Improving Quality of Care for Californians with Breast Cancer

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POWERS & ASSOCIATES
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Executive Summary

Breast cancer threatens the lives of many women in California and across the country. One in eight women in California will develop breast cancer during her lifetime. According to the American Cancer Society, some 21,325 new cases (excluding in situ cancers) of female breast cancer will be diagnosed in California in 2002, and 4,275 women will die of the disease.

The risk of developing breast cancer varies by age and race. The highest incidence of breast cancer is among non-Hispanic Caucasian females, followed by African American, Hispanic, and Asian women. In general, a woman’s risk of breast cancer increases with age. The median age at diagnosis for invasive breast cancer in Caucasian women is 65, for African American women 57, for Hispanic women 55, and for Asian women 53 (California Cancer Registry). For all ages combined, Caucasian women are more likely to develop breast cancer than African American women; however, among women under age 50, African Americans have higher incidence and mortality rates than Caucasian women. African American women are more likely to die of breast cancer at almost any age than are Caucasian women (California Cancer Registry). Although the reason for a higher death rate for African American women is not clearly understood, socio-economic status leading to reduced access to medical services and diagnosis at a later stage is one possible cause.

Improvements in cancer screening over the past decade have led to diagnosis of breast cancer at an earlier stage of progression. Although the rates of incidence and mortality from breast cancer have shown dramatic improvements over the past two decades, these trends may be in transition. Breast cancer incidence rates may begin to rise in the next decade as the post-war “baby boomer” population reaches the age when breast cancer becomes more prevalent.

Breast cancer takes an emotional, human, and economic toll on our society. According to the National Institutes of Health, cancer is second to heart disease in terms of economic cost. Nationally the cost for all cancers totals approximately $107 billion; for breast cancer this figure approaches $5 billion. In a March 2000 study commissioned by the California HealthCare Foundation (CHCF), RAND estimated the medical cost of breast cancer treatment to be
approximately $22 million per 1,000 women, or $22,000 per woman diagnosed with breast cancer.

In the past three decades a number of technological and clinical developments in the prevention, detection, diagnosis, and treatment of breast cancer paved the way for change in the way breast care is delivered. These changes led to a more complex, fragmented, and diverse treatment process. The proliferation in medical advancements has led to a great degree of specialization and complexity in terms of the patient interaction with the health care delivery system. Although there have been many advancements in treatment and therapies for breast cancer, there are still evident gaps between the optimal treatment, access to high-quality medical care, and the support a patient needs to undergo cancer therapies. Disparities in breast cancer treatment are primarily attributable to such structural and functional barriers in the delivery system, as well as to issues related to reimbursement.

Fortunately, a benchmark model exists for optimal prevention, detection, and treatment of breast cancer care. The model includes a multi-disciplinary breast care approach with all of the components linked together in an integrated continuum of care. The comprehensive breast care model represents an efficient and cost-effective way to deliver care to breast cancer patients. Moreover, it enlists the participation of the patient in every step of the continuum and allows for clear communication between the various specialists who must work together to assess a woman’s risk of getting breast cancer, accurately detect and diagnose the type, stage, and severity of the cancer, and provide the appropriate treatment.

Although some facilities within California adhere to this model of care, thousands of women are not receiving adequate services. CHCF could initiate a Centers of Excellence program to increase the number of hospitals that adhere to the benchmark model and inform breast cancer patients of their conformance to these standards. This would involve assisting interested facilities and affiliated physicians to implement key aspects of the breast cancer model to improve quality of care for breast cancer patients. In addition, CHCF could work with the purchaser and health plan communities to create a performance measurement program in this area.

Hospital systems that are unable to initiate broad change can more readily improve care by implementing a patient navigator program for patients with breast cancer. The California Health Collaborative could be used as an outsource vehicle for such a program. The Collaborative currently participates in the state of California’s statewide screening and treatment program for breast cancer, Breast Cancer Early Detection Program (BCEDP). Patient navigation and broad-based education regarding treatment options could be advanced by the expansion of the Web-based Comprehensive Health Enhancement Support System (CHESS). Alternatively, the National Center for Policy Research focuses on educating women about the best surgical treatment options.

Today, there are limited public metrics available for assessing the quality of, satisfaction with, and the process of breast cancer care. The development and adoption of an objective tool to assess the process of breast cancer care will substantially help women in evaluating and comparing treatment facilities. Additional funding is necessary to provide for more clinical quality improvement programs and programs to identify women at risk for breast cancer, and to study models designed to reduce incidence and mortality from breast cancer.
I. Introduction

This paper is one of five white papers produced by Powers & Associates at the request of the California HealthCare Foundation (CHCF). Besides breast cancer care, the other four topics are end-of-life care, diabetes, heart failure, and pediatric asthma. The primary purpose of each paper is to assist CHCF staff and other stakeholders in determining priority areas for investment in quality improvement in the state of California. Although each paper stands alone, together the five form an integrated body of work.

Each paper includes the following sections: the epidemiology of the disease/condition; costs; the state of knowledge on preventing, diagnosing, treating, and monitoring the disease/condition; the gaps between knowledge and treatment; current efforts to close the gaps; and opportunities and recommendations for potential investments by the Foundation. To preserve the readability of the paper and limit its length, most of the sections are illustrative rather than exhaustive. Any omission of specific information or an initiative does not intentionally imply it has been deemed unworthy of acknowledgement.
II. Epidemiology

Breast cancer threatens the lives of many women in California and across the country. More than 200,000 women in California, or three out of every 100 women over the age of 40, are breast cancer survivors. One in eight women in California will develop breast cancer during her lifetime. Although breast cancer sees no color and attacks women of all races/ethnicities, the risk of developing breast cancer does vary by age and race. The disparities for race/ethnicity are not clearly understood, but it is thought that dietary intake, lifestyle, socio-economic status, and environmental and genetic factors may be predisposing variables.

Breast cancer is not just a single disease. It is a combination of diseases with one element in common—the growth and spread of abnormal cells due to gene mutations.1 Cancers are a group of diseases that cause cells to change and grow uncontrollably. Breast cancer begins in the breast tissue. Breast tissue is composed in part of glands called lobules that produce milk and the ducts that connect lobules to the nipple. The remaining breast tissue is made up of a combination of fatty, connective, and lymphatic tissue. Most tumors of the breast are benign, not cancerous; they appear as abnormal tissue growth but are not life threatening. Some breast tumors are cancerous, yet are confined to the breast ducts and commonly referred to as “in situ,” which means that they have not spread beyond the area where they reside. In situ breast cancers are confined to the breast ducts (ductal carcinoma in situ, or DCIS) or lobules (lobular carcinoma in situ). Nearly all cancers at this stage can be cured. Most oncologists believe that lobular carcinoma in situ is not a true cancer, rather a marker for increased risk of developing an invasive cancer sometime in the future.

Other cancerous breast tumors are invasive or infiltrating.2 These cancers start in the duct and lobules of the breast and break through the duct and gland walls to invade surrounding fatty tissue or lymph nodes. Cells that break away from the tumor may travel through the bloodstream or through the lymph system to other areas of the body. The spread of a tumor to a new site is referred to as metastasis. Although the cancer cells may spread to other parts of the body, the cancer is still referred to according to its origin, breast cancer.
Breast cancer is the most commonly diagnosed cancer among women of any race/ethnic group in California. According to the American Cancer Society, some 21,325 new cases (excluding in situ cancers) of female breast cancer will be diagnosed in the year 2002. In the year 2002, some 4,275 women in California will die of breast cancer. In retrospect, until the 1980s, breast cancer incidence rates were steadily on the rise. These increases may be attributable to the changing pattern of reproduction for women who delayed their first childbirth and had fewer children. It is also thought that DES and the increased use of oral contraceptives and hormone replacement therapy may have contributed to the increase. All are said to be risk factors for developing breast cancer. In addition, the increase in breast cancer incidence may be noted in part due to better methods for collecting and reporting these data, improvements in the quality of mammography, improvements in the training of radiologists, and a growing awareness of women about breast cancer.

Between the years 1988 and 1993, breast cancer was the leading cancer diagnosed in California women and the second leading cause of cancer-related mortality. Between 1993 and 1998, more than 115,000 cases of female breast cancer were diagnosed in California, more than any other form of cancer among women. During that same period more than 25,000 women died from the disease. In 1998 the incidence rate was the highest for non-Hispanic Caucasian women, followed by African American, Asian/Pacific Islanders and Hispanic women (see Appendix, Figure A1).

Today, in general, the highest incidence of breast cancer is among non-Hispanic Caucasian females, followed by African American, Hispanic, and Asian women. Since 1988, the breast cancer incidence rate for Asian/Pacific Islander women has increased by 20 percent, while mortality rates among this population remain unchanged. Although breast cancer is diagnosed less often among Hispanic women it is important to note that it is more frequently diagnosed at a later stage. Breast cancer incidence and mortality increase as the population ages. In general a woman’s risk of breast cancer increases with age. For women under the age of 50, age-specific incidence rates were highest for African Americans and lowest for Hispanics, while for women over the age of 50, age-specific rates were highest for Caucasians and lowest for Asian/Pacific Islanders. The median age at diagnosis for invasive breast cancer in Caucasian women was 65, for African American women 57, for Hispanic women 55, and for Asian/Pacific Islander women 53. For all ages combined, Caucasian women are more likely to develop breast cancer than African American women; however, for women under age 50, African Americans have higher incidence and mortality rates than Caucasian women. Also, African American women are more likely to die of breast cancer at almost any age than are Caucasian women.

