COMMUNITY PROFILE REPORT 2015

SUSAN G. KOMEN®
IOWA

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Acknowledgments

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Executive Summary

Introduction to the Community Profile Report

Within four years of the first Susan G. Komen Race for the Cure® event being held in Des Moines, Iowa, Susan G. Komen® Des Moines was established to support Komen's global promise to save lives and end breast cancer forever.

In 2011, the Des Moines Affiliate changed its name to Komen Iowa and in the summer of 2014, Komen Iowa in Des Moines joined forces with Komen Southeast Iowa in Ottumwa to increase the overall scope of Komen Iowa to its current configuration of 91 counties. This encompasses all county jurisdictions in the state of Iowa with the exception of those counties served through Komen Siouxland in Sioux City and Komen Quad Cities based in Bettendorf. This area also contains eight of the state's top ten most populated cities and approximately 82 percent of the state's total population.

For over 15 years, Komen Iowa was run exclusively by volunteers, but beginning in 2010, four full-time professional staff have been added to work as specific partners with key Board leadership volunteers from a 15 person Board of Directors. Much of the work of the Board is accomplished through the delegation of responsibilities to six standing committees. Each of these committees may in turn develop sub-committees, task forces or ad-hoc work groups to carry out specialized assignments throughout the year.

In the last three years, Komen Iowa has emerged as a leader within the Iowa Cancer Consortium (ICC) formed in 2012 to provide structure to coalition building among agencies working to achieve the goals of the Iowa State Cancer Control Plan. Komen Iowa's role in particular has been to articulate the case for breast cancer screening, diagnosis, treatment and follow-up care, a case accomplished primarily through the presentation of findings from the Community Profile. Audiences have included health care workers, agency executives, public officials and medical students.

Funds provided through Komen Iowa's Community Grants Program average over $680,000 per year to an average of seven grantee partners. Through these grants, a total of almost 24,000 educational materials, 13,400 screening services, and 4,500 diagnostic services have been provided. Perhaps most critically, these services have detected almost 150 breast cancers.

In addition to large Community Grants, Komen Iowa also provides smaller grant awards for hospitals, clinics and agency staff to receive training in breast cancer education, awareness or technical support. An average of over $7,500 per year has been awarded to applicants in the last three years. Small grants are available in amounts up to $10,000 for a single grant, while Community Grants are awarded in amounts from $10,0000- $150,000 per grantee each year.

Both of these grant processes involve a competitive grant awards system through which applicants respond to a Request for Applications (RFA) that has been reviewed and approved by the Komen Iowa Board of Directors and designed to support one or more priorities as defined by the Community Profile. Community Grant applications are reviewed by an independent panel of experts drawn primarily from the fields of oncology, public health and philanthropy. Small

grant applications are reviewed through the Mission Initiatives Committee, a standing sub-committee of the Komen Iowa Board of Directors. Both of these committees recommend approval to the Board of Directors, which has the final authority in providing grant funding.

Purpose of the Community Profile Report

The Community Profile and the information obtained is used by Komen Iowa to align strategic and operational plans, shape granting priorities, drive public policy and community inclusion efforts, establish educational needs and direct fundraising efforts.

Findings from the Community Profile define where needs for breast cancer services are most critical. These needs help to prioritize services for the annual Request for Applications that initiates the grant process and helps the independent Grant Review Panel in evaluating the merits of each proposal when making recommendations for grant funding to the Komen Iowa Board of Directors.

The Community Profile also identifies needs that may be met through legislative action, which in turn informs advocacy priorities and information sharing systems with legislators at the state and federal levels.

The qualitative analysis conducted in the Community Profile process allows for the collection of knowledge and attitudes about breast cancer and breast cancer screening practices which may have a strong impact on such educational programs as Continuing Medical Education for health care providers.

Because the Community Profile helps to define the priorities for funding support from Komen Iowa, it has a huge impact on fiscal management practices. Recommendations from the Grant Review Panel are weighed by the Board of Directors with respect to overall financial strength to make informed decisions that maximize efficiency and effectiveness.

The Community Profile has become useful as well in the development of partnerships between Komen Iowa and other cancer serving organizations. Observations from the Community Profile that replicate data found by other organizations help define trends in breast cancer knowledge and awareness. Updates of these findings, for example, are used to monitor progress in improving the rates of mammography screening services and knowledge about breast health and breast cancer management.

The Community Profile process is the heart of continuous improvement for Komen Iowa. Ongoing learning about the needs around the service area and the issues concerning breast cancer incidence, late-stage diagnoses and deaths provide the best method for assuring that the Affiliate is continuously providing timely and relevant services through the grantee network.

Quantitative Data: Measuring Breast Cancer Impact in Local Communities

For several years, Susan G. Komen Iowa has used comparative data on breast cancer incidence, death, late-stage diagnosis and mammography rates along with demographic and socioeconomic indicators to identify trends and priorities to achieve certain quantifiable goals in reducing the burden of breast cancer throughout the 91 county service area. Over the next

several years, Komen Iowa will focus on influencing the achievement of the following Healthy People 2020 (HP 2020) objectives for breast cancer death rates and late-stage diagnosis rates:

1. Reduce the breast cancer death rate to 20.6 breast-cancer related deaths per 100,000 females;
2. Decrease the number of breast cancers diagnosed at a late-stage to 41.0 per 100,000.

To reach these goals and to track progress to date, credible sources and the most current data available have been used for a comparative data and trend analysis on the size and direction of incidence, death and late-stage diagnosis rates at the national, state, and county levels. This analysis defined the breast cancer burden in each county within Komen Iowa's service area and allowed the Affiliate to make projections as to the likelihood for each county to achieve the HP 2020 objectives described above. In making these projections, the Affiliate found that the longer time period projected for each county to achieve either or both of the HP 2020 objectives defined the level of priority for intervention from Komen Iowa. The analysis indicated that twenty seven counties in Komen Iowa's service area are not likely to meet the death and/or late-stage incidence rate targets defined by HP 2020.

Since this list of twenty seven counties represents almost 30 percent of the entire number of counties in a geographically dispersed service area, a regional grouping method was developed to help create a manageable set of targeted efforts. A commonly used practice in public safety and other state wide planning efforts is to use transportation routes as boundary lines to define geographically unique parts of the state and to divide Iowa into quadrants based on the two main Federal Highway Administration interstate highway routes (Interstate 35 running north to south and Interstate 80 running east to west).

Developing these four subsets allowed for a view of the geographic proximity of each priority county. This view demonstrated that 14 of the 18 counties defined as "highest priority" were located in the Northwest or Southwest Iowa regions (seven counties in each region). The remaining four counties listed as highest priority were evenly grouped in the Northeast and Southeast regions (two counties in each region). As a result, rankings were assigned to each of the four regional groupings to further refine the Affiliate's focus and better inform additional data gathering efforts. Northwest and Southwest Iowa became the priority regions for further study and Northeast and Southeast regions were used as reference points to affirm or invalidate any inferences that were drawn.

Particular information was needed about where women from each region might go to receive services throughout the breast cancer continuum of care, especially screening services obtained through the National Breast and Cervical Cancer Early Detection Program (NBCCEDP) and what impact the Iowa Health and Wellness Plan (Iowa's version of Medicaid expansion) may have on access to services. Additional understanding about what drives women to seek mammography, the use of patient navigators, presence of mammography reminder systems and/or mobile service units was desired as well.

Health System and Public Policy Analysis

Determining the relative strengths and weaknesses of the Continuum of Care in these regions required a more in-depth understanding of the Continuum itself, as well as identification of the hospitals, clinics and agencies that are available to provide services along the Continuum in each region.

The Breast Cancer Continuum of Care (CoC) shows how someone typically moves through the health care system for breast care. Ideally, the Continuum is entered through screening via a clinical breast exam or screening mammogram. If the screening test results are normal, follow-up care, including another screening exam at the recommended interval takes place. If a screening exam produces abnormal results, diagnostic tests would be needed to determine if the finding is, in fact, breast cancer. If the tests were negative (or benign) and breast cancer was not found, routine screening and follow-up is resumed at the recommended intervals .If breast cancer is diagnosed, treatment becomes the next step in the Continuum of Care.

For some breast cancer patients, treatment may last a few months and for others, it may last years. While the CoC model shows that follow up and survivorship come after treatment ends, they may actually occur at the same time. If there are delays in moving from one point of the Continuum to another, such delays can contribute to poorer outcomes. In addition, there may be barriers to enter or continue in the CoC. These may include a lack of transportation, inconvenient clinic hours, language barriers, or misconceptions about breast cancer and screening procedures.

The health systems analysis undertaken to gain a comprehensive review of facilities that play a role in providing for the Breast Cancer Continuum of Care was developed from several key sources including the National Cancer Institute roster of designated Comprehensive Cancer Centers, a roster of cancer programs accredited by the American College of Surgeons Commission on Cancer, facilities accredited by the American College of Radiology, the United States Department of Health Resources and Services Administration (HRSA) roster of HRSA health centers, the Office of Population Affairs listing of facilities which receive funding under Title X of the Public Health Service Act and the United States Food and Drug Administration listings of Mammography Qualified Standards Act (MQSA) approved facilities. Other accreditations that were sought included facilities that were recognized by the National Accreditation Program for Breast Centers and radiology facilities designated as a Breast Imaging Center of Excellence.

Internet searches were conducted on all facilities listed to determine the quantity and nature of services and the websites for each facility were reviewed to determine both the particular emphasis placed on screening, diagnostic, treatment and follow-up care services as well as the specific detail of services provided within each element of the Continuum.

A spreadsheet program was used to record basic information for each facility and then these records were grouped into four categories, consistent with the four geographic target areas. A numerical record was kept so that the total number of facilities and percentage of services provided along the Continuum of Care could be determined. In this way, an analysis could be conducted in each target area of the prevalence of services available.

Ninety seven facilities were identified in the four target areas. Screening services were highly prevalent in all of these areas, but other dimensions of the continuum of care varied from region to region. This prevalence of screening services in all four target areas indicate that those who wish to obtain a regular, routine mammogram and/or clinical breast exam may not encounter excessive difficulty in locating facilities to provide these services. In addition, the provisions made through the Iowa Department of Public Health and the Iowa Health and Wellness Plan (Iowa's version of Medicaid expansion) provide financial support, reminder systems and navigation to help assure uninsured and underinsured residents receive screening services.

Aside from screening support however, substantial inconsistencies are noted in the availability of additional services along the continuum of care. Mobile mammography and other radiological procedures have made diagnostic services more readily available but options for treatment and support services are more limited for residents of several counties in Southeast Iowa. Moreover, since the more advanced treatment and support options tend to be more readily available in larger population areas of the state, rural residents may still have to travel some distance for treatment and support. This need is particularly pronounced in Northwest and Southeast Iowa, where there are no nationally accredited facilities exists to provide a more complete range of services along the continuum of care.

As mentioned above, Iowa public policy has been critical in extending affordable screening services through the Iowa Health and Wellness Plan and encouraging the work of the Iowa Cancer Consortium to execute the state's Cancer Control Plan. With more women having insurance coverage that provides screening at no cost, fewer women will be needing assistance to pay for screening services. A greater emphasis on outreach and education may be needed however to ensure that those who have newly-acquired insurance coverage will actually move forward to get breast cancer screening and other services. The Iowa Health and Wellness Plan for example, has helped to reduce the number of uninsured Iowans by almost 60,000, yet there are still an estimated 240,000 residents who remain uninsured. Moreover, those who wish to continue receiving services through federally funded programming such as the National Breast and Cervical Cancer Early Detection Program (NBCCEDP), may find that money is still needed to support specific screening or diagnostic-related services. As an example, NBCCEDP does not allow states to pay for computer-aided detection services. In addition, navigation services can be crucial for those that are newly insured or who may not understand how insurance works. Newly insured women may still need prompts to seek the screening that they are now eligible for and guidance on how to navigate the health care system if abnormal screening results are found. Preserving these basic levels of service for uninsured or underinsured women will be an important part of Komen Iowa's advocacy agenda for the future.

The results of the Heath Systems and Public Policy Analysis indicated that there may well be disparities in how breast health and breast cancer services are accessed by women in Iowa who have received an abnormal initial screening result. Correlating demographic data with incidence, late-stage diagnosis and death rates indicated that financial hardship, geographic location and health literacy may be contributing to these disparities in certain counties within each of the four regions. In order to obtain a more in-depth understanding of the barriers and disparities which women may be facing in these regions, Komen Iowa sought to gather information directly from people who may be dealing with these disparities.

Qualitative Data: Ensuring Community Input

The Qualitative Data analysis was commissioned to gather the information needed by Komen Iowa to better assess individual perceptions about breast cancer and the resources available to access the breast cancer Continuum of Care. Hanser & Associates, a Des Moines-based public relations and research firm that has conducted health care research nationwide carried out a series of 24 in-depth, one-on-one telephone interviews in the fall of 2014. These interviews were conducted among women aged 40-65 who said they had their annual screenings in the past 12 months and came primarily from three counties that were found to have a breast cancer incidence rate significantly higher than the Affiliate service area as a whole. Variations were noted in age, race/ethnicity, health insurance status, and tenure of residence. In addition, fifty percent of those interviewed had never been diagnosed with breast cancer, but did obtain a regular screening and the other fifty percent had been diagnosed with breast cancer, and completed treatment. Women who completed treatment were selected to provide a qualitative voice from survivors regarding what they wished they had known earlier. Researchers sought to sort out, with those who have been diagnosed and treated, the role of screening in their breast cancer diagnosis, treatment and survival and to gain their insight into the process of accessing the continuum of care with specific emphasis on what was or wasn't helpful for these women and what they might suggest to improve screening and survivorship.

Follow up telephone surveys were conducted with health care coordinators from eight counties that ranked higher than average in breast cancer incidence, late-stage diagnosis and/or death rates. The counties selected for follow up were also chosen based on the correlations seen between high breast cancer rates and certain demographic and socio-economic data. Relationships between these higher than average rates and such socio-economic conditions as low educational achievement, unemployment, and linguistic isolation required further investigation to "ground " the perceptions of the 24 women surveyed and allow for more definitive conclusions to be drawn about the underlying causes for higher than average rates in certain counties.

The key assessment questions and variables focused on the context of individual health outlook, understanding of expectations, guidelines, and best practices, the perceived importance of and motivations for breast health and wellness, barriers to access along the continuum of care, and advice for others. In order to compare and contrast the views expressed in these two surveys, the group of 24 women came to be referred to as "Health Care Service Recipients (Recipients)" while the health care coordinators were referred to as "Health Care Providers (Providers)".

Results of these surveys tended to demonstrate contrasting views between "Recipients" and "Providers".

In general, Recipients said they are very engaged in actively managing their health, while Providers felt that most clients in their area are not very engaged in health maintenance and tend to take a more "reactive" approach.

Recipients felt that, when considering their health as a whole, breast health was important to very important. Many of these Recipients also said they encourage friends and family to get annual screenings and describe themselves as "advocates" for screening due to its ability to

provide for early detection. Providers most often expressed the view that while many of their clients understood the importance of screening procedures and early detection, several other factors inhibit their ability to acquire breast health and breast cancer services. Most often, these factors had to do with financial access either because of the cost of the procedures, lack of insurance or job demands that did not allow for time off to seek health care services.

While Recipients said that they generally did not encounter any barriers to getting their annual screenings, they did suggest barriers for other women that were validated by the results of the Providers survey. Those barriers identified by Recipients included cost, time, personal approaches to health and wellness, other existing health conditions, lack of family history of breast cancer, and a lack of reminders or anxiety about the screening procedure. Providers identified these barriers as well but also included language issues and the unavailability of reliable transportation.

Most Recipients reported an excellent care experience from screening to diagnosis, treatment and follow-up. Providers said that accessing diagnostic, treatment and follow- up services became much more problematic for their clients than screening services, due primarily to financial access issues and a lack of information about insurance and how to use insurance in managing care costs. They also felt that appointment reminder systems, language specific materials, support group opportunities for peer to peer interaction and additional free clinics were the most cost effective methods for extending services.

Based on the work done by external researchers with Health Care Service Recipients and the follow up work with Health Care Service Providers, Komen Iowa was able to determine that disparities likely exist in accessing breast health and breast cancer services and are probably linked with particular demographic and socio-economic conditions that combine to create access issues in obtaining these services which ultimately result in higher than average rates of incidence, late-stage diagnosis and deaths in several counties within each of the four targeted regions.

Mission Action Plan

Problem Statements

Northwest Iowa Target Area Problem Statement

O'Brien County, in the Northwest Target Area, has higher than average rates of incidence, deaths and late-stage diagnosis and these figures correlate with higher than average rates of low educational achievement, poverty level income, and rural isolation, all of which may combine to create Geographic Access, Information Access and Financial Access Issues for county residents seeking breast health and breast cancer care. Ida County in the Northwest Target Area has percentages approaching twice the average number of the Affiliate in incidence and death rates and these findings are correlated with higher than average percentages of poverty income, low educational attainment and rural isolation. The demographics and socio-economics of the Northwest Target Area can be generally described as high in concentrations of rural poor, many of whom are also linguistically isolated with low educational achievement. These trends are particularly acute in the counties described above.

Southwest Iowa Target Area Problem Statement
Cass County in the Southwest Target Area has higher than average percentages of late-stage diagnosis and death rates and is likely dealing with Financial Access and Geographic Access issues since their percentages of poverty level income, rural residency and lack of health insurance all exceed the averages for the Affiliate service area. Madison and Warren counties in the Southwest Target Area both have a combination of higher than average rates of incidence, late-stage diagnosis and death rates and also exhibit higher than average percentages of rural residency which may indicate issues stemming from Geographic Access barriers. Polk and Dallas counties, also in the Southwest Target Area both have higher than average rates of incidence. Polk County also has a higher than average rate of deaths while Dallas County has a higher than average rate of late-stage diagnosis. Both counties have higher than average indicators that correlate with Information access issues and Polk County also has a higher rate of unemployment which may indicate Financial Access issues.

Southeast Iowa Target Area Problem Statement
Keokuk County in the Southeast Target Area has higher than average rates of late-stage diagnosis which may be correlated with both Geographic Access and Financial Access issues stemming from the higher than average percent of the population living in a rural, medically underserved area at or below 250 percent of poverty level income with no health insurance.

Northeast Iowa Target Area Problem Statement
Bremer County in the Northeast Target Area has higher than average rates of incidence, late-stage diagnosis and death rates which may be correlated with Geographic Access arising from the high percentage of residents who live in a rural setting.

Priorities and Objectives:
To provide for a manageable set of initiatives in addressing the barriers in accessing care, Komen Iowa determined that late-stage diagnosis was the most commonly occurring problem in several counties in each of the four target regions and that these rates were brought about by the web of barriers created from financial, geographic and information access issues that women in these counties encounter. Financial Access issues were the most commonly seen set of data that correlates with areas of higher than average rates of late-stage diagnosis. These issues are driven primarily by the number of county residents who are unemployed and may live at or below federally defined levels of poverty income, and are without health insurance.

The first priority for Komen Iowa therefore is to decrease the barriers created by Financial Access issues in those counties that demonstrate higher than average percentages of late-stage diagnosis and also demonstrate higher than average percentages of unemployment, poverty level income and lack of health insurance. The next priority is to decrease the barriers created by Geographic Access issues in those counties that demonstrate higher than average percentages of late- stage diagnosis and also demonstrate higher than average percentages of residents who live in medically underserved and/or rural areas. The third priority is to decrease the barriers created by Information Access issues in those counties that demonstrate higher than average percentages of late-stage diagnosis and also demonstrate higher than average percentages of linguistic isolation and /or low educational achievement.

To address these priorities, Komen Iowa determined the following objectives for each of these priorities:

Priority #1 - Decrease the barriers created by Financial Access issues to the breast cancer continuum of care in those counties that demonstrate higher than average percentages of late - stage diagnosis and also demonstrate higher than average percentages of unemployment, poverty level income and lack of health insurance.

> *Objective:* Beginning with the FY2017 Community Grant Request for Application, funding priorities will include programs that provide financial assistance to individuals seeking breast cancer service from the following counties: Buena Vista, Calhoun, Ida, Wright, Adair, Cass, Decatur and Keokuk.
>
> *Objective:* From FY16- FY19, on an annual basis the Affiliate will meet with at least two Iowa policymakers regarding state and federal breast cancer issues and legislation that would increase access to services by decreasing financial barriers.

Priority #2 - Decrease the barriers created by Geographic Access issues to the breast cancer continuum of care in those counties that demonstrate higher than average percentages of late-stage diagnosis and also demonstrate higher than average percentages of residents who live in medically underserved and/or rural areas.

> *Objective:* Beginning with the FY17 Community Grant Request for Application, funding priorities will include programs that maximize convenience to access the continuum of care (e.g., transportation, telemedicine, scheduling assistance, and flexible hours of service) for residents of Buena Vista, Calhoun, Ida, O'Brien, Wright, Adair, Cass, Decatur, Madison, Bremer and Keokuk Counties.

Priority #3 - Decrease the barriers created by Information Access issues related to the breast cancer continuum of care in those counties that demonstrate higher than average percentages of late-stage diagnosis and also demonstrate higher than average percentages of linguistic isolation and /or low educational achievement.

> *Objective:* Beginning with the FY17 Community Grant Request for Application, funding priorities will include programs that provide multi-cultural education, navigation, reminder services and plain-language resources for residents of Buena Vista, Ida, O'Brien and Decatur Counties.
>
> *Objective:* From FY16-FY19, annually provide at least two health care providers or community-based organizations in each county (Buena Vista, Ida, O'Brien and Decatur) with resource sheets of where residents can go for continuum of care services along with appropriate breast cancer information brochures/fact sheets.
>
> *Objective:* By April 2019, the Affiliate will conduct at least two breast cancer educational sessions in each of the following counties: Buena Vista, Ida, O'Brien and Decatur.

Disclaimer: Comprehensive data for the Executive Summary can be found in the 2015 Susan G. Komen® Iowa Community Profile Report.

Affiliate History

In the spring of 1991, the first Susan G. Komen Race for the Cure® event was held in the Des Moines area with approximately 600 people gathered to walk together in the fight against breast cancer. By 1995, the community was ready to support more than a Race event, and Susan G. Komen® Des Moines was established to support Komen's global promise to save lives and end breast cancer forever. In 2011, Komen Des Moines changed its name to Komen Iowa in order to better represent the 81-county service area.

On July 1, 2014, Komen Iowa in Des Moines joined forces with Komen Southeast Iowa in Ottumwa, thus increasing the overall scope of Komen Iowa to 91 counties. This encompasses all county jurisdictions in the state of Iowa with the exception of those counties served through Komen Siouxland in Sioux City and Komen Quad Cities based in Bettendorf.

For over 15 years, Komen Iowa was run exclusively by volunteers, but in April 2010, a full-time Executive Director was hired and charged with building on existing infrastructure to strengthen the Affiliate for the next phase of its development. This development focuses on human resources, revenue diversity, and solidifying community relationships critical to success. In recent years, a full-time Special Events Coordinator, Operations Manager and Mission Initiatives Manager have been added.

The Affiliate is also led by a Board of Directors committed to enhancing the public standing of the Affiliate by serving as ambassadors in the community.

In the last three years, Komen Iowa has emerged as a leader within the Iowa Cancer Consortium (ICC) in articulating the case for breast cancer screening, diagnosis, treatment and care. The ICC was formed in 2012 to provide structure to coalition building among agencies working to achieve the goals of the Iowa State Cancer Control Plan. Komen Iowa staff serve as co-chairs of the ICC Screening Implementation Group and serve on the Raise the Rates sub-committee to help promote screening practices in Iowa. Affiliate staff have presented findings from the most recent Community Profile to the Iowa Cancer Consortium's spring meeting in 2013, as well as the 2013 and 2014 Care for Yourself Coordinators meeting, the group of agencies that administer Iowa's Breast and Cervical Cancer Early Detection Program. Similar information has been presented via webinar training for the Iowa Rural Health Association and most recently, this past October 2014, Komen Iowa received accreditation to provide Continuing Medical Education units to faculty and staff at Des Moines University, Iowa's largest college of osteopathy.

Komen Iowa's grant program is broadly divided into two levels: the Community Grants Program and Small Grants Program. Community Grants are provided to hospitals, clinics and agencies that meet Komen Iowa's grant criteria and support priorities defined through the Community Profile. In the last three years, Komen Iowa has granted an average of over $680,000 per year to an average of seven grantee partners per year. Through these grants, a total of almost 24,000 educational materials, 13,400 screening services, and 4,500 diagnostic services have

been provided. Perhaps most critically, these services have detected almost 150 breast cancers.

The Small Grants program is designed to provide funding support for hospitals, clinics and agency staff to receive training in breast cancer education, awareness or technical support. An average of over $7,500 per year has been awarded to applicants in the last three years. Small grants are available in amounts up to $10,000 for a single grant, while Community Grants are awarded in amounts from $10,0000- $150,000 per grantee each year.

In both cases, grant applicants respond to a Request for Applications (RFA) which has been reviewed and approved by the Komen Iowa Board of Directors and designed to support one or more priorities as defined by the Community Profile. Community Grant applications are reviewed by an independent panel of experts drawn primarily from the fields of oncology, public health and philanthropy. Small grant applications are reviewed through the Mission Initiatives Committee, a standing sub-committee of the Komen Iowa Board of Directors. Both of these committees recommend approval to the Board of Directors, which has the final authority in providing grant funding.

Affiliate Organizational Structure

Komen Iowa currently employs four full time staff, all of whom are assigned specific partner relationships with key Board leadership volunteers. As an example, the Operations Manager, who is responsible largely for controlling operations, preparing financial reports and budget monitoring, is the key staff support person to the Finance Committee and staff support to the Secretary /Treasurer on the Board of Directors. The Mission Initiatives Manager works in a similar fashion with the Mission Initiatives Committee and its Committee Chair. The Special Events Coordinator is the primary support staff for Public Relations/Communications while the Executive Director is the primary staff support for the Governance and Executive Committees as well as to the Board as a whole. The Executive Director also serves as a secondary support staff for all other committees and sub-committees of the Board. The organizational charts below outline these reporting relationships (Figures 1.1 and 1.2).

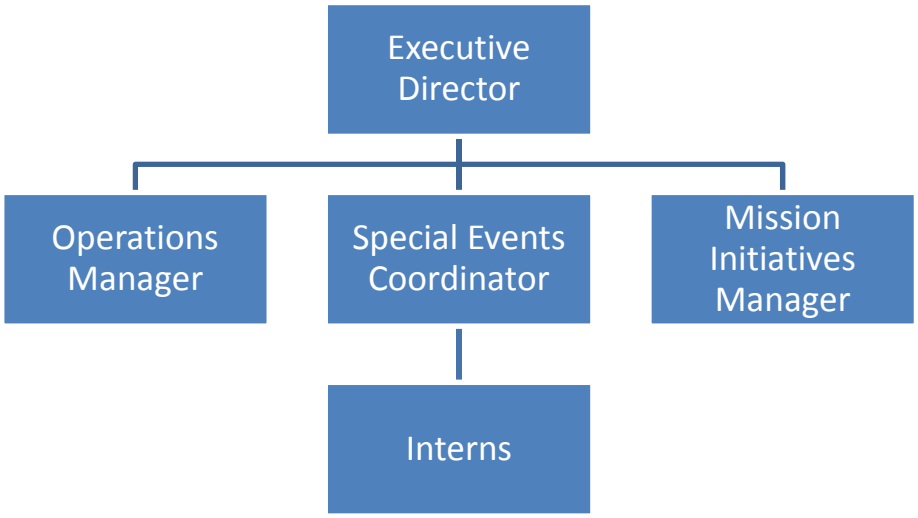

Figure 1.1. Komen Iowa staff

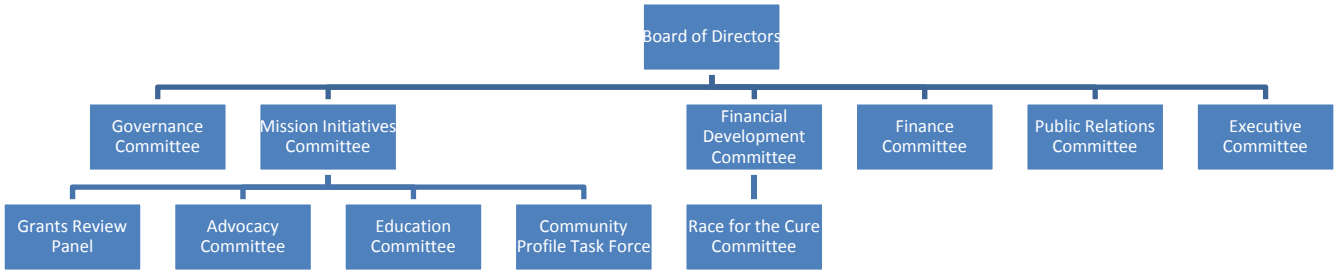

Figure 1.2. Komen Iowa Board Committees

The Board of Directors for Komen Iowa can best be described as a governing board and, as such, is the architect of the strategy management process for the Affiliate. Its overall strategic responsibilities are to define the strategy management framework based on input from the various standing committees of the board and the Executive Director (ED). This framework in turn defines and /or affirms the strategy statement of the Affiliate, its value propositions, goal statements, projects, initiatives, and indicators of success.

In defining the strategy management architecture, the Board assures that organizational elements are properly aligned with the strategy themes, domains of work, and value propositions. In turn, the Board delegates responsibilities to the Standing Committees (Executive, Governance, Finance, Financial Development, PR/Communications and Mission Initiatives) to work with the Executive Director in linking operational planning to the budget process as well as to human resources, information technology and other key support functions. The Board also makes broad policy decisions for the Affiliate and appoints, evaluates, and manages the performance of the Executive Director in matters related to compensation, benefits, and retention.

As mentioned above, the Board of Directors does much of its work through the delegation of responsibilities to six standing committees. Each of these committees may in turn develop sub-committees, task forces or ad-hoc work groups to carry out specialized assignments throughout the year. Descriptions of the responsibilities of the standing committees and certain key sub-committees are found below.

Executive Committee
The Executive Committee acts for the Board as a whole in between regular meetings of the full Board or in the event of an emergency or urgent matter. Any action taken by The Executive Committee is submitted to the full Board for ratification at its next meeting.

