



COMMUNITY PROFILE REPORT

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2011

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- Maine's Cancer Consortium
- Maine's State Cancer Registry
- Eastern Maine Healthcare Systems Planning Department
- Eastern Maine Medical Center – Cancer Registry
- Eastern Maine Medical Center – Performance Improvement & Data Management

Sources of Qualitative Data

- [Healthy Maine Partnerships](#)
- [Calais Reach to Recovery](#)
- [American Cancer Society](#)
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- [Maine Center for Disease Control and Prevention](#)
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Executive Summary

Introduction

The Maine Affiliate of Susan G. Komen for the Cure® began as a Susan G. Komen Race for the Cure® event in 1997 in Bangor and was officially incorporated as a Komen Affiliate in 1999. Our service area covers the entire State of Maine. During our fourteen years of service, the Komen Maine Affiliate has strived to educate Maine men and women about breast cancer risk and make a positive difference in cancer-related public policy.

Since inception, the Komen Maine Affiliate has invested more than \$2.25 million in education, screening and treatment programs in the State of Maine, as well as \$650,000 to breast cancer research through the Susan G. Komen for the Cure® Grants Program.

The purpose of this biennial Community Profile is to provide a resource of information regarding breast health and breast cancer in the State of Maine. This report creates an overview of the continuum of care, including breast health education, screening and treatment access in our target communities. The results of the 2011 Community Profile will inform decisions of the Komen Maine Affiliate regarding strategic planning, educational efforts, granting priorities, public policy efforts and other activities.

Statistics and Demographic Review

A variety of sources were used for data analysis, including the 2010 U.S. Census, National Cancer Institute's State Cancer Profiles, the 2010 OneMaine Community Health Needs Assessment, Thomson-Reuters research and data from the State of Maine. We made an effort to not only seek out a variety of statistical data for comparison, but also speak to a wide variety of people from our target communities for their perspectives in the gaps in services.

The State of Maine is not racially diverse, but is culturally and economically diverse, based on the population and development of various areas of the state. Coastal areas tend to be dominated primarily by fishing and tourism, while northern Maine has more farming communities and southern Maine has a more diverse economic base and larger population. Surrounded completely by Canada on both northeastern and northwestern borders, Maine is somewhat unusual in the Komen Affiliate network.

Maine is currently the "oldest" state in the U.S., with a median age of 42.2 – well above the U.S. median age of 36.5. Not surprisingly, the largest employment sector in Maine is healthcare. Over 52% of Maine households fall below the state's poverty level.¹

Maine ranks the 3rd highest in the U.S. for women 40 and over having a mammogram in the last two years. Incidence rates for the state are 65.4% for Stage I, 27.1% for Stage

II, 3.3% for Stage III and 4.2% for Stage IV. Rates across all counties are consistent with the state percentages. While mortality rates for breast cancer are trending down statewide, Washington and Hancock Counties remain the two highest. We looked at where people were falling out of the system specific to the continuum of care and recommendations and plans are based on those findings.

Health Systems Analysis

Key Informants were selected initially based on our past and present grantee lists, specifically those who serve our target counties. Each interview garnered further information and suggestions for additional interviews. Informants included current and former grantees (Caring Connections, Maine Breast Cancer Coalition, Beth C. Wright Cancer Resource Center); state agencies (Maine Breast and Cervical Health Program); as well as other funding organizations (American Cancer Society, Maine Cancer Foundation).

The asset map was created through a careful inventory of breast health education, screening, treatment programs in Washington and Hancock Counties, as well as breast cancer survivor support groups and other services. Although our target communities are Washington and Hancock Counties, many of those living there must travel to Penobscot County for services at CancerCare of Maine.

The main issues uncovered in key informant interviews were insurance, communication among organizations, transportation, lack of grant writing expertise and stigma about getting help.

Not only is a lack of insurance an issue for some, but being under-insured is as well. High premiums, low coverage and high deductibles are the norm for those trying to provide insurance for themselves (i.e. self-employed) or those who work for small businesses.

Communication and collaboration among organizations exists, but more of it would avoid duplication of efforts and gaps in coverage that these areas face. Open dialog and sharing of information is key.

Transportation to treatment for rural communities was a common theme throughout nearly every interview and focus group.

Another factor cited as the private and independent nature of rural Maine citizens and the stigma surrounding receiving financial assistance of any kind. Some view this as welfare and refuse it outright, while others are embarrassed to take advantage of it and worry that their neighbors will find out.

All issues noted above point to gaps in the continuum of care at the point after diagnosis, when treatment is required. There are programs in place, but as eluded to

above, there is a lack of communication among stakeholders. Building partnerships and collaborations are key to the success of all effected organizations.

Qualitative Data Overview

One focus group was conducted in each of the target communities, Washington and Hancock Counties. Each focus group was recruited in different ways, depending on the community and the situation. Held in public venues and welcoming to all who wished to join, the purpose of conducting the focus groups was to back up findings from key informant interviews, as well as to identify common themes for the issues facing these communities.

The first focus group was arranged through an existing community group who call themselves the Washington County Cancer Action Group. A newly formed group, their mission is that a person diagnosed with cancer in Washington County have access to up-to-date treatment information and resources, a voice in their treatment options, reliable transportation and support systems that will help them through their cancer journey. There were twelve participants in this focus group. Participants included three breast cancer survivors, one man whose wife died of breast cancer, a social worker, a hospice worker, etc.

The second focus group was conducted at the Barn Castle Restaurant in Blue Hill (Hancock County) with pizza and beverages served as the incentive. This meeting proved more of a challenge, as we were attempting to draw members of the public to the event. Flyers were made and distributed in person to local businesses. These interactions alone served, in some fashion, as individual interviews, as all business owners were interested in the project and engaged in lengthy discussions about the barriers to treatment. Five members of the public participated in the actual focus group meeting. Participants included one breast cancer survivor and her husband (co-survivor), a woman whose mother passed away from breast cancer, founder of Don't Lose Heart, and the head of the Women's Health Center at Blue Hill Memorial Hospital.

Komen Maine also conducted an online survey, specifically of survivors. Questions on the survey were developed after meeting with key informants and the Washington County focus group. As we had begun to get a sense of common barriers to accessing care, the goal was to see how widespread the issues were and if there were common themes throughout the service area. 445 surveys were distributed via email, with survey monkey used as the collection device. We had a 16.9% response rate, or 75 responses. All respondents were asked for their zip codes to identify their county of residence. Of the 75 respondents, 12% were from one of our target communities.

Key themes that developed from these focus groups covered both cultural issues and access to care and were very similar to those revealed in the key informant interviews.

A cultural issue that surfaced was the independence and isolation of rural Maine people and how there's a "Maine culture of taking care yourself." Rural life has changed in the

last several decades, whereas generations of family would have lived in the same area years ago, now younger generations tend to move away. This leaves older individuals to fend for themselves, but not wanting to “bother” their neighbors or share private information. Women, also, tend to put others first, which means that if money is limited, they are more likely to spend it on others in their family than on themselves.

Transportation reigned as the top concern of those residing in Washington County. This theme was found in both interviews and the focus group. Although Washington County is home to two hospitals (in Machias and Calais), breast cancer treatment is nearly non-existent (blood tests and other preparations for treatments can be done there). Most breast cancer patients must travel to Maine Coast Memorial Hospital in Ellsworth (Hancock County), or to Cancer Care of Maine in Brewer (Penobscot County) for treatment. Although there are some programs that address transportation, they are not always convenient or available to these communities.

Knowledge of existing services was an issue for both counties. There is no one place to find information about cancer patient services, and at times internet access can be a challenge for rural communities. This issue is related to the communication and collaboration between organizations, which was cited in key informant interviews. If more collaboration and cross-promotion of services took place, patients would have multiple opportunities for discovery.