Mortality is an important measure in assessing the impact of breast cancer on individuals and the community as a whole. Advances in screening methods, prevention efforts, and treatment affect the shifting rates of mortality from breast cancer. From a historical perspective the number of deaths increased steadily from 3,100 in 1973 to 4,400 in 1994. The age-adjusted rate, which takes into account the size and age distribution of the population, reflects a fairly stable mortality rate from 1973 (28.4 deaths per 100,000 women) when compared to 1985 (28.1 deaths per 100,000 women). The mortality rate declined steadily from 1985 to 1992 to 23.8 deaths per 100,000 women and remained constant until 1995. The age-adjusted mortality rate, however, declined dramatically by 14 percent over the ten-year period from 1985 to 1994. This represents a statistically significant average decrease of 2 percent per year. The rate of mortality from breast cancer does show dramatic differences comparing race/ethnicity variables. Although incidence rates for breast cancer are the highest among the non-Hispanic Caucasian population,
the mortality rate is highest for African American women. Asian/Pacific Islander women have
the lowest mortality rate, followed closely by Hispanic women. American Indian/Alaska Natives
have the lowest mortality rates in the state of California. According to the CDC National Center
for Health Statistics, from 1994 to 1998 the death rate in California for African American women
was nearly two and a half times that of Hispanic and Asian/Pacific Islanders (seeAppendix,
Figure A2). The stage of cancer at diagnosis summarizes how far a cancer has spread when first
discovered. Diagnosis of breast cancer at earlier stages is one of the strongest predictors of
overall survival (see Appendix, Table A1).

The majority of breast cancers are diagnosed at Stages 0-I. From 1988 to 1998 the number of
breast cancers diagnosed in Stages 0-I increased, while those diagnosed in Stages II-IV
decreased. This is attributable to improved detection, screening, and early diagnosis efforts for
all populations in California over the past decade. About 70 percent of female breast cancers
diagnosed in California in 1998 were found at an early stage. African American and Hispanic
women experience a higher rate of diagnosis at later stages of cancer. The five-year survival rate
is lower for women whose cancer is diagnosed at a more advanced stage. The five-year survival
rate for localized cancer is 98 percent. In contrast, the survival rate for cancers spread to distant
organs is only 22 percent. From a national perspective African American women with breast
cancer are less likely to survive five years: 71 percent versus 86 percent. It is thought that the
cause of this disparity is rooted in later stage of detection and more aggressive tumors. Other
factors may include the presence of co-morbid conditions and other socio-economic factors such
as lack of insurance and lower income status. Income status does appear to have an indirect link
to diagnosis of breast cancer at a later stage. While breast cancer incidence and mortality rates
continue to show positive results, this trend may be in transition. Breast cancer incidence rates
may begin to rise in the next decade as the post-war “baby boomer” population reaches the age
where breast cancer becomes more prevalent. To complicate matters, this population has more
predisposing risk factors, such as early age of menarche, delayed childbirth, and smaller family
size. Finally, about 150 men in California are diagnosed each year with breast cancer and 30 die
of the disease annually. Breast cancer in men is clinically similar to that of their female
counterparts, however their prognosis is often worse due to diagnosis at a later stage.
III. Cost

Breast cancer takes an emotional and economic toll on individuals diagnosed with cancer, those affiliated with the patient, and society as a whole. According to the National Institutes of Health, cancer is the second most costly disease in terms of gross dollars and cost per individual. Heart disease costs the nation more than $116 billion. Nationally the annual cost for cancers of all types is approximately $107 billion. Of that, $37 billion are attributed to direct costs, or those directly related to medical care expenditures. An additional $11 billion are expended for the cost of illness defined as lost productivity. Finally, $59 billion are spent on premature loss of life from this devastating illness. The treatment of lung, breast, and prostate cancers alone accounts for more than half of the medical costs. It is estimated that the annual cost of cancer is increasing at a rate of 15 percent.

As the population of post–World War II babies come into the age when cancer strikes, the rate of incidence will accelerate and dramatically increase the future projected cost of cancer. Oncology.net states that cancer patients consume 12 to 20 percent of the total claim dollar. According to the 1996 Surveillance, Epidemiology, and End Results (SEER) program approximately $5.98 billion are spent nationally on the direct cost of breast cancer care.12

Cancer care costs vary over the course of the disease. Cancer costs are greater during the first six months following diagnosis and at the time of disease staging, primary treatment, and adjunctive or chemotherapy. The next period of greatest cost is during the six months before death in those who develop a recurrence of the disease. The greatest average annual cost is seen in patients with an advanced disease who require continuous and palliative treatments. According to the Advanced Medical Technology Association, the cost of breast cancer treatment for the pre-invasive stages is approximately $10,000 to $15,000 when detected early. Many clinicians think that non-invasive cancers may never progress and therefore overtreatment of cancer at this stage could be an unnecessary expense. In contrast, later-stage breast cancers can reach total costs of between $60,000 and $145,000 to treat the advanced stages.

In a March 2000 study commissioned by the California HealthCare Foundation, RAND estimated the medical cost of breast cancer treatment for diagnostic evaluation, breast conserving
surgery, mastectomy, radiation, and adjuvant therapy. In addition, they estimated costs for bone marrow transplants, reconstruction, and follow-up of breast cancer patients. Costs were evaluated for a 60-year-old woman, node negative with early breast cancer. Based on California Cancer Registry data, they assumed that half of the patients would choose breast conserving surgery and the other half mastectomy. Costs were based on Medicare-allowed charges and average wholesale prices for drugs and priced according to the state-of-the-art benefits for breast cancer care. They estimate that the cost of breast cancer care is approximately $22 million per 1,000 women diagnosed with breast cancer. This translates into an estimated $22,000 per woman diagnosed with early stage breast cancer. RAND also states that the treatment cost for women with metastatic breast cancer, including palliative chemotherapy, hormone therapy, pain management, and hospice care, exceeds $30,000 per woman. As the American Cancer Society projects that the 2002 breast cancer incidence rate will climb to more than 21,000 women, the projected economic burden is substantial given these treatment cost estimates.
IV. State of Knowledge, Prevention, Diagnosis, Treatment, and Monitoring

Today there is a significant amount of research on the factors that predispose a woman to develop breast cancer at some point in her life. A risk factor is anything that increases a person’s chance of getting the disease. While some cancers share similar risk factors, for the most part, different cancers have different risk factors associated with them. The presence or absence of a risk factor does not predict with assurance if or when a person will get the disease. Much of what we now know about risk factors pertains to personal characteristics, and these factors present indirect links. Direct links such as hormones have a stronger influence on the disease’s occurrence.

Being a woman is the main risk factor for getting breast cancer. Breast cancer is 100 times more common in women than it is in men.\textsuperscript{14} Besides being female, age is the single most important risk factor for developing cancer.\textsuperscript{15} The National Cancer Institute estimates that one in eight women in the United States will develop breast cancer in her lifetime. This estimate is based on data from the Surveillance, Epidemiology, and End Results program publication \textit{SEER Cancer Statistics Review} and is based on cancer rates from 1995 through 1997. These results are similar to the lifetime risk estimates for the same period in California by the Department of Health Services. Risk accumulates over a woman’s life and is not the same each year. That is, as a woman ages her risk of breast cancer increases. Therefore, for all races, at age 30, it is estimated that 1 in every 2,451 women in California is expected to be diagnosed with breast cancer. The cumulative risk increases with age so that by 40 years of age the risk is 1 in 227; by 50 years of age, 1 in 53; by 60 years of age, 1 in 24; and by 70 years of age, 1 in 14.

Women with a family history of breast cancer, especially in a first-degree relative (mother, sister, or daughter) have an increased risk of developing the disease. The risk is even higher if more than one first-degree relative had breast cancer, or if the relative developed breast cancer at an early age or in both breasts.\textsuperscript{16,17} Approximately 5 to 10 percent of the breast cancers are hereditary and result from altered genes or mutations in susceptibility genes such as BRCA1 and BRCA2.\textsuperscript{18} These mutations appear in far less than 1 percent of the general population.\textsuperscript{19} It is not
yet possible for us to accurately predict which women with the mutation will in fact develop breast cancer. Women who know that they carry the mutated gene may use this information to decide upon a prophylactic course of treatment to include the use of the drug tamoxifen. Recent studies indicate that tamoxifen does not work with women possessing BRCA1 gene. Women may also opt for more dramatic treatment such as surgical removal of the breast. Preliminary studies show that the drug raloxifene may also decrease cancer risk; however, it is limited to women with osteoporosis who are known to be at low risk for breast cancer. We have not yet determined if it will reduce risk for women who are at high risk.

