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Addressing Barriers to Breast Cancer Care in California: The 2016-2017 Landscape for Policy Change

A report to the California Breast Cancer Research Program

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Executive Summary

Introduction

In 2017, an estimated 27,980 women will be diagnosed with breast cancer in California, and approximately 4,440 will die from the disease.[1] Unfortunately, it appears uninsured and underinsured breast cancer patients continue to face delayed and restricted access to life-saving, life-extending treatments and to services that enhance quality of life. A landmark study published in 2015 using the California Cancer Registry found patients with stage III breast cancer had the best 5-year relative survival if they were covered by private insurance (80.3%) while Medicare-Medi-Cal dual eligible and uninsured patients had the lowest 5-year relative survival rates (59.4% and 62.5%, respectively). Approximately 60% of women with stage 0-II breast cancer with private insurance (and 61% with Medicare) underwent breast-conserving surgery, compared to 52% with Medi-Cal and 53% who were uninsured. Health coverage improves breast cancer outcomes compared to those with no insurance, but challenges may remain even for the insured. Among those insured, there appear to be significant health system barriers to cancer care as health insurance premiums and the cost of breast cancer drugs are increasing, and provider networks are narrowing.

This report provides an assessment of the significant barriers and challenges to accessing breast cancer care in California by insurance status (uninsured, underinsured, on public or private health insurance). This was accomplished through a synthesis of the peer reviewed literature, news media, reports and policy briefs, social media, legislative scan, and a series of key informant/stakeholder interviews. This assessment synthesized the findings from these differing yet interlinked sources of information, producing the themes as well as specific barriers identified as the most significant for women with breast cancer in California. We report here in this Executive Summary the Key Findings of the report. These findings can be used to guide efforts of policy-makers to improve timely access to breast cancer care among all women in California.

This updated report represents a compilation of 2 phases of the study. In Phase 1 (Patient Perspectives), research included a review of literature and social media, legislative scan and key stakeholder interviews with patient educators and navigators. Phase 1 key informants were recruited from patient education, support, and advocacy groups. In Phase 2 (Provider Perspectives), a second round of stakeholder interviews was conducted with health care providers and social workers.

It is important to note that the timeline of this study corresponded with a dramatically changing political environment with potential implications for breast cancer care. The early phase of the study occurred in early 2016, prior to the 2016 Presidential Election. However, the second phase occurred after the election and the United States Congress and the newly-elected Trump administration have been working on a repeal and/or replace of the Affordable Care Act (ACA). In May 2017, the United States House of Representatives voted to pass the American Health

Care Act (AHCA), as a replacement to the Affordable Care Act. While the AHCA has not yet been voted on by the United States Senate as of July 2017.

It is clear that the AHCA is changing the landscape of the discussions on health care, with the return in conversations on who gets access, what is the scope of coverage and how much more will people pay, especially for people with breast cancer and other chronic conditions that incur expensive treatments. According to the Congressional Budget Office score as of May 24, 2017, the House version of the AHCS would result in 23 million people losing coverage—largely through the repeal of the ACA's provision to expand Medicaid eligibility. Affordability would also be affected by reduced subsidies for non-group insurance and elimination of lifetime coverage limits. The House AHCA replaces the ACA's protections from denial of coverage of people with pre-existing conditions with access to coverage through high-risk pool coverage programs. The AHCA's current provisions have been debated to be inadequate to meet the needs of people with pre-existing conditions where their only option is to purchase health insurance through the non-group market. Our report thus uniquely presents insights on barriers to breast cancer care straddling a period of the Obama and Trump presidential administrations.

Key Findings of the Report

After collecting data on the key barriers to breast cancer treatment faced by women in California, the barriers were organized into 5 common themes. Below, we provide a table featuring policy insights that hone in on the issues of key concern identified in this report for the five identified themes by insurance type. We anticipate that these project results can be used to guide efforts of policy-makers to improve timely access to breast cancer care among all women in California.

Policy Insights by Theme and Insurance Type

Themes	Uninsured & underinsured	Medi-Cal	Covered California	Private/commercial insurance
Health System Fragmentation/Navigation	State policy that bolsters the preservation of coverage for the uninsured given the uncertainty of the ACA;	State policy that preserves the Medi-Cal coverage levels that currently exist under the ACA & policy focus on specifically improving the quality of care provided to Medi-Cal enrollees to address disparities that currently exist	State policy targeted to the ensuring subsidy support for Covered California and ensure low income population has access to navigation and support services	Provide navigation services, reimbursement for these services, and promotion of system integration
	State policy to mandate navigation services, reimbursement for these services, and			

Themes	Uninsured & underinsured	Medi-Cal	Covered California	Private/commercial insurance
	consideration of payment models that encourage care coordination			
Insurance/Health Benefits	Policy mandates to extend program benefits (such as BCCTP) to accommodate full course of treatment and policies to strengthen the link between screening, diagnosis, and treatment	Adjust Medi-Cal provider rates to increase the number of providers accepting Medi-Cal	Policies that limit narrow provider networks, with focus on improving network for oncology care	Increase the patient's awareness of a plan's covered benefits for reconstructive surgery and second opinions.
	Policies that streamline authorization processes and meet a set target for turnaround time. Women face delays in care due to prolonged insurance authorization, thus failing to receive timely treatment			
Cost	State policy that bolsters the preservation of coverage for the uninsured given the uncertainty of the ACA; Invest in programs to improve awareness of financial assistance programs targeted to low income, uninsured	Provision of financial assistance for non-medical costs, including transportation, childcare, and lost wages	State policy targeted to the ensuring subsidy support for Covered California; Policies that restrict placement of essential oncology drugs on the highest cost tier and other policies that address high costs of oncology drugs	Policies to reduce the burden of costs to enrollees from treatment and drugs, particularly in high deductible health plans Provision of decision support tools to consumers regarding costs of care, for example cost calculators, lists of all covered breast cancer drugs, up-to-date formularies & information on tiers and restrictions on drug access, provider directories and information on in and out of network use of providers and costs
	Consider health system reform cost containment strategies that increase affordability of breast cancer care.			
Individual and Cultural Characteristics	Support programs that increase awareness of the availability of services to	Establish funding for support service programs, for example programs providing	Support telehealth services to improve a patient's geographic access to providers and integrate	Design and implement payment models that reward providers and larger health delivery

Themes	Uninsured & underinsured	Medi-Cal	Covered California	Private/commercial insurance
	undocumented women to ensure timely treatment	transportation and childcare to women undergoing cancer treatment	technologies that increase the provider’s ability to evaluate the patient	systems that provide culturally appropriate services to patients who need them
	State programs such as the Office of Health Equity should provide resources and programs to encourage cultural competency training for health providers on breast cancer care.			
Language/Health Literacy	Establish programs for limited-English proficient women to increase their awareness of eligibility for public insurance programs and public programs (BCCTP) for breast cancer care	Incentivize providers more to provide language support and other culturally appropriate services where needed; integrate with payment for in-language navigation services	Require coverage or reimbursement for interpretation and translation services that extend beyond the visit, to include the entire span of the care experience such as making appointments, patient education, and support services	Support programs that expand the number of providers who are bilingual, and incentivize the use of language services
	Enforce compliance of the law of the Health Care Language Assistance Act and the ACA section 1552 across all health plans especially Medi-Cal plans that serve a disproportionate number of LEP patients.			

Introduction

In 2017, an estimated 27,980 women will be diagnosed with breast cancer in California, and approximately 4,440 will die from the disease.[1] Research has documented disparities in breast cancer outcomes by socioeconomic status and race/ethnicity.[4] Although the factors underlying disparities are complex and multi-focal, unequal access to high-quality breast cancer treatment is likely a key cause of disparities in breast cancer outcomes.[5,6] Prior research examining barriers to care have identified barriers that are structural (e.g., access to services, geographic location of services, transportation needs, insufficient or undertrained workforce), sociocultural (e.g., misconceptions, stigma, language barriers, discrimination, religious beliefs), personal (e.g., fear of a cancer diagnosis, low health literacy, competing family and work obligations) and financial (e.g., lack of insurance, large out-of-pocket payment, indirect costs of transportation, childcare, and lost wages).[4,7-11]

Since its major implementation in 2014, provisions of the Affordable Care Act (ACA) has successfully expanded access to health insurance and breast cancer care. Today, in 2017, Federal legislative discussions on repeal of the ACA brings new concerns on unraveling the gains from the ACA as millions of women facing a new diagnosis of breast cancer will lose coverage and will lose protections in purchasing coverage. Uninsured and underinsured breast cancer patients continue to face delayed and restricted access to life-saving, life-extending treatments and to services that enhance quality of life.

Although insurance improves breast cancer outcomes compared to those with no insurance, challenges remain even for the insured. Among those insured by their employers, there may be significant barriers to cancer care as health insurance premiums are increasing; for example, in California, health plan premiums have increased by 189% between 2002 and 2014, and 28% of large California firms reduced health benefits or increased cost sharing in 2014.[12] Among both the publicly and privately insured, other barriers to cancer care include delays in timely access to specialists in oncology, narrow networks of breast cancer specialists, restricted prescription drug formularies for oncology drugs and oncology support (e.g. drugs for chemotherapy-related anemia), all of which affect patients facing costly cancer treatment. Access may still be a barrier as a growing number of insured patients are discovering that their oncology care providers were no longer considered in-network. In March 2014, the Centers for Medicare & Medicaid Services (CMS) responded with network adequacy standards to help determine whether health plans offered in healthcare exchanges provide access without unreasonable delay to certain health care providers, including oncology providers and hospital systems.

This report provides a comprehensive assessment of the significant barriers and challenges to accessing breast cancer care in California through the three key approaches: (1) a synthesis of the peer reviewed literature, (2) an analysis of social media and the grey literature (news media, reports, and policy briefs), (3) completion of a series of key informant/stakeholder interviews. A legislative scan was also conducted to understand the types of policies that have been introduced to address barriers and then to identify the gaps in policy that could be filled by new legislative action (see Appendix E). Although many barriers are shared across insurance types, where possible, we provide insight on barriers unique to the insurance status of women, specifically for the uninsured, those covered by Medi-Cal, and those covered by commercial insurance. We anticipate that these project results can be used to guide efforts of policy-makers to improve timely access to breast cancer care among all women in California.

Technical Approach

Approach 1: A Narrative Synthesis of the Barriers to Breast Cancer Care

We conducted a narrative synthesis review of the recent evidence (January 2013-December 2015) on the barriers to breast cancer care in the U.S. and California. As part of our review, we included both the peer-reviewed literature as well as non-peer reviewed sources. A literature search was performed to retrieve publications that described any aspect of barriers to breast cancer care for which a conceptual framework helped identify search terms (see Appendix A for conceptual framework and list of terms). The literature search was limited to articles published in English from 2013-2015. A total of 710 papers were retrieved in this search; 99 of these were studies/papers based on California data. We then reviewed and sorted the list to exclude papers on prevention, early-detection, and screening. With examination of the titles and abstracts, the list of papers was then further narrowed down to only papers that made reference to barriers to care.

Approach 2. Examination of Gray Literature and Social Media

For the gray literature (news media, reports, and policy briefs) synthesis, a total of 35 papers (of which 15 are California-based) were identified and full text articles were retrieved. Over 100 articles were retrieved in the non-peer reviewed search with mention of health care barriers post-ACA. However, the vast majority of these articles were duplicate reports of findings that had been published in peer-reviewed journals. The most relevant non-peer reviewed sources on potential health care barriers in California are reports from the California Health Care Foundation, which have been used throughout this report to provide context and insight regarding the current landscape of healthcare in California and its potential influence on breast cancer care.

Social media – for example, Twitter and Facebook – are a major repository of information to examine campaigns by organizations and to capture the conversations/discussions among members of the public that occur in these platforms. In 2014, about 23% of adults online used Twitter (up from 18% in 2013) and approximately 71% of adults online use Facebook, and the usage among older adults is increasing.[13]

In social media analysis, identifying particular hashtags or keywords are crucial as they are the means to identify data that speak to a particular problem. For this purpose, we harvested hashtags and names of breast cancer patient organizations with a presence on social media from our key informant interviews and the gray literature review.

Findings from the social media scan were combined with the gray literature because there was a good deal of alignment between the gray literature and social media, namely because much of the discussion occurring on platforms such as Twitter and Facebook are related to gray literature news articles.

Approach 3: Key Informant Interviews to Understand Patient Barriers to Care

An important aspect of this project is to gain an understanding of barriers to breast cancer care in California from the perspective of both the patient and the provider. In an effort to represent a maximum amount of voices, the research team identified organizations that interface directly with breast cancer patients and would be in a position to hear feedback from patients on their perceptions of the continuum of care. Thus, to gain insight from the patient's perspective, key informants included breast health educators, on-site clinic workers, patient navigators, and individuals involved with support groups. In order to recruit participants for key informant interviews, we invited organizations that have previously partnered with the UCLA Center for Health Policy Research, the UCLA Center for Cancer Prevention and Control Research, and the California Pan Ethnic Health Network, resulting in the completion of 12 key informant interviews from the patient perspective. In Phase 1, semi-structured interviews were conducted by phone from January 3 – March 18, 2016. In Phase 2, a second round of interviews were conducted with health care providers. To ensure representation of providers working across the entire breast cancer care continuum, recruitment efforts targeted a broad spectrum of providers including primary care providers, breast surgeons, medical and radiation oncologists, medical directors, program administrators, and social workers. These providers worked in a variety of health care settings including public and private hospitals, private practices, safety net clinics, and support programs. Eleven interviews were conducted by phone April 12 – May 17, 2017.

The semi-structured interviews were designed to assess barriers to breast cancer care across the continuum of care. Respondents were also asked to describe how the experience of a patient obtaining care may differ based on insurance status – uninsured, underinsured, and publicly or privately insured. (see Appendix B for list of codes).

Our goal was to recruit informants who collectively can provide input on the range of health insurance experiences of California cancer patients and the barriers that these patients face. Using snow-ball sampling technique, we identified known key informants, including members of the California Breast Cancer Research Program staff and its Policy Research Advisory Group, who could provide recommendations for, and connections to, study participants meeting our criteria of representative providers, organization types, and geographic locations. Across Phases 1 and 2, we sought to achieve diversity in geography across in California. Our final sample included informants from Berkeley, Chico, Duarte, El Dorado Hills, Fresno, Greenbrae, Long Beach, Los Angeles, Oakland, Redlands, Sacramento, San Francisco, Santa Monica, and Visalia, many working in health systems serving patients from wider geographical areas. The sample includes informants with programs that cater to specific race/ethnic groups in order for project findings to be reflective of the racial/ethnic diversity of California.

Findings

As intended, each Approach generated themes on differing yet interlinked sources of barriers to breast cancer care and disparities in treatment. Using the findings from the approaches described above, the appearance of keywords related to the barrier addressed were documented and then tallied. The predominant keywords that emerged in the narrative synthesis, key informant interviews, and the scan of social media/gray literature were then compared to identify major themes. The following **barrier themes** were identified as the most significant for women with breast cancer in California: (1) **Health System Fragmentation and Navigation**, (2) **Insurance/Health Benefits**, (3) **Cost**, (4) **Individual and Cultural Characteristics**, and (5) **Language**. Table 1 presents a “heat map” of the frequency of mentions of each theme generated by the key informant interviews, peer-reviewed literature, and gray literature/social media. (see Appendix F for detailed summary table and figure).

