mailed the survey to 283 providers of breast health services in Komen Central New York's service area. Forty-four surveys were returned as of February 23, 2011. Key findings from this survey are presented below.

Of the 44 respondents, nine (20.5 percent) identified themselves as men, and 32 (72.7 percent) identified themselves as women. Three respondents (6.8 percent) did not answer this question. Mean age of respondents was 51.9 years. Among the respondents, 15 (34.1 percent) were Nurses, 11 (25.0 percent) were Medical Doctors, 8 (18.2 percent) were Radiation Technologists, 6 (13.6 percent) were Physician Assistants, and 4 (9.1 percent) were members of other occupational groups. All but one of those who responded to the question about race/ethnicity (90.9 percent) identified themselves as white. The one exception identified him/herself as Asian. Three respondents chose not to identify their racial or ethnic identity.

We asked the providers to estimate the percentages of women they served from various racial and ethnic groups. The vast majority of women they served were Caucasian (median = 93 percent), followed by African American (median = 3 percent), multi-ethnic (median = 2 percent), Latina (median = 2 percent), Asian/Pacific Islander (median = 1.5 percent), and Native American (median = 1 percent). These numbers are consistent with the known population percentages in Komen Central New York's service area. It is important to note, however, that 17 of the 44 (38.6 percent) respondents serve at least 10 percent minority (non-white) women, and 5 of the 44 (11.4 percent) respondents serve at least 25 percent minorities. Twenty-one (47.7 percent) of the respondents indicated that there are non-English speaking members of their communities who would benefit from breast health messages in other languages, most commonly, Spanish.

Respondents also estimated the percentages of women they served in various age groups. Median percentages were 20 percent of women under age 40, 25 percent of women between ages 40 and 49, 30 percent of women between ages 50 and 64, and 25 percent of women 65 years and older.

The vast majority of respondents (93.2 percent) indicated that they provided breast health education materials and services. Ninety-one percent also provided screening and diagnostic services, of which 60 percent indicated that they could accommodate women with disabilities. A minority (37 percent) indicated that they provided breast cancer treatment services. Fifty-seven percent of the respondents indicated that they provided outreach to women who did not typically have access to screening services, while 73 percent indicated that they offered some type of financial assistance or discounted services for uninsured, underinsured and/or low income women. Many programs (70.5 percent) partnered with other organizations, for example Cancer Services Program Partnerships, to provide breast health services to women in their communities.

Figure 5, below, shows the types of screening and diagnostic services that the respondents offered. The highest proportion of respondents provided clinical breast examinations, more than half provided screening mammograms, ultrasound and biopsies, and just under half provided diagnostic mammograms.

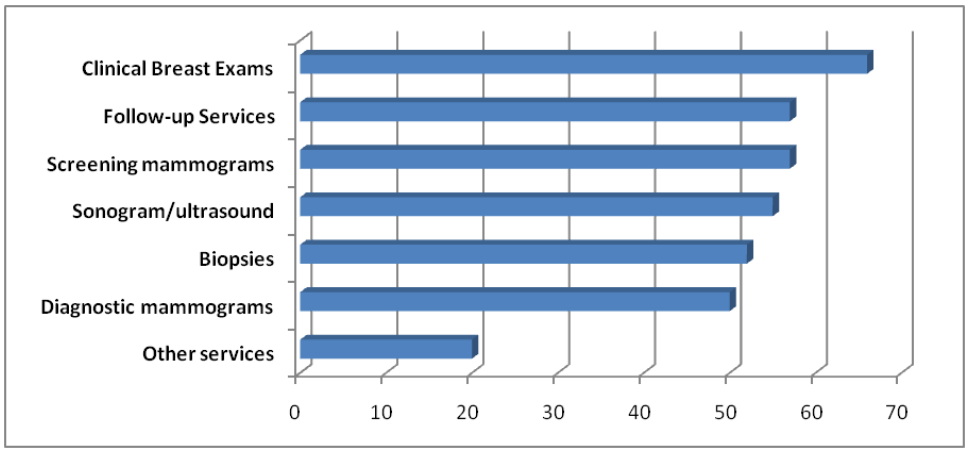

Figure 5. Types of Screening and Diagnosis Services Listed by Respondents

Figure 6 shows the various methods of payment that providers of breast health services accept. Almost all providers accept private insurance and Medicare, and most accept Medicaid. Note that more than 35 percent of the respondents indicated that some women were unable to pay for breast health services.

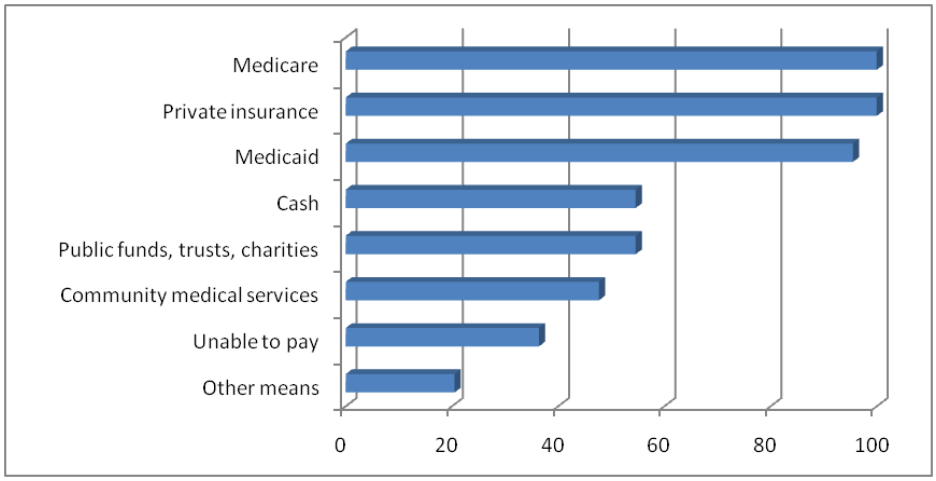

Figure 6. How Women Pay for Breast Health Services (Percent)

Of great interest were the barriers that prevented women from accessing screening that providers identified. Figure 7 illustrates these barriers. Note that the barrier that the most providers identified was lack of money or health insurance. This was consistent with what we knew or suspected about access to breast health services in the current health care system. Most other barriers that many respondents identified related to individual misconceptions, fear, embarrassment or lack of knowledge.

