

Qualitative Data: Ensuring Community Input

Qualitative Data Sources and Methodology Overview

Methodology. The key focus of the qualitative analysis was to understand how women in rural communities and communities of color access and utilize breast care. Surveys, key informant interviews, and a focus group were used to gather information on over-arching themes that could be explored in the richer context of key informant interviews.

Surveys were chosen for the first stage of data analysis based on their ease of administration and ability to capture information from many people at once. To identify themes relative to breast care access and service utilization, participants attending Komen workshops and meetings were surveyed regarding the communities in which they work and their perceptions of underserved populations, barriers to accessing services, successful community collaborations, strategies for improving services, and the impact of the Affordable Care Act.

Surveys were collected over the past two years at various meetings, including the FY15 Grant Writing and Networking Conference, held August 8, 2014, in Sacramento and the Sister's Circle Brunch, held in Fairfield on June 7, 2014. Organizations new to the Komen Sacramento Valley grant-writing program are required to attend the grant-writing conference, so survey respondents represent a combination of returning and prospective applicants. The Sister's Circle brunch was organized to bring together 30 Black/African-American women from Solano County to discuss breast health in a four-hour social forum.

Survey data were summarized by staff and interns at the Sacramento Valley Affiliate. When multiple respondents from the same county shared an observation, the comment was labeled with the county name and +1, +2, etc. to indicate that more than one person, more than two people, etc. shared the sentiment. Table 1 shows which sources of qualitative data were used in the target communities and the themes that emerged from the survey data that were explored in the key informant interviews.

Key informant interviews were conducted with representatives of the target counties when available. To enrich the findings from the target counties and capture regional issues related to the care continuum, proxy key informants in neighboring counties were approached to speak to challenges working with diverse ethnic populations, uninsured/underinsured women, and those needing to travel for breast cancer treatment.

Table 1. Sources of Qualitative Data for Target Counties

<i>County</i>	<i>Amador</i>	<i>Solano</i>	<i>Yuba</i>
Surveys	Survey of FY15 Grant Writing Conference attendees	Survey of Sister Circle Brunch attendees	Survey of FY15 Grant Writing Conference attendees
Key Informant Interviews	<ul style="list-style-type: none"> ▪ Office Manager, Amador STARS ▪ Executive Director, Amador Community Foundation ▪ Two staff at Sutter 	<ul style="list-style-type: none"> ▪ Nurse Navigator, Sutter ▪ Solano Midnight Sun Foundation ▪ Nurse Navigator, NorthBay Cancer Center 	<ul style="list-style-type: none"> ▪ Services Director, Planned Parenthood ▪ Patient Navigator, Freemont Rideout Health Group, Marysville

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County	Amador	Solano	Yuba
	Health, Amador	<ul style="list-style-type: none"> ▪ Sutter Radiation Oncology ▪ Solano County Health and Social Services 	<ul style="list-style-type: none"> ▪ Chief Operating Officer, Chief Executive Officer, and Medical Director, Women's Health, Peach Tree Health, Marysville ▪ Harmony Health Medical Clinic
Proxy Key Informant Interview (chosen based on geographic proximity to target county)	<ul style="list-style-type: none"> ▪ CommuniCare, Yolo County ▪ Chap-De, Auburn, Placer County 	N/A	<ul style="list-style-type: none"> ▪ Patient in Chico, Butte County ▪ Hmong Cultural Center, Oroville, Butte County ▪ California Health Care Collaborative, Chico, Butte County
Themes	<ul style="list-style-type: none"> ▪ Treatment compliance ▪ Lack of knowledge about services 	<ul style="list-style-type: none"> ▪ Lack of knowledge about services ▪ Transportation ▪ Fear/lack of trust 	<ul style="list-style-type: none"> ▪ Outreach to Southeast Asians/minorities in native language ▪ Transportation Help for uninsured/underinsured

Some of the key informant interviews and a focus group were used to identify the needs of specific racial/ethnic communities. Table 2 describes the individuals and groups who participated in qualitative research activities. The Sacramento Valley Affiliate conducted a focus group in Stanislaus County in 2014 to assess the views of Hispanic women toward screening, treatment, and outreach. Although Hispanic women do not make up a significant proportion of women in Amador, Solano, or Yuba County, they make up 25.2 percent of the population of the 19 county service area of the Sacramento Valley Affiliate and as such are an important population to target.