Table 1. Most common Barrier Themes by Approach

Approach / Barrier Themes	1. Peer-reviewed literature	2. Social media/Gray Literature	3. Key informant interviews	
			Patient Perspective	Provider Perspective
Health System Fragmentation/Navigation	🟥	🟧	🟥	🟧
Insurance/Health Benefits	🟨	🟥	🟨	🟥
Costs	🟧	🟥	🟨	🟥
Individual/Cultural	🟥	🟨	🟥	🟨
Language	🟥	🟨	🟥	🟥

Legend:

Most often mentioned	Medium	Least or No mention
🟥	🟧	🟨

The peer-reviewed literature focused on variations in receiving timely and high-quality care by individual patient characteristics (e.g. race/ethnicity); there was also a body of literature that elaborated on the role of patient navigation in addressing patient level barriers to care. The gray literature/social media space, however, delved in conversations on high cost of treatment and narrow provider networks in insurance markets. Key informant Phase 1 interviews highlighted patient-level barriers and the ways in which system-level barriers compounded patient-level challenges. Phase 2 interviews, similar to the gray literature /social media scan identified insurance and cost issues as top barriers. To a lesser degree, Phase 2 interviews also reinforced the health system and navigation barriers raised in both the peer-reviewed literature and in the key informant interviews from the patient perspective. Across all Approaches, language barriers registered as a top theme, with the exception of the social media approach, where it was least mentioned. Social media posts may tilt towards the experience of care among English-proficient women with breast cancer.

We also probed from our quantitative and qualitative data sources whether these themes vary by insurance status. While there are specific barriers, such as public program time limits for treatment for uninsured women, we found that a multitude of barriers cross insurance lines. No single insurance status – uninsured, underinsured, and publicly or privately insured – exempts women with breast cancer from the possibility of facing barriers identified by this study. Not surprisingly, we did find that among women with breast cancer who are insured, barriers are often patient-centered. Among women without insurance, system-level barriers dominate, delaying and restricting access to life-saving, life-extending treatments.

Our approach provides insights from multiple perspectives and key informant interviews at two pivotal points of time for our federal healthcare system. Our interviews from the patient perspective began in early 2016, a recent period post the major implementation in 2014 of the Affordable Care Act (ACA), where expanded coverage evolved the health access discourse to concerns on narrow networks and improving the patient experience. Our second set of interviews in 2017 aimed to pair the patient perspectives with provider perspectives on barriers, but these insights were of course shaped by federal legislative activities to repeal the ACA, thus propelling the return of coverage concerns as a top barrier. Taken together, our project provides current evidence to inform removal of critical barriers to breast cancer care for Californians—where some barriers are constant regardless of coverage whereas other barriers would be amplified with potential repeal of the ACA. Below, we organize our findings and our recommendations by 5 themes to help guide policy discussions.

Themes

Health System Fragmentation / Navigation

Data collected across all Approaches emphasized the fragmentation of the health system as a major barrier to the receipt of timely, high quality care. The lack of connections between providers, facilities, and payment systems add to the challenges of receiving cancer care that is already complex, involving treatment and support from multiple providers and services. For example, one respondent noted a challenge at her facility dealt with prescribing radiation, because the facility had to refer patients elsewhere for treatment, which caused delays in care. Services that are integrated and co-located can lead to improved timeliness and completion of care.

Another respondent expressed frustration in the lack of coordination: “In Los Angeles County, perhaps even in the state, we just had a spider web of different programs, and that spider web left plenty of room for people to fall through the cracks.” The lack of coordination has also been cited as a barrier to effective breast cancer care by providers in California and is considered one of the key challenges in cancer care.[14,15]

Patient navigation could counter the challenges of system fragmentation. Navigation helps patients overcome barriers to cancer care through care coordination and support. Patient navigation emerged as a significant theme in this study, both as something that was desperately needed when absent, and extremely helpful when present (which was less often the case).

A seminal article on patient navigation by Wells and colleagues (2008) provides an ideal frame for considering our results; in their paper the following five characteristics are used to describe patient navigation for cancer - 1) it focuses on overcoming individual patient level barriers to accessing care; 2) it reduces delays in obtaining care; 3) is provided to patients for a defined episode of cancer care; 4) focuses on a defined set of health services relevant to that episode of care; and 5) has a definitive endpoint when provided services are complete.[16] Patient navigation is most commonly offered by health services providers (hospitals or physician practices), and less often by health insurance plans. A large body of scientific research has documented the benefits of navigation for patient satisfaction and clinical outcomes.[10,17-24]

Many interview respondents had direct experiences demonstrating the need for navigators. More than one acknowledged that their organization was not explicitly tasked with navigation services, but often ended up playing the role. Screening and community outreach programs in particular – because they are a known entity – become de facto resource centers and, in some cases, provide navigation because women don’t know where else to go. But their services are limited by their often indirect link to any one health care system.

One provider noted this was particularly important for women who are new to certain programs such as the revised Medi-Cal program.

> "I would think that, at least in our state, the change from Medi-Cal to the HMO plans where women are covered by certain groups, I don't think that gets explained to them very well and I don't think they understand how that works until they try to make an appointment with the doctor."

Another important role for navigators is to connect women with non-medical support services. Even though many services for breast cancer patients currently exist, these services are likewise fragmented and can be challenging to locate and connect with. One patient educator mentioned that she often hears from cancer patients and survivors the desire to start their own support service organizations, because they had not been able to find the services they needed for themselves.

> "I said (to the patient) you mean to tell me you have founded an organization that provides hats and wigs for women? And she was like, yeah. And I said 'why don't you join (with) this other organization…..this is what (they do). "

Findings from the key informant interviews indicated differences in availability of existing navigation programs by health insurance, and which providers/programs best supported patient navigation.

Other respondents noted that some specific insurance plans, but not all, play a role in access to navigation. One reported that HMOs help with navigation better than other plans. However, one respondent provided this insight: women with private insurance are assumed to have a support system, and thus those receiving care from private providers were generally less likely to be offered patient navigation services. On the other hand, some respondents suggested that healthcare safety net providers, such as public health systems and Federally Qualified Health Centers, were most helpful with navigation.

Some respondents particularly noted the value of navigators in the context of a *change* in insurance status, particularly for the newly insured population under the ACA who have very limited experience inside a medical system.

One provider-based navigator offered this opinion:

> "I think the navigation function is incredibly important, especially for our highest risk patients. There's plenty of online nutrition information, and exercise videos out there and whatever, there's access to all kinds of expertise, but the function of someone whose job it is…to look over the shoulder of the patient and make sure that they are getting to their appointment on time, making sure that they are signed up for the services they need, making sure that they are getting a ride to their radiation, it's invaluable, especially for our highest risk patients."

Overall, although informants differed in their opinion of specific health care settings, most agreed that a well-run navigation program was valuable for helping women succeed in moving through the complex process of receiving high quality breast cancer care. However, there is a key difference in the perspectives of patient educators and of providers. Often, the providers that noted the value of navigation were associated with facilities that had social workers and/or navigation services available to their patients. This perception reveals a gap in the patient experience, as the patient educators that participated in this study, most of whom are outside physician practices, reported that patients they talked with were not getting sufficient services, particularly navigation.

Respondents indicated that navigation programs varied in the range of services offered as well as quality. There was consensus that navigation cannot stop at the hospital doors, and must extend to support services. Respondents felt strongly that navigators should:

- Communicate with the doctors to help ensure timely delivery of services.
- Follow-up on mail sent to patients, ensure timely follow through. Lack of follow-through could force changes in insurance, impacting care.
- Help interpret technical medical terms into common language to explain the diagnosis and treatment options, enabling the patient to make more informed decisions about care.
- Be available to all women, regardless of insurance status; some women who have insurance still do not know how to navigate the health system.
- Have a repository of resources for support services for referrals. Often providers and their staff are unaware of outside programs.

Respondents also noted challenges in implementation of quality navigation services. First, HIPPA regulations can cause issues with programs that are not officially tied to a hospital or provider, as doctors cannot discuss private patient information with a third party. These barriers are amplified when the navigator is assisting someone with limited English proficiency, and is needed to help translate clinical discussions with providers, schedule appointments. Second, there may be a lack of coordination between providers and navigators, particularly if providers are unfamiliar with community-based navigation programs. Third, navigators who are not knowledgeable about support services may not be as helpful as those with experience both in healthcare and community resources.

Several provider respondents noted the presence of navigators within their practices, and felt their services were extremely valuable to patients.

> "Our navigator is absolutely wonderful, there's only one of her, so she does get stretched kind of thin, but especially for our most vulnerable patients, I think that single service has made the most difference."

These provider respondents were associated with a facility such as a comprehensive care clinic with co-located services. But one provider noted that is not always the case:

> "Some providers are well-equipped with a list of different resources and some providers have case managers. They have a front staff that maybe not assigned any specific name but they have specific duties to provide patient support and provide case management so they can tell women how to get (help), maybe give her free tickets for bus rides or for some sort of, some other commuters. Other clinics, they have extensive lists of peer support and charity organization, but not all the offices are well-equipped like that. Actually most of the time they're not, especially if these are the small offices. In small offices and solo practices, it's usually one staffer who's front desk or manager does everything and it's a lot of things fall between cracks."

A few patient educator and provider respondents noted either recent expansion of navigator activities, or planned expansion to meet patient needs. One provider spoke specifically about efforts at her facility:

> "Our facility has case management so we try our best to offer when we find patients in need in like a dire situation or may need food stamps we would send them to get those services."

The role of a navigator does not need to be limited to serving the patient. Due to their intimate knowledge of challenges, barriers, and possibly successful solutions, they can feed back valuable information to providers and health systems. One respondent relayed a specific example of a Thai health navigator, who was well known to local health systems. Area hospitals provided her parking access and a badge, and designated certain days for screenings of Thai women. The navigator participates on the health system's tumor board, where she helps the provider understand the patient perspective in treatment decisions. She offers the point of view of a patient and women, commenting on what was being recommended and what could be a barrier to care. This is an example of a successfully collaborative relationship between providers and navigators.[17,19,25-29] A recent study shows patient navigation resulted in a more timely diagnosis for a diverse group of minority, low-income women with breast cancer screening abnormalities.[30]

One respondent noted that her organization recognizes that patients have better outcomes when they work with a patient navigator to develop an individual treatment plan:

> "Not everybody has the ability to understand their choices or make medical decisions without having something really laid out in front of them that specifically. Especially for medically underserved patients who do experience limited access to medical care and they have language barriers."

In our literature retrieval, a study on patient navigation argued for the need for navigators to be better trained to identify legal issues their patients are facing as a part of their patients' cancer treatment plan.[31] Patients are protected by non-discrimination laws directed at housing and employment. Patients who are unaware and face issues with their jobs or residences will face additional barriers beyond treatment.

Fragmentation of the payment system as a barrier to timely access to quality cancer care was also raised in both the peer reviewed literature and key informant interviews. In the peer-reviewed literature, there is a large body of recent research on new payment models for cancer care coordination, with the bulk of the literature focusing on financial incentives for adhering to clinical pathways, patient-centered medical homes, bundled payments, and specialty accountable care organizations (ACOs).[46-50] There have also been calls for more radical change, with the endorsement of single payer system - in the cancer literature. The single-payer program is likened to Medicare for all in which it would provide universal, comprehensive insurance– covering provider visits, hospital care, prescription medication, and long term care and rehabilitation.[51] The calls for single payer, however, have been called aspirational and there remains uncertainty regarding how a shift of this nature would be implemented in the U.S.[52] California is at the forefront of this issue as it is debating legislation that would create a statewide single-payer health care system. The Healthy California Act (SB-562), 2017 would provide health care to all Californians, including those who are currently either uninsured or underinsured.

Four of the 11 providers interviewed felt that there is a need to revisit healthcare delivery systems and financing mechanisms altogether for a way forward in facilitating care coordination and reducing costs of care for breast cancer treatment. As our interviews coincided with the policy discussions on SB-562, there adopting a single-payer health care system was called out as a viable policy solution to reforming health system fragmentation.

> "If we're talking about reform policy changes moving towards, you know, single-payer health is huge."

One provider stated:

> "Even though it would be very messy to get here, I think the cleanest thing would be like a single-payer healthcare system because there's so much waste in the system that we have now with all these levels of different insurances and everybody, there's so many resources spent on, you know, middlemen basically. So if it was up to me I would choose single-payer."

Another provider offered:

> "From a policy standpoint I have always felt that a universal single payer health care system is far and away the most functional thing…"

A report by the Political Economy Research Institute at the University of Massachusetts Amherst examined SB-562's provisions and estimated that the single payer system could produce savings of about 18%.[53] While the immediate costs and savings of a single payer system may still be up for debate, it is the long term administrative efficiencies associated with eliminating the fragmentation of multiple payers that appears to be the strength of the economic argument for this system.[52]

Recommendations to Address Health System Fragmentation/ Navigation Barriers

- Improve system integration and co-location of services, including connections to, and financial support for, social services.
- Provide reimbursement for patient navigation services, especially in private health plans that currently lack these services.
- Establish quality standards for patient navigation.
- Expand existing screening and prevention programs to educate women diagnosed with breast cancer on patient navigation, including what the role of a navigator is, what services are included, and how to obtain navigation services.
- Support the development of a repository of information on health care service providers and support services that can be locally tailored and available to providers and navigators.
- Consider the redesign of fragmented payment systems for breast cancer care to improve care coordination

Insurance/Health Benefits

Type of insurance and the structure of health benefits been shown as a strong determinant of variation in breast cancer treatment decisions and outcomes. A study published in 2015 using the California Cancer Registry examined outcomes by type of health insurance among about 700,000 Californians diagnosed with breast, colon, rectal, lung, and prostate cancer between 2004 and 2012.[32] They tracked how early cancer patients were diagnosed, their quality of treatment and their five-year relative survival rates according to their type of insurance. Among a number of findings, the study reported that Medi-Cal patients with stage 0-II breast cancer were the least likely (52.2%) to receive breast-conserving surgery. Breast-conserving surgery followed by radiation therapy is generally regarded as the optimal treatment for most, as it largely mitigates the psychosocial and clinical consequences associated with the more invasive mastectomy.[33] Medicare patients were significantly more likely to receive breast-conserving surgery (61.1%) than patients having any other source of insurance. Breast cancer patients under 70 years of age, who were uninsured, or had Medi-Cal coverage, were the least likely to receive recommended radiotherapy following breast-conserving surgery (64.4% and 65.2%, respectively).

Providers in this study provided additional examples of insurance status (specifically participation in Medi-Cal) impacting care, particularly during the diagnostic phase. However, some of their perceptions were contradictory. One provider reported that Medi-Cal did not cover a PET Scan.

> "For example, right now if a woman is suspected to be metastatic, have metastatic breast cancer at diagnosis, private insurance will cover a PET-CT, which is a way of looking for metastasis in the liver or in the bones, but Medi-Cal does not cover that. Those women have to get CT scans and they have to get a nuclear medicine bone scan. Medi-Cal does not cover a PET_CT."

Another provider shared that the scan was covered, however, approvals significantly delayed care.