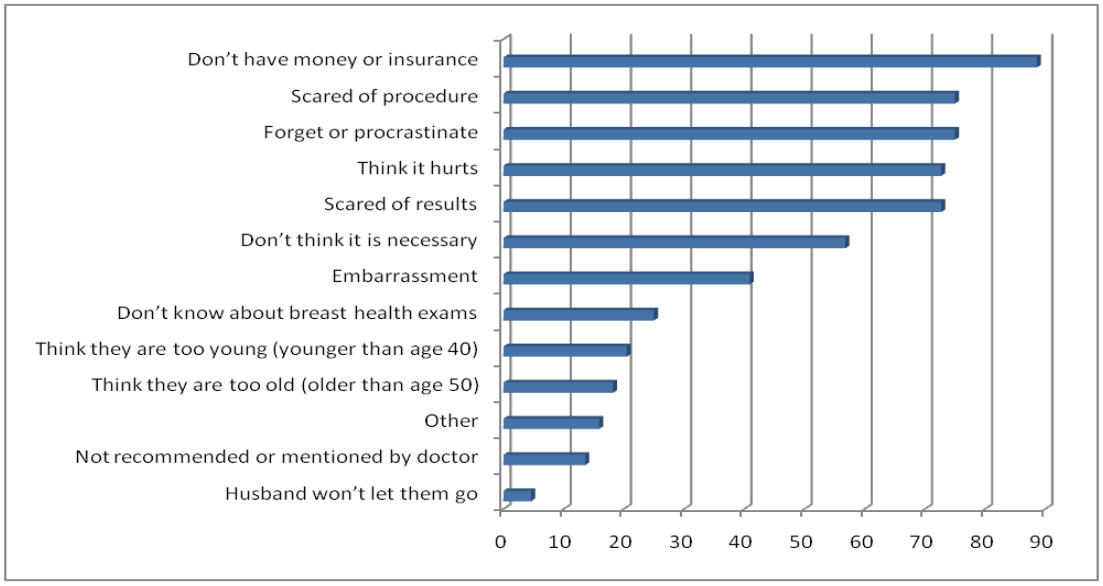

Figure 7. Barriers to Receiving Breast Health Services (Percent)

Many respondents understandably advocated for expanding services that low income women or women without insurance could access. They recommended "free screenings" or "no/low cost mammograms" or advocated for "mobile units (and) work site programs". Typical comments included the following:

> (We need) …broader expansion of guidelines for eligibility for free gyn/mammo through the Wellness Connection, which is already in place.
>
> More sponsored programs geared to women's health – women's events held in areas of lower income to make women aware of opportunity for preventive care coverage.
>
> Need help for people who don't qualify for cancer services/Medicaid but don't have the $ or want to spend the $ for exams, have more fairs/ days of inexpensive access, etc.

Some noted the reluctance of poor women to access services and the need to assist them.

> Continued education – health care for the poor remains a priority. They are reluctant to take advantage of programs offered to improve their health.
>
> Consistency of message, maintain presence in community and urban health centers, patient navigation for underserved populations is most important.

Another common theme was the need to increase awareness of available services among women in poverty or with no insurance. Comments included the following:

> (We need) …to reach the lower income or people that don't realize there are programs that cover mammograms for people who qualify or have no insurance

> Need more awareness in community of importance of SBE/clinical exam/mammography. Need community aware of programs such as cancer services (program) that can help them get these evals.

Respondents offered suggestions about how to reach out to women who may be unaware or reluctant to access available services.

> Greater advertising, more public outreach! I really believe that lack of advertising is our greatest barrier. Getting the word out and really educating people about early detection and services available to help with the cost of treatment if diagnosed.

> Distribute information at grocery stores, MD's offices, clinics – non-traditional places. Television advertising should be better utilized not during breast cancer awareness month.

> Marketing and just getting the word out. Posters and pamphlets in community centers, etc.

Conclusions from the Health Systems Analysis

Target communities in Komen Central New York's service area are fortunate to have a more than adequate number and high quality of providers of breast cancer screening, diagnostic, treatment and follow-up services. This is due, in part, to the university-affiliated clinical centers in Syracuse and Rochester. The New York State Cancer Services Program adds another layer of services. As the quantitative and survey data suggest, however, women in the target communities, particularly women from low-income and/or minority groups, do not access the services that are available. Many women who are eligible for free or low-cost screening programs either do not take advantage of those services or do not receive follow-up diagnostic and/or treatment care. Reasons for reduced access to available services are many and varied, but many of the problems that prevent low-income and minority women from accessing breast cancer services are related to poverty or cultural differences within the community. These issues will be explored in greater depth in the following section which discusses the qualitative data obtained from the two target communities.

Qualitative Data: Ensuring Community Input

Background

The goal of the qualitative component of the Community Profile is to provide a clearer understanding of current barriers to breast care, screening, and treatment in the urban populations in Komen Central New York's service area through in-depth interviews with key informants. To achieve this goal, one of our objectives was to reveal persistent as well as potential new and changing factors that could affect access to care and use of services in the target populations. We wanted to learn from provider and advocate experts. A further objective was to establish procedures for future focus groups involving at-risk women who do not use breast screening services - how to find, engage, and effectively lead such groups.

We interviewed key informants in Syracuse and Rochester and made observations of survivors who were reaching out to other women. Key informants are community members who know about the breast-care needs of underserved women in their communities. They are also long-time community advocates, cancer services employees, and providers of breast health services for breast cancer patients and at-risk populations. We also attended and took notes at an outreach event of Syracuse's Witness Project, at which survivor advocates spoke to the local chapter of the National Council of Negro Women to inform, encourage, and support its members through the continuum of care for breast cancer screening, treatment, and recovery.

