Hearing Their Voices

Lessons from the Breast and Cervical Cancer Prevention and Treatment Act

FOCUS GROUP FINDINGS FROM CALIFORNIA

THE HENRY J. KAISER FAMILY FOUNDATION

Fall 2004

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EXECUTIVE SUMMARY

On October 24, 2000, the Breast and Cervical Cancer Prevention and Treatment Act of 2000 (BCCPTA) was signed into law, giving states the option to establish access to Medicaid for any uninsured woman under 65 who has been screened and diagnosed with breast and/or cervical cancer conditions through state screening programs funded by the Centers for Disease Control and Prevention (CDC). California adopted the BCCPTA to expand its Medicaid program, Medi-Cal, in October 2001. At the same time, California implemented a "state-only" program that uses state funds to cover cancer treatment costs for uninsured women who have been diagnosed with breast or cervical cancer through one of the screening programs, but do not meet the eligibility criteria for BCCPTA Medi-Cal.

This brief provides: 1) an overview of California breast and cervical cancer screening programs for low-income women, 2) description of California's implementation of the BCCPTA and state-funded treatment coverage, and 3) findings from a series of 15 focus groups with low-income women in San Diego and San Francisco discussions conducted to learn more about BCCPTA coverage and its implementation in California. The purpose of the study was to hear directly from women in California about their experiences, knowledge, and opinions of breast and cervical cancer screening and treatment services after the implementation of the BCCPTA.

The major insights and suggestions from focus group discussions include:

- **Clients found this to be an invaluable program.** Women who were able to obtain BCCPTA coverage consistently stated that they were grateful for the program and that the coverage was critical in their ability to seek and obtain screening as well as treatment.

- **Uninsured women and health care providers alike would benefit from increased education and outreach about screening programs, BCCPTA Medi-Cal coverage and the state-only program.** Women seeking health care services through community health centers and public health departments may be more knowledgeable about screening services than women without a regular source of care or those seeing private doctors. Participants stress that knowledge about potential health coverage for cancer treatment would allay fears about paying for medical care if diagnosed.

- **BCCPTA Medi-Cal and State-only program are easily accessed with help of screening providers.** Enrollment is easy for women diagnosed with breast or cervical cancer conditions due in large part to assistance from health care provider staff.

- **Women's cultural backgrounds play a significant role in their use of and experience with screening and treatment services.** Cultural traditions continue to play a major role in women's receptivity to screening and decisions about treatment. Translation services are crucial throughout screening and treatment experience for non-English speaking patients.

- **The scope and duration of coverage for BCCPTA Medi-Cal and State-only Program need to be clarified.** Confusion about what services are covered and for how long persist for both BCCPTA Medi-Cal and state-only program participants.

- **Operation of BCCPTA Medi-Cal and State-Only Program should be monitored.** Patients should be tracked to ensure quality of health care and access to services. Women enrolled in state-only program may have different health outcomes than women enrolled in BCCPTA Medi-Cal due to differences in services offered and length of eligibility.

INTRODUCTION

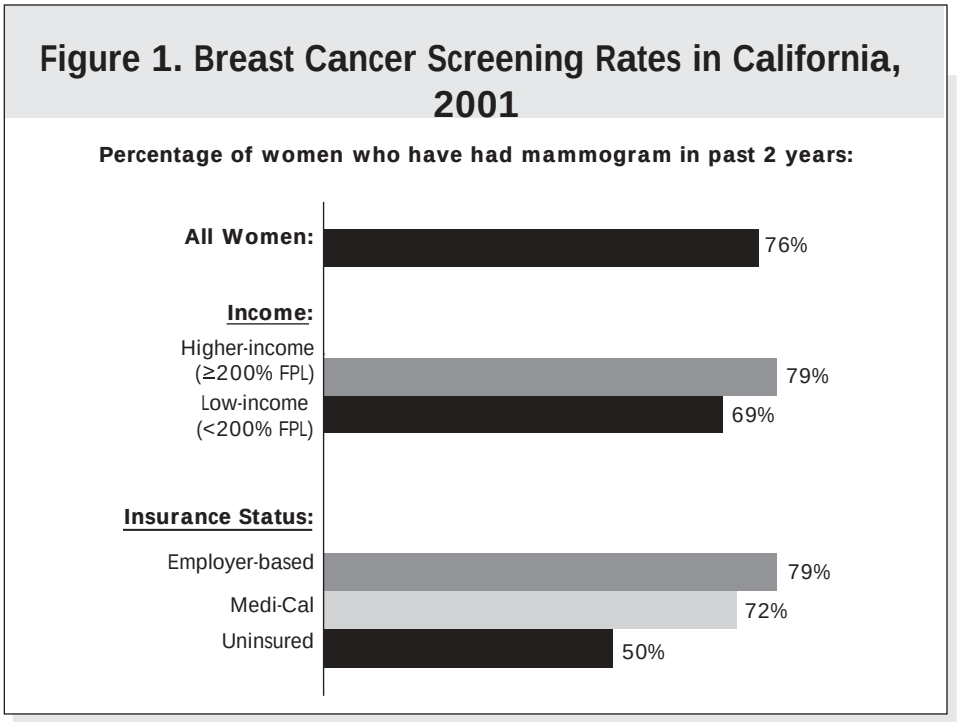
On October 24, 2000, the Breast and Cervical Cancer Prevention and Treatment Act of 2000 (BCCPTA) was signed into law. This law established a new coverage option under Medicaid that permits states to extend Medicaid to any uninsured woman under 65 who has been screened and diagnosed with breast and/or cervical (B/C) cancer under the National Breast and Cervical Cancer Early Detection Program administered by the Centers for Disease Control and Prevention (CDC). Established in 1990, the B/C screening program supports state B/C screening programs in 50 states, the District of Columbia, 6 U.S. territories, and 15 American Indian/ Alaska Native tribal organizations. The creation of a Medicaid coverage option by the BCCPTA was groundbreaking as the first effort to use a population-based public health screening program as a pathway to publicly funded health insurance and resulted in new interagency partnerships at both federal and state levels. By creating this unique disease-based category for Medicaid coverage, BCCPTA has generated considerable interest as a viable policy approach for addressing the challenges of being uninsured and facing serious illness.

To learn more about this coverage and its implementation in California, we conducted a series of focus groups with low-income women in the San Diego and San Francisco metropolitan areas.[1] This brief provides: 1) an overview of publicly-funded breast and cervical cancer screening programs in California prior to the state's adoption of BCCPTA, 2) a description of California's implementation of the BCCPTA and state-funded B/C cancer treatment coverage and 3) findings from 15 focus group discussions about the B/C screening program and BCCPTA Medi-Cal coverage in California.