Governance Committee
The Governance Committee monitors and assesses current organizational performance strengths and weaknesses with particular attention to standing committee performance as well as Board leadership recruitment, training and succession. Among the strengths and weaknesses the Governance Committee may consider are revenue growth and productivity improvement opportunities that can close any gaps between current performance and

overarching projects and initiatives. They may accept input from the Financial Development Committee in particular to ensure the recruitment of Board members who are able and willing to secure financial resources for the Affiliate. The Committee may in turn establish a pool of board candidates by identifying and cultivating interest and availability among prospects and then nominate individuals to prepare a slate of candidates for election to the board

The Governance Committee also leads the assessment of current and anticipated needs for board composition with emphasis on the knowledge, attributes, skills, abilities, influence and access as well as demographic balances to achieve broad-based community representation. It does this in part by conducting a regular review and update of the board's role and areas of responsibility as well as the expectations of individuals based on the Affiliate's strategic plan.

The Committee regularly reviews and updates the board's policy manuals, guidelines and practices, including those regarding member participation, conflict of interest, confidentiality, etc., and suggests improvements as needed. They may conduct exit interviews for retiring or resigning board members and take the lead in succession planning to assess current and anticipated needs for board composition. If necessary, the Committee may propose changes in board structure, roles and responsibilities and assure a corresponding update for all appropriate committee job descriptions and charters. They may conduct a periodic assessment of board performance and effectiveness based on current best practices for nonprofit boards, or review recommended actions on board member conflict of interest and ethics issues. They help to design, oversee and implement a process of board orientation for new board members as well as an ongoing program of information and education for all board members.

Finance Committee

The Finance Committee, in partnership with Financial Development, Governance and the Executive Committee, assures that the Affiliate has the capacities needed and the learning required to deliver on key value propositions as defined by the Affiliate's overall strategy. Specifically, it monitors and assesses current and past financial performance strengths and weaknesses, works with the Financial Development Committee to consider revenue growth and productivity improvement opportunities, monitors any threats to sustaining or improving financial performance, and oversees opportunities for internal process improvement in achieving capacity building and learning objectives.

The Finance Committee is the key in providing oversight to linking financial planning and monitoring to strategic goals, projects and initiatives. It advises and reports to the Board on all matters relating to the finances of the Affiliate and presents the annual budget to the Board of Directors. In turn, the Committee monitors income and expenditures against budget, presents financial statements to the Board of Directors at all regularly scheduled meetings, reviews any contracts that have significant financial or funding implications, recommends them to the Board for approval, and assures that the Affiliate maintains adequate liability, bonding and other types of insurance as necessary. They may also review the adequacy of internal financial control policies and procedures; performance and staffing of the accounting and financial functions; and the accuracy and completeness of all financial statements and records

Financial Development Committee
The Financial Development Committee works to assure the ongoing expansion and diversification of Komen Iowa's revenue stream. This includes the development of long-range revenue strategies for Komen Iowa and partnering with staff to define and implement funding models which are relevant for both corporate and individual donors.

PR/Communications Committee
The PR/Communications Committee acts on behalf of the Board of Directors as the guardian of the public image of Komen Iowa. In this capacity, the PR/Communications Committee is responsible for designing, implementing and monitoring key communications strategies and an ongoing communications effort to maintain a high level of visibility for Komen activities. This may lead to involvement in the development, implementation and monitoring of website and social media content, updating of an Affiliate Crisis Communications Plan, defining communications positioning on key Affiliate messages, supporting the development and publication of an annual stewardship report, defining appropriate methodologies to assess client and beneficiary satisfaction and assuring knowledge gained from satisfaction monitoring is transferred and used for operational improvement.

Mission Initiatives Committee
The Mission Initiatives Committee advises the Board regarding current issues in education, community health, research and advocacy in a manner that drives the achievement of all mission related goals and objectives. The specific tasks of the Mission Initiatives Committee include but are not limited to the following:

- Assist with identification, recruitment and orientation of the Community Profile Task Force and ensure timely completion of the Community Profile project;
- Authorize the work of the Grant Review Panel to review applications for funding and make recommendations to the Board of Directors for disbursement in a manner consistent with the priorities and objectives identified in the Community Profile;
- Provide coordination among Grants, Education and Advocacy projects and initiatives;
- Identify opportunities to improve services provided through the Continuum of Care that will inform the grantmaking process;
- Assemble scientific, diversity, and survivorship advisory groups or task forces for the board and Affiliate as appropriate.

The Mission Initiatives Committee also provides the context for the work of two critical sub-committees; Education and Advocacy:

- The Education Sub-Committee assures delivery of specific educational activities and provides information about needs and issues within the field of public education concerning breast cancer. It works to build the capacity to assure accurate and timely information is disseminated, receives regular updates concerning education opportunities, monitors the ongoing cultivation of relationships with partners and grantees, and oversees the ongoing work of information and referral services for Komen Iowa
- The Advocacy Committee works with the support of Komen Iowa staff to provide liaison with elected officials concerning legislation that is important to Komen Iowa and Komen HQ. This work is done in part through the creation of an annual legislative agenda to help prioritize advocacy activities as well as the ongoing monitoring of legislative activity in cooperation with Komen Iowa partners and Komen HQ.

Affiliate Service Area

Komen Iowa's service area covers 91 of the 99 counties in Iowa (Figure 1.3). Only those counties served through Komen Siouxland in Sioux City and Komen Quad Cities in Bettendorf are not part of Komen Iowa's service area. This area also contains eight of the state's top ten most populated cities and approximately 82 percent of the state's total population. Approximately two-thirds of that population base live in what are defined as "urban" areas.

The demographics of Komen Iowa's service area are very homogenous. The largest racial minority group are Black/African-Americans followed by Asian/Pacific Islanders. Only five percent of the service area is of Hispanic/Latina ethnicity. Almost half of the service area's female population are aged 40 or older. Slightly more than four percent of Komen Iowa's population base are foreign born and almost two percent are defined as "linguistically isolated" in which no household member aged 14 years and older speaks English "very well." Unemployment ranges from 6.2 percent in Cherokee County to 2.4 percent in Shelby County. The percentage of those aged 40-64 who have no health insurance approaches 12 percent in some areas, and the percent of 40-65 year olds living below 250 percent of the defined poverty level is as high as 38 percent, particularly in southeast Iowa. In addition, almost 39 percent of the population of southeast Iowa lives in a "Medically Underserved Area", defined by the US Department of Health and Human Services as having too few primary care providers, high infant deaths, high poverty and/or a high elderly population. Between 12-15 percent of Komen Iowa's service area population report income below 100 percent of the defined poverty level and between 9-12 percent of the population have less than a high school education.

Transportation hubs in Iowa begin with Des Moines, where Interstate Highways 80 and 35 intersect. In addition, Interstate Highway 29 connects western Iowa to the Dakotas and Kansas City while Interstate Highway 380 defines what is known as the "Corridor" connecting Waterloo, Cedar Rapids and Iowa City in eastern Iowa. Families from rural areas seeking more advanced medical care would likely access these interstate systems to specialized facilities located in Des Moines, Cedar Rapids, Waterloo, Iowa City, Council Bluffs, Ames and Mason City.

KOMEN IOWA SERVICE AREA

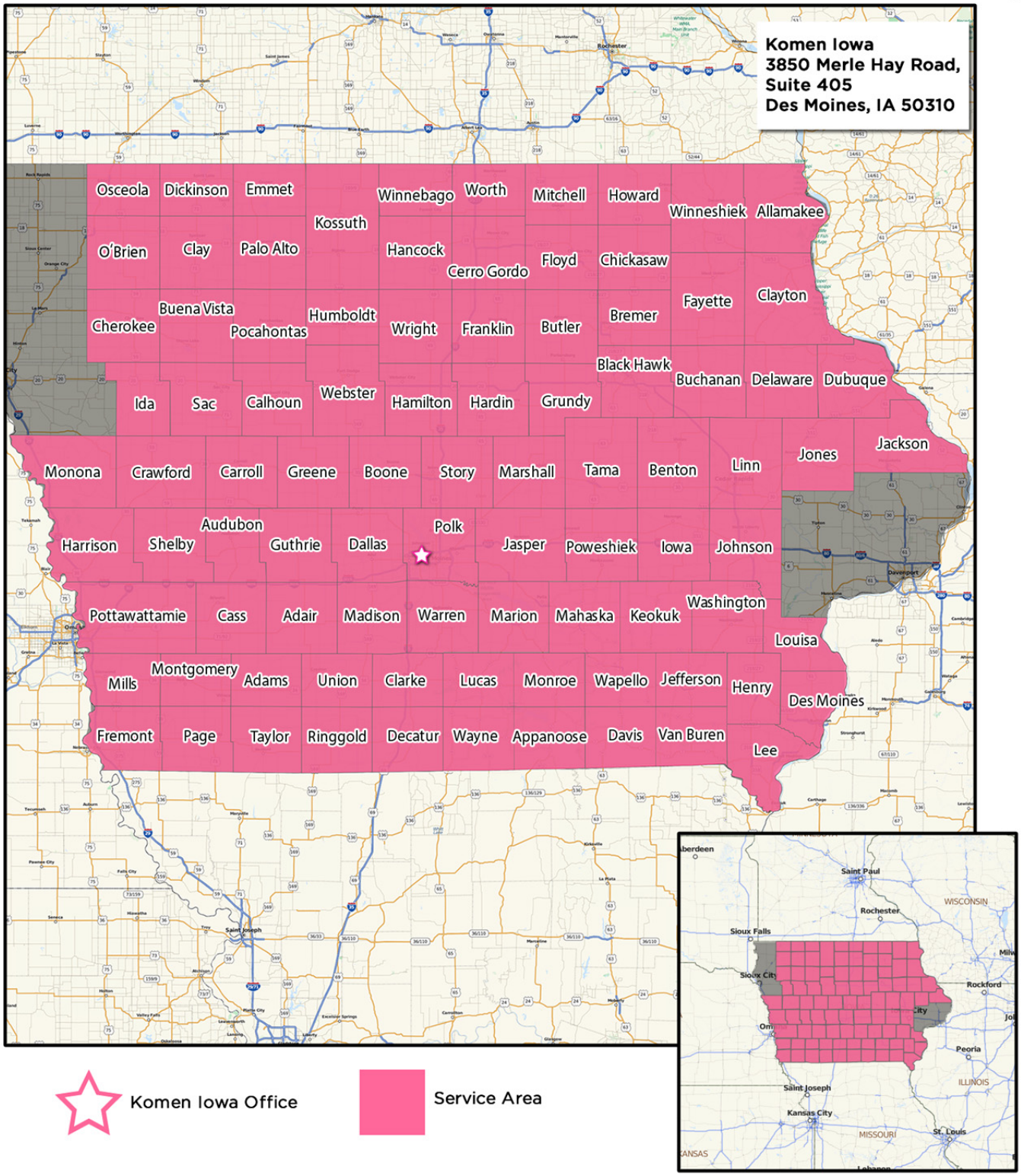

Figure 1.3. Susan G. Komen Iowa service area

Purpose of the Community Profile Report

To fulfill Komen's promise of saving lives and ending breast cancer forever, Komen Iowa relies on the Community Profile and the information obtained to guide the Affiliate's work. This information aligns the Affiliate's strategic and operational plans, shapes granting priorities, drives public policy and community inclusion efforts, establishes focused educational needs as well as directions for marketing and outreach and serves to strengthen sponsorship efforts.

Overall management of Komen Iowa operations is defined into three domains: Mission Initiatives, Fiscal Management and Continuous Learning. In all three of these areas, the Community Profile is integral in developing the goals, objectives, measurements and benchmarks used to achieve the Affiliate's mission.

Findings from the Community Profile define where needs for breast cancer services are most critical. These needs help the Affiliate to prioritize the services it is most interested in funding through the annual Request for Applications to award Affiliate grant funds. Evaluating the merits of each proposal as they relate to meeting needs defined in the Community Profile becomes the work of the independent Grant Review Panel, who in turn makes the recommendations for grant funding to the Komen Iowa Board of Directors.

The Community Profile may also identify needs that are best met through legislative action. This in turn informs Advocacy priorities and quite often, relevant findings from the Community Profile are shared with legislators at the state and federal levels to help support measures that will ease the burden of breast cancer in Iowa.

Through the qualitative analysis conducted in the Community Profile process, certain knowledge and attitudes about breast cancer and breast cancer screening practices may be uncovered which help the Affiliate to make adjustments in its educational programs. These programs may include Continuing Medical Education for health care providers, based on findings from the qualitative assessment section of the Community Profile.

As indicated above, the Community Profile is used primarily to help define the priorities for funding support from Komen Iowa. In this sense, the Community Profile also has a huge impact on the fiscal management of Komen Iowa. Recommendations from the Grant Review Panel are weighed by the Board of Directors with the Affiliate's overall financial strength to help make informed decisions which maximize the efficiency and effectiveness of the donations received.

As a continuous improvement process, the Community Profile is perhaps the heart of this particular strategic domain in the operations of Komen Iowa. Ongoing learning about the needs around the service area and the issues concerning breast cancer incidence, late-stage diagnoses and deaths provide the best method for assuring that the Affiliate is continuously providing timely and relevant services through its grantee network.

The Community Profile has become particularly useful in the development of partnerships between Komen Iowa and other cancer serving organizations. Perhaps the best example of this has been the involvement Komen Iowa has with the Iowa Cancer Consortium, a group of public and private sector agencies that work in partnership to achieve the goals of the Iowa Cancer Control Plan through calendar 2017. Komen representatives participate in screening

implementation groups with particular emphasis on breast cancer screening and share results and observations from the Community Profile with other organizations to investigate the likelihood of replicative data that may be helpful in defining trends in breast cancer knowledge and awareness. Updates of these findings are in turn used to monitor progress in improving the rates by which women in Iowa seek screening services and improve their knowledge about breast health and breast cancer management.

Quantitative Data: Measuring Breast Cancer Impact in Local Communities

Quantitative Data Report

Introduction

The purpose of the quantitative data report for Susan G. Komen® Iowa is to combine evidence from many credible sources and use the data to identify the highest priority areas for evidence-based breast cancer programs.

The data provided in the report are used to identify priorities within the Affiliate's service area based on estimates of how long it would take an area to achieve Healthy People 2020 objectives for breast cancer late-stage diagnosis and death rates (http://www.healthypeople.gov/2020/default.aspx).

The following is a summary of the Komen Iowa's Quantitative Data Report. For a full report please contact the Affiliate.

Breast Cancer Statistics

Incidence rates

The breast cancer incidence rate shows the frequency of new cases of breast cancer among women living in an area during a certain time period (Table 2.1). Incidence rates may be calculated for all women or for specific groups of women (e.g. for Asian/Pacific Islander women living in the area).

The female breast cancer incidence rate is calculated as the number of females in an area who were diagnosed with breast cancer divided by the total number of females living in that area. Incidence rates are usually expressed in terms of 100,000 people. For example, suppose there are 50,000 females living in an area and 60 of them are diagnosed with breast cancer during a certain time period. Sixty out of 50,000 is the same as 120 out of 100,000. So the female breast cancer incidence rate would be reported as 120 per 100,000 for that time period.

When comparing breast cancer rates for an area where many older people live to rates for an area where younger people live, it's hard to know whether the differences are due to age or whether other factors might also be involved. To account for age, breast cancer rates are usually adjusted to a common standard age distribution. Using age-adjusted rates makes it possible to spot differences in breast cancer rates caused by factors other than differences in age between groups of women.

To show trends (changes over time) in cancer incidence, data for the annual percent change in the incidence rate over a five-year period were included in the report. The annual percent change is the average year-to-year change of the incidence rate. It may be either a positive or negative number.

- A negative value means that the rates are getting lower.
- A positive value means that the rates are getting higher.

- A positive value (rates getting higher) may seem undesirable—and it generally is. However, it's important to remember that an increase in breast cancer incidence could also mean that more breast cancers are being found because more women are getting mammograms. So higher rates don't necessarily mean that there has been an increase in the occurrence of breast cancer.

Death rates

The breast cancer death rate shows the frequency of death from breast cancer among women living in a given area during a certain time period (Table 2.1). Like incidence rates, death rates may be calculated for all women or for specific groups of women (e.g. Black/African-American women).

The death rate is calculated as the number of women from a particular geographic area who died from breast cancer divided by the total number of women living in that area. Death rates are shown in terms of 100,000 women and adjusted for age.

Data are included for the annual percent change in the death rate over a five-year period.

The meanings of these data are the same as for incidence rates, with one exception. Changes in screening don't affect death rates in the way that they affect incidence rates. So a negative value, which means that death rates are getting lower, is always desirable. A positive value, which means that death rates are getting higher, is always undesirable.

Late-stage incidence rates

For this report, late-stage breast cancer is defined as regional or distant stage using the Surveillance, Epidemiology and End Results (SEER) Summary Stage definitions (http://seer.cancer.gov/tools/ssm/). State and national reporting usually uses the SEER Summary Stage. It provides a consistent set of definitions of stages for historical comparisons.

The late-stage breast cancer incidence rate is calculated as the number of women with regional or distant breast cancer in a particular geographic area divided by the number of women living in that area (Table 2.1). Late-stage incidence rates are shown in terms of 100,000 women and adjusted for age.

Table 2.1. Female breast cancer incidence rates and trends, death rates and trends, and late-stage rates and trends

		Incidence Rates and Trends			Death Rates and Trends			Late-stage Rates and Trends		
Population Group	Female Population (Annual Average)	# of New Cases (Annual Average)	Age-adjusted Rate/ 100,000	Trend (Annual Percent Change)	# of Deaths (Annual Average)	Age-adjusted Rate/ 100,000	Trend (Annual Percent Change)	# of New Cases (Annual Average)	Age-adjusted Rate/ 100,000	Trend (Annual Percent Change)
US	154,540,194	182,234	122.1	-0.2%	40,736	22.6	-1.9%	64,590	43.8	-1.2%
HP2020	.	-	-	-	-	20.6*	-	-	41.0*	-
Iowa	1,525,409	2,241	123.4	1.1%	431	21.3	-2.4%	755	42.7	1.0%

		Incidence Rates and Trends			Death Rates and Trends			Late-stage Rates and Trends		
Population Group	Female Population (Annual Average)	# of New Cases (Annual Average)	Age-adjusted Rate/ 100,000	Trend (Annual Percent Change)	# of Deaths (Annual Average)	Age-adjusted Rate/ 100,000	Trend (Annual Percent Change)	# of New Cases (Annual Average)	Age-adjusted Rate/ 100,000	Trend (Annual Percent Change)
Komen Iowa Service Area**	1,230,953	1,809	123.7	1.5%	344	21.1	NA	606	42.6	1.3%
White	1,165,318	1,770	124.4	1.8%	336	21.0	NA	591	42.8	1.3%
Black/African-American	37,330	22	103.9	-15.5%	6	30.2	NA	10	44.4	-1.5%
American Indian/Alaska Native (AIAN)	4,837	SN	SN	SN	SN	SN	SN	SN	SN	SN
Asian Pacific Islander (API)	23,467	9	57.1	16.2%	SN	SN	SN	SN	SN	SN
Non-Hispanic/ Latina	1,183,592	1,792	124.4	1.5%	342	21.2	NA	599	42.8	1.2%
Hispanic/ Latina	47,361	17	75.4	3.1%	SN	SN	SN	7	29.6	10.3%
Adair County - IA	3,928	7	120.6	7.4%	SN	SN	SN	4	66.9	16.3%
Adams County - IA	2,087	4	106.9	NA	SN	SN	SN	SN	SN	SN
Allamakee County - IA	7,046	13	135.8	-4.3%	SN	SN	SN	5	52.7	-9.2%
Appanoose County – IA	6,719	13	130.9	-10.3%	SN	SN	SN	5	51.8	-11.5%
Audubon County - IA	3,204	5	113.0	11.9%	SN	SN	SN	SN	SN	SN
Benton County - IA	13,091	19	124.3	12.5%	SN	SN	SN	6	39.6	-1.9%
Black Hawk County - IA	66,572	87	118.6	5.2%	16	19.9	-3.0%	33	47.2	21.5%
Boone County - IA	13,247	20	113.0	-6.4%	5	26.3	-0.3%	7	40.8	-8.0%
Bremer County - IA	12,385	21	135.2	2.1%	5	24.0	-1.6%	7	46.4	4.6%
Buchanan County - IA	10,568	14	109.9	13.6%	SN	SN	SN	4	36.3	-2.1%
Buena Vista County - IA	10,013	15	118.0	5.1%	SN	SN	SN	6	47.3	5.3%
Butler County - IA	7,575	12	112.3	-10.2%	SN	SN	SN	5	55.4	-11.0%
Calhoun County - IA	5,038	9	117.8	-1.8%	SN	SN	SN	4	48.8	-2.1%
Carroll County - IA	10,697	12	84.6	7.8%	4	20.4	-6.3%	6	41.5	15.9%
Cass County - IA	7,140	11	112.6	-7.4%	4	37.9	1.9%	4	45.8	-15.5%
Cerro Gordo County - IA	22,812	41	131.9	-8.8%	7	20.5	-4.8%	14	45.6	-8.7%
Cherokee County - IA	6,116	10	105.7	-11.5%	SN	SN	SN	3	38.9	11.4%
Chickasaw County - IA	6,203	10	108.5	-4.2%	SN	SN	SN	4	43.8	NA
Clarke County - IA	4,638	5	89.2	-2.8%	SN	SN	SN	SN	SN	SN
Clay County - IA	8,527	15	126.8	10.5%	SN	SN	SN	3	27.0	5.7%
Clayton County - IA	9,093	9	71.2	-2.7%	SN	SN	SN	SN	SN	SN
Crawford County - IA	8,392	13	122.9	-10.1%	SN	SN	SN	6	65.5	-17.6%
Dallas County - IA	31,483	38	125.8	0.7%	7	23.4	-1.1%	12	39.5	6.3%
Davis County – IA	4,385	5	95.4	14.1%	SN	SN	SN	SN	SN	SN
Decatur County - IA	4,268	8	139.8	3.5%	SN	SN	SN	4	65.5	3.6%
Delaware County - IA	8,975	13	113.3	-9.5%	3	32.2	0.3%	4	36.7	-6.3%
Des Moines County - IA	20,728	34	119.7	3.8%	6	19.0	-0.2%	13	44.0	8.3%
Dickinson County - IA	8,462	17	124.6	4.9%	SN	SN	SN	5	34.5	2.9%

		Incidence Rates and Trends			Death Rates and Trends			Late-stage Rates and Trends		
Population Group	Female Population (Annual Average)	# of New Cases (Annual Average)	Age-adjusted Rate/ 100,000	Trend (Annual Percent Change)	# of Deaths (Annual Average)	Age-adjusted Rate/ 100,000	Trend (Annual Percent Change)	# of New Cases (Annual Average)	Age-adjusted Rate/ 100,000	Trend (Annual Percent Change)
Dubuque County - IA	47,095	68	122.4	2.6%	15	22.6	-3.3%	22	41.2	-3.4%
Emmet County - IA	5,222	7	118.1	16.5%	SN	SN	SN	SN	SN	SN
Fayette County - IA	10,554	17	104.2	-8.8%	4	24.0	-0.2%	6	36.4	-12.6%
Floyd County - IA	8,364	14	124.2	9.2%	SN	SN	SN	3	34.5	NA
Franklin County - IA	5,348	8	111.3	-22.0%	SN	SN	SN	SN	SN	SN
Fremont County - IA	3,777	8	151.7	-13.9%	SN	SN	SN	3	62.8	-26.1%
Greene County - IA	4,786	9	118.1	17.2%	SN	SN	SN	SN	SN	SN
Grundy County - IA	6,272	10	120.1	0.0%	SN	SN	SN	5	64.0	-11.9%
Guthrie County - IA	5,579	10	117.5	2.3%	SN	SN	SN	4	46.2	52.6%
Hamilton County - IA	7,983	10	98.2	-2.7%	SN	SN	SN	SN	SN	SN
Hancock County - IA	5,771	8	91.9	-11.4%	SN	SN	SN	SN	SN	SN
Hardin County - IA	8,910	16	124.4	5.0%	4	23.6	-2.1%	5	42.1	-16.6%
Harrison County - IA	7,685	12	114.1	-13.3%	SN	SN	SN	5	52.2	-29.4%
Henry County - IA	9,873	15	122.0	27.2%	SN	SN	SN	3	29.7	33.1%
Howard County - IA	4,856	6	100.9	12.3%	SN	SN	SN	SN	SN	SN
Humboldt County - IA	5,040	8	106.1	-5.7%	SN	SN	SN	SN	SN	SN
Ida County - IA	3,609	10	206.7	4.1%	SN	SN	SN	3	81.9	2.0%
Iowa County - IA	8,286	15	136.1	-9.2%	3	29.0	NA	5	47.3	-27.3%
Jackson County - IA	10,065	15	116.2	31.5%	SN	SN	SN	5	39.2	18.8%
Jasper County - IA	18,193	32	131.6	9.0%	5	18.5	-3.0%	10	42.2	8.7%
Jefferson County – IA	7,875	14	137.9	-16.6%	SN	SN	SN	6	53.7	-7.7%
Johnson County - IA	63,661	75	139.3	5.7%	9	17.0	-3.6%	22	41.4	17.0%
Jones County - IA	9,915	15	112.5	15.8%	SN	SN	SN	4	32.4	10.4%
Keokuk County – IA	5,352	9	116.0	80.1%	SN	SN	SN	3	46.1	84.0%
Kossuth County - IA	7,957	14	118.4	5.4%	4	25.8	-2.3%	7	59.2	7.9%
Lee County - IA	17,883	27	108.1	12.2%	4	16.6	-4.5%	9	35.3	10.0%
Linn County - IA	105,611	141	121.5	3.1%	26	21.5	-1.0%	45	38.7	1.2%
Louisa County - IA	5,724	8	123.4	-1.3%	SN	SN	SN	3	51.1	-7.4%
Lucas County – IA	4,613	6	84.6	4.0%	3	39.3	NA	SN	SN	SN
Madison County - IA	7,799	12	134.0	9.4%	4	36.2	1.5%	5	59.5	13.3%
Mahaska County – IA	11,124	13	100.9	-4.6%	SN	SN	SN	4	32.6	-1.8%
Marion County - IA	16,812	24	118.3	0.6%	7	27.1	0.5%	8	40.3	-2.0%
Marshall County - IA	20,008	28	109.9	-7.7%	6	20.2	-3.3%	9	36.0	4.9%
Mills County - IA	7,518	11	125.6	-2.6%	SN	SN	SN	4	41.3	NA
Mitchell County - IA	5,490	9	111.3	-10.2%	SN	SN	SN	4	45.3	NA
Monona County - IA	4,770	7	101.9	-1.6%	SN	SN	SN	SN	SN	SN
Monroe County – IA	4,006	4	79.7	29.0%	SN	SN	SN	SN	SN	SN

		Incidence Rates and Trends			Death Rates and Trends			Late-stage Rates and Trends		
Population Group	Female Population (Annual Average)	# of New Cases (Annual Average)	Age-adjusted Rate/ 100,000	Trend (Annual Percent Change)	# of Deaths (Annual Average)	Age-adjusted Rate/ 100,000	Trend (Annual Percent Change)	# of New Cases (Annual Average)	Age-adjusted Rate/ 100,000	Trend (Annual Percent Change)
Montgomery County - IA	5,651	9	116.5	10.4%	SN	SN	SN	3	35.6	1.5%
O'Brien County - IA	7,282	17	144.9	-9.1%	4	29.8	-1.0%	7	59.3	-17.4%
Osceola County - IA	3,298	6	120.8	10.5%	SN	SN	SN	3	77.1	6.3%
Page County - IA	7,777	14	126.3	-5.9%	SN	SN	SN	4	39.4	20.4%
Palo Alto County - IA	4,802	8	116.8	-5.4%	SN	SN	SN	SN	SN	SN
Pocahontas County - IA	3,793	8	149.3	-6.3%	SN	SN	SN	SN	SN	SN
Polk County - IA	214,068	295	134.0	-0.5%	51	22.3	-2.4%	90	40.7	2.2%
Pottawattamie County - IA	46,829	83	149.4	-2.3%	12	21.4	-2.0%	31	58.0	-9.6%
Poweshiek County - IA	9,738	12	91.1	-1.0%	3	22.8	NA	4	28.1	-1.7%
Ringgold County - IA	2,660	4	101.5	-1.7%	SN	SN	SN	SN	SN	SN
Sac County - IA	5,345	11	129.6	1.2%	SN	SN	SN	SN	SN	SN
Shelby County - IA	6,287	12	139.6	-8.6%	SN	SN	SN	5	58.5	-19.3%
Story County - IA	42,266	49	132.3	-1.8%	8	19.7	-3.5%	17	46.0	-6.2%
Tama County - IA	9,112	13	104.0	13.5%	SN	SN	SN	5	45.8	-12.4%
Taylor County - IA	3,241	5	117.4	33.0%	SN	SN	SN	SN	SN	SN
Union County - IA	6,380	11	127.5	5.3%	SN	SN	SN	SN	SN	SN
Van Buren County – IA	3,807	5	93.2	-1.4%	SN	SN	SN	SN	SN	SN
Wapello County – IA	18,157	26	111.5	1.9%	5	18.3	-4.9%	11	44.5	5.4%
Warren County - IA	23,233	36	140.1	1.6%	7	26.8	0.3%	12	45.9	2.0%
Washington County - IA	11,042	16	112.5	16.8%	4	21.1	-2.1%	5	40.7	46.5%
Wayne County – IA	3,299	4	70.6	8.4%	SN	SN	SN	SN	SN	SN
Webster County - IA	18,722	26	103.0	8.9%	5	19.8	-3.8%	9	37.8	8.8%
Winnebago County - IA	5,545	6	79.6	-4.8%	SN	SN	SN	SN	SN	SN
Winneshiek County - IA	10,600	18	143.1	-5.4%	SN	SN	SN	4	38.2	-12.0%
Worth County - IA	3,820	6	117.7	5.3%	SN	SN	SN	SN	SN	SN
Wright County - IA	6,758	11	114.0	6.4%	SN	SN	SN	4	43.6	5.6%

*Target as of the writing of this report.