Interview topics for key informants originated with breast cancer statistics and demographic data for the service area and survey results from the 44 providers who responded to our questionnaire. From these, select and new topics were probed and expanded.

Qualitative findings can be used as the "formative" basis of new initiatives or research and to suggest changes to existing programs. Limitations of qualitative data include its lack of generalizability in using personalized accounts that may not apply to all members of a community and lack of empirical bases with non-scientific selection of key informants and non-significant numbers of interviews. Therefore, qualitative findings should be used only to inform and not to direct program changes. Yet, qualitative research is used extensively and successfully as a basis for finding new approaches and solutions to intractable problems.

Methodology

We interviewed five key informants, four in Syracuse and one in Rochester, and observed an outreach activity by African-American breast cancer survivor-advocates for other women of color.

Key informants were selected by convenience and snowball sampling, beginning with current Komen grantees and their recommendations. Two informants were breast care providers for at-risk populations (one from Rochester), two were community advocates for underserved women and were associated with the Cancer Services Program, and one informant was an expert in qualitative medical research. All key informants had decades of experience in their fields of expertise.

All interviews were in-person, and interview locations were the workplaces of each informant. All but one of the interviews lasted one to two hours; the one exception was limited to twenty minutes due to scheduling. We provided key informants with a series of open-ended questions

to which they replied (See Appendix 3, Key Informant Interview Tools for Providers, Advocates, and Qualitative Researcher). We also encouraged key informants to offer their opinions about any other issues related to barriers to care among underserved women in their communities. Responses were recorded by hand-written notes and subsequently transcribed and codified.

Five key informant interviews were considered adequate for this qualitative component because information and ideas became repetitive, and no new information was gathered from the last interview. The small number of interviews was also adequate for formative research because our focus was the singular target population of urban poor women of color who face similar barriers to breast cancer screening and use of services. As a qualitative tool for the target population, our number of key informant interviews does not need to satisfy statistical representation of the entire population.

We also attended and took notes at an outreach event of Syracuse's Witness Project, at which survivor advocates spoke to the local chapter of the National Council of Negro Women to inform, encourage, and support its members through the continuum of care for breast cancer screening, treatment, and recovery. (For privacy reasons, only summary topics rather than specific observations from this outreach activity are included in this report).

We did not provide any incentives to key informants or to survivor advocates from the Witness Project for their participation.

Process and Qualitative Findings from Key Informant Interviews and Observations

We began by showing the key informants a data summary of breast cancer diagnosis stages in Komen Central New York's service area displayed by zip code, racial mix, and insurance status. (Thomson Reuters, ©2009) The data showed that the highest levels of late stage diagnoses were in urban neighborhoods of Syracuse and Rochester, both of which had high proportions of African-Americans and uninsured persons (See Table 3). These groups were identified as the at-risk population. We then asked the key informants open-ended questions that covered the following topics:

A. Description of at-risk populations and how these groups may be changing
B. How low-income and underserved urban women learn about breast care services
C. How this population obtains mammograms and treatment when necessary
D. Barriers to screening among the underserved
E. The nature of breast health services for underserved women in each city
F. Constraints that providers experience in delivering breast health services to underserved women
G. Outreach and educational services and their perceived effectiveness
H. Thoughts on needs and improvements for outreach, screening, and treatment services.

Summary responses to the eight interview topics (A through H, above) are listed below:

A. **Description of At-risk Population and Recent Changes**
Underserved women who are eligible for mammography screening in the Syracuse and Rochester programs are typically very poor, undereducated, and members of minority groups, usually African-American or Latina. These women have many issues, including lack of health literacy and poor lifestyle including substance abuse. The women may feel marginalized and simply "fall through the cracks." This group is also changing with increasing refugee

populations from diverse countries. Both Rochester and Syracuse are now seeing more women who are recently unemployed and underemployed and who no longer have health insurance. Another increasing group in the underserved category is Native Americans of Onondaga County. The end of annual mobile mammography clinics at the Nation Health Center has left this population without a familiar, trusted, and convenient source of breast health services.

B. **How Underserved Women Learn of Breast Care Services**
Outreach activities are constantly underway to reach the underserved population (See G and H). Rochester providers spend as much time as possible at free city clinics to reach women at risk. In spite of these efforts, many who register for the program indicate they heard about it through "word of mouth."

C. **How the Target Population Receives Mammograms and Breast Cancer Treatment**
The underserved populations, when reached, have access to screening programs both at clinics and through partner medical practices. If a woman receives a diagnosis, she is enrolled in the Cancer Services Program for treatment at no cost. Rochester uses patient navigators to help women through the care cycle, and members of the Onondaga County Health Department in Syracuse help with navigator-type assistance as much as they are able.

D. **Barriers to Breast Cancer Screening among the Underserved**
Our key informants described various barriers to breast cancer screening that underserved urban women in Syracuse and Rochester experience. These barriers fall into six categories: knowledge, communication, fear, expense (including insurance), belief systems, and "life situations."

> **Knowledge** barriers begin with a lack of understanding about mammograms - what they are, why they are needed, and who needs them. Also, many underserved women (and others) do not know about the Cancer Services Program and its accessibility to those in need. Additionally, some women stated that their doctors did not tell them to get mammograms. These knowledge barriers relate to a general problem with "health literacy."
>
> **Communication** barriers are generally not affected by lack of telephones but can be caused by a "lack of minutes" on low-priced cell phone plans. Language barriers exist, with Spanish as the most common foreign language spoken in the two cities. Translation services for Spanish are available (including university-based translation services), although Syracuse's west side clinic with Spanish-speaking caregivers is reported as overburdened. Communications for a growing immigrant population of wide-ranging ethnicities was cited as a problem in Syracuse. Here providers often do not use the "language lines" of hospitals because this service is an added cost. A growing issue in immigrant groups is the use of family members, often adolescent children, as interpreters for breast health services. Cultural influences can stifle truthful communications when women must use children, particularly males, to relay their symptoms and concerns.
>
> **Fear** about mammography is experienced by low-income women. Fear of a diagnosis and fear of death are prominent, along with fear of the effects of radiation, fear of cancer returning - when and where, fear of what will happen to family members, and fear of the cost of treatment. Women generally did not express a fear of disfigurement. Cancer Services Programs work hard to spread the message that breast cancer is "no longer a death sentence."

