

Susan G. Komen for the Cure Global Initiative for Breast Cancer Awareness

COSTA RICA

INSTITUTE OF
INTERNATIONAL
EDUCATION



Community Profile Executive Summary and References

San José
Alajuela
Limón

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The information contained in this Community Profile/Executive Summary has been compiled by Course for the Cure™ participants and comes from a variety of sources. Participants have attempted to obtain the latest and most reliable data available and to accurately reflect breast cancer challenges and resources in their city at the time of the profile. Susan G. Komen for the Cure does not recommend, endorse or make any representations or warranties of any kind with respect to the accuracy, completeness, timeliness, quality, efficacy or non-infringement of the information contained in this summary.

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Executive Summary

Introduction of the Susan G. Komen for the Cure Global Initiative for Breast Cancer Awareness

An estimated 25 million women around the world will be diagnosed with breast cancer over the next 25 years, and up to 10 million could die without a cure. With this in mind, Susan G. Komen for the Cure® - the world's largest grassroots network of breast cancer survivors and activists - launched the Komen for the Cure Global Initiative for Breast Cancer Awareness. The Institute of International Education (IIE) - one of the world's most experienced global higher education and professional exchange organizations - designed and manages the Initiative through its West Coast Center, in collaboration with local partners in eight pilot countries: Brazil, Costa Rica, Jordan, Mexico, Romania, Saudi Arabia, Ukraine and United Arab Emirates.

The goal of the Initiative is to create a dynamic global network of dedicated activists with the skills, knowledge and vision to play a strategic role in shaping their countries' response to breast cancer. This is accomplished by (1) empowering diverse stakeholders with the training, tools and support needed to influence strategic, locally-appropriate programming and funding decisions around breast cancer; and (2) strengthening individual and organizational capacity to launch effective education, awareness and advocacy campaigns to increase early breast cancer detection and reduce mortality.

At the core of the program is Course for the Cure™, a series of training modules based on Komen's 25 years of experience in breast cancer awareness and advocacy. The training modules, which have been customized in each country, cover five key topics: Community Assessment, Volunteer and Organization Development, Awareness and Education, Fundraising, and Advocacy.

Goal of the Community Profile

This Community Profile represents an assessment of the breast health needs and resources in a given community. It also serves to inform the work of local breast health organizations and activists in their fight against breast cancer. Participants in the Course for the Cure™ are trained on types of data collection, identifying and prioritizing gaps, and devising strategic long-term goals and objectives. By collecting and analyzing available data on breast health, participants identify and prioritize the community's unmet needs or "gaps". These gaps form the basis for developing strategic plans for education outreach, awareness programs, and advocacy efforts to improve breast health outcomes.

Demographic, statistical, and service provider data all play a key role in the development of the Community Profile. Additionally, data from Key

Informants, formal and informal leaders in the community, provide insights into the attitudes and beliefs surrounding breast health and breast cancer. All this information is critical for identifying and addressing barriers to improving a community's breast health. The target population for the Community Profile is women over 40 in the middle to lower socioeconomic level.

The Community Profile is a living document. It should be used on an on-going basis to inform strategic planning in the community around breast health and to strengthen existing programs and services. As a living document, it also needs to be updated on a regular basis as circumstances change and new information becomes available.

This Community Profile Report details the findings and priorities of participants in the Course for the Cure™ in San José, Alajuela, and Limón regions. The Methodology section explains how the data was collected and how the priorities were identified. In most cases, this report will represent the first time breast health data has been compiled for certain communities and should be made widely available to community members.

COSTA RICA OVERVIEW

Costa Rica is located in Central America. It is a small country of over 51,000 square kilometers. It has coasts on both the Atlantic and Pacific Oceans. The total population is 4,401,845 people.

Costa Rica has the oldest Latin American democracy and prides itself on the defense of human rights. Free mandatory education and universal health care have been available to its citizens since the 1940s and 50s. During this time, the army was also abolished, bringing stability to a country surrounded by armed conflicts.

Although most of the population is Hispanic, small minorities exist in the country. Some of these groups are: Afro Caribbean, indigenous populations such as the Bribrií, Cábecar, Guaymí, and a small Asian community. There have also been significant migrations to Costa Rica among both Nicaraguans (from 500,000 - 700,000) and Colombians (about 10,000).

Costa Rica has a complex public health system, made up of hospitals, clinics, and community medical centers. To upkeep this service, the country spends about 5.81% of the GNP. This system provides all medical services to the country's population, including prevention, screening, diagnosis and treatment for all conditions.

