



jdcPartnerships
integrating information for impact

**EVALUATION REPORT
LATINO CANCER COLLABORATIVE/
SPANISH-SPEAKING WOMEN'S CANCER
INITIATIVE**

Prepared for:

Kathleen Tabor
Tabor Consulting
2108 Devonshire Court
Walnut Creek, CA 94596

Submitted by:

jdcPartnerships
28 Knoll Rd
San Rafael, CA 94901
415.482.7839

Contact:

Jara Dean-Coffey, MPH, Principal
jara@jdcPartnerships.com

Submitted:

October 2010

OVERVIEW

The Latino Contra Costa Cancer Collaborative/Spanish-Speaking Women Cancer Initiative (LC4/SSWCI) serves disadvantaged and uninsured Spanish-speaking women and men of Contra Costa County, California. The Collaborative is strongly committed to using evaluation to inform its development. In 2004, the Center for Applied Local Research conducted a three year evaluation followed by jdcPartnerships in 2007. In 2010, LC4/SSWCI engaged jdcPartnerships to conduct another three-year evaluation of the Collaborative's progress toward the following three goals:

1. Increase awareness of breast and cervical, colon and other cancers and improve screening rates among uninsured, underserved Spanish-speaking men and women.
2. Improve access to screening, medical care and reduce loss to follow-up for women referred for/or undergoing screening, diagnostics or treatment for breast, cervical or other cancers.
3. Improve access to enabling and survivorship services and education for Spanish-speaking women undergoing and following treatment from breast, cervical cancer and other cancers.

The goals and objectives are targeted toward achieving the following outcomes:

1. Reduced risk of late diagnosis of cancer;
2. Increased access to and utilization of cancer screening;
3. Increased community knowledge of cancer, early detection and available services;
4. Improved access to culturally and linguistically appropriate medical care and coordinated support services for women diagnosed with cancer;
5. Improved quality of life and health outcomes for women diagnosed with cancer;
6. Improved institutionalized systems of care for Spanish-speaking women and their families; and,
7. Increased cultural competency of participating organizations.

This report includes background on LC4/SSWCI, a discussion of the evaluation framework and data collection methodology, summary of findings from a range of data collection methods, including reflections on the findings, and next steps for the future of the Collaborative.

SUMMARY OF EVALUATION FINDINGS

This introductory section summarizes accomplishments of LC4/SSWCI, lessons learned and key areas to address as the Collaborative moves forward.

LC4/SSWCI Accomplishments

Performance Measures

As part of its internal and external accountability framework, LC4/SSWCI developed a set of performance measures to track progress on meeting goals and objectives.

The SSWCI met or exceeded program goals and objectives for the entire period from September 1, 2007 to August 31, 2010. There were no significant changes to the objectives articulated in 2004 although the responsibilities of the organizations evolved to reflect the reduction in services provided through Contra Costa County Health Services. All services and activities were conducted in Spanish by bicultural SSWCI staff. Specific interventions undertaken provided outreach and services primarily to Latinas living in two areas of Contra Costa County where much of the Spanish-speaking population is concentrated.

Figure 1 below describes the primary interventions and numbers served from September 2007 to August 31, 2010 as well as previous three year period. Totals services for 2004-2010 are also provided. The performance measures are aggregated across the Collaborative and reflect individual partner objectives as well as collaborative efforts.¹

Figure 1. Performance Measures

LC4/SSWCI PERFORMANCE ON OBJECTIVES SEPTEMBER 2004 TO SEPTEMBER 2010				
INTERVENTIONS	3 YEAR TARGETS	SERVICES 9/04 – 9/07	SERVICES 9/07 – 9/10	TOTAL 9/04-9/10
Outreach	6,000 individuals	11,156	6,032	17,188
Screening Navigation, Translation at the county health clinics & hospital	900 individuals	9,980	9,895	19,875
Screening & Referral for Mammograms at community clinics	900 individuals	3,464	4,783	8,247
Health Insurance/Referral for diagnostics & treatment	150 referrals	1065	600*	1665
Case Management, Treatment Navigation, referrals and case coordination	300 clients	402 clients	742 served/ 272 new	692 unduplicated clients
Patient Support Services during Treatment (interpretation, referrals, home visits, telephone support, emotional support, referrals)	150 clients	678 clients	742 clients 8,573 instances	1,420 clients
Cancer Health Education (Preventive & Treatment)	150 individuals	1,685	3,287 **	4,972
Wellness Support Groups and Classes	78 groups 12 workshops	141 groups 159 unduplicated 909 total	114 groups 231 unduplicated 549 total clients	155 groups 390 unduplicated 1299 total clients
Transportation to diagnostics and treatment*	NA	702 rides	1026	1828 rides

*Lower instances for this grant period are reflective of changes in eligibility for services and support for undocumented in Contra Costa County and under 40 women through California's Every Woman Counts program.

** Increase from previous period reflective of a shift toward deeper community education efforts rather than blanket outreach.

¹ OMH Progress Report for April 1, 2009-September 30, 2009

Other Successes

In addition to progress towards performance measures, evaluation findings revealed other areas of accomplishment which supported the overall goals of LC4/SSWCI. These included:

- Increased awareness and fostering proactive behavior with regard to cancer prevention, detection, and treatment within the Latino community.
- Building a local delivery system for bilingual services that was evidence-based and culturally competent.
- Increasing access to culturally and linguistically competent cancer services in Contra Costa County.
- Implementation of a continuum of care encompassing a range of services and benefits from diagnosis to end-of-life care, including education, screening, treatment, complementary services, and social and financial support.
- Institutionalized services within collaborative agencies that fulfill their role within the continuum of care.
- Improved professional and cultural competency among collaborative agencies, health care providers and other partners.
- The Promotores de Salud program has integrated community leadership development with disease education and become a strong cadre of community educators.
- Jointly identified needs and funding opportunities pursued by Collaborative partners.

Lessons Learned

To continue to strengthen LC4/SSWCI, we identified a set of lessons learned which would inform ongoing program design, collaborative development, and overall effectiveness. These ranged from acknowledgement of the importance and value of relationships to specifics around program design such as screening. Following is a summary:

- Strong personal relationships among staff and leadership help sustain the Collaborative.
- The specialization that is possible when partners trust each other leads to a more effective and comprehensive continuum of care.
- It is important not to make assumptions about individuals' knowledge and to provide information and support that assists clients in taking charge of their own care.
- There is desire for a greater number of supportive services in Richmond and Oakley.
- Screening is not yet as high a priority for community members as providers believe would be optimal for early detection.
- Celebrations of survival and other community gatherings are important for dispelling myths of cancer as a "death sentence."
- Promotores are a critical link between community members and Collaborative partners.
- Greater and/or more consistent support may increase promotores' satisfaction and retention.
- A highly skilled facilitator has been critical to the success of the Collaborative by fostering trusting relationships and consistently providing evaluation and other learning opportunities.

-
- There is a need for bilingual, bicultural health care providers committed to working in the Latino community.
 - Adaptability in a changing environment is critical to sustainability.

Recommendations for Increased Impact/Improvement

LC4/SSWCI has much to build on and to be proud of. However, there are always opportunities and areas where increased attention, added financial resources and potential changes to program design and intent would support even more effectiveness. These primarily fall into the areas of education, outreach, access, and integration, and include:

- Education
 - Increase the amount and clarity of information available in print, on television, and in video format about cancer, prevention, and treatment.
 - Research and provide more information about care for undocumented immigrants.
- Outreach
 - Look for opportunities to reach high schools, churches, markets, and rural areas of the County.
 - Host more health fairs and support groups.
- Access
 - Increase participation across all genders, ages and sub populations in screening events
 - Increase free and low-cost transportation options for clients.
 - As resources allow, assure that patients and providers have consistently easy access to a bilingual/bicultural case manager.
 - Adapt the continuum of care and programs to address the changing healthcare access problems for undocumented Latinos within the county healthcare system.
- Integration
 - Integrate more partners into the Collaborative who can help Latinos with cancer, including legal services for immigration issues, complementary medical care and supportive therapies, and support for childcare, housing, and other basic needs. *(Note: The Collaborative currently makes outside referrals to these services.)*
 - Explore ways to increase support and recognition of the contributions of community health educators (promotores).

BACKGROUND

The Spanish-Speaking Women's Cancer Initiative formed in 2002 in response to the death of a Latino woman with breast cancer who simply fell through the cracks of the private and public healthcare systems. Her story was emblematic of the social-ecological and system barriers to health that create racial and ethnic disparities.² With initial funding from the John Muir Mt. Diablo Community Health Fund and the California Endowment, the Spanish-Speaking Women's Cancer Initiative (SSWCI) has been serving disadvantaged, uninsured Spanish-speaking women of Contra Costa County since 2002. A key focus of LC4/SSWCI (also known as "the Collaborative") is to expand outreach to underserved parts of the County where significant populations of Latinos reside.

SSWCI brings together Latino-serving agencies, public and private healthcare providers, and community-based agencies to develop culturally and linguistically competent cancer-related services (e.g., support groups, community education, patient navigation) in order to improve screening rates for cancer, reduce barriers to quality care, and provide survivorship support to underserved Spanish-speaking women in Contra Costa County. In September 2004, SSWCI received a three-year grant from the federal Office of Minority Health (OMH) as part of its Community Programs to Improve Minority Health funding. Additional funding support has come from the Safeway Foundation, Kaiser Permanente, the Mt. Diablo Health Care District, the Avon Foundation, and a second OMH grant in 2007.³

The Collaborative has aimed from the outset to develop culturally specific programs, not just translate English-language programs into Spanish. As lessons are learned and the community included in planning, programs have evolved. For example, starting in 2009, the partners of SSWCI refined and enhanced their outreach, awareness, and education strategies to include a family wellness approach, which includes engaging partners or spouses and children and providing information about prostate cancer. A media PSA depicts a grandmother and granddaughter talking about how important it is for every generation to be screened. A new name – the Latino Cancer Collaborative of Contra Costa (LC4) – was adopted to convey its broader reach. The Spanish-Speaking Women's Cancer Initiative (SSWCI) remains the primary program within the larger LC4. The change can be exemplified by a recent event held at a local school where 200 people (approximately 100 families) attended a LC4/SSWCI Cancer Awareness Day. During the risk screening consultations, men listened to breast and other cancer information provided to their female partners, and men and women sought information to provide their spouses about prostate screening.⁴

Collaborative Members

A combination of public agencies and community-based providers has created a network of services and support which builds on institutional capacities and community-based knowledge and experience. Each partner in the Collaborative brings particular expertise to achieving goals. This public-private grassroots level partnership has changed the way services within the County healthcare system are provided for Latinos with cancer, and has also raised awareness in the community.

LC4/SSWCI is comprised of six agencies that provide free or low-cost cancer-related programs to disadvantaged Spanish-speaking women (and, in some instances, men) in Contra Costa County. As the primary providers of healthcare for low income uninsured or underinsured, and of survivorship services for those with cancer in Contra Costa County, the agencies are linked to provide a breadth of services and

² OMH Project Proposal: *La Clínica de La Raza*

³ LC4 Website: www.latinocancerco.org

⁴ OMH Progress Report for April 1, 2009-September 30, 2009

programs that meet the specific needs of Spanish-speaking low income women, men, and their families. Each agency has fully-qualified bilingual, bicultural staff.

The partner organizations in the Latino Cancer Collaborative/Spanish-Speaking Women's Cancer Initiative are:

La Clínica de La Raza, Inc. (La Clínica) La Clínica is a comprehensive health services network with 23 service sites in three East San Francisco Bay Area counties. Its target population includes Latino immigrants and other low income underserved populations. La Clínica provides health care services to people at all life stages through a delivery model that employs a family-oriented, multi-disciplinary team approach. It has become a leading member of federal and local chronic disease collaboratives.

La Clínica provides primary medical services in the local community at two community health clinics in Contra Costa, offers educational workshops on breast health and other cancer prevention topics in the community, and provides cancer screening and referral services. Through the *Escuela de Salud*, La Clínica trains and supports Latino health *promotores* (community health educators).