Cost concerns centered around loss of wages and costs of treatments and medications. Uninsured and under-insured women often believe they cannot afford the costs and are not aware that services will be free for them.

One type of **Belief System** barrier is associated with religious convictions, a fatalism that a woman has been given the cancer and she cannot change the outcome. All outreach efforts urge women to use available services in order to help achieve their best possible outcomes. A second belief barrier involves a general distrust of institutions, including healthcare institutions. One remark that a key informant heard from a breast cancer patient who was recertifying for the Medicaid Cancer Care program, through which she had already received care, was:

> "I hope Obama's healthcare does not go through because I don't want the government to get involved. I might lose my (cancer care) benefits."

Life Situations. The most challenging barrier that all informants expressed in various ways was the **difficult lives** of poor inner city women. Their own needs, including healthcare needs, are often the last to be met. For these women, priorities are determined by life's challenges - getting enough money and enough food, how to get to work, having adequate clothing to wear, paying bills, caring for those who need them. Being raised poor affects outlooks and futures; the poor can be any race, but more African Americans are affected. Poverty can instill a feeling of unworthiness in those it affects. One interview provided an example of this. A woman in her late 40s who had never had a mammogram enrolled in the program after noticing a breast lump; she later cancelled when the lump disappeared. She was encouraged to be screened anyway but the woman said, "No, save it for someone who needs it."

Certain expected barriers to screening were not identified. Our informants heard less mention of transportation, childcare, and scheduling issues than in the previous report. Regarding transportation, rides are offered free of charge in both cities, and the urban populations are also more accustomed to public transportation. Scheduling of mammograms is less of an issue because both cities offer mammography on Saturdays and at least one weekday evening.

E. **Breast Health Services - Syracuse vs. Rochester**

Key informants from both Syracuse and Rochester expressed the vital role that Susan G. Komen for the Cure played both in providing clinical services to women in need and in its support of outreach and educational programs aimed at capturing more underserved women. Syracuse and Rochester appear to differ in their recent approaches toward reaching more at-risk women. Syracuse efforts have shifted toward establishing partnerships with existing medical practices to care for underserved women; here, the objective is to give "medical homes" to patients to ensure access for all medical needs and to provide these women with the best available care in their communities. In contrast, Rochester is focusing new efforts on providing breast health services in neighborhood clinic settings, while many underserved women are treated at established medical practices. This approach tries to reach those who are uncomfortable leaving their own immediate communities. Both strategies offer potential benefits in coverage and quality of services.

F. **Provider Constraints in Delivering Breast Health Services**

One person stated, "Our numbers of people using (CSP) services should be 'over the top' but they are not. We might be missing half of the eligible women." Reaching the target population

is the first step in delivery of breast health services and the objective of education and outreach programs. Providers also expressed two new problems with delivery. First, the paperwork burden is more cumbersome than in the past. It may now take up to 30 minutes of help from a healthcare professional or advocate to assist a woman to enroll in the Cancer Services Program. Second, the costly problem of missed appointments continues to burden practices in spite of extensive attempts at contacts and follow-up.

G. **Outreach and Educational Services and their Perceived Effectiveness**
"Customized community level" outreach initiatives in both Rochester and Syracuse are extensive and varied. These programs include awareness/educational efforts, service days, promotional literature, and support groups. Specific activities include media engagement and airtime, free screening days, health fairs, workshops, participation in community events, and information pamphlets, billboards, and advertising. Free screening days are well attended in both cities. For example, Rochester offers three free screening days annually and each is always fully booked. During the screening programs, they also provide massages and Reiki relaxation therapy to make the experience pleasant and positive.

The effectiveness of most outreach events can be evaluated on "adequacy" of delivery levels, where attendance or services provided are counted. More in-depth evaluations of "plausibility" or "probability" in improving outcomes are beyond the scope (and resources) of many outreach activities.

H. **Ideas on Improvements Needed for Outreach, Screening, and Treatment Services**
Improvements in outreach continue to center on the need to inform the public of the Cancer Services Program so that women know that free screening and treatment are available and to convince women to take advantage of the services. Information and participation efforts could focus on the following: employers who do not offer health insurance and those companies experiencing layoffs, so that eligible women learn that care is available at no charge; intense community media coverage so that the Cancer Services Program becomes a household word; increased partnering with other healthcare events and holding more "free screening" event days; events/activities to highlight the Cancer Services Program to the medical community to recruit partners; continued educational efforts to promote wellness and early detection; and more support groups to meet the cultural needs of targeted populations.

The outreach event of The Witness Project of Syracuse involved breast cancer survivors who spoke to the local chapter of the National Council of Negro Women. Breast cancer survivors revealed their personal cancer experiences – what made them seek medical care, how they handled the news and treatments, and how their lives were changed. The messages of survivors emphasized the need for women to get screened and to get support from friends and family.

Conclusions

Review of the Findings

The analyses presented above emphasize the following key findings:

- Komen Central New York's service area has both urban and rural communities that often have different problems and needs for breast health services. The vast majority of women from minority backgrounds are located in the two urban communities surrounding Rochester and Syracuse.

- The highest levels of late stage diagnosis are found within urban communities that have high numbers of women from traditionally underserved minority groups. Many providers within the service area work with significant numbers of women from these groups.

- Screening services, including clinical breast exams and screening mammography, ultrasound and diagnostic mammography are available within the urban areas of Komen Central New York's service area. Treatment services are also available. Many clinics that offer these services provide assistance for women who are unable to pay for these services.