Just as we saw in key informant interviews, insurance was cited as an issue by focus groups, primarily for uninsured and under-insured. The unemployed, self-employed, employees of small businesses and undocumented individuals face specific hardships when it comes to insurance and do not always qualify for public programs.

Action Plan

Based on the findings of this assessment, the Komen Maine Affiliate has developed the following priorities and action plan. Action steps were developed using SMART goals that we feel are achievable given our mission and current resources and are steps that can be built upon in future years as the Affiliate grows.

Priority 1: Increase opportunities for breast health awareness and breast cancer services through outreach, grants, resources, and awareness.

- **ACTION: Outreach**

Increase the Komen Maine Affiliate’s capacity for community outreach as well as rebuild and strengthen volunteer mission committees.

- **ACTION: Grants**
Develop and conduct an annual grant writing workshop, which will not only inform potential grantees of the Komen granting process, but also provide a baseline of information regarding grant writing best practices and techniques.
- **ACTION: Resources**
Develop an online resource list of current local breast health resources for komenmaine.org.
- **ACTION: Awareness**
Through a network of volunteers and community partners, ensure that doctor's offices, mammography centers and other appropriate locations have access to and display breast health education information.

Priority 2: Develop and foster effective community collaborations and partnerships among breast health stakeholders in order to address barriers to education and access to care.

- **ACTION: Collaboration**
Encourage collaboration and non-duplication of services through the Komen grant-making process, with a focus on Washington and Hancock Counties, related to the specific barriers to treatment outlined in this Community Profile (including transportation, patient navigation and insurance gaps).
- **ACTION: Partnership**
Participate in community groups who are already trying to come up with some solutions for issues in Washington and Hancock Counties and encourage community groups where none exist.
- **ACTION: Partnership**
Conduct a meeting with major cancer program funders and service providers in Washington and Hancock Counties to discuss the outcomes of this assessment and ways the needs can be addressed.

Priority 3: Support efforts to both maintain existing resources and foster new solutions addressing the barriers to treatment identified in Washington and Hancock Counties through legislative action.

- **ACTION: Public Policy**

Support and spearhead public policy efforts to protect existing programs for the uninsured.

- **ACTION: Advocacy**

Recruit volunteers to populate our Public Policy Committee. Develop a list of volunteers and train them on grassroots advocacy efforts.

Introduction

Susan G. Komen for the Cure® History

Nancy G. Brinker promised her dying sister, Susan G. Komen, she would do everything in her power to end breast cancer forever. In 1982, that promise became Susan G. Komen for the Cure® and launched the global breast cancer movement. Today, Komen for the Cure is the world's largest grassroots network of breast cancer survivors and activists fighting to save lives, empower people, ensure quality care for all and energize science to find the cures. Thanks to events like the Komen Race for the Cure®, we have invested more than \$1.9 billion to fulfill our promise, becoming the largest source of nonprofit funds dedicated to the fight against breast cancer in the world.

Affiliate History

The Maine Affiliate of Susan G. Komen for the Cure® began as a true grassroots effort. The first Susan G. Komen Maine Race for the Cure® event took place in 1997 in Bangor, Maine, organized by a few women hoping to make a difference. That race drew nearly 500 participants and enabled the Affiliate to grant nearly \$40,000 to the local community in 1998. The Maine Affiliate of Susan G. Komen for the Cure® was incorporated as a Komen Affiliate in 1999, at which time it recruited its first Board of Directors.

The Susan G. Komen Race for the Cure® continues to be the Affiliate's largest fundraiser. The Bangor Race has seen tremendous growth in the last five years, drawing over 5,600 participants and raising over \$330,000 in 2010. That year also marked a great milestone for the Komen Maine Affiliate: the first Race held in Portland, Maine. The Komen Maine Affiliate was one of only five Komen Affiliates to conduct a second Race in 2010, a first in Susan G. Komen for the Cure history. The inaugural Portland Race was a great success, drawing over 1,300 participants and raising over \$130,000. These events, in addition to other fundraising strategies, enabled the Affiliate to grant \$345,000 in FY11, the highest in Affiliate history, as well as invest over \$114,000 in research through the Susan G. Komen for the Cure® Grants Program.

Since inception, the Maine Affiliate of Susan G. Komen for the Cure® has invested more than \$2.25 million in education, screening and treatment programs in the State of Maine, as well as \$650,000 in research. To date, nearly \$500,000 has returned to the state in the form of research grants through Komen's grant program.

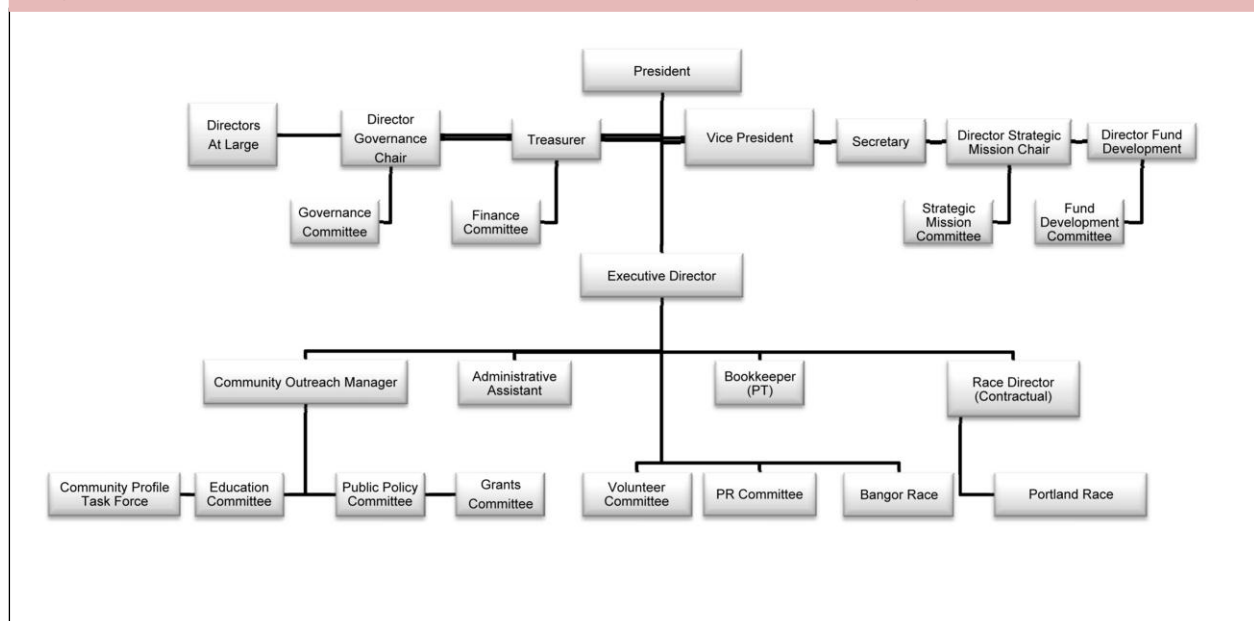
Throughout our history, the Komen Maine Affiliate has made great efforts to not only grant funds to community partners, but to spread the breast health message ourselves, through health fairs, speaking engagements, fundraisers and other avenues. The recent hiring of a Community Outreach Manager will allow us to take these efforts to the next level.

Organizational Structure

The Komen Maine Affiliate has seen steady growth over the years, hiring its first part-time employee in 2007 and first full-time Executive Director in 2009. Now entering our fifteenth year, the Affiliate recently hired its third full-time employee. Therefore the staff now consists of an Executive Director, Administrative Assistant, Community Outreach Manager and part-time Bookkeeper. In 2011, we also hired a Race Director for the Portland Race, to help this new event expand public relations and sponsorship reach.