American Cancer Society, California Division, Inc. (ACS) is a community-based voluntary health organization dedicated to eliminating cancer as a major health problem by preventing cancer, saving lives, and diminishing suffering from cancer through research, education, advocacy, and service. ASC provides transportation to medical appointments for women with cancer, technical assistance for *promotores'* training, Spanish-language materials and free education, and supportive programs for Latinos.

Contra Costa County Navigator Program provides "navigators" to help Spanish-speaking women and men access free or low-cost breast and cervical cancer screening, diagnostics, and treatment services offered by Contra Costa County Health Services. Navigators provide insurance enrollment, medical interpretation, education, and patient advocacy. A nurse case manager provided case management, patient assessment, and linkage to services within the Collaborative and beyond.

Hospice of the East Bay is an independent, not-for-profit, community-based health care provider. Hospice provides end-of life support to enable people to remain at home. A bilingual, bicultural social worker and volunteers provide services to LC4/SSWCI clients and consultation to providers.

The Wellness Community (TWC) is a national non-profit organization with 21 sites dedicated to providing free emotional support and education as well as stress reduction through support groups to Spanish-speaking women with cancer and their loved ones. Licensed bicultural therapists facilitate free support groups in Spanish for individuals and family members and patient education workshops in Spanish.

Women's Cancer Resource Center (WCRC) works onsite at the Contra Costa Regional Medical Center where a WCRC patient advocate/case manager is available to women with all types of cancer undergoing screening, diagnostics, and treatment. WCRC's mission is to empower women with cancer to be active and informed consumers and survivors, to provide community for women with cancer and their supporters, to educate the general community about cancer, and to be actively involved in the struggle for a life-affirming cancer-free society. Services in Spanish focus on practical support and include education, information, referral, patient advocacy, benefits assistance, and emotional support.

A full-time case manager works with patients. Other staff manages the emergency financial assistance program. In addition, WCRC operates a multi-lingual Information and Referral Help-line. ,⁵

Community Specific Cancer Data and Recommendations for Providers

LC4/SSWCI focuses on a population facing a notably high rate of cancer. Nationally, cancer is the second leading cause of death among Latinos accounting for 20% of deaths overall and 13% of deaths in children. Breast cancer is the leading cause of cancer death, accounting for 15% of total cancer deaths, followed by lung cancer (13%), and colo-rectal cancer (10%).⁶ About one in three Hispanic women and one in two Hispanic men will be diagnosed with cancer in their lifetime. The probability of *dying* from cancer is about one in six for Hispanic women and one in five for Hispanic men.⁷

Socio-economic Factors

Cancer occurrence and survival are affected by economic, social, and cultural factors. Socio-economic status, as a measured by income and education, is the most critical factor affecting health and longevity. Figure 2 below compares socio-economic characteristics, health care coverage, and medical care access among various Latino and non-Latino populations.

Figure 2. Socio-economic and Health Care Access Characteristics (%) by Hispanic Origin⁸

	Hispanic					Non-Hispanic White
	All	Mexican	Puerto Rican	Cuban	Central or South American	
Socioeconomic characteristics*						
Foreign born	39.9	40.1	1.2	61.0	68.9	3.9
Income below poverty level	21.6	23.0	25.0	14.8	15.5	9.2
Less than a high school degree (age > 25 yrs)	40.0	46.4	28.5	25.6	34.2	11.1
A language other than English in the home	78.1	78.7	68.7	84.4	90.0	5.9
Health care characteristics†						
No health care coverage						
Age < 65 years old	32.6	36.2	13.1	19.6	37.5	12.7
Age > 65 years old	4.6	4.7	0.4	1.9	10.3	0.4
No regular source of medical care (ages 18-64)						
Men	36.0	40.8	19.9	29.9	32.9	19.7
Women	21.1	23.9	4.2	22.9 [‡]	25.5	11.0

* Source: American Community Survey, 2005-2007. Accessed via DataFerrett May 7, 2009.

† Source: National Health Interview Survey, 2007, National Center for Chronic Disease Prevention and Health Promotion, Centers for Disease Control and Prevention; Estimates age adjusted to the 2000 US Standard Population. ‡ Estimate is considered unreliable due to sample size.

Since 1988, cervical cancer incidences in California have decreased by 29 percent among women. Hispanic women however, have the highest rate of cervical cancer incidence and are two times more likely than non-Hispanic white women to be diagnosed with the disease. One in 35 Hispanic women ages 40 to 59 is likely to develop breast cancer, and one in 62 Hispanic men ages 40 to 59 are likely to develop prostate cancer.⁹

⁵ CDC REACH US Action Community Proposal

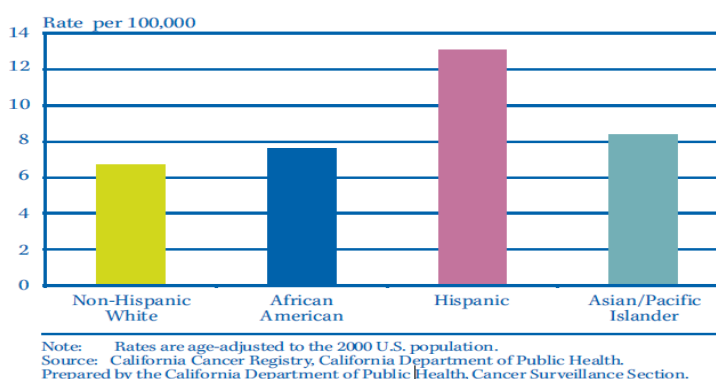
⁶ Cancer Facts & Figures for Hispanic/Latinos 2009-11

⁷ Cancer Facts & Figures for Hispanic/Latinos 2009-11

⁸ Cancer Facts & Figures for Hispanic/Latinos 2009-11

⁹ Cancer Facts & Figures for Hispanic/Latinos 2009-11

Figure 3. Invasive Cervical Cancer Incidence by Race/Ethnicity in California 2005-10



Screening and Diagnosis

Although screening is the most effective way to increase chances of survival, lack of access to proper health care and lack of insurance are factors that may affect cancer occurrence and survival in the Latino Community. For example, the proportion of Hispanic women under the age of 65 in a recent study who reported *no* regular source of medical care was almost twice that of non-Hispanic white women.¹¹ Lack of insurance is also a factor in the percentage of women and men who participated in yearly cancer screenings nationwide. Among Hispanic women nationwide, only 33% of women above the age of 40 with no insurance reported having a mammogram within the past year compared to 53% of all non-Hispanic white women.¹² In addition, Latinos are most likely to be without health insurance in the greater San Francisco Bay Area.

Hispanic women are also less likely to receive routine screening when compared to African-American and non-Hispanic white women. In 2006, the percent of women ages 18 and older in California who reported having a Pap smear in the previous three years was 88% for non-Hispanic white women compared to 84% for Hispanic women.¹³ In addition, although cancer mortality has decreased among women in various racial/ethnic groups in California, the decline in Hispanic women was less than the decline among non-Hispanic white women and other ethnic groups. This modest decline in cancer mortality (five percent) among Hispanic women still reflects a 26 percent increase in liver cancer mortality, a 22 percent increase in pancreatic cancer mortality, and a 16 percent increase in brain cancer mortality among Latino women.¹⁴

Cancer in the Hispanic Population of Contra Costa County

Hispanic women in Contra Costa County have a lower percent of early stage breast cancer diagnoses compared to that of non-Hispanic white women in the County. In 2005, 67% of breast cancer cases among Hispanic women were diagnosed at an early stage compared to 71% of non-Hispanic white women.¹⁵ Among men in the Greater Bay Area, Hispanic men were more likely to have never received a PSA test for prostate cancer detection (58% for Hispanic men) compared to non-Hispanic white men (33%).¹⁶ In addition, among

¹⁰ California Cancer Facts & Figures 2009

¹¹ Cancer Facts & Figures for Hispanics/Latinos 2009-2011

¹² California Cancer Facts & Figures 2009

¹³ California Cancer Facts & Figures, 2009

¹⁴ California Cancer Registry: Cancer in California 2008 April 2008

¹⁵ Northern California Cancer Center: Finding Answers, Making a Difference December 2008 "Cancer Risk Factors and Screening Behavior in the greater Bay area: Data from the California Health Interview Survey"

¹⁶ *ibid*

adults age 50 years or older, Hispanics (36%) were also more likely to have never received a colo-rectal cancer screening compared to non-Hispanic whites (20%) in the Greater San Francisco Bay Area.¹⁷

According to the California Health Interview Survey, among Latino women in Contra Costa County over age 18, 19.1% reported never having had a pap test. This is almost double the percentage statewide. In California, only 9.1 % of women 18 years or older reported never having a pap test.¹⁸ However, only 4.7% had not had a pap test within three years. When asked the reason for not having had an exam, all listed “expensive/ no insurance” as a reason. Among Hispanic women over 30 in Contra Costa County, only 62.5% of those surveyed had had a mammogram in the past two years (compared to 70% percent of white women), although this was up from 53.1% in 2005.¹⁹ The percentage of Hispanic women over the age of 30 who have never had a mammogram has dropped from 39.4% in 2005 to 27% in 2007.²⁰

In 2005, out of 24,000 men surveyed, 80.1% of Latino men in Contra Costa County reported never having had a PSA test. In 2007, only 36.3% of Latinos surveyed over the age of 50 in Contra Costa County reported having a colonoscopy as the most recent type of cancer screening, and 25% reported having a sigmoidoscopy.²¹ In addition, 34.9% of Latinos over 50 years of age surveyed in Contra Costa County reported never having had a sigmoidoscopy or colonoscopy, compared to 21.2% of white adults over the age of 50.²²

Recommendations for Providers²³

The Latino Cancer Collaborative is based on a set of values and assumptions that are grounded in research and experience with the Latino population. All staff is bilingual, bicultural and brings their cultural understanding to the programs. Strategies are designed to address cultural factors that may influence health behaviors among Latinos.

The American Cancer Society has identified a set of factors that are important to consider when addressing cancer issues in the Latino community. Cultural factors including language, beliefs, values, and traditions may influence underlying risk factors, health behaviors, beliefs about illness, and approaches to medical care. Cultural proficiency is an important element in providing high-quality health care and preventive services. The American Cancer Society awarded the Latino Cancer Collaborative of Contra Costa the Harold P. Freeman Award for “outstanding contributions in the fight against cancer in medically underserved communities”.) According to the American Cancer Society, traditional values within the Latino culture emphasize the importance of family (*la familia*), respect (*respeto*), personal familiarity (*personalismo*), trust (*confianza*), and spirit (*espíritu*). Below is a summary of each of these values and their relevance for health care providers, as identified by the American Cancer Society.

¹⁷ Northern California Cancer Center: *Finding Answers, Making a Difference* December 2008 “Cancer Risk Factors and Screening Behavior in the greater Bay area: Data from the California Health Interview Survey”

¹⁸ California Health Interview Survey (CHIS), 2007

¹⁹ *ibid*

²⁰ CHIS, 2007

²¹ *ibid*

²² CHIS, 2007

²³ The following is a summary of information provided by the American Cancer Society, *Cancer Facts & Figures for Hispanic/Latinos 2009-11*. All information is taken directly from *Cancer Facts & Figures for Hispanics/Latinos 2009-2011*

The Family (La Familia)

The Hispanic family network may include close friends in addition to immediate and extended family members and plays a major role in decisions regarding health care. Interdependence and cooperation are emphasized over autonomy. For example, family members may frequently accompany or consult with Hispanic patients during medical visits. Providers can show sensitivity to the collective nature of these interactions by:

- Extending appointment times
- Facilitating family involvement

Respect (Respeto)

Respect and trust are often critical and necessary elements in a successful relationship between patient and provider. Health care providers are afforded a high level of respect as authority figures due to their training, education, and healing abilities. As a result, Hispanic patients tend to look forward to what the health care provider have to say and value the direction and services. In addition, Hispanic patients may avoid disagreeing with providers about care and treatment. At times, they may be reluctant to ask questions or admit confusion about their medical care and treatment.

- Providers should be aware that cultural respect promotes trust, which increases the likelihood of patient confidence and compliance.

Personal Familiarity (Personalismo)

Hispanic/Latino culture values personal over institutional relationships.

- Hispanic loyalty to the individual provider has significant implications for continuity of care.
- If a trusted provider leaves the area, a Latino patient may stop treatment unless the provider initiates a relationship between the patient and a new provider.