**Affiliate expanded their service area in July 2014. Therefore, Affiliate service area data does not include the following counties: Appanoose, Davis, Jefferson, Keokuk, Lucas, Mahaska, Monroe, Van Buren, Wapell o and Wayne

NA – data not available

SN – data suppressed due to small numbers (15 cases or fewer for the 5-year data period).

Data are for years 2006-2010.

Rates are in cases or deaths per 100,000.

Age-adjusted rates are adjusted to the 2000 US standard population.

Source of incidence and late-stage data: North American Association of Cancer Center Registries (NAACCR) – Cancer in North America (CINA) Deluxe Analytic File.

Source of death rate data: Centers for Disease Control and Prevention (CDC) – National Center for Health Statistics (NCHS) death data in SEER*Stat.

Source of death trend data: National Cancer Institute (NCI)/CDC State Cancer Profiles.

Incidence rates and trends summary

Overall, the breast cancer incidence rate in Komen Iowa's service area was slightly higher than that observed in the US as a whole and the incidence trend was higher than the US as a whole. The incidence rate and trend of the Affiliate service area were not significantly different than that observed for the State of Iowa.

For the United States, breast cancer incidence in Black/African-Americans is lower than in Whites overall. The most recent estimated breast cancer incidence rates for Asians and Pacific Islanders (APIs) and American Indians and Alaska Natives (AIANs) were lower than for Non-Hispanic Whites and Black/African-Americans. The most recent estimated incidence rates for Hispanics/Latinas were lower than for Non-Hispanic Whites and Black/African-Americans. For the Affiliate service area as a whole, the incidence rate was lower among Black/African-Americans than Whites and lower among APIs than Whites. There were not enough data available within the Affiliate service area to report on AIANs so comparisons cannot be made for this racial group. The incidence rate among Hispanics/Latinas was lower than among Non-Hispanics/Latinas.

The following counties had an incidence rate **significantly higher** than the Affiliate service area as a whole:

- Ida County
- Polk County
- Pottawattamie County

The incidence rate was significantly lower in the following counties:

- Carroll County
- Clayton County
- Poweshiek County
- Winnebago County

Significantly less favorable trends in breast cancer incidence rates were observed in the following counties:

- Jackson County
- Johnson County
- Keokuk County

Significantly more favorable trends in breast cancer incidence rates were observed in the following county:

- Franklin County

The rest of the counties had incidence rates and trends that were not significantly different than the Affiliate service area as a whole.

It's important to remember that an increase in breast cancer incidence could also mean that more breast cancers are being found because more women are getting mammograms.

Death rates and trends summary
Overall, the breast cancer death rate in Komen Iowa's service area was slightly lower than that observed in the US as a whole and the death rate trend was not available for comparison with the US as a whole. The death rate of the Affiliate service area was not significantly different than that observed for the State of Iowa.

For the United States, breast cancer death rates in Black/African-Americans are substantially higher than in Whites overall. The most recent estimated breast cancer death rates for APIs and AIANs were lower than for Non-Hispanic Whites and Black/African-Americans. The most recent estimated death rates for Hispanics/Latinas were lower than for Non-Hispanic Whites and Black/African-Americans. For the Affiliate service area as a whole, the death rate was higher among Blacks/African-Americans than Whites. There were not enough data available within the Affiliate service area to report on APIs and AIANs so comparisons cannot be made for these racial groups. Also, there were not enough data available within the Affiliate service area to report on Hispanics/Latinas so comparisons cannot be made for this group.

Significantly less favorable trends in breast cancer death rates were observed in the following county:

- Madison County

Significantly more favorable trends in breast cancer death rates were observed in the following county:

- Carroll County

The rest of the counties had death rates and trends that were not significantly different than the Affiliate service area as a whole or did not have enough data available.

Late-stage incidence rates and trends summary
Overall, the breast cancer late-stage incidence rate in Komen Iowa's service area was slightly lower than that observed in the US as a whole and the late-stage incidence trend was higher than the US as a whole. The late-stage incidence rate and trend of the Affiliate service area were not significantly different than that observed for the State of Iowa.

For the United States, late-stage incidence rates in Blacks/African-Americans are higher than among Whites. Hispanics/Latinas tend to be diagnosed with late-stage breast cancers more often than Whites. For the Affiliate service area as a whole, the late-stage incidence rate was slightly higher among Blacks/African-Americans than Whites. There were not enough data available within the Affiliate service area to report on APIs and AIANs so comparisons cannot be made for these racial groups. The late-stage incidence rate among Hispanics/Latinas was lower than among Non-Hispanics/Latinas.

The following county had a late-stage incidence rate **significantly higher** than the Affiliate service area as a whole:

- Pottawattamie County

Significantly less favorable trends in breast cancer late-stage incidence rates were observed in the following county:

- Washington County

Significantly more favorable trends in breast cancer late-stage incidence rates were observed in the following county:

- Pottawattamie County

The rest of the counties had late-stage incidence rates and trends that were not significantly different than the Affiliate service area as a whole or did not have enough data available.

Mammography Screening

Getting regular screening mammograms (and treatment if diagnosed) lowers the risk of dying from breast cancer. Screening mammography can find breast cancer early, when the chances of survival are highest. Table 2.2 shows some screening recommendations among major organizations for women at average risk.

Table 2.2. Breast cancer screening recommendations for women at average risk

American Cancer Society	National Cancer Institute	National Comprehensive Cancer Network	US Preventive Services Task Force
Mammography every year starting at age 40	Mammography every 1-2 years starting at age 40	Mammography every year starting at age 40	Informed decision-making with a health care provider ages 40-49 Mammography every 2 years ages 50-74

Because having regular mammograms lowers the chances of dying from breast cancer, it's important to know whether women are having mammograms when they should. This information can be used to identify groups of women who should be screened who need help in meeting the current recommendations for screening mammography. The Centers for Disease Control and Prevention's (CDC) Behavioral Risk Factors Surveillance System (BRFSS) collected the data on mammograms that are used in this report. The data come from interviews with women age 50 to 74 from across the United States. During the interviews, each woman was asked how long it has been since she has had a mammogram. BRFSS is the best and most widely used source available for information on mammography usage among women in the United States, although it does not collect data aligning with Komen breast self-awareness messaging (i.e. from women age 40 and older). The proportions in Table 2.3 are based on the number of women age 50 to 74 who reported in 2012 having had a mammogram in the last two years.

The data have been weighted to account for differences between the women who were interviewed and all the women in the area. For example, if 20.0 percent of the women interviewed are Hispanic/Latina, but only 10.0 percent of the total women in the area are Hispanic/Latina, weighting is used to account for this difference.

The report uses the mammography screening proportion to show whether the women in an area are getting screening mammograms when they should. Mammography screening proportion is calculated from two pieces of information:

- The number of women living in an area whom the BRFSS determines should have mammograms (i.e. women age 50 to 74).
- The number of these women who actually had a mammogram during the past two years.

The number of women who had a mammogram is divided by the number who should have had one. For example, if there are 500 women in an area who should have had mammograms and 250 of those women actually had a mammogram in the past two years, the mammography screening proportion is 50.0 percent.

Because the screening proportions come from samples of women in an area and are not exact, Table 2.3 includes confidence intervals. A confidence interval is a range of values that gives an idea of how uncertain a value may be. It's shown as two numbers—a lower value and a higher one. It is very unlikely that the true rate is less than the lower value or more than the higher value.

For example, if screening proportion was reported as 50.0 percent, with a confidence interval of 35.0 to 65.0 percent, the real rate might not be exactly 50.0 percent, but it's very unlikely that it's less than 35.0 or more than 65.0 percent.

In general, screening proportions at the county level have fairly wide confidence intervals. The confidence interval should always be considered before concluding that the screening proportion in one county is higher or lower than that in another county.

Table 2.3. Proportion of women ages 50-74 with screening mammography in the last two years, self-report

Population Group	# of Women Interviewed (Sample Size)	# w/ Self-Reported Mammogram	Proportion Screened (Weighted Average)	Confidence Interval of Proportion Screened
US	174,796	133,399	77.5%	77.2%-77.7%
Iowa	2,713	2,106	78.2%	76.2%-80.1%
Komen Iowa Service Area*	1,848	1,440	78.6%	76.1%-80.8%
White	1,799	1,401	78.4%	76.0%-80.7%
Black/African-American	18	15	86.3%	57.4%-96.7%
AIAN	SN	SN	SN	SN
API	SN	SN	SN	SN
Hispanic/ Latina	21	17	85.1%	54.1%-96.5%
Non-Hispanic/ Latina	1,825	1,421	78.5%	76.0%-80.7%
Adair County - IA	SN	SN	SN	SN
Adams County - IA	SN	SN	SN	SN
Allamakee County - IA	16	13	82.0%	54.0%-94.6%
Appanoose County - IA	SN	SN	SN	SN
Audubon County - IA	SN	SN	SN	SN

Population Group	# of Women Interviewed (Sample Size)	# w/ Self-Reported Mammogram	Proportion Screened (Weighted Average)	Confidence Interval of Proportion Screened
Benton County - IA	14	11	79.8%	44.1%-95.2%
Black Hawk County - IA	104	89	82.8%	72.1%-90.0%
Boone County - IA	27	20	78.5%	57.1%-90.9%
Bremer County - IA	26	24	94.4%	76.0%-98.9%
Buchanan County - IA	25	18	72.9%	46.8%-89.1%
Buena Vista County - IA	67	53	81.1%	67.5%-89.8%
Butler County - IA	13	8	69.6%	37.7%-89.7%
Calhoun County - IA	SN	SN	SN	SN
Carroll County - IA	36	27	80.2%	61.6%-91.1%
Cass County - IA	17	12	64.3%	36.2%-85.1%
Cerro Gordo County - IA	33	21	65.1%	44.3%-81.4%
Cherokee County - IA	SN	SN	SN	SN
Chickasaw County - IA	SN	SN	SN	SN
Clarke County - IA	SN	SN	SN	SN
Clay County - IA	22	14	67.0%	42.8%-84.6%
Clayton County - IA	18	15	87.5%	57.0%-97.4%
Crawford County - IA	51	35	69.7%	53.0%-82.4%
Dallas County - IA	51	36	72.4%	54.1%-85.3%
Davis County - IA	SN	SN	SN	SN
Decatur County - IA	SN	SN	SN	SN
Delaware County - IA	24	14	65.8%	39.4%-85.1%
Des Moines County - IA	44	38	83.5%	63.9%-93.5%
Dickinson County - IA	13	10	81.0%	49.0%-94.9%
Dubuque County - IA	92	82	90.0%	79.5%-95.4%
Emmet County - IA	SN	SN	SN	SN
Fayette County - IA	23	18	76.4%	52.1%-90.5%
Floyd County - IA	19	15	68.8%	41.8%-87.2%
Franklin County - IA	SN	SN	SN	SN
Fremont County - IA	SN	SN	SN	SN
Greene County - IA	SN	SN	SN	SN
Grundy County - IA	SN	SN	SN	SN
Guthrie County - IA	SN	SN	SN	SN
Hamilton County - IA	15	14	95.4%	67.4%-99.5%
Hancock County - IA	SN	SN	SN	SN
Hardin County - IA	21	15	65.6%	39.1%-85.0%
Harrison County - IA	11	7	63.8%	30.7%-87.5%
Henry County - IA	22	18	85.6%	57.9%-96.3%
Howard County - IA	SN	SN	SN	SN

Population Group	# of Women Interviewed (Sample Size)	# w/ Self-Reported Mammogram	Proportion Screened (Weighted Average)	Confidence Interval of Proportion Screened
Humboldt County - IA	SN	SN	SN	SN
Ida County - IA	SN	SN	SN	SN
Iowa County - IA	13	6	57.3%	28.4%-82.0%
Jackson County - IA	18	12	70.2%	42.8%-88.1%
Jasper County - IA	30	24	74.8%	52.8%-88.7%
Jefferson County - IA	22	11	51.4%	27.8%-74.5%
Johnson County - IA	71	56	79.8%	64.9%-89.4%
Jones County - IA	24	20	84.8%	61.1%-95.2%
Keokuk County - IA	SN	SN	SN	SN
Kossuth County - IA	10	9	89.3%	54.8%-98.3%
Lee County - IA	38	29	78.5%	57.8%-90.7%
Linn County - IA	167	136	84.2%	75.7%-90.1%
Louisa County - IA	SN	SN	SN	SN
Lucas County - IA	SN	SN	SN	SN
Madison County - IA	12	8	74.0%	42.9%-91.5%
Mahaska County - IA	14	12	85.2%	50.2%-97.1%
Marion County - IA	32	23	77.5%	56.7%-90.1%
Marshall County - IA	29	21	69.4%	47.1%-85.3%
Mills County - IA	SN	SN	SN	SN
Mitchell County - IA	SN	SN	SN	SN
Monona County - IA	SN	SN	SN	SN
Monroe County - IA	SN	SN	SN	SN
Montgomery County - IA	SN	SN	SN	SN
O'Brien County - IA	19	16	85.0%	58.2%-95.9%
Osceola County - IA	SN	SN	SN	SN
Page County - IA	17	10	60.9%	32.9%-83.2%
Palo Alto County - IA	SN	SN	SN	SN
Pocahontas County - IA	SN	SN	SN	SN
Polk County - IA	285	219	75.9%	69.1%-81.5%
Pottawattamie County - IA	56	47	83.9%	69.1%-92.4%
Poweshiek County - IA	24	19	85.1%	62.6%-95.1%
Ringgold County - IA	SN	SN	SN	SN
Sac County - IA	SN	SN	SN	SN
Shelby County - IA	SN	SN	SN	SN
Story County - IA	59	45	75.8%	58.1%-87.6%
Tama County - IA	18	15	74.2%	44.3%-91.2%
Taylor County - IA	SN	SN	SN	SN
Union County - IA	SN	SN	SN	SN

Population Group	# of Women Interviewed (Sample Size)	# w/ Self-Reported Mammogram	Proportion Screened (Weighted Average)	Confidence Interval of Proportion Screened
Van Buren County - IA	SN	SN	SN	SN
Wapello County - IA	30	26	85.5%	64.2%-95.1%
Warren County - IA	33	26	75.3%	53.0%-89.2%
Washington County - IA	23	20	86.0%	58.3%-96.4%
Wayne County - IA	SN	SN	SN	SN
Webster County - IA	40	31	80.9%	61.5%-91.8%
Winnebago County - IA	SN	SN	SN	SN
Winneshiek County - IA	19	15	75.4%	49.7%-90.5%
Worth County - IA	SN	SN	SN	SN
Wright County - IA	SN	SN	SN	SN

*Affiliate expanded their service area in July 2014. Therefore, Affiliate service area data does not include the following counties: Appanoose, Davis, Jefferson, Keokuk, Lucas, Mahaska, Monroe, Van Buren, Wapello and Wayne
SN – data suppressed due to small numbers (fewer than 10 samples).
Data are for 2012.
Source: CDC – Behavioral Risk Factor Surveillance System (BRFSS).

Breast cancer screening proportions summary

The breast cancer screening proportion in Komen Iowa's service area was not significantly different than that observed in the US as a whole. The screening proportion of the Affiliate service area was not significantly different than the State of Iowa.

For the United States, breast cancer screening proportions among Blacks/African-Americans are similar to those among Whites overall. APIs have somewhat lower screening proportions than Whites and Blacks/African-Americans. Although data are limited, screening proportions among AIANs are similar to those among Whites. Screening proportions among Hispanics/Latinas are similar to those among Non-Hispanic Whites and Blacks/African-Americans. For the Affiliate service area as a whole, the screening proportion was not significantly different among Blacks/African-Americans than Whites. There were not enough data available within the Affiliate service area to report on APIs and AIANs so comparisons cannot be made for these racial groups. The screening proportion among Hispanics/Latinas was not significantly different than among Non-Hispanics/Latinas.

None of the counties in the Affiliate service area had substantially different screening proportions than the Affiliate service area as a whole.

Population Characteristics

The report includes basic information about the women in each area (demographic measures) and about factors like education, income, and unemployment (socioeconomic measures) in the areas where they live (Tables 2.4 and 2.5). Demographic and socioeconomic data can be used to identify which groups of women are most in need of help and to figure out the best ways to help them.

It is important to note that the report uses the race and ethnicity categories used by the US Census Bureau, and that race and ethnicity are separate and independent categories. This

means that everyone is classified as both a member of one of the four race groups as well as either Hispanic/Latina or Non-Hispanic/Latina.

The demographic and socioeconomic data in this report are the most recent data available for US counties. All the data are shown as percentages. However, the percentages weren't all calculated in the same way.

- The race, ethnicity, and age data are based on the total female population in the area (e.g. the percent of females over the age of 40).
- The socioeconomic data are based on all the people in the area, not just women.
- Income, education and unemployment data don't include children. They're based on people age 15 and older for income and unemployment and age 25 and older for education.
- The data on the use of English, called "linguistic isolation", are based on the total number of households in the area. The Census Bureau defines a linguistically isolated household as one in which all the adults have difficulty with English.

Table 2.4. Population characteristics – demographics

Population Group	White	Black /African-American	AIAN	API	Non-Hispanic /Latina	Hispanic /Latina	Female Age 40 Plus	Female Age 50 Plus	Female Age 65 Plus
US	78.8 %	14.1 %	1.4 %	5.8 %	83.8 %	16.2 %	48.3 %	34.5 %	14.8 %
Iowa	94.1 %	3.4 %	0.5 %	2.0 %	95.2 %	4.8 %	49.6 %	36.8 %	16.9 %
Komen Iowa Service Area*	94.1 %	3.3 %	0.4 %	2.1 %	95.6 %	4.4 %	49.5 %	36.7 %	16.9 %
Adair County - IA	99.3 %	0.3 %	0.1 %	0.4 %	98.5 %	1.5 %	58.5 %	45.4 %	24.3 %
Adams County - IA	98.4 %	0.3 %	0.6 %	0.6 %	99.1 %	0.9 %	58.6 %	45.9 %	22.6 %
Allamakee County - IA	97.7 %	0.9 %	0.6 %	0.8 %	94.8 %	5.2 %	56.8 %	44.2 %	21.5 %
Appanoose County - IA	98.5 %	0.8 %	0.3 %	0.4 %	98.6 %	1.4 %	56.1 %	43.7 %	21.9 %
Audubon County - IA	98.9 %	0.4 %	0.2 %	0.4 %	99.1 %	0.9 %	60.6 %	47.6 %	26.3 %
Benton County - IA	98.8 %	0.6 %	0.3 %	0.4 %	98.8 %	1.2 %	52.8 %	37.4 %	17.4 %
Black Hawk County - IA	87.9 %	9.8 %	0.4 %	1.8 %	96.4 %	3.6 %	45.2 %	34.3 %	15.4 %
Boone County - IA	98.2 %	1.0 %	0.4 %	0.5 %	98.1 %	1.9 %	53.5 %	40.2 %	18.4 %
Bremer County - IA	97.9 %	1.0 %	0.1 %	1.0 %	98.8 %	1.2 %	51.2 %	38.9 %	19.7 %
Buchanan County - IA	98.7 %	0.6 %	0.2 %	0.5 %	98.8 %	1.2 %	50.8 %	37.6 %	17.5 %
Buena Vista County - IA	90.4 %	2.7 %	0.6 %	6.3 %	77.8 %	22.2 %	48.8 %	36.7 %	17.3 %
Butler County - IA	98.9 %	0.5 %	0.2 %	0.4 %	99.1 %	0.9 %	55.6 %	43.4 %	21.9 %
Calhoun County - IA	99.0 %	0.4 %	0.2 %	0.3 %	98.9 %	1.1 %	60.6 %	48.9 %	26.6 %
Carroll County - IA	98.4 %	0.8 %	0.2 %	0.7 %	98.4 %	1.6 %	54.5 %	41.7 %	21.5 %
Cass County - IA	98.5 %	0.4 %	0.3 %	0.8 %	98.3 %	1.7 %	57.6 %	45.5 %	23.8 %
Cerro Gordo County - IA	97.2 %	1.6 %	0.3 %	0.9 %	96.5 %	3.5 %	56.4 %	43.6 %	20.6 %
Cherokee County - IA	98.3 %	0.6 %	0.3 %	0.8 %	97.7 %	2.3 %	59.4 %	47.1 %	24.8 %
Chickasaw County - IA	98.7 %	0.6 %	0.1 %	0.5 %	97.9 %	2.1 %	55.8 %	43.8 %	21.7 %
Clarke County - IA	97.8 %	0.9 %	0.6 %	0.7 %	90.1 %	9.9 %	52.6 %	39.7 %	19.4 %
Clay County - IA	98.4 %	0.7 %	0.3 %	0.6 %	97.6 %	2.4 %	54.5 %	42.7 %	20.8 %
Clayton County - IA	98.7 %	0.7 %	0.1 %	0.4 %	98.2 %	1.8 %	57.5 %	44.9 %	21.7 %

Population Group	White	Black /African-American	AIAN	API	Non-Hispanic /Latina	Hispanic /Latina	Female Age 40 Plus	Female Age 50 Plus	Female Age 65 Plus
Crawford County - IA	96.5 %	1.5 %	0.8 %	1.2 %	76.4 %	23.6 %	49.9 %	37.8 %	18.8 %
Dallas County - IA	94.7 %	1.9 %	0.4 %	3.0 %	94.3 %	5.7 %	42.1 %	27.5 %	10.8 %
Davis County - IA	99.0 %	0.2 %	0.3 %	0.5 %	99.0 %	1.0 %	49.4 %	37.7 %	19.1 %
Decatur County - IA	96.9 %	1.4 %	0.6 %	1.1 %	97.8 %	2.2 %	50.6 %	39.7 %	20.9 %
Delaware County - IA	99.0 %	0.5 %	0.2 %	0.3 %	99.3 %	0.7 %	54.2 %	40.1 %	18.6 %
Des Moines County - IA	92.9 %	5.8 %	0.3 %	1.0 %	97.3 %	2.7 %	53.7 %	41.2 %	19.8 %
Dickinson County - IA	98.7 %	0.6 %	0.1 %	0.6 %	98.7 %	1.3 %	62.0 %	49.7 %	24.7 %
Dubuque County - IA	95.5 %	3.0 %	0.2 %	1.4 %	98.1 %	1.9 %	50.5 %	37.6 %	17.4 %
Emmet County - IA	96.5 %	1.2 %	1.6 %	0.8 %	92.2 %	7.8 %	53.5 %	42.7 %	21.9 %
Fayette County - IA	98.1 %	1.0 %	0.1 %	0.8 %	98.3 %	1.7 %	55.4 %	43.3 %	22.3 %
Floyd County - IA	96.8 %	1.5 %	0.3 %	1.5 %	97.7 %	2.3 %	55.6 %	43.2 %	22.2 %
Franklin County - IA	98.3 %	0.9 %	0.4 %	0.5 %	90.7 %	9.3 %	55.4 %	43.0 %	21.4 %
Fremont County - IA	98.5 %	0.9 %	0.4 %	0.2 %	97.3 %	2.7 %	57.9 %	45.5 %	21.5 %
Greene County - IA	98.3 %	0.7 %	0.3 %	0.7 %	98.1 %	1.9 %	58.7 %	46.3 %	23.8 %
Grundy County - IA	99.2 %	0.4 %	0.1 %	0.3 %	99.0 %	1.0 %	55.2 %	42.5 %	21.1 %
Guthrie County - IA	98.7 %	0.4 %	0.3 %	0.6 %	98.2 %	1.8 %	58.4 %	44.3 %	22.6 %
Hamilton County - IA	96.7 %	0.9 %	0.5 %	2.0 %	94.9 %	5.1 %	55.2 %	42.2 %	21.2 %
Hancock County - IA	98.4 %	0.8 %	0.2 %	0.6 %	96.7 %	3.3 %	56.9 %	44.7 %	21.9 %
Hardin County - IA	98.5 %	0.6 %	0.4 %	0.6 %	96.9 %	3.1 %	56.9 %	44.7 %	24.7 %
Harrison County - IA	98.9 %	0.4 %	0.3 %	0.4 %	98.7 %	1.3 %	55.3 %	41.7 %	19.9 %
Henry County - IA	95.0 %	1.9 %	0.2 %	2.9 %	96.4 %	3.6 %	52.6 %	39.3 %	18.8 %
Howard County - IA	98.8 %	0.5 %	0.2 %	0.5 %	98.7 %	1.3 %	53.9 %	41.4 %	22.0 %
Humboldt County - IA	98.8 %	0.7 %	0.1 %	0.4 %	96.5 %	3.5 %	56.0 %	44.2 %	23.0 %
Ida County - IA	99.0 %	0.6 %	0.1 %	0.3 %	98.3 %	1.7 %	56.6 %	44.5 %	23.1 %
Iowa County - IA	98.5 %	0.8 %	0.3 %	0.4 %	97.9 %	2.1 %	54.7 %	40.7 %	19.8 %
Jackson County - IA	98.3 %	0.7 %	0.2 %	0.8 %	98.8 %	1.2 %	57.0 %	43.0 %	21.0 %
Jasper County - IA	98.4 %	0.8 %	0.3 %	0.5 %	98.6 %	1.4 %	55.2 %	41.3 %	19.6 %
Jefferson County - IA	95.0 %	1.7 %	0.3 %	3.0 %	97.1 %	2.9 %	58.4 %	47.0 %	18.4 %
Johnson County - IA	88.3 %	5.4 %	0.4 %	5.9 %	95.2 %	4.8 %	37.1 %	26.2 %	9.8 %
Jones County - IA	98.6 %	0.7 %	0.2 %	0.5 %	98.9 %	1.1 %	55.1 %	41.7 %	20.2 %
Keokuk County - IA	98.8 %	0.6 %	0.2 %	0.4 %	99.1 %	0.9 %	56.2 %	43.6 %	22.2 %
Kossuth County - IA	98.6 %	0.6 %	0.3 %	0.5 %	98.6 %	1.4 %	59.4 %	47.4 %	24.5 %
Lee County - IA	96.2 %	2.9 %	0.2 %	0.7 %	97.2 %	2.8 %	55.5 %	42.5 %	19.9 %
Linn County - IA	92.7 %	4.7 %	0.4 %	2.2 %	97.4 %	2.6 %	47.4 %	34.0 %	14.8 %
Louisa County - IA	97.5 %	0.9 %	0.4 %	1.2 %	84.4 %	15.6 %	51.5 %	37.1 %	17.1 %
Lucas County - IA	99.1 %	0.4 %	0.3 %	0.3 %	99.1 %	0.9 %	57.1 %	44.8 %	22.8 %
Madison County - IA	98.6 %	0.7 %	0.3 %	0.5 %	98.7 %	1.3 %	51.8 %	37.1 %	16.4 %
Mahaska County - IA	97.5 %	1.0 %	0.3 %	1.3 %	98.3 %	1.7 %	51.0 %	38.6 %	18.4 %
Marion County - IA	97.5 %	0.9 %	0.3 %	1.3 %	98.4 %	1.6 %	49.8 %	37.2 %	17.7 %

Population Group	White	Black /African-American	AIAN	API	Non-Hispanic /Latina	Hispanic /Latina	Female Age 40 Plus	Female Age 50 Plus	Female Age 65 Plus
Marshall County - IA	95.5 %	1.9 %	0.8 %	1.8 %	82.7 %	17.3 %	50.7 %	38.7 %	17.9 %
Mills County - IA	98.5 %	0.5 %	0.4 %	0.6 %	97.5 %	2.5 %	53.1 %	38.9 %	14.8 %
Mitchell County - IA	98.9 %	0.5 %	0.1 %	0.5 %	98.8 %	1.2 %	56.8 %	44.2 %	24.8 %
Monona County - IA	97.6 %	0.6 %	1.4 %	0.4 %	98.5 %	1.5 %	59.7 %	48.3 %	26.9 %
Monroe County - IA	98.3 %	0.8 %	0.2 %	0.6 %	97.3 %	2.7 %	54.2 %	41.2 %	20.1 %
Montgomery County - IA	98.9 %	0.3 %	0.4 %	0.4 %	97.5 %	2.5 %	57.0 %	44.1 %	22.8 %
O'Brien County - IA	98.1 %	0.9 %	0.3 %	0.7 %	96.3 %	3.7 %	56.9 %	45.3 %	23.7 %
Osceola County - IA	98.5 %	0.5 %	0.4 %	0.5 %	94.4 %	5.6 %	57.7 %	44.7 %	23.2 %
Page County - IA	97.4 %	1.1 %	0.5 %	1.0 %	97.6 %	2.4 %	57.3 %	46.1 %	24.4 %
Palo Alto County - IA	98.4 %	0.9 %	0.3 %	0.5 %	98.2 %	1.8 %	56.6 %	45.9 %	25.2 %
Pocahontas County - IA	98.6 %	0.6 %	0.3 %	0.6 %	97.6 %	2.4 %	61.0 %	48.1 %	25.0 %
Polk County - IA	88.8 %	6.7 %	0.5 %	4.0 %	92.7 %	7.3 %	44.6 %	30.9 %	12.5 %
Pottawattamie County - IA	96.7 %	1.7 %	0.7 %	0.9 %	93.8 %	6.2 %	50.3 %	37.2 %	16.5 %
Poweshiek County - IA	95.9 %	1.7 %	0.4 %	2.0 %	97.7 %	2.3 %	52.8 %	41.1 %	20.7 %
Ringgold County - IA	98.8 %	0.5 %	0.4 %	0.4 %	98.4 %	1.6 %	58.0 %	46.6 %	26.5 %
Sac County - IA	98.6 %	0.8 %	0.2 %	0.4 %	98.0 %	2.0 %	59.6 %	48.0 %	25.4 %
Shelby County - IA	99.0 %	0.4 %	0.3 %	0.4 %	98.4 %	1.6 %	58.3 %	45.0 %	23.4 %
Story County - IA	90.8 %	2.9 %	0.3 %	6.0 %	97.0 %	3.0 %	37.1 %	27.5 %	11.9 %
Tama County - IA	90.1 %	1.0 %	8.3 %	0.5 %	93.0 %	7.0 %	53.8 %	40.4 %	20.4 %
Taylor County - IA	98.8 %	0.6 %	0.1 %	0.5 %	94.2 %	5.8 %	56.0 %	43.8 %	23.5 %
Union County - IA	97.7 %	1.3 %	0.4 %	0.7 %	98.0 %	2.0 %	52.5 %	40.9 %	20.2 %
Van Buren County - IA	98.7 %	0.4 %	0.2 %	0.8 %	98.7 %	1.3 %	56.2 %	43.2 %	21.3 %
Wapello County - IA	96.2 %	1.8 %	0.8 %	1.2 %	91.5 %	8.5 %	52.0 %	39.8 %	18.6 %
Warren County - IA	98.1 %	0.8 %	0.3 %	0.8 %	98.0 %	2.0 %	49.3 %	35.0 %	15.2 %
Washington County - IA	98.0 %	1.1 %	0.3 %	0.6 %	95.4 %	4.6 %	53.8 %	40.4 %	19.8 %
Wayne County - IA	98.8 %	0.7 %	0.1 %	0.4 %	99.0 %	1.0 %	56.0 %	44.3 %	25.2 %
Webster County - IA	95.5 %	3.4 %	0.3 %	0.8 %	96.3 %	3.7 %	53.8 %	41.6 %	19.4 %
Winnebago County - IA	97.7 %	1.0 %	0.3 %	1.0 %	96.8 %	3.2 %	56.2 %	44.5 %	22.6 %
Winneshiek County - IA	97.7 %	0.9 %	0.1 %	1.3 %	98.2 %	1.8 %	50.7 %	39.1 %	18.9 %
Worth County - IA	98.4 %	0.8 %	0.2 %	0.6 %	98.1 %	1.9 %	55.7 %	42.6 %	20.2 %
Wright County - IA	98.3 %	0.9 %	0.3 %	0.5 %	91.5 %	8.5 %	56.2 %	44.6 %	23.8 %

*Affiliate expanded their service area in July 2014. Therefore, Affiliate service area data does not include the following counties: Appanoose, Davis, Jefferson, Keokuk, Lucas, Mahaska, Monroe, Van Buren, Wapello and Wayne

Data are for 2011.