Other factors that contribute to a woman’s risk of breast cancer include early menarche (before age 12) or late menopause (after age 55), late age at first full-term pregnancy (after age 30), and fewer pregnancies. These factors increase the risk by affecting a woman’s reproductive hormones. Recent use of oral contraceptives may slightly increase a woman’s risk; however, women who stopped using oral contraception for more than ten years have the same risk as women who never used the pill. The use of estrogen replacement therapy for more than five years also increases the risk of breast cancer. This effect may disappear after ceasing the hormones for more than ten years. Finally, there are other lifestyle-related factors that may influence a woman’s risk of breast cancer, including use of alcohol, lack of physical activity, obesity, and high-fat diets. Women who drink as few as two alcoholic drinks per day can increase their risk by approximately 25 percent. Obesity is linked to higher risk of breast cancer, particularly after menopause. While there is a great deal of research on other risk factors such as environmental pollutants, these do not appear to be clearly linked with breast cancer incidence.

New technologies are being developed to more accurately test for and pinpoint precursors to breast cancer. A simple outpatient procedure called ductal lavage can detect abnormal cells (atypical hyperplasia), which can provide important information about a woman’s risk of breast cancer. Ninety-five percent of the breast cancers originate in the milk ducts. Through ductal lavage, a tiny catheter is inserted through the nipple into a milk duct opening and a small amount of anesthetic is flushed into the duct. Saline is then slowly delivered through the catheter to rinse the duct and collect cells for analysis.

The American Cancer Society recommends that women begin a breast health program of monthly breast self-examination at age 20, a clinical breast examination by a physician every three years between ages 20 and 39 and annually at age 40, and annual mammograms beginning at age 40. The debate over mammographies dates back to the 1970s. Although the technology had diffused more widely into common clinical practice it simultaneously became a source of considerable controversy. In the past the argument focused on whether the benefits of mammogram outweighed the deleterious effects of radiation. Decreased death rates subsequently shifted the argument to focus on the appropriate age to begin mammography screening. In 1977, the National Institutes of Health convened a panel that agreed that annual screening mammography was appropriate for women 50 years of age and older yet recommended it for women 40–49 with a previous family history. In the 1980s NCI, the American College of Radiology, and 11 other organizations followed the lead of the ACS in recommending routine screening for younger women based on findings of a demonstration project. Dissent reemerged again in 1993, and NCI withdrew support for screening in younger women. In 1997, another NIH consensus panel attempted to resolve the issue, concluding that there was insufficient evidence to support routine screening mammography for women in their 40s. Despite the controversy, many

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organizations continue to recommend screening for women in their 40s. Some experts believe that Congress and the U.S. Public Health Service recommend mammograms for younger women for political reasons. The argument over screening guidelines continues. This raging controversy translates publicly into inconsistent and sometimes confusing messages to the average woman. Newspaper articles inspiring further discussion on the topic exacerbate the debate. The October 2001 issue of The Lancet criticizes seven previous studies of mammography and its link to reduced mortality or any reduction in the mastectomy rate. The article asserts, “At present, there is no reliable evidence from large randomized trials to support screening mammography programmes.”

When a woman discovers a lump in her breast it is essential to determine the cause. Eight out of ten lumps are harmless. To be sure that the lump is not cancer, a biopsy must be performed. Many current techniques for breast biopsy are minimally invasive procedures. For fine needle aspiration (FNA), a thin needle is placed into the lump and cells are aspirated from the cyst and placed on slides for evaluation. If fluid is removed and the lump disappears, it is generally not cancerous. For core biopsies, a larger needle in a spring loaded or vacuum assisted gun is used to remove small pieces of tissue from the lump. With these types of biopsies the doctor may use either mammography or ultrasound to locate a lesion that can be seen and not felt. Stereotactic needle biopsy is a fairly new procedure that pinpoints the area of concern with a double-view mammogram. The computer maps the location of the mass and guides the placement of the fine or large core needle so that the doctor can extract the tissue sample. Women may also be diagnosed with cancer by surgical biopsy, such as incisional, which removes only a portion of the lump, and excisional, which removes the entire lump.

The choice of treatment is largely dependent on the stage of the cancer, the type of breast cancer, and the cellular characteristics of the cancer (such as how aggressive the cells look). Since 1995, doctors have looked to the National Comprehensive Cancer Network (NCCN) for guidance on standards for cancer treatment. The Network has brought together experts from 18 of the nation’s leading cancer centers to describe breast cancer treatment guidelines. The guidelines represent the current standard of care for breast cancer. In California, Stanford Hospital and Clinics and the University of California, San Francisco (UCSF) Comprehensive Cancer Center are NCCN member institutions that helped to craft the guidelines. The panel of experts update the guidelines annually based on new studies. All of the breast cancer care centers interviewed for this paper say that they use the NCCN treatment guidelines or some variation thereof; however, no external body monitors or audits adherence to them.

In September 1999, the California legislature urged health service plans in the state to provide speedy access to diagnostic and screening tests for their enrollees. The resolution goes on to recommend the diagnostic and screening testing recommended by the professional guidelines, including the NCCN guidelines.

In 2001, the University of Florida College of Medicine researched the validity of the clinical guidelines for the treatment of breast cancer, including the NCCN guidelines. They examined the NCCN guidelines for invasive breast cancer on survival, quality of life, and hospital cost and compared these dimensions on patients who were treated without the guidelines. In summary, they found that the five-year survival rate was 87.6 percent for the patients treated with NCCN guidelines compared to 83.3 percent for non-NCCN guidelines. Based on cumulative quality of
life scores, patients treated using the NCCN guidelines had similar quality of life. Finally, treatment-related costs for patients using the NCCN guidelines were $20,300 (+/- $1,800) versus $59,700 (+/- $25,200) for patients not treated according to the guidelines. This suggests that adherence to NCCN guidelines can significantly reduce the cost of breast cancer care without adversely impacting survival or quality of life. The American Cancer Society prints and distributes the NCCN treatment guidelines to breast cancer patients upon request.

Treatment options for breast cancer are surgery, radiation therapy, chemotherapy, and hormone therapy. Patients may get one or more of these treatment options. Most women who have breast cancer today are diagnosed with Stages 0, I, or II. Most of these women can choose lumpectomy and radiation therapy (breast conserving surgery, BCS) or mastectomy. Based upon current data from the California Cancer Registry, approximately half of the treated women in California receive mastectomy and half receive BCS. Studies show that both options provide the same long-term survival rates. According to the American Cancer Society, Hispanic women were less likely to receive BCS than other racial and ethnic groups. African Americans, Asians, and others were not statistically different from the Caucasian group in getting BCS. Patient age, socio-economic characteristics, hospital characteristics (e.g., teaching versus community hospital), and the availability of radiation therapy appear to affect the proportion of women undergoing BCS. Between 70 and 75 percent of women diagnosed with breast cancer are possible candidates for lumpectomies, yet only half have them. Studies indicate that women are more likely to get mastectomies if their physicians were trained prior to 1981. Despite knowledge and clinical evidence, physician attitudes play a more important role in whether women choose BCS. Low-income women and those that are less educated are less likely to be offered a lumpectomy. Women who are treated in university-based hospitals are more likely to have lumpectomies, while the converse holds true for community hospitals. Women who are treated in hospitals that have radiation facilities are more likely to have lumpectomies than women treated in hospitals that do not have such facilities. Lumpectomy with radiation is more expensive than mastectomy, so patients without private insurance are less likely to have lumpectomies.23

In addition, the proportion of women who receive BCS versus mastectomy for early breast cancer varies by region of the country and state. Twenty percent of the California hospital referral regions had rates of mastectomies above the national average. California’s rates varied two-fold across the state, from 1.23 to 2.57 procedures per 1,000 female Medicare enrollees. Modesto (2.57) and Napa (2.50) were among the 50 highest regions in the state, while San Diego (1.54) and Alameda (1.41) had among the lowest in the state. San Francisco had the lowest rate in the state (1.23) and seventh lowest in the nation. Rates of BCS surgery varied by a factor of approximately three, from 0.26 to 0.74 procedures per 1,000 Medicare enrollees. Los Angeles (0.72), Santa Rosa (0.74), San Bernadino (0.69), Orange County (0.68), and Sacramento (0.64) were in the top 25 percent of the highest rates of partial mastectomies in the nation. Almost 40 percent of California hospital referral regions had rates of BCS below the national average.24

For women who opt for a lumpectomy, a surgeon removes the breast cancer, a little normal breast tissue around the lump, and some lymph nodes under the arm. Radiation is almost always prescribed for women who pursue this course of treatment. Radiation decreases the risk of cancer recurrence. The alternative is either total or modified radical mastectomy. Total mastectomy removes as much of the breast tissue as possible, the nipple and some overlying skin. In a modified radical the surgery removes as much of the breast, nipple, overlying skin and some of
the lymph nodes. Whether a woman has a lumpectomy or mastectomy, the surgeon may remove
some of the lymph nodes (axillary node dissection). Prior or subsequent to surgery many women
undergo adjuvant or chemotherapy. Research suggests that even when a woman’s breast lump is
small, cancer cells may have spread beyond the breast. In many cases this requires systemic
treatment such as chemotherapy and hormone therapy to aid in further eradicating cancer cells.
Chemotherapy is administered either intravenously or by mouth. Generally a combination of
drugs is used in cycles of treatment, followed by a recovery period. Total course of therapy
usually lasts three to six months depending on the drug combinations. Many women are treated
with a hormone blocker, tamoxifen, to prevent the body’s natural hormones from reaching the
cancer, which proliferates in their presence. A combination of chemotherapy and tamoxifen has
been shown to be effective in women with estrogen receptor-positive tumors (estrogen receptors
are molecules that attract estrogen; the growth of normal cells is stimulated by estrogen), by
decreasing mortality and breast cancer recurrence in pre- and post-menopausal women. These
studies show modestly improved breast cancer outcomes with chemotherapy, tamoxifen, and
perhaps both treatments together in patients. Although there is some benefit for cancer patients
to taking tamoxifen for one to two years, strong evidence suggests that taking tamoxifen for five
years has greater benefits, so it has now become the standard of care. Tamoxifen is also being
used as a prophylactic measure for women who have predisposing genetic factors for breast
cancer. Two drugs, anastrazole and letrozole, also known as Arimedex and Femara, that belong
to a new class of hormone-suppressing drugs were recently presented as an alternative to
tamoxifen in two major trials for metastatic breast cancer.

