



COMMUNITY PROFILE GUIDEBOOK

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Susan G. Komen®





Global Headquarters

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Welcome to the 2015 Community Profile process! Over the next 18 months or so, you will conduct a thorough community assessment to determine the state of the breast cancer burden and prioritize needs in your local communities. Through the Community Profile, you will be able to identify the populations most at risk of dying from breast cancer and their socioeconomic and demographic characteristics; identify the needs and the disparities that exist in access and utilization of quality care; identify community assets and resources; and better understand what people in your service area know, think and do about breast cancer.

The material that follows is a resource for your Community Profile Team. The Community Profile Guidebook and the accompanying toolkits that are available on myKomen will provide the Team with targeted resources to help you along the way.

At the beginning of the guidebook, the Community Profile Team will find a detailed overview of the process. The content covered in each module addresses specific components of the Community Profile process. Komen Headquarters wants the Community Profile Team to know what to expect from the beginning all the way through submission so the Team can plan accordingly, stay on track and submit the final profile documents on time.

Additionally, toolkits are provided to assist with each component of the process (e.g. Quantitative, Health Systems and Public Policy Analysis, Qualitative and Mission Action Plan). The toolkits include supporting documents that answer many of the most frequently asked questions as well as provide resources to help you navigate the most common challenges encountered by Affiliates. The toolkits also offer examples on how to address specific issues such as successfully engaging your Board of Directors or how to conduct community surveys. In addition, the toolkits provide templates that can be adapted as needed by the Community Profile Team.

Ultimately, the guidebook should help the Affiliate plan, organize, and conduct the profile process resulting in a data-driven Community Profile Report that identifies the breast health and breast cancer needs of the Affiliate's service area and a plan of action to address the needs over the next four years.

Wishing you immense success with your Community Profile!

Komen Headquarters Community Profile Team
Email: communityprofile@komen.org

Breast cancer knows no boundaries - be it age, gender, socio-economic status or geographic location.

INTRODUCTION

Our Promise

Susan G. Komen's promise is to save lives and end breast cancer forever by empowering people, ensuring quality care for all and energizing science to find the cures.

Purpose of Community Profile

An effective Community Profile will help the Komen Affiliate align its community outreach, grantmaking and public policy activities towards the same Mission goal.

The Community Profile will allow Affiliates to:

- Include a broad range of people and stakeholders in the Affiliate's work and become more diverse
- Fund, educate and build awareness in the areas of greatest need
- Make data-driven decisions about how to use its resources in the best way – to make the greatest impact
- Strengthen relationships with sponsors by clearly communicating the breast health and breast cancer needs of the community
- Provide information to public policymakers to assist focusing their work
- Strategize direction to marketing and outreach programs toward areas of greatest need
- Create synergy between Mission-related strategic plans and operational activities

Key Terms

Community Profile

Community profile refers to the *assessment* process that Affiliates complete every four years in order to understand the state of the breast cancer burden and needs in their service areas. The information is vital to Affiliates for developing grant funding and programming priorities.

There are **four** key components to a community profile:

- **Quantitative Data:** This section requires the collection and examination of secondary data on breast cancer trends that include incidence, mortality, screening and stage of diagnosis within a community. This examination also explores the social, demographic and geographic characteristics that influence breast cancer outcomes such as race/ethnicity, socioeconomic status, educational attainment, and insurance status. Komen Headquarters will provide a quantitative data report for each Affiliate's service area. The quantitative report will include tables and maps of breast cancer statistics (e.g. demographics and socioeconomic characteristics), analysis of data, and identification of target communities based on Healthy People 2020 targets. The data will come from the following sources: the North American Association of Cancer Registries (NAACR), the United States Census Bureau, the National Cancer Institute (NCI) and the Center for Disease Control and Prevention (CDC) Behavioral Risk Factor and Surveillance System (BRFSS).

- Health Systems and Public Policy Analysis: Health Systems Analysis tells the story of the breast cancer continuum of care and the delivery of health care in the community. Key to this section is the observation of potential strengths and gaps in the health care system that could compromise a woman's health as she works her way through the continuum of care (e.g. screening, diagnosis, treatment, and follow-up/survivorship services). These gaps are identified through asset mapping and analysis of public policy and services available.
- Qualitative Data: This section includes data collection methods that can vary between key informant interviews, focus groups, surveys, document review and observations. The purpose is to gain the voice of healthcare providers and community lay members as they describe the strengths, challenges and opportunities to improve breast health and breast cancer outcomes in their community. Ideally, a qualitative resource supports the Affiliate in this process as it is a significant undertaking to collect and analyze the data correctly. A **qualitative resource** would be an individual or organization that has a background or expertise in planning, implementing, conducting and analyzing qualitative data. In addition, the qualitative resource should have experience in interpreting different types of data (e.g. quantitative, health systems, and public policy) to triangulate the data to inform conclusions. During the qualitative process, the Affiliate's involvement is instrumental as the nature of this type of data collection provides opportunities to form or enhance partnerships and relationships that will play a significant role in strategically addressing both the short and long term needs.
- Mission Action Plan: The Community Profile concludes with the Mission Action Plan, which emphasizes the overarching themes of the report, identifies specific needs based on the data in the target communities, and lays out the strategies and objectives that will be implemented by the Affiliate in response to those needs.

State Profile (New for 2015)

The state profile will focus on the quantitative data that demonstrates breast cancer needs in the state and map the resources for the **entire state**. Since the Affiliate service areas are currently not entirely based on existing and/or demonstrated breast health/breast cancer needs, having a state profile will focus on additional areas in the state that may have higher or unmet needs. The benefits of having a state profile in addition to the local Affiliate Community Profile are:

- Additional areas of need (outside the Affiliate service areas) are highlighted and can help identify target areas that Affiliates could consider for an expansion request
- Identification of resources outside of the Affiliate's service areas that could be engaged to help better support the Affiliates
- Provides a state-wide document that can be used in collaborative work throughout the state, especially for advocacy purposes

Community Profile Report

The final document that the Affiliate in collaboration with Komen Headquarters prepares to describe the findings and conclusions of their community needs assessment.

The Community Profile Guidebook

The Community Profile Guidebook is a resource to give Affiliates a framework to conduct a comprehensive and collaborative Community Profile.

The guidebook contains six modules that cover the distinct components of the Community Profile process. The modules provide direction, suggestions and tools that Affiliates may find useful as they collect, review and compile the information they need to achieve a thorough understanding of their communities.

The Community Profile Guidebook Outline

- **Introduction**
- **Module 1: The Community Profile Team** ***Pages 8-17***
The first step in the Community Profile process is establishing a Community Profile Team. The composition of this team will vary by Affiliate and available resources. The Community Profile Team is responsible for conducting or overseeing those who conduct the process from start to finish.
- **Module 2: Quantitative Data Report: Measuring Breast Cancer Impact** ***Pages 18-23***
Komen Headquarters will provide each Affiliate with a user-friendly report that contains state and local breast cancer statistics, demographic and socioeconomic data. These reports will also include identified target priority areas based on the data. Module 2 describes this process and provides recommendations on other data sources.
- **Module 3: Health Systems and Public Policy Analysis: Local Issues Affecting Women's Transition through the Continuum of Care** ***Pages 24-30***
Module 3 guides the Community Profile Team through an analysis of the health system using the continuum of care framework. This module discusses how a review of programs and services can help determine resource gaps. Komen Headquarters provides each Affiliate a template to conduct the health systems analysis and maps produced based on the template information submitted by the Affiliate.
- **Module 4: Qualitative Data: Ensuring Community Input** ***Pages 31-45***
Community data collection is essential in the Community Profile process. Module 4 provides the framework and toolkits for various types of qualitative data collection (e.g. focus groups, key informant interviews and surveys) the Community Profile Team can use these items separately or in combination to gather input from the target communities.
- **Module 5: Mission Action Plan** ***Pages 46-53***
Module 5 provides the suggestions on how to organize, summarize and analyze the data from modules 2, 3 and 4. This module outlines the recommended analysis process and common analysis pitfalls. It also provides methods and suggestions for determining priorities and action plans.
- **Module 6: Putting The Community Profile Report Together** ***Pages 54-62***
Module 6 walks the Community Profile Team through the required report specifications. This module shows what needs to be included in each section of the report.

Community Profile Toolkits

The resources provided by Komen Headquarters assists the Affiliate in successfully completing all required components of the Community Profile process.

All toolkits are available online on myKomen in the Community Profile section. The content of each toolkit was designed to assist the Affiliate/Community Profile Team while completing the required steps, processes and components of each module. The toolkits also contain example documents that may be customized by the Affiliate. **Please note:** The examples provided will need to be adapted to the Affiliate Community Profile Team's specific needs.

Community Profile Reporting

The Community Profile Team will be required to submit to Komen Headquarters a report for each section of the Community Profile. Each section's report will be due by a specified deadline as outlined in the Community Profile Timeline and below. In addition, prior to submitting the reports to Komen Headquarters, each section with require approval from the Board President, Executive Director or the Board of Directors.

Komen Headquarters advises Affiliates to not move too far along in completing the next section of the Community Profile process without receiving approval from Komen Headquarters on the previous submitted section. Some Affiliates may want to begin certain tasks of the CP process before receiving approval in the interest of time. Some obvious tasks that might be started prior to receiving approval on a previous section include public policy data collection, and initial planning and preparation for qualitative data collection. However, an Affiliate **must** receive approval of submitted Community Profile section(s) prior to submission of subsequent sections. For example, an Affiliate's Quantitative Data Report section must be approved by Komen Headquarters before the Affiliate can submit the Health System and Public Policy Analysis section.

Section	Approval By	Deadline
Quantitative Data Report	Board President or Executive Director	May 22, 2014
Health System and Public Policy Analysis	Board President or Executive Director	August 4, 2014
Qualitative Data	Board President or Executive Director	December 8, 2014
Introduction and Acknowledgements Page	Board President or Executive Director	January 14, 2015
Mission Action Plan	Board of Directors	March 16, 2015
Executive Summary	Board President or Executive Director	April 13, 2015
Final Review of Report	Board President or Executive Director	June 22, 2015

Community Profile Process Flow Chart:



MODULE 1: THE COMMUNITY PROFILE TEAM

The first step in the Community Profile process is establishing a Community Profile Team. The composition of this Team will vary by Affiliate and available resources. The Community Profile Team is responsible for conducting and overseeing those who carry out the process from start to finish. Module 1 will provide the Affiliate with an understanding of the Community Profile process and the tools necessary to establish their Community Profile Team.

Learning Tasks:

- Understand the role of staff and volunteers in the Community Profile process
- Be able to recruit and organize the Community Profile Team
- Be able to conduct an orientation for Team members
- Be able to guide Team consensus on mission, goals, roles and actions
- Be able to identify needed resources for the Community Profile process

Recruiting Team Members

Completing the Community Profile process requires a team effort. Because of the amount of work involved, it is important that the Affiliate make sure Team members are committed and engaged. The ideal Community Profile Team should include Affiliate staff (where applicable), volunteers, as well as community members who represent the population the Affiliate serves and who may have little or no current involvement with the Affiliate.

The Affiliate should strive to assemble a diverse team with a variety of perspectives and skills that will result in a better process and product. Recruiting and retaining dedicated team members takes time and energy, but the reward is priceless! Start by thinking of places in the community that would consist of potential members.

Including key community members from outside the Affiliate is valuable. These individuals bring a unique perspective of the problems the community faces and the resources available. Recruiting members who reflect the community in which they live is also important, as they add a perspective that may be over looked. Creating a strong Community Profile Team made up of individuals

It is essential that your Community Profile Team reflect the diversity in your service area. Creating diversity requires acceptance and respect. It means understanding and recognizing that each individual is unique. Individual differences can be along the dimensions of race, ethnicity, gender, sexual orientation, socioeconomic status, age, physical abilities, religious beliefs, political beliefs, or other ideologies. Diversity is about understanding each other and moving beyond simple tolerance to embracing and celebrating the rich dimensions within each individual.

with diverse and useful skill sets will help the Affiliate develop appropriate priorities in order to increase the mission impact in its service area.

Example from an Affiliate:

During Community Profile training the Community Profile Team Lead realized she needed a qualitative data resource on the team. She did some research and found a community college about 20 miles from the Affiliate. The Team Lead emailed a sociology professor at the local college and described Komen, the Community Profile process and the skills the team needed in a qualitative resource. The professor replied almost immediately that his mother had been diagnosed with breast cancer a few years ago and this was a small way he could help in the fight against breast cancer. He agreed to serve as the qualitative data resource for the project!

During recruitment, be prepared to discuss the Community Profile, why it is important to the Affiliate, the project timeline, the specific role the volunteer would play, the required time commitment and Affiliate expectations. The more information you have, the easier it will be for the volunteer to make a commitment. Refer to Module 1 Toolkit for an example “elevator speech” and text for a recruitment letter for Team members.

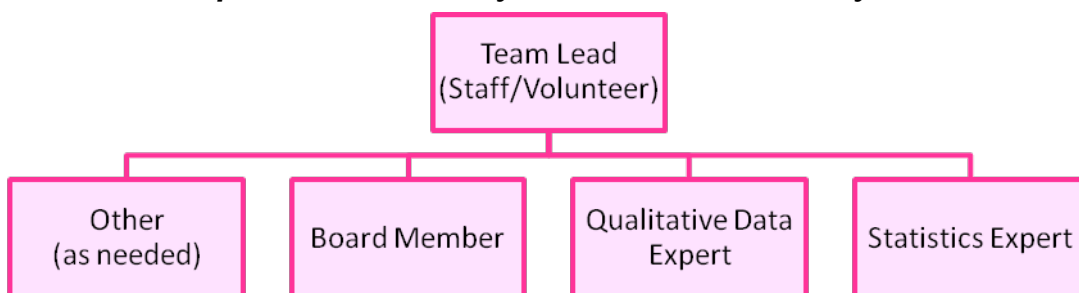
Organizing the Community Profile Team

The size and structure of the Community Profile Team are established by the Affiliate. The group’s size will reflect the amount of work necessary based on the Affiliate’s service area, the needs of the community and the skills needed to complete the assessment. There are two main types of teams: Advisory and Working. Each Affiliate’s Team may look different; some teams may choose one type exclusively, while others may be a combination of both.