Data are in the percentage of women in the population.

Source: US Census Bureau – Population Estimates

Table 2.5. Population characteristics – socioeconomics

Population Group	Less than HS Education	Income Below 100% Poverty	Income Below 250% Poverty (Age: 40-64)	Un-employed	Foreign Born	Linguistic-ally Isolated	In Rural Areas	In Medically Under-served Areas	No Health Insurance (Age: 40-64)
US	14.6 %	14.3 %	33.3 %	8.7 %	12.8 %	4.7 %	19.3 %	23.3 %	16.6 %
Iowa	9.7 %	11.9 %	27.6 %	5.5 %	4.2 %	1.6 %	36.0 %	10.9 %	9.4 %
Komen Iowa Service Area*	9.3 %	11.6 %	26.8 %	5.4 %	4.2 %	1.6 %	36.3 %	9.5 %	9.1 %
Adair County - IA	9.1 %	11.5 %	31.7 %	4.4 %	0.6 %	0.1 %	100.0 %	13.4 %	10.6 %
Adams County - IA	10.1 %	10.7 %	37.6 %	3.6 %	0.4 %	0.0 %	100.0 %	15.9 %	12.3 %
Allamakee County - IA	12.4 %	11.1 %	34.7 %	6.9 %	5.6 %	2.1 %	74.0 %	34.2 %	14.6 %
Appanoose County - IA	13.5 %	15.8 %	42.8 %	10.3 %	1.0 %	0.5 %	58.3 %	100.0 %	11.6 %
Audubon County - IA	12.1 %	10.2 %	31.8 %	3.0 %	0.6 %	0.2 %	100.0 %	100.0 %	12.2 %
Benton County - IA	7.8 %	6.8 %	24.9 %	4.7 %	1.1 %	0.6 %	80.7 %	2.1 %	9.0 %
Black Hawk County - IA	10.8 %	17.1 %	29.7 %	7.1 %	4.6 %	1.7 %	13.5 %	7.5 %	9.1 %
Boone County - IA	7.8 %	10.0 %	25.0 %	4.2 %	0.5 %	0.0 %	50.6 %	6.0 %	8.1 %
Bremer County - IA	6.5 %	7.7 %	21.0 %	5.1 %	1.3 %	0.3 %	64.5 %	10.0 %	7.4 %
Buchanan County - IA	9.2 %	10.2 %	27.6 %	5.2 %	0.6 %	0.1 %	68.5 %	12.9 %	9.7 %
Buena Vista County - IA	21.3 %	11.3 %	33.6 %	3.6 %	16.7 %	9.6 %	43.9 %	0.0 %	14.0 %
Butler County - IA	11.1 %	11.1 %	26.0 %	4.7 %	0.9 %	0.2 %	100.0 %	35.9 %	9.6 %
Calhoun County - IA	8.5 %	11.9 %	29.0 %	3.9 %	0.4 %	0.6 %	100.0 %	0.0 %	10.0 %
Carroll County - IA	10.5 %	9.4 %	27.3 %	2.8 %	0.9 %	0.0 %	52.0 %	0.0 %	8.5 %
Cass County - IA	8.2 %	13.8 %	33.8 %	5.2 %	0.9 %	0.2 %	53.6 %	4.6 %	11.0 %
Cerro Gordo County - IA	8.3 %	13.5 %	28.8 %	6.1 %	2.2 %	0.8 %	20.6 %	0.0 %	8.5 %
Cherokee County - IA	7.9 %	5.3 %	29.1 %	3.3 %	1.0 %	0.4 %	61.4 %	0.0 %	10.1 %
Chickasaw County - IA	11.6 %	9.2 %	31.1 %	5.5 %	1.8 %	1.0 %	73.5 %	27.9 %	10.9 %
Clarke County - IA	13.2 %	12.0 %	35.2 %	5.2 %	5.6 %	2.7 %	48.1 %	31.1 %	12.6 %
Clay County - IA	7.6 %	11.7 %	28.7 %	5.3 %	2.0 %	1.0 %	34.3 %	0.0 %	10.4 %
Clayton County - IA	9.1 %	13.4 %	32.9 %	5.2 %	1.7 %	0.4 %	96.6 %	5.3 %	12.9 %
Crawford County - IA	21.6 %	12.1 %	31.7 %	4.4 %	13.4 %	7.9 %	51.8 %	2.7 %	13.3 %
Dallas County - IA	6.7 %	6.7 %	15.4 %	4.2 %	6.6 %	1.8 %	30.6 %	0.0 %	7.1 %
Davis County - IA	16.5 %	12.7 %	41.1 %	6.8 %	0.9 %	1.6 %	100.0 %	0.0 %	16.0 %
Decatur County - IA	15.8 %	19.0 %	45.8 %	6.7 %	1.6 %	0.7 %	100.0 %	100.0 %	12.7 %
Delaware County - IA	9.9 %	8.3 %	28.9 %	3.9 %	1.0 %	0.5 %	71.5 %	23.7 %	10.4 %
Des Moines County - IA	9.6 %	14.4 %	34.8 %	8.1 %	1.8 %	0.6 %	26.7 %	8.5 %	9.4 %
Dickinson County - IA	6.8 %	8.5 %	24.4 %	4.8 %	1.0 %	0.5 %	35.0 %	0.0 %	8.8 %
Dubuque County - IA	9.5 %	9.3 %	26.9 %	5.0 %	1.8 %	0.7 %	27.0 %	7.4 %	8.8 %
Emmet County - IA	12.3 %	11.4 %	30.2 %	4.3 %	4.0 %	1.5 %	39.9 %	0.0 %	12.3 %
Fayette County - IA	10.8 %	11.7 %	35.5 %	5.4 %	0.8 %	0.3 %	70.6 %	2.9 %	12.1 %
Floyd County - IA	9.0 %	13.6 %	32.9 %	5.9 %	1.7 %	0.9 %	52.7 %	0.0 %	10.1 %
Franklin County - IA	16.9 %	12.3 %	29.5 %	3.5 %	5.6 %	1.8 %	60.2 %	100.0 %	12.7 %

Population Group	Less than HS Education	Income Below 100% Poverty	Income Below 250% Poverty (Age: 40-64)	Un-employed	Foreign Born	Linguistic-ally Isolated	In Rural Areas	In Medically Under-served Areas	No Health Insurance (Age: 40-64)
Fremont County - IA	8.6 %	9.1 %	29.1 %	4.5 %	1.0 %	0.4 %	100.0 %	100.0 %	9.3 %
Greene County - IA	12.9 %	11.2 %	31.4 %	5.9 %	1.7 %	0.6 %	58.2 %	0.0 %	9.9 %
Grundy County - IA	7.9 %	6.9 %	21.2 %	3.3 %	0.3 %	0.3 %	100.0 %	0.0 %	7.5 %
Guthrie County - IA	8.7 %	8.1 %	28.8 %	5.6 %	1.2 %	0.4 %	100.0 %	5.0 %	10.0 %
Hamilton County - IA	10.1 %	9.0 %	27.7 %	4.9 %	2.4 %	1.7 %	50.5 %	0.0 %	9.5 %
Hancock County - IA	10.3 %	10.0 %	27.2 %	5.5 %	1.8 %	1.1 %	70.0 %	0.0 %	10.0 %
Hardin County - IA	9.6 %	8.1 %	28.0 %	5.4 %	2.0 %	1.2 %	71.1 %	5.0 %	11.0 %
Harrison County - IA	8.8 %	9.8 %	27.6 %	4.8 %	0.8 %	0.4 %	81.1 %	8.4 %	9.3 %
Henry County - IA	9.4 %	16.8 %	34.3 %	6.6 %	4.0 %	2.6 %	57.1 %	7.1 %	11.7 %
Howard County - IA	13.0 %	10.6 %	32.3 %	3.7 %	1.0 %	0.5 %	63.0 %	3.9 %	11.8 %
Humboldt County - IA	11.8 %	9.1 %	27.9 %	3.4 %	1.8 %	0.8 %	46.6 %	7.2 %	10.4 %
Ida County - IA	10.5 %	11.0 %	29.2 %	3.9 %	0.4 %	0.0 %	100.0 %	0.0 %	10.1 %
Iowa County - IA	7.1 %	8.5 %	23.4 %	3.3 %	0.6 %	0.1 %	82.2 %	4.6 %	7.6 %
Jackson County - IA	12.5 %	9.4 %	32.6 %	4.7 %	0.6 %	0.2 %	53.3 %	0.0 %	11.3 %
Jasper County - IA	8.7 %	11.2 %	28.2 %	5.9 %	0.9 %	0.4 %	57.5 %	0.0 %	9.2 %
Jefferson County - IA	7.4 %	13.0 %	38.2 %	5.6 %	11.5 %	0.7 %	38.7 %	19.2 %	13.4 %
Johnson County - IA	4.7 %	17.8 %	20.7 %	4.5 %	8.5 %	2.3 %	18.5 %	0.0 %	7.3 %
Jones County - IA	9.4 %	7.4 %	27.5 %	4.7 %	1.0 %	0.1 %	58.0 %	2.9 %	9.4 %
Keokuk County - IA	11.0 %	11.2 %	36.7 %	5.1 %	0.7 %	0.1 %	100.0 %	40.1 %	11.4 %
Kossuth County - IA	9.2 %	8.2 %	28.1 %	.7 %	0.9 %	0.6 %	65.6 %	11.1 %	9.6 %
Lee County - IA	12.5 %	14.5 %	35.3 %	8.4 %	1.8 %	0.4 %	40.6 %	10.4 %	10.8 %
Linn County - IA	6.5 %	9.9 %	22.4 %	5.0 %	2.9 %	0.7 %	12.7 %	0.0 %	7.7 %
Louisa County - IA	18.3 %	10.7 %	31.8 %	7.6 %	7.7 %	3.8 %	100.0 %	52.0 %	12.5 %
Lucas County - IA	12.0 %	17.3 %	37.2 %	10.5 %	4.4 %	2.0 %	56.2 %	100.0 %	12.3 %
Madison County - IA	6.1 %	8.9 %	24.6 %	5.4 %	0.8 %	0.4 %	67.8 %	0.0 %	8.8 %
Mahaska County - IA	10.2 %	16.1 %	32.8 %	7.5 %	1.7 %	0.4 %	43.9 %	8.3 %	9.4 %
Marion County - IA	8.7 %	9.1 %	25.2 %	5.1 %	2.0 %	0.7 %	48.7 %	0.0 %	7.6 %
Marshall County - IA	15.5 %	13.5 %	31.5 %	7.1 %	10.2 %	4.3 %	33.9 %	100.0 %	11.3 %
Mills County - IA	8.8 %	7.6 %	24.9 %	4.7 %	1.5 %	0.1 %	59.6 %	26.3 %	7.9 %
Mitchell County - IA	10.3 %	6.8 %	27.0 %	4.2 %	1.4 %	0.4 %	67.2 %	0.0 %	10.4 %
Monona County - IA	12.0 %	11.8 %	33.9 %	5.5 %	0.8 %	0.0 %	71.2 %	33.2 %	11.6 %
Monroe County - IA	12.8 %	11.2 %	35.1 %	7.9 %	2.5 %	0.8 %	55.2 %	100.0 %	11.9 %
Montgomery County - IA	12.6 %	15.2 %	34.8 %	7.5 %	1.8 %	0.1 %	47.9 %	2.4 %	10.7 %
O'Brien County - IA	10.3 %	10.4 %	29.3 %	2.9 %	2.3 %	1.0 %	66.3 %	17.2 %	10.1 %
Osceola County - IA	14.4 %	8.8 %	31.2 %	3.1 %	3.1 %	0.9 %	58.4 %	11.9 %	12.6 %
Page County - IA	12.3 %	11.6 %	32.2 %	5.3 %	2.6 %	0.4 %	33.4 %	0.0 %	9.6 %
Palo Alto County - IA	12.1 %	9.8 %	32.0 %	6.7 %	0.9 %	0.4 %	61.5 %	100.0 %	9.8 %

Population Group	Less than HS Education	Income Below 100% Poverty	Income Below 250% Poverty (Age: 40-64)	Un-employed	Foreign Born	Linguistic-ally Isolated	In Rural Areas	In Medically Under-served Areas	No Health Insurance (Age: 40-64)
Pocahontas County - IA	8.1 %	12.5 %	31.5 %	5.0 %	1.2 %	0.0 %	100.0 %	13.3 %	10.8 %
Polk County - IA	9.0 %	10.6 %	24.9 %	5.8 %	8.1 %	3.4 %	4.9 %	9.3 %	8.0 %
Pottawattamie County - IA	11.1 %	12.8 %	28.3 %	6.4 %	3.1 %	1.3 %	26.4 %	7.8 %	10.0 %
Poweshiek County - IA	7.4 %	11.6 %	27.7 %	6.0 %	2.2 %	0.2 %	52.0 %	0.0 %	8.8 %
Ringgold County - IA	10.5 %	12.7 %	36.9 %	5.3 %	1.8 %	1.3 %	100.0 %	15.7 %	13.7 %
Sac County - IA	10.3 %	9.3 %	30.2 %	3.8 %	1.3 %	0.2 %	100.0 %	5.8 %	11.6 %
Shelby County - IA	9.2 %	10.6 %	28.6 %	3.8 %	1.1 %	1.2 %	59.4 %	3.6 %	9.2 %
Story County - IA	4.5 %	19.0 %	19.5 %	5.4 %	8.0 %	2.1 %	16.9 %	0.0 %	7.3 %
Tama County - IA	11.3 %	11.1 %	29.2 %	5.1 %	3.0 %	1.7 %	72.4 %	100.0 %	13.0 %
Taylor County - IA	11.4 %	13.5 %	36.8 %	6.1 %	2.1 %	0.4 %	100.0 %	8.6 %	12.9 %
Union County - IA	11.0 %	17.4 %	35.4 %	6.1 %	0.4 %	0.0 %	39.2 %	4.1 %	9.7 %
Van Buren County - IA	11.7 %	16.4 %	39.6 %	9.0 %	0.7 %	0.6 %	100.0 %	100.0 %	12.0 %
Wapello County - IA	15.4 %	17.8 %	38.7 %	8.2 %	6.1 %	2.9 %	30.5 %	0.0 %	11.1 %
Warren County - IA	4.9 %	7.0 %	19.2 %	4.1 %	1.4 %	0.1 %	42.0 %	0.0 %	7.3 %
Washington County - IA	11.4 %	11.0 %	29.4 %	3.9 %	2.7 %	1.4 %	69.5 %	0.0 %	11.0 %
Wayne County - IA	12.8 %	14.5 %	43.2 %	8.9 %	0.7 %	0.0 %	100.0 %	100.0 %	15.1 %
Webster County - IA	12.1 %	14.4 %	32.2 %	9.4 %	2.1 %	0.8 %	33.9 %	0.0 %	10.2 %
Winnebago County - IA	10.0 %	9.2 %	27.0 %	5.1 %	2.6 %	1.1 %	66.1 %	0.0 %	8.9 %
Winneshiek County - IA	8.4 %	9.2 %	26.2 %	4.1 %	2.1 %	0.6 %	59.0 %	8.5 %	9.1 %
Worth County - IA	9.9 %	12.5 %	29.6 %	5.5 %	1.0 %	0.0 %	100.0 %	0.0 %	10.0 %
Wright County - IA	12.3 %	11.4 %	32.1 %	3.9 %	4.6 %	2.1 %	56.8 %	0.0 %	11.6 %

*Affiliate expanded their service area in July 2014. Therefore, Affiliate service area data does not include the following counties: Appanoose, Davis, Jefferson, Keokuk, Lucas, Mahaska, Monroe, Van Buren, Wapello and Wayne
Data are in the percentage of people (men and women) in the population.
Source of health insurance data: US Census Bureau – Small Area Health Insurance Estimates (SAHIE) for 2011.
Source of rural population data: US Census Bureau – Census 2010.
Source of medically underserved data: Health Resources and Services Administration (HRSA) for 2013.
Source of other data: US Census Bureau – American Community Survey (ACS) for 2007-2011.

Population characteristics summary

Proportionately, Komen Iowa's service area has a substantially larger White female population than the US as a whole, a substantially smaller Black/African-American female population, a substantially smaller Asian and Pacific Islander (API) female population, a slightly smaller American Indian and Alaska Native (AIAN) female population, and a substantially smaller Hispanic/Latina female population. The Affiliate's female population is slightly older than that of the US as a whole. The Affiliate's education level is substantially higher than and income level is slightly higher than those of the US as a whole. There are a substantially smaller percentage of people who are unemployed in the Affiliate service area. The Affiliate service area has a substantially smaller percentage of people who are foreign born and a substantially smaller percentage of people who are linguistically isolated. There are a substantially larger percentage of people living in rural areas, a substantially smaller percentage of people without health

insurance, and a substantially smaller percentage of people living in medically underserved areas.

The following county has substantially larger Black/African-American female population percentages than that of the Affiliate service area as a whole:

- Black Hawk County

The following counties have substantially larger API female population percentages than that of the Affiliate service area as a whole:

- Buena Vista County
- Johnson County
- Story County

The following county has substantially larger AIAN female population percentages than that of the Affiliate service area as a whole:

- Tama County

The following counties have substantially larger Hispanic/Latina female population percentages than that of the Affiliate service area as a whole:

- Buena Vista County
- Clarke County
- Crawford County
- Louisa County
- Marshall County
- Wapello County

The following counties have substantially older female population percentages than that of the Affiliate service area as a whole:

- Adair County
- Adams County
- Appanoose County
- Audubon County
- Calhoun County
- Cass County
- Cherokee County
- Dickinson County
- Fayette County
- Floyd County
- Greene County
- Guthrie County
- Hardin County
- Humboldt County
- Ida County
- Keokuk County
- Kossuth County
- Lucas County

- Mitchell County
- Monona County
- Montgomery County
- O'Brien County
- Osceola County
- Page County
- Palo Alto County
- Pocahontas County
- Ringgold County
- Sac County
- Shelby County
- Taylor County
- Wayne County
- Winnebago County
- Wright County

The following counties have substantially lower education levels than that of the Affiliate service area as a whole:

- Buena Vista County
- Crawford County
- Davis County
- Decatur County
- Franklin County
- Louisa County
- Marshall County
- Osceola County
- Wapello County

The following counties have substantially lower income levels than that of the Affiliate service area as a whole:

- Decatur County
- Henry County
- Lucas County
- Union County
- Wapello County

The following county has substantially lower employment levels than that of the Affiliate service area as a whole:

- Lucas County
- Webster County

The counties with substantial foreign born and linguistically isolated populations are:

- Buena Vista County
- Crawford County

The following county has substantially larger percentage of adults without health insurance than does the Affiliate service area as a whole:

- Allamakee County
- Davis County
- Wayne County

Priority Areas

Healthy People 2020 forecasts

Healthy People 2020 (HP2020) is a major federal government initiative that provides specific health objectives for communities and for the country as a whole. Many national health organizations use HP2020 targets to monitor progress in reducing the burden of disease and improve the health of the nation. Likewise, Komen believes it is important to refer to HP2020 to see how areas across the country are progressing towards reducing the burden of breast cancer.

HP2020 has several cancer-related objectives, including:

- Reducing women's death rate from breast cancer (Target as of the writing of this report: 41.0 cases per 100,000 women).
- Reducing the number of breast cancers that are found at a late-stage (Target as of the writing of this report: 41.0 cases per 100,000 women).

To see how well counties in Komen Iowa's service area are progressing toward these targets, the report uses the following information:

- County breast cancer death rate and late-stage diagnosis data for years 2006 to 2010.
- Estimates for the trend (annual percent change) in county breast cancer death rates and late-stage diagnoses for years 2006 to 2010.
- Both the data and the HP2020 target are age-adjusted.

These data are used to estimate how many years it will take for each county to meet the HP2020 objectives. Because the target date for meeting the objective is 2020, and 2008 (the middle of the 2006-2010 period) was used as a starting point, a county has 12 years to meet the target.

Death rate and late-stage diagnosis data and trends are used to calculate whether an area will meet the HP2020 target, assuming that the trend seen in years 2006 to 2010 continues for 2011 and beyond.

Identification of priority areas

The purpose of this report is to combine evidence from many credible sources and use the data to identify the highest priority areas for breast cancer programs (i.e. the areas of greatest need). Classification of priority areas are based on the time needed to achieve HP2020 targets in each area. These time projections depend on both the starting point and the trends in death rates and late-stage incidence.

Late-stage incidence reflects both the overall breast cancer incidence rate in the population and the mammography screening coverage. The breast cancer death rate reflects the access to

care and the quality of care in the health care delivery area, as well as cancer stage at diagnosis.

There has not been any indication that either one of the two HP2020 targets is more important than the other. Therefore, the report considers them equally important.

Counties are classified as follows (Table 2.6):

- Counties that are not likely to achieve either of the HP2020 targets are considered to have the highest needs.
- Counties that have already achieved both targets are considered to have the lowest needs.
- Other counties are classified based on the number of years needed to achieve the two targets.

Table 2.6. Needs/priority classification based on the projected time to achieve HP2020 breast cancer targets

		Time to Achieve Late-stage Incidence Reduction Target				
		13 years or longer	7-12 yrs.	0 – 6 yrs.	Currently meets target	Unknown
Time to Achieve Death Rate Reduction Target	13 years or longer	**Highest**	**High**	**Medium High**	**Medium**	**Highest**
	7-12 yrs.	**High**	**Medium High**	**Medium**	**Medium Low**	**Medium High**
	0 – 6 yrs.	**Medium High**	**Medium**	**Medium Low**	**Low**	**Medium Low**
	Currently meets target	**Medium**	**Medium Low**	**Low**	**Lowest**	**Lowest**
	Unknown	**Highest**	**Medium High**	**Medium Low**	**Lowest**	**Unknown**

If the time to achieve a target cannot be calculated for one of the HP2020 indicators, then the county is classified based on the other indicator. If both indicators are missing, then the county is not classified. This doesn't mean that the county may not have high needs; it only means that sufficient data are not available to classify the county.

Affiliate Service Area Healthy People 2020 Forecasts and Priority Areas

The results presented in Table 2.7 help identify which counties have the greatest needs when it comes to meeting the HP2020 breast cancer targets.

- For counties in the "13 years or longer" category, current trends would need to change to achieve the target.
- Some counties may currently meet the target but their rates are increasing and they could fail to meet the target if the trend is not reversed.

Trends can change for a number of reasons, including:

- Improved screening programs could lead to breast cancers being diagnosed earlier, resulting in a decrease in both late-stage incidence rates and death rates.
- Improved socioeconomic conditions, such as reductions in poverty and linguistic isolation could lead to more timely treatment of breast cancer, causing a decrease in death rates.

The data in this table should be considered together with other information on factors that affect breast cancer death rates such as screening percentages and key breast cancer death determinants such as poverty and linguistic isolation.

Table 2.7. Intervention priorities for Komen Iowa service area with predicted time to achieve the HP2020 breast cancer targets and key population characteristics

County	Priority	Predicted Time to Achieve Death Rate Target	Predicted Time to Achieve Late-stage Incidence Target	Key Population Characteristics
Adair County - IA	Highest	SN	13 years or longer	Older, rural
Buena Vista County - IA	Highest	SN	13 years or longer	%API, %Hispanic/Latina, education, foreign, language, rural
Cherokee County - IA	Highest	SN	13 years or longer	Older, rural
Clay County - IA	Highest	SN	13 years or longer	
Decatur County - IA	Highest	SN	13 years or longer	Education, poverty, rural, medically underserved
Dickinson County - IA	Highest	SN	13 years or longer	Older
Guthrie County - IA	Highest	SN	13 years or longer	Older, rural
Henry County - IA	Highest	SN	13 years or longer	Poverty, rural
Ida County - IA	Highest	SN	13 years or longer	Older, rural
Jackson County - IA	Highest	SN	13 years or longer	Rural
Jones County - IA	Highest	SN	13 years or longer	Rural
Keokuk County - IA	Highest	SN	13 years or longer	Older, rural
Madison County - IA	Highest	13 years or longer	13 years or longer	Rural
Montgomery County - IA	Highest	SN	13 years or longer	Older, rural
Osceola County - IA	Highest	SN	13 years or longer	Older, education, rural
Page County - IA	Highest	SN	13 years or longer	Older
Warren County - IA	Highest	13 years or longer	13 years or longer	Rural
Wright County - IA	Highest	SN	13 years or longer	Older, rural
Bremer County - IA	High	10 years	13 years or longer	Rural
Dallas County - IA	High	12 years	13 years or longer	
Kossuth County - IA	High	10 years	13 years or longer	Older, rural
Calhoun County - IA	Medium High	SN	9 years	Older, rural
Cass County - IA	Medium High	13 years or longer	1 year	Older, rural
Linn County - IA	Medium High	5 years	13 years or longer	
O'Brien County - IA	Medium High	13 years or longer	2 years	Older, rural, medically underserved
Polk County - IA	Medium High	4 years	13 years or longer	

County	Priority	Predicted Time to Achieve Death Rate Target	Predicted Time to Achieve Late-stage Incidence Target	Key Population Characteristics
Washington County - IA	Medium High	2 years	13 years or longer	Rural
Black Hawk County - IA	Medium	Currently meets target	13 years or longer	%Black/African-American
Boone County - IA	Medium	13 years or longer	Currently meets target	Rural
Carroll County - IA	Medium	Currently meets target	13 years or longer	Rural
Delaware County - IA	Medium	13 years or longer	Currently meets target	Rural, medically underserved
Des Moines County - IA	Medium	Currently meets target	13 years or longer	
Fayette County - IA	Medium	13 years or longer	Currently meets target	Older, rural
Hardin County - IA	Medium	7 years	1 year	Older, rural
Jasper County - IA	Medium	Currently meets target	13 years or longer	Rural
Johnson County - IA	Medium	Currently meets target	13 years or longer	%API
Lee County - IA	Medium	Currently meets target	13 years or longer	
Marion County - IA	Medium	13 years or longer	Currently meets target	Rural
Marshall County - IA	Medium	Currently meets target	13 years or longer	%Hispanic/Latina, education, foreign, medically underserved
Wapello County - IA	Medium	Currently meets target	13 years or longer	%Hispanic/Latina, education, poverty
Webster County - IA	Medium	Currently meets target	13 years or longer	Employment
Allamakee County - IA	Medium Low	SN	3 years	Rural, insurance, medically underserved
Appanoose County - IA	Medium Low	SN	2 years	Older, medically underserved
Butler County - IA	Medium Low	SN	3 years	Rural, medically underserved
Crawford County - IA	Medium Low	SN	3 years	%Hispanic/Latina, education, foreign, language, rural
Dubuque County - IA	Medium Low	3 years	1 year	
Fremont County - IA	Medium Low	SN	2 years	Rural, medically underserved
Grundy County - IA	Medium Low	SN	4 years	Rural
Harrison County - IA	Medium Low	SN	1 year	Rural

County	Priority	Predicted Time to Achieve Death Rate Target	Predicted Time to Achieve Late-stage Incidence Target	Key Population Characteristics
Iowa County - IA	Medium Low	NA	1 year	Rural
Jefferson County - IA	Medium Low	SN	4 years	Foreign
Louisa County - IA	Medium Low	SN	3 years	%Hispanic/Latina, education, rural, medically underserved
Pottawattamie County - IA	Medium Low	2 years	4 years	
Shelby County - IA	Medium Low	SN	2 years	Older, rural
Tama County - IA	Medium Low	SN	1 year	%AIAN, rural, medically underserved
Cerro Gordo County - IA	Low	Currently meets target	2 years	
Story County - IA	Low	Currently meets target	2 years	%API
Benton County - IA	Lowest	SN	Currently meets target	Rural
Buchanan County - IA	Lowest	SN	Currently meets target	Rural
Mahaska County - IA	Lowest	SN	Currently meets target	
Poweshiek County - IA	Lowest	NA	Currently meets target	Rural
Winneshiek County - IA	Lowest	SN	Currently meets target	Rural
Adams County - IA	Undetermined	SN	SN	Older, rural, medically underserved
Audubon County - IA	Undetermined	SN	SN	Older, rural, medically underserved
Chickasaw County - IA	Undetermined	SN	NA	Rural, medically underserved
Clarke County - IA	Undetermined	SN	SN	%Hispanic/Latina, rural, medically underserved
Clayton County - IA	Undetermined	SN	SN	Rural
Davis County - IA	Undetermined	SN	SN	Education, insurance, rural
Emmet County - IA	Undetermined	SN	SN	
Floyd County - IA	Undetermined	SN	NA	Older, rural
Franklin County - IA	Undetermined	SN	SN	Education, rural, medically underserved
Greene County - IA	Undetermined	SN	SN	Older, rural
Hamilton County - IA	Undetermined	SN	SN	Rural

County	Priority	Predicted Time to Achieve Death Rate Target	Predicted Time to Achieve Late-stage Incidence Target	Key Population Characteristics
Hancock County - IA	Undetermined	SN	SN	Rural
Howard County - IA	Undetermined	SN	SN	Rural
Humboldt County - IA	Undetermined	SN	SN	Older, rural
Lucas County - IA	Undetermined	NA	SN	Older, poverty, employment, medically underserved
Mills County - IA	Undetermined	SN	NA	Rural, medically underserved
Mitchell County - IA	Undetermined	SN	NA	Older, rural
Monona County - IA	Undetermined	SN	SN	Older, rural, medically underserved
Monroe County - IA	Undetermined	SN	SN	Medically underserved
Palo Alto County - IA	Undetermined	SN	SN	Older, rural, medically underserved
Pocahontas County - IA	Undetermined	SN	SN	Older, rural
Ringgold County - IA	Undetermined	SN	SN	Older, rural, medically underserved
Sac County - IA	Undetermined	SN	SN	Older, rural
Taylor County - IA	Undetermined	SN	SN	Older, rural
Union County - IA	Undetermined	SN	SN	Poverty
Van Buren County - IA	Undetermined	SN	SN	Rural, medically underserved
Wayne County - IA	Undetermined	SN	SN	Older, insurance, rural, medically underserved
Winnebago County - IA	Undetermined	SN	SN	Older, rural
Worth County - IA	Undetermined	SN	SN	Rural

NA – data not available.
SN – data suppressed due to small numbers (15 cases or fewer for the 5-year data period).