> "I have less trouble getting people worked up in, under the Partnership heading, which is our Medi-Cal, it just takes forever."

In breast cancer care, there may not always be a definitive guideline or evidence base to determine whether one treatment is "better" than another. Ideally, providers and patients would then engage in a shared decision-making process to select among treatment alternatives; insurance status would not have an impact on treatment decisions. However, we identified two studies that found that insurance status was also related to receipt of two types of treatment.

- *Bilateral mastectomy*. Although removal of only the breast cancer tumor or the affected breast is the most typical surgical treatment for breast cancer, bilateral mastectomy use is increasing over time. The increase in use of bilateral mastectomy may be indicated, especially when results of genetic testing results suggest the potential benefit, or may reflect overtreatment among more affluent populations. In a study of California women who had undergone surgery, women who had unilateral mastectomy have public/Medi-Cal insurance, and were treated in hospitals serving predominantly patients of lower SES.[34,35] Another study found that women who underwent bilateral mastectomy were more likely to be non-Hispanic white and privately insured, to live in high SES neighborhoods, and to be treated in NCI-designated cancer centers.[19]
- *Brachytherapy.* Radiation therapy is accepted as an important component of adjuvant treatment of breast cancer. For patients with certain disease characteristics, brachytherapy (radiation therapy given in or near the tumor itself such that a high radiation dose hits the tumor while reducing the radiation exposure in the surrounding healthy tissues) is considered to be a relatively cost-effective alternative to traditional external beam radiation therapy. In a national study, among patients who had Medicaid coverage or were uninsured brachytherapy was less often used in the definitive or postoperative management of cancer compared to those with non-Medicaid insurance.[36]

Findings from key informant interviews suggest that treatment paths may vary by insurance status in part due to the providers and facilities that a patient can access. There is no doubt that there has been a growth in health insurance plans offering limited provider networks: A

California Health Care Foundation report in 2015 reported that Covered California plans offered narrower hospital networks than commercial plans.[37] However, they also found the quality of care (measured using an index made up of twelve AHRQ quality indicators reported by California hospitals) provided by these restricted networks was not significantly different than the care provided in non-Covered California plans, and in some cases may be of higher quality.[38] There have not been studies examining quality, including timeliness, of care, of Covered California plans specifically for breast cancer.

There were limited findings in regard to narrow networks specifically under Covered California. In key informant interviews, one patient educator respondent noted the presence of cultural issues, rather than reimbursement issues, affecting access for patients with insurance under Covered California:

> "The (geographic) area is also conservative, and some providers will not accept certain insurance because they don't want to appear to support Obamacare."

However, several patient advocates reported that women have had difficulty finding providers that accepted Medi-Cal or uninsured patients. One respondent noted Medi-Cal reimbursement rates as an issue contributing to narrow networks:

> "The decrease in Medi-Cal reimbursement rates for providers is posing a huge barrier for us. We see our network of referral providers diminishing on a pretty significant basis…that has been unprecedented."

The difficulty in finding a provider, particularly a specialist, who accepts Medi-Cal, can lead to undue delays in receiving treatment. County hospitals have long wait times for appointments, and the uninsured have very limited options. Furthermore, the limited number of providers who accept Medi-Cal can also lead to disparities in quality of care. For example, multiple respondents pointed out that Medi-Cal recipients have less access to cutting-edge treatments being explored at institutions such as the UCLA Medical Center or City of Hope.

This barrier is heightened for women on Medi-Cal, who may particularly have trouble finding oncologists that accept their plan, much less one that is located in a preferred, or conveniently located, facility. Providers further noted a challenge in identifying specialists for Medi-Cal patients, particularly plastic surgeons offering reconstructive surgery. One provider lamented the lack of choices for women in the program:

> "They don't have necessarily the freedom of choice to go, even it's difficult to get a second opinion with those insurances. So I would say that's probably one of the bigger barriers, at least in the state of California, is that for women under public insurance, it's not really explained to them how it works."

Among key informants, it was not only simply lacking insurance or underinsurance that was perceived as a barrier, but also the challenges of enrollment and authorization among insured women- both publicly and privately insured.

The insurance authorization process contributes to delays in care. A provider respondent said approvals for OncotypeDX, a genomic test that can help guide treatment decisions, can delay treatment up to a month and half. She noted that this is a new delay, as recently as 2014 the approvals were only taking two weeks. Barriers were less common with certain forms of treatment, namely surgery or chemotherapy. Consistent with our key informant interviews, a 2013 study of breast cancer patients in California found that the prolonged insurance authorization process led to delays in performing diagnostic tests, thus delaying treatment 3 months or more.[39]

The delays due to authorization have even driven some women with private insurance to seek care from safety net providers. A patient navigator reported that some women had given up waiting for authorizations for procedures with their regular doctors and had turned to the community clinic for quicker access to biopsies, mammograms or surgeries.

Providers were extremely familiar with issues in insurance approval processes, one specifically noting that the difference between the time from diagnosis to surgery can be 3-4 weeks for some, and nearly 2 months for others, particularly those on public programs. Another provider lamented about the bureaucracy of Medi-Cal plans: “when people are newly diagnosed with breast cancer, you know, ideally, they’re going to surgery within a two to four-week period and it can take me two to four weeks just to get their MRI approved. Never mind if they need more invasive testing like a PET-CT or an additional biopsy or whatever.”

This barrier is seen when uninsured women start the screening process in a public program, such as Every Woman Counts (EWC).

> “Some women are already being referred, then they start seeing an oncologist before even getting BCCTP [Breast and Cervical Cancer Treatment Program] eligibility and then all of the sudden once they get eligibility they have to transfer care to somebody else so there might be a break in continuity of care. There also might be what I’m aware of one of the barriers is that usually it’s very difficult to find who will really take the case, and once they become managed care patients or Medi-Cal patients, they really don’t know where to go and who would be the right physician for them. Sometimes they don’t want to go to certain physicians so it’s a barrier when it comes to finding the right oncologist because, for example, you may be referred to an oncologist that your primary physician knows but once you receive Medi-Cal it’s not the oncologist that takes Medi-Cal and that might be the problem. I think that the continuity of care might be a huge issue, especially for our population (in EWC).”

One provider noted:

> “I definitely would combine my program (EWC) with BCCTP and make it more comprehensive in public health and I would say that the treatment program, the 800 number, should be the number where the woman can get enrolled, at least presumptive eligibility. It will take a lot of different components to be established but I think that it would be great. Or at least that maybe EWC providers, Family PACT providers and BCCTP workers have equal access for patients’ enrollment.”

Providers identified other barriers caused by insurance, including the lack of coverage under some plans for reconstructive surgery, genomic testing, support services, and second opinions. Two respondents specifically called out challenges of insurance coverage regarding inpatient vs. outpatient services. One provider noted he has had to admit patients in order to get a biopsy covered. He stated that from a system perspective, “that’s not the most cost-effective way of doing it.”

Some of our key informant respondents worked with programs that helped uninsured and/or low-income patients sign up for insurance or public programs. This is perceived as helpful, but does not reach all populations.

One key informant noted that undocumented women-- in particular cannot get biopsy services covered, and many are not having the procedure since they cannot afford to pay out of pocket. Some are not aware of assistance through public or charitable programs.

Additionally, limitations and changes in access-enhancing programs interrupt continuity of care. For example, the length of public programs can become a barrier to completing treatment:

> “The (Breast and Cervical Cancer Treatment Program) BCCTP program is 18 months. One woman did not know she could get reconstruction under the program in that time.”

Providers can also suddenly opt out of programs:

> “Programs have limited shelf life…women go every two weeks or every so often to get (a specific) medicine. And then all of the sudden the doctor calls and says that medicine is not covered anymore and we’re not gonna see you.”

Treatment delays may also be created by the eligibility process for insurance coverage:

> “I had one lady….one of the ladies that she cleaned the house for was going to help pay, you know, the $1000 consultation fee here out of pocket. But we couldn’t take her out of pocket, because of her Medi-Cal being in process. And so she kind of felt at a loss, because she wanted to get this started but the Medi-Cal was taking a long time to process her application.”

Recommendations to Address Insurance/Health Benefits Barriers

- Review Medi-Cal provider rates and consider adjustments as necessary so they are more acceptable to providers. Women covered by Medi-Cal and the Breast and Cervical Cancer Treatment Program will face fewer delays in care if more providers can be incentivized to participate in the Medi-Cal program.
- Streamline authorization processes and meet a set target for turnaround time. Women face delays in care due to prolonged insurance authorization, thus failing to receive timely treatment.
- Evaluate health insurance plans for narrow provider networks specific to breast cancer diagnosis and treatment. Support investigation to quantify the extent to which narrow networks and the lack of providers accepting Medi-Cal lead to delays in care, and ultimately, adverse clinical outcomes.
- Extend benefits for the Breast and Cervical Cancer Treatment Program beyond 18 months. Due to delays in locating providers, authorization processes, and above all, the lengthy treatment course for some women (which can last 5 or more years), the BCCTP should be extended from 18 months to time deemed medically necessary to complete treatment.
- Allow participation in Medi-Cal and Covered California regardless of immigration or documentation status.
- Increase the patient’s awareness of a plan’s covered benefits for reconstructive surgery and second opinions.
- Ensure continuity of care from screening, diagnosis to treatment for uninsured women screened by the Every Women Counts Program, and who transition to breast cancer treatment from the Breast and Cervical Cancer Treatment Program.

Cost

A diagnosis of breast cancer is a catastrophic personal event that brings on stress and worry on how to pay for medical and non-medical bills associated with getting timely and appropriate care.

Even for women covered under private insurance, access to and the high cost of copayment for oncology treatment and drugs is a commonly discussed issue in the literature and in key informant interviews. While the ACA requires states to establish marketplaces that allow the public to easily compare different healthcare plans, comparing costs and coverage of plans is not simple and consumers appear to have trouble deciding which plans to enroll in when choices are given.[40]

Multiple reports have highlighted the cost of cancer drugs as a financial burden to patients receiving treatment. A study by the American Cancer Society Cancer Action Network (ACS CAN) revealed that cancer drugs are most often placed on the highest cost-sharing tier; in California, the coinsurance for the highest cost tier is 20%.[41] ACS CAN authors also observed significant gaps in the transparency of prescription drug coverage, and challenges to being able to compare and thus pick plans. In an analysis by Avalere Health looking at Covered California plans, they found plans tended to place all drugs used to treat complex diseases such as cancer on the highest formulary cost-sharing tier.[42] Recent reports by California Health Care Foundation also suggest costs of drugs likely affects access to care.[12,43]

Key informant interviews reinforced the studies that suggest low-income women who have insurance, but prohibitively high co-payments, face substantial barriers to care. One patient educator was succinct:

> "$100 is a lot of money if you have to go to the doctor three times a year."

In addition, cost of a second opinion is a major issue. There are some programs that offer free second opinions in an attempt to address these barriers, but as with other support services, they are not common, nor easy for patients to identify and locate.

Both patient educators and providers voiced similar opinions as patient educators about co-pays, second opinions, and uncovered procedures:

> "It doesn't matter what your income level is, when you have cancer, bills add up and priorities have to change."

and

> "There is so much hidden cost. I mean, just think about like well your copay is ten dollars, when you're being worked up for breast cancer you've got ten visits in two weeks, that's a hundred bucks that people don't have. It doesn't matter if you're insured if you can't afford to fill your car with gasoline."

and

> "You know the bottom line is that a lot of these drugs cost a fortune of money, some of the newer medicines cost more."

Providers felt more could be done educating patients on how to manage costs. One provider stated:

> "I wish that would be mandatory [to talk to a financial counselor] because there are lots of financial people to talk to after you get bills, but there's not a lot of people to talk to before you even get started."

Respondents also noted that low-income women are especially discouraged when, after receiving a free screening mammogram, discover that they face many expenses such as co-payments and deductibles to obtain follow-up tests and treatments after a suspicious mammogram. Women may not be aware of programs such as Every Woman Counts that exists to help women with costs of treatment and follow-up, however individuals must meet financial requirements to qualify (income at or below 200% of federal poverty level and be uninsured or not able to afford payments if insured).

Providers were also aware that a fear of costs can cause some patients to delay or forego care, and this is a particular cause of frustration. “Particularly in the cancer world, I think the thing that’s hardest for those of us that work in cancer to see is people who are going to die of their disease when they could have been cured…”

In addition to financial barriers related to paying for medical services, patients going through treatment may face additional cost barriers related to family care (if a patient needs household help during treatment), transportation to appointments, and/or childcare during treatment times.

One respondent was very pointed about the perception that insurance equated to access:

> “People who do not have a copayment seemed to have an easier time actually being able to go to their doctor’s appointment, *if* they have a sitter.”

On transportation, one patient educator noted:

> “Okay, we can educate women all we want. We can give them the brochure with the number. We can call for them and we can make an appointment for them, but if they can’t physically get there because of transportation, we’ve failed them in that way.”

A provider echoed this concern:

> “Sometimes (patients) don’t even have a bus fare, and I think that gets left out of some of the care models.”

And all of this may be more complicated for patients for whom lost time at work means lost wages. Respondents noted the difficult choices faced by some patients on paying for expensive treatments and medications:

> “She had to decide putting a roof over her and her children’s head and food on the table or pay for the Tamoxifen…and so, she wasn’t taking her Tamoxifen.”

Several providers worked for organizations that provided support services for patients. Most of the services were funded by the organization, many through grants or private philanthropic efforts, or on-site partnerships with organizations such as the American Cancer Society (ACS). Services include navigation, social workers, psychosocial aid through support groups or peer-to-peer connections, bodily care, and nutrition and exercise counselors. Some organizations were able to assist patients with transportation barriers through partnerships with local taxi companies or the ride-share company Uber. One medical director spoke of the importance of cooperation between providers and programs:

> “That’s a whole other conversation, this artificial division between social services and healthcare. I believe that division is maintained because it’s easier for us to think about but there should be far more cooperation between healthcare and social services to make sure that there’s some kind of concerted effort around the whole person to maintain health and well-being.”

Another commented:

> “People who are marginally housed, who are marginally employed who are trying to recover from surgery, keep their housing, you know, support their children, single mom’s trying to support small children recovering from surgery. I do see people who present with surgical complications that are essentially socially mediated; (they get) infections because they haven’t been taking their antibiotics, or they haven’t been taking care of their drains, or their wound is separating because they’ve been sic (hauling) their two-year-old around because there’s nobody to help take care of the baby. I see those things, not frequently but enough that I know it’s a problem. And those are very complex things. I mean I’m not sure that there are easy solutions to people’s complex and chaotic social environments, but it’s definitely something we see.”

However, there is concern about the availability and sustainability of funds for support services, with one provider at a private practice complaining that these ancillary costs of battling a disease were not reimbursed, “Well the problem with support services is that the government does not compensate you for it. I mean that’s just the reality of it. You know it comes out of our hide.”

One provider noted that there are also lasting impacts of breast cancer that require on-going support. While there are programs that may offer a mastectomy bra to patients during treatment, it will wear out and is expensive to replace. Insurance coverage for psychosocial support may also be limited, or nonexistent in some plans.