Trust (Confianza)

Respecting the patient's culture and showing interest can help providers establish a relationship of trust.

- Patient trust in the provider is central for identifying and treating health concerns, and for encouraging patient adherence to recommended treatment.

Spirit (Espiritu)

Latino culture tends to view health care from a more synergistic point of view. The view is expressed as the continuum of body, mind, and spirit (*espíritu*). Providers should be aware of this connection.

The American Cancer Society recognizes that cultural competency is an important element in providing health services in the Latino community. Cultural competency can be improved through the education of health care providers. In addition, community health workers (*promotores*) can be helpful in assisting Hispanic patients obtain health care and other services, facilitating communication between providers and patients, and promoting prevention and early detection programs within Hispanic communities.²⁴ The American Cancer Society has developed a set of principles that providers can refer to when offering culturally proficient health services to Latino families and communities.

²⁴ *Cancer Facts & Figures for Hispanic/Latinos 2009-11*

Figure 4. Culturally Proficient Principles for Health Services

PRINCIPLES FOR CULTURALLY PROFICIENT HEALTH SERVICES FOR HISPANIC/LATINO FAMILIES AND COMMUNITIES²⁵

- Involve family members.
- Show respect. Always be respectful, and explain without being condescending.
- Get personal. Latinos typically prefer being closer to each other in space than non-Hispanic whites do.
- Ask about their life (family, friends, and work) and share life stories and pictures.
- Encourage Latino patients to ask questions.
- Take seriously the responsibility and respect conferred on the provider.
- Reach out to the community. Community-based organizations within Latino neighborhoods, barrios, colonias, and other ethnic enclaves provide a significant point of entry and opportunity to expand on any outreach effort.
- Respect traditional healing approaches. Latino/Hispanic patients may combine respect for the benefits of mainstream medicine, tradition, and traditional healing with a strong religious component.

²⁵ *Cancer Facts & Figures for Hispanic/Latinos 2009-11*

OVERVIEW OF THE LATINO CANCER COLLABORATIVE/SPANISH SPEAKING WOMEN'S CANCER INITIATIVE

LC4/SSWCI is organized around a set of goals and strategies to address the cancer-related needs of a specific population. *The strategies of the Collaborative are in alignment with the American Cancer Society recommendations discussed above.*

LC4/SSWCI goals and objectives are presented in Figure 5.²⁶

Figure 5. LC4/SSWCI Goals and Objectives

Goal I. Increase awareness of breast and cervical, colon and other cancers, dispel myths and improve screening rates among uninsured, underserved Spanish-speaking men and women	Goal II. Improve access to screening, medical care and reduce loss to follow-up for women referred for/or undergoing screening, diagnostics or treatment for breast, cervical or other cancers	Goal III. Improve access to enabling and survivorship services and education for Spanish-speaking women undergoing and following treatment from breast, cervical cancer and other cancers
<p>Objective 1.1. By August 31, 2010, 65% of 75-80 Latino men and women participating in community health education through 2 annual the Escuela de Salud programs will increase community leadership skills, awareness of health promoting behaviors, importance of early detection of screening for breast, cervical, colon and other cancers, and reduce myths and improve knowledge about cancer.</p> <p>Objective 1.2. By August 31, 2010, 12 additional cancer outreach health promoters with specialized training in cancer reach out to 30 family or community members each and participate in at least 3 outreach activities annually.</p> <p>Objective 1.3. By August 31, 2010, reach 6,000 Spanish-speaking men and women in targeted areas of Contra Costa County to increase awareness, dispel myths about cancer and identify those needing screening by utilizing grassroots outreach, community presentations and screening events.</p> <p>Objective 1.4. By August 31, 2010, reach 25,000 Spanish speakers to improve awareness of resources and increase regular screening for breast, cervical and colon cancer through grassroots and media campaigns that involve the health promoters in the planning and execution.</p>	<p>Objective 2.1. By August 31, 2010, reduce cultural, linguistic and economic barriers to breast, cervical and colon cancer screening for 6,000 low income, underinsured women (2,000 annually) through navigation and medical interpretation.</p> <p>Objective 2.2. Improve referral and data collection capacity and provide information, assistance and referral to Spanish-speaking callers and community providers to cancer support resources for Latinos through culturally competent toll-free telephone based assistance line linked to the ACS regional cancer network (CRN) and the SSWCI navigators.</p> <p>Objective 2.3. By August 31, 2010, 200 underserved Latino women diagnosed with cancer will receive health system navigation and personal support needed to utilize and follow through with medical care as well as actively participate in treatment decisions including appointment support, insurance enrollment, medical interpretation and one to one education and support.</p>	<p>Objective 3.1 Provide coordinated care management to 200 low income Spanish-speaking women diagnosed with cancer linking them to community resources and services and providing practical support to enable them to better manage the consequences of their illness and treatment.</p> <p>Objective 3.2. 60 Spanish-speaking women undergoing cancer treatment participating in 3 monthly stress reduction/wellness education groups will demonstrate reduced stress levels, increased coping skills, and knowledge of healthy nutrition.</p> <p>Objective 3.3. By August 29, 2010, increase provider knowledge about advanced health and social services and utilization of comprehensive services for Latina patients with advanced disease from 15 to 25 patients annually.</p>

Initiative Target Population

LC4/SSWCI focuses on underserved, uninsured women, men, and their families identified as Latinos/Hispanics living in concentrated Latino communities throughout Contra Costa County in Northern California. 23%, about 210,000, of Contra Costa's population of one million is Hispanic or Latino. Contra Costa is one of the most rapidly growing counties of the nine comprising the Greater San Francisco Bay Area. Latinos constitute the fastest growing segment of the population of the County and will double as a percentage of the population in a decade.²⁷ In the communities of Central, East, and Far Eastern Contra Costa County, 6% to almost 40% of the population is Hispanic/Latino depending on the city and surrounding area.²⁸ The communities served by the Collaborative range from neighborhoods in the more densely populated urban areas of the County to rural communities.

²⁶ OMH Progress Report for April 1,2009-September 30, 2009

²⁷ US Census

²⁸ CDC REACH US Action Community Proposal

Cities with the highest concentration of residents living in poverty also include the largest percentage of Latino residents. 42.8% of residents in San Pablo and 33.4% of residents in Bay Point live in poverty.²⁹ Latinos constitute 44.6% of residents in San Pablo and 38.6% of residents in Bay Point.³⁰ In Contra Costa County, residents of low-income communities of color are more likely to develop and die from many health issues.³¹ Cancer is the leading cause of death among Latinos in Contra Costa County accounting for almost one quarter (23.7%) of all deaths in the Latino community.³² Latinos are also most likely to be uninsured compared to residents of other races in the Bay Area. According to Community Health Indicators for Contra Costa County, June 2007, Latinos represented 27.9% of residents 0 to 64 years old without health insurance in the Greater San Francisco Bay Area, reflecting 391,000 of uninsured residents versus only 8.6% of white residents.³³

Continuum of Care

The member organizations of LC4/SSWCI provide an array of services that are needed by the target population and that when lacking, have been associated with underutilization of cancer screening and treatment services, lack of adherence to physician/health care provider recommendations, and failure to follow up on treatment and care. LC4/SSWCI integrates a multi-faceted and familial approach to providing support services and case management. The Collaborative addresses the relative lack of awareness of cancer and cancer prevention activities among low income and limited English-speaking women, integrates peer educators and facilitators in community outreach and navigation of the healthcare system, and implements an ongoing marketing and outreach plan that is linguistically matched to the language nuances of various Latino communities in Contra Costa. Health educators are seen as an integral part of the continuum of care which begins with prevention.

In order to reduce the risk of late diagnosis of cancer and improve health outcomes among uninsured, underserved Spanish-speaking women and men in Contra Costa County, LC4/SSWCI implements strategies to increase community knowledge about cancer and to provide education about screening and care. These strategies seek to reduce cultural and systemic barriers to addressing cancer and to promote early detection among Latinos through outreach by community members, educational workshops, increased access to screening for uninsured women and men, and screening and treatment navigation, and case management.

La Escuela for the *Promotores de Salud* educates women and men from the community in order to dispel myths about cancer and change preventive practices. Through strategic training and support, the *Promotores de Salud* program builds the leadership skills of women and men in the community so that they may actively engage in protecting and promoting their health and that of their family and other community members. The program seeks to overcome cultural beliefs and practices that may act as barriers to early detection and effective treatment of cancer. Promotores are provided a minimum of 24 hours of health education in 12 sessions to assist them in reaching out to other Latinos and their families in the community. Cancer promotores receive additional 24 hours of workshops and training in breast, cervical, and other cancers.

Utilizing a collaborative case coordination approach and support services model, LC4/SSWCI case managers served 692 unduplicated clients over the three-year period from October 2007 through September 2010. The program and services of multiple agencies are linked to provide a continuum of linguistically and culturally competent cancer patient and family care and services ranging from case management, to practical and socio-economic and psychosocial to support during treatment and end of life. SSWCI's continuum of care is

²⁹ *Community Health Indicators for Contra Costa County June 2007*

³⁰ *US Census 2000*

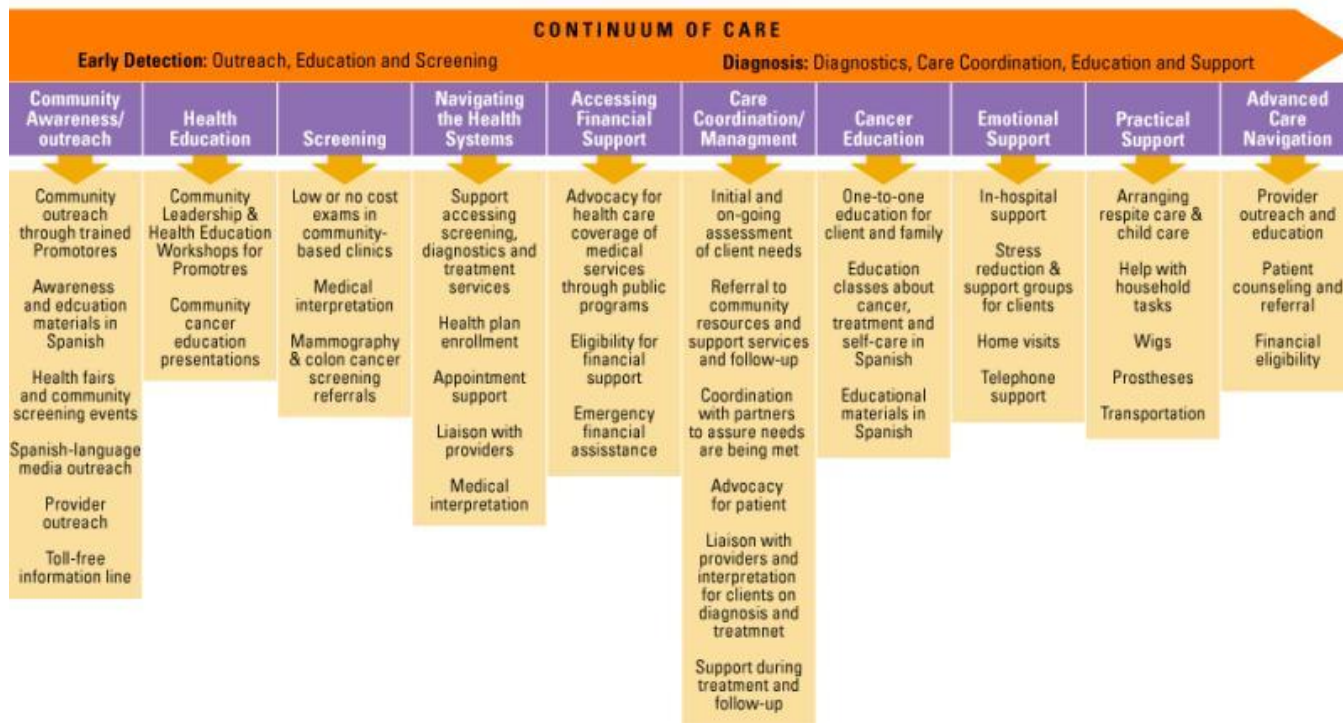
³¹ *Community Health Indicators for Contra Costa County June 2007*

³² *Community Health Indicators for Contra Costa County June 2007*

³³ *ibid*

illustrated in Figure 6 below. All of these concurrent and interconnected service methods can build and maintain an infrastructure that enhances the ability of Latino women to access culturally and linguistically appropriate health care services.