A. Background and History

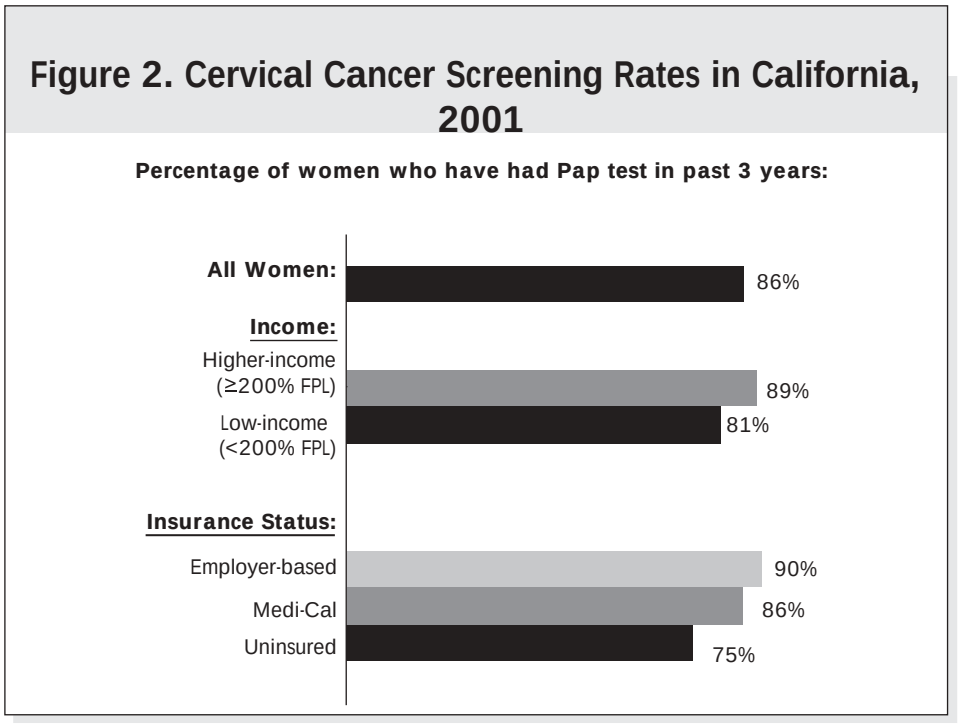
Both breast and cervical cancers are known to respond to a variety of treatments, but experts widely agree that early detection is critical for achieving the best outcomes. Regular screenings are a key element for early identification of cancer or pre-cancerous lesions. While guidelines do vary, the US Preventive Services Task Force (USPSTF) recommends that women ages 40 and older obtain a screening mammogram every 1 to 2 years and women 21 years and older obtain a pap test at least every three years.[2] In California, most women meet these guidelines, but there are notable differences between women of different incomes and insurance coverage, with low-income and uninsured women less likely to receive screenings for both breast and cervical cancers (Figures 1, 2).

Figure 1. Breast Cancer Screening Rates in California, 2001



Note: All women and Income measures include women 40 years and older. Insurance status includes women ages 40 to 64 only. The federal poverty level (FPL) for an individual in 2001 was $8,590.
Source: UCLA Center for Health Policy Research, *Cancer Screening in California: Findings from the California Health Interview Survey,* December 2003.

Figure 2. Cervical Cancer Screening Rates in California, 2001



Note: All women and Income measures include women 18 years and older. Insurance status includes women ages 18 to 64 only. The federal poverty level (FPL) for an individual in 2001 was $8,590.
Source: UCLA Center for Health Policy Research, *Cancer Screening in California: Findings from the California Health Interview Survey,* December 2003.

Public health practitioners have recognized these disparities, and since 1990, the CDC National Breast and Cervical Cancer Early Detection Program has been successful in providing cancer screening services to low-income uninsured or underinsured women across the nation. As part of the CDC program, the state breast and cervical (B/C) screening programs have provided more than 2 million mammograms and Pap tests to underserved women. However, because the authorization for the screening program specifically precludes the use of federal funds for provision of treatment services for women diagnosed with breast and/or cervical cancer, these women faced significant barriers to treatment if diagnosed with cancer if they were uninsured.

As a condition of the CDC cooperative agreement with states, prior to the passage of BCCPTA, state B/C screening programs were required to help these women initiate treatment. The programs relied on state, local, and private funds, as well as a carefully crafted but fragile network of charity care, hospitals, and physicians to provide free or

discounted cancer treatment to the uninsured women diagnosed through the screening program. Although these efforts were generally successful, the situation was very tenuous and the process was very challenging and stressful for both the women and the state B/C program staff. The accomplishments of the CDC program in identifying new cases of breast and cervical cancer within the underserved populations highlighted the need for these women to have health insurance coverage and created the impetus for the BCCPTA.[3]

Under BCCPTA, women have full Medicaid coverage throughout the duration of their breast or cervical cancer treatment. That is, they are covered for the full range of health care services covered by their particular state's Medicaid program. Women with cancer may have other health needs, and this coverage can be vital for facilitating access to the broad spectrum of health care services that many women with cancer seek.

For women to be eligible for BCCPTA Medicaid coverage, they must be "screened under the Program" (SUP) and meet other specific eligibility criteria (Figure 3).

Figure 3. Medicaid Eligibility Criteria Under the Breast and Cervical Cancer Prevention and Treatment Act

Women eligible for Medicaid under the BCCPTA are:

(1) screened for breast and/or cervical cancer by the CDC B/C screening program (i.e., "screened under the Program") and found to need treatment for either breast and/or cervical cancer (including pre-cancerous conditions);

(2) under the age of 65;

(3) uninsured or lacking creditable coverage, [as specified under the Health Insurance Portability and Accountability Act (HIPAA)]; and

(4) otherwise ineligible for Medicaid.

Source: Centers for Medicare and Medicaid Services.

Initially, the definition of "screened under the program" was limited to women who received at least one screening and/or diagnostic service paid for with federal funds (i.e. NBCCEDP funds). However, federal officials, aware that many states had existing breast and cervical cancer programs supported with federal, state and private funding and that some states might wish to expand the group of women potentially eligible for BCCPTA Medicaid to include women who did not receive a federally-funded screening service, determined that the SUP requirement could be interpreted more broadly to include these women. States were given the flexibility to select broader screening scenarios as the basis for BCCPTA Medicaid eligibility (Figure 4).

Figure 4. State Screening Options for the Breast and Cervical Cancer Prevention and Treatment Act

Option 1:

Women are considered screened under the program if they have received at least one federally-funded screening service through the state B/C program.