Recommendations to Address Costs Barriers

- Remove cancer drugs that are recommended by national clinical guidelines from the highest tiers. Drugs that are cited as standard of care, e.g. recommended by the National Comprehensive Cancer Network, should be removed from the highest tiers (and thus highest cost-sharing).
- Provide financial assistance for co-payments and deductibles for breast cancer diagnosis and treatment services. Such assistance is particularly needed for women whose incomes are low enough to qualify for subsidies for Covered California premiums.
- Provide financial assistance for non-medical costs, including transportation, childcare, and lost wages.
- Provide tools, information and or financial counselors for consumers to make informed choices, including cost calculators, complete lists of all covered breast cancer drugs, up-to-date formularies which includes information on tiers and restrictions on drug access,

and up-to-date and complete provider directories and information on in and out of network use of providers and costs.
- Consider health system reform cost containment strategies that increase affordability of breast cancer care.

Individual and Cultural Characteristics

Sociodemographic factors also lend themselves to barriers experienced by breast cancer patients. These include personal traits such as employment/economic situation, personal support system and educational attainment, as well as lifestyle choices. Individuals are also impacted by their racial/ethnic identity and affiliation with cultural communities.

In the peer-reviewed literature on barriers to breast cancer care, a number of descriptive studies on the disparities in breast cancer incidence, mortality and quality of care by race/ethnicity and socioeconomic status. [3,34,35,54-58] While racial/ethnic differences in breast cancer mortality may very well be related to tumor characteristics, aggressiveness of the cancer, and biologic response to treatment, disparities may also be attributed to differences in stage at diagnosis and the quality of breast cancer care received. Results of studies conducted among women from four racial/ethnic groups (African American, Asian American, Latina, and non-Latina White) in the California Breast Cancer Survivorship Consortium suggest that even after adjusting for age, tumor characteristics, and lifestyle, compared with non-Latina Whites, the breast cancer-specific mortality is higher for African Americans, lower for Latinas, and lowest for Asian Americans.[59,60] Compared to other racial/ethnic groups, African American women in California are the most likely to present at late stage of diagnosis. Nonetheless, African American women have the highest breast cancer screening rates (African American 67%, Hispanic 56%, non-Hispanic white 63%, Asian/PI 55%),[61] which suggests that screening is not driving stage of diagnosis. It is possible that other barriers, such as those stemming from insurance status, may impede African American women from receiving a timely diagnosis and timely access to treatment.

Although some barriers to receiving breast cancer care such as lack of appropriate health insurance are universal, other barriers may be specific to a particular cultural group. The literature retrieval covering the period 2013-2015 generated a few papers on the impact of culture on the breast cancer experience among Asian Americans,[2,62] Hmong immigrants,[63,64] Latinas,[65,66] Jordanian- and Palestinian American women,[67] however these papers were largely concerned with perceptions regarding screening and survivorship. There were, however, key informant interview responses that point to cultural barriers to breast cancer treatment. For example, several respondents noted that there is a lack of awareness, as well as myths and misconceptions, about breast cancer and treatment in many ethnic minority communities. One community educator heard women from a particular culture say that they believed mammograms *caused* breast cancer. A few providers serve in communities with enclaves of the population who prefer non-traditional, alternative medicine. Adhering to those preferences may cause patients to delay or completely forego modern medical solutions.

Across several cultures, perspectives on cancer is linked to fatalistic beliefs.[68] Women from these cultures may perceive cancer as a death sentence, and they simply accept it or may not even want to know when it is present. They hear stories from other women who have had chemotherapy about all of the negative aspects to the process.

Our respondents also noted that in some cultures, health is just not discussed. Consequently, women may be unaware that they are at increased risk for breast cancer due to family history.

This can be particularly evident to primary care physicians who first detect a health problem and refer patients to others for further care. Primary care providers reported having some patients return without having seen other providers (specialists), saying they had no one who could take time from work to give them a ride, or no one to take over home care duties during treatment. Similarly, respondents are aware that many patients experience guilt in taking time away from their own responsibilities, and may delay treatment seeking due to fear of being a burden on their family. One provider shared:

> "Some take care of family members and they are caregivers and so there's an inherent guilt, not sure who else is going to help them take care of their family member who has a stroke."

Some respondents noted specifically that there seemed to be a lack of familiarity and understanding of the Family Medical Leave Act (FMLA). Several providers hear patient concerns about taking the time from work themselves to undergo treatment, much less having an eligible family member miss days at work. One social worker respondent shared her efforts to educate patients:

> "I spend a lot of time talking to families about FMLA, about the medical leave that's available to them, you know, for the 12 weeks of guarantee because lots of times you know they're not aware that they can take time off to take a loved one to an appointment or that that is covered and that they have that as part of their protection and I think once I start explaining that on a regular basis to some of my patients' families then it was like, oh, we could do this."

Our findings are consistent with substantial prior research, conducted in California and throughout the country that has found racial/ethnic differences in attitudes towards breast cancer and perceived barriers to accessing breast cancer services.[69-75]

In our literature retrieval, we found that in a study of Latinas with abnormal mammograms, ethnic differences in communication needs and experiences with health-care providers appeared to contribute to delays in obtaining care.[76] While Latinas and Non-Latina White women differed in how they rated their comprehension of abnormal results and follow-up care, both groups felt empathic communication was important. Patient-provider interaction/communication was found to be an important predictor of well-being and quality of life in large longitudinal study of women enrolled in the California Breast and Cervical Cancer

Treatment Program examined 921 low-income women with breast cancer. Better patient perceptions of patient-physician interactions were found to be associated with better mental well-being and quality of life. Patients reporting having received more information from providers, reported better mental well-being and quality of life; patients reporting having received more emotional support from their doctors reported better well-being; and, patients reporting having received more social support reported having better quality of life.

Our key informants shared examples of how cultural differences impact provider interactions with patients, above and beyond linguistic differences. One respondent representing an organization that focuses on Black women noted she often heard that her clients do not have providers that talk to them in a language (culturally) that they can understand. She reported this was also an issue for Asian American and Pacific Islander women. Beyond language barriers, many women who are ethnic minorities would see a provider from their same racial/ethnic group, which they feel can improve communication and satisfaction with care.

Both key informants and the reviewed literature identified extensive barriers experienced by women with limited English proficiency. These findings were considered so substantive as to merit a separate discussion, presented below (see *Language*).

Respondents described the anxiety that goes beyond the fears associated with diagnosis, treatment, and affordability. Fear and stigma in certain cultures cause women to keep diagnosis to themselves, adding to their personal burden. Women who are caregivers and feel a cultural obligation to take care of others also fear of what happens to their families. Many face questions of disclosure Keeping a breast cancer diagnosis private can be very important in some communities, and women with this perception may be willing to take long bus rides to see a provider that is from outside of their cultural and geographical community. Respondents reported that women from some cultures feel there is a shame in being a burden and try to avoid burdening others with their breast cancer diagnosis. These fears can lead to delays in seeking care and locating a provider for breast cancer treatment.

Breast cancer patients have care needs that are outside their course of treatment. While some services such as support groups are not covered by insurance, others services might be. One provider specifically noted that she has specific language needed to get wigs covered by Medi-Cal. But some experience cultural barriers to seeking and utilizing support services. Just as patients may prefer providers that they can relate to culturally, patients feel more comfortable identifying with a navigator of the same culture.

> “People may be more inclined to follow through…if they would have someone who is from their own community who speaks (culturally) like them.”

Similarly, women are most comfortable joining a support group with women who look like they do, and speak the same language (see *Language*). Several respondents noted the need for more culturally appropriate services.

> "Some people tell me that the support groups didn't look like them, so they kind of felt like they didn't belong, and they didn't go back."

While barriers to support services were not often associated with insurance status, providers discussed the barriers that were particular to socially-disadvantaged women:

> "Educated and empowered women will often access those services whether the cancer program offers them, and if it doesn't then they'll go find them someplace else, right? So, some of my patients are seeing the naturopaths, and chiropractors, and getting lymphatic cranial sacral massages every day, and they have all that tuned up. A lot of my low income and non-English speaking patients, we have trouble even getting them in to see the nutritionist, and maybe they don't understand why it's important or they don't have time or they're working or they don't have a ride or, you know, I think it can be hard to, it can be hard to compensate for the fact that people who have tremendous social stress don't have a lot of extra bandwidth for those services, even when they're available."

Geography does not eliminate barriers to care, it may just change the type of barriers most prevalent. It is well established that rural cancer patients across the U.S. face challenges in receiving oncology care, stemming largely from the limited availability of cancer treatments and cancer support providers, transportation and financial limitations, and poor access to clinical trials.[77] Rural women have also been shown to be less likely to receive radiation therapy for breast cancer compared to their urban counterparts.[78,79]

While our key informant interviews commented that rural areas often have a small number of providers and fewer transportation options for access both care and support services, respondents from urban areas - where there are a higher number of providers - reported similar barriers. Large urban areas have more options (like specialists can accommodate multiple languages) and better public transportation systems, but can be more difficult to navigate than less densely populated communities. One respondent noted that if a patient "doesn't have transportation and the doctor's office is on the other side of town, even though they live in LA, it's still an hour or two hours away."

Providers also noted challenges that distance created for some of their patients. Often, larger hospitals and those connected to academic centers are sought for second opinions. A provider in Santa Monica noted she has people from Bakersfield, more than 100 miles away, seeking second opinions. Providers also note that at times the referral system in an insurance plan with narrow networks sends patient's great distances:

> "…we do care for people that come from as far away as 150 miles away, even when they're geographically closer to a Stanford or UCLA, the referral pattern is this way just because culture or farming communities and we take care of that."

Still, inequities in cancer treatment may in part be due to where patients go to get care. Geographic variation in breast cancer surgery rates has been examined by the California Health Care Foundation (CHCF).[80] CHCF found breast cancer patients in several California communities undergo mastectomy, lumpectomy, radiation, and other treatments for breast cancer at rates notably higher or lower than other communities and the California rate.

Recommendations to Address Individual and Cultural Barriers

- State programs such as the Office of Health Equity should provide resources and programs to encourage cultural competency training for health providers on breast cancer care.
- Design and implement payment models that reward providers and larger health delivery systems that provide culturally appropriate services to patients who need them.
- Provide additional funds to breast cancer screening programs, such as Every Woman Counts, to conduct community education and outreach to address fears and stigma regarding breast cancer diagnosis and treatment.
- Increase awareness of Family Medical Leave Act (FMLA) that may provide time off for employees to obtain treatment or to recover from treatment.
- Support telehealth services to improve a patient's geographic access to providers and integrate technologies that increase the provider's ability to evaluate the patient.

Language/Health Literacy

The literature suggests patients may experience challenges understanding the communication they receive from their health care provider, made worse when English is not their first language.[76,82-93] Even patients who are proficient in English (or the language of their health care provider) may not understand complicated, technical medical terms and may have low health literacy. Health literacy, as defined by the US Department of Health and Human Services, is " the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions."[81] These patients may have difficulty understanding instructions from the doctor, and medication instructions from the pharmacist. Even some patients who can verbally understand instructions may have difficulty reading written instructions from a health care provider or follow-up appointment notifications sent through the mail. In addition, printed educational materials are often not available for all of the diverse immigrant communities of California. This is a challenge given interpretation is only available at the doctor's office and cannot help patients overcome barriers to understanding written materials once at home.

Even within the doctor's office, interpreter service has its challenges. Starting in 2009, California's Health Care Language Assistance Act went into full effect, requiring health insurers (except self-insured health plans) to cover translation services, at least by telephone, while visiting their doctor, pharmacist, ophthalmologist, and dentist. Medi-Cal, Medicare and most health plans are subject to that law, thus key informants did not call out any differential barriers by insurance status. However, an analysis of the California Health Interview 2015 points to differential language service need by insurance status: among women age 30 and older, over half of the uninsured and about 40% of women covered by Medi-Cal are limited English proficient (LEP), compared to under 10% of the commercially insured who are LEP (askchis.ucla.edu). Although these estimates are not limited to women who have been diagnosed by breast cancer, these population estimates suggest that language assistance services are most needed for women who are uninsured or covered by Medi-Cal.

Moreover, despite California's language assistance mandate, many study respondents felt there was a lack of interpreters overall, and indicated that interpreters were often not available for the full interaction between a patient and a provider's office. For example, although an interpreter can be called in for the brief period when the patient actually sees the physician, interpretation is often not available for interactions with the front office staff when in the waiting room, or for making clinic appointments, or completion of insurance paperwork. Clinic staff often do not have the language skills to fill in when interpreters are not available and in-person interpretation is not available in all languages (for example, Hmong). One respondent had heard a patient was told by a doctor to change providers in order to access an interpreter.

For LEP patients who are likely to be uninsured or on Medicaid, community health centers (CHCs) may provide the culturally and linguistically competent services that they need. Yet, CHCs function in a primary care setting and breast cancer treatment is delivered in hospital and specialty settings. Thus, CHCs may at times take on more of the uncompensated language bridging role for their LEP patients across the continuum of cancer care. One primary care provider serving predominantly a low-income Asian population noted that while her clinic had staff speaking multiple languages, they had only one local oncology option for referring patients whose primary language was Mandarin. Some respondents who worked in practices that had extensive in-office language services (one provider noted 12 at her organization), expressed concerns about referring their patients needing language services to facilities that were not co-located, since then they would lose control over the ability to make sure patients received services.

LEP patients may also not be aware of their right to an interpreter and thus rely on family members to bridge the communication with their doctors. In some cases, key informants noted that cultural and language issues can clash. Providers shared that children in Hmong and Middle-Eastern households may be resistant to sharing a negative diagnosis with their parents, causing doctors to feel caught between their obligation to the patient and the sensitive nature of the family interactions. Cultural/family dynamics issues aside, because of quality and safety risks, the ACA (section 1557) includes a final rule that requires plans offer qualified interpreters to their patients, and bans minor children and family members to serve as interpreters except in emergency situations. Knowledge and compliance of this final rule could reduce language barriers to cancer care.

Many resources available through public programs, support groups, and online are limited to English, and perhaps Spanish. This presents a barrier to even searching for support services or resources on eligibility for public insurance or public programs such as the BCCTP. One provider also noted that support groups are not available for less common languages, and suggested making smaller peer-to-peer connections would be extremely valuable. "They're not going to come to an English-speaking support group, we do some peer-to-peer matching so that people who are non-English speaking…we try to match them with a linguistic speaker, somebody in their language group who's had a similar experience and try to facilitate them at least having a peer support person in addition to the support staff."

Recommendations to Address Language Barriers

- Require coverage or reimbursement for interpretation and translation services that extend beyond the visit, to include the entire span of the care experience such as making appointments, patient education, and support services.
- Support the integration of language services with patient navigation services through the promotion of programs that provide language training to navigators and enhance the availability of translation services to navigators.
- Expand the number of providers who are bilingual.
- Enforce compliance of the law of the Health Care Language Assistance Act and the ACA section 1552 across all health plans especially Medi-Cal plans that serve a disproportionate number of LEP patients.
- Encourage health plans to convey the right to an interpreter and to facilitate in-language peer-support programs for LEP patients.
- Support the primary care safety net's efforts in language bridging services across the breast cancer care continuum in specialty and hospital care.
- Establish programs for limited-English proficient women to increase their awareness of eligibility for public insurance programs and public programs (BCCTP) for breast cancer care.