Advisory Team

In many cases, the core team will take an advisory role. The team may consist of a staff person (Mission director/coordinator, outreach director, etc.) and three or four advisors including, at minimum, a Board member and a qualitative data resource. Members of the advisory team provide support and guidance for their specific areas of expertise and are especially important during the data analysis. In this team structure, the work is usually delegated to a lead position such as an Affiliate staff person or a volunteer to carry out the bulk of the project.

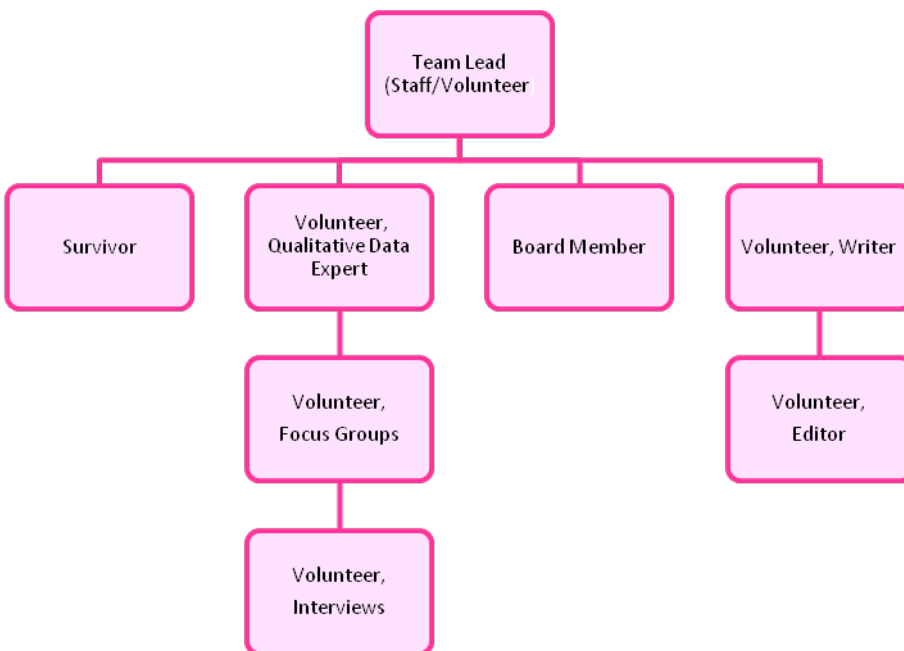
Example of a Community Profile Team- Advisory Team



Working Team

There are many benefits of a working team to complete the Community Profile. In this structure, the work is shared among team members who are assigned a specific component of the project. An Affiliate representative is still required to lead the process. The team must still include members with specific expertise such as a qualitative data resource. However, the addition of “worker bees” for various roles ensures that the work is not left to one person. While the size and structure of the team and each of its sub-groups will be unique, key people within each group should be assigned the responsibility of moving the process along and communicating with the team lead.

Example of a Community Profile Team- Working Team



The Community Profile Team

The Board’s role is to agree on the direction of the Community Profile, make recommendations and offer feedback; but it is the Community Profile Team that leads or completes the work needed to collect data, review it and establish priorities for the Affiliate service area. Refer to Module 1 Toolkit on myKomen for a Community Profile Team job description example.

Affiliates should make every effort to recruit members with specific areas of expertise. For example, it is useful to include someone with a strong background in qualitative data collection and research methods on the team. This person ideally is from a local university or college, or a state or county Department of Public Health (DPH) (Refer to Module 1 Toolkit for an example of a job description for a qualitative resource). Understanding proper qualitative data collection and analysis methods can be a daunting task; having a resource that can help the Team gather and interpret this information can result in a professional community assessment with accurate, specific community feedback to help inform priorities.

Potential Community Profile Team members should include:

- Affiliate staff and volunteers
- A statistics or quantitative data expert (optional)
- A resource in qualitative research methods. Refer to Module 1 Toolkit on myKomen for an example job description.
- Professor, or resource, who can train others on methods
- Intern from Masters in Public Health program or similar field. Refer to Module 1 Toolkit for an example intern job description
- Health care providers, community members and/or leaders who know the community and are well-connected
- A survivor or co-survivor
- An individual with a public policy background
- People with connections in areas that are underserved and high priority (e.g. minority communities, rural communities, communities with high poverty)

Duties of the Community Profile Team include:

- Leading the Community Profile process
- Attending Headquarters Community Profile trainings/webinars
- Carrying out or delegating data collection activities
- Interpreting findings and determining needs/gaps in care
- Establishing Mission priorities and objectives (Affiliate Action Plan)
- Completing required components of the Community Profile Report (e.g. Executive Summary, Introduction, Quantitative Data Report, Health Systems Analysis and Public Policy, Qualitative Data, and Mission Action Plan narratives and templates)

The Role of the Community Profile Team Lead

The person assigned to lead the Community Profile Team **MUST** be an Affiliate staff or volunteer, and will serve as the facilitator who coordinates meetings, keeps the Community Profile process moving and makes sure that all Community Profile Team members are aware of the progress as well as the next steps. An example job description for the Community Profile Team Lead is available in the Module 1 Toolkit on myKomen.

NOTE: It is important that every Affiliate have a Community Profile Team Lead. Even if the Affiliate uses a consultant (see below for more information about consultants) an internal staff member or volunteer should still be appointed as the lead. Direct Affiliate participation is vital to a successful Community Profile that will lay the foundation for future work. An Affiliate who is directly involved in the Community Profile process has the potential of connecting with future leadership, promoting Komen and the Affiliate to different community audiences, identifying potential grant recipients and establishing promising partnerships.

Duties of the Community Profile Team Lead include:

- Keeping the assessment process on schedule
- Making sure assignments are completed on time
- Delegating tasks as necessary
- Coordinating and attending meetings/trainings
- Ensuring minutes are taken at minutes and monitoring work distribution
- Making sure information and tools needed are available
- Coordinating access to support materials
- Serving as the central contact person for Team members

Partnering with Academic Institutions

An Affiliate may consider partnerships with different organizations to complete the Community Profile. Local schools of public health make excellent partners as they often have graduate level students looking for internship opportunities. Furthermore, public health students receive training in statistics, epidemiology, and community needs assessment. To find a public health program in your area, visit the website of the Association of Schools of Public Health: www.asph.org. When working with an academic institution, an Institutional Review Board (IRB) process may have to be completed. Recommended IRB guidance from Komen Headquarters is available in the Module 1 Toolkit.

College or university programs in health education, social work, public administration, nonprofit management or nursing may also be a source of interns. An intern, for example, can help collect community data or can provide technical support and in this way reduce the amount of work required of Affiliate staff/volunteers. An example intern job description is available in the Module 1 Toolkit on myKomen.

Depending on the academic institution, interns may be available year round. Talk to the person in charge of internships to find out at what level interns are available (bachelors, masters, doctorate), the school's internship schedule (fall, winter, spring, summer) and what expense is attached to using an intern. Although it is nice to offer an intern a stipend, it is not mandatory to do so. Many interns will select internship sites regardless of a stipend offer. The motivation is providing experience from which they benefit academically.

Example:

For one Affiliate, the Community Profile Team Lead approached the local college of public health and created a partnership that allowed a small group of master-level students to assist with data collection and analysis for the Community Profile. The students completed literature reviews and asset mapping, collected data from target communities, provided support with data entry, and worked with the Team to analyze data.

Hiring a Consultant

In certain circumstances, an Affiliate may hire a consultant to help complete the Community Profile. While consultants bring valuable expertise, Affiliates should carefully weigh the pros and cons before using a consultant. If the Affiliate does choose to hire a consultant, they must be part of the Community Profile Team (Refer to Module 1 Toolkit on myKomen for an example consultant job description). Ideally, the consultant would facilitate the Community Profile process, execute certain tasks and guide the Team through the analysis and development of priorities. In this way, the Team would be part of the process and would ultimately make the decisions as to the target communities and the priorities the Affiliate will address. In addition, the Team must ensure that they follow the Komen Community Profile process and that community members are part of the process.

When looking for consultants, be sure that they are an expert in the area of qualitative data collection and research methods, or have access to one. There are a lot of opportunities to misunderstand or misrepresent data. A good consultant will help ensure the data is accurately interpreted and that priorities are based on sound data.

NOTE: Consultants are expensive. In the past, fees have ranged from \$14,000 to \$20,000 or more for doing the entire Community Profile. However, many Affiliates chose to cut consulting costs by only using them for parts of the assessment. For example, for a cost of \$3,000 to \$5,000 a consultant can collect and analyze qualitative data. Affiliates have various options and, if resources are available, a consultant may be appropriate.

The Role of the Board of Directors

The Community Profile Report and its corresponding Mission Action Plan is the foundation of the Affiliate Mission strategic and operational plans as it dictates the work the Affiliate will undertake. It is crucial that the entire Board of Directors be familiar with the report and approves the Affiliate’s Mission Action Plan (priorities and objectives).

The Affiliate’s Board of Directors is responsible for ensuring that the Affiliate completes the Community Profile as required by the Affiliate agreement. The Board’s role may be limited to providing oversight and advice. However, the Board may assign someone to be a part of the Community Profile Team. For best results, clearly establish the Board’s role early on and receive their buy-in for the Community Profile process and Team.

The Board’s understanding and communication are critical to your Affiliate’s success. Frequent and on-going communication with your Board of Directors will help to ensure your Board is

involved in the Community Profile process from the beginning and will assist in securing their final approval of the resulting Mission Action Plan. For this reason, while assembling the Community Profile Team, Affiliates should appoint a Community Profile Team member to serve as the Board Liaison. The Liaison will present or submit status reports/updates during Board meetings. Frequent updates during the process are important in order to guarantee support, feedback and approval during each completed phase of the process. Refer to Module 1 Toolkit for an example job description for a Board Liaison and Board update template.

NOTE: The Community Profile Board Liaison will be responsible for ensuring that the Affiliate's Board of Directors is fully informed regarding the profile status at each phase of the Community Profile process.

To ensure a successful Community Profile process and that the resulting Mission Action Plan is fully understood, accepted and ultimately approved by the Board of Directors, the Affiliate should:

- Educate the Board about the Community Profile. Include access to the new Community Profile Guidebook and an introduction to the process, the work required to determine priorities and the nature of the report they will be required to approve.
- Allow the Board to ask questions and ensure they understand the role and structure of the Community Profile Team, including the Board Liaison.
- Provide regular Board updates throughout the process and clearly communicate challenges and successes encountered at each phase. The new checklist process will provide convenient touch points to update the Board regarding Community Profile progress.
- Early in the process, clearly establish the Board's role and provide timeline/deadlines for required Board approvals. Remember: The Board is required to approve the Mission Action Plan before it is submitted to Komen Headquarters.

Below are some examples of how Affiliates can involve the Board and keep communication lines open during the process:

- Hold an orientation. Affiliates could use the slide deck on myKomen as a foundation for their Board presentation. An orientation provides an opportunity for the lead to discuss resources available, a realistic approach to the Community Profile and how the entire Board will be kept informed.
- Bring in the experts. If the Affiliate utilizes a consultant or data resource, they could attend a meeting to provide Board updates to address specific methods, preliminary findings and to ensure that findings were data driven.

Community Profile Planning

There are many aspects of the Community Profile process that will require the Board's input, feedback and/or approval. Scheduling an initial planning meeting that includes Board members is one way to include them in the process.

After you have completed Community Profile training (either in person or via webinar series), schedule planning meeting(s) with the Affiliate's Board of Directors. These could be incorporated into the regularly scheduled Board meetings, as well.

During the Community Profile Planning meeting you should:

- Review the Community Profile Process Timeline provided by Komen Headquarters (Refer to Module 1 Toolkit on myKomen for a copy of the timeline)
- Identify Community Profile needs (e.g. intern stipends, potential consultant costs) and existing resources that may be utilized during the process
- Work with the Board of Directors to confirm/establish Affiliate's Community Profile budget
- Identify a representative to serve as the Community Profile Board Liaison (e.g. Affiliate Board member, staff or volunteer)
- Develop the Affiliate's work plan (Refer to Module 1 Toolkit on myKomen for a work plan example). This work plan should align with Komen Headquarters' established Community Profile Process Timeline to include submission deadlines.
- Select a target date for your Affiliate to submit Community Profile documents for final review and approval.
- Discuss Community Profile Team composition and determine team type (e.g. advisory or workgroup)

Community Profile Budget

The financial resources needed to complete the Community Profile will depend on the size of the Affiliate service area and the amount of in-kind resources available. On average, Affiliates with existing staff or a dedicated volunteer to lead the process spent between \$1,000 and \$5,000 for the 2009 and 2011 Community Profile (Refer to Module 1 Toolkit on myKomen for an example of a budget). While we require that the Community Profile Team Lead be an Affiliate staff or volunteer, we acknowledge that some Affiliates may use consultants for a portion or sections of the profile. If this is the case please budget accordingly.

Costs associated with the Community Profile are considered mission expenses and may include:

- Printing, supplies
- Incentives and/or gifts (focus groups)
- Mileage
- Intern stipends
- Consultant fees
- Web fees (surveys)
- Phone costs (key informant interviews)
- Postage
- Food (focus groups)

Community Profile Orientation/Training

One way to get the Community Profile process off the ground is for the Affiliate to host an orientation for the members of the Community Profile Team. This orientation should help unite the Community Profile Team and provide a foundation for future work.

The Community Profile Report provides information that will influence all aspects of the Affiliate's work. An orientation is a good opportunity to ensure that the Community Profile Team understands the history and mission of Susan G. Komen®, the purpose of the Community Profile, the methods involved in preparing the profile and how the results form the foundation of the Affiliate's strategic and operational Mission plans. Refer to Module 1 Toolkit for an orientation checklist example.

At the beginning of the orientation, assign a member to take minutes. Minutes should be taken at all Community Profile related meetings and should be used by the Board Liaison to regularly update the Board of Directors.

During the orientation, define the community or service area that the Team will be studying. Affiliates differ in coverage areas making the process different for each. Some Affiliates complete a profile for an entire state, others for several counties and others for just one county. It is important that the Community Profile Team understand the size of the service area and the impact of the Community Profile process.

A great deal of time, energy and commitment is needed to complete the Community Profile process. A brainstorming session using *The Community Profile Resources Worksheet* (Refer to Module 1 Toolkit on myKomen) may be helpful to the Team as the group tries to identify community resources to use during each part of the process.

Creating a work plan during the orientation meeting, or soon after, is important to give the Team a timeline of the process. It is not always necessary to finish one section before moving to the next; some work can be done at the same time (e.g. such as completing the health systems analysis template and collecting qualitative data). Refer to Module 1 Toolkit on myKomen for a work plan example.