Map of Intervention Priority Areas

Figure 2.1 shows a map of the intervention priorities for the counties in the Affiliate service area. When both of the indicators used to establish a priority for a county are not available, the priority is shown as "undetermined" on the map.

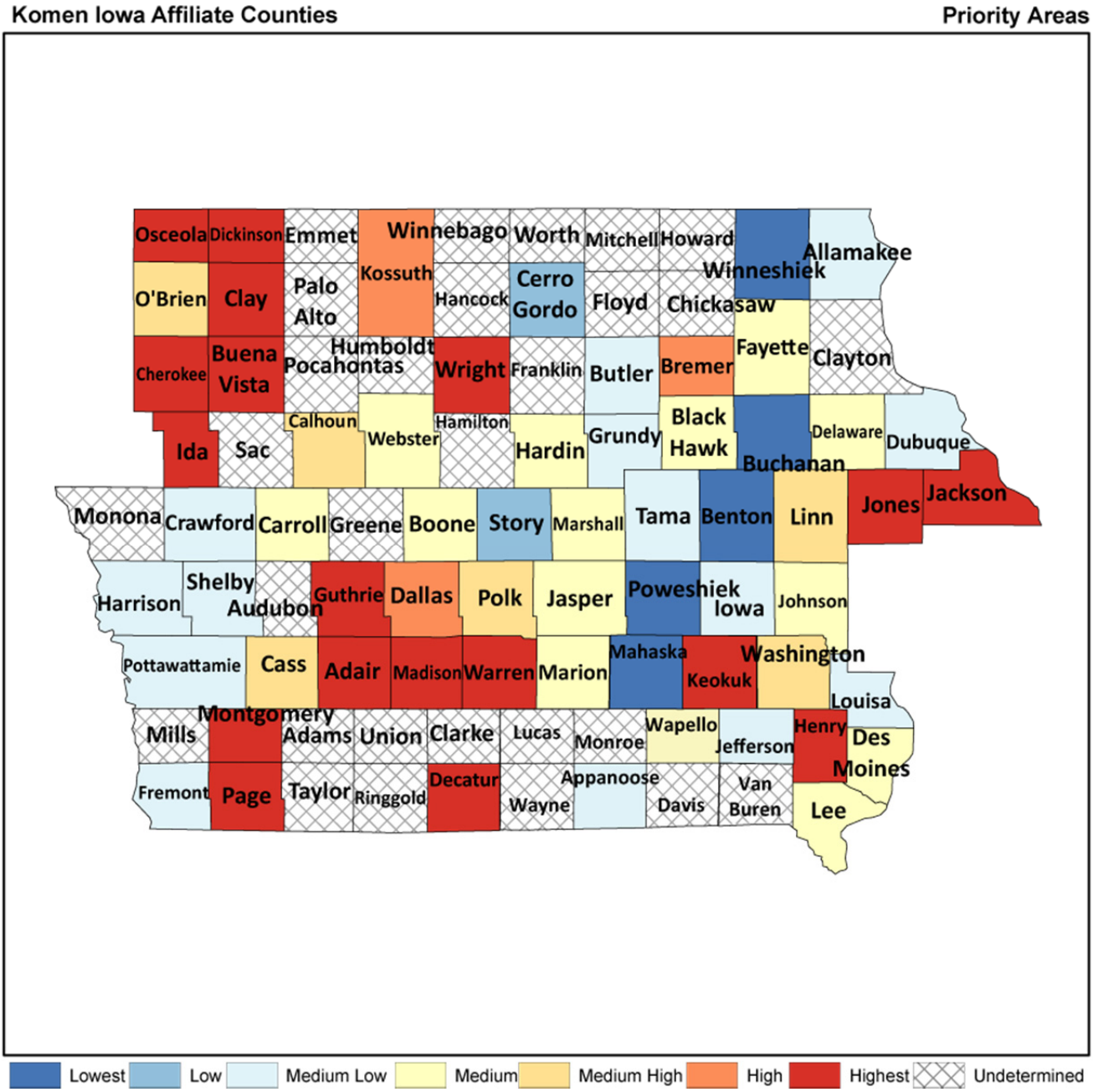

Figure 2.1. Intervention priorities

Data Limitations

The following data limitations need to be considered when utilizing the data of the Quantitative Data Report:

- The most recent data available were used but, for cancer incidence and deaths, these data are still several years behind.
- For some areas, data might not be available or might be of varying quality.
- Areas with small populations might not have enough breast cancer cases or breast cancer deaths each year to support the generation of reliable statistics.
- There are often several sources of cancer statistics for a given population and geographic area; therefore, other sources of cancer data may result in minor differences in the values even in the same time period.
- Data on cancer rates for specific racial and ethnic subgroups such as Somali, Hmong, or Ethiopian are not generally available.
- The various types of breast cancer data in this report are inter-dependent.
- There are many factors that impact breast cancer risk and survival for which quantitative data are not available. Some examples include family history, genetic markers like HER2 and BRCA, other medical conditions that can complicate treatment, and the level of family and community support available to the patient.
- The calculation of the years needed to meet the HP2020 objectives assume that the current trends will continue until 2020. However, the trends can change for a number of reasons.
- Not all breast cancer cases have a stage indication.

Quantitative Data Report Conclusions

Highest priority areas

Eighteen counties in Komen Iowa's service area are in the highest priority category. Two of the eighteen, Madison County and Warren County, are not likely to meet either the death rate or late-stage incidence rate HP2020 targets. Sixteen of the eighteen, Adair County, Buena Vista County, Cherokee County, Clay County, Decatur County, Dickinson County, Guthrie County, Henry County, Ida County, Jackson County, Jones County, Keokuk County, Montgomery County, Osceola County, Page County and Wright County, are not likely to meet the late-stage incidence rate HP2020 target.

The incidence rates in Ida County (206.7 per 100,000) are significantly higher than the Affiliate service area as a whole (123.7 per 100,000). Incidence trends in Jackson County (31.5 percent per year) and Keokuk County (80.1 percent per year) are significantly less favorable than the Affiliate service area as a whole (1.5 percent per year).

Adair County has an older population. Buena Vista County has a relatively large API population, a relatively large Hispanic/Latina population, low education levels, a relatively large foreign-born population and a relatively large number of households that are linguistically isolated. Older populations are observed in Cherokee, Dickinson, Guthrie, Henry, Ida, Montgomery, Page, and Wright counties. Decatur County has low education levels and high poverty levels. Henry County has high poverty levels and Osceola County has an older population and low education levels.

High priority areas
Three counties in Komen Iowa's service area are in the high priority category. All of the three, Bremer County, Dallas County and Kossuth County, are not likely to meet the late-stage incidence rate HP2020 target.

Kossuth County has an older population.

Selection of Target Communities

For several years, Susan G. Komen Iowa has used comparative data on breast cancer incidence, death and late-stage diagnosis rates and mammography percentages, along with demographic and socioeconomic indicators, to identify trends and priorities which inform Affiliate Mission activities, including the grantmaking process. The intent is to ensure that grant funds are used by hospitals, clinics and agencies to achieve certain quantifiable goals in reducing the burden of breast cancer throughout the 91 county service area. Over the next several years, Komen Iowa will focus on achieving the following Healthy People 2020 (HP 2020) objectives for breast cancer deaths and late-stage diagnosis:

1. Reduce the breast cancer death rate to 20.6 breast-cancer related deaths per 100,000 females;
2. Decrease the number of breast cancers diagnosed at a late-stage to 41.0 per 100,000.

To reach these goals and to track progress to date, credible sources and the most current data available have been used for this comparative data and trend analysis.

Comparisons on the size and direction of incidence, death, and late-stage diagnosis rates and trends are made at the national, state, and county levels to develop a breast cancer threat index which defines the breast cancer burden at the county level for Komen Iowa's service area. Counties with trends and rates significantly higher than averages for the service area as a whole are defined as having the greatest burden and highest threat indices. Similar methodologies are employed to determine the trends and proportions for compliance with breast cancer screening recommendations among women aged 50-64.

Significantly higher rates are those defined by statistical methods which indicate a likelihood that female breast cancer occurred more frequently among women in the county than among those in the Affiliate service area as a whole. Unfavorable trends are those defined as having a statistically significant likelihood of an increase in the occurrence of female breast cancer among women in the area. This means the rate of female breast cancer occurrence decreased less (or increased more) than the overall Affiliate service area rate.

In the case of breast cancer screening percentages, significantly higher findings are considered favorable since it can be concluded from statistical modeling that female breast cancer screening occurred more frequently among the county residents than among the Affiliate service area rate.

Once the threat index and cancer burden have been defined for each county, projections are then made to determine the likelihood for each county in achieving the HP 2020 objectives described above. In simple terms, the longer the time period projected for each county to

achieve either or both of the HP 2020 objectives, the higher the level of priority for intervention from Komen Iowa.

The breast cancer screening proportion in Komen Iowa's service area was not significantly different than that observed in the US as a whole and none of the counties in the Affiliate service area had substantially different screening proportions than the Affiliate service area as a whole. This indicates that efforts to maintain and/or improve these rates should continue.

Death and late-stage diagnosis data analysis indicates that eighteen counties in Komen Iowa's service area are not likely to meet either the death rate and/or late-stage incidence rate HP 2020 targets, thus placing them at the "Highest" priority level:

Highest Priority Counties

Adair	Jackson
Buena Vista	Jones
Cherokee	Keokuk
Clay	Madison
Decatur	Montgomery
Dickinson	Osceola
Guthrie	Page
Henry	Warren
Ida	Wright

Three counties have been listed as "High Priority" counties due to the likelihood of missing the HP 2020 objectives for late-stage incidence rates:

High Priority Counties

Bremer
Dallas
Kossuth

An additional six counties are defined as "Medium High Priority" due to the likelihood of missing HP 2020 objectives either for death or late-stage incidence rates:

Medium High Priority Counties

Calhoun
Cass
Linn
O'Brien
Polk
Washington

These lists collectively represent almost 30 percent of the entire number of counties included in the Affiliate service area. With such a large number of counties listed as priorities, and with the geographic distribution stretching across the state of Iowa, approaching these priorities through regional groupings is a logical method for creating a manageable set of targeted communities.

The Federal Highway Administration (FHWA) interstate highway system roughly divides Iowa into quadrants, with Interstate 35 running north to south and Interstate 80 running east to west. It is a common practice in public safety and other state wide planning to use these transportation routes as boundary lines to define geographically unique parts of the state. In

looking at the 27 counties listed above and using the interstate highway system as approximate boundaries, the Affiliate can arrive at four regional subsets which make up the target communities:

Northwest Iowa
Buena Vista
Calhoun
Cherokee
Clay
Dickinson
Ida
Kossuth
O'Brien
Osceola
Wright

Northeast Iowa
Bremer
Jackson
Jones
Linn

Southwest Iowa
Adair
Cass
Dallas
Decatur
Guthrie
Madison
Montgomery
Page
Polk
Warren

Southeast Iowa
Keokuk
Henry
Washington

With these subsets in mind, a further review of the highest priority counties shows that 14 of the 18 counties defined as “highest priority” are located in the Northwest or Southwest Iowa regions (seven counties in each region). The remaining four counties listed as highest priority are evenly grouped in the Northeast and Southeast regions (two counties in each region).

The Northwest and Southwest Regions have the greatest number and percentage of the “Highest Priority” counties, putting these two regions at the top of the Affiliate’s list of Targeted Communities. Based on the number of counties impacted and the level of priority assigned, targeted communities for the Affiliate are ranked by region as follows:

Table 2.8. Target communities and priority counties

Target Community/Region	# of Counties	% of counties in “Highest Priority” Category
Northwest	10	70%
Southwest	10	70%
Southeast	3	66%
Northeast	4	50%

Issues and Concerns for Future Study

Residents of the Greater Des Moines metro area and eastern Iowa have perhaps the greatest choices and availability of quality medical services in Iowa. Specifically, health care centers in the Des Moines area as well as the Waterloo/Cedar Rapids/Iowa City Corridor provide women in those areas access to a broader spectrum of services. Residents of northwest and southwest Iowa however may have to travel some distance to access similar services.

In order to better understand how these geographical issues may present barriers in accessing services, more information is needed about where women from each of the targeted regions tend to go to receive services throughout the breast cancer continuum of care. Particular emphasis will be placed on where and how screening services are obtained through the National Breast and Cervical Cancer Early Detection Program (NBCCEDP) and what impact the Iowa Health and Wellness Plan (Iowa's version of Medicaid expansion) may have on access to services.

A better understanding as to what is driving women to seek mammography at a rate greater than the national average will also help to determine what practices or services can be maintained or expanded. Determinants such as the presence of NBCCEDP supported programs, use of patient navigators, mammography reminder systems and mobile mammography units all need to be better understood. Demographic factors such as age will also be examined to determine if the propensity to get screened increases with age and if younger women are seeking mammograms for early detection purposes.

The Health Systems Analysis will also focus on what regional systems, health care providers and agencies are doing in assigning priorities and providing services to a geographically disparate area. Counties that may not individually have enough late-stage cases/deaths to figure a reliable rate (SN) could add up to a large number in aggregate. Therefore, additional information about how these "small numbers" are reached through health care systems in Iowa will be helpful.

Komen Iowa's service area is contiguous with Komen Siouxland in northwest Iowa and Komen Quad Cities in eastern Iowa. Both of these Komen Affiliates may share relationships with providers in the Affiliate service area that can provide perspectives on additional collaborative opportunities.

Introduction

After reviewing the quantitative data to determine areas of high priority, the Community Profile process explores the health systems in these areas, as well as federal/state-level public policy issues and efforts. The purpose of this Health Systems and Public Policy Analysis is to recognize how the Breast Cancer Continuum of Care can be understood in the target communities through mapping of assets, health care provider data and public policy efforts. This information can be used to better understand gaps, needs and limitations in the health system that affect transition through the breast health and breast cancer continuum of care.

The Breast Cancer Continuum of Care

The Breast Cancer Continuum of Care (Figure 3.1) is a valuable lens through which all aspects of this Health Systems and Public Policy Analysis will be viewed. The Continuum of Care also provides a method to define and understand knowledge, awareness and attitudes about breast health and breast cancer that are explored in a qualitative data collection and analysis.

The Breast Cancer Continuum of Care (CoC) shows how someone typically moves through the health care system for breast care. Ideally, these moves would be made quickly and seamlessly and allow for timely, quality care in order to have the best outcomes. Education plays an important role throughout the entire continuum.

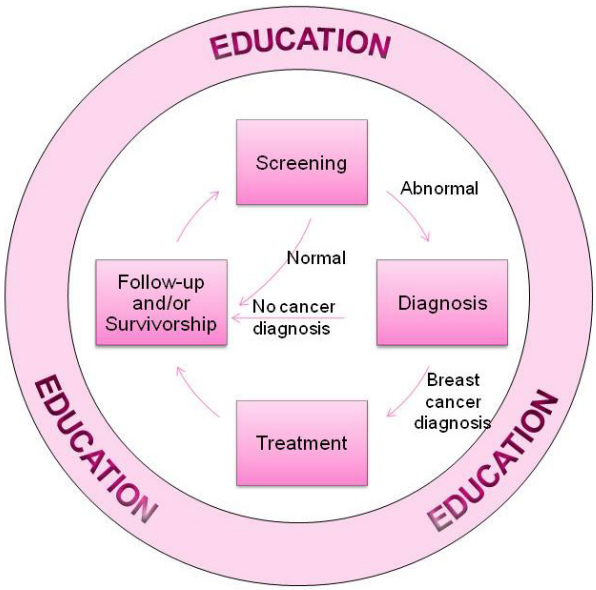

Figure 3.1. Breast Cancer Continuum of Care

Ideally, the continuum is entered through screening via a clinical breast exam or screening mammogram. If the screening test results are normal, follow-up care, including another screening exam at the recommended interval takes place. Education plays a role in encouraging regular screening and reinforcing the need to continue such screening routinely. If a screening exam produces abnormal results, diagnostic tests would be needed to determine if the abnormal finding is, in fact, breast cancer. These tests might include a diagnostic mammogram, breast ultrasound or biopsy. If the tests were negative (or benign) and breast cancer was not found, routine screening and follow-up is resumed at the recommended intervals. These intervals may range from three to six months or perhaps up to 12 months in many cases. The importance of proactively acquiring test results, keeping follow-up appointments and understanding the continuum of care can be very empowering when communicated through an effective breast cancer education and awareness program.

If breast cancer is diagnosed, treatment becomes the next step in the Continuum of Care. Education can cover such topics as treatment options, how a pathology report determines the

best options for treatment, how to understand and manage the side effects of treatment, and what questions to ask health care providers.

For some breast cancer patients, treatment may last a few months and for others, it may last years. While the CoC model shows that follow up and survivorship come after treatment ends, they may actually occur at the same time. Follow up and survivorship may include navigation of insurance issues, locating financial assistance, and/or symptom management (e.g. pain, fatigue, sexuality, bone health, etc.). Education can address such topics as healthy lifestyles, long term effects of treatment, managing side effects, the importance of follow-up appointments and communication with health care providers. Most breast cancer patients will return to screening at a recommended interval after treatment ends, or for some, during treatment (such as those taking long term hormone therapy).

There are often delays in moving from one point of the continuum to another such as follow-up to abnormal screening results or beginning and completing a treatment regimen. Such delays can all contribute to poorer outcomes. There may be several other reasons why someone does not enter or continue in the CoC. These barriers may include a lack of transportation, inconvenient clinic hours, language barriers, fear, or myths and misconceptions about breast cancer and screening procedures. Education can address some of these barriers and help progression through the CoC.

Health Systems Analysis Data Sources

Understanding the programs and services available in the target areas for this health systems analysis requires a comprehensive review of hospitals, clinics, public sector agencies, nonprofit organizations and others that play a role in providing for the Breast Cancer Continuum of Care. In order to obtain such *a* comprehensive understanding of programs and services data, the following sources were used:

1. National Cancer Institute roster of designated Comprehensive Cancer Centers;
2. Roster of cancer programs accredited by the American College of Surgeons Commission on Cancer as well as those recognized by the National Accreditation Program for Breast Centers;
3. Facilities accredited by the American College of Radiology with particular emphasis on those designated as a Breast Imaging Center of Excellence;
4. United States Department of Health Resources and Services Administration (HRSA) roster of HRSA health centers;
5. Office of Population Affairs listing of facilities which receive funding under Title X of the Public Health Service Act.
6. United States Food and Drug Administration listings of Mammography Qualified Standards Act (MQSA) approved facilities;

Internet searches were conducted on all facilities listed to determine the quantity and nature of services provided along the Breast Cancer Continuum of Care. Websites for each facility were reviewed to determine the particular emphasis placed on screening, diagnostic, treatment and follow-up care services. More detail was also sought from each facility website to determine the specific services provided within each element of the Continuum.

A spreadsheet program was used to record the geographic location, public contact information, service provision, and quality of care indicators (e.g. accreditation, quality awards, etc.) for each facility. These records were then grouped broadly into four categories, consistent with the four distinct geographically defined target areas identified in the Quantitative Data Review.

As these facilities were grouped, the spreadsheet program allowed for a numerical record to be kept so that the total number of facilities and the percentage of services provided along the Continuum of Care could be determined. In this way, an analysis could be conducted in each target area of the prevalence of services available.

Health Systems Overview

Based on the source information described above, 97 facilities were identified in the four target areas.

Screening services are highly prevalent in all of these areas. Northwest Iowa has the most comprehensive focus on screening, diagnostic and treatment services among its 15 facilities, but does not have the same highly prevalent level of support services (Figure 3.2). The most comprehensive care in Northwest Iowa is found primarily in three counties: Buena Vista (via the Buena Vista Regional Medical Center in Storm Lake), Clay (via the Abben Cancer Center at Spencer Hospital), and Dickinson (via Lakes Regional Health Care in Spirit Lake). These facilities are located along a north-south corridor defined roughly by US Highway 71 and are generally accessible via east-west routes to women in the other priority counties. Lakes Regional Medical Center in Storm Lake has the most comprehensive set of support services among priority counties in Northwest Iowa so consequently, women seeking such specialized care would have to look here or to the Cherokee Regional Medical Center in Cherokee County. Access to services may be most acutely felt by women living in Ida County, which may explain the high rates of late-stage diagnosis and deaths.

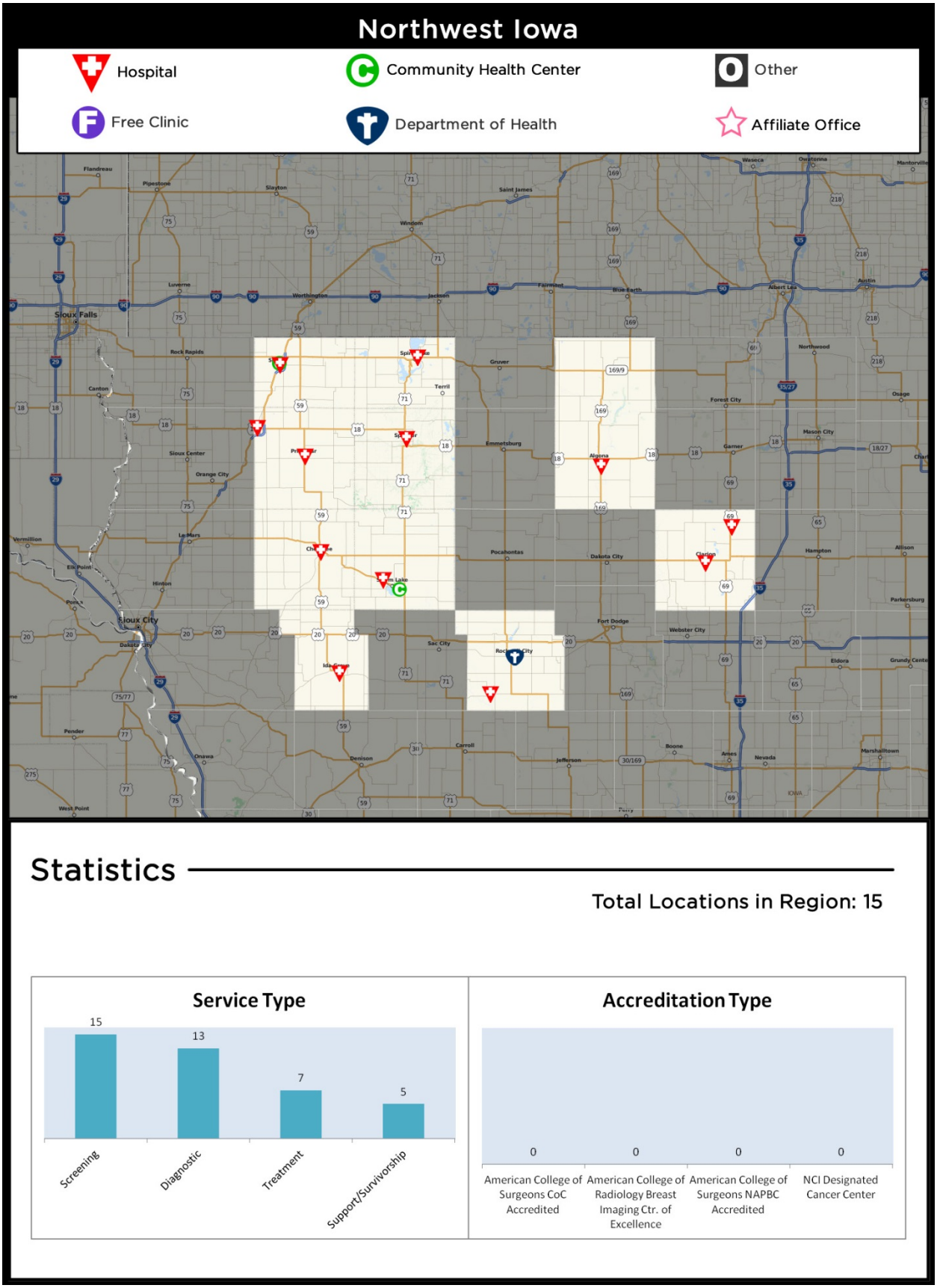

Figure 3.2. Breast cancer services available in Northwest Iowa

Southeast Iowa has the highest percentage of facilities that offer support services, although this finding might be skewed due to the small number of facilities (6) that are found in the priority counties of the Southeast Iowa target area (Figure 3.3.). Of these facilities, the most comprehensive care is found at the Henry County Health Center in Mt. Pleasant, and the most comprehensive set of support services is found at the River Hills Community Health Center, located in Keokuk County. The only other facility identified in Southeast Iowa that offers any support services is HCI Care Services in Mt. Pleasant, which is a hospice care unit. More comprehensive care for women in Southeast Iowa would have to be sought via facilities in Wapello County (Ottumwa), Mahaska County (Oskaloosa) or Marion County (Knoxville). Henry County Health Center is also the only facility identified among the Southeast Iowa priority counties that offers diagnostic and treatment services.

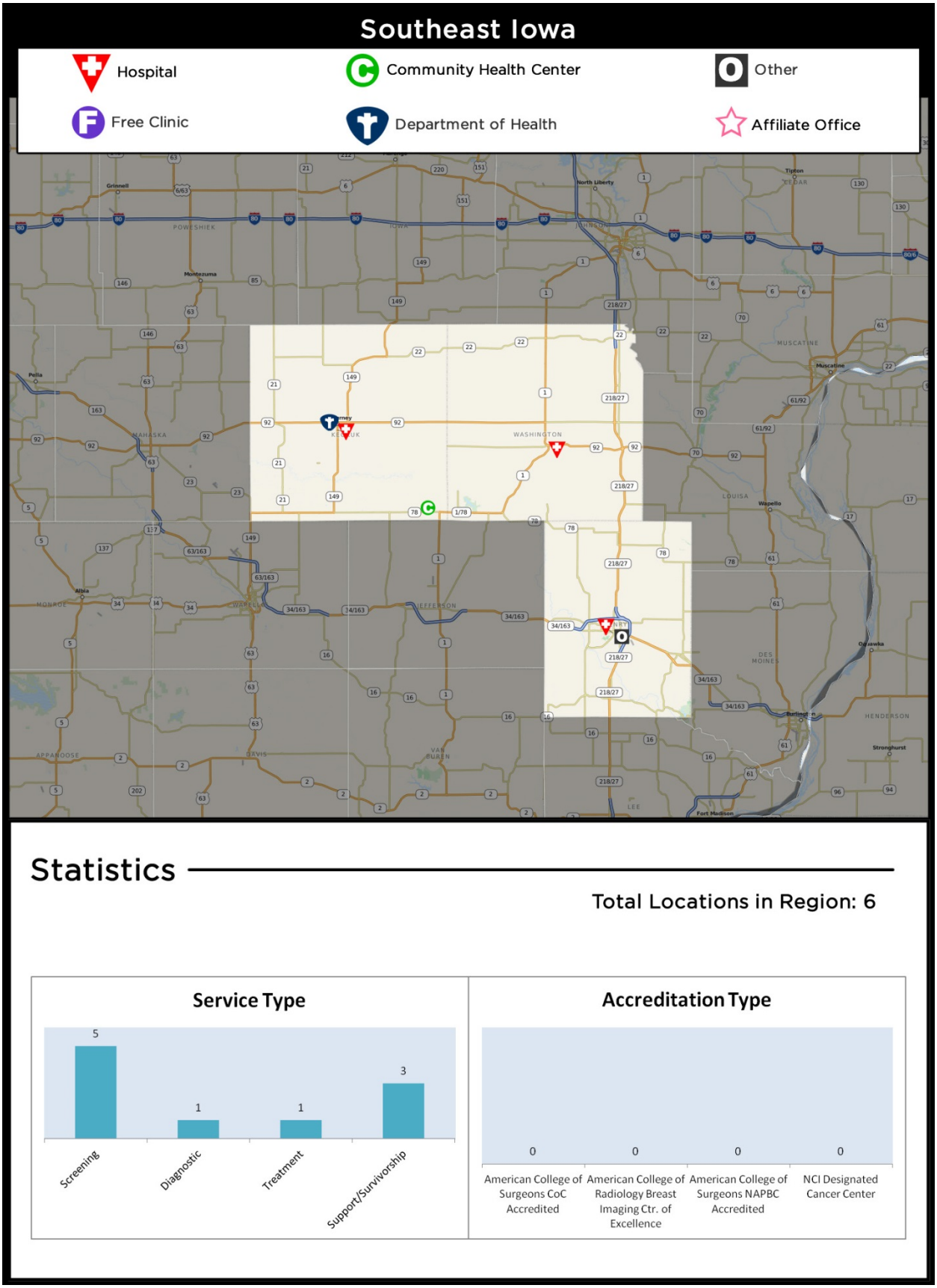

Figure 3.3. Breast cancer services available in Southeast Iowa

In Southwest Iowa, the availability of facilities are substantially greater than in the other four target areas, although the percentage of facilities offering comprehensive care is not as extensive (Figure 3.4). Polk County offers the greatest diversity of choice in provision of services along the Continuum of Care and contains all of the accredited facilities in the Southwest Iowa target area. For residents of Polk County, these facilities offer both a diversity of choice as well as the assurance of a high level of quality care. Dallas, Warren and Madison Counties are also considered part of the Greater Des Moines Metropolitan areas and as such may have quicker access to these high level services than more remotely located priority counties such as Adair, Cass, Decatur, Guthrie, Montgomery and Page. While residents of these “geographically outlying” priority counties may have availability to high levels of screening and diagnostic options they may have to travel some distance after receiving referrals to the more specialized treatment and support options found within Polk and surrounding metropolitan area priority counties.