Table 2. Qualitative Research Focused on Ethnic/Racial Communities

Community	African American	Asian	Hispanic
Data Source	Key Informant Interviews	Key Informant Interviews	Focus Group
Stakeholders	Nurse Navigator at Sutter Solano Cancer Center	<ul style="list-style-type: none"> ▪ Chief Operating Officer, Peach Tree Health ▪ Hmong Cultural Center, Oroville 	Women living in Stanislaus County (proxy data)

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Community	African American	Asian	Hispanic
Themes	Extreme poverty and substance abuse make outreach and support for services difficult	Punjabi and Hmong women experience shame and stigma with breast cancer diagnosis	Fear and anxiety prevent women from following up after abnormal mammogram

Sampling. A convenience sample was chosen for both the grant writing and Sister's Circle Brunch audiences. These respondents already had relationships with the Sacramento Valley Affiliate or were interested in developing a relationship with Komen as a grantee. Although the respondents were largely service providers, women from the community were included as well. In total, 32 respondents completed surveys at grant writing-workshop in August 2014, and 28 respondents completed surveys at the Solano Sister's brunch in Vacaville. Key informant interviews were conducted over the phone with 18 respondents representing Amador, Solano, and Yuba service providers or medically underserved populations of women. To maintain the anonymity of the survey respondents, no demographic details were collected, which prevents responses from being stratified by key demographic variables such as age or race.

Ethics. Participants completing surveys at the grant-writing conference disclosed their names and the agencies they represented because participation in the conference was a requirement for submitting a grant. Respondents participating in the key informant interviews chose to share their roles and agency affiliations. This was not a requirement of participation. Written consent was not required for phone interviews; by participating in the interviews, the consent of respondents was inferred. Respondents were not required to answer questions they did not want to answer and were told that the purpose of the interview was to understand resources and gaps within/barriers to care and health services provided in the communities of interest. Data have been reported anonymously so that individual respondents cannot be associated with their names. Notes recorded from key informant interviews have been stored in a locked file cabinet in the Sacramento Komen Affiliate's administrative offices.

Qualitative Data Overview

The themes gathered from the surveys provided a foundation for coding key informant interviews conducted in 2013 and 2014. When the surveys were coded, five key themes emerged: diagnostic services, treatment compliance, lack of insurance, cultural diversity, and transportation.

Combining the surveys and the key informant interviews helped coalesce areas of common concern related to diagnostic services, treatment compliance, cost of care, the needs of culturally diverse women, and transportation to services. Insurance, education, and access to care in rural areas were areas of concern reported in the 2011 Sacramento Valley Community Profile Report.

Qualitative Data Findings

From the survey data collected in August 2014, a number of key themes emerged:

1. Diagnostic services are not widely available in the target communities.

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2. Women may not comply with treatment if they have competing health concerns or trouble accessing care.
3. Women will not access services if they cannot afford them.
4. Rural communities have to serve a small number of culturally diverse women (i.e., Mexican American, Hmong, American Indian, South Asian) and need materials tailored to each cultural group
5. Women who live in rural communities may not be able to afford travel to urban areas for care.

These findings were corroborated with key informant interviews that were conducted in 2014-2015. A summary of the interviews by county follows:

Amador County

Document Review: The Amador County Assessment for 2014 was used to provide a context for qualitative analysis findings. The report reinforced the fact that Amador County has an aging socially isolated population, with 48 percent of Amador County residents being age 50 or older. Approximately 13 percent of households live in poverty. The estimate for households without access to a vehicle is estimated at 593, with 190 of those households being located in Jackson. Amador STARS averages 550 trips to cancer treatment annually, and Common Grounds Senior Services, Inc., provides transportation for seniors to doctors' appointments as well as the grocery store, post office, and other community service providers. In 2013, 51,502 individuals received services from the Interfaith Food Bank, including 970 seniors. The food bank provides supplemental food twice a month through its main site and 15 remote sites located throughout the county.