Module 1 Toolkit

An online Community Profile Team Toolkit is available on myKomen in the Community Profile- Resources section to assist in completing the steps outlined in Module 1. The toolkit contains examples of job descriptions, recruitment letter, work plan and additional resources that may be helpful in forming the Community Profile Team. Please understand that the examples provided will need to be adapted to the Community Profile Team's specific needs.

Questions for the Community Profile Team (see Module 1 Toolkit) suggests discussion points the Affiliate can use to help the Team voice their expectations and interests regarding the Community Profile process. These questions should help Team members reach a shared understanding of the goals and objectives of the process.

Conclusion

The Community Profile is a long term (approximately 18 months) process and therefore requires a collaborative effort. The required work is not overwhelming if the time and work load are distributed appropriately. A collaborative team approach to completing the Community Profile ensures a better and timely result. Refer to Community Profile Resources on myKomen for a complete Community Profile timeline.

Before moving to the next step in the process- Quantitative Data: Measuring Breast Cancer Impact- the Affiliate should have:

- Established a Community Profile Team
- Identified the Community Profile Team lead
- Conducted a Community Profile Team and Board orientation
- Identified Affiliate capacity/resources for the Community Profile process
- Considered key partners such as colleges, the Department of Health, etc.
- Discussed and established the budget for the Community Profile

MODULE 2: QUANTITATIVE DATA REPORT

MEASURING BREAST CANCER IMPACT

Module 2 begins the Community Profile process by exploring the breast cancer statistics in an Affiliate's service area to determine target communities. From Module 2, the Community Profile Team will have the skills to understand and use the statistics available to them through the Quantitative Data Reports provided by Komen Headquarters.

Learning Tasks:

- Become familiar with basic statistical terms used to discuss breast cancer data
- Become familiar with what data was collected and why
- Understand basic interpretation of breast cancer statistics
- Understand how to select target communities

Introduction

The first step in any assessment is reviewing the available data, determining what data gaps exist and collecting the data to fill those gaps. Gathering the right information requires a good understanding of the type of data needed. In general, there are two types of data – quantitative and qualitative. Quantitative data may also be referred to as statistical data or statistics. Statistics offer information in the form of numbers, such as counts of events (e.g. the number of cancer deaths) and rates (e.g. the new numbers of cases diagnosed in a certain population), and are usually calculated for a defined geographic region (e.g. a county or state) and time period (e.g. 1 year, 5 years). Module 2 will provide an overview of the Quantitative Data Report that will be provided by Komen Headquarters for the 2015 Community Profile process.

Breast Cancer Statistics

In order to truly understand and address the breast cancer needs in the Affiliate service area, it is important to first understand the statistics associated with breast cancer. To know the statistics means not just looking at the numbers, but understanding what those numbers represent and how to interpret their accuracy and reliability.

By becoming familiar with the terms commonly used when discussing breast cancer, Teams will be more likely to understand why and how priority communities were identified and effectively communicate the breast cancer burden in their service area.

The following table defines some common statistical terms associated with breast cancer that may be used in the quantitative data report. For the purpose of the community profile reports, only female breast cancer statistics will be presented in the quantitative data reports

Common Statistical Definitions

Age-Adjusted Rate	A rate statistically modified to remove the effect of different age distributions in the different populations. Because breast cancer, like many chronic diseases, occurs more often among older people, age-adjustment is necessary in order to compare different communities.
Incidence	The number of NEW cases during a period of time (e.g. the number of people newly diagnosed with breast cancer in the year).
Incidence Rate	Calculated by dividing the number of new cases during a given period of time by the number of people known to be at risk.
Mortality (Death) Rate	Calculated by dividing the number of people who have died of a particular disease (e.g. breast cancer) during a given period of time by the total population at risk.
Prevalence	The number of EXISTING cases at a point in time (e.g. the number of people living with breast cancer at this moment).
Proportion	The number of persons of interest divided by the total number of persons in the population. If 100 persons have breast cancer in a community of 400, then 1/4 are survivors.
Trend	A long-term movement or change in frequency, usually upwards or downwards. Data tables should define how long the trend period is. Most trends presented in the quantitative data reports will be for the most recent 5-year period.

Population Statistics

While it takes much more than statistics to understand the dynamics of a population, it is a good place to start. By examining the statistics that summarizes the Affiliate's service area, the Community Profile Team will begin to uncover additional questions and areas of focus related to breast health and/or breast cancer.

To establish sound conclusions on the make-up of target communities, it is necessary to understand population statistics. For the purpose of the Quantitative Data Report, population statistics consist of demographic data (e.g. gender, race/ethnicity, and age) and socioeconomic data (e.g. education, income, foreign born, linguistically isolated, and insurance status). It is important to understand how demographic and socioeconomic indicators can be associated with breast health and breast cancer outcomes. Factors such as insurance status, poverty, and race/ethnicity can affect a woman's knowledge of and impact access to quality breast cancer care. The following is a brief list of some commonly used terms to describe the population statistics that will be used in the Quantitative Data Report.

Common Population Definitions

Average/Mean	The result obtained by adding several quantities together and dividing the sum by the number of quantities.
Census	The inventory of an entire population with details as to age, sex, occupation, ethnicity, etc.
Demographics	The statistical data of a population such as age, income, education, etc.
Educational Attainment	In the Quantitative Data Report, the percentage of the population 25 years and over that did not complete high school.
Foreign Born	In the Quantitative Data Report, the percent of the population who are born outside the United States.
Health Insurance Coverage	In the Quantitative Data Report, the percentage of the population between 40 and 64 who have no health insurance.
Income	In the Quantitative Data Report, the percentage of people with incomes less than the poverty level as well as the percentage of people with income less than 2.5 times (250%) the poverty level.
Linguistically Isolated	In the Quantitative Data Report, households in which all adults have poor English language skills.
Median	The midpoint value of a range of values.
Percentage	A proportion where the denominator is expressed as 100; for example 25/100, is expressed as 25%.
Population	The total number of persons inhabiting a country, city, or any defined district or area.
Population Projections	Projections are estimates of the population for future dates. They illustrate plausible courses of future population change based on assumptions about future births, deaths, international migration, and domestic migration.
Sociodemographic	The statistical data of a population such as education level, income, foreign born, linguistically isolated, and insurance status.
Rate	Indicates the frequency of a given event (e.g. 100 late state breast cancer diagnoses per 100,000 women). It is a way of knowing the proportion of a population, possessing a particular variable, in order to compare areas or groups of different sizes.

Affiliate Quantitative Data Report

Komen Headquarters, in partnership with a data research organization that has extensive expertise in working with cancer registries, will provide quantitative data reports for each Affiliate (for service area as it existed August 2013). The data reports will include the most recent breast cancer statistics, primarily from state cancer registries and population statistics (demographic and socioeconomic); as well as, suggested target communities based on risk prioritization. This risk prioritization will be determined using Healthy People 2020 (HP2020) targets, specifically those related to breast cancer late stage diagnosis and mortality (see the following Analysis Variables section for more information). Data sources that were used in developing the report include the North American Association of Central Cancer Registries (NAACCR), National Center for Health Statistics, Center for Disease Control and Prevention Behavioral Risk Factor Surveillance System (BRFSS), and the United States Census Bureau.

Data Limitations

Both the quantitative and qualitative data used by the Community Profile Team will have limitations, even when best-practices are used. Limitations are conditions that can affect the scope or outcome of the assessment that cannot be controlled by the Community Profile Team. Limitations can often relate to inadequate measures of issues/problems, loss or lack of participants, small sample sizes, and inaccurate data collection and analysis. Identifying the limitations assists the Team in making correct generalizations about the data collected.

NOTE: The Quantitative Data Report provided by Komen Headquarters will include a discussion of the limitations of the data presented in the report.

Analysis Variables

The Quantitative Data Report will provide extensive data on key breast cancer data, demographics for the area and the associated socioeconomic variables. An added element this year, the report uses the framework of the Healthy People 2020 (HP 2020) to provide a platform for Komen to differentiate between geographic areas with various levels of needs with respect to breast cancer prevention and control.

Healthy People 2020 (HP2020) is a major initiative of the federal government that aims to “provide measurable objectives and goals that are applicable at the national, state, and local levels”. HP2020 identifies a number of cancer-related measurable objectives, including the targets of **reducing the rate of late-stage breast cancer diagnoses and reducing the death rate from female breast cancer**. The specific target for the late-stage diagnosis, **adjusted for this report**, is 19.6 cases per 100,000 women. The specific target for the breast cancer death rate proposed by the HP2020 is the disease-specific mortality rate of 20.6 breast-cancer related deaths per 100,000 women. To identify counties in the Affiliate’s service area of highest priority, the annual percentage of change data and the trend data for these two variables were applied into an algorithm, or formula, that classified each county based on the time projected to achieve the HP 2020 goals.

NOTE: For the Quantitative Data Report, late-stage breast cancer is defined as a patient diagnosed at American Joint Committee on Cancer (AJCC) stage III or IV. HP2020 uses the SEER Summary Staging 2000 classification. SEER Summary Staging 2000 classification includes cases with no distant metastases, but has regional lymph node involvement to define late stage. For the purpose of this report, AJCC classification was used instead of the SEER staging for the projection of trends as used by HP2020. This results in the difference reflected between the target specified here as 19.6 cases per 100,000 women and number on the HP2020 website. Please refer to the Quantitative Data Report for additional information regarding the use of AJCC staging.

Risk prioritization, or classification, for counties within the Affiliate's service area will be assessed primarily by considering trend data for both late stage diagnosis rates and mortality rates, and their relation to the HP2020 time-related (number of years) targets set by the Centers for Disease Control and Prevention (CDC). Those communities where it is anticipated it will take longer to reach the HP2020 goals will be identified as highest priorities.

Identifying Target Communities

Once the Community Profile Team has reviewed the quantitative data report and has clearly identified communities with the greatest risk of not achieving the HP 2020 targets, the Team must select **target communities**. Target communities refer to specific focus areas that the Team will study further. Target communities may be determined based on geographic location (e.g. specific counties or areas within counties) or population characteristics (e.g. African Americans, women 65+). These target communities will determine where to focus efforts in the Health Systems Analysis and qualitative data sections of the Community Profile. Headquarters strongly recommends that Affiliates select at least two, but no more than five, target communities. The majority of target communities chosen by the Affiliate must be selected from areas classified in the report as highest/high risk, where available. In cases where there are no counties identified in the highest or high risk categories, the selection must be made from the category assigned the next level of risk (e.g. medium high, medium). Other target communities might be chosen based on population characteristics or other factors determined important by the Affiliate. The Affiliate must be able to make a strong case for selection of all target communities.

Utilizing the information from the Quantitative Data Report, the Community Profile Team will be responsible for submitting to Komen Headquarters a narrative that summarizes the target communities selected and justification for the selection of the target communities.

NOTE: The Affiliate might also choose to do an in-depth analysis or "deeper dive" into some of the statistics at a more local level or for a special population. For example, while key statistics by race will be presented in the Quantitative Data Report, data on sub-ethnicities (other than Hispanic/non-Hispanic) will not be provided. If an Affiliate wants statistics on a certain ethnic group (e.g. Somali or Korean population) in its service area, they would need to acquire this information using state or local sources- most likely with the help of a quantitative data expert or epidemiologist.

Preparing for the Health Systems Analysis

Once the Affiliate thoroughly reviews its Quantitative Data Report and target communities are identified, the Team is ready to move on to the Health Systems and Public Policy Analysis section in order to explore specific questions for each target community. To prepare, the Team should discuss the findings from the Quantitative Data Report and brainstorm what factors may be contributing to the breast cancer statistics as well as what issues the target communities face when trying to access care. This will lead the Team to questions that can be asked of women, providers and stakeholders in the community later in the Community Profile process.

The following are example questions the Team might consider for their Health System and Public Policy Analysis:

1. What health system issues may be contributing to the statistics in target communities?
2. What gaps and/or issues may contribute to high mortality rates? Late stage diagnosis? Low screening rates? Quality of care?
3. What existing services, programs and policies in the Affiliate's service area are *effective* at delivering breast health services to meet the CDC guidelines? (CDC guidelines: Time between referral and initial mammogram less than 90 days. Time between initial mammogram and date of diagnosis less than 60 days. Time between diagnosis and start of treatment is less than 60 days.)

Module 2 Toolkit

An online Quantitative Data Report Toolkit is available on myKomen in the Community Profile-Resource section to assist in completing the steps outlined in Module 2. The toolkit contains the resources that may be helpful in reviewing and completing the requirements for the Quantitative Data Report process. Please understand that the examples provided will need to be adapted to the Community Profile Team's specific needs.

Reporting to Komen Headquarters

The Community Profile Team will be required to submit to Komen Headquarters a report about the Quantitative Data Report. The report will consist of one narrative section: Quantitative Data Report Findings. A report template, scoring criteria and additional information is provided in the Module 6: Putting the Community Profile Report Together Toolkit on myKomen.

Board President or Executive Director Approval

Prior to submitting the Qualitative Data Report to Komen Headquarters, approval must be obtained from the Affiliate's Board President or Executive Director as evidenced by completion and submission of the Affiliate Approval Form via Documents Due in myKomen.

Conclusion

Module 2 begins the assessment process for the Community Profile Team. Before moving on to the next step in the process-Health Systems and Public Policy Analysis: Local Issues Affecting Women's Transition through the Continuum of Care, the Team should have:

- Become familiar with basic statistical terminology for breast cancer
- Reviewed the quantitative data report provided by Komen Headquarters and understand the implications for their service area
- Identified target communities from those identified by risk prioritization in the quantitative data report
- Compiled a list of questions based on analysis of the quantitative data

MODULE 3: HEALTH SYSTEMS AND PUBLIC POLICY ANALYSIS: LOCAL ISSUES AFFECTING WOMEN'S TRANSITION THROUGH THE CONTINUUM OF CARE

After review of the Quantitative Data Report, the Community Profile Team will explore the health system of the selected target communities and federal/state-level public policy issues and efforts. From Module 3, the Team will recognize how the continuum of care, asset maps, provider data and public policy can be used to understand gaps, needs and limitations in the health system that affect a woman's transition through the breast health and breast cancer continuum of care.