Finally, women who have had mastectomy may opt for breast reconstructive surgery. This
procedure does not treat the cancer; rather it restores the breast’s appearance after mastectomy
through the use of implants or tissue from other parts of the body.

In 1993, California breast cancer activists joined forces with scientists, researchers, clinical
professionals, legislators, and the University of California to take a leadership role in the area of
breast cancer research. The team wrote and won passage of legislation to push breast cancer
research. The California Breast Cancer Act raised the tobacco tax by two cents a pack, with 45
percent of the proceeds dedicated to the largest breast cancer research effort in the nation.
Funded primarily by the tobacco tax and supplemented with taxpayer donations and private
contributions, the California Breast Cancer Research Program (BCRP) has provided more than
$97 million in research funds since 1995. In 2000, BCRP awarded more than $16 million for 70
single- and multiple-year grants at 22 California institutions. Research dollars are applied to
some of the most promising new technologies for the prevention, early detection, and treatment
of breast cancer. Current grants are applied to research pertinent to the biology of the normal
breast, earlier detection, etiology, health care delivery needs, innovative treatments,
pathogenesis, prevention, and socio-cultural, behavioral, and psychological aspects of the
disease. Breakthroughs and advances in breast cancer are emerging each day, and we move
closer to improving the quality of care for breast cancer patients in California and around the
world.
V. Gaps Between Knowledge and Treatment

In the past three decades a number of technological and clinical developments in the prevention, detection, and treatment of breast cancer have paved the way for change in the way breast care is delivered. Before 1975, breast cancer was diagnosed and managed by surgeons. In the early days, breast cancer was diagnosed primarily through palpation, and the subsequent course of treatment was prescribed and sequential. The treatment centered on invasive surgical intervention in the form of radical mastectomy followed by a course of radiation treatment. Although the evolution in the 1970s shifted the focus of treatment to encompass less surgical interventions, surgeons were still the focal point of breast cancer treatment. A number of developments in the late 1970s changed breast cancer management, including: (1) the beginning of population-based screening mammography; (2) acceptance of breast conservation; (3) proof that adjuvant systemic therapy increases survival; (4) the option of reconstruction offered to women after mastectomy; and (5) the fact that women were asked to participate in the decision-making process.27 These changes led to a more complex, fragmented, and diverse treatment process.

The pivotal shift occurred with the use of screening mammography when the focal point of diagnosis shifted to include the radiologist. With the discovery of smaller non-invasive cancer, such as ductal carcinoma in situ, the pathologist’s role became critical in pinpointing the type of cancer and the recommendation for treatment. As research validated the efficacy of breast conserving surgery, women became more involved in the treatment decision. Finally, more detailed information and choices were put into the hands of women with books like Dr. Susan Love’s Breast Book, which helped women to make informed decisions. Developments in adjuvant therapy and reconstructive surgery changed the complement of health care providers involved in the detection and treatment of breast cancer. The proliferation in medical advancements has led to a great degree of specialization and complexity in terms of the patient interaction with the health care delivery system. Breast cancer patients may be exposed to as many as 12 or 13 clinicians in the process of treatment and recovery.

Although there has been improvement in prevention, detection, and treatment of breast cancer, there are still many gaps between state-of-the-art therapy, access to high quality medical care,
and the support a patient needs to undergo cancer therapies. The disparities in breast cancer treatment can be encapsulated into three key areas: (1) structural and functional barriers pervade the medical delivery system; (2) a lack of professional education and competency create quality shortfalls; and (3) funding and other factors impede access to care for low-income women.

**Structural and Functional Barriers Pervade in the Medical Delivery System**

Changes in the way breast cancer is detected and treated have led to the development of a more complex and fragmented delivery of medical care to breast cancer patients. The majority of breast cancer care is provided at the tertiary level in community hospitals, where there is little organization, coordination, and cooperation among providers in treating the breast cancer patient. Often, after a woman is diagnosed with breast cancer, she is left to her own devices to digest the diagnostic information and navigate the health care delivery system alone. Her primary care physician/gynecologist will quickly refer her to a host of other providers for treatment including a surgeon, medical oncologist, radiation oncologist, radiology technologist, pathologist, radiologist, radiation therapy technologist, anesthesiologist, physical therapist, psychologist or social worker, and nurse. Women are left to determine whether the providers and the medical care they receive are of the highest quality yielding the most favorable outcome. Women must independently decide whom to turn to for clinical, emotional, financial, and social support.

Many hospitals in the California delivery system do not have a highly structured and organized approach to breast care delivery, thus leaving the patient to navigate the complex delivery system on her own. Hospitals that specialize in and treat cancer often have a breast care center, yet they focus on therapy rather than screening, evaluation, and diagnosis.

Several notable California hospitals have developed patient navigator programs to help facilitate the patient’s journey through the delivery morass. Although this expedites and assists patients undergoing the frightening process, this assistance is often temporary, understaffed, and sporadic. Navigator positions are often funded by grants and are not permanent line items in the hospital budget as they are not considered revenue-generating positions. Some California hospitals have developed women’s health and breast care clinics as a marketing tool to attract more women to use their services. Others state that they have breast centers, when in fact their services are limited to breast cancer imaging alone. Many physician organizations provide information to access support groups for women newly diagnosed with breast cancer. Hospital breast centers often have complete libraries and provide information on classes that help directly with treatment or indirectly with the effects of the illness. Many hospitals provide information to women about myriad community resources to help them deal with the financial, psychological, and personal issues confronting breast cancer patients. However, there is little formal coordination or cooperation between the medical community and support resources. Confused, angry, and impaired by the frightening diagnosis, women are forced to individually navigate the complex delivery system as well as support resources. Finally, many hospitals perform a limited number of breast surgeries, which calls into question the quality of patient care when volume is low. An analysis of discharge data from the Office of Statewide Health Planning reflects that in 1998, some 25 percent of the breast cancer surgeries, e.g., mastectomy and breast conserving surgery, were performed at a hospital that performed seven or fewer surgeries per year; 50 percent of the cases were performed at a hospital that did 19 or fewer; and 75 percent of the
cases were performed at a hospital that performed 46 or fewer breast surgeries. In 1998, the maximum number of cases at an individual hospital was 212.

A study conducted by the New York State Department of Health found that hospital volume of breast cancer surgical cases has a strong positive effect on five-year survival rates for breast cancer patients. They determined that at five years post surgery, patients from very low volume hospitals had a 60 percent greater risk of all-cause mortality than patients from high-volume hospitals. Research is still needed to identify whether process of care, especially post-surgical adjuvant treatments, contribute to survival differences. Further research and analysis are needed to substantiate whether volume does in fact impact the outcome of breast cancer patients. Age may also be a factor, since older women tend to stay in their small community hospitals while younger women travel to academic medical centers. Statistics may also be confounded in academic medical centers if DCIS is included in their volume numbers.

Data and information collection are critical for tracking, monitoring, and researching trends and predicting patterns in breast health in California. The California Cancer Registry (CCR) collects data on incident breast cancer and monitors cancer trends and risk over time by geographic region, age, sex, race/ethnicity, and other characteristics of the California population. Since 1991, CCR has published annual reports with detailed information on the risk of developing and dying from cancer in California. Although the data collected by CCR is robust, it is limited when assessing issues related to health care access, quality, outcome, and patient satisfaction data. Most breast centers and hospitals lack the information systems to capture good data on breast care. Most breast health centers that participated in the interview process for this report stated that their data collection efforts and systems are woefully antiquated. Many hand-calculate ratios such as the ratio of negative biopsy to all biopsies. There is room for considerable error in this manually driven process. Many institutions do not correlate the data, for example, comparing mastectomy rate to tumor sizes. Patient characteristics are rarely assessed and treatment regimens are not related to treatment outcomes. Data need to be collected and analyzed for diagnosis, inpatient treatment modalities, radiation, chemotherapy regimens, site of cancer, and provider type.