As staffing levels have changed, board structure has changed as well. The Komen Maine Affiliate is in the final stages of moving from an operational board structure to a strategic, or governing board, structure. Figure 1 below illustrates the board, staff and committee structure that will be in place once this transition is complete.

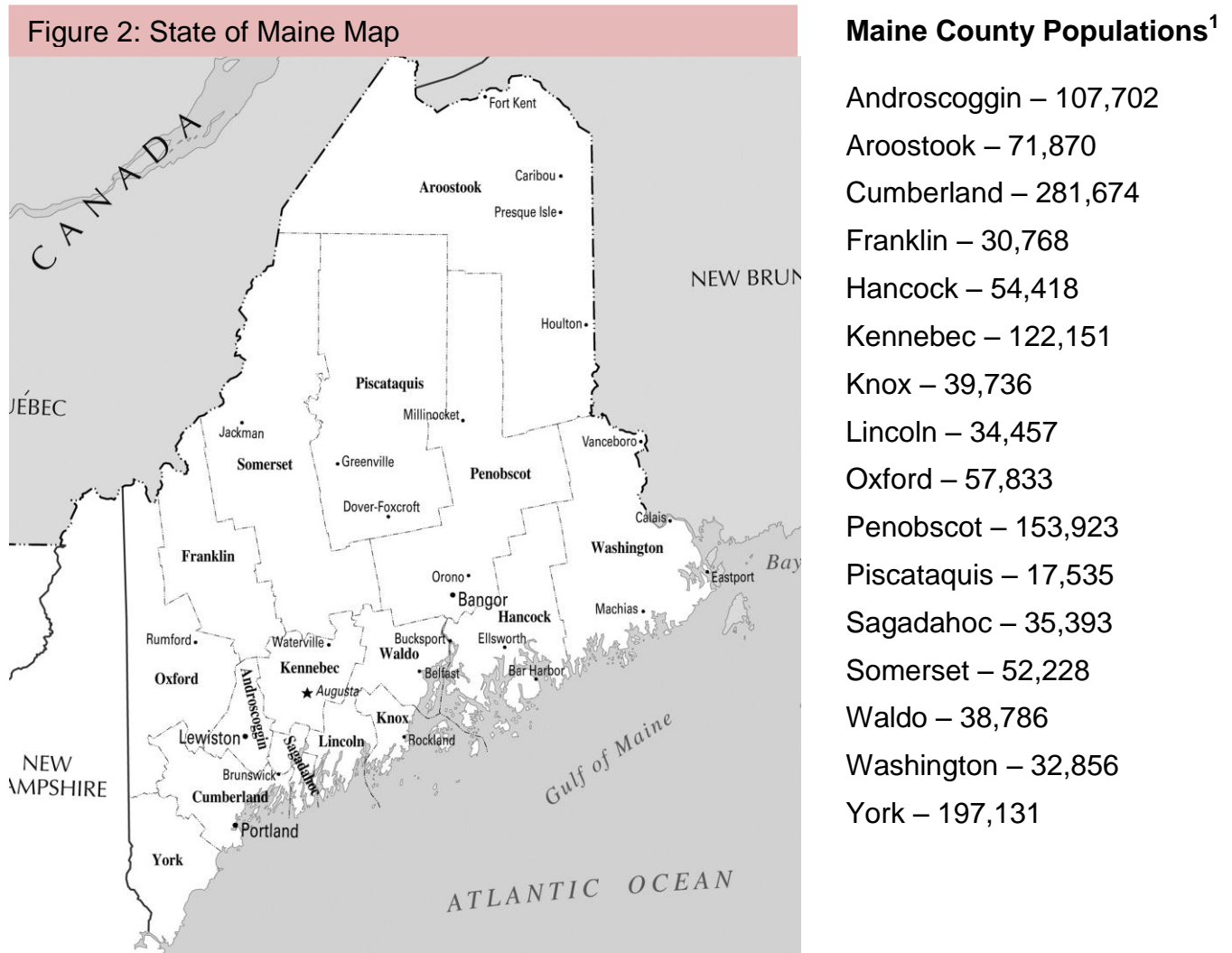
Figure 1: Maine Affiliate of Susan G. Komen for the Cure® Organizational Chart



Still primarily a volunteer organization, committee chairs and members work with staff to implement operational activities of the organization, including fundraising, education, public policy and grants.

Description of Service Area

The Komen Maine Affiliate’s service area is the entire State of Maine (see Figure 2).



The State of Maine is the United States’ northeastern tip, bordering New Hampshire to the southwest, the Atlantic at the southeast and the Canadian provinces of Quebec to the northwest and New Brunswick to the northeast. Maine has one major highway, Interstate 95, which travels from the southernmost tip in York to Houlton. Maine’s total population is 1,328,461.¹

¹ 2010 U.S. Census

There are distinct cultural, economic and demographic differences throughout the state's sixteen counties. Out of the top twelve most populated cities in Maine, Bangor is the only city north of Augusta, the State Capital. Said another way, 61% of Maine's population resides in the seven counties on the southwestern tip, roughly Augusta south (York, Cumberland, Androscoggin, Sagadahoc, Lincoln, Kennebec and Knox). Consequently, southern Maine and everything north of Augusta are often referred to as "two Maines" by those who live in either area.

Purpose of this Report

The purpose of this biennial Community Profile is to provide a resource for information regarding breast health and breast cancer in the Komen Maine service area. This report creates an overview of the continuum of care, including breast health education, screening and treatment access in our communities.

This Community Profile builds upon information collected in previous studies and focuses attention on two of the most underserved counties in our state. Information contained in this document has been collected from local, state and federal resources for quantitative analysis. The 2011 Profile further develops our qualitative analysis, including key informant interviews and focus groups in our target areas, thus getting to the core of the issues as described by the residents of those areas themselves.

The results of the 2011 Community Profile will inform decisions of the Komen Maine Affiliate regarding strategic planning, educational efforts, granting priorities, public policy efforts and other activities.

Disclaimer

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

Breast Cancer Impact in Affiliate Service Area

Methodology

Our primary sources of data for demographics, incidence and mortality are listed below, numbered as the references throughout this section.

1. 2010 U.S. Census
2. National Cancer Institute's State Cancer Profiles
3. 2010 OneMaine Community Health Needs Assessment
4. Thomson-Reuters research for Susan G. Komen for the Cure®
5. State of Maine Department of Labor
6. Wikipedia

Overview of the Affiliate Service Area

Maine is, overall, a rural state, with 61% of its population in the seven southernmost counties. The state is not significantly racially diverse. As Figure 3 shows below, 97% of the female population describe themselves as Caucasian. However, undocumented individuals would include migrant workers who tend to work in the seasonal industries, such as blueberries.