Learning Tasks:

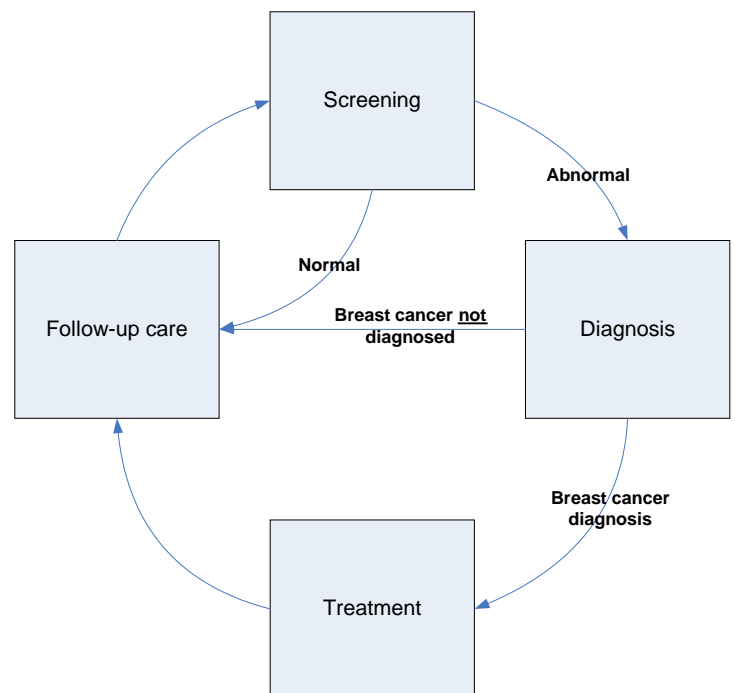
- Complete an analysis of gaps, needs and barriers throughout the continuum of care by utilizing the Health Systems Analysis template and corresponding maps
- Provide a review of community assets including current and potential partners
- Examine Komen's current and future role in health policy issues
- Discuss Komen's current and future partnership with NBCCEDP and state cancer consortium
- Discuss the Affordable Care Act and the implications for breast health care in the service area

Introduction

The analysis of health systems is a vital component of the Community Profile process. This in-depth analysis should be completed in the target communities selected by the Affiliate based on those counties identified as highest priorities in the Quantitative Data Report provided by Komen Headquarters.

The Continuum of Care

The continuum of care (refer to figure on the right) is a valuable lens through which all aspects of the Health Systems Analysis (HSA), as well as qualitative data collection and analysis (Module 4) will be viewed.



The continuum of care can be used to help organize the data collected in the Health Systems Analysis template and help identify what gaps and/or barriers exist that delay or prevent access to care. The continuum can also be used to help define and understand existing and needed partnerships, advocacy efforts and legislator support.

Assessing Service Providers

Health Systems Analysis Template

For the purpose of the Community Profile, the recommended first step of the Health Systems and Public Policy Analysis is to begin with an inventory of all breast cancer programs and services in the target areas by completing the HSA template. The inventory should not be limited to just Komen grantees; be as comprehensive as possible in documenting providers and services offered. The purpose of this exercise is to help the Affiliate understand the services offered by breast cancer providers serving the target communities and where they fit in the continuum of care. It can also assist the Team in determining what specific topics to explore through qualitative data collection and whom to approach for such information.

The Community Profile Team should refer to the Module 3 Toolkit on myKomen for specific sources to gather the information needed to complete the template. Other sources could include:

- GeMS or other Affiliate databases (grantee information)
- Internet search (e.g. Google)
- State Comprehensive Cancer Control plans
- Reports from reputable organizations (government, research institutions, etc.)

Once the Affiliate has completed the HSA template, the Team will submit it to Komen Headquarters in order for maps to be produced of the target communities.

Mapping

Mapping is an effective way of visualizing where and what services exist, concentration of services, gaps in care, and distance barriers. It can be especially useful if the Affiliate has little knowledge of the resources or barriers that may exist in the identified target communities.

The service provider data in the submitted HSA template will be mapped for Affiliates by Komen's Informational Technology (IT) department. Komen IT will use Geographic Information System (GIS) software to map service providers listed in the submitted HSA template. These maps of target communities will be returned to Affiliates so they can be considered along with other data in drafting the Mission Action Plan and will also be included in the final Community Profile Report.

Partnerships

Completing the HSA template should give Affiliates a good sense of existing resources and help them assess current and potential partners. If the completion of the HSA template reveals gaps in the continuum of care in the target communities, the Affiliate may have the opportunity to develop relationships with potential partners and serve as a liaison, linking talents and resources together in that community.

In order to have a measurable and sustainable impact in the community it is crucial that Affiliates be aware of resources and opportunities available at all levels. Awareness encourages collaborative efforts, but involvement increases the scope of success in finding the cures.

Public Policy and Advocacy

It is important to understand how federal and state public policies affect breast health along the continuum of care. The next step of the Health System and Public Policy Analysis is to discuss, through narrative, the key breast health and breast cancer policies that affect the Affiliate's state in regards to the Affordable Care Act and the National Breast and Cervical Cancer Early Detection Program (NBCCEDP). In addition, the narrative should discuss the Affiliate's relationship with their state's NBCCEDP and Comprehensive Cancer Control Program. To conclude the policy section of the health systems analysis, discuss the Affiliate's public policy work within Komen's Public Policy Model. Be sure to include any advocacy successes or challenges.

The Affordable Care Act

The ACA has many provisions that will in some way affect breast health care access and quality. In this discussion, the Affiliate will consider implications for its service area. In 2010, the Patient Protection and Affordable Care Act (ACA) was enacted. Parts of the ACA legislation that have gone into effect so far include:

- Insurance companies are limited on how they spend their customer's premiums. If they spend too much on administrative costs and profits, they must issue rebates to plan participants. This is known as the 80/20 Rule.
- Many preventive services including mammograms are available at no cost through Medicare and through some new private insurance companies.
- Medicare participants receive help with their drug costs.
- Young adults can stay on their parents' insurance policies until age 26.
- Some small businesses receive tax breaks to help them pay for health insurance for their workers.
- There are no lifetime limits on health coverage.
- Children with pre-existing health conditions cannot be turned down for coverage.

Some of the biggest changes will begin January 1, 2014, including:

- All Americans will be required to have health insurance or pay a penalty. For more information and a list of exemptions, go to <http://kff.org/infographic/the-requirement-to-buy-coverage-under-the-affordable-care-act/>.
- Americans will be able to purchase health insurance through a health marketplace exchange, with open enrollment beginning October 1, 2013. The marketplace will give consumers more options and encourage insurance companies to offer competitive prices.
- It will become illegal to deny adults (in addition to the earlier provision for children) insurance coverage because of a pre-existing condition.
- The Medicaid program will be expanded to cover all low-income individuals at or below 133% of the federal poverty level (FPL) (\$15,282 for an individual in 2013). However, this provision is optional for States.

Because it is important to understand how the ACA impacts breast health care, the Community Profile Team should include the following in the HSA section:

- Which health insurance exchange program the state has opted for
- State's decision regarding expanding Medicaid coverage
- Estimated number of uninsured in the state prior to and after the insurance mandate (effective January 1, 2014)
- Implications of ACA on state NBCCEDP eligibility and utilization
- Implications of ACA for health care providers
- Implications of ACA for your Affiliate service area and possible impact on the Affiliate's mission work

National Breast & Cervical Cancer Early Detection Program (NBCCEDP)

The Centers for Disease Control and Prevention (CDC) provides low-income, uninsured, and underserved women access to timely, high-quality screening and diagnostic services through the National Breast and Cervical Cancer Early Detection Program (NBCCEDP). Through the NBCCEDP, uninsured women under age 65 who are diagnosed with cervical or breast cancer may have access to full Medicaid benefits under the Breast and Cervical Cancer Prevention and Treatment Act of 2000, if their state has opted to provide such benefits. See: <http://www.cdc.gov/cancer/nbccedp/legislation/law106-354.htm>

Komen Affiliates are encouraged to build relationships with NBCCEDP representatives and providers in their service area. For Affiliates who are unsure who their state or regional director is, a complete list of NBCCEDP contacts by States and U.S. Territories is available by visiting http://apps.nccd.cdc.gov/dcpc_Programs/default.aspx?NPID=1.

In states where there are multiple Affiliates, it is important that Affiliates partner and work together when collaborating with state or regional NBCCEDP directors. It is imperative that we, together as Komen, send a unified message that we are a united front with the same message as it relates to breast cancer, especially when there are efforts that affect the entire state.

Because it is important to understand how Affiliates can work with NBCCEDP, the Community Profile Team should include the following information in the Health Systems and Public Policy Analysis section:

- How women get access to Medicaid treatment in the state, including if the State is an Option 1, 2, or 3 state
- The working relationship between the state NBCCEDP screening program and Medicaid
- The Affiliate's current relationship with state NBCCEDP directors
- The Affiliate's plan to establish/strengthen a working relationship with state NBCCEDP directors

State Cancer Control Programs

CDC started the National Comprehensive Cancer Control Program (NCCCP) to help states, tribes, and territories form coalitions to fight cancer. State Comprehensive Cancer Control (CCC) program activities include: implementation of strategies designed to reduce cancer risk, promote healthy lifestyles, ensure access to screenings/diagnostic technologies and improve the quality of treatment and support services to enhance survivorship.

A key element of CCC is the formation and ongoing work of a CCC coalition. Coalition members represent diverse organizations who are involved in cancer control and who commit to work together in order to:

- Leverage their collective strengths and resources
- Document areas of greatest need and gaps in cancer related efforts
- Identify efforts that no one organization would do alone, and
- Avoid duplication of activities

Affiliates can benefit from engaging with CCC coalitions. For example, it provides the opportunity to:

- Share your Affiliate's breast cancer expertise with a statewide network
- Network and collaborate with organizations addressing breast cancer in your service area and statewide
- Share information from your Community Profile
- Participate in a platform to inform a State Cancer Plan with Affiliate goals and strategies
- Increase awareness of what Komen does at the community level

Because it is important to understand how Affiliates can work with their state's CCC program, the Community Profile Team should include the following information in the Health Systems and Public Policy Analysis section:

- Breast cancer objectives in the State CCC Plan
- The Affiliate's current relationship with the state CCC program, if applicable
- The Affiliate's plan to establish/strengthen a working relationship with the CCC program.

Affiliate Advocacy

Public policy efforts are included in mission priorities. Discuss the Affiliate's public policy work, including advocacy successes and challenges. Headquarters encourages Affiliates to be informed of and forge relationships with elected officials at all levels in their state. For a list of elected officials in your area, along with contact information, please visit <http://www.usa.gov/Contact/Elected.shtml>. Affiliates that share a state should partner and work in collaborations with members of congress. It is important that elected officials know Susan G. Komen® is a united front with one voice and one vision to end breast cancer forever. The Community Profile is an excellent tool to share with elected officials.

Data Limitations

Some possible HSA limitations that the Team may need to acknowledge when drawing conclusions include:

- Completed template may have missed some breast health/cancer providers
- Information about services provided by the health care providers is inaccurate
- Providers were included that do not provide services related to the continuum of care
- Health care services not in the continuum of care were excluded (e.g.. education, outreach)

Module 3 Toolkit

An online Health System and Public Policy Analysis Toolkit is available on myKomen in the Community Profile- Resources section to assist in completing the steps outlined in Module 3. The toolkit contains the Health System Analysis template and additional resources that may be helpful in completing the Health System and Public Policy Analysis process. Please understand that the examples provided will need to be adapted to the Community Profile Team's specific needs.

Reporting to Komen Headquarters

The Community Profile Team will be required to submit to Komen Headquarters a report about the continuum of care and public policy activities in the selected target communities. The report will consist of four narrative sections: Health Systems Analysis Data Sources, Health Systems Overview, Public Policy Analysis Overview, Health Systems and Public Policy Analysis Findings. A report template, scoring criteria and additional information is provided in the Module 6: Putting the Community Profile Report Together Toolkit on myKomen.

Board President or Executive Director Approval

Prior to submitting the Qualitative Data Report to Komen Headquarters, approval must be obtained from the Affiliate's Board President or Executive Director as evidenced by completion and submission of the Affiliate Approval Form via Documents Due in myKomen.

Conclusion

Module 3 continues the assessment process by collecting data on service providers in the target areas. Before moving on to the next step in the process- Qualitative Data: Ensuring Community Input- the Team should have:

- Completed the HSA template and submitted it to Komen Headquarters
- Reviewed and sorted data using the continuum of care
- Discussed the ACA and its implications and impact on the Affiliate
- Collected data on and discussed public policy, including the NBCCEDP and State Comprehensive Cancer Control Coalition
- Organized, analyzed and summarized findings

MODULE 4: QUALITATIVE DATA COLLECTION

ENSURING COMMUNITY INPUT

Module 4 provides different options the Community Profile Team can use to better understand their target communities. Regardless of the qualitative data collection methods used, the methods share common components. Module 4 contains a brief summary of these components; however, a comprehensive detailed step-by-step process for each qualitative data collection method can be found in the online Module 4 Toolkits on myKomen. From Module 4 and its supporting toolkit, the Community Profile Team will be provided the necessary tools to plan, implement, analyze and interpret qualitative data from the selected target communities.

Learning Tasks:

- Become familiar with the qualitative data collection process and its components
- Understand where the Module 4 Toolkit is located on myKomen
- By using the Module 4 Toolkit, understand how to develop data collection tools and supporting documents (recruitment letters/scripts, interview scripts, etc), coordinate logistics and collect data, and organize, analyze and summarize findings

Introduction

Quantitative and qualitative data are both equally important in developing a comprehensive assessment of the community. It is just as important to have the numbers to provide evidence of need, as it is to have the insights and stories that speak to the issues reflected from the numbers. Qualitative data collection is used to provide a deeper examination of the community to answer questions that the quantitative data cannot by directly involving the community in assessing its issues and needs¹.

To further explore the breast health and breast cancer issues highlighted by the quantitative data (e.g. late stage diagnoses rates), qualitative data collection can be utilized to provide insight into the community's attitudes, beliefs and behaviors about disparities, access to services, utilization of services, quality of care, and additional breast health and breast cancer issues (e.g. reasons behind low screening mammography percentage). In addition, the qualitative process can provide the community perspective as to what is working, what is not working, and what are the various barriers that lead to gaps in access, utilization and quality of services.