Sources of Key Informant Interviews: 1) Amador Community Foundation, 2) Amador STARS, 3) patient services representative at Sutter Health, and 4) nurse at Sutter Health.

Findings: Sutter Amador Hospital is the only provider of care within a community that relies on low-wage jobs and struggles with poverty. The community is small and spread out. Almost 4,000 people come through the local food bank per month, and people commonly work three to four jobs in service related jobs to make ends meet. Every Woman Counts Program is available but is not accessed frequently. Patients who do not meet criteria for EWC, such as being under the age of 40, may have difficulty accessing services.

Although the ACA has covered more lives in California, barriers to care remain. For example, Sutter contracted with Blue Cross and not the Covered California Blue Cross product. Additionally, different insurance products exist for geographic managed care Medi-Cal, creating additional barriers to receiving services. Specialty clinics in Amador County (i.e., OB/GYN) struggle to keep up with demand. One local OB/GYN retired and sold his practice to a physician who works at Lodi Memorial Hospital, so outpatient visits are offered in Amador, but procedures are performed in Lodi. Sutter provides free mammograms for uninsured women one day a year in October. Radiation is not provided in the community, and only one local oncologist offers chemotherapy part time in the community, making transportation services critical.

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The demographic characteristics of the community also affect access. Spanish-speaking women in the community have a need for interpreter services. The community also consists of an older population that is uninterested in technology, does not own a home computer, or cannot travel to the public library for free Internet access. Many elderly residents rely on public buses, whose schedules are spread out over the day. Amador STARS drives patients to services in Sacramento, Lodi, Stockton, Roseville, Carmichael, and Rancho Cordova – generally most locations within a one-hour drive of Amador.

Community education has been a priority for Amador County but could also be enhanced by other community groups, such as First Five, which is aware of community contacts and forums for outreach and education. Currently, emphasis is on resources for early detection. Although transportation is provided for patients in treatment, reliable transportation is also needed for support groups and events organized for caregivers.

Strengths: Organized transportation services for people needing care outside of the community, strong community relationships (i.e., First Five), free or low-cost mammograms for women who qualify

Weaknesses: Poverty, lack of access for women with Covered California insurance that is not accepted by Sutter Hospital, lack of specialty providers, large population of older women who may need help accessing support groups and caregiver events, limited support for Spanish-speaking women

Solano County

Document Review: The Solano County Community Health Needs Assessment of 2013 was used to identify threats and opportunities to improving breast health across underserved groups of women. In the report, six zip codes in Solano County were identified as having high rates of poverty, low educational attainment, high unemployment, and high rates of being uninsured. The zip code 94590 in Vallejo has a particularly high proportion of households over age 65 living in poverty. The rate for this zip code was 13.0 percent compared to 8.7 percent for the United States. This same zip code has a high rate of families with children living in poverty – 19.5 percent vs. 15.1 percent for the United States. The Needs Assessment identified several factors that constrain women's ability to access breast health services and cancer treatment: 1) lack of access to health education, 2) limited access to follow-up treatment and specialty care, 3) lack of transportation, 4) limited access to medications and prescription drugs, and 5) lack of preventive services and community programs. Qualitative findings from focus groups associated with the Community Health Needs Assessment indicated that many families could not get refills for medications because they could not afford to see the doctor. Others compared health care to "a maze," and others found it difficult to obtain referrals for specialty care. All of these factors can affect women's ability to access care and stay engaged in treatment for breast cancer.

Sources of Key Informant Interviews: 1) Solano Midnight Sun Foundation, 2) North Bay Cancer Center, 3) Sutter Radiation Oncology, and 4) Solano County Health and Social Services Department.