Figure 3: Maine County Population by Gender and Ethnicity⁴

County	2009 Female Population	% White Females	% Black Females	% American Indian Females	% Asian Pacific Islander Females	% All Other Females	% Hispanic Females
Cumberland	141,977	94.9%	1.3%	0.2%	1.3%	0.9%	1.3%
York	103,913	97.8%	0.4%	0.1%	0.6%	0.4%	0.7%
Penobscot	77,362	97.2%	0.4%	0.6%	0.7%	0.6%	0.6%
Kennebec	62,452	97.9%	0.2%	0.1%	0.5%	0.6%	0.6%
Androscoggin	54,793	95.7%	1.2%	0.2%	0.5%	1.3%	1.1%
Aroostook	36,512	97.4%	0.3%	0.7%	0.5%	0.3%	0.6%
Oxford	29,555	98.5%	0.2%	0.1%	0.3%	0.5%	0.4%
Hancock	26,528	97.6%	0.3%	0.1%	0.5%	0.9%	0.6%
Somerset	26,517	98.4%	0.2%	0.2%	0.3%	0.7%	0.3%
Knox	20,639	98.6%	0.1%	0.2%	0.2%	0.4%	0.5%
Waldo	19,791	98.7%	0.2%	0.1%	0.3%	0.3%	0.4%
Sagadahoc	18,576	96.4%	0.8%	0.1%	0.6%	1.0%	1.1%
Lincoln	17,815	99.0%	0.0%	0.2%	0.2%	0.2%	0.4%
Washington	16,888	94.4%	0.2%	3.4%	0.3%	0.6%	1.0%
Franklin	15,256	98.6%	0.1%	0.1%	0.4%	0.4%	0.4%
Piscataquis	8,527	98.6%	0.1%	0.2%	0.2%	0.5%	0.4%
MAINE	677,101	97.0%	0.6%	0.3%	0.7%	0.7%	0.8%

All Maine counties contain a disproportionately elderly population, relative to other age demographics. Maine is currently the “oldest” state in the U.S., with a median age of 42.2 – well above the U.S. median age of 36.5. The counties with the highest proportion of people age 65 and older are in the North and East.³

Figure 4: Maine Household Income by County⁴

		Income	Income	Median
	2009	Below Poverty Level	Below Poverty Level	Household
County	Families	Families	%	Income
Cumberland	71,690	3,970	5.5%	\$55,683
York	55,973	3,511	6.3%	\$53,265
Penobscot	40,707	4,202	10.3%	\$41,812
Kennebec	33,437	2,876	8.6%	\$44,367
Androscoggin	29,393	2,154	7.3%	\$45,295
Aroostook	21,182	2,141	10.1%	\$35,634
Oxford	16,441	1,472	9.0%	\$41,232
Hancock	15,327	1,085	7.1%	\$44,913
Somerset	15,136	1,760	11.6%	\$38,266
Knox	11,370	762	6.7%	\$47,430
Waldo	11,175	1,239	11.1%	\$43,433
Lincoln	10,316	719	7.0%	\$47,035
Sagadahoc	10,293	763	7.4%	\$53,243
Washington	9,429	1,382	14.7%	\$32,093
Franklin	8,189	863	10.5%	\$38,249
Piscataquis	5,079	572	11.3%	\$35,343
MAINE	365,137	29,471	8.1%	\$46,678

Over 52% of Maine households fall below the state’s poverty level.⁴ Figure 4 to the left breaks household income down by county, further clarifying the differences between northern and southern Maine.

However, Maine’s seasonally adjusted unemployment rate is 8.1%. This is down from a peak of 9.4% and still below the US average of 9.5%.⁵

Given these seemingly contradictory statistics, it can be said that many Maine citizens are underemployed.

Currently, the health care industry is the largest employment sector in Maine, with approximately 84,200 positions in 2008. Nursing and residential care positions account for the majority of health care employment in Maine – much higher than the national

percentage - due primarily to the high ratio of elderly patients. This trend is expected to continue in both the short- and long-term. The Maine Department of Labor estimates an increase in demand for physician services of 22%, as well as a pronounced increase in demand for specialty care (e.g. cardiologists, other internal subspecialties) within the

Figure 5: Incidence by County and Stage⁴

County	2009 Female Per 100K Pop Rate	Stage I %	Stage II %	Stage III %	Stage IV %
Lincoln	146	65.90%	26.60%	3.30%	4.20%
Cumberland	141.58	65.30%	27.20%	3.30%	4.20%
Sagadahoc	141.14	65.30%	27.20%	3.30%	4.20%
Oxford	139.39	65.60%	26.90%	3.30%	4.20%
York	137.03	65.40%	27.10%	3.30%	4.20%
Knox	132.39	66.00%	26.50%	3.30%	4.30%
Androscoggin	131.18	65.40%	27.10%	3.30%	4.20%
Piscataquis	127.56	65.80%	26.70%	3.30%	4.20%
Washington	120.42	66.00%	26.50%	3.30%	4.30%
Hancock	119.18	65.60%	26.90%	3.30%	4.20%
Franklin	118.06	65.20%	27.30%	3.30%	4.20%
Kennebec	118	65.40%	27.10%	3.30%	4.20%
Waldo	115.84	65.40%	27.10%	3.30%	4.20%
Somerset	115.79	65.50%	27.00%	3.30%	4.20%
Aroostook	109.69	65.90%	26.60%	3.30%	4.30%
Penobscot	109.18	65.20%	27.30%	3.30%	4.20%
MAINE	128.3	65.40%	27.10%	3.30%	4.20%

next two decades. This demand will be especially explicit in areas that have aging populations and shortages of needed health professionals – namely, in rural communities located outside of the metropolitan areas of Portland and Bangor.³

Maine’s screening statistics continue to be positive. For women age 40 and over, Maine ranks 3rd for the highest percentage to report having a mammogram in the past two years. For women 50 and over, Maine drops to 4th place.²

Incidence of breast cancer at all stages is fairly consistent across all counties (see Figure 5 to the left).

Mortality rates, however, show a large disparity among counties in Maine. Although across 2003 to 2007 mortality due to breast cancer decreased by 2.7%, and Maine’s age adjusted mortality is in the lowest quartile nationally @ 20.3 (national is 22.8)², Washington, Hancock and Androscoggin Counties had breast cancer mortality rates higher than the national rate.⁴ Figure 6 on the next page demonstrates the wide range of mortality rates in the state. The three counties in red show rates above the national rate, while those in pink highlight the eight counties below the Maine average.

Figure 6: Mortality Rate by County⁴

County	2009 Female Population	Mortality Per 100K Pop Rate
Washington	16,879	28.71
Hancock	26,519	24.96
Androscoggin	54,777	23.67
Lincoln	17,832	23.31
Cumberland	141,982	23
Kennebec	62,454	22.85
Piscataquis	8,528	22.75
York	103,952	22.51
Oxford	29,575	21.24
Penobscot	77,365	21.02
Franklin	15,268	20.78
Somerset	26,527	20.62
Knox	20,652	19.84
Aroostook	36,506	19.57
Sagadahoc	18,563	18.34
Waldo	19,768	16.9
MAINE	677,147	22.15
USA	155,475,902	23.61

Washington County

Sometimes referred to as the “Sunrise County” because it is the easternmost county in the United States, and it is often where the rising sun first shines on the 48 contiguous states. Many small seaside communities have small scale fishing-based economies. Tourism is also important along the county’s shoreline, but it is not as important as elsewhere in the state⁶ (primarily due to distance from I-95).

Compared to the rest of the state, Washington County reported the highest percentage of obese residents (33% vs. 28%), a high percentage of sedentary lifestyle reporting (25% vs 21%) and a high percentage of chronic heavy drinking reported in the last month (7.8% vs 6.4%).³

37% of residents in Washington County are enrolled in Medicaid.³ Washington County also has the highest percentage of uninsured females in the state (16.2% vs. 10.1% for Maine as a whole).

Hancock County

Hancock County has the longest coastline of any Maine county. Commercial fishing and tourism are the county’s most important industries.⁶ Although Hancock’s inland areas have many similarities to Washington County, Hancock has more breast health and breast cancer services, as well as closer proximity to Bangor/Brewer, the location of [Cancer Care of Maine](#).

Hancock County has a high percentage of no usual source of medical care (26% vs. 18% for Maine) and, similarly, a high percentage of adults with no checkup in the past two years (13% vs. 10% for Maine). Hancock residents also report a high percentage of prescription drug misuse (13% vs. 11% for Maine).³

CONCLUSION

The State of Maine is not racially diverse, but is culturally and economically diverse, based on the population and development of various areas of the state. Coastal areas tend to be dominated primarily by fishing and tourism, while northern Maine has more farming communities and southern Maine has a more diverse economic base and larger population. Surrounded completely by Canada on both northeastern and northwestern borders, Maine is somewhat unusual in the Komen Affiliate network.