Collecting qualitative data can be time-consuming; however, engaging stakeholders can make the process a learning experience and a relationship building process. Some suggested ways to engage stakeholders include:

- Affiliate Board of Directors: conduct interviews and recruit participants
- Non-Mission Affiliate Staff: recruit participants through media avenues, conduct interviews, and assist in script development

- Volunteers: recruit participants, conduct interviews, and provide office support for mailing surveys and/or data entry
- Community Partners: recruit participants, provide incentives, provide location and food for focus groups, provide a qualitative resource for data analysis, and provide in-kind printing

Collecting qualitative data is a science. Having an individual with qualitative experience helps ensure that the planning, implementation, data analysis and interpretation processes all utilize methods that are sound and credible. In addition, qualitative data collection is a fluid process. As information is gathered, it may further refine subsequent data collection techniques. For example, the Community Profile Team may begin by conducting key informant interviews and the data from the interviews may assist in the development of questions used during the focus groups. Then, the information gathered at the focus groups may guide the questions on a survey. All of the data collection methods may guide the Team as to potential opportunities for observation and/or document review. For additional information on finding an individual with qualitative experience, please refer to Module 1: The Community Profile Team section of the Community Profile Guidebook.

Strengths of Qualitative Data²:

- Captures more depth and provides insight to an individuals or groups attitudes, beliefs, and behaviors (e.g. **What** are their attitudes, beliefs and behaviors towards breast health screening?; **Why** do they have those attitudes, beliefs, and behaviors towards breast health screening?; and **How** can their attitudes, beliefs, or behaviors about breast health screening be positively changed?)
- Clarifies quantitative data and sometimes puts it into the context of people’s lives and experiences, and/or situational/environmental context
- Makes quantitative data easier to understand
- Provides more details and nuances
- Explains what the program means to the people involved

Limitations of Qualitative Data²:

- Time consuming to capture and analyze
- Subjective and generally viewed as less reliable
- May be difficult to summarize and compare systematically
- Yield smaller sample sizes

Please refer to Module 4a Toolkit- Qualitative Data Support Materials for additional information about strengths and weaknesses.

Gather and Review Data

Prior to beginning the qualitative data collection process, the Community Profile Team needs to review the summaries of the quantitative data section and the Health Systems and Public Policy Analysis section. The Affiliate could also review historical and current data collected from grantees in progress/final reports along with local community health assessments that might contain additional breast health and breast cancer data. In addition to the quantitative data, a literature review may be conducted to add to the understanding of the quantitative data. Potential literature review topics can include breast cancer incidence, screening rates, late-stage diagnosis, mortality rate, disparities, quality of care, access to services, utilization of services, and/or Affordable Care Act.

Determine the Questions to be Answered

The review of the quantitative data should highlight breast health and breast cancer concerns (e.g. late stage diagnosis, mortality) that warrant further investigation. In other words, “What questions still require answers in order to fully understand how breast cancer affects the community?” These questions provide the purpose behind conducting qualitative data collection. Clearly defined questions can be used as a reference throughout the qualitative process to ensure that the correct sources of data collected are identified and that the right information is being gathered to answer the questions. In order for the process to be successful, the Community Profile Team needs to make sure that the questions are clearly defined so that everyone is working towards the same answers (e.g. What does access mean? What does utilization mean?). ***Module 4a Toolkit on myKomen has a Qualitative Data Question Bank that can be used as a resource.***

Common questions that are answered utilizing qualitative data collection are³:

- What are the breast health/cancer problems in the target community(ies)?
- Why do these breast health/cancer problems exist in the target community?
- What factors create or determine the breast health/cancer problems in the target community?
- What resources are available to address the breast health/cancer problems in the target community?
- What are the breast health/cancer needs of the target community from a population-based perspective?

Example: The Community Profile Team is concerned about utilization of screening mammography in County X because the quantitative data indicates that County X has the lowest breast cancer screening percentage and breast cancer incidence rate, but the highest late stage diagnosis (stages III-IV) incidence rate in the service area. The Team decides that one of the questions that they want answered through qualitative data collection is:

- Why are women ages 40 and above in County X not utilizing breast cancer screening mammography services?

Community Data Sources

In order to answer the questions, the Community Profile Team will need to determine whom in the target community will need to be engaged to provide reliable information on the breast health and/or breast cancer problem. These individuals are considered the community data sources. The community data sources may consist of individuals within the community, from community organizations, health care systems or other groups that are impacted by the identified problem. The Affiliate will need to establish selection criteria to define which sources of data collection should be included or excluded in the data collection process. This information should be based on the specific questions that need to be answered about the target communities. ***Module 4a Toolkit on myKomen has a support document about potential target populations and where they could be located.***

Example: One of the questions developed by the Community Profile Team is “Why are women ages 40 and above in County X not getting breast cancer screening mammograms?”. Based on this question, possible target populations to collect data from are:

- Women 40 years and above that reside in County X that have either never received a mammogram or have not received a mammogram in the past two years.
- Community Health Advisors that may work in the community.
- Local primary care physicians and gynecologists/nurses/mammography technicians.

Select Data Collection Method(s)

Based on the identified breast health and/or breast cancer problem, the sources of data collection, the available resources and what is realistic for the Affiliate within the timeline, the Community Profile Team must determine which data collection method(s) will be used to gather qualitative information. The most commonly utilized qualitative data collection methods are key informant interviews, focus groups, surveys, document reviews, and observations.

Interviews use open-ended questions and probes to gather responses about people’s experiences, perceptions, opinions, feelings and knowledge. Interviews include key informant interviews and focus groups. Surveys may utilize a combination of open-ended and closed-ended questions to gather information about provider and community delivery gaps/needs/barriers, knowledge level and behaviors, beliefs or attitudes. Document review uses written materials and other documents from organizational, clinical, or program records; memoranda and correspondence; official publications and reports; and personal diaries, letters, artistic works, photographs and memorabilia. Finally, observation methods use a personal perspective to gather descriptions of activities, behaviors, actions, conversations, interpersonal interactions, organizational or community processes, or any other aspect of observable human experience.

The Module 4 Toolkits, available on myKomen, focus on five common data collection methods (key informant interviews, focus groups, surveys, document review, and observations).

Another data collection method that may have been previously used by Komen Affiliates for Community Profile development is a method commonly referred to as Photovoice, or participatory photography. Photovoice is a method that engages the target communities by having them take photographs that represent their point of view on an issue or topic, discuss the photographs together as a group, and lastly the participants develop narratives that go along with their photos. More information about Photovoice can be found in The Community Toolbox: Implementing Photovoice in Your Community, which is a service of the Work Group for Community Health and Development at the University of Kansas: http://ctb.ku.edu/en/tablecontents/chapter3_section20_main.aspx

A Qualitative Data Collection Strengths and Weakness resource is available in the online Module 4a Toolkit and provides a summary on when each method could be used, the strengths and limitations of each method, and some resources needed for each data collection method. Qualitative data collection best-practice suggests that the Community Profile Team utilize a combination of data collection methods so that results of one method can be triangulated, or cross-validated, with the results of the other method(s). However, using multiple qualitative methods **may not be realistic**. Teams should try to be as thorough as possible by at least using two qualitative data collection methods and including provider and non-provider data to have a realistic understanding of the community influences.

In the myKomen Community Profile toolkits there are separate toolkits for each qualitative data collection method discussed in the matrix. These toolkits include a resource that describes each method step-by-step and additional resources that can be used.

- Module 4b Toolkit: Key Informant Interviews
- Module 4c Toolkit: Focus Groups
- Module 4d: Surveys
- Module 4e: Document Reviews
- Module 4f: Observations

The Community Profile Team should also look within the community for additional qualitative resources. For example, the implementation of the Affordable Care Act requires non-profit hospitals to complete a Community Health Needs Assessment every three years. In addition, local health departments also complete community assessments. These assessments may be utilized by the local Affiliate as another data resource, or may even provide an opportunity for the Affiliate and community partners (e.g. hospital, health department) to collaborate in completing the profile/assessment (e.g. include breast health and breast cancer questions on assessment tools).

Note: *When planning the Affiliate's profile process, the Community Profile Team should discuss if health care provider key informant interviews and the Health System Analysis data collection could be completed simultaneously.*

Develop Data Collection Tools

The Affiliate will need to develop or adapt data collection tools based upon the data collection method(s) selected. Some data collection tools that the Community Profile Team may use include interview scripts, consent forms, interview or survey questions, field note guides, and checklists. **Example qualitative data collection tools are available for each method in the Module 4 Toolkits on myKomen.**

Prior to using revised or adapted interview or survey questions, it is best practice that the questions be pre-tested to identify problems with the data collection tool and find possible solutions prior to collection. This assists in ensuring that the tools produce stable and consistent results (reliability) and that the tools are measuring what they are supposed to (validity). Tools can be pre-tested by using a small group similar to the target population (20-30 people) or by using a panel of subject-matter experts (3-8 people). The examples provided in the toolkit **have not** been pre-tested; therefore, the Community Profile Team should plan to pre-test the tools to ensure appropriateness to the target community.

Things to consider when selecting a method:

- What information is the team trying to collect (e.g. opinions, interactions, or processes)
- Which method(s) is the target population most likely to respond to (e.g. is a physician more likely to participate in a focus group or a survey)

During development of collection tools, the Community Profile Team will also need to determine how the data will be recorded for analysis (e.g. typed directly into online program, voice recorded and transcribed, written notes, typed notes). This is important to ensure that the collection and recording processes align with the analysis process. If these processes are not interlinked, unnecessary time and resources may have to be expended to collect additional data or in reformatting the data into a useable format for analysis.

Select Sampling Technique

Sampling determines the sources of data collection that are selected to represent the target communities. In some situations, if the sources of data collection are small, sampling may not be warranted as each source's input is needed for an accurate representation of the target community. For the Community Profile, the Community Profile Team will most likely not be able to collect data from every person, organization, health care system or group identified in the target population. Therefore, the Team will need to strategically and purposefully select a sample appropriate to the assessment's purposes and resources.

Descriptions, advantages and disadvantages for each of the following sampling techniques can be found in the Module 4a Toolkit on myKomen:

Types of Probability Sampling Techniques:

- Simple Random
- Systematic Random
- Stratified Random

Types of Non-Probability Sampling Techniques:

- Quota
- Snowball Sampling
- Convenience
- Purposive

There are two types of sampling strategies: Probability and Non-Probability. Probability sampling gives every individual in a group the same chance of being chosen. Although this type of sampling is more difficult, the findings are able to be generalized to a larger population. Non-probability sampling selects individuals based on defined characteristics that are of interest such as gender, age, county of residence, health insurance status, screening status, and breast cancer diagnosis. In other words, not every individual has a chance of being selected when non-probability sampling is used. There are a variety of sampling techniques that may be used in selecting your sample from the target community. Please refer to the document titled Advantages and Disadvantages of Sampling Techniques in the Module 4a Toolkit on myKomen for additional information on each technique.

Determining Sample Size

Qualitative data collection typically involves the use of small samples. That being said, sample size is an important consideration as it determines the extent to which generalizations about the target community can be made⁴. For example, if the sample size is small and is not diverse enough to represent the target community, then the conclusions can only be made about those that participated in the data collection, not the community they were drawn from. There are trade-offs between depth and breadth (e.g. between doing fewer cases in greater depth, or more cases in less depth) given limitations of time and money.

Sample size recommendations for some qualitative data collection methods ⁶:

- Interview: 12 participants **per topic area**
- Focus Group: 6-12 participants per group, 3-6 focus groups **per topic area or group**
- Case-studies: 3-5 participants
- Surveys: Utilize a sample size calculator to have a 95% Confidence Level (how sure you can be of how often the percentage of the population would pick an answer), ± 5 Confidence Interval (margin of error)
 - <http://www.raosoft.com/samplesize.html>
 - <http://www.surveysystem.com/sscalc.htm>

The sample size needed will be determined by the breast health and/or breast cancer issue(s), sources of data collection, data collection method(s) and sampling technique(s) used. In general, sample sizes should not be too large that it is difficult to extract data, but not too small that it is difficult to achieve data saturation or information redundancy⁴. For example, when using key informant interviews and focus groups as the data collection method, it is best-practice to sample until nothing new is being learned and the same issues keep coming up (redundancy).

The Community Profile Team should remember that the sample size is the number of sources of data collection needed to complete the selected data collection method. Therefore, recruitment of sources for each data collection method will need to be greater than the sample size. For example, the Team has determined that a sample size of 79 completed surveys from

African American women that are 40 years old and older is needed for a qualitative survey in County Z. From reviewing the literature, the Team finds the average response rate for women in that age group to be 33% when no incentive is included⁵. However, the literature also indicated a lower response rate for women in minority zip codes. The Team conservatively planned on a 30% response rate from the women. Therefore, the Team would need to send the qualitative survey to 265 women that are 40 years and older in County Z to receive 79 completed surveys.

Some strategies that may be used to determine sample size include⁷:

- Sample to the point of redundancy
- Emergent sampling design- start out and add to the sample as fieldwork progresses
- Determine sample size and scope in advance (commonly used with surveys)

Using Incentives to Increase Participation

Incentives may assist with recruiting participants to be engaged in the data collection method selected by sending the message that their time and perspective is valuable. Some incentives may be donated by a local supporter that could be recognized as a partner in the final report. Keep in mind that the opportunity to discuss their experiences and opinions may also be an incentive to some potential participants. In addition, the Community Profile Team should ensure that any ethical considerations have been discussed in regards to offering incentives in order to be prepared to respond to questions from donors and/or sponsors (e.g. biased response, donor acceptance of using funding for incentives, perspective of paying for opinions, participants already being compensated if completing interview/focus group/survey during work time)⁸.

Examples of Incentives⁸:

- Komen-branded products
- Komen Race t-shirts from previous years
- Goodie bags (e.g. Komen ribbon pin, ink pen, coupons, educational materials)
- Gift Cards that exclude tobacco and alcohol products
- Lunch for focus groups
- Movie tickets
- Restaurant gift certificates
- Offer childcare reimbursement
- Offer transportation and/or reimburse for gas, parking or tolls
- Money (Research suggests values between \$50.00 to \$75.00 usually work for public and nonprofit studies⁷. For elite categories (e.g. physicians, upper-level managers) the value may begin at \$100.00⁷.)

Collecting Data

The Community Profile Team's qualitative resource should lead the data collection process. The data collection process may involve various activities including, but not limited to recruitment of participants, acquiring a mailing list, sending out surveys, setting up appointments for interviews, scheduling locations/dates/times for focus groups, training data collectors, interaction with individuals or groups, going to the community of the participants, asking detailed questions, and detailed documentation. Depending on the capacity of the Community Profile Team, sometimes a third-party consultant (e.g. bi-lingual focus group facilitator) may need to be contracted with to assist in collecting the data. Please refer to Module 1: The Community Profile Team for additional information on consultants.