- Many barriers prevent women from using available services, including those that are provided at low- or no-cost. Lack of money or insurance is most often mentioned as a barrier. Other barriers result from fear, bureaucracy and inconvenience, perceived lack of medical need or fatalism on the part of women within the service area communities.

- Services meant for women from underserved populations are not being fully used. In other areas, services are being withdrawn due to budget cuts at the state and federal level.

Conclusions

Our qualitative findings from interviews and observations complement the conclusions of the quantitative data for urban women of color, with similar issues echoed about fear of mammography, lack of knowledge about the importance of breast cancer screening, lack of awareness of free screening programs, cost concerns, and a need for continued and heightened culturally-appropriate outreach programs for underserved urban women, including patient navigation.

The target community of urban underserved women of color experiences severe access barriers similar to those identified in studies from across the country (Adams et al, 2006; Vona-Davis, 2009; Ansell et al, 2009), all related to poverty. Further, this population is at risk for additional reasons. First, women of color, particularly African Americans, tend to develop more aggressive forms of breast cancer with earlier onset, and screening must take place early to treat the disease when it is most curable. Second, our data show urban underserved women present with higher rates of advanced stage breast cancers as compared to their white counterparts. Third, national data from the NCI's Surveillance Epidemiology and End Results (SEER) survey show that, although African-American women have an age-adjusted breast cancer rate 7

percent lower than whites (118.6 vs. 127.4 cases per 100,000 women, 2007), their age-adjusted mortality from breast cancer is 41 percent higher than breast cancer mortality for white women (31.43 vs. 22.23 deaths per 100,000 women). (National Cancer Institute, 2011)

The qualitative component also shows new trends in at-risk populations and challenges to access. At-risk groups also include women who are recently unemployed and underemployed and have lost their insurance. Onondaga County's rural Native Americans are now without mobile mammography, upon which they had come to rely. In addition, growing numbers of diverse immigrant groups have special needs surrounding language and culturally-sensitive outreach methods.

Our key informants describe at-risk women in newer terms, more reflective of their life situations than simply stated "low socioeconomic status, lack insurance, percent in poverty." Accounts of day-to-day challenges of women who do not make their own health a priority lend a depth of understanding to their hardships; this may help inform sensitive approaches to reducing their barriers to screening services. Reports on how underserved women hear about the Cancer Services Program show the need to increase support for these women. Although there are many outreach programs, most key informants reported that their communities hear of the program through "word of mouth". A more effective way to reach these communities may be to work with supportive advocates. The Witness Project uses this type of outreach with survivors sharing their own stories and urging other women to seek the services of an experienced medical community.

Komen Central New York identified three priority areas in response to the data presented in this report.

1) Increased awareness of free and reduced-cost services that counties and charitable agencies provide is needed, particularly among underserved women. Lack of health insurance is known to reduce mammography participation, (American Cancer Society, 2011) and it is the most common barrier to screening that survey respondents identified. This is a significant problem among women of color in urban communities. Comments of survey respondents also suggest that the populations they serve are not aware of available services and, therefore, do not take advantage of them.

2) Better programs and methodologies designed to reach underserved women. This has been a focus of Komen Central New York's grant program in the past and will continue to be a focus in the future. Although Komen Central New York's goal is to continue to educate all women about the importance of screening mammography and clinical breast exams, the data suggest that Komen Central New York can most effectively accomplish this goal through building community capacity. The urban communities in Komen Central New York's service area are served by cancer clinics that provide low-, or no-cost screening and treatment services, yet the women most in need of those services are not accessing them. The reasons for this are many and varied, but there is a need within these communities to reach out to underserved women. By identifying and empowering grass-roots organizations within urban communities, Komen Central New York can improve outreach to underserved women through culturally-sensitive programs that are acceptable to community members.

3) Navigation through the continuum of care is crucial to insure that women are screened and that those with positive screening findings receive the appropriate follow-up diagnostic and treatment services. Navigation services have been used successfully in large urban areas targeting racial and ethnic minorities. (Robinson-White, Conroy, Slavish and Rosenzweig

2010) Navigation services can help overcome fear and procrastination, both of which a large majority of survey respondents identified as barriers to obtaining breast health services.

Action Plan

Priority 1: Promote breast health awareness and the importance of screening and early detection among women in Central New York

Objective 1: Conduct targeted outreach to solicit grant applications from not-for-profit organizations with knowledge of, and experience in, underserved minority communities located in Monroe and Onondaga counties, particularly in the cities of Rochester and Syracuse. Komen Central New York will accomplish this objective by, among other things, proactively identifying a target list of at least 25 qualifying organizations before the next grant cycle with the ultimate goal of receiving at least four completed RFAs from first-time non-profit organizations and conducting a grant writing and coaching workshop for these organizations.

Objective 2: Partner with local not-for-profit organizations in underserved communities and create "train the trainer" programs to help these organizations draft appropriate RFAs and continue to follow up with the organizations that receive grants to ensure the success of their programs to reach underserved women to increase knowledge of, and access to, free and reduced-cost screening and diagnostic services. Komen Central New York will accomplish this objective by, among other things, defining a graduate intern level position and securing a qualified intern to lead this project by the middle of 2012 and hosting a Lay Health Advocate (LHA) training program and summit in summer 2012.

Objective 3: Facilitate partnerships among agencies in an affirmative fashion, i.e., between providers or provider agencies and non-traditional breast health organizations like faith-based organizations, social and cultural organizations, etc. to extend the reach and penetration of breast health messaging. Komen Central New York will accomplish this objective by, among other things, proactively seeking and inviting qualified people of racial, ethnic, and geographical diversity who work and live in the targeted communities to join Board committees.

Priority 2: Promote breast health awareness and the importance of screening and early detection among women in Central New York.

Objective 1: Through grant efforts, improve consumer awareness about screening programs and services in targeted communities throughout Central New York including increasing awareness about free and low-cost breast health programs and services.

Objective 2: Brain storm with identified organizations to create programs through media that appeal to underserved populations. Komen Central New York will accomplish this objective by, among other things, publishing at least four news releases each year profiling survivors, grant awardees, and other stories of interest.