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Findings: The Sutter Solano Cancer Center provides free mammogram screening in October and in 2014, along with other Sutter Health facilities, reached 395 uninsured women from Solano to Yuba to Amador counties. The Sutter System has four nurse navigators in the region who help patients follow up with diagnostic services and understand their insurance for the next steps in their care. The nurses combined carry a caseload of 50 to 60 patients, with about a third of those having metastatic disease. Solano Cancer Center has a strong relationship with the faith communities, particularly Reverend Carolyn Dyson, who offers a support group called Overflowing Cup. Additionally, the Sisters' Network has a local chapter to support women dealing with breast cancer.

Insured women may still have trouble accessing care. Although NorthBay Cancer Center provides the entire continuum of care from diagnosis and screening to reconstruction, support is extremely limited for women who are underinsured or uninsured. Additionally, if women start treatment being insured but lose their insurance due to changes in employment, there is no way of ensuring compliance with treatment. Although the ACA has helped by providing more insurance to women, many are coming in with later-stage cancers because they deferred screening. One 32-year-old woman paid for a mammogram out of pocket due to her age and learned that she had stage three breast cancer. The Solano Midnight Sun Foundation helps with financial support for care but only up to \$5,000, which is only offered to patients who can confirm financial need. A large amount of fundraising, including a Lobster Feed, Railroad Museum tour, wine tastings, and live auctions, are used to raise funds for the foundation. Overhead is very low, and 90 percent of all funds collected go back to Solano County.

Although cancer screening programs are widely advertised in the community, little interest seems to exist in using services. The community doesn't turn out for these events, so the approach may need to be modified. People in Solano County face challenges accessing services and information based on limited health literacy, extreme poverty, support in organizing follow-up care, and competing public health problems, such as substance abuse.

NorthBay promotes an Annual Breast Cancer Day in October. Free mammogram screenings are offered as are breast care events. More information needs to be provided at the time people sign up for insurance – if patients do not have a regular care provider, they will need additional education about the services they need. Other avenues for sharing information about mammograms, health screenings, and resources available are emergency rooms and urgent care centers. Questions about access and prior health care utilization can be asked as part of the triage process.

Future needs include improving interpreting services, as half of clients are Spanish speaking, and providing childcare services for women with families. Wait times in county clinics can also be a barrier to establishing ongoing care. County clinics see the largest number of at-risk patients, so a stronger alliance between community care and public health is needed. Additionally, people who need advanced diagnostic procedures, such as biopsies, are unlikely to get the support they need from the Midnight Sun Foundation.

Strengths: Financial support for women who are uninsured/underinsured, free mammograms in October for women who qualify, full range of breast cancer care service, strong outreach in faith-based community for African-American women

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Weaknesses: Poverty and substance abuse in segments of the community, lack of interpreting services for Spanish speaking women, no effective means for sharing information about services at the point of care (i.e., emergency room, urgent care), community education not well received, weak link between community care and public health, women presenting with later stage breast cancers because they deferred screening

Yuba County

Document Review: The Rideout Health System Community Benefit Report, 2012-2013, was used to ascertain health priorities and resources for Yuba County. The Rideout Health System serves Yuba and Sutter counties. Income in both counties is lower and the poverty rate higher than the state-wide average; 12.5 percent of Yuba families live below the poverty level vs. 9.8 percent for the state. Unemployment in the Sutter-Yuba region was 19.5 percent in 2010; the rate for California was 12.4 percent. In 2000, Rideout Health reported that more than 600 patients travelled outside of Yuba-Sutter each year to seek outpatient cancer treatment. Yuba County's rate of cancer deaths exceeds state and national goals for Healthy People 2010.

Rideout Health provided low-cost mammograms in October 2013 and has cancer support groups, peer navigation, and a patient resource center. The Rideout Cancer Center is affiliated with the UC Davis Cancer Care Network, which is a collaboration of hospital-based cancer centers in Northern and Central California. Through the network, the expertise of a National Cancer Institute-designated cancer center is linked to the unique insights of hospital-based community cancer centers. Oncology teams at both sites participate in collaborative care to identify the best diagnostic and treatment approaches for patients. To address the needs of a multicultural population, Rideout Health hosts a booth at the annual Punjabi Festival to reach the East Indian population with culturally appropriate education about breast cancer awareness.