Lack of Professional Education and Competency Creates Quality Shortfalls

During the first European Breast Cancer Conference in 1998, Europa Donna published the first jointly developed European consensus statement on breast cancer care. On quality of care the statement reads, “Given the importance of quality of surgery, radiotherapy, and chemotherapy in determining outcome, quality assurance programs should become mandatory for breast cancer services to qualify for funding from healthcare providers.” The statement further calls for adherence to evidence-based guidelines and programs to benchmark, monitor, and guide quality efforts in breast care.

Although guidelines for breast cancer care and treatment do exist and are allegedly used in facilities across the state, there are still a number of quality shortfalls that need to be addressed. Two of these critical shortfalls are in radiology and pathology. Mammography facilities are licensed according to standards set forth in 1992 and revised in accordance with regulations in 1999 by the FDA under the Mammography Quality Standards Act (MQSA). Congress enacted MQSA to ensure that all women have access to high quality mammography for the detection of
breast cancer in its earliest, most treatable stages. The regulations set forth stringent guidelines for establishing a mammography center and monitoring performance and quality. MQSA requires that a mammography center read a minimum of 480 mammograms a year. In contrast, Canadians must read a minimum of 2,500 mammograms in order to be licensed. More research is necessary to determine the impact of this volume disparity on the quality of the readings, false positive rates, and inaccurate assessments.

Another quality issue involves the high degree of specialization necessary to accurately read mammographic films. Optimum mammography technique involves: (1) production and maintenance of high contrast and high-resolution mammography images; (2) responsibility for all mammography relegated to a few dedicated and well-trained radiology technologists; and (3) system quality control. One breast center consultant reported that one breast center has thirteen to fifteen radiologists cycling through for mammography readings. She reported that outcomes were not good given the number of physicians reading the films. She also reported circumstances under which various physicians read the breast mammography, as well as other body part images. Radiologists who read the mammograms are expected to perform at a high degree of specificity. This requires that a radiologist specialize in reading breast mammographies and devote undivided attention to reading the image. Radiologists must know the breast anatomy, imaging capabilities, and constraints.

Finally, good diagnostic breast radiology should include independent double reading of mammograms. As technology is further perfected, this function may be better executed by computer. Implementation of independent double reading with consensus is necessary, but does not occur in all institutions. Double reading of mammograms has been demonstrated consistently to improve the sensitivity of mammography screening by approximately 10 to 15 percent. Several health care experts reported a long appointment wait time for both screening and diagnostic mammography. Mission Neighborhood Health Center for example, reported that women often wait three to four months for an appointment at San Francisco General for a screening mammography. Although the exact cause of the long wait time is not yet known, lack of staff to read mammographies was cited as one possible cause.

There is a low supply of skilled mammographers in the United States. Many medical students are reluctant to specialize in this area due to high malpractice insurance costs, and a number of existing radiologists have elected not to specialize in this area. According to the Radiologic Society of North America, mammography is one of the most litigious fields of medicine, because 10 to 20 percent of breast cancers are not detected at all or are detected at a later stage. This is a growing trend that must be considered to ensure the quality of breast care for women.

Many breast cancer providers and advocates reported a widespread lack of knowledge among providers of the appropriate method of conducting clinical breast examination (CBE), and reported wide variation in the manner in which it is performed. Some experts believe that clinical breast exams for screening purposes should be performed on an annual basis beginning at the age of 40. There is debate about the efficacy of CBE in diagnosing breast cancer. Although the state Cancer Detection Section does have a program for education and training it is imperative that efforts be expanded to ensure that all providers are educated, and reeducated using continuing medical education, in the proper way to perform CBE.
Finally, due to low reimbursement from Medicare and health care carriers and a low volume of procedures, mammography centers are closing at an alarming rate. Across the country, industry analysts estimate that more than 200 centers have closed in the past three years. This may greatly limit access to necessary screening and diagnostic services for women. This is a disturbing trend given the increasing needs for such services as the aging population begins requiring annual screenings.

Quality issues pervade the area of pathology as well. Pathologists examine breast tissue or breast fluid under a microscope to determine the types of cells that are present and their extent. Decisions by other breast specialists, e.g., chemotherapists, radiologists, etc., are made on the basis of the pathologist’s findings, thus making it one of the most critical components in the breast cancer diagnosis. In an example, Dr. Lagios at the Tabar Interdisciplinary Conference in San Diego in September 1998 discusses a case in which a 38-year-old patient was inaccurately diagnosed because the pathologist did not evaluate the entire slide sample. The patient was told she had DCIS, when in fact she had invasive carcinoma. More than one breast care expert reported that more monitoring of breast pathology is essential. They report that although there are pathology standards for taking and processing the breast specimen, these standards are not always adhered to or monitored thereafter. It is essential to institute a method of quality assurance to ascertain strict adherence to established guidelines and standards.

**Funding and Other Factors Impede Access to Care for Low-income Women**

In California, some 880,000 women aged 40 and older are estimated to be eligible for state-funded breast cancer screening and diagnostic services. Resources are available to serve only about 20 percent of that number. Through the Breast Cancer Early Detection Program (BCEDP) and the Breast and Cervical Cancer Control Program (BCCP), services are available for women aged 40 and older who have low income (up to 200 percent of the Federal Poverty Level) and medical insurance that does not cover these services or that has a high deductible or copayment. Women receive cancer screening from a series of 14 regional breast cancer partnerships. Although the screening is only able to serve 20 percent of the eligible population, the program has made great strides in improving access to screening overall. However, 80 percent of the eligible population is still left uninsured for breast cancer screening services.

In October 2001, the U.S. Department of Health and Human Services approved California’s request to expand Medi-Cal coverage to low-income uninsured women with breast and cervical cancer. Under the federal Breast and Cervical Cancer Prevention and Treatment Act of 2000, Medi-Cal will cover the treatment of breast and cervical cancer for women who undergo screening through BCEDP, BCCP, or at a Family Planning, Access Care and Treatment site. Uninsured women under age 65 with incomes up to 200 percent of the Federal Poverty Level are eligible. An estimated 4,400 women will receive coverage under this program. Industry experts report that reimbursement under this program is insufficient to cover their expenses. One community health center said that the program reimbursed for only about 50 percent of the cost of providing such coverage. Health care providers also report that they are reluctant to take these patients due to low reimbursement levels. Additionally, health care providers reported that there is no coverage for women under age 40 who may or may not have suspicious symptoms or predisposing risk factors.
Access to health care services can be impeded by a number of socio-economic, cultural, educational, and psychological factors. Fears, anxiety, and embarrassment about securing services for breast care inhibit some women from getting screened and treated for breast cancer. Women with lower screening rates are generally found to be low-income, less educated, less acculturated, and over age 65. As a result, older, poor, and minority women are more likely to die of breast cancer.

A recent study supported in part by the Agency for Healthcare Research and Quality, for example, reveals that knowledge of screening recommendations and access to free mammograms often are not enough to get poor black women to keep mammogram appointments. Age was inversely related to appointment compliance; women aged 70 and older were less likely to miss a mammogram compared with women 40 to 49 years of age. Women referred by a nurse practitioner or physician’s assistant were 70 percent less likely to miss their appointments than women referred by their physician.35

African American women are also more likely to refuse treatment for breast cancer. Language, cultural barriers, lack of transportation, and overall mistrust of the health care delivery system factor into whether women get screened and treated for breast cancer. Culturally appropriate case management for people of color is virtually nonexistent. Few psychological and support services are provided by clinicians who are culturally responsive and/or native speakers of a minority woman’s language. Consent forms for clinical trials are generally provided only in the English language, thus reducing access to potentially life-saving treatment for those who need it. Although these barriers are more difficult to quantify, they are equally important to address.
VI. Current Efforts to Close the Gaps

Several notable efforts are underway in California to close gaps in coverage and service for breast cancer patients. A number of model programs and approaches provide access to high-quality detection, treatment, follow-up care, and support services. Although the programs outlined below are not an exhaustive presentation of all available services, they do provide a benchmark or model for program delivery in California.

**Interdisciplinary Breast Care Center**

The breast care continuum is characterized by a wide variety of procedures and pathways leading to similar outcomes. This variation leads to substantial differences in costs and patient experience, dependent upon physician choice of procedure or pathway. A breast center is uniquely positioned to develop disease management for the breast, including sub-specialized care, the adoption of evidence-based protocols, comprehensive management of outcome information, and audits of quality of care.

Although there are a number of outstanding breast care centers in California, one in particular stands out as a model cancer center. As part of the UCSF Comprehensive Cancer Center, the Carol Franc Buck Breast Center is a notable model to benchmark, designed to meet the complex needs of patients with breast cancer. A multidisciplinary team of surgeons, oncologists, radiologists, psychologists, nutritionists, and pathologists works together to ensure that all concerns are thoroughly addressed. The Center provides a comprehensive array of services, including screening examinations, training in breast self-exam, screening mammography, diagnostic imaging, second opinion services, diagnosis of lumps, treatment of cancer, emotional support, and financial and insurance counseling.