In addition to the required Screening Option 1, states may choose one or both of the following:

Option 2:

Women who have not received a federally-funded screening service can be considered screened under the program if they receive at least one screening service through the state B/C program.

and/or:

Option 3:

Women who have not received a federally-funded screening service can be considered screened under the program if they receive a screening service from a provider designated by the state B/C program as a BCCPTA screening provider.

Source: Centers for Medicare and Medicaid Services.

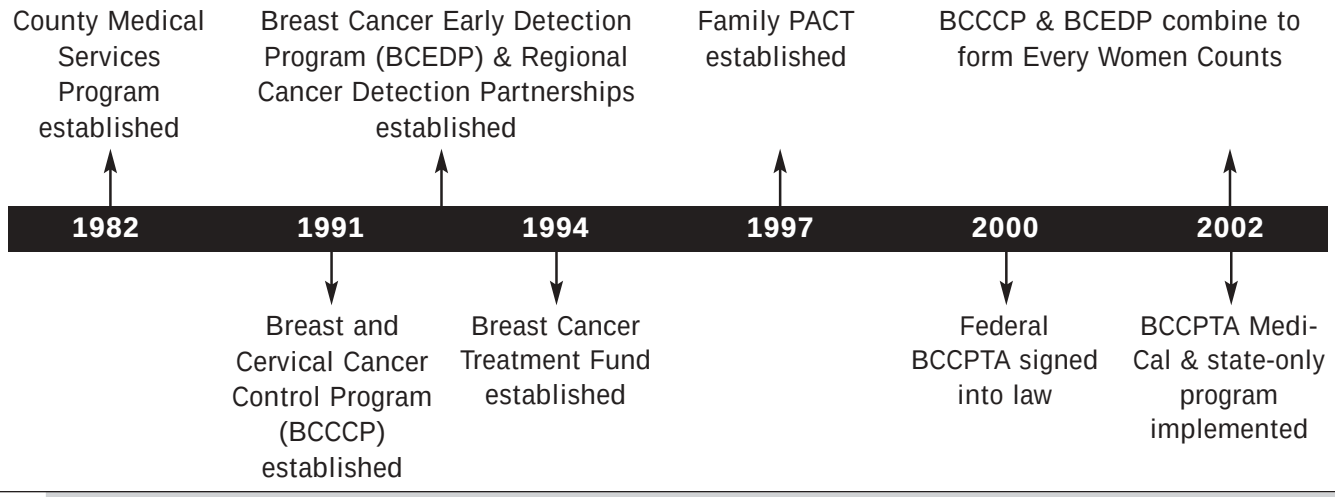
All states participating in the BCCPTA program *must* select Option 1, which provides Medicaid coverage to women who have received a federally-funded screening service through the state B/C program. States that also select Options 2 and/or 3 can create two distinct and complementary eligibility pathways for women who have received a screening outside of the traditional network of qualifying providers. Under Option 2, all women screened by providers through the state B/C program can be eligible for BCCPTA Medicaid. Under Option 3, all women screened by *other* providers who are recognized by the state B/C program as screening providers within the context of BCCPTA Medicaid can be eligible. Examples of screening providers under Option 3 include a family planning clinic or a community health center (CHC). Options 2 and 3 demonstrate the extent to which states have expanded the range of existing screening providers that can satisfy the BCCPTA Medicaid eligibility requirement their patients.

In California, state officials reported that their intention was to extend BCCPTA Medi-Cal benefits to all women screened by Family Planning, Access, Care, and Treatment (PACT) providers and *all* women screened by the state's existing B/C screening program providers, whether or not they received a federally-funded service, can meet the "screened under the program" eligibility requirement for BCCPTA. California used this opportunity to expand BCCPTA Medicaid coverage by selecting Option 3 to include women who receive cervical cancer services through the state's family planning program.

B. California Implementation

On January 1, 2002, California implemented the BCCPTA after passage of state legislation authorizing funds for the expansion of Medi-Cal, California's Medicaid program. As of August 2004, 10,038 women have been enrolled in Medi-Cal or the state-only program as a result of BCCPTA or state-only eligibility.[4] California's approach to adopting the BCCPTA centered on the state's extensive and long-standing bipartisan support for B/C screening and treatment services for low-income women. In California, several programs existed prior to BCCPTA implementation to assist women in accessing these services, including the *Breast and Cervical Cancer Control Program (BCCCP), Breast Cancer Early Detection Program (BCEDP), California Breast Cancer Treatment Fund (BCTF), Family Planning, Access, Care, and Treatment (Family PACT), and Every Woman Counts.* Following BCCPTA implementation, California decided to incorporate these programs as important pathways for women to access BCCPTA Medi-Cal and also created a state-only look-alike program that provides treatment services to uninsured or under-insured patients who would not be eligible for BCCPTA Medi-Cal. California's approach to BCCPTA implementation reflected the state's regional and decentralized approach to establishing systems of health care for low-income and disadvantaged populations, whereby counties have the primary responsibility for local health care programs and services. A chronology of these programs is provided in Figure 5, as well as an overview of program characteristics in Table 1.

Figure 5. Timeline of Breast and Cervical Cancer Programs in California



The "state-only" breast and cervical cancer treatment program was implemented concurrently with BCCPTA Medi-Cal. It is entirely state-funded and available to women and men ineligible for BCCPTA Medi-Cal. This includes women and men of any age with breast cancer, women with cervical cancer and many non-citizen residents. Unlike BCCPTA Medi-Cal coverage, the state-only coverage is limited to cancer treatment-related services and is available for specific time periods: 18 months for breast cancer patients and 24 months for cervical cancer patients. State officials' goal in creating the state-only program was to ensure that persons ineligible for the BCCPTA Medi-Cal would have access to breast and cervical cancer treatment services.

Enrollment Redetermination Procedures

State officials established one set of enrollment procedures for the BCCPTA Medi-Cal and state-only program. Persons who have been diagnosed with either breast, cervical cancer or pre-cancerous conditions by an EWC provider or Family PACT provider may apply for either BCCPTA Medi-Cal or the state-only program. Providers assist patients with completing a 23-question online application that is submitted electronically to the Department of Health Services. A paper application with the applicant's signature is then mailed to the state by the provider. Because California has elected presumptive eligibility for BCCPTA Medi-Cal, providers are assured payment for all services provided to women applying for BCCPTA Medi-Cal before the state officially determines eligibility, expediting women's access to treatment. While presumptive eligibility is not available to state-only program applicants, these applications are given high priority by Medi-Cal eligibility specialists and turn-around time averages less than two days.