Figure 6. LC4/SSWCI Continuum of Cancer Model



LC4/SSWCI Partners' Roles in Providing Services within Continuum of Care

Each organization provides services to the community and to clients by drawing upon specific areas of expertise and strength. Duplication of services is avoided and services available to individual clients and communities are expanded.

Figure 7. Partner Organizations' (Coalition) Roles and Responsibilities

SSWCI ROLES AND RESPONSIBILITIES		
Coalition Member	Continuum Roles	3 Year Initiative Goals and Responsibilities
La Clínica de la Raza	<ul style="list-style-type: none"> Community outreach and awareness Community education Screening and referral 	<ol style="list-style-type: none"> Recruit and train 75 community health promoters Train and support 12 Promotores specializing in cancer outreach Screen 900 uninsured women at two community clinics and refer or mammography as indicated. Coordinate grassroots outreach and distribute information to 6,000 residents (with partners) Link uninsured women to free mammography and colon screening Provide 60 community presentations. Coordinate 9 risk screening and other events.
American Cancer Society	<ul style="list-style-type: none"> Transportation Cancer education Patient support Information and assistance 	<ol style="list-style-type: none"> Provide free rides to medical appointments and education groups for SSWCI clients Provide Spanish language materials and media Provide technical support to cancer education strategies Hold 6 Look Good, Feel Better workshops for women undergoing radiation/chemotherapy Distribute wigs Support resource and referral for patients and providers
Contra Costa County Health Services	<ul style="list-style-type: none"> Community education Screening Navigation/translation Patient advocacy Financial Assistance Cancer education (individual) Case management –breast and cervical cancer 	<ol style="list-style-type: none"> Conducted cancer screening navigations and interpretations for 7,000 Spanish-speaking women Conducted 12 breast and cervical cancer health classes for Spanish-speaking women and distributed Spanish language brochures and information to each. Provide navigation and case management for 100 -125 Latinas diagnosed with breast or cervical cancer.
Hospice of the East Bay & Anna's Program	<ul style="list-style-type: none"> Advanced care education Case management Practical and emotional support for recurrent breast cancer patients Cancer education (individual and group) 	<ol style="list-style-type: none"> Provide outreach and education to providers and staff about advanced care services for low income Latinas. Provide education, counseling and support to link 60 women to advanced care services. Provide practical support 60 women with advanced disease.
The Wellness Community	<ul style="list-style-type: none"> Cancer patient education (individual and group) Patient emotional support 	<ol style="list-style-type: none"> Facilitate 3-4 monthly (36-48 annually) stress reduction/educational groups for patients Conduct 9-12 wellness workshops on nutrition, physical activity and stress reduction.

SSWCI ROLES AND RESPONSIBILITIES

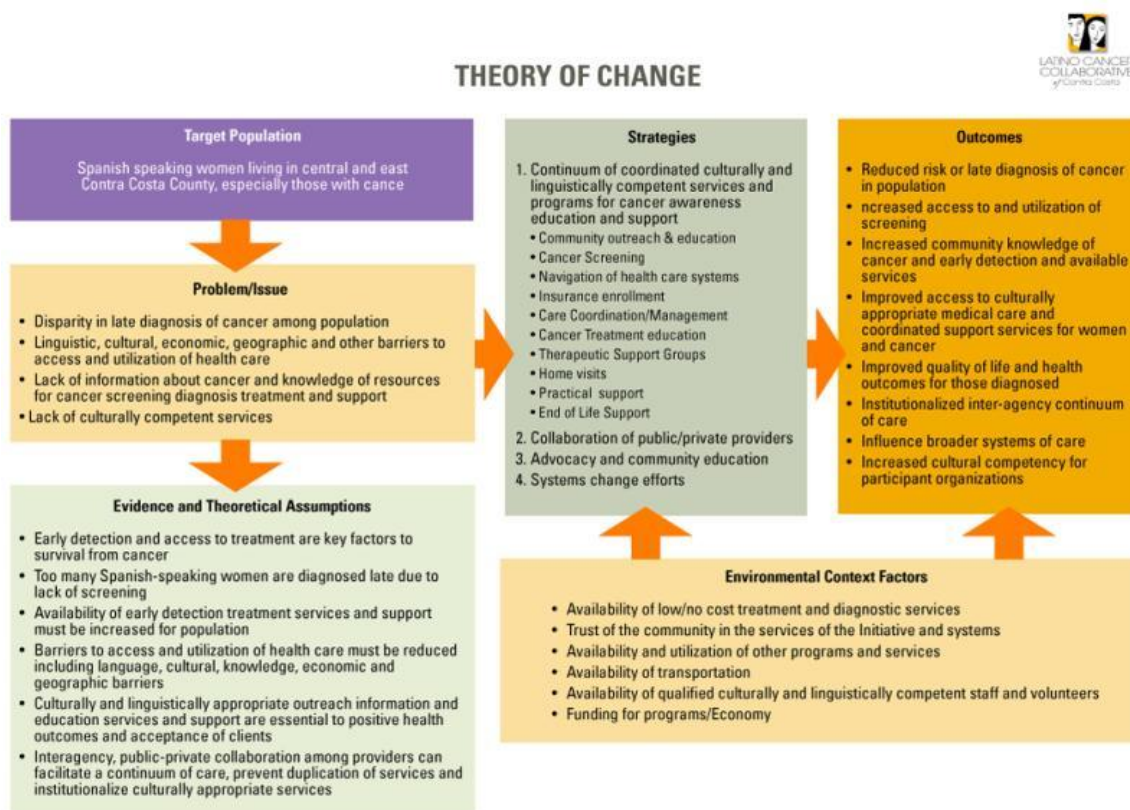
Coalition Member	Continuum Roles	3 Year Initiative Goals and Responsibilities
Women's Cancer Resource Center	<ul style="list-style-type: none"> • Navigation/translation • Patient advocacy • Case management – cervical and other cancers • Cancer patient education (individual and group) • Information and assistance • Financial Assistance 	<ol style="list-style-type: none"> 1. Provide patient advocacy, medical interpretation and one to one cancer treatment education for women under-going treatment and their families onsite at the County Cancer Center 2. Provided navigation, medical interpretation and case management to 50 – 75 women with cancer. 3. Provide hospital, clinic, in-home or telephone support to 50 women. 4. Coordinate community information and referrals through the toll free line 5. Provided prosthesis 6. Manage emergency financial aid fund and distribute as available
All	<ul style="list-style-type: none"> • Social Marketing • Community Outreach/Education • Coordination • Advocacy • Evaluation 	<ol style="list-style-type: none"> 1. Media outreach 2. Screening Events 3. Patient support 4. Annual Celebration of Life

EVALUATION FRAMEWORK

Theory of Change

Figure 8 provides a theoretical model for the Latino Cancer Collaborative/Spanish-Speaking Women’s Cancer Initiative that describes the desired change process. The model outlines the problem addressed by the Collaborative and to whom it applies. The model articulates the assumptions behind the approach, specifying key strategies to promote change and describes which outcomes define success. It also identifies specific environmental factors that influence the ability (both positively and negatively) to achieve the desired change, including community trust, availability of services and access to quality bilingual staff. The theory of change model provides a foundation for the evaluation plan and evaluative instruments.

Figure 8. LC4/SSWCI Theory of Change



Evaluation Questions

A series of questions was developed with members of the Latino Cancer Collaborative/Spanish Speaking Women's Cancer Initiative based on the Theory of Change. These questions, which guided the current evaluation, are listed below in one of five main areas of inquiry:

Knowledge of Cancer: To what extent has LC4/SSWCI contributed to an increased awareness and knowledge of cancer in the community?

- What are the most frequent myths about cancer in the community?
- To what extent has increased knowledge of cancer changed personal behavior about health or health care?
- To what extent do clients feel confident in their knowledge of cancer-related issues?
- To what extent are clients and promotores likely to share information regarding screening and services provided by LC4/SSWCI to other members of the community?
- What are the most effective ways to increase cancer awareness in the community?

Access to Care: To what extent do the programs provided by LC4/SSWCI contribute to increased and improved access to culturally and linguistically appropriate medical care for Spanish-speaking women and men in Contra-Costa?

- What barriers do clients continue to face in receiving services?
- How does LC4/SSWCI help clients overcome barriers to receiving services?
- In what ways do clients find services to be helpful?
- To what extent does LC4/SSWCI enhance communication between patients and providers?
- To what extent are LC4/SSWCI staff members knowledgeable?
- To what extent do staff-members help make clients feel welcomed and comfortable?
- To what extent are LC4/SSWCI agencies' staff members culturally and linguistically competent to work with Spanish-speaking cancer patients?
- What are other ways in which cultural competency of participating organizations/providers can be increased to serve clients more effectively?

Community Impact: What changes have occurred within the Latino community with regard to knowledge and utilization of resources, services, and treatment options related to cancer?

- How has LC4/SSWCI led to changes in individual behavior, treatment, and self-care?
- How has participating in LC4/SSWCI changed the lives of participants?
- What changes have been noted in the community with regard to knowledge of cancer (services, resources, treatment options etc.)? In what ways has LC4/SSWCI contributed to this change?
- In what ways has SSWCI increased engagement of community members, faith-based organizations, and providers in changing perceptions and norms with regard to knowledge of cancer?
- To what extent has SSWCI connected uninsured and underserved Spanish-speaking women and men to diagnostic services?

- What are the most important contributions that SSWCI makes to people with cancer and the community at-large?

Systems of Care: To what extent has SSWCI strengthened and institutionalized inter-agency collaboration to sustain continuum of care for Spanish-speaking women and the Latino community at-large?

- How has LC4/SSWCI been successful in expanding coordinated care to Spanish-speaking women and men diagnosed with cancer?
- What strategies have been most successful? What strategies have been most difficult to implement?
- Are there any particular skills/competencies that partners feel their organization has developed and/or provided through their work with LC4/SSWCI?
- To what extent has LC4/SSWCI contributed to collaboration among providers serving Spanish-speaking clients?
- To what extent have LC4/SSWCI service partners effectively established cross-partner goals, as opposed to organizational goals?
- What are changes to consider in LC4/SSWCI to increase effectiveness?
- What other organizations should be considered as possible partners in continuing to help build a continuum of care and the work of LC4/SSWCI?
- What are other possible ways to help improve services and linkages among agencies working toward a seamless continuum of care?

Expansion/Replication: To what extent can LC4/SSWCI assist communities and organizations in replicating the core strategies of LC4/SSWCI?

- What are possible next steps for LC4/SSWCI?
- To what degree is this model transferrable to other communities, geographically, and ethnic communities?
- What are critical elements of the LC4/SSWCI model that would be fundamental in replicating/scaling? What would be some challenges in replicating the SSWCI model?

Methodology

Both quantitative and qualitative data collection methods were used to conduct this evaluation, the purpose of which was to not only document the impact of LC4/SSWCI on the health outcomes of those it serves but also to describe and understand the ways in which it was able to do so. This provided a rich array of data representing the voices and experiences of Collaborative partners, promotores, and clients. The following summarizes the various data collection methods.

Client Focus Groups

Fifteen LC4/SSWCI clients (those women who are provided LC4 case management services during and after treatment for breast, cervical and other cancers) participated in two focus groups. The first, with eight participants (six clients and two family members) took place on July 19, 2010 at the Wellness Community in Walnut Creek. The second with seven participants (seven clients) took place on July 20, 2010 at the Women's Cancer Resource Center in Oakland.

Promotores Focus Groups

Eighteen promotores (community members trained as community cancer health advocates) participated in two focus groups ranging from 60 to 90 minutes each. The first, with 10 recently trained promotores took place on July 16, 2010 at the Pittsburg La Clínica de la Raza and was conducted in English. The second, with eight more experienced promotores took place on August 2, 2010, also at the Pittsburg La Clínica de la Raza and was conducted in Spanish.

Client Interviews

A subset of six clients who participated in the client focus groups also participated in individual 30-45 minute interviews by phone to provide more in-depth information. Interviews took place between August 16, 2010 and August 31, 2010 and were conducted in Spanish.