Maine is currently the “oldest” state in the U.S., with a median age of 42.2 – well above the U.S. median age of 36.5. Not surprisingly, the largest employment sector in Maine is healthcare. Over 52% of Maine households fall below the state’s poverty level.¹

Maine ranks the 3rd highest in the U.S. for women 40 and over having a mammogram in the last two years. Incidence rates for the state are 65.4% for Stage I, 27.1% for Stage II, 3.3% for Stage III and 4.2% for Stage IV. Rates across all counties are consistent with the state percentages. While mortality rates for breast cancer are trending down statewide, Washington and Hancock Counties remain the two highest per 100K population rate.

Given that incidence data are fairly consistent across all Maine counties, the disparity in mortality rates is particularly perplexing. For this reason, we chose to focus on Washington and Hancock Counties, the two counties with the highest mortality rates.

Health Systems Analysis of Target Communities

Overview of Continuum of Care

In this section, we analyze information collected from Washington and Hancock Counties themselves, through key informant interviews and asset mapping. In order to fully understand the information offered, however, it is important to keep the continuum of care in mind. Continuum of care simply refers to the course of actions involved in the

Figure 7: Continuum of Care

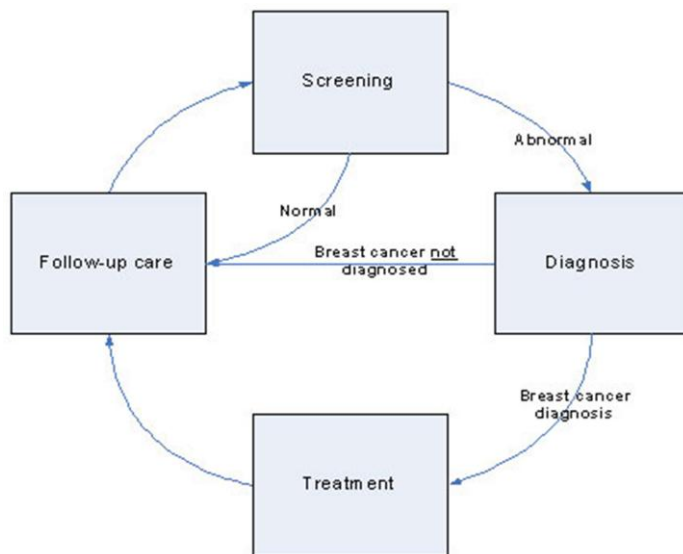


Illustration provided by Susan G. Komen for the Cure®

breast cancer screening (and if necessary, treatment) process. As illustrated in the diagram to the left (Figure 7), the continuum of care is an ongoing process. If a diagnosis occurs and treatment takes place, follow up care and screening continues. The continuum of care should be considered when identifying the barriers to screening and treatment, because a breakdown in one phase in a certain geographic area can influence the statistics found in the quantitative analysis.

Methodology

The asset map was created through a careful inventory of breast health education, screening, treatment programs in Washington and Hancock Counties, as well as breast cancer survivor support groups and other services. Although our target communities are Washington and Hancock Counties, many of those living there must travel to Penobscot County for services at CancerCare of Maine.

Key Informants, listed on our Acknowledgements page, were selected initially based on our past and present grantee lists, specifically those who serve our target counties. Each interview garnered further information and suggestions for additional interviews. Informants included current and former grantees (Caring Connections, Maine Breast Cancer Coalition, Beth C. Wright Cancer Resource Center), state agencies (Maine Breast and Cervical Health Program), as well as other funding organizations (American Cancer Society, Maine Cancer Foundation).

Time was our biggest limiting factor in gathering qualitative data. Interviewees were welcoming and appreciative of the chance to be heard, and we fully intend to continue expanding this dialog on a year-round basis through our new Community Outreach Manager.

Overview of Community Assets

Hancock County is home to three hospitals:

1. Maine Coast Memorial Hospital, Ellsworth, www.mcmhospital.org
 - a. Offering digital mammography, breast surgery (but not reconstruction), chemotherapy and home health services.
2. Mount Desert Island Hospital, Bar Harbor, www.mdihospital.org
 - a. Offering digital mammography, chemotherapy (an oncologist takes appointments one day per week), and home health services.
3. Blue Hill Memorial Hospital, Blue Hill, www.bhmf.org
 - a. Offering digital mammography, breast surgery (but not reconstruction), chemotherapy, radiation and home health services.

Washington County is home to two hospitals:

1. Calais Regional Hospital, Calais, www.calaishospital.com
 - a. Offering mammography and home health services.
2. Downeast Community Hospital, Machias, www.dech.org
 - a. Offering mammography and home health services.
 - b. The State of Maine put this hospital in receivership in July of 2009, with Eastern Maine Healthcare Systems (which owns CancerCare of Maine) out of Bangor as the receiver. Doug Jones, who was named by EMH as interim CEO, was recently voted in as permanent CEO in December 2010 by the hospital's new Board of Trustees. At this time, CancerCare of Maine does not provide services at this hospital.⁷

A past (2010) grantee, [Beth C. Wright Center](#), is a primary player in providing women's health education, in both Washington and Hancock Counties. They collaborate a great deal with other organizations, including [Caring Connections](#) at the Bangor Y, to provide support group services in the target communities as well.

A review of community assets in Washington and Hancock Counties would not be complete without mention of Eastern Maine Medical Center's [CancerCare of Maine](#). Although located in Brewer (outside Bangor, in Penobscot County), CCOM serves as the primary source of cancer treatment in northern and eastern Maine. In December of 2009, CCOM opened the new state-of-the-art Lafayette Family Cancer Center. It houses outpatient medical oncology, radiation oncology, hematology, and diagnostic services - including a blood laboratory, basic imaging, and PET-CT scanning on the first two floors. The new facility provides a healing and supportive environment for patients,

⁷www.dech.org

families, and staff. With plenty of natural light, landscaped gardens, incredible views of nearby Copeland Hill, and both communal and private space in which patients can receive treatment, find support from other patients and families, meet with providers, or find quiet, personal moments of reflection, the new CancerCare of Maine anticipates the variety of needs cancer patients experience during the course of treatment.⁸