Concerns about a Repeal of the Affordable Care Act (ACA, Obamacare)

In 2017, under the new presidential administration, federal legislation regarding changes to the ACA, and state policy actions in response, may disrupt coverage for many Californians. Changes in the healthcare landscape may further increase barriers and challenges to accessing timely and appropriate breast cancer care. Due to the timing of the second round of interviews, health care providers were asked specifically for their perceptions regarding anticipated impacts of the federal proposals. We note that some interviews occurred prior to the House bill vote and all of the interviews occurred prior the CBO scoring of the House bill.

Under the ACA breast cancer care was impacted in several ways. The bill mandated that insurance plans cover preventive screenings with no cost-sharing, removed lifetime coverage limits, and forbid plans to refuse coverage or impose increased costs for pre-existing conditions, crucial for any woman who experiences recurrences in breast cancer. Most respondents felt the removal of provisions for the individual mandate and rules requiring plans to cover pre-existing conditions would be damaging to the whole health care system.

> "The whole purpose of the mandate as I understand it is to make sure the system is paid for. If young people, you know, specifically young people, people who feel invincible, don't pay into the system, then the system would collapse because the system would have to be held up by people who are sick…. (and) a system that allowed insurers to reject and at best charge extra to people with preexisting conditions which prevented them from moving around and finding the best health care was ridiculous…..So these changes, you know, they're going to send us back to the dark ages of healthcare"

Two of the 11 providers did expect little to no impact on care and access for breast cancer care, feeling California's generous public programs provide adequate, even generous, care. One provider shared this assessment: "I don't think much will happen, honestly. I don't. They got access to care beforehand and they'll get access to care afterwards. I mean that's just a reality. They show up to the emergency room, they get treated and they get referred. I mean before the ACA I took care of a lot of people pro bono, you know, and drug companies provided medicines. Sometimes it was even more timely."

The remaining provider participants voiced concerns about the levels of uninsured increasing, as well as the number of patients seeking care in emergency rooms (ER) and safety net facilities.

> "I trained at L.A. County and at L.A. County, you know, people would walk in, this was before Obamacare, I was down there in 2008, 9, and 10, you know, people would walk in off the streets with these fumigating tumors, you know, infected and bleeding, well I knew there was something wrong but I didn't have insurance.

> And I don't know how many times I've heard that refrain in my career, it's just sickening."

And

> "A few years ago when there were more uninsured patients, like before the Affordable Care Act, I think one big barrier was access at that time, like wait times to see specialists were higher because we had to send more patients to Highland and there were fewer specialists accepting – there were fewer patients with Medi-Cal so there were fewer specialists you could send them to."

And

> "I think 90 percent of our patients who are insured, publicly-insured, would go back to an uninsured status which means that they would end up getting the county insurance again which, you know, if you're siphoning everyone towards the county there, you're going to get increase in your ER admissions, right, ER visits. You're going to have decreased, just access to primary care, decreased access to specialists that they would potentially need to see. I mean there's medications that they can't even continue taking (if they become uninsured again."

Most providers agreed that reverting to a system similar to that before the ACA would significantly increase the number of uninsured patients, which would cascade into other barriers increasing as well as public programs, and the providers that serve them, absorb more patients.

Summary and Conclusion

While medical technology and clinical treatment of breast cancer has improved significantly over the years, barriers to cancer care still vex the healthcare system and contribute to delays between each step along the breast cancer care continuum and may even block a person from receiving a specific service/treatment, or a prematurely end access to a service/treatment. This report examined barriers and challenges to accessing breast cancer care in California by insurance status using a multi-method approach, including a synthesis of the peer reviewed literature, news media, reports and policy briefs, social media, a legislative scan, and a series of key informant/stakeholder interviews. This assessment synthesized the findings from these differing yet interlinked sources of information, producing the themes as well as specific barriers identified as the most significant for women with breast cancer in California.

After collecting data on the key barriers to breast cancer treatment faced by women in California, the barriers were organized into common themes or categories. Five themes were identified: (1) Health System Fragmentation, (2) Insurance/Health Benefits, (3) Cost, (4) Individual and Cultural Characteristics, (5) Language/Health Literacy. Using this organization structure, the key informant interviews – leaders in patient education, support, and navigation and oncology providers– offered a wealth of insight regarding recommendations for improvement. We provide specific policy recommendations for each of these themes above that can be used to guide efforts of policy-makers to improve timely access to breast cancer care among all women in California. We provide below in Table 2 policy insights that hone in on the issues of key concern identified in this report for the five identified themes by insurance type. We hope that potential solutions can be found in policy remedies that address these key issues and affect global changes at the health care system level and assistance for nonclinical support services for breast cancer patients.

Table 2. Policy Insights by Theme and Insurance Type

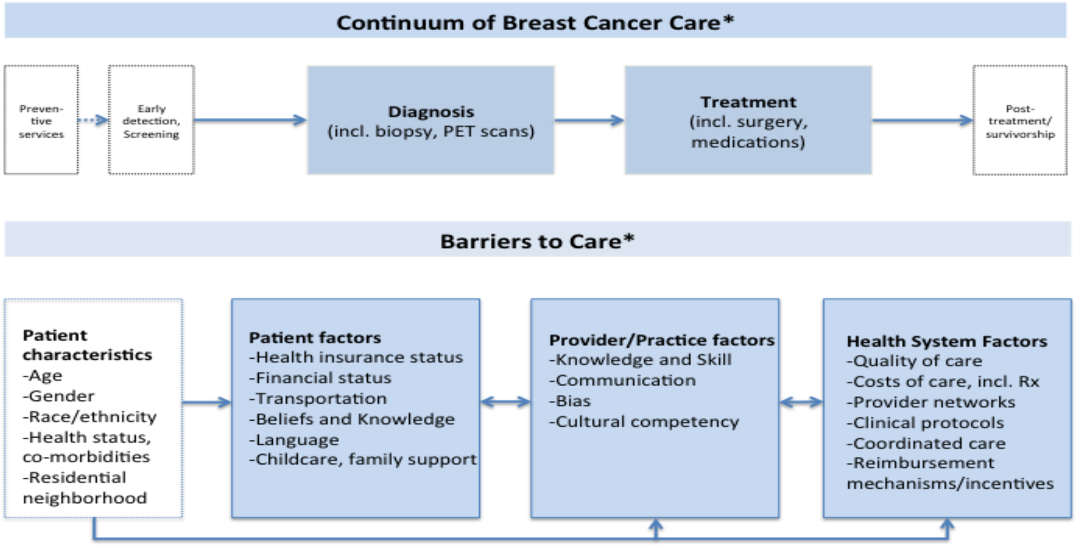
Themes	Uninsured & underinsured	Medi-Cal	Covered California	Private/commercial insurance
Health System Fragmentation/Navigation	State policy that bolsters the preservation of coverage for the uninsured given the uncertainty of the ACA;	State policy that preserves the Medi-Cal coverage levels that currently exist under the ACA & policy focus on specifically improving the quality of care provided to Medi-Cal enrollees to address disparities that currently exist	State policy targeted to the ensuring subsidy support for Covered California and ensure low income population has access to navigation and support services	Provide navigation services, reimbursement for these services, and promotion of system integration
	State policy to mandate navigation services, reimbursement for these services, and consideration of payment models that encourage care coordination			
Insurance/Health Benefits	Policy mandates to extend program benefits (such as BCCTP) to accommodate full course of treatment and policies to strengthen the link between screening, diagnosis, and treatment	Adjust Medi-Cal provider rates to increase the number of providers accepting Medi-Cal	Policies that limit narrow provider networks, with focus on improving network for oncology care	Increase the patient's awareness of a plan's covered benefits for reconstructive surgery and second opinions.
	Policies that streamline authorization processes and meet a set target for turnaround time. Women face delays in care due to prolonged insurance authorization, thus failing to receive timely treatment			
Cost	State policy that bolsters the preservation of coverage for the uninsured given the uncertainty of the ACA; Invest in programs to improve	Provision of financial assistance for non-medical costs, including transportation, childcare, and lost wages	State policy targeted to the ensuring subsidy support for Covered California; Policies that restrict placement of essential oncology drugs on the highest cost tier and other	Policies to reduce the burden of costs to enrollees from treatment and drugs, particularly in high deductible health plans Provision of decision support

Themes	Uninsured & underinsured	Medi-Cal	Covered California	Private/commercial insurance
	awareness of financial assistance programs targeted to low income, uninsured		policies that address high costs of oncology drugs	tools to consumers regarding costs of care, for example cost calculators, lists of all covered breast cancer drugs, up-to-date formularies & information on tiers and restrictions on drug access, provider directories and information on in and out of network use of providers and costs
	Consider health system reform cost containment strategies that increase affordability of breast cancer care.			
Individual and Cultural Characteristics	Support programs that increase awareness of the availability of services to undocumented women to ensure timely treatment	Establish funding for support service programs, for example programs providing transportation and childcare to women undergoing cancer treatment	Support telehealth services to improve a patient's geographic access to providers and integrate technologies that increase the provider's ability to evaluate the patient	Design and implement payment models that reward providers and larger health delivery systems that provide culturally appropriate services to patients who need them
	State programs such as the Office of Health Equity should provide resources and programs to encourage cultural competency training for health providers on breast cancer care.			
Language/Health Literacy	Establish programs for limited-English proficient women to increase their awareness of eligibility for public insurance programs and public programs (BCCTP) for breast cancer care	Incentivize providers more to provide language support and other culturally appropriate services where needed; integrate with payment for in-language navigation services	Require coverage or reimbursement for interpretation and translation services that extend beyond the visit, to include the entire span of the care experience such as making appointments, patient education, and support services	Support programs that expand the number of providers who are bilingual, and incentivize the use of language services
	Enforce compliance of the law of the Health Care Language Assistance Act and the ACA section 1552 across all health plans especially Medi-Cal plans that serve a disproportionate number of LEP patients.			

Appendix A. Literature Synthesis Methods

Conceptual Framework

A conceptual framework was developed to illustrate and organize the different types of barriers that might limit access to breast cancer diagnostic and treatment services. Figure 1 illustrates this conceptual framework, juxtaposing the breast cancer care continuum from prevention/screening to treatment initiation and post-treatment care with the barriers and delays that might limit access to breast cancer diagnostic and treatment services at the individual, provider, and system levels. While barriers may occur anywhere along this continuum of breast cancer care that spans from prevention to rehabilitation, our review focuses on the care that occurs from diagnosis of the cancer to treatment. We thus exclude preventive services, early-detection/screening and post-treatment and rehabilitation in this report.



*This report focuses on the blue shaded boxes- diagnosis and treatment along the continuum of care and patient, provider, health system barriers

Figure 1. Conceptual Framework of Breast Cancer Barriers for Diagnosis and Treatment

Patient level characteristics, such as race/ethnicity, age, and comorbidities influence not only what we call patient-level barriers, such as language, financial status, access to transportation, family support, but likely also impact the provider/practice and health system barriers. For example, patient's ethnicity is associated with provider communication style[2] and an individual's residential neighborhood is associated with quality of care.[3] Barriers may contribute to delays between each step along the breast cancer care continuum, complete lack of access to a service, or a premature end to treatment. While some patient level characteristics are unchangeable (e.g., demographics), policies and programs can be used to overcome many barriers. Thus, our discussions below focus less on research documenting disparities, and more on research and observations identifying modifiable barriers that can be used to inform the development of policies and programs to improve access to breast cancer care in California.

MeSH and Keywords Search

As part of our review, we included both the peer-reviewed literature as well as non-peer reviewed sources. Utilizing the methodology used to generate reviews of medical effectiveness by the California Health Benefits Review Program (http://chbrp.ucop.edu), a literature search was performed to retrieve publications that described any aspect of barriers to breast cancer care. The conceptual framework (Figure 1) helped identify search terms (see list of terms). The literature search was limited to articles published in English from 2013-2015. The following databases that index peer-reviewed journals were searched: PubMed (MEDLINE), the Cochrane Library, and Web of Science. The list below includes all search terms used for the review – we used search strategies that included MeSH terms, which generate specific and very targeted responses, along with keyword searches that cast a wider net and can capture the most recent papers which MeSH searches may miss. All results were filtered to include only papers in English with human subjects. Because there were only a handful of California-based studies, U.S. based studies were also included in the literature pull. We also reviewed the non-peer reviewed material for our specified time frame retrieved from LexisNexis Academic database, Google News Archives, and Google (reports and news sources).

MeSH terms used to search PubMed	Keywords
Breast Neoplasms (all searches included this MeSH term)	Breast cancer
Used one by one with AND “breast neoplasms”)	**Used one by one with AND “breast cancer” AND “access to care”)**
Costs and Cost Analysis	Barriers to care
Patient Protection and Affordable Care Act	Access to care
Health Expenditures	Delay in care
Drug Costs	Affordable Care Act*
Health Services Accessibility	Health reform
Community Networks	Network adequacy
Consumer Participation	Narrow network
Insurance Coverage	Costs of care
Communication Barriers	Prescription drug costs
Patient Navigation	Cost sharing
Social Determinants of Health	Out of pocket costs
Cultural Competency	Patient costs
Social Discrimination	Access to drugs
Racism	Oncology drugs
Ageism	Oncology support
Sexism	Formularies
Registries	Registry tracking
United States	Race
California	Ethnicity
	Gender
	California

Appendix A.1 Citation List of Literature (2013-2015) Identified for Abstraction

Author	Title	Journal	Year	Level	Geography
Adepoju L, Wanjiku S, Brown M, et al.	Effect of insurance payer status on the surgical treatment of early stage breast cancer: data analysis from a single health system	JAMA Surg	2013	Patient-level, System-level	Michigan
American Cancer Society	Cancer Facts & Figures 2016.	ACS	2015	Patient-level	USA
American Cancer Society Cancer Action Network	ACS CAN Examination of Cancer Drug Coverage and Transparency in the Health Insurance Marketplaces	ACS CAN	2015	System-level	USA
Ashing-Giwa, K.; Rosales, M.; Lai, L.; Weitzel, J.	Depressive symptomatology among Latina breast cancer survivors	Psychooncology	2013	Patient-level	California
Avalere Health	Exchange Benefit Designs Increasingly Place All Medications for Some Conditions on Specialty Drug Tier	Avalere Report	2015	System-level	USA; California
Bestvina, C. M.; Zullig, L. L.; Yousuf Zafar, S.	The implications of out-of-pocket cost of cancer treatment in the USA: a critical appraisal of the literature	Future Oncol	2014	Patient-level, System-level	USA
Bickell, N. A.; Paskett, E. D.	Reducing inequalities in cancer outcomes: what works?	Am Soc Clin Oncol Educ Book	2013	Patient-level, Provider-level, System-level	USA
Bourdeanu L, Luu T, Baker N, Swain-Cabriales S, Chung CT, Mortimer J, Hurria A, Helton S, Smith D, Ferrell B, Juarez G, Somlo G.	Barriers to treatment in patients with locally advanced breast cancer.	J Natl Compr Canc Netw.	2014	Patient-level; Provider-level; System-level	California
Bradley, C. J.; Wilk, A.	Racial differences in quality of life and employment outcomes in insured women with breast cancer	J Cancer Surviv	2014	Patient-level; System-level	Virginia
Bradley, C.J.	Economic recovery: A measure of the quality of cancer treatment and survivorship?	J Cancer Surviv	2014	Patient-level	USA
Brot-Goldberg Z, Chandra A, Handel B, Kolstad J.	What Does a Deductible Do? The Impact of Cost-Sharing on Health Care Prices, Quantities, and Spending Dynamics.	NBER Working Paper No 21632 2015.	2015	Patient-level; System-level	USA
California Cancer Registry	California: Cancer Facts and Figures 2014	CCRC	2015	Patient-level	California