Ethical principles to be considered when collecting data⁹:

- Ensure participant confidentiality at all times and anonymity where possible
- Participants provide their consent to participate
- Participants need to be informed about the purpose of the data collection
- Information shared as “off the record” should be omitted from documentation and analysis
- Data collector should refrain from providing own experiences
- Ensure that reciprocity/incentives for participation do not influence responses
- Ensure that the participant does not experience any repercussions from choosing to participate or not (e.g. refused services)
- Disclosure of ownership of collected data and how it will be used

Analyzing the Data

Qualitative data analysis involves the identification and examination of patterns and themes in textual data and determines how the data may help answer the question(s) identified at the beginning of the process^{3,10}. The quality of the analysis of the qualitative data collection process is highly dependent upon the skills of the Community Profile Team's qualitative resource (e.g. individual or organization).

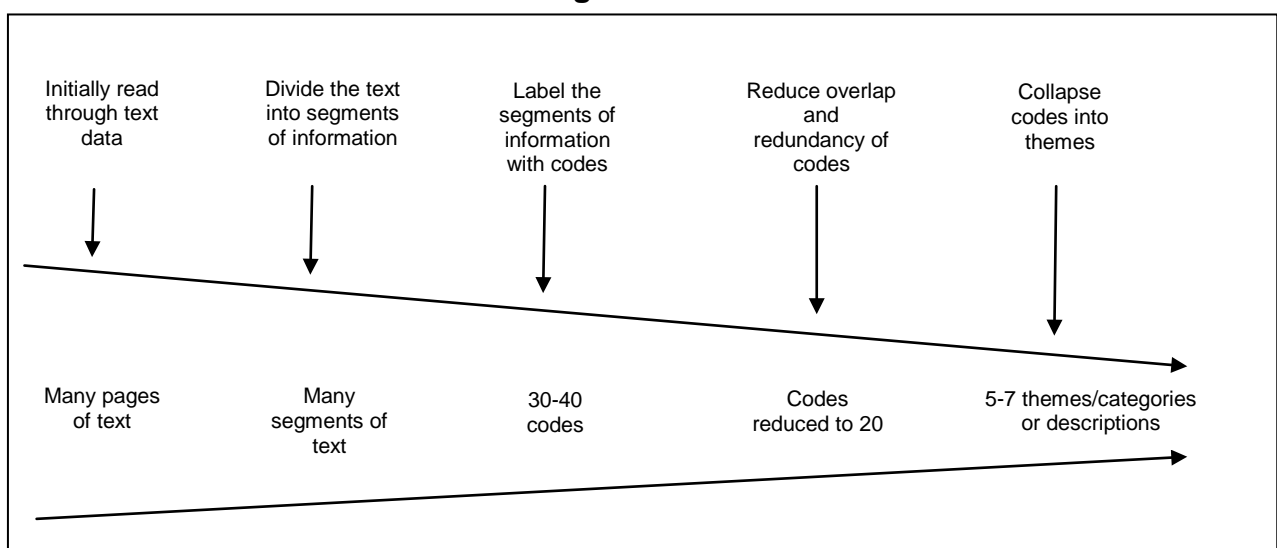
There are five best-practice steps that can be used as a guide to analyze qualitative data^{9,10}.

- **Step 1- Process and Record Data Immediately:** Raw field notes do not always contain all the information from a key informant interview, focus group, and/or observation. These field notes may also contain note taker abbreviations and side notes. In fact, it is best to make additional notes about interactions while it is still fresh so that thoughts and reactions are accurate.
- **Step 2- Begin Coding and Analyzing as Data is Being Collected:** Coding is a precursor to analysis. Codes are tags/labels for assigning units of meaning to the textual data (e.g. words, phrases, sentences or paragraphs). These tags/labels are

used to retrieve and organize the data for interpretation and drawing conclusions. As the data is being analyzed, the development of a codebook can reduce overlap and redundancy. Qualitative data collection results in a massive amount of textual information that may be overwhelming when trying to analyze; therefore, it is best-practice to begin the coding and analyzing data as soon as the first key informant interview, focus group, survey, observation or document review is completed. In addition, early coding and analysis of the data can alert the Community Profile Team if there are additional topics or problems that need to be addressed during data collection to further understand the breast health and/or breast cancer issue(s). An example codebook is available in the Module 4 Toolkit on myKomen.

- **Step 3- Data Reduction:** Initial coding of the text may result in 30-40 codes. During this stage of the analysis, the data should be reviewed again to identify and focus on the data that is meaningful to the breast health and/or breast cancer issue(s). After the second review of the data there should be an end result of about 20 codes. This may help to identify overlap or redundancy of codes that will need to be modified into one representative code.
- **Step 4- Identify Meaningful Themes/Categories or Descriptions:** After the codes are reduced to about 20, they are then reduced into five to seven themes/categories or descriptions. Themes, or categories, are similar codes combined together to form a major idea. Themes/categories are identified by examining codes that the participants discuss most frequently, are unique or surprising, have the most evidence to support them, or are those you expect to find when studying the issue. Descriptions are depictions of people, places, or events in a setting (e.g. race/ethnicity, facial expressions, verbal reactions). It is best practice to reduce the number of codes from 20 to about five to seven. It is easier to write a summary of the data with fewer themes/categories or descriptions than a summary with 20 themes/categories or descriptions when the data may be too general from which to draw conclusions.

A Visual Model of the Coding Process in Qualitative Research⁹



- **Step 5- Format the Data:** Data needs to be assembled, organized and compressed into a format that facilitates development of a summary, and setting priorities and action plan. Some common formats that have been used for qualitative data include:
 - Direct Quotes/Written Statements: Provide narrative of quotes or written statements provided by participants.
 - Comparison Table: Used to compare groups on one of the themes/categories and/or descriptions (e.g. Screening Mammography: women over 40 that never received a mammogram and women over 40 that had not received a mammogram in the last two years).
 - Hierarchical Tree Diagram: Used to visually represent themes/categories and/or descriptions and their interconnections.
 - Figure: Figure with boxes show the connections among themes/categories and/or descriptions. Similar to a logic model.
 - Diagram Map: Depicts the physical layout of the setting.
 - Demographic Table: Describes personal or demographic information for each participant. Some examples of information contained in a table include age, race/ethnicity, county of residence, mammography status, breast cancer diagnosis status, occupation, educational level achieved, household income, and insurance status.
 - Pie and/or Bar Charts: Used to visually display percentages. This could include participants' race/ethnicity, insurance status, or mammography status.

Analyzing and interpreting qualitative data can be both time and labor intensive. The Community Profile Team should allow adequate time for this step to ensure an accurate presentation of the link between the qualitative and quantitative data. Due to the open-ended nature of qualitative data, it is easy to become sidetracked during analysis and end up with qualitative results that are not related to the original questions, quantitative data or Health Systems and Public Policy Analysis. While it is important to explore unanticipated outcomes, side effects and unexpected consequences, the Community Profile Team **must ensure** that the analyzed data used in the final report to Komen Headquarters represents a synergy between the quantitative data, Health Systems and Public Policy Analysis and qualitative data.

Questions to Ask Throughout the Qualitative Analysis Process³:

- What patterns/common themes emerge around specific items in the data?
- How do these patterns (or lack thereof) help shed light on the problem identified by the quantitative data and in the purpose statement?
- Are there any deviations from these patterns? If yes, what factors could explain these atypical responses?
- What interesting stories emerge from the data?
- How can these stories help to shed light on the broader problem?
- Do any of the patterns/emergent themes suggest that additional data needs to be collected?
- Do the patterns that emerge support the findings of other corresponding quantitative and/or qualitative analyses that have been conducted?

During analysis, there may be outliers, or data that appears to be inconsistent with the rest of the data. It may be tempting to “smooth over them, ignore them, or explain them away”¹¹. However, outliers should be reviewed to determine how they (the data) are different from the majority. Outliers may signal self-selecting biases (e.g. only chose the theme that matters to the person analyzing the data), sampling differences (e.g. over/under sampled a specific group), participant discrepancies (e.g. ovarian cancer survivor participating in a breast cancer survivor group), inconsistency of asking questions (e.g. focus group moderator strayed from script and rephrased the question), or a different topic that may need further exploration¹¹.

Analysis of qualitative data can be performed by hand or computer. Hand analysis means that the data is read, marked with codes and divided into broad categories to be interpreted. An example of hand analysis is provided in the Module 4 Toolkit on myKomen. Computer analysis means using a qualitative computer program to store, analyze and sort the data for analysis. Regardless of the analysis method utilized, the data will be examined in detail to develop and describe broad categories of ideas by the Community Profile Team’s qualitative resource.

Examples of qualitative computer programs (Some programs offer a free trial that may be suitable for the Community Profile timeframe):

- QDA Miner Lite (<http://provalisresearch.com/products/qualitative-data-analysis-software/freeware/>) : FREE
- Qualitative Data Analysis Program (QDAP) (www.umass.edu/qdap): FREE
- Atlas.ti (www.atlasti.com): single user, non-commercial use= \$1,290.00
- Dedoose (www.dedoose.com): single user = \$10.00 per month, charged only when used.
- Ethnograph 6 (www.qualisresearch.com): single user = \$299.00
- HyperRESEARCH (<http://www.researchware.com/products/hyperresearch.html>): single user, non-profit = \$699.00
- MAXqda (www.maxqda.com): single user, government/charitable organizations = \$713.00
- NVivo (www.qsrinternational.com) : single user, education/charitable organizations= \$670.00

Drawing Conclusions About The Data

Drawing conclusions attaches meaning and significance to the data coded in the analysis process. One advantage of qualitative data is that open-ended questions allow participants to provide as much, or as little, information that they want. Due to the potential amount of detailed information that can be provided, it is easy to get distracted from the original intent of the data collection. Interpretation depends on the perspective of the individual(s) reviewing the data. A qualitative resource/expert can assist in drawing accurate conclusions from the data. To assist in maintaining focus when developing conclusions, follow these simple steps¹²:

- Review the “unanswered questions” from the quantitative data that guided the qualitative process.
- Develop a list of key points or important findings from the analysis using the following questions as a guide:
 - What is important in the data?
 - Why is it important?
 - What can be learned from it?
 - How does it answer the “unanswered questions”?
- Develop an outline. The outline can include quotes and descriptive examples collected from the qualitative process.

Data Limitations

Both the quantitative and qualitative data used by the Community Profile Team will have limitations, even when best-practices are used. Limitations are conditions that can affect the scope or outcome of the assessment that cannot be controlled by the Community Profile Team. Limitations can often relate to inadequate measures of issues/problems, loss or lack of participants, small sample sizes, and inaccurate data collection and analysis. Identifying the limitations assists the Team in making correct generalizations about the data collected. It is important that the Team acknowledges that the conclusions derived from the data will have some limitations and should address the limitations in a professional and appropriate manner in the written Community Profile Report.

Some common qualitative data limitations that the Team may need to acknowledge that impact the ability to make generalizations about a target community include:

- Use of convenience samples (e.g. Affiliate survivor database allows generalizations to be made about those in the database, not all survivors)
- Poor response rates
- Small sample sizes
- Data collected outside of target communities (e.g. target population was women in County Y, but data gathered was from County A)
- Facilitator, interviewer or observer bias
- Inaccurate recall of information provided by participant
- Participants giving what they believe to be the desirable response, even if untrue

- Participants selected for key informant interviews did not represent diverse backgrounds and viewpoints
- Not all members of the target community had an equal chance of participating in the focus group and/or survey
- Poor question wording may have resulted in inaccurate responses from participants
- Participants in the survey or focus groups are different from those that did not participate (e.g. those that participated may have less barriers than those that did not participate)

Module 4 Toolkits

Online Qualitative Data Toolkits are available on myKomen in the Community Profile-Resources section to assist in completing the steps outlined in Module 4. The toolkits contain examples of interview/focus group scripts, informed consent forms, a question bank and additional resources that may be helpful in completing the qualitative data collection process. Please understand that the examples provided will need to be adapted to the Community Profile Team's specific needs.

Community Profile Qualitative Data Toolkits on myKomen:

- Module 4a Toolkit: Qualitative Data Support Materials
- Module 4b Toolkit: Key Informant Interviews
- Module 4c Toolkit: Focus Groups
- Module 4d Toolkit: Surveys
- Module 4e Toolkit: Document Reviews
- Module 4f Toolkit: Observations

Reporting to Komen Headquarters

The Community Profile Team will be required to submit to Komen Headquarters a report about the breast cancer perspectives in the target communities. The report will consist of three narrative sections: Qualitative Data Sources and Methodology Overview, Qualitative Data Overview and Qualitative Data Findings. A report template, scoring criteria and additional information is provided in the Module 6: Putting the Community Profile Report Together Toolkit on myKomen.

Board President or Executive Director Approval

Prior to submitting the Qualitative Data Report to Komen Headquarters, approval must be obtained from the Affiliate's Board President or Executive Director as evidenced by completion and submission of the Affiliate Approval Form via Documents Due in myKomen.

Conclusion

Module 4 moves the assessment process forward by providing different options the Community Profile Team can use to better understand their target communities. In order to satisfy the minimum requirements for completing the Community Profile, the Team must use at **least two** of the methods described in Module 4 (e.g. key informant interviews, focus groups, surveys) and may use document reviews and observations to gather additional supporting data

in each target community. Komen Headquarters recommends that the Team use several data collection methods to achieve a truly in-depth understanding. However, the approach taken to collect the data is ultimately based on the resources and capacity of the Community Profile Team.

Before moving on to the next step in the process- Mission Action Plan- the Community Profile Team should have:

- Developed data collection tools and supporting documents (recruitment letters/scripts, interview scripts, etc.)
- Recruited sources of data collection
- Coordinated data collection logistics and collected data
- Organized, analyzed, and summarized findings and report submitted to Komen Headquarters.

Module 4 References

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MODULE 5: MISSION ACTION PLAN

Once all the information has been collected, the final step in the process is to compile and summarize the findings from each section to develop problem statements, determine the Affiliate's priorities and develop objectives related to the priorities. From Module 5, the Community Profile Team will have the necessary tools to assist with developing the Affiliate's Mission Action Plan.