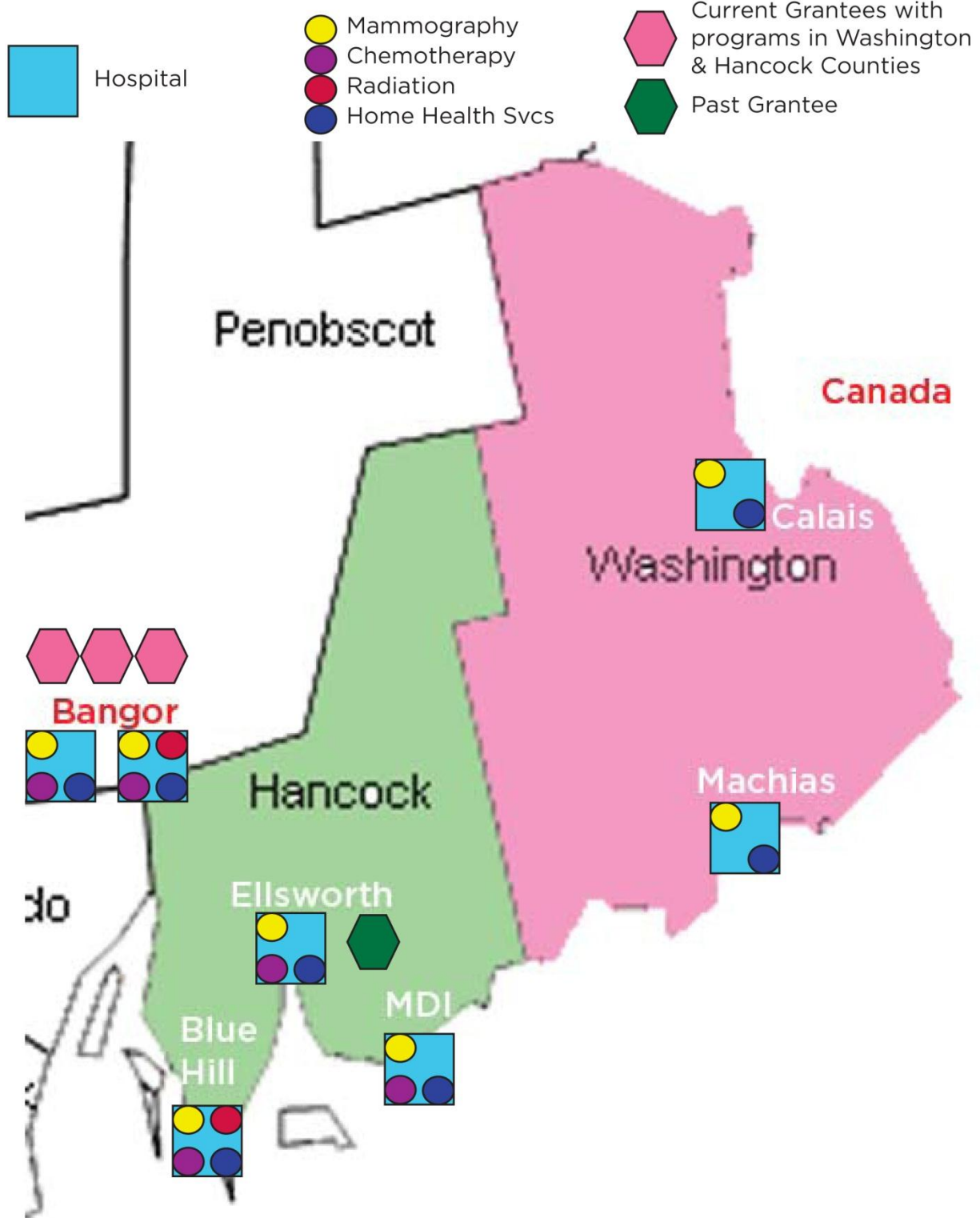


CancerCare of Maine's new home includes upgraded radiation treatment and simulation technologies, which are the first of their kind in Maine. New technologies include:

- RapidArc, which was approved by the FDA in January 2008 and delivers ultraprecise image-guided intensity-modulated radiotherapy (IMRT) two to eight times faster than the IMRT in use in other Maine sites. This approach spares healthy tissue while effectively treating the tumor;
- Stereotactic Radiation Treatment/Surgery, delivers a large, but precise radiation dose to a small tumor area and greatly reduces treatment times for some patients and helps protect health tissue surrounding the tumor;
- Large Bore Computed Tomography, significantly improves patient comfort during the process of delineating tumors and treatment planning;
- Frameless Radiotherapy, maintains precision in the treatment of brain tumors without the need for an invasive Stereotactic head frame (which requires a frame screwed into the skull to immobilize the head). Frameless radiotherapy has been shown to have levels of accuracy on par with the frame-based approach, but with less patient discomfort.⁸

CancerCare of Maine is the source of all cancer treatment options in the northeast region's hospitals, including those available in our target communities.

Asset Map



Public Policy Efforts

Primarily our positions relate to breast cancer research, early detection, and access to high-quality care. From time to time, we may also comment on other health-related topics and sign onto letters other organizations have published, which we feel have may have an impact on the breast cancer community. The Komen Maine Affiliate participates in the American Cancer Society's Lobby Day at the Maine State Capital each year and strives to collaborate as much as possible on public policy issues.

The 2011 legislative session included several noteworthy issues that affected quality of care. In particular, the Maine Breast and Cervical Health Program, which serves over 6,100 Maine women, sustained a cut of \$60,000. This cut, representing 16 percent of the state's funding for the program, eradicated funds for the program's outreach work. There was also a proposal to cut MaineCare (the state's Medicaid program) benefits by reducing eligibility; however, this proposal was defeated.

When the state cuts to the MBCHP were proposed, Komen HQ and the Komen Maine Affiliate provided testimony and reached out to state legislators. As identified in our community profile, knowledge of essential resources and access to care are key issues in Maine, especially in our rural counties, and we remain concerned that the elimination of funding for MBCHP's educational outreach will diminish both access to care and people's knowledge about the important service provided by MBCHP.

Key Informant Interview Findings

Although the questions asked of key informants were open-ended to garner a wide variety of responses, the results of the interviews uncovered very similar themes across the board. The themes are discussed below, not necessarily in the order of importance.

1. *The under-insured*

Who is the least likely to get regular breast screening? Uninsured individuals at relatively higher income levels (i.e. self-employed) and under-insured individuals with high deductibles. They don't qualify for MaineCare or other public insurance options, but cannot afford private insurance.

2. *Communication among organizations*

There are many organizations out there providing services, but there are both gaps and duplication of services because of a lack of coordination of effort.

"I have no problem with ten organizations doing ten different kinds of transportation {programs} as long as it is coordinated, but there is no coordination of services in Washington and Hancock Counties now. People like to say they are independent and rural, but the services are duplicated and costly."

3. *Transportation*

Transportation to treatment for rural communities was a common theme throughout nearly every conversation we had during the research phase.

- “If you live 100 miles away from available services, then getting to treatment is an issue no matter what”
- “If you don’t have a great car, or money, or don’t feel good... that just adds to the problem.”
- “Everything is so spread out, there is no one answer to the problem.”

4. *Grant writing expertise*

In smaller community hospitals and health centers, they don’t necessarily have professional grant writers on staff. When applying for funding, it is often the project manager who writes the grant proposal as well as administers the program if money is received.

- “There isn’t a lot of grant writing expertise out there. Not connected to the resources to be able to help them. The people interested in smaller grants... I’m not sure they have the expertise to do grant writing.”

5. *Stigma about getting help*

Some key informants felt that rural Maine communities have very private, independent residents and there is a stigma related to getting financial help.

- “A lot of people think of it as welfare.”
- “There’s something in tied up in getting a free service and I don’t want people in my hometown to know. So if I live in Dover and I might be able to get into a MBCHP provider, but I’ll come down to the Center for Family Medicine instead so people won’t know I’m getting help.”
- “I actually had a woman from Hancock County say to me that she didn’t want to go to Blue Hill or Ellsworth because she knew people who worked there.”
- “It’s a pride thing.”
- One woman tells a story of an employee at the post office asking how she was because she had received a letter from Caring Connections.

CONCLUSION

Key Informants were selected initially based on our past and present grantee lists, specifically those who serve our target counties. Each interview garnered further information and suggestions for additional interviews. Informants included current and former grantees (Caring Connections, Maine Breast Cancer Coalition, Beth C. Wright Cancer Resource Center); state agencies (Maine Breast and Cervical Health Program); as well as other funding organizations (American Cancer Society, Maine Cancer Foundation).

The asset map was created through a careful inventory of breast health education, screening, treatment programs in Washington and Hancock Counties, as well as breast cancer survivor support groups and other services. Although our target communities are Washington and Hancock Counties, many of those living there must travel to Penobscot County for services at CancerCare of Maine.

The main issues uncovered in key informant interviews were inadequate insurance, communication among organizations, transportation, lack of grant writing expertise and stigma about getting help.

The issues noted above point to gaps in the continuum of care at the point after diagnosis, when treatment is required. There are programs in place, but as explained above, there is a lack of communication among stakeholders. Building partnerships and collaborations is key to the success of all affected organizations.