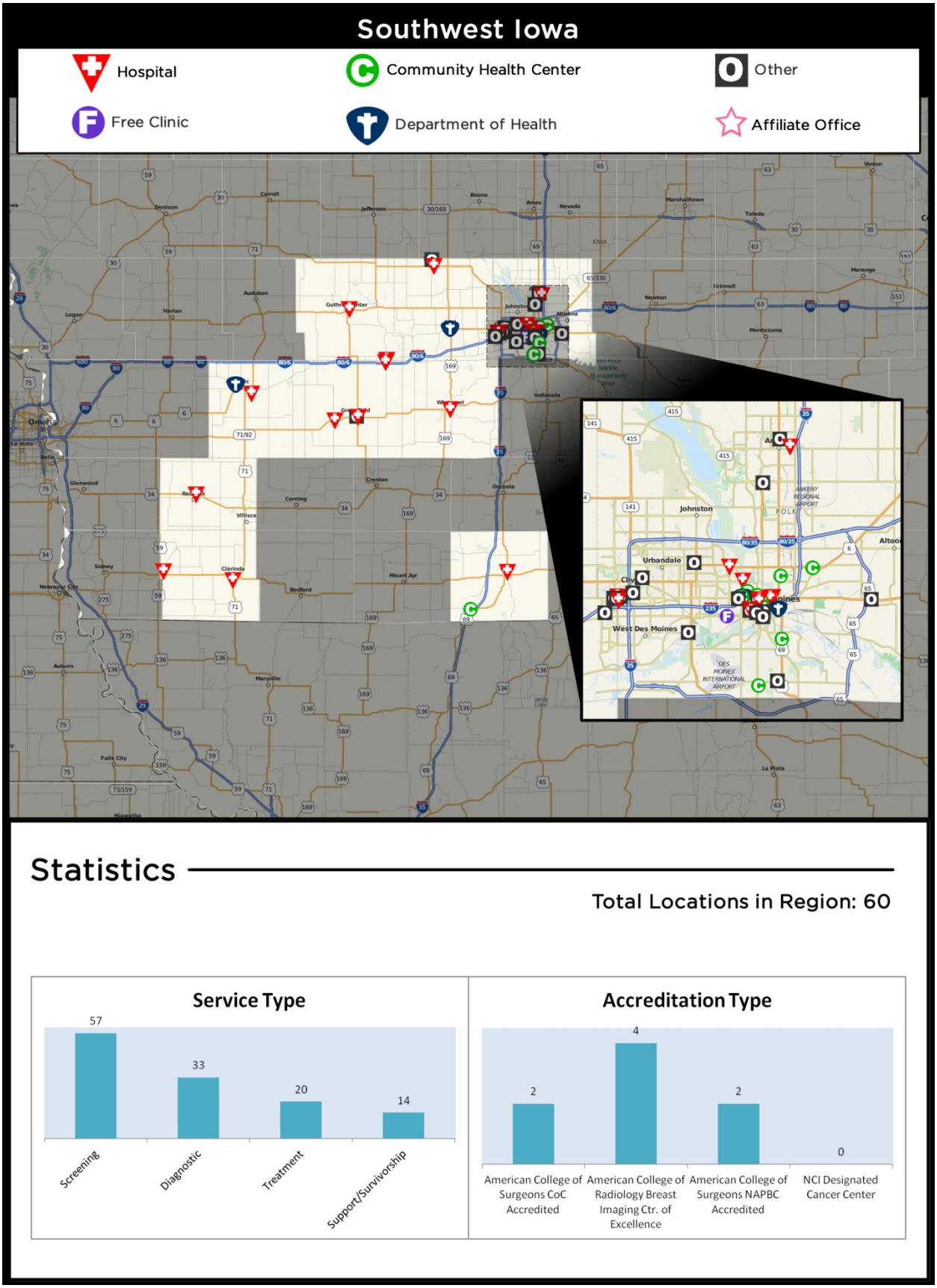

Figure 3.4. Breast cancer services available in Southwest Iowa

Northeast Iowa also provides residents with a relatively high level of diversity of choice and quality assurance, primarily through the facilities located in Linn County (Cedar Rapids) (Figure 3.5). These facilities, which are connected to the Unity Point and Mercy Hospital health care systems are examples of the extent to which larger hospital systems in the state provide care throughout the Affiliate service area. Residents of Jackson and Jones counties would likely seek more specialized services by traveling west to Cedar Rapids, while residents of Bremer County would need to look to facilities in Black Hawk County (Waterloo) to find more comprehensive treatment and support services.

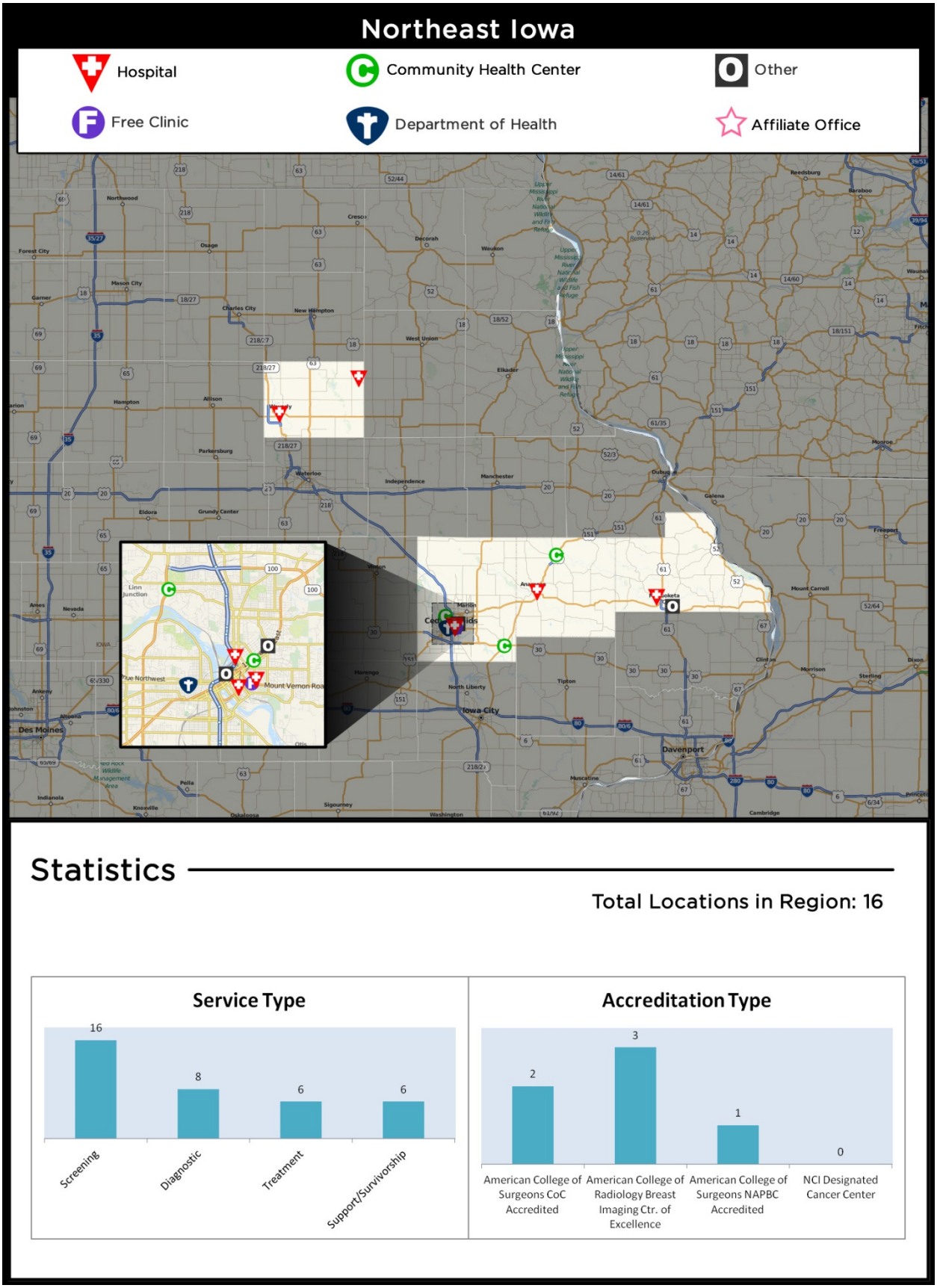

Figure 3.5. Breast cancer services available in Northeast Iowa

Partnerships

The scope and complexity of addressing the breast cancer burden in the target areas requires ongoing cultivation of partnerships to assure access to services along the Continuum of Care. Within the service area as a whole, two of those key partnerships have been with the Iowa Department of Public Health and the Iowa Cancer Consortium. These relationships have been advantageous in introducing the Affiliate to several hospitals, clinics and agencies in each of the four target areas to develop further collaborations and networks. In several cases, the collaborations have led to successful Komen Iowa grant applications and allowed the Affiliate to develop partnerships with grantees in each of the four target areas.

In assessing both current and potential mission related partnerships, the Health Systems Analysis allows for a focus on services provided in facilities that support one or more parts of the Continuum of Care. Tables 3.1, 3.2, 3.3 and 3.4 list at least one of these facilities for each county in Komen Iowa's target areas.

Table 3.1. Target area - Northwest Iowa

Facility	County	Community
Buena Vista Regional Medical Center	Buena Vista	Storm Lake
Stewart Memorial Community Hospital	Calhoun	Lake City
Spencer Hospital - Abbey Cancer Center	Clay	Spencer
Cherokee Regional Medical Center	Cherokee	Cherokee
Lakes Regional Health Care	Dickinson	Spirit Lake
Horn Memorial Hospital	Ida	Ida Grove
Kossuth Regional Health Center	Kossuth	Algona
Baum Harmon Hospital and Clinics	O'Brien	Primghar
Osceola Community Hospital	Osceola	Sibley
Iowa Specialty Hospital	Wright	Clarion

Table 3.2. Target area - Southwest Iowa

Facility	County	Community
Adair County Medical Clinic – Stuart	Adair	Stuart
Cass County Memorial Hospital - Atlantic Medical Center	Cass	Atlantic
Dallas County Hospital	Dallas	Perry
Decatur County Hospital	Decatur	Leon
Guthrie County Hospital	Guthrie	Guthrie Center
Madison County Health Care System	Madison	Winterset
Montgomery County Memorial Hospital	Montgomery	Red Oak
Shenandoah Medical Center	Page	Shenandoah
Broadlawns Medical Center	Polk	Des Moines
Unity Point Health – Des Moines	Polk	Polk
John Stoddard Cancer Center	Polk	Des Moines
Mercy Medical Center	Polk	Des Moines
Katzmann Breast Center	Polk	Des Moines
Mercy Hospital Cancer Center	Polk	Des Moines
Mercy Hospital Cancer Center – West Lakes	Polk	Des Moines
VA Hospital	Polk	Des Moines

Table 3.3. Target area - Southeast Iowa

Facility	County	Community
Henry County Health Center	Henry	Mt. Pleasant
River Hills Community Health Center	Keokuk	Richland
Washington County Hospital & Clinics	Washington	Washington
Ottumwa Regional Medical Center	Wapello	Ottumwa

Table 3.4. Target area - Northeast Iowa

Facility	County	Community
Waverly Health Center	Bremer	Waverly
Jackson County Regional Health Center	Jackson	Maquoketa
Unity Point Health - Jones Regional Medical Center	Jones	Anamosa
Unity Point Health – Cedar Rapids	Linn	Cedar Rapids
Helen G. Nassif Cancer Center of Iowa	Linn	Cedar Rapids
St. Luke's Hospital – Breast and Bone Health	Linn	Cedar Rapids
Mercy Medical Center	Linn	Cedar Rapids

These charts illustrate an important feature of health systems in the Affiliate service area. Unity Point and Mercy Hospital represent two of the largest hospital and health care systems in the state with local and specialized clinics in all four target areas. These two health systems are supplemented by Avera Health Care based in South Dakota, Alegent Creighton Health and Nebraska Methodist Health in Omaha, Wheaton Franciscan Health Care in Illinois, Mary Greeley Medical Center in Ames, Iowa (Story County) and Gunderson Health Systems of LaCrosse, Wisconsin. Hospitals and clinics associated with these health systems provide specialized care and services on a regional basis and should be considered as part of the overall health systems infrastructure of the Affiliate service area.

The Health Systems Analysis has also uncovered potential partnerships that will be explored with smaller hospitals, clinics, and community organizations in the priority counties, particularly those that are in rural areas.

In addition to these private hospital and health care systems, breast health and breast cancer services are available in the Affiliate service area through teaching and research hospitals as well as schools of public health that are associated with the University of Iowa (Holden Comprehensive Cancer Center in Iowa City) and the University of Nebraska (Nebraska Medical Center in Omaha).

Komen Iowa's service area also borders on three other Komen Affiliate areas as well (Komen Nebraska in Omaha, Komen Siouxland in Sioux City, Iowa and Komen Quad Cities in Davenport, Iowa). This proximity allows for additional partnership opportunities in support of hospitals, clinics and agencies that serve overlapping populations.

Affiliate partnerships have centered largely on improving access to screening services through a combination of education, financial assistance, reminder systems and navigation. What is needed now is a more robust system of partnership and collaboration that will increase the Affiliate's encouragement of participation in clinical trials, improve breast health literacy and cancer control systems and increase the availability of services to residents.

Public Policy Overview

Implications of the Health Systems described above for Komen Iowa's advocacy efforts is determined in part by Affiliate relationships with:

1. The Iowa Department of Public Health (IDPH) which supports the funding acquisition, enrollment and access to the National Breast and Cervical Cancer Early Detection Program (NBCCEDP) as well as how this relates to Medicaid treatment in Iowa
2. The Iowa Cancer Coalition that is responsible for meeting the objectives of the State Comprehensive Cancer Control Plan (with particular emphasis on breast cancer objectives)

In addition, the adoption of the Affordable Care Act (ACA) has become a closely monitored development in Iowa state politics, requiring ongoing attention to Medicaid expansion, the impact on the number of uninsured in Iowa prior to and after the ACA mandates, the implications of the ACA on NBCCEDP eligibility and utilization, and the overall implications of the ACA for health care providers in general and Komen Iowa in particular.

These public policy issues and current public policy activities will be focused on in the next section of this narrative.

National Breast and Cervical Cancer Early Detection Program (NBCCEDP)

The Iowa Breast and Cervical Cancer Early Detection Program (BCCEDP), known as the *Care for Yourself Program*, is administered by the Iowa Department of Public Health (IDPH) within the Bureau of Chronic Disease Prevention and Management. The program is funded primarily through a cooperative agreement with the Centers for Disease Control and Prevention (CDC). The Iowa program just entered its 3rd year of a 5-year project period within the cooperative agreement with the CDC. The program also administers funding from Komen Iowa for breast cancer screening within the NBCCEDP framework. The program is organized under the following components of the NBCCEDP:

- Partnerships, coordination, collaboration
- Public education and targeted outreach
- Screening, diagnostics, and patient navigation services
- Quality assurance & quality improvement
- Professional development
- Data management and utilization
- Program monitoring and evaluation

Enrollment for breast and cervical cancer screening services within BCCEDP can occur by several means. The IDPH contracts with 27 local boards of health across the state to provide local opportunities for enrollment of eligible women. This enables women to have a trusted local contact for enrollment, service access and case management. IDPH offers information on its website for women who are seeking to enroll in the program (http://www.idph.state.ia.us/CFY/Public.aspx). The website holds an interactive map that will guide women to the local enrollment contact nearest their home.

Another means for enrollment is phone contact through the Healthy Families Line, 1-866-227-9878, a program of Iowa State University Extension Services. The Healthy Families Line is

contracted to provide 24-hour, 7-days a week telephone answering and referral to interested women.

The program prides itself on efforts to ensure that once enrolled in the program, women are contacted annually through a mailed rescreening reminder letter. Other efforts include local outreach to health care provider facilities and social marketing initiatives that lead to the initial referral to the program.

Enrollment guidelines for BCCEDP include: A woman must be between the ages of 40-64 years of age; be 65 years old or older without Medicare Part B coverage; be under 40 years old and have a breast lump or other signs of breast cancer and must also meet the state income requirements of 250 percent of the Federal Poverty Guideline. Women may be uninsured or underinsured.

The most recent rules of the Iowa Care For Yourself Program can be found starting on page 1026 of the Iowa Administrative Bulletin (Feb. 8, 2012): https://www.legis.iowa.gov/docs/aco/bulletin/02-08-2012.pdf.

If a woman has been diagnosed with breast cancer, a precancerous cervical condition or cervical cancer, and has no creditable insurance coverage, she may apply for services under the Iowa Breast and Cervical Cancer Prevention and Treatment Act Medicaid Option. Iowa has three mechanisms for women to gain access to the Breast and Cervical Cancer Treatment (BCCT) Medicaid Option: 1) an individual may be screened through the Care for Yourself Program; 2) an individual may be screened with funds provided by Susan G. Komen®; and 3) an individual may be screened with funds paid by a nonprofit entity.

To facilitate ease in gaining presumptive eligibility for treatment services, IDPH has its local program contractors assist women served by the BCCEDP with signing up for BCCT coverage. All women seeking treatment services through these mechanisms must meet the eligibility requirements as established by the Care for Yourself Program. Through legislative action, and beginning January 1, 2014, eligible persons diagnosed in a free-clinic/nonprofit clinic (regardless of screening through BCCEPD or with Komen funding) could be deemed eligible for treatment through the BCCT. Although there are no age requirements for treatment through the BCCT in Iowa, the income guideline for the program is 250 percent of the Federal Poverty Guideline.

The main aspect of the working relationship between the state BCCEDP and Medicaid in Iowa is focused on the determination of eligibility for the BCCT. Iowa Medicaid Enterprise is the Medicaid agency in the state. IDPH BCCEDP staff administer the department's role with BCCT eligibility determination. IDPH staff collaborate with the Iowa Medicaid Enterprise staff regarding administration of the BCCT across the state.

Komen Iowa has a strong, multi-year working relationship with the Iowa Department of Public Health's Iowa Breast and Cervical Cancer Early Detection Program. The Affiliate is engaged in multiple projects with the program and its staff. Collaboration centers on a project entitled "Raise the Rates" which has a mission of reaching out to women across the state regardless of income or insurance status to raise the mammography screening percentages in Iowa. Komen Iowa is also engaged in the Iowa Cancer Consortium, a collective of entities, organizations and

individuals working to reduce the burden of cancer across the state through the continuum of care approach. The Affiliate and the program work together on the Community Profile and other projects that mutually benefit the work of the Affiliate and the program with its contractors across the state. Komen Iowa is a contractor of the State of Iowa to receive funds (special fees) raised through the sale of breast cancer license plates, and put them to use in supporting screening activity for men and women. The Iowa Department of Public Health is a current grantee of Komen Iowa. It is the Affiliate's intention over the next four years to grow this relationship by holding bi-monthly meetings to update one another on current programs and collaborate and grow opportunities to work together. Komen Iowa has been invited to work directly with local program staff throughout the state to increase outreach and education opportunities. In addition, the Affiliate plans to participate in a regional BCCEDP meeting with its contractors that is held annually. Both parties see a huge opportunity to be more intentional about creating opportunities to work together and benefit from the others' knowledge and experience.

State Comprehensive Cancer Control Coalition

The Iowa Cancer Plan is the state's comprehensive cancer control plan to provide direction for those involved in the planning, implementation, and evaluation of cancer control programs, research and policy initiatives. It is also a resource for all Iowans looking for support and advocacy. The objectives fall in line with the Continuum of Care model and are strengthened by the partnerships and collaborations around the state.

The Iowa Cancer Plan sets forth four goals with respect to breast cancer:

1. Whenever possible, prevent cancer from occurring.
2. If cancer does occur, find it in its earliest stages.
3. Improve the accessibility, availability, and quality of breast cancer treatment services and programs.
4. Ensure optimal quality of life for people impacted by cancer.

Komen Iowa is a partner and member of the Iowa Cancer Consortium and an avid supporter of the Cancer Control Coalition. Komen Iowa's Executive Director is the Chair of the Screening Implementation Group of the Iowa Cancer Consortium and both the Executive Director and Mission Initiatives Manager of Komen Iowa are actively involved with a sub-group of ICC called "Raise the Rates". The objective of the group is to increase breast cancer screening percentages across the state.

In order to align itself with the breast cancer objectives of the Iowa Cancer Plan, Komen Iowa has adopted the broad objectives listed above for its own set of strategic initiatives intended to provide context for the specific mission focus of the Affiliate. Moreover, findings from the Qualitative Analysis contained in the most recent Community Profile have been compared with similar efforts from other Consortium partners to better understand knowledge, attitudes and awareness about breast cancer and mammography. When compared to Komen Iowa's data, this analysis provided replicated data that suggested important initiatives for the Coalition in general and the Affiliate specifically. To date four separate presentations of these findings have been provided by Komen Iowa staff to Consortium meetings, IDPH staff, and rural health providers. Des Moines University (DMU) recently approved this presentation for use in providing continuing medical education to students of osteopathy as well as to DMU alumni.

Komen Iowa is committed to the mission of the state cancer coalition to reduce cancer incidence and deaths in Iowa through collaborative efforts that provide services and programs directed toward comprehensive cancer risk reduction and control. The issues faced by many of the partners of the Iowa Cancer Plan are in line with the work done at Komen Iowa and the 91-counties the Affiliate serves. Over-arching issues critical to success include: Collaboration, Health Disparities, Health Equity, Policy and Systems, and Research and Evaluation. The Affiliate sees tremendous opportunity to be involved in all. Recently, Komen Iowa has become involved with the Safety Net Leadership and Advisory Group in Iowa to access health disparities and health equity in Iowa. In addition, it provides an overwhelming opportunity to increase collaboration with health systems across the state. The Affiliate plans to continue to grow its relationships with partners such as Iowa Department of Public Health, University of Iowa School of Public Health, American Cancer Society, Iowa Cancer Consortium, Holden Cancer Center and countless other stakeholders in the fight against breast cancer. It is the goal at Komen Iowa to become a convener for those involved in state comprehensive cancer control and the mission to save lives and end breast cancer.

Affordable Care Act

Iowa is fully participating in Medicaid expansion under the Affordable Care Act. The Iowa Health and Wellness Plan (IHAWP) is a new Medicaid program which is Iowa's version of Medicaid expansion. The program was enacted through bi-partisan legislation to provide comprehensive health care coverage to low income, uninsured adults ages 19-64. The IHAWP is one program that is administered by Iowa Medicaid Enterprise (IME) and includes two separate coverage options. Eligibility is based on household income.

- ***Iowa Wellness Plan*****:** covers adults ages 19 to 64 whose income is at or below 100 percent of the Federal Poverty Level ($11,670 for individuals or $15,730 for a family of two). Members have access to the statewide Medicaid provider network and have access to care from providers and hospitals in their local communities.

- ***Iowa Marketplace Choice Plan*****:** covers adults age 19 to 64 with income from 101 percent through 133 percent of the Federal Poverty Level (between $11,671 and $15,521 for individuals or $15,731-$20,920 for a family of two). The Marketplace Choice Plan allows members to select from participating commercial health care coverage plans available through the Health Insurance Marketplace. Medicaid pays the premiums to the commercial health plan on behalf of the member. Members have access to the network of local health care providers and hospitals participating in the commercial insurance plan they choose.

Information and fact sheets regarding the Iowa Health and Wellness Plan was found on their website: http://dhs.iowa.gov/ime/about/iowa-health-and-wellness-plan.

According to the Iowa Department of Public Health the number of uninsured Iowans in 2013 was 301,601. The best-estimate scenario for uninsured is 242,691 by the end of 2014.

The eligibility guidelines for the Iowa BCCEDP have not changed through the ACA implementation period. The Iowa BCCEDP is seeing a downturn in number of women being screened. Anecdotally, contracted local programs are indicating that many previously served women have gained insurance coverage or have enrolled with the Iowa Health and Wellness Program. The program recently began collecting more detailed information on reasons why

women are not re-enrolling for service. The program began special outreach projects in the spring of 2014 with the intent of contacting the harder-to-reach population of eligible uninsured women across the state. The program continues its focused outreach efforts in July, 2014 in 12 counties that have the highest percentages of Hispanic/Latino population.

While some health care providers are still unsure of the implications of ACA, others have concerns. Many are concerned about a gap in services for those who are covered for screening as a health benefit through insurance coverage, but may not have the resources to access care due to financial constraints (e.g. high deductibles or limited diagnostic coverage) or other barriers (e.g. transportation). Resources and access to care is another concern, especially for safety net providers in Iowa.

There are several implications for the Affiliate to consider with the continued implementation of the ACA:

- Estimates done in November 2013 by IDPH BCCEDP staff indicate that only 43 percent of the BCCEDP-eligible Iowa population may remain uninsured following implementation of the ACA. That would be a population of approximately 13,000 women. While this estimate is a projection, there remains a lot of uncertainty regarding the actual number of women that have newly-gained insurance coverage.
- With more women having insurance coverage that provides screening at no cost, fewer women will be needing assistance to pay for screening services. However, in regard to women that continue to receive services through federally funded programming like the BCCEDP, funding may still be needed to support specific screening or diagnostic-related services. For instance, the national BCCEDP does not allow states to pay for computer-aided detection services. That is a gap that could be filled with Affiliate-raised funds.
- Using Affiliate funds with a greater emphasis on outreach and education may be needed to ensure that women, who have newly-acquired insurance coverage, actually move forward to get their breast cancer screening.
- Navigation services can be crucial for women that are newly insured or who may not understand how insurance works. They may still need prompts to seek the screening that they are now eligible for and guidance on how to navigate the health care system if abnormal screening results are found.
- It will also continue to be important for the Affiliate to partner with the state BCCEDP through its grant program to assist in paying for mammograms for women under age 50. The National BCCEDP maintains its requirements that no more than 25 percent of the mammograms funded with federal dollars be used for mammography for women under age 50.
- Funding that is used in conjunction with the BCCEDP can be considered as part of the matching funds requirement for the federal funding that supports screening activity in Iowa. CDC requires the state program to provide $1 in matching funds for every $3 of awarded federal funds.

Current Advocacy Activities

Komen Iowa has a robust Advocacy Committee that has been active since early 2013. In addition to meeting bi-monthly to address federal and state advocacy issues, the committee attends Komen-sponsored webinars and pursues opportunities to be involved at a local and national level. Some examples of Affiliate current public policy activities include:

- Paint the Capitol Pink – Volunteers organize visits to the state capitol during legislative session to speak with representatives in both the House and Senate and raise awareness about breast cancer issues.
- Individual meetings with state legislators at the Iowa Capitol who are involved in health care issues at the state level.
- Collaboration with partner organizations including the Iowa Department of Public Health and the American Cancer Society to protect federal funding for NBCCEDP and research initiatives.
- Collaboration on a state-wide task force with the help of the Iowa Medical Society, Iowa Primary Care Association and State Office of Rural Health to address the needs of education initiatives with particular emphasis on mammography screening and notification procedures
- Gubernatorial proclamation of October as Breast Cancer Awareness Month to focus public attention on the breast cancer burden in Iowa

It is the Affiliate goal in the next four years to continue to secure funding for NBCCEDP as well as federally funded research grants. Komen Iowa will continue to monitor health issues through its legislative network and partner organizations to determine ways to be helpful in educating women about options they have in seeking screening and patient care services. It is also the Affiliate's intention to partner with the other Affiliates in Iowa to address issues raised through Komen Headquarters Advocacy Team.

Health Systems and Public Policy Analysis Findings

The prevalence of screening services in all four target areas indicate that those who wish to obtain a regular, routine mammogram and/or clinical breast exam may not encounter excessive difficulty in locating facilities to provide these services. Provisions made through the Iowa Department of Public Health and the Iowa Health and Wellness Plan provide financial support, reminder systems and navigation to help assure uninsured and underinsured residents receive screening services.

Inconsistencies are noted however in the degree to which additional services are available along the continuum of care. Mobile mammography and other radiological procedures have made diagnostic services more readily available but options for treatment and support services are more limited for residents of Henry, Keokuk and Washington counties in Southeast Iowa. Moreover, since the more advanced treatment and support options tend to be more readily available in larger population areas of the state, rural residents may still have to travel some distance for treatment and support. This need is particularly pronounced in Northwest and Southeast Iowa, where there are no nationally accredited facilities to provide a more complete range of services along the continuum of care.

These accredited facilities however provide an important starting point for the development of key partnerships. Those associated with Unity Point Health and Mercy Medical Center in particular are often located in or near one or more of the priority counties and often serve as resources for breast cancer survivors who are referred to these facilities from other parts of the Affiliate service area.

Similar health care systems and their affiliated networks can be found as well throughout the four target areas including the private care facilities and teaching and research facilities referenced above. In particular, relationships with the Holden Comprehensive Cancer Center in Iowa City as the only NCI designated Comprehensive Cancer Center in the Affiliate Service area will be critical in expanding support for clinical trials and funding for research.
The University Of Iowa School Of Public Health will remain an important partner for the Affiliate in developing additional ways to test and evaluate improvement in breast health literacy and relating the goals of the Affiliate to the Iowa's Comprehensive Cancer Control Plan.