Partner Interviews

Individuals within Collaborative partner agencies and organizations were identified by the Collaborative Coordinator who would be able to speak about the impact of LC4/SSWCI on their organizations as well as provide insights in to areas of expansion and potential replication. An initial email was sent by the Collaborative Coordinator with follow-up attempts via both phone and email by the jdcPartnerships consulting team for scheduling. Overall eleven Collaborative partners were contacted and of those nine participated in phone interviews conducted in English during the period of August 16, 2010 and September 3, 2010. Three interviews were 20 to 30 minutes and six were 10 to 15 minutes.

LC4 Partner Retreat Notes

Notes from the annual Partner Retreat were also used. The retreat took place in the summer of 2010 and consisted of 20 participants. This retreat is an annual event during which time Collaborative partners engage in reflection of the accomplishments and learnings of the previous year, assessment their progress towards annual goals and engage in planning for the next fiscal year.

Other Sources

Performance data and various sources of qualitative evidence reported every six months were also included. Each partner agency reports on specific activities related to their individual roles as well as coordinated efforts. The data is aggregated and analyzed to understand the overall efforts of LC4 individually and collectively. A review of local and national epidemiology studies provided further information on community impact. Additional information and clarification of evaluation findings were provided by the LC4/SSWCI coordinator.

Figure 9 below provides further details about the various data sources.

Figure 9. LC4/SSWCI Evaluation Outcome Data Collection Summary

DATA COLLECTION STRATEGY	DATA SOURCE	SAMPLE SIZE	NOTES
Focus Groups	Promotores	18	Conducted in-person Experienced promotores focus group was conducted in Spanish with English translation
	Current/Past Clients	15	Conducted in-person in Spanish with English translation
Interviews	Current/Past Clients (Subset of Focus Group Participants)	6	Conducted by telephone in Spanish
	Selected Providers	9	Conducted by telephone in English
Project Performance Data	LC4/SSWCI Partner databases and data collection tools	NA	Partner performance data is reported every six months through the Office of Minority Health UDS system as well as the LC4/SSWCI Access database
	American Cancer Society: Cancer Facts & Figures 2010		Includes national data on cancer trends and rates for 2010
	American Cancer Society: Cancer Facts & Figures for Hispanics/Latinos 2009-2011		Includes national data on cancer trends and rates specifically for Hispanic/Latino community through 2006 with 2009 estimates
	2010 Contra Costa Regional Medical Center: Cancer Program Annual Report		Includes data on growth, programs, and trends for communities served by Contra Costa Regional Medical Center for 2009
Secondary Population Level Data	Community Health Indicators for Contra Costa County, June 2007	NA	Describes health status of Contra Costa residents on specific health and demographic indicators. Prepared by Contra Costa Health Services' Community Assessment, Planning and Evaluation (CHAPE).
	CHIS California Community Health Survey, 2005, 2007		Health Statistics from the California Community Health Survey Ask CHIS www.chis.ucla.edu
Other	Northern California Cancer Center: Finding Answers, Making a Difference, December 2008		Cancer Risk Factors and Screening Behavior in the Greater Bay Area: Data from the California Health Interview Survey
	2010 Collaborative Partner Retreat Notes	NA	Notes from partner retreat conducted in May 2010 includes information on lessons learned, accomplishments and challenges
	Collaborative Coordinator	1	Communication with Collaborative coordinator during planning, research, and analysis phases of evaluation

EVALUATION FINDINGS

Interview responses, focus group discussion, and insights from the partner retreat and the LC4/SSWCI coordinator were synthesized into the themes presented in the following evaluation finding sections (except the Project Performance Data section). Lessons learned are integrated in the discussion of findings and are also summarized, along with successes and recommendations, at the end of the report.

Activities for Outreach and Increasing Awareness

The activities of the Collaborative help dispel myths and increase accurate knowledge. Promotores — which include adults and young adults from the community, including college students and family members of cancer patients — receive information about cancer and how to reach and inform others through a series of training sessions and ongoing support.

In their focus groups and interviews, collaborative partners, promotores, and clients discussed some of their strategies for expanding awareness in the Latino community. These activities, along with others highlighted by the Collaborative's lead consultant, are listed below. While not intended to be a comprehensive list of all that LC4/SSWCI participants do, it serves to illustrate some of the diverse ways in which each Collaborative participant group — Collaborative partners and staff, promotores, and clients — is involved in several overlapping parts of a multi-pronged approach to dispel myths and raise awareness.

Some of the ways collaborative partners and promotores are expanding awareness *include but are not limited to*:

- Making presentations and leading workshops at clinics for the general public.
- Leading workshops at clinics for clients. (this is patient education)
- Hosting community risk screening events.
- Sponsoring media outreach through PSA using community members
- Making presentations to community groups.

Additional activities by promotores, case managers and health educators *include but are not limited to*:

- Speaking to and giving pamphlets or flyers to friends and family members
- Passing out pamphlets and speaking about cancer and where to go for free screenings to individuals at health fairs, churches, parks, and outside popular stores
- Visiting an elementary school to talk to students and their parents about cancer
- Enlisting city officials to post information on public electric signs
- Putting announcements on the radio
- Participating in interviews on Spanish-language television
- Providing one-on-one consultations at community cancer events
- Conducting community surveys
- Making presentations at various locations and for different groups in the community

Once they are a part of the Collaborative's continuum, clients too, engage in activities to raise others' awareness, including:

- Sharing their story and what they are learning with a spouse, children, and other family members
- Talking and giving out pamphlets about cancer to others

One client describes how she has taken what she learned from the Collaborative and engages in her own informal outreach and awareness-building:

"Now I can talk to people about how they don't need to be sick to get information and learn about how to take care of themselves to prevent illnesses, because cancer is an illness that does not have any warning signs, you can't tell anything....So now I tell people who say, 'Oh, it hurts when you get a mammogram,' I say, 'It's better that it hurt now for a little bit than to go through a treatment like the one I am going through,' because sometimes when we don't have go through some pain, or are embarrassed, we don't do things. Now we have to be alert at getting check-ups and continuing with treatment. So in this way I try and suggest to them, like my neighbor who has a history of cancer in her family. She is panicked to talk about cancer and I tell her no I have information. Get a lot of information and read, because then you can learn and understand that you shouldn't fear things. You should just be prepared."

Effectiveness of LC4/SSWCI Strategies in Outreach and Increasing Awareness of Cancer and Cancer-related Services

The focus of LC4/SSWCI's awareness-building work is to dispel myths, increase screening rates, and get people to services, such as screening or cancer diagnosis. The Collaborative conducts outreach and education in the Latino community primarily through promotores and health educator outreach at community events, in partnership with community organizations and gathering places such as churches, schools and community centers, and hosting health fairs where participants are given surveys, case managers conduct risk screening consultations, and refer community members to primary care and free screening services. Women at high risk are provided follow-up to assure they receive appropriate medical attention..

Clients and promotores described some of the fears and misinformation that exist within the Spanish-speaking community that outreach and awareness-building activities must overcome. Several said that cancer is commonly believed to be unpreventable and a "death sentence." There is widespread fear that cancer is spread like AIDS or even a cold. Promotores explained:

"A myth that I see exists a lot within the Hispanic community is that if you have cancer it's a death sentence. They don't think that there are possibilities to be cured and get better."

"What I have heard is that everyone says, 'Why am I going to go to the hospital, because I don't have anything and they are [the hospital] going to get me sick.'"

Some individuals are so afraid of the topic that they refuse to talk about it. New promotores pointed out that there are gender and age gaps within the community, that men – especially those of their parents' generation – are less likely to take action for their health than women. Clients, promotores, and providers all pointed to a general discomfort among Latinos about discussing anything related to breasts, the prostate, or other body parts. Others explained that misinformation about screening and treatment can be a reason people do not engage in early detection or treatment. For instance, they may have heard that a prostate cancer screening, mammogram, or breast cancer treatment is more invasive than it actually may be. One promotora explained,

"I met a woman who actually passed away from cancer, but what happened was that when they first detected the cancer in her breast, she did not want to get it treated because she thought they would remove her breast and she wasn't going to feel like the same person. Unfortunately, she tried other ways but she was never able to get the right treatment, and then when she did

try to treat it appropriately, it had spread. It was sad because it spread very quickly so that when she did want to get treatment it was too late."

Impact of Outreach and Awareness-building Activities

Collaborative partner perceptions indicate that outreach efforts are making a difference within parts of the Latino community, although there is still work to be done to effect widespread awareness throughout the population. One LC4 provider believes that many in the Latino community do not "think of asking questions or even know what to ask." However, another sees a higher level of understanding among community members as a result of outreach and education efforts, saying that often, rather than needing to be encouraged to seek screening and education services, community members now come to Collaborative partners for help in getting the screening and education they need. One promotora provided an example of the community's eagerness for information, recalling a recent health fair with more than 1,200 attendees, many of them uninsured and without health care. At that event, 400 men and women received cancer risk screening consultations and cancer education.

Addressing the Collaborative's ability to overcome fear of participating in screenings by undocumented immigrants, an experienced promotora explained,

"Many people may not come to us because they may think that because they do not have papers that we will do something. They think that La Clinica is with immigration. When we clarify everything, then they see that all of that is false. That is the beautiful aspect of it. When you gain their trust and they feel this trust to talk to you, it is a great satisfaction. You are helping them and it is helping you, as well." (This is just about screening. What about treatment barriers? Treatment barriers should be addressed in navigation and case management not awareness))

Although clients did not discuss experiences with screening, many talked about the impact of an increased awareness overall in dispelling myths and fears. One client said that, as a result of increased knowledge and awareness about cancer,

"I no longer have that fear to talk about cancer. Before, I would talk about cancer and you would of course think about death, and now I see life differently. You have to talk about cancer to be informed to get better, even though there is no cure, but there is so much modern technology now in order to keep moving forward."

Celebrations and events that involve the family members of cancer patients are another form of community outreach that clients and providers also see as important outreach opportunities. Two clients expressed great appreciation for the opportunity to come celebrate with loved ones and other cancer survivors at occasional special gatherings, such as "celebrations of life" in the park or a more formal evening event. A provider explained why these celebrations are important outreach activities:

"We have an annual survivor celebration and it's done in Spanish with music and food, and it involves family. It is helping to dismiss some of the myths that go along with cancer (like that it's a death sentence) and the Latino community fears and beliefs."

A client described why she likes to participate and bring others to the celebrations, saying,

"Once a year, they have a ball and one can take their partner, and we have dinner and there is music, with a raffle...It makes us feel special."

Although greater awareness within the community is a continuing goal, comments from clients, promotores, and Collaborative providers and staff indicate that the Collaborative has been able to conduct outreach, raise awareness, and disseminate information that helps Latinos take an active role in cancer education, prevention, and treatment.

Suggestions for Outreach and Further Increasing Awareness

Collaborative participants expressed a desire to become even more effective at outreach and awareness-building and shared ideas about what they thought would help. While not everyone will be interested or even able to read printed materials, there was a general sense among most of the promotores that continuing to have pamphlets and flyers to reiterate information they give out about cancer and free services at health fairs and other times is especially helpful. For one new promotora, this would boost self-confidence when trying to remember facts to tell community members. For others, it would help community members to trust them. One experienced promotore explained,

"Everyone knows that we are not doctors, so when we start talking to a person they look at us like, 'Who are you?,' but if we take out a pamphlet and show them the information, they know we are not making it up."

Another, echoing other experienced promotores, observed,

"When we do the health fairs and we say that people can get free shots or whatever the case may be, there are people who will say it will be free until you receive a bill at home, so the pamphlets help support us and back up what we are saying."

In general, promotores, clients, and Collaborative partners believe that adding or increasing the quality or frequency of the following strategies would be the most effective ways to further disseminate information within the community. *It must be noted that several of these strategies already take place and are noted with an asterisk in the list below.* For those items, the desire is that, with more resources, they would take place more often or on a broader scale.