In Costa Rica the main cause of death is heart disease, and the second leading cause of death is cancer-related. Breast and prostate cancer are the most common cancers in women and men respectively. Breast cancer rates have risen 45% over the past few years, becoming the most common type of cancer among women since the mid- 1990s. Among men, prostate, lung, stomach and colorectal are the most common.

There is a National Cancer Plan in place in the country. The plan consists of a national strategy by the government to control the cancer situation in the country, through strengthening of the oncology network, education campaigns and awareness. This Plan will be implemented through 2017.

Breast Cancer Incidence and Mortality Rates

As of 2006, there were 2,238,326 women in Costa Rica, according to the Central American Center for Population. With the 45% rise in rates of breast cancer, this translates into 850 new cases in 2007, and 260 deaths. Currently many studies are being conducted to find out what is causing the breast cancer rates to rise so rapidly, but there is no conclusive evidence to explain this increase. Experts believe it to be the result of a number of factors, including underreporting in the past. According to the National Tumor Registry, the breast cancer incidence in Costa Rica is 40 women for every 100,000, and the mortality rate is 10.3 for every 100,000.

According to the statistics offered by the Ministry of Health, urban counties have the highest incidence and rural counties have a higher mortality rate comparatively. There is some speculation about these trends and they may reflect factors such as under registration in rural areas, better screening in urban counties; and better access to medical facilities in urban counties.

About 89 cases have been reported in men in Costa Rica since 1995.

Breast Cancer Screening

There are no public screening policies that currently exist in Costa Rica. The only policy in place consists of a Clinical Breast Examination administered during routine gynecological visits. If a doctor considers it is necessary to further test a woman, then she will be referred to the closest screening facility. During 2007, 71,661 women were screened through the public health system. This number is quite small compared to the 600,000 women over 40 eligible for screening in Costa Rica.

An estimated 80% of the population makes use of the national public health system. The system is paid for by collaboration of employers, employees, and government. The services are free for the end user; however, the system is saturated. Currently women making appointments for mammograms must wait three years, and many who have had mammograms are waiting a year or more for their results .

Health Education

The Ministry of Health promotes healthy lifestyles and works closely with the Cancer Institute for the creation of education and awareness campaigns. Non-government organizations (NGOs) carry out many regional educational activities, including health fairs, conferences and printing or reproduction of materials which they take to their own communities. NGOs working with

breast cancer tend to be small local groups who focus their work within their own communities.

Screening

During 2007, 71,661 women were screened, meaning 196 women were screened through the public system every day. This is only 12% of the total number of women needing to be screened to reach the entire population. However, different local NGOs, suggested that about 20% of all women over 40 do get screened through private medicine. With an estimated 600,000 women in need of annual screening, and a total of 13 mammography machines throughout the public sector, the creation of a new policy represents a challenge for government agencies.

Cost

Since Costa Rica has a universal health insurance system, the cost of screening does not seem to be a concern for the general population. However, cost may become an issue once women who are not covered by the public system need to be screened. Women working in the informal sector, who are unemployed, or who depend on another family member's insurance, would have to be screened through private medicine.

Social

The main social barriers can be explained as fear and myths. Fear of finding out test results was the main issue. A common belief among Costa Ricans is that if you look for problems, you will find them. Also, Costa Ricans often associate cancer with death, and strongly believe that if one is diagnosed with cancer, death is imminent.

Education and Awareness

The largest barrier in communities was the lack of education, awareness, and information on breast cancer. Lack of relevant and simple information available to all women, the knowledge of where and how to access available information, timely education campaigns, false information, myths, and confusion were all concerns mentioned regarding education.

Doctors in the public health system try to see as many people as possible and therefore do not have time to inform patients about breast care. Often, clinical breast examinations are performed very quickly, and without much information.

Healthcare

The health care system in Costa Rica has many advantages: it is universal, it covers all diseases, for all ages and segments of the population. Also, cost is very low and people pay proportional to their wages. However, the reality according to key informants is that a significant number of people in Costa Rica do not have access to this coverage, and it is often women who are excluded from coverage.

Additionally, the system is oversaturated. It lacks equipment and a sufficient number of doctors to adequately serve the population. Our key informants also mentioned that maintaining medical personnel in rural areas is difficult.

Access

Women in Costa Rica only have access to a mammogram after a referral from a general doctor. Also, appointments for screening are given many days after patients are referred to this service. Depending on the location one month to two years can follow a referral, and test results can take up to a year or more.