Breast Cancer Perspectives in the Target Communities

Methodology

One focus group was conducted in each of the target communities, Washington and Hancock Counties. Each focus group was recruited in different ways, depending on the community and the situation. Held in public venues and welcoming to all who wished to join, the purpose of conducting the focus groups was to back up findings from key informant interviews, as well as to identify common themes for the issues facing these communities.

Focus group questions mirrored themes already identified through key informant interviews, without driving discussion to particular issues. An open format allowed participants to steer the discussion. Each focus group had a facilitator and a note taker and lasted between 90-120 minutes, depending on the group.

Attempts were made to conduct additional focus group meetings in both counties, without success. Time limitations and a lack of willing volunteers in these areas to rally participants proved the most challenging. A plan is already in place to expand these efforts for the 2013 Community Profile.

The first focus group was arranged through an existing community group who call themselves the Washington County Cancer Action Group. A newly formed group, their mission is that a person diagnosed with cancer in Washington County have access to up-to-date treatment information and resources, a voice in their treatment options, reliable transportation and support systems that will help them through their cancer journey. They were originally brought together out of a common need to overcome barriers to accessing cancer treatment of people in Washington County, and they welcomed Komen's interest in the local area. This facilitated meeting was held at Machias Savings Bank in Machias and gas gift cards were used as gifts of appreciation / incentives for the group's participation. There were twelve participants in this focus group. Participants included three breast cancer survivors, one man whose wife died of breast cancer, a social worker, a hospice worker, etc.

The second focus group was conducted at the Barn Castle Restaurant in Blue Hill (Hancock County) with pizza and beverages served as the incentive. This meeting proved more of a challenge, as we were attempting to draw members of the public to the event. Five members of the public participated in the actual focus group meeting. Participants included one breast cancer survivor and her husband (co-survivor), a woman whose mother passed away from breast cancer, founder of Don't Lose Heart, and the head of the Women's Health Center at Blue Hill Memorial Hospital.

In preparation for the second focus group, flyers were made and distributed in person to local businesses. The resulting interactions alone served, in some fashion, as individual interviews, as all business owners were interested in the project and engaged in lengthy discussions about the barriers to treatment.

Komen Maine also conducted an online survey, specifically of survivors. Questions on the survey were developed after meeting with key informants and the Washington County focus group. As we had begun to get a sense of common barriers to accessing care, the goal was to see how widespread the issues were and if there were common themes throughout the service area. 445 surveys were distributed via email, with survey monkey used as the collection device. We had a 16.9% response rate, or 75 responses. All respondents were asked for their zip codes to identify their county of residence. Of the 75 respondents, 12% were from one of our target communities.

Review of the Qualitative Findings

Lack of information and access to care were the main themes from both counties. However, Washington and Hancock County did differ in which was the primary issue.

Cultural Issues

1. Independence and putting others first

Rural populations, through necessity, tend to be fiercely independent, hard-working, private and at times isolated. While the sense of community can be strong in these areas, there's a "Maine culture of taking care of yourself."

"I don't want to bother other people or keep them too long."

Another reality of rural life that is becoming more prevalent is a lack of family in the immediate area. Years ago, families tended to stay in the same community and help each other at times of need. Today, more and more young people find that they have to leave a rural community to find work, or simply have the desire to live elsewhere. This leaves many older populations relying on friends and neighbors for help.

"Everyone is busy and may not have time to help."

Women, especially, put others first in their lives and seldom request help. A key informant commented that she often hears women say that the cost of screening would be a "waste" if it turns out that nothing is wrong... better to spend it on more immediate concerns, like a child's braces.

Access to Care

2. Transportation

Transportation reigned as the top concern of those residing in Washington County. This theme was found in both interviews and the focus group. Although Washington County is home to two hospitals (in Machias and Calais), breast cancer treatment is nearly non-existent (blood tests and other preparations for treatments can be done there). Most

breast cancer patients must travel to Maine Coast Memorial Hospital in Ellsworth (Hancock County), or to Cancer Care of Maine in Brewer (Penobscot County) for treatment.

Examples of distances to travel for treatment:

- 112 miles, Machias to Ellsworth, round trip
- 174 miles, Machias to Brewer, round trip
- 185 miles, Calais to Ellsworth, round trip
- 196 miles, Calais to Brewer, round trip

Comments from survey and focus groups:

- “We can’t pay for gas and our car is so old.”
- “Too much travel. I was always trying to find a ride. It took everything out of me and my family.”
- “The roads are bad and the weather is awful in the winter.” Winter driving often caused the cancelation of appointments.
- A cancer patient’s physical condition after a few treatments rendered her completely exhausted and riding to Bangor was a challenge (let alone driving).
- Certain programs will not reimburse for travel if the ride is provided by a relative instead of a volunteer (stranger). Most patients opt to have friends and relatives drive them instead.
- “When we try to arrange rides, some people would be in treatment all day and others just a little while. When you are sick and exhausted, it would be nice to have a comfortable place to wait for a ride.”

The Washington County Group has discussed opportunities to provide transportation, but HIPAA guidelines prohibit treating institutions from providing needed information. They must rely on those institutions to provide information to the patients.

Some respondents in Hancock County cited the cost of gas and transportation as issues, but local treatment options are more prevalent for residents near the coast of that county.

3. Knowledge of existing services

Residents of both counties reported a lack of knowledge regarding services available. Although there is some collaboration among organizations, the general public does not necessarily have access to one source of information on what is available. Some complained of inconsistent information from doctors, while others commented on being overwhelmed by the information received after diagnosis. Internet access in rural areas was a factor for some in the search for information.

Our online survey of breast cancer survivors indicated:

- Over 73% of survey respondents had never heard of the 211 system for obtaining health and human services directory information.
- Only 4.1% had called 1-877-GO-KOMEN, Susan G. Komen for the Cure®'s information hotline.
- 20% did not use the internet as a resource at all.
- 80.8% of respondents used books as their primary source of breast cancer information, while only 72.6% received information from their doctors. 52.1% and 39.7% relied on friends and family, respectively, for breast cancer information.

“We used everyone and everything to find information, knowing some of it was probably out of date, but then probe further to find out more.”

Comments from focus groups:

- “I didn’t know what was available. I drove to Bangor to get a procedure and later found out it was available in Calais. I did not know I had a choice.”
- If the doctor says I have to go to Bangor, I go to Bangor.
- There’s no one system of dispersing information.
- There was a great deal of discussion about a mentoring (or patient navigator) program and how helpful it would be to rural communities.

4. Insurance

Because coastal communities tend to have fishing and tourism industries, they are home to a large number of self-employed individuals. These entrepreneurs are not only independent individuals, but also self-supporting, which means days off for treatment and many times insurance coverage can be issues. Self-employed citizens often “fall through the cracks” because they make too much money to be eligible for public health programs, but cannot afford insurance.

Employees of small businesses, as well, can have insurance issues. Some small businesses do not offer health insurance, while others offer it with a very high deductible. Again, these individuals may have difficulties making ends meet when faced with a cancer diagnosis.

Conclusions: What We Learned, What We Will Do

Review of the Findings

Analysis of both quantitative and qualitative data revealed key gaps in the continuum of care. While the top issues vary for each target county, similar themes are found throughout. The point in which residents seem to fall out of the continuum of care is not at screening, but treatment after diagnosis. Access to and knowledge of the necessity for regular screenings does not appear to be as much of an issue for Washington and Hancock Counties as access to and knowledge of services after diagnosis. The strongest contributing factor appears to be access to care, both in distance to services and transportation to get to them. Other factors that presented themselves as obstacles to care were insurance and a culture of independence among rural and coastal communities. The need for additional communication among organizations and agencies about available services, and the development of new collaborations, is apparent. There is a danger of duplication of effort and gaps in services when not everyone is sitting at the table. Knowledge among organizations of existing services is sometimes lacking, which means that complete information is not being shared with patients either. Patient navigation is an excellent way to disseminate information, but resources are lacking for such staff.