Iowa public policy has been critical in extending affordable screening services and encouraging the ongoing work of the Iowa Cancer Consortium. The Iowa Health and Wellness Plan has helped to reduce the number of uninsured Iowans by almost 60,000, yet over 240,000 residents remain uninsured according to recent estimates. Diagnostic mammography remains a political issue in view of recent grassroots efforts to secure mandated physician notification to women with dense breast tissue that their condition may "mask certain abnormalities" that would not be discovered through routine mammograms. Komen Iowa will continue to monitor these efforts and seek input from partners regarding the need for such notification, while at the same time looking to support ways of improving financial access to more specialized screening.
Consistent with the advocacy priorities of Komen Headquarters, the Affiliate will also work to support funding for research and clinical trials, while also working with health care providers in the state to increase clinical trial enrollment and improve financial access to specialized treatment and support.

Qualitative Data Sources and Methodology Overview

In response to a desire to learn more about the knowledge, attitudes and beliefs concerning breast cancer in Iowa, a qualitative study was commissioned by Komen Iowa in 2014 to assess individual perceptions about breast cancer and the resources available to individuals in accessing the continuum of care.

The insight gained from this study provides important guidance for Komen Iowa in developing a set of priorities and an action plan. The findings include advice from women who are active in breast health regarding improvements in the process and how to overcome barriers in the screening and care for those with cancer.

Methodology

A series of 24 telephone interviews were conducted by Hanser & Associates, a public relations and research firm serving a wide variety of clients in health care/medical, education, and nonprofit sectors. Des Moines-based Hanser & Associates has conducted health care research nationwide.

In-depth, one-on-one interviews were conducted between October 24 and December 30, 2014, among women aged 40-65 in both rural and urban counties that were of interest to the Affiliate in an effort to understand potential barriers and challenges to breast cancer screening. The specific counties selected (Ida, Polk and Pottawatomie) were found in the quantitative data analysis to have a breast cancer incidence rate significantly higher than the Affiliate service area as a whole. All 24 women said they had — during the past 12 months —their annual screenings (annual physical, clinical breast exam, mammogram).

Variations in age, race/ethnicity, health insurance status, residence and tenure among those interviewed — both those who had been diagnosed with breast cancer (and already completed treatment) and those who had never been diagnosed with breast cancer — are presented in Figures 4.1, 4.2, 4.3, 4.4, 4.5 and 4.6.

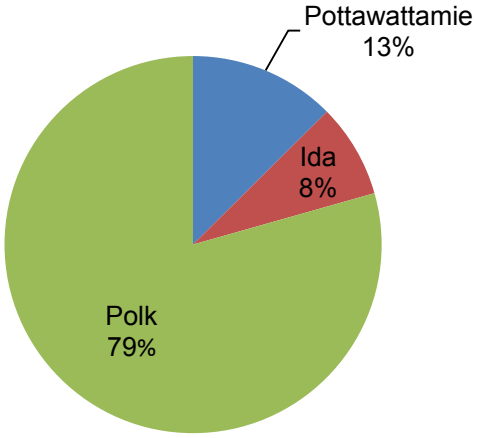

Figure 4.1. County of residence in Iowa

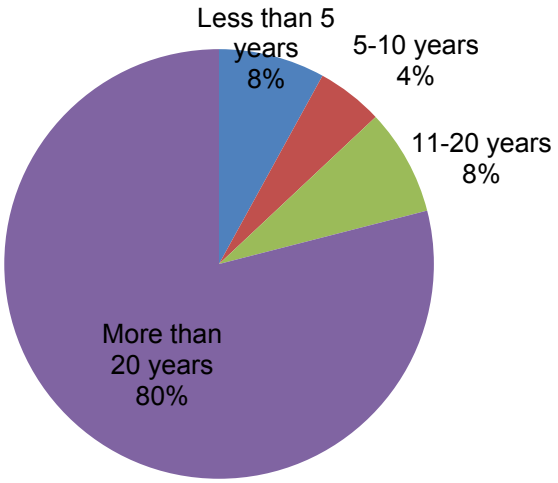

Figure 4.2. Community tenure

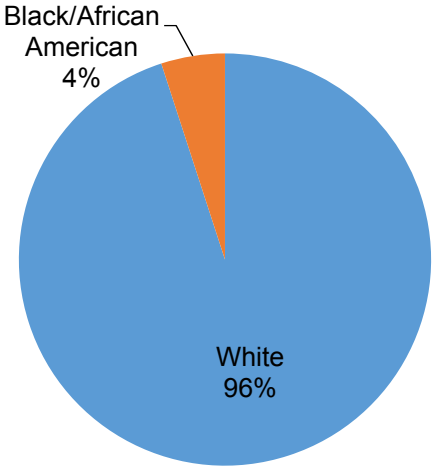

Figure 4.3. Race/Ethnicity

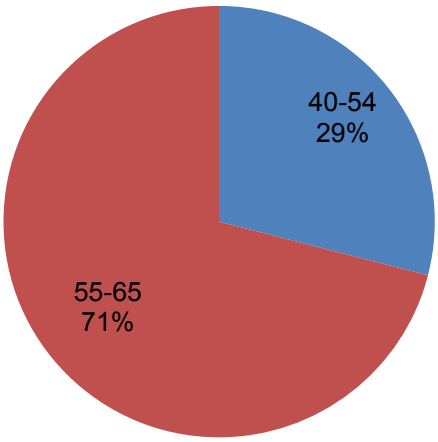

Figure 4.4. Age

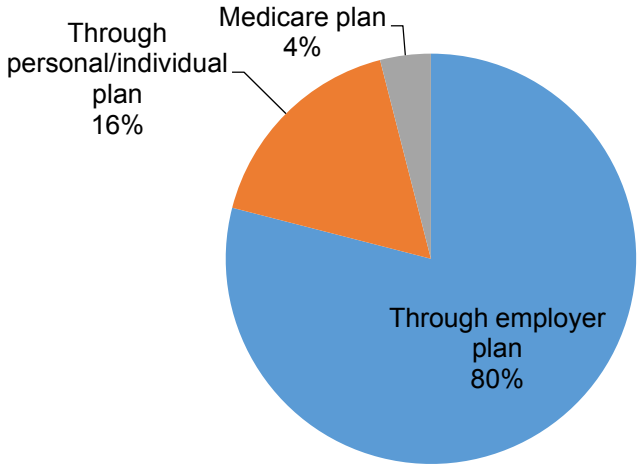

Figure 4.5. Type of health insurance coverage

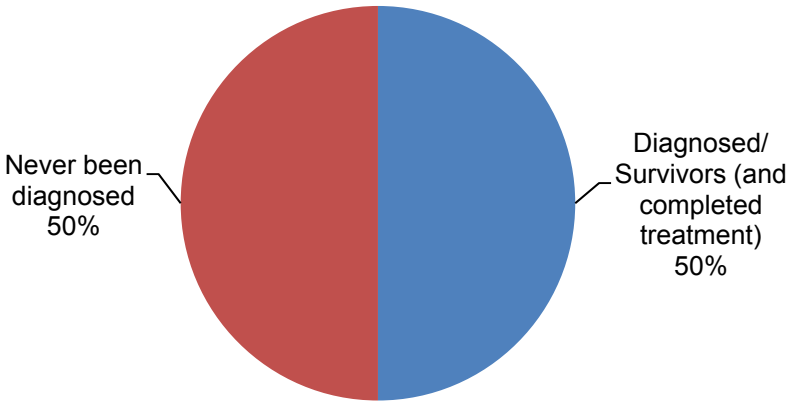

Figure 4.6. Breast cancer diagnosis status

The key assessment questions and variables identified:

1. Context of Personal Health Outlook
2. Understanding of Expectations, Guidelines, Best Practices
3. Perceived Importance of and Motivations for Breast Health and Wellness
4. Barriers
5. Advice for others
6. Access along the continuum of care

As the data collection method, researchers utilized:

- A sampling questionnaire to screen potential candidates via telephone calls and select the 24 women to participate in the one-on-one telephone interviews.
- In-depth, one-on-one telephone interviews with the 24 women.

The rationale for selecting the in-depth, one-on-one telephone interview method of data collection in relation to the target community is that telephone interviews are ideal for complex questions such as those that needed to be answered for Komen Iowa.

Components associated with each data collection method were:

- Audio recording of each in-depth interview, conducted by experienced health care researchers.
- Verbatim transcription of interviews.
- Analysis of the 24 interviews.

In order to gain additional insight about the issues faced by women in the target communities, follow up surveys were conducted with health care coordinators involved with the "Care for Yourself" program. The care coordinators chosen for this follow up survey were those involved with the "Care for Yourself" program in each selected county. This program includes breast health and breast cancer screening services for women aged 40-64 who live at or below 250 percent of the Federal Poverty Guideline. With over 70 percent of the priority counties for Komen Iowa demonstrating higher than average populations that meet those conditions, and noting that participants in the survivor interview survey did not mention "Care for Yourself" as a resource, it was felt that this group of care coordinators could provide valuable insight to the correlations between higher than average rates and key demographic and socio-economic data. The questionnaire format and methodology for the care coordinators was similar to that used for the one-on-one telephone interviews with women from the target communities.

The qualitative data collection methods provide for triangulation of the findings and point to critical needs of the population; see more below in Qualitative Data Findings section of this report.

Sampling

The population of interest for the one-on-one interviews were from Ida, Polk and Pottawatomie Counties (in relation to key questions) included females, age 40-65, who have been screened — including annual physical, clinical breast exam, mammogram — in the past year.

Researchers interviewed women from two categories:

1. Undiagnosed: Those who have never been diagnosed with breast cancer. Women who are screened regularly can provide insight into the importance of breast health before breast cancer diagnosis, suggestions for the screening process, where they go for breast health information and if they are comfortable discussing women's health issues.
2. Diagnosed: Those who have been diagnosed with breast cancer, and have completed treatment. It is noteworthy that the women who completed treatment provide the qualitative voice from survivors regarding what they wish they had known earlier. Researchers sought to sort out, with those who have been diagnosed and treated, the role of screening in their breast cancer diagnosis, treatment and survival — to gain their insight into the process and how they accessed the continuum of care; specifically, what was/wasn't helpful for these women and what might they suggest to improve screening and survival.

Komen Iowa provided a list of women in each of three counties that had previously participated in events such as Race for the Cure, as well as being served by providers and grantees that have a relationship with Komen Iowa. Through this, a simple random sample from among the database was used.

The rationale for selecting sources of data collection included:

- Compliance with HIPAA regulations.
- Speaking with women in rural and urban areas.
- Collecting a sample that reflects county populations.
- Surveying women with knowledge on screening, treatment, diagnosis and follow-up care.
- Interviewing women who live in the three Iowa counties with significantly higher incidence rates than the Affiliate service area.

The sample for the provider interviews were care coordinators involved with the "Care for Yourself" program from the following counties: Bremer, Cass, Dallas, Ida, Keokuk, Madison, O'Brien, Polk and Warren. These counties were selected based on their high rates of breast cancer incidence, late-stage diagnosis and/or death and the correlations seen between those rates and certain demographic and socio-economic data. At least one county from each of the four target areas (Northwest, Northeast, Southwest and Southeast Iowa) was included. Relationships between these higher than average rates and socio-economic conditions such as low educational achievement, unemployment, and linguistic isolation required further investigation. Such an investigation would help to "ground " the perceptions of those surveyed in the interviews described above and allow for more definitive conclusions to be drawn about the underlying causes for higher than average rates in certain counties.

Ethics

For the community and provider interviews, each potential participant was first asked to participate in a short survey, if they agreed, the qualifying survey was conducted.

For the community one-on-one telephone interviews, if the participant met the qualifying criteria, she was invited to participate in a personal one-on-one phone conversation that would last approximately 10-15 minutes. Each participant was informed that in return for her willingness to participate, $125, the equivalent cost of one mammogram, would be donated by Hanser & Associates in her name to Susan G. Komen Iowa.

Respondents that agreed to the full survey were informed that the call would be recorded and remain confidential. Respondents were told there are no right/wrong answers and that the purpose of the survey is to explore perceptions and attitudes toward breast health issues.

Anonymity of sources was protected because a list of sources who agreed to be surveyed had been provided to Komen Iowa, but no patient-specific information was provided to Komen Iowa that would allow for a specific women's responses to be connected back to them.

The procedure for maintaining anonymity also assured that patient-specific data are protected. To protect anonymity, researchers provided a list of the participants separate from the findings.

Qualitative Data Overview

The original data collected by the researchers from the 24 women was in the format of recorded telephone conversations, which were then transcribed.

The rationale for researcher's choice of this data management method is that it allows capture of all relevant information, which could then be reviewed and summarized into a report of the information and relevant, representative excerpts that are most useful and actionable for Komen Iowa.

The themes/categories reported are based on common points participants shared.

Using one method of data collection (telephone interviews) provided an accurate and efficient process to identify the common findings within the qualitative data, especially the clear identification by women who had been diagnosed with breast cancer and have completed treatment.

Interviews were also conducted with breast cancer providers, to get their perspectives, as well.

Common themes identified by women participating in the one-on-one telephone interviews:

- ***Context of Personal Health Outlook (survivors and undiagnosed women)***
    - Participants consider health and wellness to primarily include "watching what they eat," exercising, and "making healthy choices." Many also feel health and wellness includes both body and mind.
    - A representative verbatim quote from participants: *"(Health & wellness) means being proactive and taking care of yourself – mentally, physically, emotionally."*
    - Most participants said they are very engaged in actively managing their health and most often focus on maintaining a healthy weight.
    - A representative quote: *"I watch what I eat; I am pretty health conscious most of the time. I exercise daily."*
    - When asked about how they have learned about their own health and wellness, most participants referenced research and reading as the primary method for learning, but many also mentioned their doctor, family, friends and co-workers.
    - The relationship participants have with their primary health care provider ranges from good to excellent, with most participants classifying their relationship as very good. Survivors mentioned their oncologist most often; undiagnosed women mentioned "family practitioner" or "general practitioner" most often.
    - Representative quote of a survivor: *"I turn to my oncologist more than anybody else."*
    - Many of the participants have a health professional they turn to for questions about their health and wellness. It is not always their primary health provider.
    - Participants have a very high level of trust with their care providers. Some noted that they switched or would switch if there wasn't enough trust.
    - One participant said, *"It (trust) is very good now. When I was initially diagnosed, I went to a different oncologist and took treatment for the whole thing. When I had a recurrence, that person at that time said 'I want to send you to a surgeon right*

away.' I decided to switch oncologists, and I'm much happier with the check-up (current) one."

- Participants believe their care providers are as proactive as necessary in their health and wellness, with some participants saying their care provider is very proactive.
- Many of the participants could recall a recent time when they had discussed women's health issues with friends or family members and are comfortable with discussing women's health issues. This was especially prevalent with participants who are survivors. Representative quote: *"I was a teacher, so I worked around a lot of women at an elementary school. They always talk about (women's health) stuff. I would say that group of women, when I was teaching, were very influential."*
- Most participants' friends and family had some influence on their health care decisions. Often the women were influencers. Some said they listen to their friends and family, but it is their decision and some said no friends and family really influence their decisions.

- ***Understanding of Expectations, Guidelines, Best Practices (survivors)***
  - Most participants feel very well informed about breast health options, like screening, education and resources for assistance and have become advocates. They also said that if they didn't know about something they have a good idea of a starting place to get the information.
  - Representative quote: *"I'm on top of that. I really promoted it with my coworkers and extended family as well, not to take anything lightly and to check mammograms, etc."*
  - Most participants would turn to their provider or to online resources for information. Google was the dominant online resource cited.
  - Representative quote: *"(I turn to) my oncologist; I also search on the Internet, do a lot of reading."*
  - Participants believe screening at the age of 40 and every year after, even if a woman doesn't have a family history of breast cancer is not only realistic, but necessary. Some participants said it should start earlier and that the process should be more thorough.
  - Representative quote: *"… those are good guidelines, and I think that everybody should follow those. I did and do."*
  - Most participants felt their providers were doing enough to encourage them to better follow suggested breast health screening guidelines. The suggestions offered by these women included broader use of reminder systems, including emails and phone calls in advance of scheduled annual screenings.
  - A few participants shared that they wish, earlier on in the process, providers would have been more thorough so they didn't have to go through additional screenings and surgeries. Some participants said that screenings should begin at an earlier age.
  - One participant said,
  - *"I actually got (diagnosed) when I was (age) 36 because of breast exam. So, (age) 40 could be too late for some."*

- ***Perceived Importance of and Motivations for Breast Health and Wellness (undiagnosed women)***
    - Participants felt that, when considering their health as a whole, breast health was important to very important
    - Representative quote: *"I can say (breast health) is toward the top but I consider it as important as the other parts of my health – a priority within a holistic approach to health and wellness*."
    - Most were not very concerned with the risk of breast cancer or other breast health issues, because they believe they are taking the necessary precautions. However, if there was a family history of breast cancer or any abnormal screenings the participants were much more concerned.
    - The participants that cited an experience in their life that had impacted their views on mammograms and screenings said it was related to an experience a friend or family member had with breast cancer. Most participants – all of whom get annual screenings themselves – said they encourage their friends and family to get annual screenings also; these women describe themselves as "advocates" for screening.
    - The most common response concerning why it is important for the participants to get mammograms and screenings is early detection.
    - Participants did not mention the "Care for Yourself" program.
    - Most women believe they are doing enough to monitor their own breast health. A few think they could do more self-exams.

- ***Barriers (survivors and undiagnosed women)***
    - All participants said they, personally, do not have any barriers to getting their annual screenings, but did suggest some potential barriers for other women. Those included:
        - Fundamental barriers such as the costs, time, personal approaches to health and wellness and visibility of breast cancer in their communities
        - Conscious Decision barriers such as other existing health conditions or a lack of family history of breast cancer which leads to a false sense of security about risk
        - Conquerable barriers such as a lack of reminders or anxiety about the screening procedure

- ***Access along the continuum of care (survivors)***
    - Most participants had an excellent care experience from screening to diagnosis, treatment and follow-up. They referenced that people were compassionate and helpful. Participants did mention that it was an overwhelming process that you just have to go through. The most common points of pain were when the experts weren't correct, when the cancer wasn't discovered or properly diagnosed when they felt it should have been and when they felt they were lacking information.
    - Representative quotes:
        - "Everybody I worked with… was very good and helpful (but)… what was lacking was knowing other programs or resources out there."

        - "When you are first diagnosed with any type of cancer, maybe a little bit more education on how to coordinate with the various doctors that you have to see might be very helpful."
        - "I wish there was some way to get it out to more people to let them know they have options for treatment, or they have ways to get there. I wanted to go out and be able to pick the people up and take them to the doctor to get their exams."
    - Most participants knew what to do because their doctors had recommendations that started them on the path. Participants who were treated at a cancer center were more likely to comment on how smoothly the process went and all the ways their coordinator helped them.
    - Most participants selected providers based on recommendations from their physicians.
    - Physicians and cancer centers were also referenced by most participants when asked how they became aware of support/services.
    - Most participants said they had support beyond health care workers, including the help of a care coordinator or social worker. In urban Polk County, the participants' providers were close to home, while more travel and time was needed in rural counties (Ida and Pottawattamie).
    - Most participants did not have any problems finding the time for their care. Many had enough time off or worked part time.
    - Most participants said that their insurance coverage covered most things and wasn't too hard to access their benefits.
    - Representative quote: *"Although I was concerned (about the out-of-pocket cost), my health insurance was pretty good. The thing that I was nervous about was there were times they were slow in approving my treatment… so I was nervous about that, but even if I had to pay out-of-pocket for that I would have done it."*
    - All participants who were employed were able to keep their job.
    - Most participants knew they would have been able to keep their insurance under the Affordable Care Act, only a few did not know. Some cited that they may not have known since this is something they didn't need to deal with, as they were able to keep their jobs.
    - Providers should be very thorough, beginning in the early stages.

- ***Advice for others (survivors and undiagnosed women)***
    - Regarding suggestions to improve screening, diagnosis, treatment and follow-up, participants suggested:
        - Any way to make screenings more comfortable and without pain.
        - One participant said, regarding the misperception of pain, that she advises her friends as follows: *"You might be sore a little bit, but it's nothing more than if you worked out and your muscles were sore (for awhile). And with working out, your muscles are sore for a longer time."*
        - Thoroughness so patients don't receive false negatives or need multiple surgeries.
        - Preventative surgery options.
        - Don't be afraid.
        - Be proactive about your health.
        - Access Internet for more information and options.

        - Transportation programs.
    - Self-check more. Several survivors said "it is definitely important to get a mammogram every year" but also very important for them to give a self-check. One added, "I found (my lump) by doing the self-check two months after I got an OK mammogram … you need to realize if there's something that's not right with your body." ***Note**: Although interviewees expressed the need for breast self-exams (BSE), Susan G. Komen uses breast self-awareness (BSA) messaging because BSE is not an evidence-based practice. To learn more about BSA, go to http://ww5.komen.org/BreastCancer/BreastSelfAwareness.html .*
    - Regarding mobile mammography:
        - Many participants felt mobile mammography would make a difference for others. Some said it would probably be helpful. A few said they didn't think mobile mammography would be helpful, because if other women weren't proactive enough to go in to visit the office of their practitioner, with whom they would be comfortable, participants didn't believe others would be proactive enough to visit the mobile mammography.
        - Most participants who felt mobile mammography would make a difference did not have many ideas about how it should work to be available to the most women, but suggested having it available on nights and weekends, in rural areas, and visiting large employers during office hours.
        - Some participants noted that providers, working in conjunction with large employers, already "bring mammogram units to the office and everything so they're very good and supportive in that."
    - Participants were asked if they could change one thing about their experience, what would it be?
        - Most survivors said that while it was hard and they wish they didn't have cancer, it also changed their outlook and the way they view life and so they wouldn't really want to change anything.
        - Some survivors would want more efficient approval of treatments by their insurance company.

Common themes identified by the "Care for Yourself" care coordinators:

- ***Context of Personal Health Outlook***
    - Most participants said that clients in their area are not very engaged in health maintenance and tend to take a more "reactive" approach. Reminders about screening exams help however, particularly if the coordinator has defined a close relationship with other health care providers in the area to schedule these reminders
    - Most clients learn about their health issues when they are not feeling well and have come into the doctor or clinic setting for treatment.
    - The relationship that clients have with their primary health care provider is very good although connecting providers with resources that can overcome language barriers can become an issue.
    - Some coordinators expressed that they had to help clients overcome a distrust of certain health care providers due to the perception that these providers were associated with a government agency that may question their standing as a legal citizen to receive care.

- Most clients look to the health care coordinator for questions about health and wellness and not always their primary health provider
- Family influence over health care decisions is largely based on a prior family history of health care problems. Representative quote: *"Family history heightens the awareness."*

- ***Understanding of Expectations, Guidelines, Best Practices***
  - Coordinators did not express confidence that screening guidelines are well understood by their clients. They most commonly cited differences in recommended guidelines among cancer serving agencies as the rationale for this finding.

- ***Perceived Importance of and Motivations for Breast Health and Wellness***
  - Coordinators most often expressed the view that while many of their clients understood the importance of screening procedures and early detection, several other factors inhibit the client's ability to acquire breast health and breast cancer services. Most often, these factors had to do with financial access either because of the cost of the procedures, lack of insurance or job demands that did not allow for time off to seek health care services.

- **Barriers**
  - All coordinators were able to describe several barriers they see their clients struggling with to access breast health and breast cancer services. Those barriers included:
    - Language issues among those who do not speak English
    - Lack of insurance or other financial means to pay for needed screening and/or care services
    - Unavailability of reliable transportation to facilities for screening and follow up

- **Access along the continuum of care**
  - Coordinators cited that accessing diagnostic, treatment and follow- up services became much more problematic for their clients than screening services, due primarily to financial access issues.
  - Representative quotes:
    - "The biggest financial burden I see these women facing is a surgical biopsy."
    - "The process of getting financial assistance for specialized care is cumbersome"
    - "Rural economics can be a real strain"
    - "The biggest challenge women face here (in accessing care) is lack of insurance"
    - "Transportation issues are the biggest problem in accessing the continuum of care. Women simply may not have the financial means to afford reliable transportation to get to where they need to go"
  - Many coordinators also cited a lack of information about insurance and how to use insurance in managing care costs as a factor contributing to a certain "frustration" with insurance among their clients.

- The confusion about insurance focused largely on what services are or are not covered, but also cited a lack of clarity about insurance terminology.
- Many clients were first time insurance buyers and needed help in understanding the difference between premiums, co-payment levels and deductibles.

- ***Advice***
  - Regarding suggestions to improve screening, diagnosis, treatment and follow-up, coordinators offered the following:
    - Continue to support appointment reminder systems
    - Develop more language specific materials (particularly Spanish).
    - Provide more support group opportunities for peer to peer interaction among younger breast cancer survivors
    - Share more information with health care providers about options for women to seek financial assistance.
  - Regarding mobile mammography:
    - Some coordinators were uncertain how effective mobile mammography would be in increasing the ability of women to access screening services. As an alternative, additional free clinics in community facilities were cited as being more cost effective in extending screenings services to medically underserved areas.

<u>Qualitative Data Findings</u>

Based on the work done by external researchers with survivors and through the follow up work with Care for Yourself Coordinators, the following considerations will help inform Mission Action planning by Komen Iowa. However, due to the limitations of the data, the perspectives provided represent only those that participated in the surveys and do not represent the general population of the community or providers as a whole.

Access

- Access issues seem to divide broadly into the categories of financial access, geographic access, and information access.
  a. Financial access may be a problem for women in areas with high rates of unemployment, who may be living at or below federally defined levels of poverty income, and are without health insurance. Expanding coverage and sharing knowledge about insurance options and resources for uninsured women may be priorities in these areas
  b. Information access may be challenging for residents who are foreign born and may also be linguistically isolated and/or lack education beyond high school. Coordinated care that helps women understand their situation and options may help overcome language and comprehension barriers. For women with access to technology, social media that supports not only information sharing but breast cancer survivor support may be particularly helpful
  c. Geographic access issues may be a problem for residents of medically underserved counties who need to travel to obtain high quality, comprehensive breast health and breast cancer services. For residents of predominately rural counties who may be engaged in agricultural work, time and travel both become barriers at certain times of the year if sacrifices have to be made to either

agricultural production or health maintenance. Providing convenient locations and rides for women who need transportation could help with these issues

These issues are not stand alone factors but in many cases may be intertwined. For example, geographic access problems can compound financial access issues when considering the time needed to travel to specialized facilities, the loss of work time and pay, and the direct costs of travel and maintenance for those seeking breast health and breast cancer services.

Provider Relationships

- Support efforts to communicate proactively about general health and wellness and breast-health guidelines
- Expand systems for sharing important reminders, including physicals, clinical breast exams and mammograms, and any other events in accordance with guidelines
- Provide education and support options that will improve early detection and diagnosis

The extent towards which women establish a relationship with a trusted health care provider is likely to impact the level of personal responsibility that women take in their health care management. Advice concerning healthy eating habits, exercise, smoking cessation, breast self-awareness and mammography screenings can serve to educate, encourage and empower women to take personal responsibility in mitigating their breast cancer risks. What is key however is the institution and establishment of these relationships.

Where county residents have the financial means, adequate comprehension of information, and convenient access to breast health and breast cancer services, they are also more likely to enter into, establish and retain relationships with health care providers which in turn are likely to enhance their sense of personal responsibility and empowerment. Where such means, comprehension, and convenience are lacking, building these relationships and responsibilities may be less likely to occur.

Encouraging personal responsibility

- Link information about healthy lifestyle choices with risk management
- Clarify and simplify the language about breast health guidelines
- Discuss discomfort and anxiety issues about breast cancer screening in appropriate cultural contexts

Outside influence

- Facilitate peer support groups among survivors and those who may be at risk for breast cancer to encourage screening and follow up treatment

Peer support groups, whether provided in person or through social media, have been referenced as helpful for women struggling with breast cancer issues, including certain emotional and psychological barriers to following proper screening procedures. Opportunities to interact with peers who are dealing with breast cancer has been referred to as therapeutic in the survivorship phase. Women who struggle with emotional barriers to get screened have reported that encouragement from breast cancer survivors is critical in their decisions to overcome emotional and psychological barriers in obtaining breast cancer screening services.

Breast Health and Breast Cancer Findings of the Target Communities

Death rates and late-stage diagnosis data analysis indicates that twenty seven counties in Komen Iowa's service area are not likely to meet either the death rate and/or late-stage incidence rate as prescribed by the United States Department of Public Health Healthy People 2020 objectives. Longitudinal projections as to when these counties might meet these objectives led to prioritizing them as either Highest Priority, High Priority or Medium High Priority target counties. Since such a list represents almost one third of all the counties in the state of Iowa, a geographical grouping of these target counties into quadrants (Northeast, Southeast, Northwest and Southwest) was done to allow for a logistically manageable set of intervention measures.

Further analysis of priority counties in the Affiliate service area found correlations between certain demographics and high rates of breast cancer incidence, late-stage diagnosis and deaths. Of the 27 priority counties identified, 80.0 percent have higher than average populations of women over 40, almost 50 percent have higher than average percentages of low educational achievement, and virtually all of the priority counties are dealing with some combination of higher than average percentages of families living at or below poverty level income in medically underserved areas without health insurance, and likely facing unemployment and/or linguistic isolation.

In order to better understand how these issues may present barriers in accessing services, more information was gathered about where women from each of these four targeted regions go to receive services throughout the Breast Cancer Continuum of Care. The Health Systems and Public Policy Analysis revealed that while the prevalence of screening services in all four target areas is very high, inconsistencies are noted in the degree to which additional services are available along the continuum of care. For example, treatment and support services are more limited for residents of Southeast Iowa which, along with counties in Northwest Iowa, have no nationally accredited breast cancer and breast health facilities to provide a broader range of support.