San José

San José is the capital of Costa Rica, It has the highest population density in the country with 313.70 people per square kilometer. Its total population in 2006 was 1,557,689. According to the National Institute of Statistics and Census, there are 777,015 males and 780,674 females in San Jose.

As the capital, it is a fast growing city with numerous counties. San José is also home to most government offices, private sector headquarters, financial offices, health facilities, higher learning institutions, and services. It has over one million people coming into the city every day. This leads to a complicated and problematic infrastructure.

Breast Health and Breast Cancer Statistics

The province of San José is located in the central valley of the country. However, within the valley communities become rural very quickly. Due to this, the indicators vary considerably from one county to the next. Breast cancer is not the exception to the rule; the indicators for incidence and mortality vary considerably from county to county. The incidence rate (per 100,000 women) in the province of San José in the 1990s ranged from 15.80 in Turubares to 45.83 in Montes de Oca. Similarly, mortality rates (per 100,000 women) ranged from 5.67 in Puriscal to 18.22 in Alajuelita.

In San Jose, there is a high concentration of hospitals, medical facilities, and public health institutions. These include the National Cancer Institute and the Ministry of Health. Also, many NGOs working with breast cancer carry out education and awareness campaigns in different communities within the province.

The target population for the Community Profile is women over 40, in the middle to lower socioeconomic level. While we cannot find this number as an official statistic, we have calculated the target population for San Jose at 110,000 women. This number was reached considering the socioeconomic indicators available.

We have gathered qualitative information for the province from our key informants, which include doctors, nurses, social workers, survivors, public health system users and participants from the Course for the Cure™. Access to screening (physical access to the facility), was not an issue for the general population of San Jose. In addition, fear of procedures was also not a major concern for our target population in San Jose. According to the all our key informants, the biggest and most severe barrier was the lack of education, awareness and information on breast cancer. Lack of relevant and simple information available to all women, the knowledge of where and how to access available information, and timely education campaigns, were all concerns mentioned.

The public health system in San José covers 80.89% of the total population. However, this includes direct and family coverage. The direct coverage represents 32.19%, which means that a large percentage of the population relies on a family member's insurance for their own medical needs. This is a challenge divorced or single women face when looking for medical treatment. This may prevent women from consistent and reliable screenings and treatments.

Alajuela

Alajuela is a large and diverse province with both urban and rural populations. The province's capital, Alajuela, is located within the central valley of Costa Rica, about 20 kilometers from the city of San José. The population of Alajuela is very homogeneous, with only a few indigenous groups in the northern mountainous areas.

There are fifteen counties within Alajuela, most of them are rural. Our target population has been estimated at 70,000 women over 40 in the middle-to-lower socioeconomic level.

Alajuela like San José has its main cities within the central valley, but unlike San José, most of its territory lies outside the valley. Most of its counties are rural. This helps to explain vast differences in incidence and mortality rates (per 100,000 women). Incidence and mortality rates were lowest in Guatuso in the 1990's and 3.23 and 0 respectively. Incidence and mortality rates were highest in San Ramon and Palmares respectively at an incidence rate of 38.38 and a mortality rate of 17.66.

Due to its close proximity to San Jose, Alajuela has many medical facilities, government offices, programs and NGOs available to the general population. However, the further communities are from the Central Valley the scarcer their services and programs.

Access is a bigger issue in Alajuela than in San Jose. Due to the expansiveness and diversity of the landscape, transportation is difficult. A good public transportation system is in place throughout the province.

Most of our key informants and participants do not consider cost to be an issue in treatment, but once again we found that women in our target population are the most vulnerable and most commonly left out of the public system. This becomes a problem when women have to access, or pay for screening through private medicine.

According to our informants, women tend to feel embarrassed when tested, and therefore another barrier to screening is ensuring women get treatment from someone they trust.

Limón

Limón is located on the Atlantic coast of Costa Rica. This province is separated from the rest of the country by the long stretch of mountain ranges, which have historically made access to Limón difficult.

This province has many indigenous groups. These groups make up almost 1% of the total Costa Rican population, approximately 21,200 people. Each group has a unique language and traditions. In the rural areas of the country, eight different indigenous groups inhabit 22 reservations. The province of Limón also has an Afro-Caribbean population. This group constitutes almost 3%, of the national population, approximately 124,016 people. The province has a small Asian population. Limón is a mixture of many cultures and experiences contrasts between poverty and wealth.

Limón is a more rural setting than San José. Its total population is 419,512 people, including 220,721 males and 198,791 females. Limon has more poverty than the rest of the country. No official statistics can be found for our target population, but we have estimated there are about 80,000 women over 40 living in the lower socioeconomic level.