The Carol Franc Buck Breast Center is all under one roof and thus allows a woman to easily navigate services with the help of a collaborative care program. The breast center manages patients by categorizing patients into one of four discrete categories: patients with abnormal mammograms; follow-up patients a year after their diagnosis and treatment; metastatic patients; and the asymptomatic “worried well.” The Center’s Same Day Assessment Program evaluates...
and diagnoses abnormal mammograms and breast lumps, including consultation with a surgeon, radiologist, and pathologist on the day the patient is seen. The Breast Center Collaborative Care program is designed to support patients when making complex treatment decisions. The Consultation Planning component helps a patient map out questions and concerns before consulting the breast cancer specialist. A copy of the Consultation Plan is provided to both the patient and physician. A Consultation Recording guides the consult with the doctor and includes an agenda, flowchart for the discussion, and a facilitated discussion between the specialist and the patient. Once a patient is diagnosed with breast cancer the surgeon becomes the navigator to help the patient through treatment options and decisions. An interdisciplinary team that agrees upon the diagnosis and course of treatment reviews all cases. Patients also have access to clinical trials to test new therapeutic agents to treat advanced disease.

In addition to the clinical activities, Cancer Center physicians work to ensure a wide range of psychosocial support services for patients and their families. Access is provided to individual counseling, support groups, and help with physical appearance. The Carol Franc Buck Breast Care Center is located a short distance from the Cancer Resource Center, which has an extensive library of resources and database of support services for women with breast cancer. For follow-up patients, the program is designed to provide educational materials, clinical breast exams, and monthly question-and-answer sessions with physicians. Finally, for either the “worried well” or those with predisposing risk factors, the Breast Cancer Prevention Program provides a comprehensive assessment of risk and evaluation for prophylaxis, including mastectomy or tamoxifen therapy, combined with recommendations regarding lifestyle changes.

The Breast Care Center measures outcomes through the assessment of patient and physician satisfaction with clinical treatment and support services. In addition to state-of-the-art clinical care, physicians conduct research aimed at understanding genetic components of cancer, preventive efforts, basic biology, and the patient decision-making process. The Carol Franc Buck Breast Care Center is one of only a handful of breast centers in California that has the entire gamut of services from prevention to clinical trials.37

Several other breast care centers in California possess a similar structure, including the interdisciplinary approach. These include Long Beach Memorial, Alta Bates Breast Center, Scripps Health Breast Center, Sutter Health, City of Hope Revlon/UCLA Breast Center, Joyce Eisenberg Keefer Breast Center at John Wayne Cancer Center, St. Johns, and Kaiser. Kaiser Northern California boasts a successful interdisciplinary model as well. Kaiser is a self-contained delivery system where data are available on all patients seen across Kaiser Permanente hospitals. Mammogram reminders are produced for patients who are not seen and physicians remind patients at their annual visit when a screen prompt encourages them to do so. Kaiser supports another program to contact the physicians and patients who have positive mammograms and have not scheduled follow-up diagnostic work-ups. For newly diagnosed patients, R.N. Breast Care Coordinators are available in several Northern California facilities. The Coordinator helps the patient to expedite diagnosis and assess treatment options, counseling, psychological, and emotional support services. Ongoing assessments in quality of care, patient perception issues, system improvements, clinical outcomes and new technologies are conducted by the Kaiser Breast Cancer Task Force. Moreover, an internal registry to study cancer incidence, treatment, screening, mortality, and risk reduction strategies provides a feedback mechanism based on hard data.38
**Statewide Hospital System Initiatives and Patient Navigation**

Sutter Health instituted a unique systemwide approach to breast cancer in 1997. They evaluated all of the most recent literature, established clinical guidelines, and developed an evidence-based approach to their health care activities. They created internal cancer registries at nine facilities to capture data and information about breast cancer in their hospital system. They collect data on tumor size, stage at diagnosis, mammography screening, and needle versus surgical biopsy procedures, breast conservation surgery, and lumpectomy versus mastectomy. Sutter’s medical groups collect data for the California Cooperative HealthCare Reporting Initiative (CCHRI) on mammography screening. Most groups are evaluating administrative data, and four groups collect data via electronic medical records (Palo Alto, Sutter West, Sutter Sacramento, and Sutter Gould). In the coming year three additional groups will have electronic medical record capabilities. Some medical groups send out alerts to their physicians reminding them to contact patients about the need for mammography screening.

Sutter has established goals related to breast care throughout its delivery system. They deploy physician champions to implement and monitor quality of care activities at each facility. They set goals and assess adherence to them. They provide continuing medical education for all physicians to impart goals for achieving high-quality care and good clinical outcomes. Sutter Health has set specific outcome targets for breast care at its participating hospitals. Sutter’s goal for needle biopsies versus surgical biopsy is 50 percent; it is currently experiencing a level of 60 percent. Sutter Health’s quality division works with physicians at each facility to reach that goal. In 1998, Sutter measured their lumpectomy rate at 60 percent. They set a targeted goal of 65 percent and are currently experiencing a rate of 69 percent. Sutter also measures axillary dissection rates and follow-up radiation therapy rates. Sutter has also developed a service line planning approach throughout the system and has focused on cancer, women’s and children’s services, and cardiovascular disease. Sutter recently mapped patient needs and the flow process for navigating the delivery system for cancer services. They compared patient flow in those hospitals with established breast centers and those without it. Patient flow, timeliness of access, and satisfaction were lower in hospitals without established centers. As a result, Sutter developed and implemented a patient navigator program at the Sutter Sacramento facility. All patients diagnosed with breast cancer are referred to the R.N. Breast Cancer Navigator. She assists them with questions related to treatment and diagnosis and helps them to navigate the maze of delivery providers within the Sutter system. She participates in the pre-treatment planning conference with the interdisciplinary clinical team. The Navigator maintains surgery schedules and pathology reports and helps to translate the treatment regimen in terms that patients can understand. The Navigator assists patients in referrals to support groups and other family assistance. The Navigator at Sutter Sacramento reported that their post-treatment Quality of Life surveys reflect the fact that patients do well in functional recovery but don’t do as well with the emotional and social aspects of the breast cancer diagnosis and treatment. The Navigator also noted that the program can “change the experience of the cancer treatment process for women.”39
Patient Mentorship Programs

Two patient mentorship programs addressing the psychosocial and educational needs of patients newly diagnosed with breast cancer are worth discussion. The Breast Buddy Care program is a partnership between Kaiser Permanente and the Women’s Information Network Against Breast Cancer (WIN ABC), in collaboration with the American Cancer Society. In March 1997, Kaiser Permanente completed an extensive implementation and evaluation process. The program was originally piloted at the Fontana and Riverside medical centers. Now the standard of care at the health plan’s original sites, this successful practice is being expanded throughout the Southern California Region, including a third Kaiser facility in West Los Angeles.

The Breast Buddy program was designed to meet the needs of breast cancer patients and to promote a seamless system of care by blending into the existing pathway of care at each site. Each newly diagnosed breast cancer patient pairs with a trained volunteer breast cancer survivor who provides current and relevant information, ongoing education, and support throughout the patient’s course of treatment. The Breast Buddy also sets up an internal infrastructure to integrate the program with existing services and protocols to establish a streamlined and improved standard of care for Kaiser members. Evaluation through post-treatment patient satisfaction surveys indicates a high degree of satisfaction with breast cancer care at the implementation sites. The Breast Buddy Program sponsored by WIN ABC is collaborating with the State Department of Health Services BCEDP program to implement a pilot program in Los Angeles County for medically underserved and indigent breast cancer patients.

Another model mentorship program is in place at the Long Beach Memorial Breast Care Center. The program, Breast Friends, puts volunteer women through an extensive five-week training program in which they learn about the science of breast cancer. Women self-refer or are referred by treating physicians. The program is a unique one-on-one support program for women newly diagnosed with breast cancer. The mentor helps the patient navigate the delivery system and with evaluation of treatment decisions, educational information about the disease, and access to other support programs. The program coordinator reported that they have a small grant to train women of color to be Breast Friends.

State-Sponsored Breast Cancer Programs

A breast cancer partnership was established in Central California is 1994. The Breast Cancer Act of 1993 allocated an additional two-cent cigarette tax to establish a breast cancer fund. Half of this revenue goes to the California Department of Health Services for the Breast Cancer Early Detection Program (BCEDP). The remaining revenue supports breast cancer research. The state’s BDEDP provides free screening and diagnostic services. BCEDP has funded fourteen regional breast cancer partnerships to promote the early detection of breast cancer. The central California partnership includes community-based organizations, community leaders, public health departments, hospitals, clinics, doctors, employers, educators, breast cancer survivors, churches, the American Cancer Society, and other community members working to reduce mortality in breast cancer through early detection.
In 1996, the California Health Collaborative received monies to administer the Breast Cancer Treatment Fund to establish a provider network and provide reimbursement to providers who treat breast cancer patients ineligible for Medi-Cal. The Collaborative is a unique partnership of public and private entities aimed at helping diagnose and treat breast cancer in women. The Collaborative set out to negotiate three types of reimbursement arrangements with providers: case rates according to stage of diagnosis, negotiated fee-for-service, and percentage of billed amount. The Collaborative has 16 Care Coordinators who provide help with the eligibility process and assist the patient clinically in navigating the delivery system. The Collaborative states that most of the 3,000 women they have served each see more than 11 providers during their breast cancer diagnosis and treatment. Care Coordinators are all trained in oncology.