Learning Tasks:

- Understand how to draw conclusions from the breast health and breast cancer data
- Understand how to interpret findings and to determine Affiliate priorities
- Be guided in the development of SMART objectives
- Understand how to develop the Affiliate Mission Action Plan

Introduction

Every Community Profile Team will have a different experience with data analysis and establishing priorities for the Affiliate's service area. For some Teams, the priorities may be identified more easily than others based on the data collected throughout the process. While for other Teams more time and effort may be needed in analyzing data and drawing conclusions in order to identify the right priorities.

Data Summarization

Once all the data has been collected and each Community Profile section (e.g. Quantitative Data Report, Health Systems and Public Policy Analysis and qualitative data) has been appropriately analyzed and summarized, the Community Profile Team is tasked with bringing all the data together to make plausible connections regarding the issues to establish priorities. Data summarization requires an organized process of reviewing the data and interpretation of the data in a logical manner. **NOTE: The use of a qualitative data resource during this phase of the process will help ensure that the data is interpreted correctly.**

Utilizing multiple data sources, types, and methods to reveal similar patterns and conclusions is referred to as triangulation. Triangulation should be used to review the needs, barriers, and existing gaps in addressing access to, utilization of, and quality of care in the Affiliate service area. For the Community Profile, triangulation can be used to draw appropriate conclusions and identify priorities that will be used to inform the Affiliate's Mission Action Plan.

NOTE: The best way to do this is for the Team to summarize the findings from each module of the profile into a brief need or problem statement. The Team will then create a list of these need or problem statements for each target community. This list will assist the Team in triangulating the needs- resulting in an understanding of the overall picture of the target communities and help guide discussions about which issues the Affiliate should select as priorities.

Example: The quantitative data revealed that a low percentage of women over the age of 40 received a screening mammogram in County Pink. County Pink also has a significantly high percentage of its population on Medicaid. This data led the Community Profile Team to consider that utilization of screening mammography services among Medicaid-insured women residing in County Pink is a concern that should be further investigated.

The Health System Analysis revealed that County Pink has five mammography sites located throughout the county; however, only one site accepts Medicaid and is located 25 miles from the largest population center in the county. In addition, except for the one facility that accepts Medicaid, the remaining four are only open four days a week due to a low demand of services.

Focus groups with Medicaid insured women over the age of 40 revealed that women believed common barriers to utilization to be: (1) there was a lack of mammography facilities that accept Medicaid, (2) wait time for the one facility that accepts Medicaid is 6 months, and (3) transportation was a problem for women residing greater than 10 miles from the one facility that accepts Medicaid.

As the Team compared the three data methods (Quantitative Data Report, Health System and Public Policy Analysis, and qualitative data) and found similar patterns, the Team concluded that Medicaid-insured women ages 40 and older residing in County Pink are experiencing three main barriers that are impacting the utilization of screening mammography services.

Due to the amount of data collected during the Community Profile process, bringing the data together to formulate conclusions may feel overwhelming. After data collection and/or review is completed for each section (e.g. Quantitative Data Report, Health System and Public Policy Analysis, and qualitative data), developing a brief summary will keep the Team focused on the problem(s)/need(s) of the target community(ies). The following outlines a data summarization process that the Community Profile Team can utilize in managing the process:

Step 1: Quantitative Data: After reviewing the Quantitative Data Report provided by Komen Headquarters, the Community Profile Team will need to:

1. Identify and summarize target communities based on the recommendations and data contained in the reports
2. Develop conclusions as to why selected communities face any particular issue or combination of issues

Step 2: Health Systems and Public Policy Analysis: After reviewing the data from the completed Health Systems Analysis and Public Policy summary (e.g. template, maps, and policies), the Community Profile Team will need to:

1. Identify and summarize breast health and breast cancer care assets and gaps in target communities
2. Identify what role federal/state public policy has on breast health and breast cancer care
3. Develop conclusions as to why a particular issue or combination of issues exist

Step 3: Qualitative Data: After reviewing the qualitative data (e.g. key informant interviews, focus groups, surveys, document reviews, and observations), the Community Profile Team will need to:

1. Identify and summarize themes/categories and/or descriptions
2. Connect, if possible, identified themes/categories and/or descriptions to Quantitative Data Report and/or Health Systems Analysis
3. Develop conclusions as to why a particular issue or combination of issues exist

Step 4: Overall Summary: After each section has been summarized (e.g. Quantitative Data Report, Health System and Public Policy Analysis, and qualitative data), the Community Profile Team will need to:

1. Discuss and understand how all the data fits together and why a particular issue or combination of issues exist
2. Combine findings and create a list from which the priorities will be determined

Gaps in the Data

Once all the data has been sorted and summarized, the Community Profile Team must decide if there are **important** questions still not answered or issues still not understood. In other words, “Did the data gathered answer the questions about how breast cancer affects the community?”

If the answer is “no”, then before moving forward the Team must decide if the Community Profile process is at a place where not having specific information will hinder the process, or if the process can be successfully completed without additional data.

The major factor to be considered is time: “Is there sufficient time to gather additional data to include in the profile?” If the process can move forward without collecting additional data, the Community Profile Team may want to consider making note of the additional data that may be collected at a later date to enhance the profile or explore issues more deeply. If more data is needed but collecting more data is not realistic or feasible, the Team may have to supplement the gaps as best they can with relevant data that was collected via the Quantitative Data Reports, the Health Systems Analysis and/or qualitative data process. Deficiencies in the data should be listed as a limitation in the final report.

Some recommendations to facilitate the process:

Include Experts: Talk to quantitative or qualitative resources/experts. Such resources/experts will be able to triangulate the findings presented in the Quantitative Data Report, the Health Systems and Public Policy Analysis, and the qualitative data. For example, a sudden increase in breast cancer diagnoses in your community does not necessarily mean that there was an actual increase in breast cancer. The increase in diagnoses may be the result of increased mammography rates.

Understand when Data Sources Measure Different Things at Different Times: Using several different sources of information can be helpful. However, it is important to pay attention to what the different sources measure and the year in which the data was collected.

For Example: A 2009 survey in one target area indicates that health care providers believe Latina women get screened regularly. However, a review of the statistics gathered in 2010 shows that Latina women between the ages of 50-74 receive mammography screening at a significantly lower rate than non-Hispanic White and African American women.

One data source (survey) relayed provider perceptions in 2009. The other showed actual screening and death rates gathered in 2010 by the Center for Disease Control and Prevention. Both sources provide important, yet conflicting information.

Understanding discrepancies will help the Affiliate to develop better intervention strategies and education efforts. In this example, the Community Profile Team may decide that changing the knowledge, attitudes and beliefs of health care providers about breast cancer screening among Latina women is a priority since the provider perceptions did not match the statistics. The Team can then survey the providers after the intervention to see if their perceptions have changed along with changes in mammography screening among Latina women.

Small Numbers and/or Infrequent Events Affect Conclusions: Small numbers or infrequent events may result in misrepresenting the breast health and/or breast cancer problems in a target community.

For Example: Consider that one year a county has one breast cancer death and the next year the county has two breast cancer deaths. Statistically this means there has been a 100 percent increase in breast cancer deaths. It seems dramatic, but the actual increase was by one case. Remember, when considering events that happen infrequently, any change in the number of events leads to abrupt fluctuations in trends

Try to always look at data covering several years and identify trends. This strategy works as long as there has not been a major change in the way the event was measured (e.g. changes in the law, data collection methods, the definition of the problem or the cultural context). When working with small numbers it is best to look at

the raw numbers rather than percentages or rates. For the purpose of the 2015 Community Profile, trend data has been provided as part of the Quantitative Data Report to provide additional support in the interpretation of the information.

How can Trends Affect Conclusions: Trends over time can help the Community Profile Team see patterns in the behavior or event they are observing.

When considering trends in data, the following should be noted:

- What time period is being considered? (e.g. years, days)
- Is there an increase or decrease over time?
- What is the overall extent of change over time?

The Community Profile Team should keep in mind that trends can be influenced by:

- Small numbers or events
- Changes in data collection methods
- Changes in how issues are defined
- Changes in the environment (e.g. political, cultural, physical)

Developing the Affiliate's Mission Action Plan:

The Mission Action Plan consists of three components: Problem/Need Statement(s), Priorities, and Objectives. A Mission Action Plan template has been provided by Komen Headquarters and is available in the Module 5 and Module 6 Toolkit on myKomen. The template organizes the Mission Action Plan into three components:

1. **Problem/Needs Statement(s):** This component refers to the problem(s) or need (s) within a target community(ies) that the Community Profile Team has decided to address. The problem statement should be directly tied to the summary of the data.

Example: African Americans and Latinas in the two southernmost counties (Jefferson and Taylor) have higher than average rates of late-stage diagnosis.

2. **Priorities:** This component refers to the goals the Affiliate hopes to achieve in addressing the problem or need. Priorities must be measurable, though it may be many years before a change is observed.

Example: By FY 2019, reduce the occurrence of late stage diagnosis among African American and Latina women in Jefferson and Taylor counties.

An important and necessary phase that follows data summarization is identifying and establishing priorities that will inform the Affiliate's Mission Action Plan. The priorities selected will inform the Affiliate's Mission operational and strategic planning that guides the focus for all Mission-related work.

Before starting this phase of the process, the Team should invite individuals holding key Affiliate positions to attend the discussions leading to the development of priorities. Affiliate Executive Director, staff and volunteers working in grants, education, public policy, marketing and other key areas should be involved. These key individuals will know best what is realistic for the Affiliate to accomplish in each area. Having these individuals as part of the conversation is important and will help ensure there is ownership and commitment to the action plan being developed.

Once everyone is at the table, the Team must decide, based on the resources available, how many total priorities (for all target communities) to choose. Headquarters strongly recommends that Affiliates limit their priorities to no more than five. **NOTE:** Too many priorities can lead to a lack of focus or an unrealistic Mission Action Plan.

There are many methods that the Affiliate can use to establish priorities. Two of the most commonly used methods are voting and ranking which are described below.

Voting

One method commonly used for prioritization requires the Team to review the data, discuss the findings and then generate a list of potential priorities. A facilitator for this process will lead the discussion and record the list of brainstormed priorities on a flipchart. Depending on how long the list is, the facilitator will then distribute about one-third the number of “votes” (e.g. adhesive dots) and give each Team member the chance to vote on the priorities. Voting continues until the list is narrowed down to the number of desired priorities.

Ranking

One of the easiest ways for the Community Profile Team to prioritize their list is to rank those need/problem statements that can be addressed by the Affiliate within the established timeframe and with available resources.

To rank the issues, each Team member will identify what they consider to be the top issues based on the number already decided. In analyzing the group results, each issue has the potential of receiving a score based on the rank given (e.g. 5 points for #1 rank, 4 points for #2 rank, etc.), and then organized from high to low score. The top scores are the higher priorities. All issues on the list should be ranked, but not all will be scored. If the focus is to be on 5 issues, only those ranked from 1 to 5 will be scored and all others are given a 0 score.

Example of Ranking Technique:

Through the use of the ranking method, the Community Profile Team concluded that the following were the top two priorities for the Affiliate;

- Priority 1: No breast cancer partners in rural County P with high late stage diagnosis rate.
- Priority 2: A lack of mammography services in County Z

	Team Member #1		Team Member #2		Team Member #3		Total Points	Final Rank
	Rank	Points	Rank	Points	Rank	Points		
Lack of mammography services in County Z	5	1	2	4	1	5	10	2
High mortality rate among African Americans County Y	4	2	1	5	5	1	8	3
No breast cancer partners in rural County P with high late stage diagnosis rate	1	5	3	3	2	4	12	1
Low screening awareness among immigrants in County V	6	0	5	1	3	3	4	6
Latina belief that mammography causes cancer in County X	3	3	4	2	6	0	5	5
Low screening rates among elderly women in County Q	2	4	6	0	4	2	6	4

3. **Objectives:** The objectives are action statements that refer to what the Affiliate will do specifically to meet the priority over the next four years. There can be a number of objectives covering different areas of focus for that priority.

All objectives must be SMART and include the following elements:

- **S** = Specific
- **M** = Measurable
- **A** = Attainable
- **R** = Realistic
- **T** = Time bound

Example: In FY 16 develop new, collaborative relationships with at least three community-based organizations that serve Latina women in Taylor County.

Module 5 Toolkit

An online Mission Action Plan Toolkit is available on myKomen in the Community Profile-Resources section to assist in completing the steps outlined in Module 5. The toolkit contains examples priorities, objectives, an action plan and additional resources that may be helpful in developing the Mission Action Plan. Please understand that the examples provided will need to be adapted to the Community Profile Team's specific needs.

Reporting to Komen Headquarters

The Community Profile Team will be required to submit to Komen Headquarters a report about the Mission Action Plan. The report will consist of two narrative sections: Breast Health and Breast Cancer Story of the Target Communities and Affiliate Mission Action Plan. A report template, scoring criteria and additional information is provided in the Module 6: Putting the Community Profile Report Together Toolkit on myKomen.

Board of Directors Approval

The Mission Action Plan Report must be presented to the Board of Directors for approval. Approval of the Mission Action Plan Report should be noted in the Board minutes and identified on the Affiliate Approval Form in the Documents Due in myKomen. Board approval must be obtained prior to submission to Komen Headquarters.

Conclusion

Module 5 brings the Community Profile process to an end. The Community Profile Team should have:

- Summarized the findings from the target community
- Identified the Affiliate's Mission priorities based on data gathered during the quantitative data, Health Systems Analysis and Public Policy and qualitative data processes
- Developed the Affiliate's Mission Action Plan (problem/need statement, priorities and objectives)
- Presented the Affiliate's Mission Action Plan to the Board of Directors for approval

MODULE 6: PUTTING THE COMMUNITY PROFILE REPORT TOGETHER

Module 6 provides the Community Profile Team with document templates and/or guidelines to complete each section of the Community Profile Report (i.e. Executive Summary, Introduction, Quantitative Data Report, Health Systems Analysis and Public Policy, Qualitative Data and Mission Action Plan). All Community Profile report templates will be pre-formatted to include instructions on formatting and content requirements.

Learning Tasks:

- Understand the components of the Community Profile Report
- Know how to access the templates required for the Community Profile Report
- Know how to complete and submit the required templates/documents for each section of the Community Profile Report
- Know how to effectively use the Affiliate's Community Profile Report

Introduction

The Community Profile Report should be seen as a professional resource to the community-at-large, as well as partners in the community looking to understand the breast health and breast cancer needs in the target communities. When people think of where to look for local breast health and breast cancer information, they should turn to the Komen Affiliate Community Profile Report. The final report should be a document that can be proudly shared in the community to further Komen's Promise.