As with all other categories of Medi-Cal coverage, state officials established policies and procedures to redetermine eligibility for BCCPTA Medi-Cal beneficiaries. While Medi-Cal conducts yearly redeterminations for comparable Medi-Cal beneficiaries (e.g., family coverage, coverage for children), Medi-Cal does not yet have a redetermination policy for BCCPTA Medi-Cal. Although BCCPTA Medi-Cal beneficiaries are responsible for notifying Medi-Cal when their treatment is complete (i.e., a change in circumstances affecting BCCPTA Medi-Cal eligibility), Medi-Cal does not have an official record of how many BCCPTA Medi-Cal beneficiaries have completed their treatment. State officials explained that BCCPTA Medi-Cal redetermination procedures are still "a work in progress."

Table 1. California State Breast and Cervical Cancer Screening Programs

Program	Description	Services	Major Eligibility Criteria
Major Eligibility Criteria Breast and Cervical Cancer Control Program (BCCCP); 1991–2002	The Breast and Cervical Cancer Control Program is the original CDC-funded B/C program including surveillance, outreach, education, and provider education and is now a part of EWC.	Clinical breast exams, mammograms, pelvic exams, and other screening and diagnostic procedures	Age 25–65 (40 to 65 for breast cancer services); Below 200% FPL; Uninsured or Underinsured
Breast Cancer Early Detection Program (BCEDP); 1994–2002	The Breast Cancer Early Detection Program expanded the BCCCP with state funds resulting in increased access to screening for low-income women. This program has identical eligibility requirements and services as the BCCCP for breast cancer screening, but with twice the amount of funding. The BCEDP is now part of EWC.	Same as BCCCP (but more providers)	Same as BCCCP
Breast Cancer Treatment Fund (BCTF); 1994–2002	This Breast Cancer Treatment Fund financed breast cancer treatment services for low-income uninsured patients prior to the BCCPTA.	Cancer treatment services for up to 18 months	At least 18 years of age; Low-income; Ineligible for Medi-Cal or other health coverage programs
Family Planning, Access, Care, and Treatment (Family PACT); 1997–Present	The Family PACT provides comprehensive family planning services for low-income California residents.	Family planning services including cervical cancer screening and mammograms	At risk for pregnancy or causing pregnancy; Below 200% FPL; Uninsured for family planning services
Every Woman Counts (EWC); 2002–Present	Every Woman Counts resulted from the consolidation of the BCCCP and the BCEDP for administrative ease after the implementation of the BCCPTA.	Same as BCCCP and BCEDP	Same as BCCCP and BCEDP
California Breast and Cervical Cancer Prevention and Treatment Act (BCCPTA) Medi-Cal; 2002–Present	California's Medicaid program that selected Option 3 in order to include not only EWC providers, but also providers from California's state-funded family planning program, Family PACT, as pathways to BCCPTA-Medi-Cal for women diagnosed with breast and/or cervical cancer.	All Medi-Cal services including cancer-related and non-cancer-related treatment for as long as patient is in need of B/C cancer treatment	Under the age of 65; Screened for B/C cancer by EWC or Family PACT and found to need treatment; Uninsured or lacking creditable coverage; Otherwise ineligible for Medi-Cal
State-Only Look-Alike Program; 2002–Present	A state-funded look-alike program that provides treatment services to uninsured or under-insured patients who would not be eligible for BCCPTA Medi-Cal.	Cancer-related treatment only for up to 18 months for breast cancer patients and 24 months for cervical cancer patients	Uninsured or Underinsured; Otherwise ineligible for Medi-Cal

II. Focus Group Study Methods

This focus group study was designed to gain a more in-depth understanding of the experiences, knowledge, and opinions of women in California seeking breast and/or cervical cancer screening or treatment services after the implementation of BCCPTA. The two California metropolitan areas chosen for this study, San Diego and San Francisco, reflected local geographic variability, racial and ethnic diversity among participating women, and variation in health care safety net systems.

In January and February of 2003, eight focus groups were conducted in the San Diego area and seven focus groups in the San Francisco area with a total of 116 participants. The focus group discussion centered around several issues, including: (1) women's perceptions of and experiences with the screening programs; (2) community knowledge about the availability of free and reduced-cost screening services; (3) community knowledge about availability of BCCPTA Medi-Cal; (4) experiences in gaining access to B/C cancer treatment services; and (5) experiences with cancer treatment under BCCPTA Medi-Cal.

In the San Diego metropolitan area, each focus group took place in a community health center (CHC) or health department, with breast/cervical cancer screening program participants and BCCPTA Medi-Cal beneficiaries recruited by the host organization staff. Five of the eight focus groups in San Diego were conducted in Spanish with non-English speaking Mexican immigrants.

In the San Francisco metropolitan area, the focus groups were held at various provider sites including a complementary and alternative health clinic, a public hospital, CHCs and community based organizations. Marin and San Francisco county staff associated with the Regional Cancer Detection Partnership handled most of the recruitment activities for the San Francisco focus groups. Of the eight San Francisco focus groups, one was conducted in Chinese and one in Tongan, each with translation assistance.

Table 2 summarizes selected characteristics of the participants in the San Diego and San Francisco focus groups. Women ranged in age from early twenties to late seventies, with the majority of participants falling between early forties and late fifties. In San Diego, most of the 52 participants were Hispanic women of primarily Mexican origin. In San Francisco, half of the 64 participants were African American and 20 were Asian or Pacific Islanders (mainly Chinese).

Table 2. Age and Ethnicity of Focus Group Participants

Site (#of Women)	Age			Race/Ethnicity			
	<40	40–60	60	White	African American	Hispanic	Asian/Pacific Islander
San Diego (52	8	33	11	9	0	42	1
San Francisco (64)	10	38	16	7	33	4	20
TOTAL (116)	18	71	27	16	33	46	21

Focus group participants also varied with regard to insurance coverage (Table 3).[5] Forty-three of the 72 women from San Diego and San Francisco without current breast or cervical cancer are uninsured; all of these women were working. Thirty-four of the 44 women from San Diego and San Francisco with current breast or cervical cancer have BCCPTA Medi-Cal or the state-only program coverage. Only 11 of the participating women had non-BCCPTA Medi-Cal coverage.

Table 3. Insurance Status of Focus Group Participants

Site (#of Women)	Insurance Status: Participants without Current Breast/Cervical Cancer				Insurance Status: Participants with Current Breast/Cervical Cancer			
	Uninsured	Medi-Cal	Medicare/ SSDI	Other	BCCPTA Medi-Cal	State-Only	Medicare/ SSDI	Medi-Cal
San Diego (52)	21	0	3	2	14	12	0	0
San Francisco (64)	22	6	8	10	5	3	5	5
TOTAL (116)	43	6	11	12	19	15	5	5

III. FINDINGS: WOMEN'S EXPERIENCES WITH IMPLEMENTATION

A. Knowledge about Free/Reduced-Cost Screening Services

Most San Diego and San Francisco focus group participants were aware of a breast and cervical cancer screening "program" but did not know the name. Given the fact that the focus groups were recruited mainly in health care settings, it is not surprising that most women were knowledgeable about the existence of a screening program; however, some women perceived their ability to access free or reduced-cost services as a function of the health center or clinic they attended, as opposed to being part of a statewide program. Although several women across both sites knew the screening program by name, they were equally likely to know the program either as BCEDP or BCCCP. Women at one health center in San Francisco knew the program was now called EWC and had cards indicating their participation in the program.