Author	Title	Journal	Year	Level	Geography
California Healthcare Foundation.	Medi-Cal Versus Employer-Based Coverage: Comparing Access to Care	CHCF	2015	System-level	California
California Healthcare Foundation.	Early-Stage Breast Cancer Treatment in California: A Close-Up of Geographic Variation	CHCF	2013	System-level	California
California Healthcare Foundation.	California Employer Health Benefits: Rising Costs, Shrinking Coverage:	CHCF	2015	System-level	California
Dominick, S. A.; Natarajan, L.; Pierce, J. P.; Madanat, H.; Madlensky, L.	Patient compliance with a health care provider referral for an occupational therapy lymphedema consult	Support Care Cancer	2014	Patient-level	California; San Diego
Dowling, E. C.; Chawla, N.; Forsythe, L. P.; de Moor, J.; McNeel, T.; Rozjabek, H. M.; Ekwueme, D. U.; Yabroff, K. R.	Lost productivity and burden of illness in cancer survivors with and without other chronic conditions	Cancer	2013	Patient-level, System-level	USA
Dusetzina, S. B.; Muluneh, B.; Khan, T.; Richards, K. L.; Keating, N. L.	Obstacles to affordable cancer treatments	N C Med J	2014	System-level	USA
Flores, Y. N.; Davidson, P. L.; Nakazono, T. T.; Carreon, D. C.; Mojica, C. M.; Bastani, R.	Neighborhood socio-economic disadvantage and race/ethnicity as predictors of breast cancer stage at diagnosis	BMC Public Health	2013	Patient-level, Residential neighborhood	California
Gabitova, G.; Burke, N. J.	Improving healthcare empowerment through breast cancer patient navigation: a mixed methods evaluation in a safety-net setting	BMC Health Serv Res	2014	Patient-level, Provider-level (Patient Navigation)	California
Gomez SL, Shariff-Marco S, DeRouen M, et al.	The impact of neighborhood social and built environment factors across the cancer continuum: Current research, methodological considerations, and future directions.	Cancer	2015	Patient-level, Residential neighborhood	USA
Gorey, K. M.; Luginaah, I. N.; Holowaty, E. J.; Zou, G.; Hamm, C.; Balagurusamy, M. K.	Mediation of the effects of living in extremely poor neighborhoods by health insurance: breast cancer care and survival in California, 1996 to 2011	Int J Equity Health	2013	System-level	California
Grant SR, Walker GV, Koshy M, et al.	Impact of Insurance Status on Radiation Treatment Modality Selection Among Potential Candidates for Prostate, Breast, or Gynecologic Brachytherapy.	International journal of radiation oncology, biology, physics	2015	Patient-level, System-level	USA
Gunn, C. M.; Clark, J. A.; Battaglia, T. A.; Freund, K. M.; Parker, V. A.	An assessment of patient navigator activities in breast cancer patient	Health Serv Res	2014	Patient-level (Patient	USA

Author	Title	Journal	Year	Level	Geography
	navigation programs using a nine-principle framework			Navigation)	
Haeder SF, Weimer DL, Mukamel DB.	California hospital networks are narrower in Marketplace than in commercial plans, but access and quality are similar.	Health Affairs	2015	System-level	California
Hahn, E. E.; Ganz, P. A.; Melisko, M. E.; Pierce, J. P.; von Friederichs-Fitzwater, M.; Lane, K. T.; Hiatt, R. A.	Provider perceptions and expectations of breast cancer posttreatment care: a University of California Athena Breast Health Network project	J Cancer Surviv	2013	Provider-level (perceptions)	California
Haji-Jama S, Gorey KM, Luginaah IN, Balagurusamy MK, Hamm C.	Health insurance mediation of the Mexican American non-Hispanic white disparity on early breast cancer diagnosis	Springerplus.	2013	Patient-level, Residential neighborhood	California
Hershman, D. L.; Tsui, J.; Meyer, J.; Glied, S.; Hillyer, G. C.; Wright, J. D.; Neugut, A. I.	The change from brand-name to generic aromatase inhibitors and hormone therapy adherence for early-stage breast cancer	J Natl Cancer Inst	2014	Patient-level	USA
Hershman, D. L.; Tsui, J.; Wright, J. D.; Coromilas, E. J.; Tsai, W. Y.; Neugut, A. I.	Household net worth, racial disparities, and hormonal therapy adherence among women with early-stage breast cancer	J Clin Oncol	2015	Patient-level	USA; black/white comparison
Hutchins, V. A.; Samuels, M. B.; Lively, A. M.	Analyzing the affordable care act: essential health benefits and implications for oncology	J Oncol Pract	2013	Patient-level, Provider-level, System-level	USA
Jagsi, R.; Pottow, J. A.; Griffith, K. A.; Bradley, C.; Hamilton, A. S.; Graff, J.; Katz, S. J.; Hawley, S. T.	Long-term financial burden of breast cancer: experiences of a diverse cohort of survivors identified through population-based registries	J Clin Oncol	2014	Patient-level	Los Angeles, Detroit
Kapoor, A.; Battaglia, T. A.; Isabelle, A. P.; Hanchate, A. D.; Kalish, R. L.; Bak, S.; Mishuris, R. G.; Shroff, S. M.; Freund, K. M.	The impact of insurance coverage during insurance reform on diagnostic resolution of cancer screening abnormalities	J Health Care Poor Underserved	2014	Patient-level (Patient Navigation)	Massachussets
Katz, M. L.; Young, G. S.; Reiter, P. L.; Battaglia, T. A.; Wells, K. J.; Sanders, M.; Simon, M.; Dudley, D. J.; Patierno, S. R.; Paskett, E. D.	Barriers reported among patients with breast and cervical abnormalities in the patient navigation research program: impact on timely care	Womens Health Issues	2014	Patient-level (Patient Navigation)	USA
Keegan, T. H.; Kurian, A. W.; Gali, K.; Tao, L.; Lichtensztajn, D. Y.; Hershman, D. L.; Habel, L. A.; Caan, B. J.; Gomez, S. L.	Racial/ethnic and socioeconomic differences in short-term breast cancer survival among women in an	Am J Public Health	2015	Patient-level, Residential neighborhoo	California; Northern

Author	Title	Journal	Year	Level	Geography
	integrated health system			d	
Kurian, A. W.; Lichtensztajn, D. Y.; Keegan, T. H.; Leung, R. W.; Shema, S. J.; Hershman, D. L.; Kushi, L. H.; Habel, L. A.; Kolevska, T.; Caan, B. J.; Gomez, S. L.	Patterns and predictors of breast cancer chemotherapy use in Kaiser Permanente Northern California, 2004-2007	Jama	2014	Patient-level	California; Northern
Kurian, A. W.; Lichtensztajn, D. Y.; Keegan, T. H.; Nelson, D. O.; Clarke, C. A.; Gomez, S. L.	Use of and mortality after bilateral mastectomy compared with other surgical treatments for breast cancer in California, 1998-2011	Jama	2014	Patient-level	California
Lagman, R. A.; Yoo, G. J.; Levine, E. G.; Donnell, K. A.; Lim, H. R.	Leaving it to God religion and spirituality among Filipina immigrant breast cancer survivors	J Relig Health	2014	Patient-level	California
Lautner, M.; Lin, H.; Shen, Y.; Parker, C.; Kuerer, H.; Shaitelman, S.; Babiera, G.; Bedrosian, I.	Disparities in the Use of Breast-Conserving Therapy Among Patients With Early-Stage Breast Cancer	JAMA Surg	2015	Patient-level	USA
Lillie, S. E.; Janz, N. K.; Friese, C. R.; Graff, J. J.; Schwartz, K.; Hamilton, A. S.; Gay, B. B.; Katz, S. J.; Hawley, S. T.	Racial and ethnic variation in partner perspectives about the breast cancer treatment decision-making experience	Oncol Nurs Forum	2014	Patient-level	California; Los Angeles
Lim, J. W.; Paek, M. S.	The relationship between communication and health-related quality of life in survivorship care for Chinese-American and Korean-American breast cancer survivors	Support Care Cancer	2013	Patient-level	California
Maly, R. C.; Liu, Y.; Diamant, A. L.; Thind, A.	The impact of primary care physicians on follow-up care of underserved breast cancer survivors	J Am Board Fam Med	2013	Provider-level	California
Maly, R. C.; Liu, Y.; Liang, L. J.; Ganz, P. A.	Quality of life over 5 years after a breast cancer diagnosis among low-income women: effects of race/ethnicity and patient-physician communication	Cancer	2015	Patient-level, Provider-level	California
Marcus, E. N.; Koru-Sengul, T.; Miao, F.; Yepes, M.; Sanders, L.	How do breast imaging centers communicate results to women with limited English proficiency and other barriers to care?	J Immigr Minor Health	2014	Patient-level; System-level	USA
Molina Y, Hohl SD, Ko LK, Rodriguez EA, Thompson B, Beresford SA	Understanding the patient-provider communication needs and experiences of Latina and non-Latina White women following an abnormal mammogram.	J Cancer Educ.	2014	Patient-level	USA
Molina, Y.; Silva, A.; Rauscher, G. H.	Racial/Ethnic Disparities in Time to a	Med Care	2015	Patient-level	Chicago

Author	Title	Journal	Year	Level	Geography
	Breast Cancer Diagnosis: The Mediating Effects of Health Care Facility Factors				
Morrow, M.; Li, Y.; Alderman, A. K.; Jagsi, R.; Hamilton, A. S.; Graff, J. J.; Hawley, S. T.; Katz, S. J.	Access to breast reconstruction after mastectomy and patient perspectives on reconstruction decision making	JAMA Surg	2014	Patient-level	California: SEER; Los Angeles
Ohri, N.; Rapkin, B. D.; Guha, D.; Haynes-Lewis, H.; Guha, C.; Kalnicki, S.; Garg, M.	Predictors of radiation therapy noncompliance in an urban academic cancer center	Int J Radiat Oncol Biol Phys	2015	Patient-level	Unknown
Pan, I. W.; Smith, B. D.; Shih, Y. C.	Factors contributing to underuse of radiation among younger women with breast cancer	J Natl Cancer Inst	2014	Patient-level	USA
Parikh-Patel A, Morris CR, Martinsen R, Kizer KW.	Disparities in Stage at Diagnosis, Survival, and Quality of Cancer Care in California by Source of Health Insurance	California Cancer Reporting and Epidemiologic Surveillance Program, Institute for Population Health Improvement, University of California Davis. 2015.	2015	Patient-level, System-level	California
Parikh, A. R.; Kaplan, C. P.; Burke, N. J.; Livaudais-Toman, J.; Hwang, E. S.; Karliner, L. S.	Ductal carcinoma in situ: knowledge of associated risks and prognosis among Latina and non-Latina white women	Breast Cancer Res Treat	2013	Patient-level, Provider-level	California
Parise, C. A.; Caggiano, V.	Disparities in race/ethnicity and socioeconomic status: risk of mortality of breast cancer patients in the California Cancer Registry, 2000-2010	BMC Cancer	2013	Patient-level	California
Parise, C. A.; Caggiano, V.	Disparities in the risk of the ER/PR/HER2 breast cancer subtypes among Asian Americans in California	Cancer Epidemiol	2015	Patient-level, System-level	California
Patel, K. K.; Tran, L.	Opportunities for oncology in the Patient Protection and Affordable Care Act	Am Soc Clin Oncol Educ Book	2013	Patient-level, Provider-level, System-level	USA
Primeau, S. W.; Freund, K. M.; Ramachandran, A.; Bak, S. M.; Heeren, T.; Chen, C. A.; Morton, S.; Battaglia, T. A.	Social service barriers delay care among women with abnormal cancer screening	J Gen Intern Med	2014	Patient-level (Patient Navigation)	Massachussets
Ramachandran A, Freund KM, Bak SM, Heeren TC, Chen CA, Battaglia TA.	Multiple Barriers Delay Care Among Women with Abnormal Cancer Screening Despite Patient Navigation	J Womens Health (Larchmt).	2015	Patient-level (Patient Navigation)	Boston, MA

Author	Title	Journal	Year	Level	Geography
Ramirez, A.; Perez-Stable, E.; Penedo, F.; Talavera, G.; Carrillo, J. E.; Fernandez, M.; Holden, A.; Munoz, E.; San Miguel, S.; Gallion, K.	Reducing time-to-treatment in underserved Latinas with breast cancer: the Six Cities Study ((San Francisco, San Diego, New York, Miami, Houston and San Antonio, Texas)	Cancer	2014	Patient-level (Patient Navigation)	6 US cities
Retkin, R.; Antoniadis, D.; Pepitone, D. F.; Duval, D.	Legal services: a necessary component of patient navigation	Semin Oncol Nurs	2013	Patient-level	USA
Richter NL, Gorey KM, Haji-Jama S, Luginaah IN.	Care and Survival of Mexican American Women with Node Negative Breast Cancer: Historical Cohort Evidence of Health Insurance and Barrio Advantages	J Immigr Minor Health.	2015	Patient-level, Residential neighborhood	California
Rodday AM, Parsons SK, Snyder F, et al.	Impact of patient navigation in eliminating economic disparities in cancer care.	Cancer	2015	Patient-level	USA
Rousseau, S. J.; Humiston, S. G.; Yosha, A.; Winters, P. C.; Loader, S.; Luong, V.; Schwartzbauer, B.; Fiscella, K.	Patient navigation moderates emotion and information demands of cancer treatment: a qualitative analysis	Support Care Cancer	2014	Patient-level (Patient Navigation)	Unknown
Shi, R.; Taylor, H.; McLarty, J.; Liu, L.; Mills, G.; Burton, G.	Effects of payer status on breast cancer survival: a retrospective study	BMC Cancer	2015	System-level	USA
Shippee, T. P.; Kozhimannil, K. B.; Rowan, K.; Virnig, B. A.	Health insurance coverage and racial disparities in breast reconstruction after mastectomy	Womens Health Issues	2014	System-level	USA
Simon, M. A.; Ragas, D. M.; Nonzee, N. J.; Phisuthikul, A. M.; Luu, T. H.; Dong, X.	Perceptions of patient-provider communication in breast and cervical cancer-related care: a qualitative study of low-income English- and Spanish-speaking women	J Community Health	2013	Patient-level; Provider-level	Chicago, IL
Simon, M. A.; Tom, L. S.; Nonzee, N. J.; Murphy, K. R.; Endress, R.; Dong, X.; Feinglass, J.	Evaluating a bilingual patient navigation program for uninsured women with abnormal screening tests for breast and cervical cancer: implications for future navigator research	Am J Public Health	2015	Patient-level	Illinois
Stanley, S.; Arriola, K. J.; Smith, S.; Hurlbert, M.; Ricci, C.; Escoffery, C.	Reducing barriers to breast cancer care through Avon patient navigation programs	J Public Health Manag Pract	2013	System-level	USA
Tannenbaum SL, Koru-Sengul T, Miao F, Byrne MM.	Disparities in survival after female breast cancer diagnosis: a population-based study.	Cancer Causes Control.	2013	Patient-level; Provider-level	Florida