- Informative, up-to-date videos that promotores can show during presentations
- Television messages in the form of commercials, especially during popular daytime programs (e.g., telenovelas)*
- Testimonials from patients and others about the importance of screening and early intervention
- Printed flyers with clear information and phone numbers to call about available resources*
- Flyers mailed to community members who may trust information directly from an organization more than from an individual at a health fair or presentation
- Presentations at schools to families and students*
- Pamphlets in hospitals with information about resources, especially those for uninsured and low-income individuals*
- Information about cancer in high school and middle school health classes (beyond simple "don't smoke" messaging)
- Emphasis on prevention in all educational materials and activities, since that is the most affordable strategy people can implement *

Effectiveness of LC4/SSWCI in Increasing Access to Cancer-related Services

Latinos in Contra Costa County face many barriers to accessing adequate, affordable, and appropriate cancer-related care. Promotores, clients, and providers all cited n status as an undocumented immigrant as a significant barrier to some Latinos being able to access care. In addition, being uninsured and/or low-income was cited by all interview and focus group participants as a barrier. Referring to the seriousness of financial considerations, one experienced promotora explained,

"Sometimes they have all the information but they are afraid that they will not be able to feed their families because of the cost of the check-up. We prefer to feed our families than to get a check-up, but we should go get a check-up because if we are well, then we will be able to keep providing food for our families."

Several clients discussed immigration status and lack of insurance as barriers to care:

"I would say there are barriers especially for those people who do not have medical insurance. It is not easy for hospitals to give treatments, especially when it comes to cancer, where the treatment is so expensive and I have heard people talk about how it is difficult for them and if they do get services they are treated badly. They are not served well. The doctors don't pay much attention to them. That is what one of the women in the group was talking about. She went to the doctor and was talking to the doctor about how the treatment was not working, but the doctor just told her, 'Well, take the medicine if you want; if you don't want to, then don't take it.' And I don't think this is a good way for the doctor to respond. And also when one doesn't have papers, all of these things are obstacles for people. They have talked a lot about this at the support groups. People say, 'Oh, I don't have papers. I don't have insurance. So I don't have much support in these areas.'"

"With respect to Latinos, I think that the principal thing is the issues of immigration and being undocumented. Many people don't have papers, and when they come they are very afraid. Our group doesn't have anything to do with legal or illegal things, but it seems that they come so terrified because of all of these things that are going on. But we have nothing to do with that, and I hope that...when these women come they see that it is not like that here that this is a group where they can talk if they want, they begin to feel okay and they start to continue to come. But I think this is a barrier that is starting to grow especially when it comes to medical insurance...." (Note: As of March 2009 in Contra Costa, residents who are undocumented are no longer eligible for basic health care insurance through County Health Services.)

Transportation is also an obstacle to receiving care, as several clients explained:

"I think that the majority of the people who come to the programs from the Hispanic community, a lot of them are low income, and it would help them to have transportation. I knew a young girl who didn't have transportation and who I would take her to the groups, but unfortunately she passed away. I lived in one side of town but the majority of people live on the other side so it's hard for them to get there. A few years ago there was a bus that would pick them up. I think that would be something that is needed"

"Transportation is the main obstacle because many of the other women that I know now because of the support groups, many of them do not drive. I actually have tried to have my daughter to drive them, if we have time. But the majority of them say that transportation is a big issue for them to access the services....I come all the way from Richmond, so the problem is that I always

only go to the program that is closest to me. I can't go to everything because I don't have transportation and also I don't know how to ride BART or the bus, so I stay with the urge to want to attend more. There have been programs about nutrition, and how to eat healthy, jewelry making, support that they give us to learn, to distract us, there are a lot of things that they give us in these groups and I can only go to one. Very rarely I look for someone to bring me, but I want to learn more."

For many individuals, there are coexisting, compounding barriers to access:

"The two main obstacles are transportation and language for people to speak Spanish, for there to be a bilingual person present than can understand us as well as transportation. For those of us who do not drive this is a big obstacle for us."

"I know someone in church who was recently diagnosed with cancer, and I have been trying to guide her and inviting her to come but the hours are the problem for her because she works and she doesn't want to stop working. She says that if it [the support group] was in the afternoons or maybe on Saturday she could attend because she works and she doesn't want to miss work. She asks me, 'Is there another one in the afternoon?' and I tell her, no, it's only on Thursday from 12:00 to 2:00."

A summary of barriers to access that clients and promotores in interviews and focus groups described includes:

- Financial hardship, as many are uninsured and unable to afford treatment, services, medication, home health care providers, or child care for when they have appointments
- Undocumented immigration status, which leads to many individuals being too afraid to seek services and others being dropped from what limited services exist for undocumented clients during budget cut-backs
- Transportation issues, including not having a vehicle, not knowing how to drive, needing to travel too far for services, and not having the money to pay for other means of transportation to appointments
- Complex care systems, as one patient may need to visit multiple sites for appointments and treatment, as well as self-administered treatment at home
- Not knowing where to turn for information about frequently-changing resources and available services
- Language limitations, which make it difficult to understand instructions about medication or learn about and participate in treatment options
- Location, as several clients lamented the lack of services in Richmond, and a provider told of receiving calls from San Francisco and San Mateo because Spanish support groups are not available there
- Schedule, since many potential clients cannot attend daytime support groups due to work

How LC4/SSWCI is Expanding Access

By implementing a continuum of culturally and linguistically appropriate care and coordinated services, LC4/SSWCI is designed to increase access to cancer-related services and support better health outcomes and quality of life for Spanish-speaking women and men diagnosed with cancer.

Explaining how the Collaborative has improved access in the Latino community, a provider explained,

"We have our patient services, which are no cost to any cancer patient, and working with the Collaborative, we are able to disseminate that information and the partners are able to refer patients back to our 800 number or to one of our staff who can help them access those services. We also have the programs now in Spanish."

A client provides the perspective of those receiving care and services by Collaborative partners:

"They give us information about different organizations. For example, this person helped me with my mileage so that I could get reimbursed for transportation, or to find where I could get gift cards. She pays attention, and so she listens to what you need, and she looks for the best way to explain things to you. If we are confused she says to just ask her."

Providers, clients, and promotores provided several specific ways that the strategies and actions of the Collaborative have expanded client access to linguistically and culturally appropriate services, including:

- Spanish-language support and referrals 24-hours a day through a free hotline number
- Transportation to and from treatment
- Spanish-language interpreting during hospital stays and diagnostic and treatment visits
- Financial assistance for transportation or a home health aide
- Information about no-cost or low-cost services for which clients are eligible
- Conducting research and providing information about services available to undocumented immigrants
- Assistance in filling out paperwork for transportation, financial assistance, disability coverage, or other services
- Collaborative staff members assisting with patient navigation and contacting clients between appointments to clarify information and answer follow-up questions, which improves client follow-through and health outcomes
- Collaborative staff members providing feedback to providers about culturally sensitive situations, leading to a more comfortable and culturally competent experience for clients

Suggestions for Greater Access

Collaborative participants have several suggestions for how to further expand access to care for the Latino community.

- More publicity about the Collaborative for potential clients
- More transportation
- More programs in Richmond
- Longer support groups

- More frequent support groups
- More frequent health fairs
- Access to La Clínica services and health fair screenings for promotores
- Legal services to help people with immigration status so they can access more services
- Complementary services from other organizations, like child care and housing

Impact of LC4/SSWCI within the Latino Community

As a result of its strategies to build awareness and access to linguistically and culturally appropriate prevention and care, LC4/SSWCI is having an impact on the Latino community in Contra Costa County. This impact encompasses the attitudes, behavior, and actions of Collaborative participants and extends outward, as they inform and assist family members, friends, and other people they encounter during the course of their day.

Clients and promotores have:

- Gained the confidence to speak out about cancer, screening, and health care options
- Acquired knowledge about resources available to the community
- Changed cooking, eating, and exercise habits
- Committed to preventive care, early treatment, and following through on treatment plans
- Supported other Collaborative participants and individuals in the broader community by providing information, sharing experiences, and facilitating their participation in Collaborative programs
- Seen greater openness among family members and friends to hearing information, asking questions, sharing information, and engaging in conversations about cancer, prevention, and care

Collaborative partners noted that the knowledge of cancer, understanding the need for screening and treatment, and knowledge about how to access care, have all grown in the Latino community since the start of their work together. Promotores echo this observation: ‘As members of the community, they also learn to be proactive about their health.’ As one experienced promotora has learned,

“It’s important to check yourself before you feel sick, so you don’t reach the stage where nothing can be done.”

One of the many ways LC4/SSWCI has had an impact on the Latino community in Contra Costa County is by building engagement of community members who have become involved with the Collaborative, either as promotores or clients. As a result of the individual outcomes in knowledge, self-care, and confidence, these participants are engaged in outreach, education, and support efforts that may lead to positive outcomes for others in the community not directly involved as they are.

For instance, clients are talking to fellow church members about what they have learned about cancer and access to care and are encouraging them to join them at support groups. Promotores are telling friends and family members about their health education work and what they have learned about prevention and treatment and recruiting others to become promotores. These forms of engagement, where community members themselves are taking the initiative to reach out to others, exist in addition to the formal, overarching outreach strategy of LC4/SSWCI. These actions are evidence that the community is beginning to take ownership of the goals of the Collaborative. As clients explained:

"Individually, [my involvement in this program] has impacted me in such a way that, in the church that I go to there is a Spanish-speaking mass, which I usually don't go to. (My husband is American so I go to the English speaking mass.) But I put my name in the church bulletin and I have said to contact me in Spanish if any one of you get cancer. They call me and I bring them to the [support] group. So I feel like I need also to contribute because I don't want to be always receiving, but I also want to give it back."

"There are a lot of people who don't go and don't know about the services. I met a woman who didn't know anything or could get help, so I gave her information and helped orient her so that she does not get discouraged."

"When I know of a person that is going through the same thing that I am going through, I try to invite them to the programs that I know of where she will be able to get information. I tell my brothers, 'When you find someone that is sick,' because sometimes they meet people like me, I tell them to give them my phone number to call me so that I can help take them to the group we go to or if they need to find information about something I know about I can help them find information or take them to...people that can help, because we are people that have experience in this small road, and I try to help them to go to the groups we go to. And if the women decide not to go then that's up to them, but...I tell them the place and time and say if you want to go we can all go. Because when I first started, I didn't know where to go or who to ask about what to do."

Another client who used to visit patients receiving chemotherapy in the hospital in Martinez when transportation allowed said:

"I am there saying, 'Hello, how are you feeling,' and telling them to be motivated because I had it, and thanks to God here I am. Thanks to the support I received. 'Here I am', I tell them. It is very beautiful to visit all of those people who are there...so that is the most important thing I have learned to have love and to talk at least for five or ten minutes and say to talk to one person."

Effectiveness of LC4/SSWCI in Sustaining Collaboration and Systems Change

LC4/SSWCI works to improve the quality of services for underserved, Spanish-speaking women through a dynamic and strong collaboration of agencies linked to form a continuum of services. They partner with health care providers and community-based organizations to reduce barriers to care and promote institutional responsiveness to the cultural and linguistic needs of Latinos.

Providing Case Management and Support Services

Personalized, warm, and culturally and linguistically appropriate case management is at the center of the LC4/SSWCI patient care process. As discussed earlier in this report, the American Cancer Society sees these qualities as essential to working with Hispanic populations. Clients are generally referred to a case worker by a social worker or other provider at a partner agency or hospital. LC4/SSWCI case workers accompany and translate for some clients at treatment or diagnostic visits, conduct needs assessments, and provide them with information about services or benefits for which they are eligible. They also consult with them about their needs and options by phone.

One Collaborative partner talked about LC4 monthly meetings where the bilingual patient care manager and other providers discuss client needs, saying, "The ability to share difficult cases among individuals and across

organizations is really powerful.” Describing the uniqueness of the Collaborative’s case management, one partner observed,

“It is what our health care system should be about. I find it ironic that the most integrated care you get in our system is hospice. You don’t get it till you have six months left to live.”

Many clients explained in detail how the case managers have helped them, from economic support to referrals and information, to simple comfort by accompanying them and addressing their overall needs and concerns. In their own words:

“These people are like angels that help us. I don’t know what would happen to us. For me, everyone who has helped me here is like an angel who supports us because the economic support, the moral support, the spiritual support it has helped me so much.”