More than half the women across both sites reported accessing breast and/or cervical cancer screening annually. Women across both sites talked about the importance of cancer screening. Mexican women in San Diego, as well as African American women in San Francisco, explained that women in their respective communities are often wary of seeking out cancer screening services due to the fear of expensive bills or detecting cancer without any ability to pay for treatment. Women reported that the combination of the availability of free and reduced cost services, encouragement from providers, as well as familiarity with friends or relatives who had gone through cancer illnesses were the most influential factors in seeking cancer screening. In discussing the value of the screening program, one uninsured woman in San Francisco stated,

> *"With the program, it being free, it's easier… If I had to pay, it'd take a couple years before I would save up the money to go back again. The whole time I'd be nervous something was there."*

Profile: Twin African American Sisters, San Francisco[6]

Angela, appears to be in her early 50s and is uninsured but frequents a community health center for primary care as well as yearly pap smears and mammograms. She was referred to the Breast Cancer Early Detection Program (BCEDP) for screening many years ago by a doctor in Oakland. She isn't sure what would happen if she were diagnosed with breast or cervical cancer. Marsha, her twin sister, stated that the sisters feel screening is very important and they are thankful that the services are free. They explain that they know some women are afraid to get screened because they are afraid to find out if they have cancer. Their cousin passed away in 2001 from breast cancer—she had a lump that she was hesitant to see a doctor about. She was uninsured and lived in Vallejo. The twins tried to encourage her to find a place where she could get screened for free. They didn't know that the screening program was statewide, but they assumed that Vallejo would have a similar program for poor women. By the time their cousin finally saw a doctor, the cancer was very advanced and she died after surgery and chemotherapy couldn't cure her. The twins were deeply affected by their inability to convince their cousin to see a doctor, and have remained diligent about discussing the benefits of screening in their community ever since. One sister discussed the financial burden of being uninsured and stated, "Maybe you can't get screened every year, maybe you have to pay rent or buy food instead that month." She explained how important the screening services are: "Now we don't have to make that choice and we can protect our health." ■

Many San Francisco women reported actively seeking information about screening services and learning about BCEDP or BCCCP, either after moving to a new area, or losing health insurance.

Many women reported being previously uninformed about the importance of cancer screening. One uninsured Hispanic woman who had traditionally avoided getting a mammogram explained that she was fearful due to rumors from other women that the experience would be bad and particularly painful. Nurses at the health center where she takes her children informed her about the importance of getting screened. She had always taken her children to the clinic because they had Medi-Cal coverage, but she had never pursued any services for herself. She made the decision to have a mammogram and reported that the experience was much better than she expected. She concluded by recommending that other women be informed that getting a mammogram is not painful, and that it is crucial to protect their health. She said:

> *"I thank God for this place and these people. I hope they never disappear."*

Some women reported that in their culture there is a stigma to having cancer, and as a result, women in their communities do not pursue tests that might detect cancer. The focus group participants explained that women's health is a sensitive issue and there is often a lack of knowledge about the importance of getting screened. Among the Chinese women interviewed, cancer was referred to as "that thing." The focus group interpreter explained that because of the taboo associated with cancer, Chinese women were often less likely to be screened for cancer. One uninsured Tongan woman explained that she was always afraid to get mammograms in part because of the way the procedure works, but also because she is frightened of cancer. She also described how she has always been very healthy, and preventive health care is not a common pursuit for Tongan women, which was also echoed by Mexican immigrant women in San Diego. The Tongan woman stated:

> *"Most of us don't know about [preventive health care] … I want myself to get checked, but I am scared. Women of our culture only go to the doctors when we are very sick."*

B. Access to Free/ Reduced-Cost Screening Services

Many women discussed how a lack of insurance and the fear of high health care costs are major barriers preventing more women from seeking regular cancer screening. One uninsured African-American women in San Francisco explained that when one is uninsured,

> *"You have to make decisions about how to use your money when you don't have insurance. If there isn't a program, maybe you can't get screened every year, maybe you have to pay rent or buy food instead that month. Maybe you never get screened at all."*

A Hispanic San Diego woman emphasized the importance of the free and reduced cost screening services.

> *"Women do know it's important, but because of the cost, they don't go. Fear of being sick is an issue, but cost is the main reason if they don't know about the program."*

A Mexican woman in San Diego who had recovered from breast cancer echoed these sentiments:

> *"Some women are scared to find out if they have cancer, and many do not have insurance or are scared of large bills. But I tell them about the program and I say, 'You have to think of your children. What if you don't find out you have cancer?'"*

Profile: Ellen, White American, San Diego

Ellen is a 47-year old white woman who was diagnosed with aggressive breast cancer after being screened through the Every Woman Counts program and experiencing painful symptoms. She was immediately informed about the BCCPTA Medi-Cal coverage and was able to enroll right from her clinic through a process she characterized as "very easy." Despite the overwhelming challenge of fighting cancer, she is extremely grateful for the coverage. She knows she is eligible to seek any type of health care services under the BCCPTA Medi-Cal coverage. She reports having had "nothing but good experiences" navigating the Medi-Cal system and accessing quality care including a second opinion about her cancer and mental health care services. She explains that she is exhausted from chemotherapy on the day of the focus group, but she forced herself to attend the session so that she would have the opportunity to discuss the difference the BCCPTA Medi-Cal coverage has made for her. ■

Some seemingly EWC-eligible women were not getting free/reduced cost pap smears because they reported being ineligible for Family PACT (i.e., they were not at risk of becoming pregnant). These women were not aware of free cervical cancer screening through EWC, even though they were in fact receiving free/reduced cost breast cancer screening services. Indeed, most of these women did not understand that they might be eligible for cervical cancer screening through the EWC program.

Hispanic immigrants in San Diego, as well as other immigrant participants in San Francisco, reported concerns over language accessibility and translation needs related to using screening services. For example, correspondence and/or test results coming back from mammography sites and labs are often written in English and are difficult to understand for non-native speakers. One Mexican woman in San Diego stated,

> *"All the information is either in English or on the Internet, and I cannot use either."*

C. Knowledge of BCCPTA Medi-Cal Coverage

With the exception of two women, knowledge about BCCPTA Medi-Cal coverage was limited to those women diagnosed with cancer. These women learned about the BCCPTA Medi-Cal coverage from their providers. Because many women had tried unsuccessfully to qualify for Medi-Cal in the past, they were pleasantly surprised to learn that they could qualify if ever in need of cancer treatment in the future. The known difficulty of gaining eligibility for Medi-Cal unless a woman has children further highlighted the need for outreach.