Author	Title	Journal	Year	Level	Geography
Virgo, K. S.; Lerro, C. C.; Klabunde, C. N.; Earle, C.; Ganz, P. A.	Barriers to breast and colorectal cancer survivorship care: perceptions of primary care physicians and medical oncologists in the United States	J Clin Oncol	2013	Provider-level (perceptions)	USA
Wang, J. H.; Adams, I. F.; Pasick, R. J.; Gomez, S. L.; Allen, L.; Ma, G. X.; Lee, M. X.; Huang, E.	Perceptions, expectations, and attitudes about communication with physicians among Chinese American and non-Hispanic white women with early stage breast cancer	Support Care Cancer	2013	Patient-level, Provider-level	California; Northern
Weingart SN, Saadeh MG, Simchowitz B, Gandhi TK, Nekhlyudov L, Studdert DM, Puopolo AL, Shulman LN.	Process of care failures in breast cancer diagnosis.	J Gen Intern Med.	2009	System-level	Boston, MA
Wen, K. Y.; Fang, C. Y.; Ma, G. X.	Breast cancer experience and survivorship among Asian Americans: a systematic review	J Cancer Surviv	2014	Patient-level	USA
Wu, A. H.; Gomez, S. L.; Vigen, C.; Kwan, M. L.; Keegan, T. H.; Lu, Y.; Shariff-Marco, S.; Monroe, K. R.; Kurian, A. W.; Cheng, I.; Caan, B. J.; Lee, V. S.; Roh, J. M.; Sullivan-Halley, J.; Henderson, B. E.; Bernstein, L.; John, E. M.; Sposto, R.	The California Breast Cancer Survivorship Consortium (CBCSC): prognostic factors associated with racial/ethnic differences in breast cancer survival	Cancer Causes Control	2013	Patient-level	California
Yang, R. L.; Newman, A. S.; Lin, I. C.; Reinke, C. E.; Karakousis, G. C.; Czerniecki, B. J.; Wu, L. C.; Kelz, R. R.	Trends in immediate breast reconstruction across insurance groups after enactment of breast cancer legislation	Cancer	2013	System-level	USA
Zafar, SY	Financial toxicity of cancer care: it's time to intervene	JNCI J Natl Cancer Inst	2016	System-level	USA

Appendix B. Frequency of Coded Response

Overall, there were 24 codes organized into five main categories.

Category	Code	Phase 1		Phase 2	
		Number of Informants that mentioned	Number of mentions	Number of Informants that mentioned	Number of mentions
System Barriers					
	Insurance (Approvals)	3	6	6	10
	Continuity of Care	2	4	2	4
	Access/Narrow Network (including Timely Access)	7	11	7	9
Navigation					
	Navigation/Provide a Path (Need for and Benefits of)	7	23	1	1
	Availability of Information	8	10	3	3
	Provider Knowledge	2	4	2	2
	Decision Making	5	5	0	0
	Patient Follow-Through	1	1	0	0
	Support/Stability	7	9	1	1
	Fear/Anxiety (about treatment, support)	6	6	1	1
Cost					
	Cost of Care	10	10	6	7
	Transportation	4	5	6	6
	Homelessness	1	1	1	1
	Financial Assistance (Need for)	3	3	0	0
	Work Constraints	3	3	5	6
	Insurance (Status)	10	20	3	4
Culture/Individual Characteristics					
	Stigma	2	4	2	2
	Culturally Appropriate Services and Treatments	2	2	3	3
	Myths and Misconceptions	3	3	2	2
	Rural/Urban	3	3	2	2
Language – impact					
	Provider Communications (Understanding the doctor, staff, materials)	5	10	1	1
	Language barrier to information/support services	4	6	9	10
	Health Literacy (understanding condition, treatment options)	4	4	7	7
	Interpreter Availability	4	4	0	0

Appendix C. Social Media Search

Methods

We examined Twitter and Facebook for discussions pertaining to breast cancer and barriers to cancer care (see below for hashtags). Other web platforms were also examined to pull any discussions regarding breast cancer barriers to care; these include, Tumblr, Wordpress, Blogger, reddit, and message boards and patient forums and blogs, patient stories on breast cancer websites (Susan G. Komen, American Cancer Society, Pink Ribbon and Breast Cancer Action) for discussion and stories related to breast cancer barriers and for shared perspectives on the patient experience.

Our examination of social media was challenged to find high-volume discussions on breast cancer barriers on Twitter and Facebook (publicly available posts). This is not to say that discussions are not occurring, as it is possible that these conversations are occurring privately in Facebook groups or other non-publicly accessible platforms and chat sites. While searching via the hashtags #breastcancer and #barriers via Twitter, a public platform, generated very few relevant results, we identified a number of Twitter chats hosted by an organization called Living Beyond Breast Cancer (LBBC; Twitter @LivingBeyondBC), which Approachs to connect people with breast cancer information and community support. Throughout 2014 and 2015, @LivingBeyondBC has hosted a number of chats for patients that deal with issues related to breast cancer treatment decision making, coping with high costs, financial impacts of breast cancer, and follow-up care. In general, there is an incredibly large volume of Tweets (namely tweeting and re-tweeting posts related to news articles in major sources, such as the New York Times) on larger health system and health trend topics – not specifically related to breast cancer, rather to health care in general - such as those related to the high cost of drugs, high co-pays, high deductible plans, narrow networks, and the Affordable Care Act.

Blogging Platforms

- Medium
  - Search for "breast cancer"
  - https://medium.com/search?q=breast%20cancer
  - Search for "breast cancer" AND California
    - https://medium.com/search?q=%22breast%20cancer%22%20AND%20California
- Tumblr
- Wordpress
- Blogger
- Google search: "breast cancer" "California" "treatment" "blog" (1M results)

Breast Cancer Support Sites – Webpage and Facebook, Twitter Sites

- Susan G. Komen
  - Stories of inspiration http://ww5.komen.org/StoriesofInspiration.html
  - Message Boards: Forum [Treatment] [Dealing with Insurance, Employment and Disability] https://apps.komen.org/Forums/tt.aspx?forumid=68 American Cancer Society
- Pink Ribbon?
- What Next (recommended by KP as online resource: https://www.whatnext.com/)

    - Questions: Search term: insurance
    - Filters: Cancer/Breast Cancer/300 miles of 94040: 16 results
        - https://www.whatnext.com/search/questions?commit=Search&search[filters][class][]=Question&search[filters][condition_path]=45&search[query]=insurance&utf8=%E2%9C%93
- Breast Cancer Action (SF based advocacy org with social justice mission, advocates basically against money going to Pink Ribbon)
    - Blog: http://www.bcaction.org/blog/
    - Twitter: @BCAction
- Cancercare
    - Stories of Help and Hope
        - http://www.cancercare.org/stories (Not sure if stories are good, not specific to California and usually more positive?)
- American Cancer Society
    - Cancer Survivors Network http://csn.cancer.org/?_ga=1.257476808.25899981.1456465484
        - Discussion Boards: Search "insurance", Limit to 2014-2015
            - http://csn.cancer.org/forum/127/search?page=32&body=insurance&title=
    - MyLifeLine.org- cancer social networking
    - Breast Cancer Stories of Hope http://www.cancer.org/treatment/survivorshipduringandaftertreatment/storiesofhope/storiesbytopic/index?topic=Breast%20Cancer

Discussion Forums

- Reddit
    - "breast cancer" "California" – limited to posts in the past year

- Breastcancer.org
    - Discussion Boards:
        - Tests, Treatments and Side Effects: Help Me Get Through Treatment
            - Search "California," limit to past 2 years
        - Day-to-Day Matters: Employment, Insurance, and Other Financial Issues https://community.breastcancer.org/forum/113
            - Search "California", limit to past 2 years
- AskMetaFilter
- Yahoo! Answers

Twitter chats

- (@LivingBeyondBC)
    - 10/22/15 #JACR Tweet Chat about imaging during breast cancer diagnosis, treatment and follow-up
    - 12/2/15 #LBBCchat Now What? Making Treatment Decisions After Diagnosis
    - 10/15/15 #LBBCchat Breast Reconstruction
    - 6/25/14 #LBBCchat Coping with the Financial Impact of Breast Cancer

Appendix D. Legislative Scan Approach

Methods

Using http://leginfo.legislature.ca.gov, bills were first examined by searching “breast cancer” and then scanned for themes related to addressing barriers to care. In a second stage, we then searched for bills that addressed barriers to care that were not specific to breast cancer: care integration, patient navigation, health plan network adequacy, Medi-Cal reimbursement and access, cost-sharing, costs of drugs, costs of non-medical care, and language and linguistic access. We screened bill titles and text to select legislation that was specific to health care systems, delivery and coverage.

California Legislation Related to Breast Cancer, 2013-2016

Bill Number	Year	Title	Content	Status (as of 5/11/2016)
AB-1795	2016	Health care programs: cancer	Extends the time limit for the Breast and Cervical Cancer Treatment Program from a set number months (18 for breast cancer) to the time needed to complete treatment	In Review: Asssembly Appropriations
ACR-68	2015	Breast Cancer Awareness and Prevention Month.	Designate October as Breast Cancer Awareness Month	Passed
AB-1396	2015	Public health finance	Transfer funds from California Tobacco Tax Act of 2015 Fund to other funds that currently receive revenue from tobacco taxes, including the Breast Cancer Fund, that are expected to decline under the additional new taxes imposed by the California Tobacco Tax Act of 2015, due to decreases in tobacco consumption	Not passed
SBX2-14	2015	Tobacco: electronic cigarettes: taxes: managed care organization provider tax: in-home supportive services	Include e-cigarettes in tobacco taxes, continue to allocate revenues to same funds including Breast Cancer Funds	Not passed
SB-69	2015	Budget Act of 2015	Allocating funds for Breast Cancer Control Account	Not passed
AB-103	2015	Budget Act of 2015	Allocating funds for Breast Cancer Fund, Breast Cancer Control, and Breast Cancer Research	Not passed
AB-93	2015	Budget Act of 2015	Allocating funds for Breast Cancer Fund	Passed
AB-1598	2016	Budget Act of 2016	Allocating funds for Breast Cancer Fund	In review: Assembly Budget
SB-825	2016	Budget Act of 2016	Allocating funds for Breast Cancer Fund	In review: Sen Budget and Fiscal Review
AB-94	2015	Health	Continuation of breast and cervical cancer early detection program	Passed
SB-75	2015	Amendments to Professional code	Continuation of breast and cervical cancer early detection program	Passed
AB-731	2015	Maintenance of the codes	Payment parity of breast and cervical cancer early detection program with Medi-Cal, breast cancer license plates	Passed
AB-49	2014	License plates: breast cancer awareness	DHCS sponsor breast cancer awareness license plates, funds to go to Breast Cancer Control Account in Breast Cancer Fund	Passed

Bill Number	Year	Title	Content	Status (as of 5/11/2016)
AB-657	2013	Women's health	Revises guidance to DPH on literature it produces on breast cancer	Not passed
AB-1286	2013	Personal income tax: voluntary contributions: California Breast Cancer Research Fund	Allows taxpayers to designate contribution to Breast Cancer Research Fund	Passed
AB-219	2013	Health care coverage: cancer treatment	Limits co-pays and co-insurance to $200 per prescription for oral anticancer medications	Passed
SB-768	2013	Cigarette and tobacco products taxes: California Tobacco Tax Act of 2014	Transfer funds from California Tobacco Tax Act of 2014 Fund to other funds that currently receive revenue from tobacco taxes, including the Breast Cancer Fund, that are expected to decline under the additional new taxes imposed by the California Tobacco Tax Act of 2014, due to decreases in tobacco consumption	Not passed
AB-1278	2013	Integrative cancer treatment	Sets requirements for providers offering "integrative" cancer treatment, i.e. alternative or complementary treatment, of cancers; repeals one code on unprofessional conduct regarding breast cancer informed consent?	Not passed
AB-110	2013	Budget Act of 2013	Allocating funds for Breast Cancer Fund, Breast Cancer Control, and Breast Cancer Research	Passed
AB-73	2013	2013-14 Budget	Allocating funds for Breast Cancer Fund, Breast Cancer Control, and Breast Cancer Research	Not passed
SB-65	2013	2013-14 Budget	Allocating funds for Breast Cancer Fund, Breast Cancer Control, and Breast Cancer Research	Not passed
AB-1457	2014	Budget Act of 2014	Allocating funds for Breast Cancer Fund, Breast Cancer Control, and Breast Cancer Research	Not passed
SB-851	2014	Budget Act of 2014	Allocating funds for Breast Cancer Fund, Breast Cancer Control, and Breast Cancer Research	Not passed
SB-852	2014	Budget Act of 2014	Allocating funds for Breast Cancer Fund, Breast Cancer Control, and Breast Cancer Research	Passed
SB-1304	2014	Maintenance of the codes	Regulations on independent review for worker's compensation (cancer is mentioned in the case of consulting with NCI); sets minimum contribution levels for Breast Cancer Research Fund; regulations from Health and Safety code around exposures to chemicals known to cause cancer	Passed
AB-1219	2015	California Cancer Task Force	Requires a joint task force to coordinate DHCS Breast and Cervical Cancer Treatment Program with DPH screening activities	Not passed
SJR-19	2015	Women's reproductive health	Statement of support for Planned Parenthood	Passed
SB-804	2015	Public health	Requires DHCS to report to legislature quarterly on caseload, expenditures, program monitoring data for the Every Woman Counts Program (breast and cervical cancer early detection and screening)	Passed
SB-1426	2014	Breast and Cervical Cancer Treatment Program	Revises Health and Safety Code to read that provider eligibility determined by CMS (rather than HCFA)	Not passed
ABX-1-1	2013	Medi-Cal: eligibility	Exempts women in Breast and Cervical Cancer Treatment Program from semiannual reporting requirements for eligibility determination: Changing Medi-Cal determinations from semiannually to annually but requiring semiannual reports	Passed
SB-77	2013	Health	Requires DHCS to report on Every Woman Counts; requires cosmetics manufacturers to report chemical risks of cancer	Not passed
AB-82	2013	Health	Requires DHCS to report on Every Woman Counts; requires cosmetics manufacturers to report chemical risks of cancer	Passed
SB-1465	2014	Health	Exempts breast and cervical cancer treatment from 10% Medi-Cal reimbursement reduction	Passed

Findings

We found few examples of legislation that specifically addressed barriers in diagnosis and treatment of breast cancer from 2013 to April 2016.