Objective 3: Find ways to incentivize women to take advantage of free and reduced-cost services. Komen Central New York will accomplish this objective by, among other things, partnering with other organizations to conduct free breast cancer screening days and to provide women who are screened with gift cards that they can use at local grocery stores.

Priority 3: Develop partnerships with community organizations that can assist women to navigate through the continuum of care

Objective 1: Partner with local providers to develop and sustain programs to train patient navigators who will be available to underserved minority populations to ensure that these populations have the resources, e.g., translation services and culturally-sensitive materials, that they need to ensure proper care. Komen Central New York will accomplish this objective by, among other things, actively soliciting RFAs from not-for-profit organizations in Monroe and Onondaga Counties that include a plan for training and supporting patient navigators.

Objective 2: Facilitate access for racial and ethnic minority populations in the identified geographic areas by supporting culturally-appropriate, creative outreach strategies and partnerships. Komen Central New York will accomplish this objective by partnering with local faith-based organizations to provide information about available services and by partnering with community leaders who live and work in the targeted communities to educate and provide them with the materials necessary to educate other women in their communities about the importance of screening and early detection.

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Appendix 1

Cancer Services Programs in Komen Central New York's Service Area

Cayuga County Cancer Services

Cayuga County Department of Health and Human Services - Cayuga County Healthy Men and Women Partnership
8 Dill Street, Auburn NY 13021
Phone (315) 253-1455 Fax (315) 252-2085

Chenango County Cancer Services

Broome County Health Department - Southern Tier Healthy Living Partnership
225 Front Street, Binghamton NY 13905
Phone (607) 778-3900 Fax (607) 778-3998

Mobile Mammography
Our Lady of Lourdes Memorial Hospital, Inc.
69 Riverside Drive
Binghamton NY 13905
Phone (607) 798-1274 Fax (607) 772-1642

Cortland County Department of Health

Cancer Services Program of Cortland and Tompkins Counties
60 Central Avenue Room B-25
Cortland NY 13045
Phone (607) 758-5523 Fax (607) 756-3419

Herkimer /Madison/Oneida County Cancer Services

Oneida County Department of Health - Cancer Services Program of Oneida, Herkimer and Madison
185 Genesee Street, 5th Floor
Utica NY 13501
Phone (315) 798-5248 Fax (315) 798-5022

Jefferson/Lewis County Cancer Services

Lewis County Public Health Agency - Cancer Services Program of Lewis and Jefferson County
7785 N. State Street
Lowville NY 13367
Phone (315) 376-5454 Fax (315) 376-9459

Livingston County Cancer Services

University of Rochester - Livingston Wyoming Cancer Prevention Partnership
5362 Mungers Mill Rd.
Silver Springs NY 14550
Phone (800) 588-8670 Fax (585) 786-3537

Mobile Mammography (covers Livingston)
St. James Mercy Hospital
411 Canisteo Street
Hornell NY 14843
Phone (607) 324-8147 Fax (607) 324-8152

Monroe County Cancer Services
University of Rochester - Health Partnership of Monroe County
46 Prince Street
Rochester NY 14607
Phone (877) 293-0822 Fax (585) 244-2897

Onondaga County Cancer Services
Onondaga County Department of Health - Cancer Services Program of Onondaga County
421 Montgomery Street, 9th Floor
Syracuse NY 13202
Phone (315) 435-3653 Fax (315) 435-2835

Ontario County Cancer Services
Ontario County Community Health Services - Cancer Screening Partnership of Ontario, Seneca and Yates
3019 County Complex Drive
Canandaigua NY 14424
Phone (585) 396-4559 Fax (585) 396-4551

Oswego County Cancer Services
Oswego County Opportunities, Inc. - Cancer Services Program of Oswego County
10 George Street
Oswego, NY 13126
Phone (315) 342-0888 ext 1454 Fax (315) 342-9813

St. Lawrence County Cancer Services
St. Lawrence County Public Health Department - St. Lawrence County Cancer Services Screening Partnership
Address 80 SH 310, Suite 2, Canton NY 13617
Phone (315) 386-2325 Fax (315) 386-2744

Seneca County Cancer Services
Ontario County Community Health Services - Cancer Screening Partnership of Ontario, Seneca and Yates31 Thurber Drive, Waterloo NY 13165
Phone (315) 539-1936 Fax (315) 536-5146

S2AY Rural Health Network - S2AY Rural Health Network Ovarian Cancer Awareness, Education and Support Initiative
PO Box 97, Corning NY 14830
Phone (607) 962-8459 Fax (607) 962-9755

Wayne County Cancer Services
Wayne County Public Health Service - Cancer Screening Partnership of Wayne County
ViaHealth of Wayne, PO Box 111, Driving Park Ave.,
Newark NY 14513
Phone (315) 332-2255 Fax (315) 359-2111

Yates County Cancer Services

Ontario County Community Health Services - Cancer Screening Partnership of Ontario, Seneca and Yates
417 Liberty Street, Penn Yan NY 14527
Phone (315) 536-5199 Fax (585) 396-4551

Appendix 2

2010-2011 Grant Awards
Total $400,432

ARISE, FAMILY AND CHILD SERVICES, INC. — $25,000

"BREAST HEALTH AWARENESS AND OUTREACH TO WOMEN WITH DISABILITIES"

Provide women with disabilities a comprehensive, easy to understand system for breast health awareness and education. This program will present an opportunity to identify the specific physical and attitudinal barriers that prevent women with disabilities from being appropriately screened for breast cancer.

Target Population: Persons with Disabilities and Rural Population
Service Area: Onondaga, Oswego and Madison Counties

CANTON – POTSDAM HOSPITAL — $6,000

"BREAST CANCER PATIENT NAVIGATION PROGRAM"

Eliminates barriers to screening, diagnosis and treatment of breast cancer. Patient Navigator accompanies patients to appointments, follows up with patients, helps secure resources for expenses such as travel, wigs, and scarves, educates patients, and is there for moral support from diagnosis through complete treatment process.