“I had economic problems and I spoke to her [the case manager] and told her the serious problems that I was going through, and so they gave me financial assistance and later, every eight days when I was in chemotherapy, she would come see me always and also, about two or three times, she was there to translate because I only speak Spanish and very little English. She helped me a lot, and she was the person who also told me about the places where they can help you if you want to look better.”

“I like it now because of the financial help they give me. I mean I shouldn’t say that, but to start that was the best — economic help — because that is what we most need when one is sick because the husband has to keep missing work so that he can come and take us back and forth to appointments or if I can’t find someone who can bring me....That’s the part that does benefit me.”

“She told me about the bus that would take me to the groups and then she gave me vouchers for transportation to ride the bus. I would take it to and from [the groups]...and I would only have to pay a dollar difference with the tickets she gives me.”

“She [the case manager] told me I could apply to the different services, and I did so and I was able to receive help.”

“They give us information about different organizations. I usually talk to her over the phone. She helped me with my mileage so that I could get reimbursed for transportation, or to find where I could get gift cards — she connected me with someone that would help me with this. And in this way I have received a lot of help from her. And the first time I met her in person when I came here [to WCRC,] I felt comfortable and trusted her. She pays attention and so she listens to what you need, and she looks for the best way to explain things to you. If we are confused she says to just ask her if we don’t understand something. She is a really good person.”

Clients, care providers, and other Collaborative partners were consistently positive about the LC4/SSWCI bilingual care manager. However, one provider expressed a concern that the care manager is less visible at the clinic than in previous months, saying, “You need a person here, ideally in clinic, so you can introduce your patient to them. The person-to-person connection is the most critical piece.” In fact, the bilingual care manager’s workload has doubled over the past year: LC4/SSWCI is providing services to clients who would once have been served by the County, which has cut back its services. The Collaborative coordinator explains that the most critical piece of the case manager’s job actually is to “make it possible for people to participate in treatment by making sure they are enrolled in financial assistance, can pay their bills, have a place to live,

understand their treatment protocols, and are getting support from peers.” With the increased caseload, the case manager is by necessity engaged in these activities for an increasing amount of time.

One of the most important resources for emotional support and education that case managers help clients to access is support groups for patients during and after treatment. Several clients pointed to the support groups they attend through the Collaborative as invaluable sources of information, as they learn from other participants about what to expect in their treatment, how to take care of themselves, how to talk to their doctor, and how to cope with family members who are unsupportive or do not accept their diagnosis. Most importantly for some, the support groups provide an opportunity to see that it is possible to have a life after diagnosis and even to survive cancer.

In interviews and focus groups, clients talked about the benefits of the support groups:

“In the beginning, I couldn’t even speak about this topic because it hurt me too much. I couldn’t control my emotions, my nerves, my fears. I didn’t know many things, and so coming to the groups helped me to learn to talk about everything and not have those feelings stay inside. The body is very fragile, and if we keep adding stress to it, it will be worse.”

“I have friends there [in the support group] that understand my situation, and they call me and we talk. We support each other and discuss religion, and we exchange ideas about God, saying that God is giving us strength.”

“They are very welcoming and trustworthy. You feel like you are among family because it is difficult to arrive at a place and you don’t know anyone and feel like you can share. So in this way it is really great because when you get there they are kind and nice giving us trust, and telling us here is water, or something to eat. So they treat you with trust, they say come join us. Here we are among family. We are all here to help each other and you don’t have to feel shy or embarrassed. And in this way it is a beautiful thing because we feel that there are no limits to talk about our situations.”

“I think these programs have helped us be more positive and have courage....I think that when we find people that are positive, it helps lift your morale and say, ‘Yes, you can and let’s go,’ and in this way I think the group helps a lot.”

As the following client comments illustrate, the support groups are also places where clients can get information about services and care and where case managers can continue in their role of identifying and facilitating access to other forms of support:

“I have only participated in the support groups, but on one occasion in one of the meetings where I attended, they asked for information and they were able to help me by providing me with a voucher of \$500 to help me, and so I have received financial support and from there. In the meetings I have attended they tell us about the services that the initiative has, for example when the cases are more severe and the people need more help they told us about a place that is like a small hospital where they would take care of you if this was necessary and if you also can’t move around too much, for example if you are very elderly and can’t do things, a nurse can go to your home and help you. So we learn all of these things as we continue to participate. All of this is new for me because I didn’t know about it before.”

“We share and we learn, and if we have any doubts in terms of questions about medications and treatments, people give you advice. For example, I am receiving chemotherapy and someone

else is also, so we...learn different ideas on how to control our symptoms. And this helped me a lot."

Building Competency within Organizations

The experience of participating in LC4/SSWCI has led to increased competencies in a variety of areas for Collaborative partner agencies, including:

- Improved outreach to the Latino community
- Developing bilingual, bicultural services that did not exist prior to the Initiative including case outreach events, health care navigation, care management, support groups and workshops, and advanced care support
- Developing referral relationships with other organizations in the community
- Instituting classes in Spanish about nutrition, financial issues, financial support for disabilities, and information about caregivers for clients
- Using the continuum of care as a model for organizing services for the Latino and other client communities
- Expanding use of a strategic planning process and logic model throughout the organization
- Improving meeting management skills, including having outcomes and times assigned to agenda items
- Strengthening and expanding a hospital-based program that utilizes and recognizes employees with bilingual skills as translators for clients, now available for patients with issues other than cancer

Collaborative Success: Key Contributions of LC4/SSWCI

Each LC4/SSWCI partner interviewed was asked to reflect on the Collaborative as a whole and what its contribution is to systems change and the development of a continuum of care for Latinos in Contra Costa County. Each felt strongly that the Collaborative is indeed building and strengthening systems and care. Although Collaborative partners might be expected to cite their own work as being of greatest significance, several credited the mutual trust and reliance that has been cultivated through the facilitation and leadership of LC4/SSWCI for enabling them to understand and acknowledge the contributions of work beyond their individual efforts. Following are examples, some of their comments, and additional insights from promotores and clients about what they felt have been the core contributions of LC4/SSWCI.

Coordination among Agencies/Providing a Continuum of Care

Collaborative partners are specializing in their agency's strengths, institutionalizing certain services, and relying on other Collaborative partners to provide other critical pieces of the continuum of care. Partners become familiar with each others' services and refer clients to each other. They share a common intake and referral form. Each partner is able to give referrals to clients for many basic services and occasional complementary treatments that clients appreciate, like acupuncture or yoga. Partners have jointly identified needs and sought funding, and they are collaborating on funding decisions. In an indication of how coordination can increase efficiency and quality of care.

Partners gave examples of how they see or contribute to increased coordination. LC4 has developed a referral form with all of the partners listed, so that whenever a patient is seen at a any partner, clients can easily be

matched and referred to partner organizations. Another partner identified the LC4 health fairs as valuable opportunities for small community organizations to come together and collaborate in providing services and referrals.

Clients described the assistance that the Collaborative provides in obtaining services for multiple needs through the LC4 network:

"I have had experience in this, they [Collaborative staff] referred me to a service at the American Cancer Society called 'Look Good, Feel Good,' and I liked it because they help when your hair begins to fall. They help you with make up so that you feel better and look better and they provided me with a wig."

Referring to other services she learned about through the Collaborative and knowing that case managers arrange transportation, one client explained,

"Although I can't receive this because I have private insurance, there is this service in Oakland...where they give you massages and acupuncture. I am glad that if it is not for me that others can receive these services and I have benefited a lot."

Partners discussed the impact of this kind of continuum of care on partner organizations and on the clients, themselves.

"Coordinating efforts is huge. Bringing people together who are the managers of the program and being able to give up certain aspects of the continuum. Everyone thinks they've got to do everything, and you don't have to. We used to do a lot of outreach in our program. For the past three or four years, I've backed off on that and there are other partners in the Collaborative who do it just fine. We can put more of our efforts into our expertise."

"The most important fact is that people who get into systems of care have better health outcomes. Bringing uninsured, underinsured women with cancer into a system of care, like LC4, is a miracle in this day and age...and it's the warmth of the individuals that makes it work."

One partner explained:

"Before the Collaborative, there was no one doing what we do....Between us, we make sure the patient is taken care of. I think it's amazing the way all the organizations came together to work towards the wellness of the Latino community in the County and also that everybody compromises and takes it over and tries to get it done. Without the Collaborative, that wouldn't happen."

Patient Navigation

Case managers are knowledgeable and proactive about matching patients to the services they need, when they need them. Providers use the term "warm hand-off" to describe how a client is assisted, accompanied, and followed-up with by case managers and partner providers from one referral to the next, or between appointments for services within or between agencies. As one provider explained,

"The treatments are really complicated these days. Someone needs to be able to help folks navigate between all these different facilities. Surgery at UCSF, chemo here with a continuous

pump they're taking home, and radiation at another hospital. It takes a lot of coordination and care for people, and there can be issues regarding language and financial resources."

Clients attested to the great help it was to have a case manager present to help them at their appointments or to support them with issues that arose related to their care:

"I am very happy with this service....Besides the information they provide, they help. They guide us, navigate us, telling us if there is a different type of help and asking what else would we want."

"In my case, the first time that I met her [the case manager] it was at an appointment there with the doctor and she would translate for me into Spanish. A counselor here at the hospital was interviewing me and showing me different programs on television. She [the case manager] said to me, 'I'm going to be your social worker' and she was very good, I was comfortable with her....and she [the case manager] continued to be like my doctor and work with me like a social worker."

"She's [the case manager] always there during my appointments and if I have any difficulty, if I have a problem with a bill or test results, then she tells me to go to the office and take care of it. And every time I have an appointment, she is there and we are talking and she dedicates time for me, and she is really wonderful."

The comment of a client's daughter below highlights how the Collaborative welcomes and reaches out to family members with support, and also helps them to manage the demands of patient navigation. (This mirrors the American Cancer Society's recommendation to involve family members in treatment and care.)

"I try to go twice a month [with my mother] to the support groups in Martinez and Concord, and it has been a lot of help for me as the caregiver to my mom....They help with taking her to appointments and the doctor. It was a big impact for my family. We learned that cancer not only affects the person but also the entire family and here they have supported us so much."

This same client said,

"I will take my time with the doctor and he will take his time explaining to us what is going on or what is the next step, what we should look for after the chemo."

The result of a successful patient navigation component is that clients follow up more consistently on referrals and recommendations for care and complementary services.

Advancing Culturally Competent Care

Since their participation in LC4/SSWCI, providers with partner organizations have deepened their understanding of what is necessary to provide culturally competent care for the County's Latino community.

Some of the ways in which partners are building their capacity to deliver culturally competent care are:

- Hiring bilingual/bicultural staff for information and translation services
- Providing an increasing amount of literature and services in Spanish
- Inviting feedback from bilingual case managers about culturally sensitive situations so that providers can ensure a more comfortable experience for clients
- Understanding the cultural variations within the Latino community and implementing practices that reflect that understanding

- Providing consistent, personalized support by partner providers and other staff of partner organizations
- Promotores acting as liaisons between partner agencies and the community, providing culturally appropriate outreach and information

The impacts of creating and maintaining a system of culturally competent care for the Latino community include more screenings and early detection, more regular check-ups, more consistent follow-up treatments, and ultimately, improved health outcomes. A Collaborative partner explained,

"The comfort that they have truly improves their cancer treatment and the care they can receive. Without them feeling cultural sensitivity, they wouldn't come for treatment or check-ups. They feel comfortable when they hear their own language and someone from their own culture."

As clients explained:

"The person who handles the Spanish speaking program is great. I like her a lot. She is really smart. And [another staff member] has a kind heart and I always feel comfortable talking about everything in front of them and getting things off of our chest."

"I felt a lot of support from the staff members and the people there."

"They make me feel very good. They speak our language. Everything is in our language and the information they give us is in our language. In addition, when there have been cases where the presenters do not give the classes in Spanish, there is always someone there to translate for us."

"I am very, very thankful that they have this for the Latino community. I also participate in the English-speaking program that they have here, but I love this because it really it is for our own culture. They treat us a little bit differently than they treat the American group."

In a sign that cultural competency is becoming institutionalized within partner organizations that may not have done this before, one provider has seen greater awareness by staff in English-speaking programs, which often comprise individuals of various national and cultural backgrounds.