The Collaborative also has a set of unique programs to address cultural differences toward screening and treatment. The Collaborative works with providers in two communities to make sure that they are aware of the cultural differences that affect their ability to access and treat the Vietnamese Hmong population. Another of their programs, Styling for Life, trains African American hairdressers to educate their clients about the necessity for mammography screening. In the past, The Collaborative has adopted a home party model approach to inform the Latina population of the need for screening. They boast a Medical Interpreters program to train personnel to help translate at important medical visits. In 2002, the Medi-Cal program will take over administration of the Breast Cancer Treatment Fund. It is yet unclear what role the Collaborative will play in implementation and transition.

Community-based Programs

A smaller yet effective community-based model partnership exists in the Community Breast Health Project in Palo Alto. The mission of the program is to improve the lives of people touched by breast cancer. In October 1993, Ellen Mahoney, a surgeon, dreamed of a community center where breast cancer patients could go for up-to-date medical information and support from fellow survivors. The organization was born in April 1994, buttressed by a space and a director provided by Stanford University Hospital. Seven years later, CBHP has grown to four full-time and three part-time employees and more than 230 volunteers. Clients are referred by the Palo Alto Medical Group or Stanford and are assisted by staff and volunteers who provide information and support in getting resources to diagnose and treat breast cancer. Once a week a community physician and psychologist addresses issues and concerns of newly diagnosed patients. The Education Coordinator helps patients find the most recent medical information to help them become better informed about treatment options.

Other CBHP programs are noteworthy: The Gabriella Pastor Program provides funding for free screening and diagnosis of breast health problems for low-income, uninsured women under 40 years of age. The Circle of Friends is a buddy program with more than 100 volunteers. The Consultation Planning service provides help for clients preparing for upcoming medical appointments. There are also Couples and Metastatic Support Groups and a Psychological Team of therapists to offer short-term counseling. They also provide legal, employment, and insurance counseling. This small yet overarching organization provides a number of valuable services needed by breast cancer patients.
Innovative Programs

Two hospitals have innovative programs for hard-to-reach individuals. Alta Bates Medical Center received a $405,000 grant from the California Endowment for its Breast Health Access for Women with Disabilities. It provides for a model of breast health education and services tailored to the functional abilities and special needs of women with physical and vision impairments. The program will reach 800 women in Alameda and Contra Costa Counties.46

UCSF recently raised more than $1 million to fund the purchase of a van with digital mammography equipment. The van will travel throughout underserved areas in San Francisco to attract women who are economically disadvantaged. Increased financial support for these two unique programs will allow expansion and access to a broader population.

One other innovative county-based program addressing the eradication of cancer is noteworthy. In 1999, the San Diego County Board of Supervisors dedicated $100 million of the County’s share of the tobacco settlement funds over the coming 25 years toward developing a world-class Regional Cancer Institute. They formed the San Diego County Regional Cancer Institute to successfully provide a full continuum of services through collaboration, a regional multi-disciplinary approach, and an emphasis on cancer prevention, public health education, and best practices and research. The Institute Steering Committee, composed of representatives of 21 health care organizations, agencies, and other stakeholders, has worked to develop the vision, mission, and goals. The primary goal is to reduce cancer incidence and the number of deaths from cancer. Goals will be achieved through a collaborative alliance of cancer care providers, researchers, and community leaders. During the first three years, an “umbrella” organization will be formed to work with all participants to achieve a more effective delivery of cancer services by filling any evident voids and by strengthening ties among institutions, treatment modalities and service sites.

A cancer patient navigator program will be developed and implemented to improve each patient’s ability to understand and move through the cancer care system between various treatment modalities and sites of service. Outreach programs will be created to ease access to services. Presently, the Institute is expanding to include a cancer resource library, central data repository, screening/equipment, public education forums, and support services. During years six through ten the Institute will develop a consortium model exerting influence across the continuum of cancer services and research endeavors.47 Education and screening programs will be jointly developed and coordinated. Future plans include the formation of a clinical trials network, an epidemiological profile, and shared research and best practices to create a “virtual” cancer institute.
VII. Opportunities and Recommendations

Below are ten recommendations for CHCF as well as other interested stakeholders to advance quality of care for patients with breast cancer. The recommendations range from establishing a broad statewide Centers of Excellence program to assisting a specified center or geography in improving care.

Recommendation #1: Implement a Centers of Excellence program to increase the number of hospitals that adhere to the benchmark breast cancer model.

Given the evident gaps in data, information, standards, and quality of care in a field as specialized as breast cancer care, a benchmark model for quality care should be widely implemented (see Appendix, Figure A3). Although there are many notable facilities within California that adhere to this model of care, thousands of women are receiving inadequate services. CHCF could initiate a Centers of Excellence program to increase the number of hospitals that adhere to the benchmark model and inform breast cancer patients of their conformance to this standard of care. This would involve providing assistance to interested facilities and their affiliated physicians to implement key aspects of the breast cancer model to improve quality of care for breast cancer patients. To complement such a program, the purchaser and health plan communities could create a performance measurement program in this area.

A proposed Centers of Excellence model could include a multi-disciplinary breast care approach with all of the components linked together in an integrated continuum of care. Although the optimal breast center is located under one roof, it is not essential. Most important is that the patient understands each step of the continuum and there is clear communication between the various specialists who must work together. The benchmark model would incorporate quality of care issues such as the adequate training and proficiency of providers and standards of care for radiology and pathology. The model could serve as a framework for all academic and community health care systems to emulate in breast cancer disease management, treatment and evaluation. The collection of data and information to monitor and assess quality and outcomes would also be pivotal to the successful implementation of the model.
Recommendation #2: Develop a patient navigator program using the California Collaborative or other outsource vehicle.

The implementation of a patient navigator program that can be accessed by women who are being treated at any facility throughout California could significantly improve a woman’s experience with breast cancer care. As mentioned above, the California Health Collaborative could serve as one such vehicle. The California Health Collaborative currently has sixteen Care Coordinators, all trained in oncology, who help breast cancer patients with enrollment and eligibility, physician referral and clinical help in navigating the system. On average the Care Coordinator helps the patient access eleven different treating providers. The program could also involve the 14 BCEDP breast cancer partnerships around the state of California.

Recommendation #3: Utilize existing community-based resources for breast care navigation and for targeting services for high-risk populations.

Other community-based organizations around the state could be used to provide patient navigation and other services to high-risk populations. For example, the Community Breast Health Project (CBHP) in Palo Alto could be used as a base to expand staff trained in breast cancer care navigation services. With increased funding, the consultation planning service could be expanded to include patient navigation services. In addition, CBHP is uniquely providing funding for a limited number of patients under age 40 who require screening and diagnostic services. Augmenting funding in this arena could avail these services to a broader spectrum of women. Similarly, existing innovative programs targeting high-risk women can be expanded. The California Health Collaborative’s Styling for Life program that encourages African American women to receive periodic mammograms is one such example.

Recommendation #4: Consider funding for the expansion and use of a Web-based patient navigation program in California.

In 1987, a team at the University of Wisconsin-Madison, led by Industrial Engineering and Preventive Medicine Professor Dr. David Gustafson, began to develop and build the Web-based Comprehensive Health Enhancement Support System (CHESS). The system is intended to help people facing health crises, such as breast cancer, take better control of their treatment, lifestyle, and overall health. CHESS gives people information, support, and help when making medical choices and decisions and assists them with solving problems when they need it most. It provides health information that its users can trust and understand. CHESS provides high-quality medical information to patients about breast cancer treatment and treatment options. It assists them in formulating the right questions to ask their providers. It provides support for women who are also experiencing breast cancer. Users can also interact with clinical experts to get their questions answered. CHESS is updated as medical research discovers new technologies and more effective treatments. CHESS is reviewed by panels of physicians for clinical accuracy and by patients to evaluate the level of understanding to most lay users. CHESS is currently being used by several key academic breast centers, including Harvard University and the Dana-Farber Cancer Institute. There are currently no users of the system on the west coast. CHCF could fund the expansion and use of the system by key California-based breast health facilities.48
Recommendation #5: Provide funding for the distribution of educational materials developed by the National Center for Policy Research (CPR) for Women and Families targeting women more likely to undergo mastectomy.