Iowa public policy has been critical in extending affordable screening services through the Iowa Health and Wellness Plan (Iowa's version of Medicare expansion) and encouraging the work of the Iowa Cancer Consortium to execute the state's Cancer Control Plan. With more women having insurance coverage that provides screening at no cost, fewer women will be needing assistance to pay for screening services. A greater emphasis on outreach and education may be needed however to ensure that those who have newly-acquired insurance coverage will actually move forward to get breast cancer screening and other services. The Iowa Health and Wellness Plan for example, has helped to reduce the number of uninsured Iowans by almost 60,000, yet there are still an estimated 240,000 residents who remain uninsured. Moreover, those who wish to continue receiving services through federally funded programming such as the National Breast and Cervical Cancer Early Detection Program (NBCCEDP), may find that money is still needed to support specific screening or diagnostic-related services. As an example, NBCCEDP does not allow states to pay for computer-aided detection services. In addition, navigation services can be crucial for those that are newly insured or who may not understand how insurance works. Newly insured women may still need prompts to seek the screening that they are now eligible for and guidance on how to navigate the health care system

if abnormal screening results are found. Preserving these basic levels of service for uninsured or underinsured women will be an important part of Komen Iowa's advocacy agenda for the future.

Through qualitative methods conducted for Komen Iowa by independent researchers, several issues were identified for additional study. Interviews of breast cancer survivors from three of the high incidence counties in Iowa suggested a set of issues in accessing services based on certain demographic and socio-economic indicators. Correlating data from counties with higher than average rates of incidence, late-stage-diagnosis and deaths with these demographic and socio-economic indicators led to some suppositions about the conditions which can exist in certain areas to create distinct barriers in accessing services. These access barriers can be subdivided into three categories:

1. Geographic Access Barriers may be a problem for residents of medically underserved counties who need to travel to obtain high quality, comprehensive breast health and breast cancer services. For residents of predominately rural counties who may be engaged in agricultural work, time and travel both become barriers at certain times of the year if sacrifices have to be made to either agricultural production or individual health maintenance.

2. Financial Access Barriers may be challenging for residents of counties with higher than average percentages of unemployed, who may also be living at or below federally defined levels of poverty income, and are without health insurance

3. Information Access Barriers may be encountered by residents who are linguistically isolated and/or lack education beyond high school.

In addition, these demographic and socio-economic factors are often seen in combination in several of the priority counties and may combine in a matrix or "web-like" fashion to create profoundly difficult barriers for accessing breast health and breast cancer services.

In order to get a sense of how pervasive this web of barriers may be, a follow up survey was conducted among care coordinators in nine counties that demonstrated the highest combinations of incidence, deaths and/or late-stage diagnosis with higher than average demographics and socio-economic indicators that were thought to correlate strongly with the access barriers defined above. These interviews did help to validate that women in Iowa face a number of barriers to access breast health and breast cancer services and that the effects of these barriers can be readily seen in areas which have higher than average rates of breast cancer incidence, late-stage diagnosis and deaths.

Mission Action Plan

Defining appropriate interventions in the most severely impacted areas of the Affiliate service area requires the ability to further define the scale and scope of the problems to be dealt with. By subdividing the service area into quadrants, Komen Iowa was able to begin taking a closer look in each of these quadrants which may need priority attention. In addition, the use of incidence, late-stage diagnosis and death rates coupled with correlative demographics and socio-economic indicators was helpful in focusing on very specific problems faced by residents

in each quadrant of the Affiliate service area. This focus was created through the use of a scoring system which assigned one point for each county that had higher than average breast cancer indicators and higher than average demographic and socio-economic correlations. This system yielded the following observations:

Northwest Iowa Target Area Problem Statement
O'Brien County, in the Northwest Target Area, has higher than average rates of incidence, deaths and late-stage diagnosis and these figures correlate with higher than average rates of low educational achievement, poverty level income, and rural isolation, all of which may combine to create Geographic Access, Information Access and Financial Access Issues for county residents seeking breast health and breast cancer care.

Ida County in the Northwest Target Area has percentages approaching twice the average number of the Affiliate in incidence and death rates and these findings are correlated with higher than average percentages of poverty income, low educational attainment and rural isolation.

The demographics and socio-economics of the Northwest Target Area can be generally described as high in concentrations of rural poor, many of whom are also linguistically isolated with low educational achievement. These trends are particularly acute in the counties described above.

Southwest Iowa Target Area Problem Statement
Cass County in the Southwest Target Area has higher than average percentages of late-stage diagnosis and death rates and is likely dealing with Financial Access and Geographic Access issues since their percentages of poverty level income, rural residency and lack of health insurance all exceed the averages for the Affiliate service area

Madison and Warren counties in the Southwest Target Area both have a combination of higher than average rates of incidence, late-stage diagnosis and death rates and also exhibit higher than average percentages of rural residency which may indicate issues stemming from Geographic Access barriers.

Polk and Dallas counties, also in the Southwest Target Area both have higher than average rates of incidence. Polk County also has a higher than average rate of deaths while Dallas County has a higher than average rate of late-stage diagnosis. Both counties have higher than average indicators that correlate with Information access issues and Polk County also has a higher rate of unemployment which may indicate Financial Access issues.

Southeast Iowa Target Area Problem Statement
Keokuk County in the Southeast Target Area has higher than average rates of late-stage diagnosis which may be correlated with both Geographic Access and Financial Access issues stemming from the higher than average percent of the population living in a rural, medically underserved area at or below 250 percent of poverty level income with no health insurance.

Northeast Iowa Target Area Problem Statement
Bremer County in the Northeast Target Area has higher than average rates of incidence, late-stage diagnosis and death rates which may be correlated with Geographic Access arising from the high percentage of residents who live in a rural setting.

Viewed in this way, it would be easy to define the priorities for Komen Iowa according to the ranking for each county on these percentages and correlative indicators. Another look however at the statistics for the burden of breast cancer in Iowa yields a different view. Virtually all of these nine counties have higher than average rates of late-stage diagnosis (88 percent). The most prevalent demographic and socio-economic indicators that are higher than average in these nine counties are those which were used to define Financial Access issues. Four of the nine counties on the list above are dealing with two or more social economic and demographic factors that correlate with higher than average rates of incidence, late-stage diagnosis and deaths. Based on this view, the following additional observations can be made:

1. Of the three indicators of a higher than average breast cancer burden in each county, higher than average rates of late-stage diagnosis are the most prevalent.

2. Demographic and socio-economic indicators of Financial Access issues are the most commonly seen set of data that correlates with areas of higher than average late-stage diagnosis rates.

3. Data which indicates Geographic Access issues are seen in over three-fourths of the counties with high rates of incidence, late-stage diagnosis and deaths.

4. Data indicating Information Access issues are seen in less than half of the counties with higher than average rates of incidence, late-stage diagnosis, and deaths.

The finding regarding correlations between higher than average rates of incidence, late-stage diagnosis and deaths with data indicating Information Access issues should not be interpreted as one that would dismiss such issues from having an impact on the cancer rates. Rather, it indicates that such issues may be compounding higher level correlations between high cancer rates and other access issues.

In view of these findings, Komen Iowa has determined that the problem in the service area is the combination of Financial, Geographic and Information Access issues that create a web of barriers to the Breast Cancer Continuum of Care and requires a battery of initiatives to provide solutions. These barriers are strongly correlated with counties that exhibit the highest rates of late-stage diagnosis which the Affiliate also sees as the most prevalent problem contributing to the burden of breast cancer in the Affiliate service area.

To provide for a manageable set of initiatives, Komen Iowa will seek to break down these barriers both singly and in combination in those counties that exhibit the highest rates of late-stage diagnosis along with the correlating demographic and socio-economic indicators that contribute to one or more of the three sets of Access Issues. The priority assigned to these barriers will be based on how common these indicators are seen in counties that deal with a higher than average indicators of a breast cancer burden.

As stated above, Financial Access issues are the most commonly seen set of data that correlates with areas of higher than average rates of late-stage diagnosis. These issues are driven primarily by the number of county residents who are unemployed and may live at or below federally defined levels of poverty income, and are without health insurance.

To address these problems within each region, Komen Iowa will undertake the following priorities and objectives:

Priority #1 - Decrease the barriers created by Financial Access issues to the breast cancer continuum of care in those counties that demonstrate higher than average percentages of late-stage diagnosis and also demonstrate higher than average percentages of unemployment, poverty level income and lack of health insurance in the following counties:

Northwest Iowa Target Area Counties:

- Buena Vista
- Calhoun
- Ida
- Wright

Southwest Iowa Target Area Counties:

- Adair
- Cass
- Decatur

Southeast Iowa Target Area Counties:

- Decatur

Objective: Beginning with the FY2017 Community Grant Request for Application, funding priorities will include programs that provide financial assistance to individuals seeking breast cancer service from the following counties: Buena Vista, Calhoun, Ida, Wright, Adair, Cass, Decatur and Keokuk.

Objective: From FY16- FY19, on an annual basis, the Affiliate will meet with at least two Iowa policymakers regarding state and federal breast cancer issues and legislation that would increase access to services by decreasing financial barriers.

Priority #2 - Decrease the barriers created by Geographic Access issues to the breast cancer continuum of care in those counties that demonstrate higher than average percentages of late-stage diagnosis and also demonstrate higher than average percentages of residents who live in medically underserved and/or rural areas.

Northwest Iowa Region Counties:

- Buena Vista
- Calhoun
- Ida
- O'Brien
- Wright

Southwest Iowa Region Counties:

- Adair
- Cass
- Decatur
- Madison

Northeast Iowa Region County:

- Bremer

Southeast Iowa Region County:

- Keokuk

Objective: Beginning with the FY17 Community Grant Request for Application, funding priorities will include programs that maximize convenience to access the continuum of care (e.g., transportation, telemedicine, scheduling assistance, and flexible hours of service) for residents of Buena Vista, Calhoun, Ida, O'Brien, Wright, Adair, Cass, Decatur, Madison, Bremer and Keokuk Counties.

Priority #3 - Decrease the barriers created by Information Access issues related to the breast cancer continuum of care in those counties that demonstrate higher than average percentages of late-stage diagnosis and also demonstrate higher than average percentages of linguistic isolation and /or low educational achievement.

Northwest Iowa Region Counties:

- Buena Vista
- Ida
- O'Brien

Southwest Iowa Region Counties:

- Decatur

Objective: Beginning with the FY17 Community Grant Request for Application, funding priorities will include programs that provide multi-cultural education, navigation, reminder services and plain-language resources for residents of Buena Vista, Ida, O'Brien and Decatur Counties.

Objective: From FY16-FY19, annually provide at least two health care providers or community-based organizations in each county (Buena Vista, Ida, O'Brien and Decatur) with resource sheets of where residents can go for continuum of care services along with appropriate breast cancer information brochures/fact sheets.

Objective: By April 2019, the Affiliate will conduct at least two breast cancer educational sessions in each of the following counties: Buena Vista, Ida, O'Brien and Decatur.

References

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SEER Summary Stage. Young JL Jr, Roffers SD, Ries LAG, Fritz AG, Hurlbut AA (eds). *SEER Summary Staging Manual - 2000*: Codes and Coding Instructions, National Cancer Institute, NIH Pub. No. 01-4969, Bethesda, MD, 2001. Available online at http://seer.cancer.gov/tools/ssm/ (accessed 8/2/2013).

Appendices

Appendix A. Survey screening information

Screening Information

Hello, my name is Katelin and on behalf of Komen I am doing a quick two minute survey about women's health issues in Iowa. Komen shared your name with me due to your participation in one of their events like Race for the Cure. Do you have two minutes to answer a few questions? [RECORD GENDER - DO NOT ASK - If a male answers, and is discernibly male, ask if there is an adult female available to speak to.]

Thank you.

Q1 To begin, what is your ZIP code?

Q2 Which of the following best describes your age?

- 18 to 24 [THANK AND TERM]
- 25 to 39 [THANK AND TERM]
- 40 to 54
- 54 to 65
- Over 65 [THANK AND TERM]

Q3 What is your race or ethnic background?

- White/Caucasian
- Hispanic/Latina
- Black/African-American
- Asian
- Other
- Prefer Not to Say

Q4 How many years have you lived in this community

- Less than 5
- 5 to 10
- 11 to 20
- Greater than 20 years

Q5 Do you have health insurance?

- Yes If YES, ask "What sort of insurance do you have:
  - ✓ Paid through my employer
  - ✓ Personal/individual plan that I pay for
  - ✓ Public: Affordable Care Act (Medicare or Medicaid), Iowa Marketplace Choice Plan, Iowa Wellness Plan

Q5 No [flag for follow-up on how they pay]

Q6 In the past year, have you had an annual physical?

- Yes
- No

Q7 In the past year, have you had a clinical breast exam?

- Yes
- No [THANK AND TERM]

Q8 Have you had a mammogram in the past year?

- Yes - Count and continue [PLACE IN "SCREENED" GROUPS]
- No - [THANK AND TERM]

Q9 Have you ever been diagnosed with breast cancer?

- Yes - Count and continue [CONTINUE TO Q10]
- No - Count and continue [PLACE IN "SCREENED" GROUPS]

[IF YES]
Q10 Has your treatment been completed?

- Yes - Count and continue [PLACE IN "SCREENED" GROUPS]
- No - Count and continue [PLACE IN "SCREENED" GROUPS]

Great, thank you!

I would like to invite you to be a part of a personal one-on-one phone conversation regarding your opinions about women's breast health issues and the resources that may be available to you in your community.

Would you be willing to share your opinions in an in-depth phone conversation? Your feedback would remain anonymous and as a token of appreciation for your time to take the in-depth survey, we would like to make a $125 donation (equivalent to the cost of one mammogram) in your name, to Susan G. Komen Iowa Affiliate.

SCHEDULE INTERVIEWS BETWEEN 9AM - 8PM, MONDAY THROUGH FRIDAY
Time: _____
Day of Week: _____
Date: _____

What is the best phone number to reach you at during that time?
Phone number with area code: _____

Thank you very much for your time. (NAME), our interviewer, will call you at your scheduled time.

Have a great day.

Respondent Information / Demographics

Confirm the following:

Name:

Age:

County:

Tenure in the community:

Diagnosed:

- Yes – Count and continue
- No – Count and continue

Screened Past Year:

- Yes - Count and continue
- No - [THANK AND TERM]

Appendix B. In-depth interview discussion guide for diagnosed

Brief Introduction
[NOTES: Moderator Purpose/Objectives of Discussion:
Taping of Call, Objectives (open discussion), Relax; No right/wrong answers,
Purpose is to explore perceptions and attitudes toward breast health issues]

Discussion Thread 1: Context of Personal Health Outlook
Thank you in advance for sharing your feedback with me today.
I'd like to start our conversation by getting a little context for our discussion. To begin, tell me what "health and wellness" means to you. [NOTE: Check for topics including diet, activity and family history.]

PROBE: How engaged would you say that you are in actively managing your health and wellness?

PROBE: Describe specific aspects of your health that you focus on more or are more consciously managing'?

PROBE: Throughout your life, how have you learned about your own health and wellness?

PROBE: How would you characterize your relationship with your primary health care provider?

Do you have a specific provider (such as a doctor, nurse practitioner, physician's assistant, etc.) that you turn to for questions about your health and wellness?

Describe your level of trust with your care provider?

How proactive do you believe your care provider is in your own health care or wellness?

PROBE: Tell me about the last time you discussed women's health issues with your friends or family members? (Follow up with why or why not to evaluate the comfort level of discussing issues with friends and family.)

Describe the influence of your friends and family on your health care decisions?

Discussion Thread 2: Understanding of Expectations, Guidelines, Best Practices
How well informed do you feel about breast health options, like screening and education, and resources for assistance within your community? Where do you turn for information about breast health in your community? (Also, probe use of online resources)

PROBE: National guidelines suggest that women should be screened at the age of 40 and every year after, even if a woman doesn't have a family history of breast cancer. How realistic do you believe it is for you to meet those guidelines?

PROBE: What do you think your health care provider could do to encourage you to seek or better follow suggested breast health screening guidelines?

Discussion Thread 3: Barriers

Now, I'd like to discuss some of the potential challenges to getting screenings and treatment. We'll call these potential "barriers" – challenges that may get in your way. What are the barriers that would prevent you from seeking or getting breast health screenings? How would these barriers hinder or altogether prevent your ability to get screened or seek assistance?

IDENTIFY PERCEPTUAL BARRIERS; EVALUATE WHY BARRIER PRESENTS CHALLENGE AND HOW THAT WOULD ULTIMATELY EFFECT ABILITY TO GET SCREENINGS OR ASSISTANCE WITH TREATMENT:

- Unaware of options
- Mistrust of primary health care provider
- Mistrust or questions about current screening guidelines
- Don't see breast cancer screening as an important way to maintain health
- Perceive mammography to be harmful or ineffective
  Mammograms are ineffective at detecting cancer and mammograms only point out the fact that it will be difficult to find a lesion if one ever appears
-
- Mammograms seem to be a constant reminder of family history/loss of loved one
- Anxiety about the exam itself (discomfort)
- Anxiety about possible diagnosis
- Lack of knowledge about screening process
- Perceived lack of culturally sensitive services

IDENTIFY BARRIERS TO ACCESS; EVALUATE WHY BARRIER PRESENTS CHALLENGE AND HOW THAT WOULD ULTIMATELY EFFECT ABILITY TO GET SCREENINGS OR ASSISTANCE WITH TREATMENT:

- No local health care resources to provide screenings
- Have to travel to get to a health care facility
- Lack of insurance or adequate insurance to cover screenings
- Lack of sufficient coverage for routine mammograms
- Level of deductible is a barrier for screening
- Unaware of local programs to help cover the costs of routine mammograms (for low-income women)
- Unaware of federal or statewide programs to help cover costs of mammograms (for low-income women)
  (If unaware – consider follow-up prompting: Ask if the respondent has heard mammography provisions of:
  - Affordable Care Act (new federal program paying for Medicaid expansion in Iowa)
  - Iowa Wellness Plan (covers adults age 19-64 whose income is at or below 100 percent of Federal Poverty Level)
  - Iowa Marketplace Choice Plan (covers adults age 19-64 whose income from 101 percent through 133 percent of Federal Poverty Level)
- Language barriers
- Didn't know where to get treatment
- Uninsured/underinsured

What would you say was the biggest challenge that you had to overcome with *screening* and diagnosis?

What barriers have you faced in getting your annual screenings, or difficulties that may have made it difficult for you to get your annual screenings?

Discussion Thread 4: Access along the continuum of care

Now let's talk a bit more specifically about your diagnosis and treatment. Tell me about your care experience -- from screening, diagnosis to treatment to follow-up.

PROBE: How did you know what to do? Did you have someone's help in coordinating your care? Was this coordination effective?

How did you select providers?

How did you become aware of support/services?

Did you have support beyond health care workers?

PROBE: Were your providers close to home? How did you find the time?

PROBE: Tell me about paying for all of this care. How was your insurance coverage?

(If employed) Did you keep your job? Did you know you can keep your insurance under the Affordable Care Act?

PROBE: How would you describe the quality of care during diagnosis? Treatment? Follow-up?

PROBE: Based upon your experience, what suggestions would you make to health care providers to improve the process that you have experienced? What else would be helpful to navigate the health care resources?

DISCUSSION THREAD 5: Advice for others

Finally, I'd like to talk briefly about ways your experience can benefit others. What suggestions do you have to improve screening, diagnosis, treatment and follow-up?

PROBE: Do you think mobile mammography (bringing screens to smaller towns or large employers on a weekday) makes a difference? YES/NO

- If YES, How do you think that should work to be available to the most women? And what hours of service would be most convenient for people to access mobile mammography or other needed services?

PROBE: If you could change one thing about your experience, what would it be?

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Appendix C. In-depth interview discussion guide for un-diagnosed

Brief Introduction
[NOTES: Moderator Purpose/Objectives of Discussion:
Taping of Call, Objectives (open discussion), Relax; No right/wrong answers,
Purpose is to explore perceptions and attitudes toward breast health issues]

Discussion Thread 1: Context of Personal Health Outlook
Thank you in advance for sharing your feedback with me today.
I'd like to start our conversation by getting a little context for our discussion. To begin, tell me what "health and wellness" means to you. [NOTE: Check for topics including diet, activity and family history.]

PROBE: How engaged would you say that you are in actively managing your health and wellness?

PROBE: Describe specific aspects of your health that you focus on more or are more consciously managing'?

PROBE: Throughout your life, how have you learned about your own health and wellness?

PROBE: How would you characterize your relationship with your primary health care provider?

Do you have a specific provider (such as a doctor, nurse practitioner, physician's assistant, etc.) that you turn to for questions about your health and wellness?

Describe your level of trust with your care provider?

How proactive do you believe your care provider is in your own health care or wellness?

PROBE: Tell me about the last time you discussed women's health issues with your friends or family members? (Follow up with why or why not to evaluate the comfort level of discussing issues with friends and family.)

Describe the influence among your friends and family on your health care decisions?

Discussion Thread 2: Perceived Importance of and Motivations for Breast Health and Wellness
In considering your health, as a whole, where does breast health fall in terms of importance, as compared to other aspects of your health?

PROBE: How concerned are you, personally, with the risk of breast cancer or other breast health issues?

PROBE: Has there been an experience in your life that has impacted your views on mammograms and screenings? How so?

Why would it be important for you to get mammograms or screenings? What would you consider to be benefits of routine screenings?

PROBE: Do you believe that you are doing enough to monitor your own breast health?

Discussion Thread 3: Understanding of Expectations, Guidelines, Best Practices

How well informed do you feel about breast health options, like screening and education, and resources for assistance within your community? Where would you turn for information about breast health in your community? (Also, probe use of online resources)

PROBE: Talk to me about some of the things you've learned from other organizations about breast health. How has this influenced your approach to your own breast health and wellness?

PROBE: National guidelines suggest that women should be screened at the age of 40 and every year after, even if a woman doesn't have a family history of breast cancer. How realistic do you believe it would be for you to meet those guidelines?

PROBE: In thinking of common guidelines for breast health, what would be areas that you would want to know more about?

What do you not feel well-enough informed about?

What information do you feel you are lacking to make decisions about your own breast health and wellness?

PROBE: What do you think your health care provider could do to encourage you to seek or better follow suggested breast health screening guidelines?

Discussion Thread 4: Barriers

Now, I'd like to discuss some of the potential challenges to getting screenings. We'll call these potential "barriers" – challenges that may get in your way. What are the barriers that would prevent you from seeking or getting breast health screenings? How would these barriers hinder or altogether prevent your ability to get screened or seek assistance?

IDENTIFY PERCEPTUAL BARRIERS; EVALUATE WHY BARRIER PRESENTS CHALLENGE AND HOW THAT WOULD ULTIMATELY EFFECT ABILITY TO GET SCREENINGS OR ASSISTANCE:

- Unaware of options
- Mistrust of primary health care provider
- Mistrust or questions about current screening guidelines
- Don't see breast cancer screening as an important way to maintain health
- Perceive mammography to be harmful or ineffective
  Mammograms are ineffective at detecting cancer and mammograms only point out the fact that it will be difficult to find a lesion if one ever appears
-
- Mammograms seem to be a constant reminder of family history/loss of loved one
- Anxiety about the exam itself (discomfort)
- Anxiety about possible diagnosis

- Lack of knowledge about screening process
- Perceived lack of culturally sensitive services

IDENTIFY BARRIERS TO ACCESS; EVALUATE WHY BARRIER PRESENTS CHALLENGE AND HOW THAT WOULD ULTIMATELY EFFECT ABILITY TO GET SCREENINGS OR ASSISTANCE:

- No local health care resources to provide screenings
- Have to travel to get to a health care facility
- Lack of insurance or adequate insurance to cover screenings
- Lack of sufficient coverage for routine mammograms
- Level of deductible is a barrier for screening
- Unaware of local programs to help cover the costs of routine mammograms (for low-income women)
- Unaware of federal or statewide programs to help cover costs of mammograms (for low-income women)
  (If unaware – consider follow-up prompting: Ask if the respondent has heard mammography provisions of:
  - Affordable Care Act (new Iowa program for Medicaid expansion)
  - Iowa Wellness Plan (covers adults age 19-64 whose income is at or below 100 percent of Federal Poverty Level)
  - Iowa Marketplace Choice Plan (covers adults age 19-64 whose income from 101 percent through 133 percent of Federal Poverty Level)
- Language barriers
- Didn't know where to get treatment

What would you say was the biggest challenge that you had to overcome with screenings?

What barriers have you faced in getting your annual screenings, or difficulties that may have made it difficult for you to get your annual screenings?

DISCUSSION THREAD 5: Advice for others

Finally, I'd like to talk briefly about ways your experience can benefit others. What suggestions do you have to improve screening?

PROBE: Do you think mobile mammography (bringing screens to smaller towns or large employers on a weekday) makes a difference? YES/NO

- If YES, How do you think that should work to be available to the most women? And what hours of service would be most convenient for people to access mobile mammography or other needed services?

PROBE: If you could change one thing about your screening experience, what would it be?

Appendix D. In-depth interview discussion guide for "Care for Yourself" coordinators

Brief Introduction
[NOTES: Purpose/Objectives of Discussion:
(open discussion), Relax; No right/wrong answers,
Purpose is to explore perceptions and attitudes toward breast health issues

Discussion Thread 1: Context of Personal Health Outlook
Thank you in advance for sharing your feedback with me today.
I'd like to start our conversation by getting a little context for our discussion. To begin, tell me what "health and wellness" means to your clients. [NOTE: Check for topics including diet, activity and family history.]

PROBE: How engaged would you say that people you work with are actively managing

their health and wellness?

PROBE: Describe specific aspects of health that people focus on more or are more consciously managing?

PROBE: How do people you work with learn about their health and wellness?

PROBE: How would you characterize their relationships with health care providers?

Do they have a specific provider (such as a doctor, nurse practitioner, physician's assistant, etc.) that they turn to for questions about health and wellness?

Describe the level of trust they have with their care provider.How proactive do you believe care providers are in managing health care or wellness?

PROBE: Tell me about the last time you discussed women's health issues with a client (Follow up with why or why not to evaluate the comfort level of discussing issues with friends and family.)

Describe the influence of friends and family on health care decisions.

Discussion Thread 2: Understanding of Expectations, Guidelines, Best Practices
How well informed do you feel people you work with are about breast health options, like screening and education, and resources for assistance within your community? Where do they turn for information about breast health in your community? (Also, probe use of online resources)

PROBE: National guidelines suggest that women should be screened at the age of 40 and every year after, even if a woman doesn't have a family history of breast cancer. How realistic do you believe it is for people you work with to meet those guidelines?

PROBE: What do you think health care providers could do to encourage following breast health screening guidelines?

Discussion Thread 3: Barriers
Now, I'd like to discuss some of the potential challenges to getting screenings and treatment. We'll call these potential "barriers" – challenges that may get in the way. What are the barriers that you see prevent people from seeking or getting breast health screenings? How would these barriers hinder or altogether prevent the ability to get screened or seek assistance?

IDENTIFY PERCEPTUAL BARRIERS; EVALUATE WHY BARRIER PRESENTS CHALLENGE AND HOW THAT WOULD ULTIMATELY EFFECT ABILITY TO GET SCREENINGS OR ASSISTANCE WITH TREATMENT:

- Unaware of options
- Mistrust of primary health care provider
- Mistrust or questions about current screening guidelines
- Don't see breast cancer screening as an important way to maintain health
- Perceive mammography to be harmful or ineffective
  Mammograms are ineffective at detecting cancer and mammograms only point out the fact that it will be difficult to find a lesion if one ever appears
-
- Mammograms seem to be a constant reminder of family history/loss of loved one
- Anxiety about the exam itself (discomfort)
- Anxiety about possible diagnosis
- Lack of knowledge about screening process
- Perceived lack of culturally sensitive services

IDENTIFY BARRIERS TO ACCESS; EVALUATE WHY BARRIER PRESENTS CHALLENGE AND HOW THAT WOULD ULTIMATELY EFFECT ABILITY TO GET SCREENINGS OR ASSISTANCE WITH TREATMENT:

- No local health care resources to provide screenings
- Have to travel to get to a health care facility
- Lack of insurance or adequate insurance to cover screenings
- Lack of sufficient coverage for routine mammograms
- Level of deductible is a barrier for screening
- Unaware of local programs to help cover the costs of routine mammograms (for low-income women)
- Unaware of federal or statewide programs to help cover costs of mammograms (for low-income women)
  (If unaware – consider follow-up prompting: Ask if the respondent has heard mammography provisions of:
  - Affordable Care Act (new federal program paying for Medicaid expansion in Iowa)
  - Iowa Wellness Plan (covers adults age 19-64 whose income is at or below 100 percent of Federal Poverty Level)
  - Iowa Marketplace Choice Plan (covers adults age 19-64 whose income from 101 percent through 133 percent of Federal Poverty Level)
- Language barriers
- Didn't know where to get treatment
- Uninsured/underinsured

What would you say was the biggest challenge that people you work with have in overcoming barriers to screening and diagnosis?

What barriers have they faced in getting annual screenings, or difficulties that may have made it difficult to get annual screenings?

Discussion Thread 4: Access along the continuum of care

Now let's talk a bit more specifically about diagnosis and treatment. Tell me about your care experience with people you work with-- from screening, diagnosis to treatment to follow-up.

PROBE: How did they know what to do? Do they have someone's help in coordinating care? Was this coordination effective?

How do they select providers?

How do they become aware of support/services?

Is there support beyond health care workers?

PROBE: Are providers close to home? How do people you work with find the time?

PROBE: Tell me about paying for all of this care. What is insurance coverage like in this area?

Do people know they can keep their insurance under the Affordable Care Act?

PROBE: How would you describe the quality of care during diagnosis? Treatment? Follow-up?

PROBE: Based upon your experience, what suggestions would you make to health care providers to improve the process that people experience in this area? What else would be helpful to navigate the health care resources?

DISCUSSION THREAD 5: Advice for others

Finally, I'd like to talk briefly about ways your experience can benefit others. What suggestions do you have to improve screening, diagnosis, treatment and follow-up?

PROBE: Do you think mobile mammography (bringing screens to smaller towns or large employers on a weekday) makes a difference? YES/NO

- If YES, How do you think that should work to be available to the most women? And what hours of service would be most convenient for people to access mobile mammography or other needed services?

PROBE: If you could change one thing about the experience for breast cancer survivors in this area, what would it be?

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