Women also believe that informing others about the availability of BCCPTA Medi-Cal coverage will increase the willingness of uninsured women to be screened. The women explained that this coverage would alleviate fears about having to incur personal responsibility for costs for cancer treatment.

D. Outreach about Screening Services and BCCPTA Medi-Cal

In both San Diego and San Francisco, and across all age and race categories, women reported that information about health care services spreads mainly through word of mouth and through the community health centers. In each focus group, women reported that there is a lack of outreach about the benefits of screening and the availability of free services and access to BCCPTA Medi-Cal. A common theme in two separate focus groups in San Francisco was that while most women are eventually made aware of the benefits of cancer screening, practical information about available resources is less available. One group discussed how there are often television commercials and public service announcements about the importance of mammograms, however, there is no information about where women can go for the services.

Women suggested targeted outreach to address specific barriers and/or cultural norms in minority populations. Suggestions included radio and TV advertisements and posting information in public places, such as Medi-Cal offices. Women also recommended door-to-door and face-to-face outreach as effective ways to inform women. Other suggestions included outreach at health fairs, advertisements in discount newspapers, local and community newsletters, posters and flyers in public places.

E. Medi-Cal Enrollment and Coverage

Women who had experience with BCCPTA Medi-Cal or state-only coverage generally found it easy to apply for coverage. They reported that the overall process was very easy with the Medi-Cal application completed by the computer "in seconds." Women were often confused, however, about whether they were enrolled in BCCPTA Medi-Cal or the state-only program. This confusion also meant that they were unsure about the duration of their eligibility and about the types of services other than cancer treatment they could access. Some women were often unaware that their eligibility for BCCPTA Medi-Cal would last through their course of treatment for breast and cervical cancer, and that they have coverage for any non-cancer related medical services. On the other hand, some women receiving state-only program coverage were acutely aware that their coverage was limited to cancer-related services and would only last up to 18 months for breast cancer treatment and 24 months for cervical cancer treatment thus jeopardizing access to Tamoxifen therapy, for example, which normally is prescribed to be taken for five years.

One BCCPTA Medi-Cal beneficiary had the impression that Medi-Cal had not been very "organized" in notifying doctors and hospitals about the details of the coverage. Participants in several groups suggested providing more information to staff in provider sites so that women could be better informed. Two women in San Francisco reported that they were diagnosed with cancer by providers who were not aware that the BCCPTA Medi-Cal coverage existed. Both women had to pursue assistance from DHS caseworkers and make many phone calls before getting access to the coverage. One woman explained that information should be very clear for potential BCCPTA Medi-Cal beneficiaries. She stated:

> *"A cancer diagnosis causes you so much stress and anxiety, trauma … They should address coverage right up-front because you have enough to deal with."*

Profile: Elsa, Mexican immigrant, San Diego

Elsa is in her late forties and is currently recovering from breast cancer. She is a Mexican immigrant to the U.S. and speaks little English. There is a history of breast cancer in her family, and her older sister—another focus group participant—is also currently being treated for breast cancer. She sought regular breast and cervical cancer screenings for many years at a San Diego clinic where providers speak Spanish. She was diagnosed with breast cancer before BCCPTA Medi-Cal and the state look-alike coverage were implemented. A delay in accessing charity care and support from the Breast Cancer Treatment resulted in the cancer spreading to Elsa's arm; however the Treatment Fund paid for surgery to remove the cancer. Since the implementation of the BCCPTA and state coverage programs, Elsa receives coverage for radiation, chemotherapy, as well as Tamoxifen therapy (through the state's look-alike program). She is extremely grateful for the coverage for her cancer treatment, but is concerned and disheartened that the coverage is set to expire several years before she is to complete Tamoxifen therapy. ■

Proflie: Beatriz, Mexican immigrant, San Diego

Beatriz is a single Mexican woman, in her mid 40s, with one son. She does not speak English and cleans houses for a living. She never used to use health care services because she could not afford it and was uninsured. A year ago she noticed a painful lump in her breast; she thought it was an abscess. She tried to ignore the lump for a long time but finally her friends convinced her to see a doctor at a San Diego community health center with Spanish-speaking providers. She received free screening services and was diagnosed with breast cancer that had metastasized to her back. She felt very alone, scared, depressed, and uninformed about her condition. She explained, "I felt like I had a monster inside me." She states that her biggest worry was how she would pay for treatment. Fortunately the clinic enrolled her into the state-only program for her cancer-related treatment only. She described how her thoughts turned to money as soon as she found out she had cancer, and how lucky she is to have coverage. "I was thinking, 'I won't be able to afford even a coffin for myself' and now at least I am getting help." Beatriz received a lot of useful information in Spanish from the American Cancer Society in the mail. Her doctors told her that surgery would not help her because the cancer had spread so aggressively and rapidly. She has been treated with chemotherapy and alternative therapies. She is afraid that she is going to die, but is hopeful and tries to keep a positive attitude. She focuses on trying to take everything day by day. ■

Most women served by community health centers reported that they received good staff assistance and substantial help navigating services and gaining access to care. CHC staff also helped with Medi-Cal enrollment and billing questions as well as administrative problems. CHC staff were reportedly especially helpful for non-English speaking women. Several cancer survivors reported that they would not be able to navigate the Medi-Cal system without the assistance of clinic staff to translate and provide information. One BCCPTA Medi-Cal beneficiary in San Francisco with breast cancer stated that she has a patient navigator that helps coordinate her care. She commented,

> *"She stays in touch with me, makes sure everything's going okay with my appointments and everything … that I like."*

All BCCPTA Medi-Cal beneficiaries in San Diego and San Francisco were extremely grateful for the coverage. One breast cancer survivor from Puerto Rico claimed,

> *"If not for this program, we would not have gotten the help we needed, and we'd be dead. With this, one can have confidence that they can get help even without being able to pay."*

There were indeed many compelling stories. One woman with cervical cancer said the coverage is "almost too good to be true." One Mexican woman with breast cancer described how her thoughts turned to money as soon as she found out she had cancer and how lucky she feels to have coverage:

> *"I was thinking, 'I won't be able to afford even a coffin for myself' and now at least I am getting help."*

F. Access to Treatment

Receipt of treatment services seemed to be prompt and straightforward for both BCCPTA Medi-Cal beneficiaries and state-only program participants. Women reported that there were no problems initiating their cancer treatment. As noted above, some women in the state-only program expressed concern about not knowing how they would pay for medications after their coverage ended.