Sources of Key Informant Interviews: 1) Planned Parenthood, 2) Peach Tree Health (i.e., physician, chief executive officer, chief operating officer), 3) Rideout Cancer Center, and 4) Harmony Health Medical Center.

Findings: Although Peach Tree Health, a federally qualified health center, has a full-time OB/GYN who has been an asset for expanding knowledge about breast health, patients are very price sensitive to mammograms and may avoid care if they cannot afford the copay. Almost 80 percent of the population lives below the federal poverty level, and 20 to 25 percent of women do not show up for their appointments at Peach Tree Health. Patients don't pay premiums or pay for missed appointments, so there are no financial disincentives for missing appointments. Many patients are Spanish speaking and lack transportation. Some walk to clinic or come on the bus. Although the ACA has helped the poorest patients, those who are most at risk for deferring care are the working poor and those who have Covered California, which tends to have large out-of-pocket deductibles. Peach Tree Health has a large number of male providers, and specific segments of the population – Hmong and East Indian – would probably be more comfortable with female providers. These cultures also experience a bias against preventive health and feel the outcome of disease is beyond their control, thus resulting in low compliance with treatment. Harmony Health Medical Clinic also provides comprehensive primary care from cradle to grave and uses the Every Woman Counts Program to help uninsured women connect with breast care services; unfortunately, services do not exist for women who are under 40 who need screening and treatment.

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Transportation for women seeking health care at Rideout Cancer Center is less of an issue for women who are in wheel chairs or need to use a walker because Medi-Cal reimburses for transportation. Most radiologists are located in Sutter while the hospital is located in Yuba County. This has created a care gap that needs to be closed. Specialty physicians should feel as comfortable discussing breast health for relevant populations as primary care is. Additionally, breast health should be promoted year round, not just in October.

A breast cancer survivor group has been organized by Rideout Health System and consists of 40 survivors who continue to get together once a month at a local restaurant. Free mammograms are provided over three days at Peach Tree Health in the month of October to women who cannot afford them. The Giweke Foundation pays up to \$2,000 for medical bills for breast cancer patients experiencing financial hardship. Rideout Cancer Center has worked hard to connect veterans to VA services, which are well coordinated, comprehensive, and include transportation services.

Strengths: Strong primary care advocate for underinsured women, popular breast cancer support groups, financial assistance for women who need treatment, good local connections to VA system, some free services during October

Weaknesses: Cultural barriers to seeking care and complying with treatment, particularly among Hmong and East Indian Women; high levels of poverty in the community; limited patient commitment to keeping appointments; lack of integration between primary and specialty care; no resources to launch public awareness campaign or staff to support it

Specific observations were pulled from the key informant interviews to enrich the discussion of the key themes of access to diagnostic services, treatment compliance, affordability of care, and managing diverse cultural needs.

Key Insights from Racial and Ethnic Communities

From the key informant interviews related to racially and ethnically underserved populations, areas of improvement were identified and substantiated with verbatim comments from respondents. Sources of feedback included focus group participants in Stanislaus County, Auburn, and Butte County.

Treatment Compliance. Accessing all of the care that is needed for effective treatment is difficult and requires coordination and assistance getting to multiple providers for diagnostic procedures, surgery, radiation, and chemotherapy. Women who have competing priorities at home, little knowledge of how to coordinate their care or financial barriers, may drop out of treatment before it is complete. Ensuring treatment compliance is critical and challenging in rural populations.