Patient Advocacy

LC4/SSWCI plays an important role in educating Spanish-speaking women and men with cancer about treatments, services, and resources. In addition, the Collaborative builds confidence among Latinos to speak to their health care providers about cancer. By helping with patient navigation, education, and translation, LC4/SSWCI partner organizations, providers, and promotores are advocates for their clients' health care rights and provide Spanish-speaking patients with the tools they need to become their own advocates.

A Collaborative partner described the impact of this:

"What happens is that the clients actually become self-sufficient after the Collaborative has guided them onto the right track."

Another provider mentioned an impact of the Collaborative's successful work in engaging in and fostering patient advocacy which inspires further commitment to working with the community:

"It's impacted me. To work at the health and education fairs, to see the need for this and the people actually stepping outside of their comfort zone to seek information. It empowers me as an individual to see people going out and getting information for themselves and taking information home to family members. They're being advocates. That's inspiring."

One client now has the confidence to ask about symptoms, saying:

"I no longer just wait there, waiting for the doctor to ask me something."

The daughter of another client explained:

"I have my mother's doctor sitting for 30 minutes and have him explain all of the information to me, asking him all of the questions I have."

Through Collaborative partners and, specifically, the case managers, clients reported that they had learned about the need to make positive choices about eating and exercise too.

Suggestions for Greater Systems Change and Improved Continuum of Care

Observations by providers with partner organizations, clients, and promotores point to the following list of ways for LC4/SSWCI to further improve systems and the continuum of care for Latinos in Contra Costa:

- Increase recruitment for screening events.
- Research and provide more information about care available to undocumented immigrants.
- Provide psychotherapy, either individual or in a group, for help coping with issues related to life after diagnosis.
- Ensure that a bilingual patient care manager is in the clinic as much as possible where patients come for appointments.
- Offer child care (or funding for child care) during treatment. (Note: LC4/SSWCI has offered reimbursement for child care through County funded emergency financial assistance in the past but these resources are no longer available)
- Continue looking for ways to support clients with health issues that may not be related to cancer but that become apparent during the assessment process with Collaborative providers. (e.g., referring a cancer patient with heart problems to accessible services to address that problem).
- Ensure that agency staffs at partner organizations are educated about available programs.
- Research and provide more information on complementary services and treatment supports, such as dental care for patients experiencing dental problems with chemotherapy or yoga, acupuncture, or gym memberships that are accessible to people with and without insurance.
- Increase retention and satisfaction of promotores by providing more frequent and consistent support and incentives. Find out what they need to help them build their knowledge and presentation skills, assist them in their own health care needs, and make them feel valued for their role as liaison between the community and the partner organizations.

Considerations for Expansion and Replication of LC4/SSWCI

Collaborative participants are enthusiastic about the success and potential of LC4/SSWCI. They have the following suggestions for ways in which the Collaborative might consider extending its reach and effectiveness for the Latino community in Contra Costa County. It is important to note that several of these suggestions reflect the lack of access to general care for Latinos/Latinas in West Contra Costa and a desire to have the LC4/SSWCI serve as a foundation for a more culturally appropriate and accessible primary health care delivery system. Also, in some instances, LC4/SSWCI is already engaged in some of the activity areas and is so noted.

- Send promotores to rural areas in Oakley to reach farm workers who may only be in the community for a short time and have less opportunity to learn about services without proactive, in-person contact. (Note: Health educators currently engaged in this work.)
- Support clients in obtaining secondary opinions including more information about treatment and medication, either by providing a number they can call for advice or helping them connect with another health care provider.
- Include community organizations in resource fairs that can provide basic services that cancer patients need, such as child care, housing, and financial assistance.
- Expand the Collaborative by bringing in more general hospitals, since those emergency rooms are where many people start out when they need medical care which might increase access to general physical health services for client families,

Several partner providers and promotores felt that the continuum of care exemplified by the LC4/SSWCI model can and should be replicated in for every population and every disease.

Figure 10. Considerations for Replication of LC4/SSWCI

CONSIDERATIONS FOR REPLICATION OF LC4/SSWCI	
Critical Components in Replication	Potential Obstacles to Replication
<ul style="list-style-type: none"> • Mutual trust among partner agencies is essential, so that each agency can focus on what it provides best and allow partners to take on complementary responsibilities, rather than feeling territorial about trying to provide every service. • It is important to bring together organizations that will be able to address the multiple facets of the continuum of care, including medical, emotional, financial, and other needs. • Hire a facilitator to provide structure for the collaboration, and meetings and to reflect back lessons learned on a consistent basis. • Create a case management position for an individual who speaks the language and is of the culture of the population of focus to link each client who comes into the system through any collaborative partner with appropriate referrals and tracks that client over time. • Engaging key health care institutions, including those providing county services, to support efforts. 	<ul style="list-style-type: none"> • A lack of coordination, strong leadership, and commitment to working together within entities in a county infrastructure can undermine collaboration efforts, as partners must feel accountable to one another. • Competition for resources by and for different ethnic communities within a county may also undermine the creation of an initiative aimed at providing culturally competent care for a specific population.

PROJECT PERFORMANCE DATA

Throughout the life of the Collaborative, LC4 partners have met or exceeded performance on objectives. The following chart aggregates interventions and clients and individuals served over two 3-year grant/strategic plan periods from 2004 to 2010.

Figure 11. LC4/SSWCI Performance Objectives September 2004-September 2010

LC4/SSWCI PERFORMANCE ON OBJECTIVES SEPTEMBER 2004 TO SEPTEMBER 2010				
INTERVENTIONS	3 YEAR TARGETS	SERVICES 9/04 – 9/07	SERVICES 9/07 – 9/10	TOTAL 9/04-9/10
Outreach	6,000 individuals	11,156	6,032	17,188
Screening Navigation, Translation at the county health clinics & hospital	900 individuals	9,980	9,895	19,875
Screening & Referral for Mammograms at community clinics	900 individuals	3,464	4,783	8,247
Health Insurance/Referral for diagnostics & treatment	150 referrals	1065	600*	1665
Case Management, Treatment Navigation, referrals and case coordination	300 clients	402 clients	742 served/ 272 new	692 unduplicated clients
Patient Support Services during Treatment (interpretation, referrals, home visits, telephone support, emotional support, referrals)	150 clients	678 clients	742 clients 8,573 instances	1,420 clients
Cancer Health Education (Preventive & Treatment)	150 individuals	1,685	3,287 **	4,972
Wellness Support Groups and Classes	78 groups 12 workshops	141 groups 159 unduplicated 909 total	114 groups 231 unduplicated 549 total clients	155 groups 390 unduplicated 1299 total clients
Transportation to diagnostics and treatment*	NA	702 rides	1026	1828 rides

REFLECTIONS: SUMMARY OF SUCCESSES, LESSONS LEARNED, AND RECOMMENDATIONS

Successes

- The multi-faceted work of LC4/SSWCI is beginning to **promote awareness and foster proactive behavior** with regard to cancer prevention, detection, and treatment within the Latino community.
- The Collaborative is building a **local delivery system for bilingual services**.
- **Access to culturally and linguistically competent cancer services has increased** in Contra Costa County.
- Collaborative partners have **developed and implemented a replicable continuum of care** that encompasses a range of culturally specific strategies and supports from community education for early detection. Agencies have institutionalized services and are filling their role within the continuum of care. Partners trust each other to accomplish their respective roles.
- Collaborative partners have **institutionalized services within their agencies** that fulfill their role within the continuum of care.
- Collaborative partners and staff learn from each other and build **professional and cultural competency** as a result of their participation.
- **The Promotores de Salud program** has integrated community leadership development with disease education and **become a strong cadre of community educators**.
- Collaborative partners have **jointly identified needs and pursued funding opportunities**.
- The Collaborative has been **sustained and strengthened**, even in difficult financial times.

Lessons Learned

- Strong personal relationships among staff and leadership help sustain the Collaborative.
- The specialization that is possible when partners trust each other leads to a more effective and comprehensive continuum of care.
- It is important not to make assumptions about individuals' knowledge and to provide information and support that assists clients in taking charge of their own care.
- Screening is not yet as high a priority for community members as providers believe would be optimal for early detection.
- Celebrations of survival and other community gatherings are important for dispelling myths of cancer as a "death sentence."
- Promotores are a critical link between community members and Collaborative partners.
- Greater and/or more consistent support may increase promotores' satisfaction and retention.
- A highly skilled facilitator has been critical to the success of the Collaborative by fostering trusting relationships and consistently providing evaluation and other learning opportunities.
- There is a need for bilingual, bicultural health care providers committed to working in the Latino community.
- Adaptability in a changing environment is critical to sustainability.

Recommendations for Increased Impact/Improvement

- Increase the amount and clarity of information available about cancer, prevention, and treatment in print and on television and video format.
- Research and provide more information about care for undocumented immigrants.
- Look for opportunities to reach high schools, churches, markets, and rural areas of the County.
- Host more health fairs and support groups.
- Increase participation in screening events.
- As resources allow, increase the number of supportive services in Richmond and Oakley.
- Increase free and low-cost transportation options for clients.
- Increase number of supportive services in Richmond and Oakley.
- As resources allow, ensure that patients and providers have consistently easy access to a bilingual/bicultural case manager. (At the time of this evaluation, demand for services had been increasing and County resources declining, leading to a widening gap between supply and demand for the case manager's assistance.)
- Integrate partners into the Collaborative who can provide more services to help Latinos with cancer, including legal services for immigration issues, complementary medical care and supportive therapies, and support for child care, housing, and other basic needs. (The Collaborative already makes referrals for these services.)
- Explore ways to increase support and recognition of the contributions of community health educators (promotores).

Footnotes

- OMH Progress Report for April 1, 2009-September 30, 2009
- ² OMH Project Proposal: *La Clínica de La Raza*
- ³ LC4 Website: www.latinocancercoco.org
- ⁴ OMH Progress Report for April 1, 2009-September 30, 2009
- ⁵ CDC REACH US Action Community Proposal
- ⁶ *Cancer Facts & Figures for Hispanic/Latinos 2009-11*
- ⁷ *Cancer Facts & Figures for Hispanic/Latinos 2009-11*
- ⁸ *Cancer Facts & Figures for Hispanic/Latinos 2009-11*
- ⁹ *Cancer Facts & Figures for Hispanic/Latinos 2009-11*
- ¹⁰ *Cancer Facts & Figures for Hispanics/Latinos 2009-2011*
- ¹¹ *Cancer Facts & Figures for Hispanics/Latinos 2009-2011*
- ¹² *California Cancer Facts & Figures 2009*
- ¹³ *California Cancer Facts & Figures, 2009*
- ¹⁴ *California Cancer Registry: Cancer in California 2008 April 2008*
- ¹⁵ *Northern California Cancer Center: Finding Answers, Making a Difference December 2008 "Cancer Risk Factors and Screening Behavior in the greater Bay area: Data from the California Health Interview Survey"*
- ¹⁶ *Northern California Cancer Center: Finding Answers, Making a Difference December 2008 "Cancer Risk Factors and Screening Behavior in the greater Bay area: Data from the California Health Interview Survey"*
- ¹⁷ *Northern California Cancer Center: Finding Answers, Making a Difference December 2008 "Cancer Risk Factors and Screening Behavior in the greater Bay area: Data from the California Health Interview Survey"*
- ¹⁸ *California Health Interview Survey (CHIS), 2007*
- ¹⁹ CHIS, 2007
- ²⁰ CHIS, 2007
- ²¹ CHIS, 2007
- ²² CHIS, 2007
- ²³ CHIS, 2007
- ²⁴ *American Cancer Society, Cancer Facts & Figures for Hispanic/Latinos 2009-11*
- ²⁵ *Cancer Facts & Figures for Hispanic/Latinos 2009-11*
- ²⁶ *Cancer Facts & Figures for Hispanic/Latinos 2009-11*
- ²⁷ OMH Progress Report for April 1,2009-September 30, 2009
- ²⁸ US Census
- ²⁹ CDC REACH US Action Community Proposal
- ³⁰ *Community Health Indicators for Contra Costa County, June 2007*
- ³¹ US Census
- ³² *Community Health Indicators for Contra Costa County, June 2007*
- ³³ *Community Health Indicators for Contra Costa County, June 2007*
- ³⁴ *Community Health Indicators for Contra Costa County, June 2007*