Women expressed concern about the lack of coverage for the side effects of their cancer treatment. Several women, for whom it was unclear if they were covered by BCCPTA Medi-Cal or the state-only program, had dental care and mental health needs that they reported were a direct result of their cancer illness and treatment. Participants reported that these health concerns were not met, because the women were informed by their providers that they were not covered for such services either through Medi-Cal or the state-only program.

Accessing complementary and alternative health care services was a concern for several women. Medi-Cal covers some complementary or alternative medicine services and some women reported being able to access these types of services with help from their providers. One Chinese woman with breast cancer explained that she was not willing to undergo a mastectomy, but he was grateful that her physician continued to work with her to find alternative therapies regardless of whether they were covered by Medi-Cal. Women expressed concern, however, that access to alternative therapies would not be as easy for all women who preferred those approaches, rather than traditional cancer treatment services, because either their providers would not be as helpful and understanding or Medi-Cal would eventually decide not to cover these services in the future.

One woman in San Diego who had recovered from breast cancer and had been covered by BCCPTA Medi-Cal explained the value of being covered for all services. She stated that fighting cancer requires a range of cancer-related and non-cancer related services. She explained that cancer virtually renders a woman unable to work or lead a normal life; therefore, flexibility of the coverage program is essential. She stated,

> *"You essentially lose a year of your life. You need all those services in order to be able to fully recover."*

Profile: Kim, Chinese Immigrant, San Francisco

Kim, age 49, was diagnosed with breast cancer in February 2002. She speaks fluent English as well as her native Chinese dialect. At the time of her diagnosis, she was uninsured and unemployed, even though in the past she had had private insurance through work. Initially, she noticed a lump in her breast, but had been wary of seeking health care as an uninsured patient and had trouble finding resources. Soon she noticed the lump was growing and becoming more painful. After many calls and referrals, she finally received a mammogram and follow-up testing at a San Francisco hospital. The screening revealed two cancerous lumps in her breast. The doctor at the hospital had her enroll in BCCPTA Medi-Cal online. The doctor then suggested that she first undergo chemo to shrink the tumors and then decide about surgical options. After four rounds of chemotherapy, she decided she didn't want surgery. She felt her body was communicating to her, by responding badly to the chemo and that it was not ready to lose a body part. She discussed this with her doctor and decided to explore other treatment options to boost her immune system. Although her doctor thought she needed surgery, she was supportive of Kim's pursuit of alternative therapies that were not covered by Medi-Cal. She got support, information, and care through alternative therapies at a San Francisco area cancer clinic for women. She has finished chemotherapy and feels she has improved her spiritual and emotional health. Unfortunately, the tumors have started to grow again, but not as quickly. Her doctor monitors her health frequently and respects her desire to delay surgery until she is ready to give up her breast. ■

IV. POLICY IMPLICATIONS

California's adoption of BCCPTA Medi-Cal and the creation of the state-only program build upon several state programs that were already in place to assist low-income women obtain screening and treatment services for breast and cervical cancers. However, prior to 2002, the state's ability to provide treatment services was limited and tenuous, with the state shouldering the costs entirely and only offering coverage for cancer treatment for 18 months through the Breast Cancer Treatment Fund. BCCPTA Medi-Cal offers the opportunity to broaden and strengthen women's access to cancer treatment as well as the full range of health services available through Medi-Cal.

The findings from the focus groups in San Diego and San Francisco provided revealing insights about the experiences and perceptions of low-income and uninsured California women regarding their access to breast and cervical cancer screening and treatment services. While the focus groups in each site were characterized by diverse women with a range of life circumstances, several themes about the California programs emerged from the groups. At least in the San Diego and San Francisco metropolitan areas, California seems to have begun successful implementation of BCCPTA, by establishing this new form of Medi-Cal eligibility and creating a new program of coverage for uninsured residents of California. Looking forward, the focus groups suggest strongly that greater outreach to low-income uninsured women as well as to health care providers about the B/C screening program and potential coverage options would enhance the program's reach and potential. In addition, it will be important that the health outcomes of BCCPTA Medi-Cal and state-only program patients be monitored. Key conclusions and recommendations based on the focus group findings are discussed below.

Enrollment in BCCPTA Medi-Cal and state-only program is relatively easy once women know about the program.

Although most focus group participants were initially unaware of the new insurance, when women were diagnosed with breast or cervical cancer, they were rapidly linked to the appropriate coverage (i.e., BCCPTA Medi-Cal or state-only program). Based on the focus groups, the consolidation of the two screening programs to create the EWC program created some confusion among women as well as providers, but knowledge about and access to screening services did not seem to be affected. However, there was some variability

between San Diego and San Francisco with respect to providers' knowledge about BCCPTA Medi-Cal, with the CHCs in San Diego County displaying more consistent knowledge about BCCPTA than those in San Francisco.

Women were able to enroll easily in BCCPTA Medi-Cal and state-only programs, although they were not always aware of their benefits or their length of coverage. The Regional Cancer Detection Partnerships appeared to have an important role in educating providers about the availability of coverage through BCCPTA Medi-Cal and state-only program for women diagnosed with breast or cervical cancer. Enrollment and access to treatment services was easy for most women due in part to the help of local providers and their staff.

Source of health care may affect women's knowledge of screening program and BCCPTA Medi-Cal coverage.

Our findings indicate that the location and type of health care provider site where women seek health care services may make a difference in women's access to information about the screening programs as well as the BCCPTA Medi-Cal and state-only program. The focus groups held in community health departments and clinics revealed that these women were more likely to know about the screening programs, and to some extent about the BCCPTA Medi-Cal and state-only program coverage for treatment. This finding may be due to the fact that the screening programs are often administered through these provider sites, thus women recruited by the provider staff were likely to be clients of the screening programs.

Outreach about BCCPTA Medi-Cal might increase willingness to get screened.

Few women participating in the focus groups knew about the BCCPTA Medi-Cal and state-only programs; those who did know were more likely to already be in treatment. Information about the BCCPTA Medi-Cal seems only to be provided to women once they have been diagnosed and in need of cancer treatment. Women in the focus groups overwhelmingly agreed that knowing about the availability of BCCPTA Medi-Cal and state-only programs would allay their fears about costs associated with treatment and thus encourage them to seek screening.

Outreach and education about the program should be strengthened.

Uninsured women and health care providers alike would benefit from increased education and outreach about the screening program, BCCPTA Medi-Cal, and the state-only program. Women seeking health care services through community health centers and public health departments may be more knowledgeable about screening services than women without a regular source of care or those seeing private doctors. Participants stress that knowledge about potential health coverage for cancer treatment would allay fears about paying for treatment if diagnosed.