Breast Health and Breast Cancer Statistics

Incidence and mortality rates (per 100,000 women) range by county in the province of Limón. Guacimo had the lowest incidence rate of 11.96 in the 1990s, and Limón had the highest at 23.94. Mortality rates ranged from 4.5 in Talamanca to 14.61 in Limón.

Limon has few medical facilities with screening services. This makes testing very difficult for local women. Prior to our work with Course for the Cure™ there were no NGOs dedicated to the fight against breast cancer in this area. Government offices are accessible, but the resources and programs are much more limited than in San José and Alajuela.

Religion is a much bigger factor in Limón than in other areas of the country. While the population throughout the country is largely Catholic, Limón has a variety of faiths. Religious centers are an important part of education efforts, communications and social activities.

Limón is a large province with diverse settings, ranging from mountainous volcanic ranges to coastal regions. Transportation is a major concern for residents. The public transportation system currently in place does not cover the needs of residents. Distances that women must travel to get screened are very vast and can make medical care inaccessible. Socially, women believe many myths and misconceptions regarding breast cancer. These beliefs are widespread and deeply imbedded within the population and create barriers to screening.

Gaps, Goals & Objectives

As we have mentioned before, Costa Rica is a small country and shares many, but not all barriers across communities. We have included national prioritized gaps, goals, and objectives, as well as local prioritized gaps for each community.

National Prioritized Gaps, Goals, and Objectives

1. Lack of simple and pertinent information. Although there is information in Costa Rica, most women do not know how to access it and believe it is presented as complex and complicated.

Goal: Create a commission of experts, in conjunction with the Ministry of Health and Costa Rican Institute of Cancer, to develop clear and simple material on breast health, adapted to the local reality.

Objective 1: This commission would distribute the material to the NGOs and health centers within a year. In addition, the commission would work with local county governments to research the health needs of that particular community, and deliver the material pertinent to that area within the next six months.

- An example given by one of our key informants from San José on how to distribute the information is to distribute information to the local beauty parlors to offer to the clients as reading materials while they are getting their hair done.
- In Limón, one of our key informants suggested adapting the materials through the religious groups and distributing them to the women who attend the services on Sundays.
- In Alajuela, the recommendation was to channel the information through the medical facilities, as well as in the work places to both men and women, thus raising awareness among families and not just among women.

Objective 2: This information would be distributed in an effective manner by people who the target community can relate to who is also from their own community.

2. Lack of a mandatory public screening policy. The Steering Committee for the Costa Rican Susan G. Komen Global Initiative for Breast Cancer Awareness believes that if a public screening policy were developed, despite all the current limitations, all women over 40 could be tested at least once every two years.

Goal: Costa Rica will have a national public breast screening policy.

Objective 1: Lobby at the highest government levels to ensure that the policy will be placed in effect within the next two years, and that it will be developed in accordance to the national reality.

Objective 2: Create an awareness campaign regarding screening directed to all women over 40. Currently the Costa Rican Cancer Institute is conducting a mass media and local government campaign to do so.

This issue was a larger concern for the grass roots and medical community who were interviewed for this profile. The recommendations regarding this subject conclude that as long as screening is not mandatory within the public health system, many women will not get the necessary or timely treatments. With the equipment that we have today, 600,000 women over 40 all over the country would get screened every two years. Although in regards to international standards, this would be insufficient, at least it would guarantee permanent and continuous testing of women over 40.

3. Access to mammography screening facilities. The public health care system is saturated and therefore women must wait for a referral from their doctor to receive screening.

Goal: Facilitate the access women over 40 have to breast cancer screening through an increase in the number of available equipment and trained medical personnel, combined with a mandatory national breast cancer screening policy.

Objective 1: Acquire more equipment for the public health system within the next year. It is expected that through the National Cancer Plan, eight new mammography machines will be purchased for the system.

Objective 2: Ensure there are more physicians at the existing medical facilities so that more screening can take place. The National Cancer Plan has begun hiring and distributing the new staff throughout the country. A new oncology unit will start in the Pacific. Prior to this, patients from this location had to travel to Alajuela or San José for specific screening and treatment.

Objective 3: Lobby the government to allow more money to be destined for this particular gap. The Costa Rican Steering Committee has informed

us that as a part of the National Cancer Plan, medical services are being contracted to perform and analyze screening with the new equipment.