Conclusions

These findings have informed the action plan below by providing a framework of priorities we can use in developing programs and collaborations in the next two years.

Susan G. Komen for the Cure® and its Affiliates strive to be part of the solution by encouraging working relationships and collaborations between organizations. By working together, we can make a significant difference in the lives of Maine women and men.

Create S.M.A.R.T. Goals



In the development of this action plan, we were careful to develop only SMART goals that are Specific, Measurable, Achievable, Realistic and Timely. With a limited staff going through a transitional period, it is important to set attainable goals that can make a significant impact using the resources currently at our disposal.

The hiring of a Community Outreach Manager will be critical to achieving these goals, however proper training and development of that position is equally critical.

The Komen Maine Affiliate will commit significant time and effort to the achievement of these goals, with the hope of building upon them in the years to come.

Action Plan

Priority 1: Increase opportunities for breast health awareness and breast cancer services through outreach, grants, resources, and awareness.

- **ACTION: Outreach**

Increase the Komen Maine Affiliate's capacity for community outreach as well as rebuild and strengthen volunteer mission committees.

Education Committee: Our volunteer base is the strength of our organization, but our current education programs are being implemented by a small number of them. Our goal is to recruit eight new active members to the education committee by January of 2012, and to recruit a committee chair in that same time. Working with the committee, we will establish a formal process for succession planning by March of 2012.

Grants Committee: We will work to define the new roles of the grants committee members, recruit a committee chair, as well as develop succession planning process. Our goal is to develop these definitions and processes for implementation in the 2012-13 grants cycle.

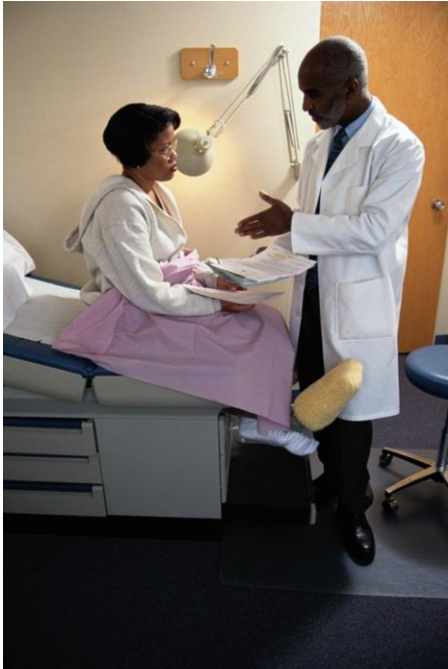
- **ACTION: Grants**

Develop and conduct an annual grant writing workshop, which will not only inform potential grantees of the Komen granting process, but also provide a baseline of information regarding grant writing best practices and techniques. Workshops will utilize webinar technology in order to bring the content to the desktops of potential grantees, rather than forcing them to drive to a workshop location. Regional trainings will be offered to those without the technology to participate in this way. Goal is to utilize webinar technology for the 2012-13 grants cycle and fully develop the best practices training for 2013-14.

Although helpful to understand the specific requirements of Komen grant applications, the Komen Maine Affiliate grant writing workshops have not historically included grant writing instruction at its core. One finding from key informant interviews is that those seeking funding in rural communities are not always well trained on the best practices of grant writing. Writing a grant proposal can be quite intimidating, and by providing this information, we plan to receive applications from five applicants who have never before applied for a Komen grant.

- **ACTION: Resources**

Develop an online resource list of current local breast health resources for komenmaine.org.



As a statewide organization, the Komen Maine Affiliate has a certain responsibility to keep ourselves and our community up to date on breast health programs and services throughout our catchment area. In the past attempts have been made to print books detailing the state's breast health resources, but unfortunately those lists became out of date very quickly and frequent publication is costly. Though parts of rural Maine lack comprehensive broadband coverage, we believe that putting such a list online, where it can be maintained and updated, is a positive, if imperfect, way to address this challenge.

We will start by developing the list for Washington and Hancock Counties by March 2012, and expand the list to cover the entire state by March 2013. The list will be reviewed annually and can also be updated as needed, since the resources are constantly evolving. We will recruit and train one or more volunteers for the purposes of developing and maintaining this list as part of the project, as well as utilize our community partners as resources.

- **ACTION: Awareness**

Through a network of volunteers and community partners, ensure that doctor's offices, mammography centers and other appropriate locations have access to and display breast health education information. Goal to develop list of those offices and make initial outreach contact to them by March 2013.

Although mammography rates are good in Maine, an effort to maintain, or improve upon, those rates should always be in effect.

Priority 2: Develop and foster effective community collaborations and partnerships among breast health stakeholders in order to address barriers to education and access to care.

- **ACTION: Collaboration**

Encourage collaboration and non-duplication of services through the Komen grant-making process, with a focus on Washington and Hancock Counties, related to the specific barriers to treatment outlined in this Community Profile (including transportation, patient navigation and insurance gaps).



- **ACTION: Partnership**

Participate in community groups who are already trying to come up with some solutions for issues in Washington and Hancock Counties (e.g. Washington County Cancer Action Group) and encourage community groups where none exist.

Embracing existing collaborative efforts and continuing to listen to the people of our target counties is crucial to expanding our efforts in these areas. Becoming a regular member of these groups is important to the long-standing relationship and demonstration of commitment by the Komen Maine Affiliate. During the research phase of this project, Komen was welcomed with open arms and residents of these areas sincerely appreciated being heard. We need to continue these efforts as an ongoing part of our mission fulfillment.

- **ACTION: Partnership**

Conduct a meeting with major cancer program funders (e.g. Susan G. Komen for the Cure, Maine Cancer Foundation, etc.) and service providers (e.g. Cancer Care of Maine, American Cancer Society, Beth C. Wright Center, Caring Connections, etc.) in Washington and Hancock Counties to discuss the outcomes of this assessment and ways the needs can be addressed. Focus discussion specifically on transportation and an action plan for coordination of resources in one location. Goal is to schedule meeting by December 31, 2011.

Bringing all players to the table is essential in further identifying gaps in services, avoiding the duplication of effort and determining next steps to find solutions to the problems facing our target communities. While our initial focus would remain Washington and Hancock Counties, opening this sort of dialog will lead to additional collaborations and discussions for other rural areas of Maine. Goal is to convene a statewide meeting by December 31, 2013.

Priority 3: Support efforts to both maintain existing resources and foster new solutions addressing the barriers to treatment identified in Washington and Hancock Counties through legislative action.



- **ACTION: Public Policy**

Support and spearhead public policy efforts to protect existing programs for the uninsured.

The current political climate in Maine is unsettled, with the last legislative session bringing key cuts in funding that we fear will adversely affect access to care in Maine. Our Public Policy Chair, along with the Executive Director and the Board of Directors, actively engaged in opposing the cuts. We are now strategizing around moving our public policy efforts forward in this changing climate. We remain concerned about the effect that the elimination of MBCHP's outreach budget will have on the citizens of Maine, and are preparing to help address the gaps left behind in the wake of the cuts.

An expansion of our Public Policy efforts will not only help the citizens of Maine, but place Komen as a strong voice in advocacy.

- **ACTION: Advocacy**

Recruit volunteers to populate our Public Policy Committee. By August 2012, we will develop list of ten active advocacy volunteers who wish to receive information on public policy efforts of the Komen Maine Affiliate and assist in grassroots lobbying efforts with their representatives.

By November 2012, mission staff and the Public Policy Chair will provide training to advocacy volunteers on how to engage in grassroots efforts.