Specific strategies might include: 1) clarifying EWC and Family PACT eligibility and 2) improving training of screening providers about the eligibility for screening services and about referring women to the BCCPTA Medi-Cal and state-only programs. Regional Cancer Detection Partnerships seem to be the logical choice for these activities, due to their connection with California's local communities and health care providers, and given their responsibilities for assisting women in need of cancer services.

Sensitivity to cultural issues is important for reaching many underserved women.

The focus group discussions show that cultural traditions continue to play a major role in women's receptivity to cancer screening and decisions about treatment. Translation services are crucial throughout screening and treatment experience for non-English speaking patients. Outreach efforts should be culturally appropriate and address issues of concerns of specific populations of women.

Scope and duration of coverage should be clarified to both patients and providers.

Because most of the participants in the focus groups who were BCCPTA Medi-Cal beneficiaries or covered under the state-only program did not fully understand the scope or length of their coverage under these programs, precise information should be provided to women once they become eligible. Focus group participants were confused about whether or not they had access to non-cancer related services, or to ancillary services such as dental and mental health care. Providers and their staff should be better informed and trained to provide this information to program beneficiaries. Medi-Cal should also take responsibility in providing this information to enrollees once they are deemed eligible for either program.

Impact of limited coverage for State-Only program clients should be examined.

While the state-only program coverage extends services to many women who might otherwise be uninsured, state-only beneficiaries are limited to cancer treatment services and to specific time frames in their eligibility for treatment services. As such, there is the potential that these clients do not have all of their health care needs met and thus, may have different health outcomes than women covered under BCCPTA Medi-Cal. As reported, many of the women in the focus groups who had coverage through the state-only program reported confusion about the scope and length of their coverage. For women in need of long-term breast cancer treatment, such as Tamoxifen therapy, they would not be covered for any period of time beyond 18 months. Because these women are of low-income status, they would most likely be unable to afford to continue the treatment beyond their eligibility in the state-only program.

Operation of BCCPTA Medi-Cal and State-Only program should be monitored.

Since the focus groups were conducted only a year after California implemented the BCCPTA Medi-Cal and state-only program and less than four months after state officials created EWC, monitoring is needed to assess the ongoing operation of these two programs. Given California's severe financial crisis, it will be important to determine whether and how budget cuts affect women's utilization of the screening program and access to the BCCPTA Medi-Cal and state-only coverage. Finally, Medi-Cal's redetermination procedures for BCCPTA Medi-Cal will need to be assessed to determine whether it is easy for women to keep their Medi-Cal coverage for as long as their providers certify that they need treatment.

ENDNOTES

1 This study builds upon earlier work funded by the Centers for Disease Control and Prevention (CDC) and Centers for Medicare and Medicaid Services (CMS) that examined the BCCPTA implementation efforts of 16 states, including California. A brief summary of the findings from this research can be found at http://www.gwhealthpolicy.org/downloads/BCCPTA.pdf.

2 U.S. Preventive Services Task Force, "Breast Cancer- Screening," "Cervical Cancer –Screening," available online at http://www.ahrq.gov/clinic/uspstfix.htm.

3 Lantz, P., et al. "A Disease-Specific Medicaid Expansion for Women: The Breast and Cervical Cancer Prevention and Treatment Act of 2000 *Women's Health Issues* 13:79-82 2003

4 Personal Communication with California Department of Health Services, Medi-Cal Division, August 2004.

5 While not a program specifically for women with breast and cervical cancer treatment needs, 2 focus group participants in San Diego and 4 in San Francisco reported being enrolled in County Medical Services Program (CMSP) when they needed cancer treatment services in the past. State officials established the CMSP in 1982 to provide medical and dental care to medically indigent adults ages 21 to 64 who are of marginal income and who are not eligible for Medi-Cal. For more information see http://www.dhs.ca.gov/hisp/ochs/cmsp/index.htm.

6 Names of women profiled in personal story boxes are fictional.

GLOSSARY

B/C Screening Program: State Breast and Cervical Cancer Programs funded by CDC National Breast and Cervical Cancer Early Detection Program (NBCCEDP). The NBCCEDP supports the development of systems to assure breast and cervical cancer screening for low income, underserved, uninsured women with special emphasis on reaching those who are geographically or culturally isolated, older, or members of racial/ethnic minorities. http://www.cdc.gov/cancer/nbccedp/.

BCCCP: Breast and Cervical Cancer Control Program is California's federally-funded breast and cervical cancer screening program. In October 2002, CDS consolidated this program and the Breast Cancer Early Detection Program (BCEDP) into one program known as Every Woman Counts (EWC).

BCCPTA: Breast and Cervical Cancer Prevention and Treatment Act of 2000 (Public Law 106-354); This Act gives states the option to provide medical assistance through Medicaid to eligible women who were screened through the Centers for Disease Control and Prevention's (CDC) National Breast and Cervical Cancer Early Detection Program (NBCCEDP) and found to have breast or cervical cancer, including pre-cancerous conditions.

BCEDP: Breast Cancer Early Detection Program is California's state-funded breast cancer screening program. In October 2002, CDS consolidated this program and the Breast and Cervical Cancer Control Program (BCCCP) into one program known as Every Woman Counts (EWC).

Breast Cancer Treatment Fund: Created in 1994 by the California Endowment, this program paid for breast cancer treatment for low-income, uninsured women in the state of California prior to implementation of the BCCPTA.

CDC: Centers for Disease Control and Prevention

CDS: California Department of Health Service's Cancer Detection Section

CHC: Community Health Center

CMS: US DHHS Centers for Medicare and Medicaid Services

DHS: California Department of Health Services

EWC: Every Woman Counts; In October 2002, CDS consolidated two programs, (1) Breast and Cervical Cancer Control Program (BCCCP) that received CDC funding, and (2) Breast Cancer Early Detection Program (BCEDP), into one screening program known as Every Woman Counts (EWC).

Family PACT: Family Planning, Access, Care, and Treatment (PACT) is California's innovative approach funded under Medicaid demonstration grant to provide comprehensive family planning services to eligible low-income men and women.

FPL: Federal Poverty Level

HIPAA: The Health Insurance Portability and Accountability Act of 1996 (Public Law 104-191)

Medi-Cal: California's Medicaid Program

Regional Cancer Detection Partnerships: Local coalitions of public and private agencies collaborating to ensure low-income women receive breast and cervical cancer screening services.

SUP: Screened under the Program; To be eligible for BCCPTA Medicaid, women must be 'screened under the Program.' The definition of SUP varies by state. At a minimum, all women who receive a federally-funded breast and/or cervical screening or diagnostic service under the National Breast and Cervical Cancer Early Detection Program (NBCCEDP) are considered SUP and thus, eligible for BCCPTA.

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