Objective 4: Involve the private sector in an effort to pay for their employees' exams at private clinics, with breast cancer screening becoming part of company policy. For this objective, work has started through the Susan G Komen for the Cure™ Global Initiative for Breast Cancer Awareness, through conferences and trainings offered to the private sector. These trainings aim to sensitize the sector about the existing gaps which are barriers to early detection and awareness about breast cancer. By the end of the year, we would like to sensitize at least 50 additional companies.

4. *Misinformation and lack of awareness* - These barriers include both social factors, which can be divided into fear and myths, as well as a lack of awareness about current available government services. Many people are unaware of the services currently available to them through the government, as well as of their rights within the system. This is definitely a problem when a community searches for solutions to problems that have already been provided to them.

Goal: Women will have access to correct screening and breast health information, as well as information on the related current government services available to them.

Objective 1: Deliver this information to all communities at least during a specific period of the year, such as during International Cancer Awareness Month of October. This could be accomplished through national media campaigns and local NGOs.

Objective 2: Conduct a national education campaign which includes breast health information and the related government programs available to the populace.

Objective 3: Through government assistance, have breast health information included as part of the secondary public education curriculum within the next two years.

SAN JOSÉ: Local Gaps, Goals, and Objectives

In addition to the five prioritized national gaps, the gaps for San José include:

1. *Lack of insurance by vulnerable groups of women over 40.* Although access to the public health system is universal in theory, many women do not have coverage. This includes women who work in the informal job sector, women who are single or divorced, and undocumented immigrant women. If women

do not have insurance, they will not seek medical assistance, and will often prioritize their children's medical needs above their own.

Goal: All women will have health insurance so they can access the public health system.

Objective 1: Lobby for the creation of an insurance policy directed at women in these particular vulnerable groups, with lower premiums and specific breast health plans, to be in place within the next two years.

Objective 2: The creation of a "grant" program through the private sector and breast cancer NGOs. After analyzing each case, exams could be paid for these women. The program would also include a pay back plan.

2. High cost of private medicine. Because the public health system is saturated, private medicine might be an option for screening, but the cost does not allow women in our target population the ability to access the existing services in the area.

Goal: Develop cooperation agreements between private medical centers and local non-profits to offer discount prices to women referred to the medical centers by the NGO by mid 2009.

Objective 1: Create a strategic collaboration between a screening facility, an NGO and a private company to facilitate low cost mammograms to women.

3. Child care. Working mothers require a better child care system which would allow them to visit doctors more regularly.

Goal: Create a child care network which allows mothers to get screened and ensures the children are safe.

Objective 1: Create an alliance among different non-profit organizations who work with breast cancer, in order to create a program at each local organization in which women can arrange to leave their children there while getting screened.

Objective 2: Lobby the local public child care facilities to care for the children while their mothers get medical attention, within the next nine months.

ALAJUELA and LIMÓN: Local Gaps, Goals, and Objectives

1. *Access to Mammography Screening Facilities-* Both Alajuela and Limón are large provinces. Some women have to travel as far as 150 miles to get screened. For the target population, the cost of transportation to the medical facilities added to the cost of food and shelter if they need to stay over night, are much higher than they can afford.

Goal: Make mammography screening accessible to women over 40 from Alajuela and Limón.

Objective 1: Purchase mammography machines to install in already existing medical facilities. As a part of the National Cancer Plan, more than eight new mammography machines will be purchased in 2008, and that medical services are being contracted to perform and analyze screening with the new equipment.

Objective 2: Fundraise with local governments to purchase diagnostic equipment for each community and to spread this plan to all 81 local governments throughout the country, within three years.

2. *Child care-* Working mothers would require a better child care system which would allow them to visit doctors more regularly.

Goal: Improve and facilitate low cost child care for women while they get screened.

Objective 1: Inform the general population about all the services offered free of charge, through local radio programs, women magazines and TV. An example of one of these programs is the government-run child care program CENSINAI, available to them and their families.

Objective 2: Create a dynamic local network of women to provide daycare services while women seek medical attention, in Alajuela and Limón, within two years.

3. *Lack of doctors in local medical facilities-* Although there are medical facilities within the province, it is difficult to retain medical personnel in very rural settings, causing a lack of doctors even when screening facilities are available.

Goal: Recruit additional doctors to the local clinics.

Objective 1: Have local companies hire doctors as part of their benefit programs in situ. Our key informants believe that if the doctors are hired by the companies, competitive salaries are ensured. This will help with the saturation of the public system, as well as guaranteeing more doctors for longer periods of time. Our participants believe that local companies can be convinced of this plan within one year.

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