NOTE: Komen Headquarters has developed pre-formatted templates for each section of the 2015 Community Profile Report that must be used. The Community Profile Team will be required to complete each template and submit each section of the report for review and approval by Komen Headquarters prior to completing the next phase in the process. Utilization of the templates will ensure that an Affiliate's Community Profile Report adheres to Komen's general branding guidelines and formatting for consistent quality across the network. Affiliates are encouraged to follow the American Psychological Association (APA) writing style. The Community Profile Report required templates and APA guidelines can be found on myKomen under the Module 6 Toolkit.

Community Profile Report Outline (*Templates and scoring criteria for each section are available in the Module 6 Toolkit on myKomen*):

Cover Page and Disclaimer Statement: The cover page and disclaimer will be a standard template that Komen Headquarters will include on the final approved Community Profile Report. The cover page will include the Affiliate's name/logo and year of the report.

Acknowledgments Page: This section is intended to acknowledge anyone who played a key role in the Community Profile process. Please make sure that anyone who is listed provided permission to include their name and/or the organization's name on this page.

Acknowledgments Page Components:

- Contact information for the Affiliate that prepared the report
- Listing of Community Profile Team members and the organization they are representing.
- Listing of entities that provided assistance with data collection and analysis as well as providing information for the report. This could include sources of qualitative data (e.g. Smith County Breast Cancer Support Group, Health Care Providers from Henry County), or other individuals or organizations that assisted in the process but were not part of the formal Community Profile Team (e.g. facilitator for focus groups, grocery store that donated incentives).

Table of Contents: This will be a pre-formatted template developed by Komen Headquarters and included in the final report.

Executive Summary: The Executive Summary previews the main points of the overall report. It is written for all audiences and should contain enough information for the reader to become familiar with what is discussed in the full report without having to read it. This section is usually written last and can be put together using a condensed version of the material used for the main report. The Executive Summary should be able to be used as a stand-alone document.

Executive Summary Section Components:

- Introduction to the Community Profile Report
- Quantitative Data: Measuring Breast Cancer Impact in Local Communities
- Health Systems and Public Policy Analysis
- Qualitative Data: Ensuring Community Input
- Mission Action Plan

Introduction: This section provides an overview of the Affiliate's history, organizational structure and service area. In addition, this section should include the name of the state and specific places in the Affiliate's service area (e.g. highlighting important or commonly known counties, towns, etc). The Community Profile Team should thoroughly discuss geography of the area, population characteristics and cultural issues if they exist. Finally, this section should also include the purpose of the Community Profile Report, how it will be used by the Affiliate and how it will be shared with the community.

Introduction Section Components:

- Affiliate History
- Affiliate Organizational Structure (Can include chart)
- Affiliate Service Area (Can include map)
- Purpose of the Community Profile Report

The Purpose of the Community Profile Report is to:

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

Quantitative Data Report: Measuring Breast Cancer Impact in Local Communities:

Part of this section will be provided by Komen Headquarters and will include a description of the breast cancer, demographic and socioeconomic statistics in the Affiliate's service area. This section includes a narrative, tables, maps and figures that will identify high priority target communities based on risk assessment. Affiliates will choose target communities from among those identified as high priority areas.

The Affiliate will be responsible for submitting a "Selection of Target Communities" narrative that provides justification of why and how the target communities were chosen based on the Quantitative Data Report.

Note: If the Affiliate Community Profile Team chooses to conduct a deeper dive into specific quantitative data variables, a summary of the process and results should also be included in the section "Additional Quantitative Data Exploration".

Quantitative Data Report Section Components:

- Quantitative Data Report (provided by Komen Headquarters)
- Additional Quantitative Data Exploration (if applicable)
- Selection of Target Communities: Provides justification of why and how the target communities were chosen based on the Quantitative Data Report.

Health Systems and Public Policy Analysis: This section provides an in-depth analysis of the current continuum of care in the target communities, as well as federal/state public policies that affect breast health and breast cancer care.

Health Systems and Public Policy Analysis Section Components:

- **Health Systems Analysis Data Sources:** Provides a brief description of sources used to obtain a comprehensive understanding of programs and services data.
- **Health Systems Overview:** Includes a general overview of the assets and gaps within the target communities. It is important to address what programs do or do not exist along the entire continuum of care that may be contributing to high statistics or disparities issues. Discuss the strengths and limitations providers in target communities have, as well as the challenges related to service delivery and access. In addition, include a description of existing and potential partnerships or collaboration opportunities to address breast cancer in the target communities.
- **Public Policy Overview:** Provides an overview of the Affiliate's current and potential future role in public policy and advocacy efforts. Discusses the state's NBCCEDP program including the state policy, how women gain access to the program, the working relationship that exists between the screening program and Medicaid, and the Affiliate's current and future relationship with state NBCCEDP directors. Discuss the state's Comprehensive Cancer Control Plan's breast cancer objectives and the Affiliate's current and future relationship with the state's comprehensive cancer control coalition. Discuss the state's response to the Affordable Care Act (e.g. insurance exchange program, estimated number of underinsured) and its implications on the state NBCCEDP program, health care providers and the Affiliate.
- **Health Systems and Public Policy Analysis Findings:** This is a brief summary of the findings for this section that includes the needs in the target community(ies) related to health systems and CoC, key current and future partnerships in the target community(ies), state policy work and impact of ACA.

Qualitative Data: Ensuring Community Input: This section provides a description of the method(s) used to collect qualitative data and its findings. The Community Profile Team must ensure that the qualitative data collected is from the target community(ies), using other data only to corroborate or support the findings.

Qualitative Data Section Components:

- **Qualitative Data Sources and Methodology Overview:** Provides a brief narrative that describes the key assessment questions and variables, which data collection methods were used and rationale, how the data collection was conducted, and how the data will be used in supporting

the Quantitative Data Report and Health System and Public Policy Analysis (triangulation). This section should also discuss the sampling techniques used including description of the population of interest, who were the community data sources, and the rationale for selecting the sampling technique.

- **Qualitative Data Overview:** Discusses findings based on key informant interviews, focus groups, surveys, document reviews and observations. These findings should be linked directly to the key questions. In addition, it needs to describe the community's feedback on specific issues addressed during the data collection. No need to present everything found, but rather the themes/categories and/or descriptions that were most common. Use quotes, as needed, to reinforce discussion of the themes/categories and/or descriptions.
- **Qualitative Data Findings:** This is a brief summary of the qualitative data that includes the findings that are linked to the key questions, limitations of the data, and conclusion statements that are easily linked to the qualitative data.

Mission Action Plan and Reference Page: This section summarizes and ties together the findings of the entire Community Profile process. This part of the report discusses the findings from all target communities studied, the process used to determine priorities and the Affiliate Mission Action Plan.

Mission Action Plan Section Components:

- **Breast Health and Breast Cancer Findings of the Target Communities:** In this section the Affiliate will summarize the findings from the target community(ies). This section should identify the key questions and the findings from each data section (e.g. Quantitative Data Report, Health System and Public Policy Analysis and Qualitative Data) related to the key questions. The Community Profile Team should ensure that there is a clear link between the findings of all three data sections.

For example, discuss how the Quantitative Data Report informed the Health Systems and Public Policy Analysis; which then led to targeted and in-depth community qualitative data collection.

- **Mission Action Plan:** This section should include the developed problem statement(s) from the Community Profile findings, the priorities that were selected and why they were chosen in relation to the problem/needs statement(s), and the objectives that will be implemented for each priority. The narrative should clearly and concisely describe the priorities and objectives for each problem statement using Specific, Measurable, Attainable, Realistic, Time-bound (SMART) objectives. This section should clearly layout the Affiliate's Mission Action Plan for the next four years.

Action items can include but are not limited to:

- Community Partnerships-This may discuss new opportunities for partnering that will directly or indirectly impact one or more priorities. This may include specific ways existing partnerships can be strengthened to address one or more priorities.
- Existing Grant Solutions-This may discuss how grantmaking can be tailored to address priorities based on the Community Profile. This may include changes to the Affiliate's grants program (e.g. the addition of grant writing workshops, tailored outreach efforts to encourage organizations in targeted communities to participate).
- Potential Grantmaking Opportunities-This may discuss needs not currently being met by grantees and ways the Affiliate can work in the target community to strengthen existing partnerships or seek potential grantees to address the unmet needs.
- Public Policy/Advocacy Efforts-This may discuss specific public policy/advocacy needs identified during the Community Profile process (e.g. specific action items necessary to prepare for the implementation of the Affordable Care Act).
- Education/Outreach-This may discuss how the Affiliate's efforts in this area can be updated or changed to align with the identified priorities in an impactful way.

Some Recommendations to Avoid Resubmission and Ease the Submission Process:

- Do NOT use Breast Self Exam (BSE) messaging
- Do NOT use the old name and logo
- Be sure to reference all data with appropriate citations
- Clearly identify the target communities
- Collect data from community members in targeted communities
- Do NOT skip sections of the process flowchart
- Do NOT use survivors as the only source of qualitative data
- Mission Action Plan should address targeted communities
- Use SMART objectives in Mission Action Plan
- Have more than one person proofread your documents
- Utilize the Board Liaison to ensure all documents are vetted at each phase in the process with the Board of Directors
- Obtain the Board of Directors approval before submission to Komen Headquarters
- Submit all checklists with appropriate signatures
- EDIT, EDIT, EDIT!!!

Sharing the Community Profile Report

The Affiliate should take advantage of this valuable tool and share it with relevant stakeholders and the community-at-large. Once the final approved Community Profile Report is received from Komen Headquarters, the Affiliate should post the final report on its website for public access.

As a reminder, the local Komen Affiliate owns all materials and data collected during the Community Profile process and the final report. Therefore, the local Komen Affiliate retains all publication and presenting rights. The local Affiliate may decide to collaborate with local partners (e.g. university or health care system) to publish and present information from the Community Profile Report; however, the partner **may not** publish or present the information on its own without Affiliate involvement. If data or information from the Community Profile Report is going to be published in a journal, the manuscript should be submitted to the Komen Headquarters via e-mail (communityprofile@komen.org) for review prior to final submission to the journal.

How to Effectively Use Your Community Profile Report

At the end of the process an Affiliate should come away with a document that is credible, reliable, professional and marketable to the communities that the Affiliate serves. The Community Profile Report is the Affiliate's main Mission communication tool and should be used to educate and inform the Affiliate's stakeholders (e.g. grantees, partners, donors, sponsors, legislators, other breast cancer-focused organizations and the community-at-large) regarding the state of breast cancer in the service area, the Affiliate's current Mission priorities, and the plan to address the identified breast health and breast cancer needs within the target communities.

The final Community Profile Report should be used to inform the Affiliate's:

- Inclusion Efforts (within the service area and more specifically the target communities and populations)
- Proposed Education/Outreach Activities
- Proposed Grantmaking
- Community Organizing/Engagement
- Advocacy/Public Policy Efforts
- Marketing/Communications Plans
- Sponsorship/Fundraising (Development) Activities
- Strategic and Operational Planning

The following are some points to consider when sharing and marketing the Community Profile:

1. *Who Is The Audience?* The Affiliate will need to tailor the information to the audience of interest and their understanding of the issue (e.g. the community-at-large may have a different level of understanding of the issue compared to health care providers).
2. *What Issues are Important?* Focus on the issue(s) of importance to the audience and make the points concise. Most audiences are interested in a few solid numbers and a couple of anecdotes to illustrate the findings and recommendations.
3. *What Should Be Emphasized?* Decide which findings most strongly justify or support the Affiliate priorities, action plan strategies and/or policy efforts. Frame these findings in a way that "speaks" to the audience.
4. *What formats can the Community Profile Report be used to share with diverse audiences?* Based on the target communities/populations/audiences the Affiliate would like to reach, the Affiliate should determine which formats, methods, or mediums will be most effective. (e.g. press release, e-mail blast, e-newsletter communication, website posting, hard copy distribution at public meetings, conferences or forums). An example press release is available in the Module 6 Toolkit on myKomen.

Module 6 Toolkit

An online Putting the Community Profile Report Together Toolkit is available on myKomen in the Community Profile- Resources section to assist in completing the steps outlined in Module 6. The toolkit contains checklists, templates, scoring criteria and additional resources that may be helpful in putting the final report together. Please understand that any examples provided will need to be adapted to the Community Profile Team's specific needs.

Reporting to Komen Headquarters

The Community Profile Team will be required to submit to Komen Headquarters a report for each section of the Community Profile via Documents Due on myKomen. Each section's

report will be due by a specified deadline as outlined in the Community Profile Timeline and below. By submitting the documents, the Affiliate is verifying that the Community Profile section has been approved for submission by either the Board President or Executive Director. Please note that Komen Headquarters may contact the Board President and/or Executive Director if questions or concerns arise and updates need to be made. When submitting via myKomen Documents Due, the name, title and position of the either the Board President or Executive Director will need to be completed.

Komen Headquarters advises Affiliates to not move too far along in completing the next section of the Community Profile process without receiving approval from Komen Headquarters on the previous submitted section. Some Affiliates may want to begin certain tasks of the Community Profile process before receiving approval in the interest of time. Some obvious tasks that might be started prior to receiving approval on a previous section include public policy data collection, and initial planning and preparation for qualitative data collection. However, an Affiliate **must** receive approval of submitted Community Profile section(s) prior to submission of subsequent sections. For example, an Affiliate’s Quantitative Data Report section must be approved by Komen Headquarters before the Affiliate can submit the Health System and Public Policy Analysis section.

Section	Approval By	Deadline
Quantitative Data Report	Board President or Executive Director	May 22, 2014
Health System and Public Policy Analysis	Board President or Executive Director	August 4, 2014
Qualitative Data	Board President or Executive Director	December 8, 2014
Introduction and Acknowledgements Page	Board President or Executive Director	January 14, 2015
Mission Action Plan	Board of Directors	March 16, 2015
Executive Summary	Board President or Executive Director	April 13, 2015
Final Review of Report	Board President or Executive Director	June 22, 2015

Contacting Komen Headquarters

If the Affiliate’s Community Profile Team has additional questions, Komen Headquarters can be reached through the following avenues:

- myKomen Community Profile Forum
- Submission of a Helpdesk Ticket via myKomen
- Contact the Affiliate’s Regional Director
- Email Komen Headquarters at communityprofile@komen.org