- We identified provisions within bills that exempted breast cancer treatment from proposed cuts in Medi-Cal reimbursement.
- Another bill contained a provision requiring breast and cervical cancer screening programs, i.e. Every Woman Counts, to provide information on insurance coverage for women who receive services through their program.
- A bill that limited the cost-sharing for oral anticancer medications was passed in 2013.
- More often, we found legislation that continued funding for breast cancer screening and outreach, breast cancer research, and the Breast and Cervical Cancer Treatment Program (but no changes to the program).
- We found one bill (AB 1795, 2016, under review by Committee on Appropriations) that directly addresses coverage for breast cancer treatment. This bill proposes to extend the time limit for the Breast and Cervical Cancer Treatment Program from a set number of months (18 for breast cancer) to the time needed to complete treatment. Given the delays in locating providers, as well as treatment regimens such as hormonal therapies that continue for multiple years, this type of policy addresses a barrier for particularly vulnerable women would not otherwise have coverage for care.

We found bills that addressed costs and access to healthcare, and breast cancer patients could potentially benefit.

- Legislators proposed multiple bills Approached at network adequacy within health plans and limits on cost-sharing in general as well as specifically for prescription drugs.
- Legislation to provide reimbursement for interpreter services has been passed and vetoed twice.
- We also identified bills specific to other health conditions that could serve as examples for policy on breast cancer, such as subsidies for copayments and deductibles, network adequacy of specialists, and bundled Medi-Cal payments for integrated health, behavioral and social services.

Notably,

- We found no legislation that addressed patient navigation services for cancer care.
- We found no legislation that mandated insurance coverage for patient navigation services for clinical or supportive care.
- We found no legislation that addressed network adequacy specific to breast cancer care, or cancer care in general.
- We found no legislation that addressed the numerous costs that patients experience outside of direct medical care for breast cancer.

- We found no legislation that addressed **Provider-Patient Interactions, Cultural Barriers,** or **Fear and Stigma,** specific to breast cancer or applicable to breast cancer patients.
- We found vetoed legislation that addressed language barriers: AB-1263 (2013) and AB-2325 (2014), which would have required the Department of Health Care Services to establish CommuniCal, a program to provide and reimburse for medical interpreter services.

Health System

The Fragmented Health System We found no legislation specifically addressing the challenges of receiving breast cancer care across a fragmented set of providers and services.

AB-1568 (2016) and SB-815 (2016) propose to establish the PRIME (Public Hospital Redesign and Incentives in Medi-Cal) program, which would offer payment incentives to safety net hospitals to redesign systems to better integrate and coordinate services. Both bills are currently under review by the Committee on Appropriations. If passed, the PRIME program could serve as a vehicle for a health system to develop a coordinated path of breast cancer treatment for low-income women.

Other To address the lack of access to clinical trials among minority and other underserved populations, AB-1060 (2015, vetoed) and AB-1823 (2016) have proposed the creation of a Cancer Clinical Trials Program that would be administered by the University of California. The program would offer grants to providers, community-based organizations, or other services such as patient navigator programs, to increase patient access to clinical trials. AB-1823 is currently under review by the Committee on Appropriations.

Navigation

We found no legislation that addressed patient navigation services for cancer care.

AB-94 and SB-75 (2015, passed) were both omnibus health bills that, among other measures, proposed the State Department of Public Health create the Pre-Exposure Prophylaxis (PreP) Navigator Services Program for communities and populations at high risk for HIV infection. The program would award grants to community-based organizations or local health departments. We also found one example of legislation that Approachs to provide information to assist enrollees in navigating health care. SB-571 (2015, not passed) proposed to create CalCareNet, website to assist with navigation of long-term care services.

These bills offer examples of how the state could support patient navigator services for breast cancer care. We found no legislation that mandated insurance coverage for patient navigation services for clinical or supportive care.

Insurance

Narrow Provider Networks We found no legislation that addressed network adequacy specific to breast cancer care, or cancer care in general.

We found multiple examples of legislation addressing network adequacy. SB-964 (2014, passed) required the Department of Managed Health Care to establish health plan standards for timeliness of care and network adequacy, and required plans to submit reports annually on network adequacy. SB-137 (2015, passed) requires health plans to publish updated provider directories, both print and online, with provider location and acceptance of new patients, and languages spoken by provider and staff.

We found one example in which legislation addressed network adequacy for a single type of care/treatment. Both AB-796 and SB-1034 (2016) required health plan network adequacy for autism service providers. Both bills are in review (Committees on Health and Appropriations).

Public Programs We found two types of legislation that addressed Medi-Cal provider reimbursement. First, SB-243 (2015, not passed) proposed an increase of Medi-Cal hospital rates to 16% and physician rates to parity with Medicare reimbursement. Second, omnibus health bills (AB-94, SB-75) contained provisions to exempt breast and cervical cancer treatment from cuts in Medi-Cal provider reimbursement. Thus, Medi-Cal reimbursement rates while inadequate, have neither been increased nor decreased for breast cancer care.

We identified one bill, AB-209 (2013, not passed), that would have required the Department of Health Care Services to develop and implement a plan to monitor quality, access and utilization in Medi-Cal managed care plans. This is the only example we could identify of legislation that addressed barriers around lack of providers who accept Medi-Cal and the quality of care provided.

In regards to eligibility and authorization for Medi-Cal, SB-1005 (2015, not passed) proposed that all individuals who would otherwise qualify for full-scope Medi-Cal benefits, were it not for their immigration status, to be eligible for Medi-Cal. SB-1005 also proposed that all eligible individuals may participate in Covered California as well.

AB-94 and SB-75 also contained provisions to require that state breast and cervical cancer screening programs, i.e. Every Woman Counts, provide enrollees with information on applying for insurance coverage.

Cost

Out of Pocket Costs-- Cost-Sharing and High Deductible Health Plans We found one example of legislation that was specific to out-of-pocket cancer costs, AB-219. This bill proposed that co-payments and co-insurance be capped at $200 per 30-day prescription for oral anti-cancer medications, with increases tied to the Consumer Price Index. AB-219 was passed and signed into law in 2013.

We found multiple examples of legislation that addressed general out-of-pocket costs for enrollees. SB-639 (2013, passed) set limits for deductibles and out-of-pocket maximums for small group health plans. Small group bronze plans were exempted from these limits if they would render the plans unable to meet actuarial requirements. The deductibles under this legislation ($2000 per individual or $4000 for family) are considerably lower than the Covered California plans examined in this report, although the out-of-pocket maximum costs are similar ($6350 for individual/$12,700 family). AB-1305 (2015, passed) set limits on out-of-pocket maximums for individuals within families. SB-1176 (2014, not passed) would have required to health plans to monitor out-of-pocket spending for enrollees and reimburse payments over the out-of-pocket maximum within five days.

AB-533 (2015, not passed), would have prohibited an out-of-network provider from charging an enrollee for cost-sharing in excess of in-network cost-sharing. In the case of breast cancer care, this is salient for women with Covered California plans in rural areas who have difficulty finding local in-network specialists such as surgeons, oncologists and radiation oncologists. Enrollees are required to pay any excess amounts charged by out-of-network providers, and this costs are not subject to the out-of-pocket maximum.

We found multiple examples of legislation that addressed the cost of prescription drugs. AB-2436 (2016, passed) requires health plans to provide information on enrollees' share of cost for prescription drugs. AB 2144 (2016, in committee) SB-715 (2015, not passed) would have authorized (not required) health plans to provide coverage for investigational drugs. AB-1917 (2014, not passed) would have limited cost-sharing a single prescription drugs to 1/12 the annual out-of-pocket limit.

We found one example of legislation that addressed out-of-pocket costs specific to a health condition. AB-1462 (2014, not passed) included a provision that authorized the State Department of Public Health to subsidize costs to health plans, including copayments, deductibles and premiums, for HIV treatment if such a program would lower overall costs to the state. A similar case could be made for breast cancer, if cost-sharing burdens lead to delayed or missed care.

Costs Beyond Care We found no legislation that addressed the numerous costs that patients experience outside of direct medical care for breast cancer.

AB-1568 (2016) and SB-815 (2016) proposed the Whole Patient pilot as part of a larger Medi-Cal demonstration project bill. The pilot would allow providers to receive capitated payment for a range of health, behavioral and social services; for breast cancer patients, such a program could provide coverage for needs such as transportation, meals, childcare and financial assistance. Both bills are under review by the Committee on Appropriations.

Individual and Cultural Characteristics

We found no legislation that addressed **Provider-Patient Interactions, Cultural Barriers,** or **Fear and Stigma,** specific to breast cancer or applicable to breast cancer patients.

Language

AB-1263 (2013, vetoed) and AB-2325 (2014, vetoed) would have required the Department of Health Care Services to establish CommuniCal, a program to provide and reimburse for medical interpreter services.

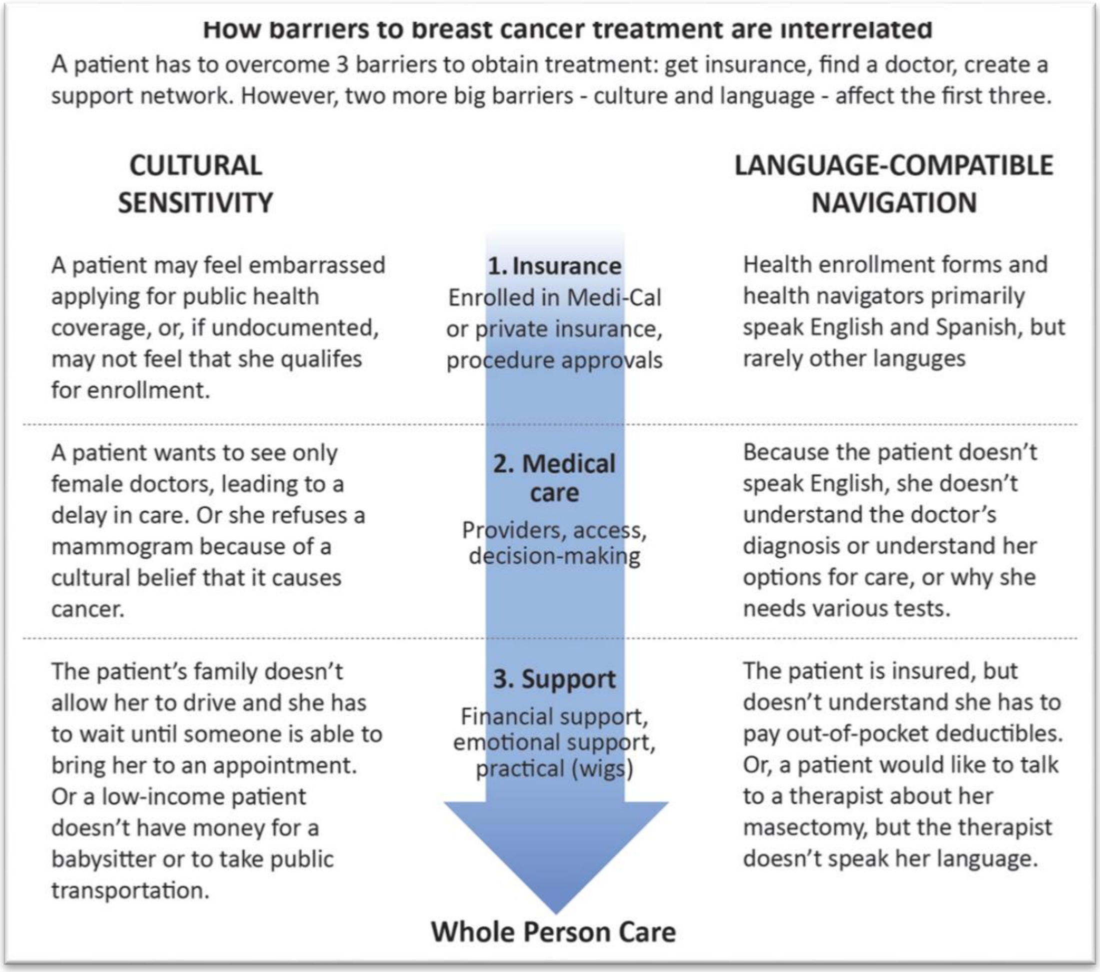
Appendix F. Summary Tables and Figures

Heat map table of barrier types addressed in the key informant interviews, peer-reviewed, non peer reviewed literature, and social media

Barrier Type	Keyword	Peer-reviewed literature	Gray/literature /social media	Key informant Phase 1 interviews	Key informant Phase 2 interviews
Health System Fragmentation/Navigation	Navigation	🟥	🟧	🟥	🟧
	Low resourced facility	🟨	🟨	🟨	🟨
	Provider-patient	🟥	🟧	🟥	🟨
Insurance/Health Benefits	Provider networks	🟨	🟥	🟨	🟥
	Insurance type	🟧	🟧	🟨	🟥
	Out-of-pocket costs	🟧	🟥	🟥	🟨
	Rx costs	🟧	🟥	🟨	🟨
	Payment model	🟨	🟧	🟨	🟨
	Coverage	🟨	🟨	🟨	🟧
Costs	Costs of care	🟧	🟥	🟨	🟥
	Financial	🟧	🟧	🟨	🟨
	Work loss	🟧	🟨	🟥	🟧
	Child care	🟧	🟨	🟥	🟧
	Transportation	🟧	🟨	🟨	🟨
	Travel distance	🟨	🟨	🟨	🟨
	Legal support	🟨	🟨	🟨	🟨
	Scheduling	🟧	🟨	🟨	🟨
Individual/Cultural	Socioeconomic &	🟥	🟨	🟥	🟨
	Cultural preferences	🟧	🟨	🟥	🟧
	Family support	🟧	🟨	🟨	🟨
	Information/Health	🟧	🟨	🟨	🟥
	Safety - disadvantage	🟧	🟨	🟨	🟨
	Decision making	🟨	🟨	🟨	🟨
	Emotional support	🟨	🟨	🟨	🟨
	Discrimination	🟨	🟨	🟨	🟨
	Distrust	🟨	🟨	🟨	🟨
	Community/Neighbor	🟧	🟨	🟨	🟨
	Beliefs/fear	🟧	🟨	🟨	🟨
	Comorbidities	🟧	🟨	🟨	🟨
Language	Language	🟥	🟨	🟥	🟥

Most often	Medium	Least or No
🟥	🟧	🟨

Figure. How Barriers to Cancer Care Affect Treatment



How barriers to breast cancer treatment are interrelated

A patient has to overcome 3 barriers to obtain treatment: get insurance, find a doctor, create a support network. However, two more big barriers - culture and language - affect the first three.

CULTURAL SENSITIVITY		LANGUAGE-COMPATIBLE NAVIGATION
A patient may feel embarrassed applying for public health coverage, or, if undocumented, may not feel that she qualifes for enrollment.	**1. Insurance** Enrolled in Medi-Cal or private insurance, procedure approvals	Health enrollment forms and health navigators primarily speak English and Spanish, but rarely other languges
A patient wants to see only female doctors, leading to a delay in care. Or she refuses a mammogram because of a cultural belief that it causes cancer.	**2. Medical care** Providers, access, decision-making	Because the patient doesn't speak English, she doesn't understand the doctor's diagnosis or understand her options for care, or why she needs various tests.
The patient's family doesn't allow her to drive and she has to wait until someone is able to bring her to an appointment. Or a low-income patient doesn't have money for a babysitter or to take public transportation.	**3. Support** Financial support, emotional support, practical (wigs)	The patient is insured, but doesn't understand she has to pay out-of-pocket deductibles. Or, a patient would like to talk to a therapist about her masectomy, but the therapist doesn't speak her language.

Whole Person Care

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