Target Population: Caucasian, Breast Cancer Patients and Rural Population
Service Area: St. Lawrence County

CARTHAGE AREA HOSPITAL — $19,000

"BREAST CANCER OUTREACH PROGRAM – MAKE SURE YOU ARE INFORMED"

Provide breast health educational opportunities for migrant population, women of military families, and to women residing in the high incidence rate communities.

Target Population: Hispanic/Latina, Military & Migrant, Caucasian and Rural Population
Service Area: North Lewis, Southern St. Lawrence and Eastern Jefferson Counties

CAYUGA COUNTY DEPARTMENT OF HEALTH — $18,440

"BREAST CANCER SCREENING AND EDUCATION"

Breast cancer screening and diagnostic procedures for uninsured and/or underinsured women in Cayuga County who could not otherwise access services.

Target Population: African-American, Caucasian and Rural Population
Service Area: Cayuga County

CHENANGO HEALTH NETWORK **$20,000**

"EVERY WOMAN COUNTS IN CHENANGO COUNTY"

Community-based outreach activities geared to women living in communities scattered throughout the rural county. The program will also provide educational activities designed specifically to teen girls in promoting the importance of screening and early detection of breast cancer.

Target Population: Elderly, Low-Literacy and Rural Population
Service Area: Chenango County

CORTLAND COUNTY HEALTH DEPARTMENT **$20,492**

"CANCER SCREENING, OUTREACH & EDUCATION"

Breast cancer screening and diagnostic procedures for uninsured and underinsured women in Cortland County.

Target Population: Uninsured and underinsured women
Service Area: Cortland County

CROUSE HEALTH FOUNDATION **$14,000**

"INCREASING ACCESS TO CARE FOR THOSE WHO NEED IT MOST"

Provide breast cancer screening and physician access to women in Onondaga County without health insurance

Target Population: Uninsured Women
Service Area: Onondaga County

FAXTON-ST. LUKE'S HEALTHCARE, REGIONAL CANCER CENTER **$23,500**

"LYMPHEDEMA TREATMENT AND MANAGEMENT PROGRAM"

Educational outreach activities to increase awareness and education for breast cancer patients about lymphedema and its treatment options. Financial assistance to breast cancer survivors with lymphedema treatment supplies.

Target Population: Breast Cancer Patients, Breast Cancer Survivors, Lymphedema Patients
Service Area: Oneida, Herkimer and Madison Counties

GILDA'S CLUB ROCHESTER / CANCER ACTION, INC. **$8,500**

"REACHING THE UNDERSERVED: EDUCATION AND OUTREACH FOR AFRICAN AMERICAN AND HISPANIC WOMEN"

Culturally appropriate outreach, educational programs and support services to African American and Hispanic women living with breast cancer.

Target Population: African American and Hispanic Women
Service Area: Rochester

HIGHLAND BREAST IMAGING, HIGHLAND HOSPITAL **$25,000**

"CLINIC BASED BREAST CANCER OUTREACH"

Outreach program designed to provide preventive breast cancer screenings and diagnostic imaging services and breast health education.

Target Population: African-American, Hispanic/Latina and Medically Underserved
Service Area: Rochester and Monroe County

LEWIS COUNTY PUBLIC HEALTH AGENCY **$20,000**

"CANCER SERVICES PROGRAM OF LEWIS & JEFFERSON COUNTY"

Outreach and education program designed to provide breast cancer screening and diagnostic services to underserved women.

Target Population: Hispanic/Latina, Breast Cancer Survivors and Rural Population
Service Area: Jefferson & Lewis Counties

LIVINGSTON COUNTY DEPARTMENT OF HEALTH **$10,000**

"SCREEN TODAY"

Outreach and awareness on importance of breast cancer screening.

Target Population: Hispanic/Latina, Caucasian and Rural Population
Service Area: Livingston County

NEWARK-WAYNE COMMUNITY HOSPITAL **$24,000**

"ENHANCED BREAST CANCER RELATED SERVICES AND EDUCATION/OUTREACH TO MEDICALLY UNDERSERVED, ETHNICALLY DIVERSE WOMEN, WITH OR WITHOUT MEDICAL INSURANCE"

Program to enhance need of breast care education and services necessary in the diagnosis of breast cancer.

Target Population: All medically underserved women
Service Area: Wayne County

ONEIDA COUNTY DEPARTMENT OF HEALTH **$23,000**

"CANCER SCREENING PROGRAM"

Breast cancer screening and diagnostic services for medically underserved women unable to access services in the rural community. Educational outreach activities to raise awareness of preventative breast health care and early detection services.

Target Population: African-American, Caucasian and Rural Population
Service Area: Herkimer, Madison & Oneida Counties

ONONDAGA COUNTY HEALTH DEPARTMENT **$25,000**

"OUTREACH TO AFRICAN-AMERICAN, AMERICAN INDIAN & HISPANIC WOMEN IN ONONDAGA COUNTY"

Preventative health program that provides education and breast cancer screening for medically underserved men and women living in Onondaga County. The goal is to improve breast health screenings rates and reduce late detection of breast cancer through education, screening, and referral for women of color.

Target Population: Uninsured/Underserved African-American, American Indian and Hispanic women
Service Area: City of Syracuse and Onondaga County

ONONDAGA COUNTY HEALTH DEPARTMENT **$25,000**

"OUTREACH AND SCREENING SERVICES FOR UNINSURED WOMEN IN ONONDAGA COUNTY"

Preventative health program that provides education and breast cancer screening for medically underserved men and women living in Onondaga County. The goal is to improve breast health screenings rates and reduce late detection of breast cancer through education, screening, and referral for uninsured women and to fund breast diagnostic services for uninsured or underinsured women who could not otherwise seek or would delay their care.