CPR is a research-based national organization that focuses on the health and well-being of women, children, and families. CPR recognizes the need to educate women with breast cancer about treatment options. It wants to ensure that all breast cancer patients get the information they need to make the surgical decisions that are best for them. Experts agree that for most early-stage breast cancer (stage 0, I, II), lumpectomy (which removes just the cancer and the breast tissue around it) is just as safe as mastectomy (which removes the entire breast), when lumpectomy is followed by radiation treatment. One out of two women, however, undergo mastectomy. Women without insurance, women with lower income or education, women living in certain states, older women, and those with older doctors or using community hospitals are especially likely to undergo mastectomies, even when they are eligible for less radical surgeries. Therefore, CPR is rolling out an educational campaign to educate women with breast cancer about treatment options. With the use of a patient booklet coupled with public awareness efforts, CPR hopes to get the word to all California women diagnosed with breast cancer regardless of age, race, income, or geographic location. CPR is working in partnership with the 600 breast and imaging centers in the National Consortium of Breast Centers. Sixty-three of the breast centers are located in California. They plan to work with national organizations to disseminate the booklet, including the American Cancer Society, National Women’s Health Network, Y-Me Breast Cancer Organization, Sisters Network, Inc., and the National Asian Women’s Health Organization. More funding is necessary to ensure widespread dissemination of CPR’s treatment option educational materials to patients, providers, and the general population. In addition, more funding is necessary to educate women about the availability of state-funded programs for mammography screening and breast cancer treatment, e.g., BCEDP and the Breast Cancer Treatment Fund. Finally, more research funding is needed to evaluate the factors that predispose women to choose mastectomy rather than lumpectomy with radiation treatment.

Recommendation #6: Develop a broader range of metrics for assessing the quality of, the satisfaction with, and the process of care for breast cancer services.

Today, there are a limited number of metrics used to publically measure the quality of breast cancer care for women. Health plans focus their measurement on mammogram compliance for women over age 50, based on guidelines adopted by NCQA. Little else is publicly available to help women objectively assess the quality of care and service provided for breast cancer treatment. Although there are many clinical indicators that could be measured, the ability to collect comparable data across health care entities is often sporadic. Experts in this area recommend that a good starting point would be to develop and administer a uniform patient satisfaction and self-reported quality assessment tool. The tool should aim to maximize feedback throughout the process of care rather than merely evaluate post-treatment satisfaction. These data can then be compared to benchmark norms for optimal treatment and compared across all administering health care entities. A broad based report card on breast cancer care could be developed and used by women to assess their choice of facility based on optimal care and treatment modality. In addition, more work is necessary to define other clinical measurements that can be used for comparative purposes in assessing other clinical quality dimensions for breast cancer care.
Recommendation #7: Fund studies to assess adherence to clinical guidelines established for breast cancer care.

Many breast cancer facilities report the widespread use of NCCN clinical guidelines for breast cancer care. Further study in the form of an audit is necessary to ascertain whether facilities are in fact adhering to the guidelines in actual clinical practice. In addition, it would be helpful to compare the use of clinical guidelines to patient outcomes of care. Specifically, more research is needed to assess adherence to clinical practice guidelines for pathology sample extraction, as issues related to poor quality in this area are well documented. The California Breast Cancer Research Program at the University of California would be a good source to use to conduct these studies regarding clinical guidelines.

Recommendation #8: Assess the availability of breast care for women in underserved communities.

One community health center reported that due to low reimbursements from the state, many imaging centers will not agree to provide screening mammograms for patients. The community health center reportedly terminated its relationship with a local imaging center and negotiated a deal with an imaging center across town. Patients in the economically disadvantaged service area did not want to take public transportation across town, citing lack of money and the cultural stigma or fear of leaving the community to receive medical care. Further study is needed to assess the cultural factors that impede access to care for women in underserved communities. The community health center also reported a four-to-six month lead time for access to diagnostic mammographies for women diagnosed with a suspicious lump. Further study is essential to substantiate this finding in other underserved communities and to assess the reasons for and barriers to more immediate access to health care services. Breast centers report that in most cases, consent forms for clinical trials are available only in English. Funding is necessary to ensure that there is adequate translation and understanding of clinical trial information for people of all ethnicities and races. In addition, further study is necessary to find out whether there is culturally appropriate case management for women diagnosed with breast cancer. Although it is widely reported that mammography centers are closing across the country due to low reimbursement, further study is needed to evaluate the reasons behind the imaging center closures and their relative impact on access to quality health care services.

Recommendation #9: Provide funding for the advancement of clinical quality improvement (CQI) programs in breast centers.

The Carol Franc Buck Breast Center, in conjunction with the Department of Engineering at Stanford University, worked together to develop a model for breast cancer treatment decision analysis. A Princeton University fellow measured the efficacy and turnaround times for pathology specimens. These programs constitute valuable clinical quality improvement efforts for breast cancer care. More funding is necessary to financially support the development and implementation of such programs at facilities across California.

Recommendation #10: Fund a study to assess the efficacy of a countywide effort to eradicate or reduce the incidence of cancer.

In June 1999, the San Diego Board of Supervisors was the first in the state to “Declare War on Cancer” by taking an unprecedented step of forming a countywide collaborative effort to eradicate cancer. Using tobacco settlement funds, they formed the San Diego Regional Cancer
Institute to decrease cancer incidence in the county of San Diego. Twenty-one organizations worked together to develop a 25-year business plan to reduce cancer incidence. To achieve this vision the Cancer Institute has formed an alliance of cancer care providers, researchers, and community leaders to leverage existing resources. Seed monies could be provided to other counties to replicate this unique model. Funding is also necessary to assess the efficacy on the counties’ efforts to eradicate cancer or reduce cancer incidence.
VIII. Conclusion

Breast cancer affects the lives of many women and their families. As the post-World War II population progresses into the age in which women are at higher risk for breast cancer, the incidence of breast cancer is likely to increase. Many scientific and technological advances have paved the way for earlier detection, risk analysis, and more sophisticated treatments for breast cancer. There are, however, still gaps and variability in the structure and organization of breast care delivery, the quality of care provided, and the outcome of breast cancer treatment. California incorporates examples of several integrated delivery models of breast care. Replication of these models would improve the experience, quality, and outcome of health care services for women with breast cancer. By establishing a benchmark for hospitals to model, quality care for breast cancer patients will be made transparent and lead to continuous improvements.
Appendix: Figures and Tables

Figure A1. Female Breast Cancer Incidence by Race, 1998

Source: California Department of Health Services, Cancer Surveillance Section, Cancer Registry.
Note: In situ cancers are excluded. Race/ethnicity categories are mutually exclusive.

Figure A2. Breast Cancer Mortality Rate by Race, 1994-1998 (Avg. Adjusted)

Figure A3: Benchmark Model for Breast Cancer Care

BENCHMARK MODEL FOR BREAST CANCER CARE

Table A1: Staging of Breast Cancer

<table>
<thead>
<tr>
<th>Stage of Cancer</th>
<th>Definition of Cancer Staging</th>
</tr>
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<tbody>
<tr>
<td>Stage 0</td>
<td>Localized cancer in breast duct (DCIS) or lobular tissue (LCIS). No invasion of surrounding tissue.</td>
</tr>
<tr>
<td>Stage I</td>
<td>Tumor is 2.0 cm (about 3/4 inch or less). Has not spread beyond breast.</td>
</tr>
<tr>
<td>Stage II</td>
<td>Tumor larger than 2.0 cm and it has spread to lymph nodes</td>
</tr>
<tr>
<td>Stage III</td>
<td>Tumor larger than 5.0 cm (more than 2 inches) and/or has spread to lymph nodes. Cancer may have spread to skin, chest wall, or mammary lymph nodes.</td>
</tr>
<tr>
<td>Stage IV</td>
<td>Cancer regardless of size has spread to distant organs such as bone, lungs or lymph nodes.</td>
</tr>
</tbody>
</table>

Endnotes

9. CDC National Center for Health Statistics, vital statistics data, underlying cause of death, 1993-1997 and 1944-1998. (Some data were excluded because there were 75,000 or fewer persons in the denominator or 20 or fewer deaths in the denominator.)


27. Link JS. “History and Overview of Comprehensive Interdisciplinary Breast Centers.” *Surgical Oncology Clinics of America*. Volume 9, Number 2, April 2000.


33. Ibarra, J. “The Pathologist in Breast Cancer.” *Surgical Oncology Clinics of America*. Volume 9, Number 2, April 2000. (Note: Dr. Lagios discusses a case in which a 38-year-old patient had a partial resection for suspicious calcifications that yielded a 40 X 30 X 20 mm tumor. Six sections were submitted that had high nuclear grade ductal carcinoma in situ. When the patient seeks a second opinion, the pathologist requested that the entire tissue be submitted for microscopic evaluation. The additional tissue revealed a 1.6 mm focus of invasive carcinoma. Dr. Lagios analyzed the cost of both approaches and found that the total cost of reviewing the six slides was $49.00, while the total cost for the additional slides was $82.60.)


36. Kolb GK. “Disease management is the future, breast cancer is the model.” *Surgical Oncology Clinics of America.* Volume 9, Number 2, April 2000.


38. Personal communication with Kaiser Health Plan staff, Dr. Susan Kutner, Joan Tanzer, November 2001.

39. Personal communication with Sutter Health staff Krystin Dozier, Mary Pare, November 2001.


42. www.dhs.cahwnet.gov, Breast Cancer Early Detection Program.


44. Personal communication with staff of California Collaborative, Kathy Yarmo, Carolyn Lane. Fresno, California, December 2001.

45. Personal communication with staff at Community Breast Health Project, Amy Moody. Palo Alto, California, December 2001.


48. www.chess.chrsa.wisc.edu/bc and personal communication with Dr. David Gustafson, University of Wisconsin.