The following key insights were identified from focus groups and interviews:

“Fear would prevent me from getting follow up care. I wouldn’t tell anyone. It’s only my business.” (Hispanic respondent, Stanislaus County)

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“Our program at Chapa-De is designed to help serve the underserved population in the Nevada, Placer, and Sierra counties. The main thing we are focusing on is treatment compliance. A lot of our patients have problems with follow-throughs and keeping current with their health care.” (Chapa-De, Auburn)

Cultural Diversity. Although rural communities of Northern California can be sparsely populated, they may also include small but significant representation from a variety of ethnic and cultural groups who will require tailoring of appropriate health information. Some cultural groups common to the Sacramento Valley Affiliate’s target communities include American Indian, Hmong, and Hispanic women. Although younger members of these ethnic groups may feel comfortable accessing and discussing information from a variety of sources, this may not be true of older women who are less acculturated and more strongly bound to their cultural traditions and beliefs. During key informant interviews, service providers at Peach Tree Health and Rideout Cancer Center said that Hispanic, Punjabi, and Hmong women were more likely to present in the health care system with advanced cancer due to stigma associated with illness and a lack of awareness of the importance of breast cancer screening. Additionally, these providers said that older women in these cultural groups did not understand the association between early treatment for breast cancer and better health outcomes. A related factor is the dearth of culturally appropriate educational materials available to Hmong and Punjabi women in the Marysville area.

The following key insights were identified from interviews:

“We have a huge Punjabi speaking population here and are finding that they have a hard time finding services because they don’t present until they’re late stage. We’ve been trying to work with this population to stop this, but there is not enough education in their community about breast cancer and, at least here, there’s a stigma.” (Rideout Cancer Center, Marysville)

“Our goal with this project is to increase community awareness about breast cancer and to give [the Hmong] the knowledge that breast cancer does exist and that it is really serious.” (Hmong Cultural Center of Butte County, Oroville)

“Culture is also a bit of a barrier. There is some distrust of modern Western medicine in our [American Indian] patients.” (Chapa-De, Auburn)

Limitations

There are several limitations of note in this qualitative analysis. Collection of survey data was based on a convenience sample. Service providers attending the FY15 Grant Writing and Networking Conference responded to nine questions on successes, challenges, future priorities, and assistance needed from Komen. Although there was some overlap between respondents and the target communities of the Sacramento Valley (i.e., Solano, Yuba, and Amador counties), respondents were more likely to represent population-dense communities where staff, community partnerships, or funding already exist to improve breast cancer outreach and treatment. Additionally, survey data were collected from women attending the Solano County’s Sister’s Circle Brunch on June 7, 2014. Responses were gathered from 30 participants in five broad areas: barriers, community collaborations, strategies for improving knowledge/education, and needed assistance from Komen. For both the Grant Writing Conference and Sister’s Circle

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Brunch, the survey approach was efficient for reaching a large number of stakeholders at once but it did not allow for the rich contextualization of experience that is traditionally gained through focus groups and informant interviews.

Key informant interviews were gathered over past two years from Sacramento Valley Affiliate grantees and breast health community leaders. There is not a large concentration of community providers in Amador, Solano, and Yuba counties; instead, services are more likely to be concentrated in adjacent counties that have the population base to support a robust health care infrastructure. As such, interviews from respondents representing neighboring high-population counties have been used to extrapolate information related to the challenges and experiences of women living in the target rural counties. For example, interviewees representing Butte County (population of 222,090) have been used as a proxy for women living in Yuba County (population of 73,340). Interviewees from Sacramento (population of 1.46 million) and San Joaquin (population of 704,379) counties have been used as proxies for the women of Amador County (population of 36,519).

Summary

Despite these limitations, the analysis of the surveys and key informant interviews has yielded four areas of focus that could guide emerging relationships with Amador, Solano, and Yuba counties to improve access and service utilization for women who are beginning care for breast cancer:

1. To strengthen the care continuum for the women of Amador and Yuba counties, evaluate the feasibility of strengthening relationships with Sacramento, San Joaquin, and Butte counties for access to diagnostic services. This should include improving transportation to urban centers for care and treatment through organized shuttle service or through gas cards and vouchers.
2. Introduce care navigators in target communities to assist women with scheduling diagnostic services or treatment with different providers in the CoC.
3. Maintain information and support for Every Woman Counts; although the ACA will help many women find affordable insurance, others may forgo insurance or avoid care if the insurance premium/deductible is too high.
4. Create and market breast information that is appropriate for culturally diverse populations; community health workers who represent the population of interest may be ideal agents for providing socially acceptable outreach to women and developing culturally appropriate health education materials.