Target Population: Uninsured/underinsured women
Service Area: City of Syracuse and Onondaga County

OSWEGO COUNTY OPPORTUNITIES, INC. **$20,000**

"BREAST HEALTH PROGRAM"

Breast healthcare outreach to link medically underserved women and men to breast health education and screening services.

Target Population: Hispanic/Latina, Caucasian and Rural Population
Service Area: Oswego County

S^{2}AY RURAL HEALTH NETWORK, INC. **$25,000**

"BREAST CANCER SCREENING AND SUPPORT SUPPLEMENT FOR ONTARIO, SENECA AND YATES COUNTIES"

Financial resources to ensure that uninsured or underinsured women who do not qualify for breast screening services through the New York State Cancer Services Program receive breast screenings; transportation to treatment facilities for breast cancer patients; assist cancer patients who are under- or uninsured to obtain prosthetics, as well as provide education to breast cancer patients and their families.

Target Population: Rural Population
Service Area: Ontario, Seneca and Yates Counties

SPANISH ACTION LEAGUE OF ONONDAGA COUNTY INC. **$10,000**

"LATINAS AL MANDO BREAST HEALTH AND CANCER PREVENTION CAMPAIGN"

Using radio program and special events to provide culturally and linguistically appropriate information regarding breast health care and cancer prevention.

Target Population: Latino Community
Service Area: Onondaga County

ST. JOSEPH'S HOSPITAL HEALTH CENTER FOUNDATION **$21,000**

"LYMPHEDEMA EDUCATION & PREVENTION FROM STAGE 0"

Program to provide education about lymphedema and comprehensive treatment for this disease when it occurs as a result of treatment for breast cancer.

Target Population: Breast cancer survivors dealing with Lymphedema
Service Area: Onondaga, Broome, Cayuga, Chenango, Cortland, Delaware, Herkimer, Jefferson, Lewis, Madison, Oneida, Oswego, Otsego, St. Lawrence, Tioga and Tompkins Counties

ST. LAWRENCE COUNTY PUBLIC HEALTH DEPARTMENT **$15,500**

"CANCER SERVICES PROGRAM OF ST. LAWRENCE COUNTY"

Program to provide breast cancer screening, education and diagnostic services for uninsured or underinsured women who could not otherwise access service.

Target Population: Caucasian and Rural Population
Service Area: St. Lawrence County

UNIQUE CONNECTIONS **$2,000**

"HEALING CONNECTION – COMPLIMENTARY THERAPY AWARD VOUCHERS"

Complementary therapies that are used to help manage symptoms, reduce side effects, and restore and promote a sense of control and vitality for cancer patients.

Target Population: Breast cancer patients
Service Area: Onondaga County

Appendix 3

Content of in-depth interviews for Providers, Advocates, and Qualitative Researcher

PROVIDER INTERVIEWS:

1. Pre-interview remarks

2. Description of practice - pt. volume, area served, proportion of patients from underserved population
   - Partnership arrangements with Health Dept for screening mammography.
   - Your perception of medically underserved female population in your city and county (race, ses, eth, immigrant status)

3. What capacity do you have to provide breast health services to underserved women (medicaid, not insured, under-insured) in the community - i.e. limits on pts served ?

4. What constraints (barriers) exist for you as a provider to providing services to the underserved?

5. Regarding your patients from underserved populations, what difficulties do you encounter in providing service to them? (communication-phone,etc, their knowledge, language, transportation, childcare, scheduling, keeping appointments)

6. If you cannot provide service to more underserved women now, what could change that? (compensation? scheduling? communication? patients keeping appointment better?)

7. How do you reach out to underserved women in your community to encourage and support breast cancer screening?

8. Do you currently have "patient navigators" to assist breast cancer patients through the continuum of care? (including knowledge of support services, paperwork, transportation, interpretation of results, decision-making)

9. What assistance do you need to address the needs of underserved women in the community?

10. What do you see as barriers for underserved women to SEEK breast cancer screening?

11. What do your patients tell you about how their experiences could have been better?

12. What proportions of your recent screening patients (approximately) lack insurance?

13. Regarding stage at diagnosis, how would you describe those diagnosed at later stages (3 and 4) within your practice?

Who is being diagnosed at later stages? (Age, income, life situations, race/ethnicity?)

What do you see as reasons for late stage diagnosis?

13. What problems do you have with loss to follow-up?

14. What changes have you observed in patient use of services related to the recent and continued economic downturn?

Extra Notes:

COMMUNITY ADVOCATE INTERVIEWS:

1. Background information - various topics relating to breast cancer in general

2. How do low-income or uninsured women obtain breast care services?

3. Focus group advice for underserved population - who, where, when, ideas for finding women at risk and survivors, influence of recording on groups.

4. County/city - screening mammography services for underserved population

Eligibility criteria for free services - ease of navigation
Populations at risk
Populations reached
Populations difficult to reach (age, infirmity, disabilities, income, life/family issues, language?)

5. Barriers to screening
Beliefs
Costs
Knowledge/Perceptions/Fear
Scheduling (inc. work conflicts)
Support (transportation, child care/family, work)
Communication
Non-English Speaking Population

6. Breast Health Education

7. Cooperation/communication with advocates in other counties

8. How do you reach out to underserved women in your community to encourage and support breast cancer screening?

9. Do you currently have "patient navigators" to assist breast cancer patients through the continuum of care? (including knowledge of support services, paperwork, transportation, interpretation of results, decision-making)

10. Thoughts on breast cancer screening and services for city populations - needs, improvements

QUALITATIVE RESEARCHER INTERVIEW:

1. Sampling techniques for key informants

2. Focus groups

    Number and type of group leaders/helpers
    Audiotaping, videotaping
    Recording observations of group conditions/participants
    Note taking
    Participant types - managing
    Benefits of videotaping
    Interaction among participants
    Optimal size of focus group
    Optimal sites and time of day
    What to provide (food, beverage)
    Length of time for focus group
    Interviewer appropriate for group members and topic
    Strategies to elicit information
    Strategies to include less talkative participants
    Evaluation

3. Research on human subjects, risk to subjects, IRB requirements