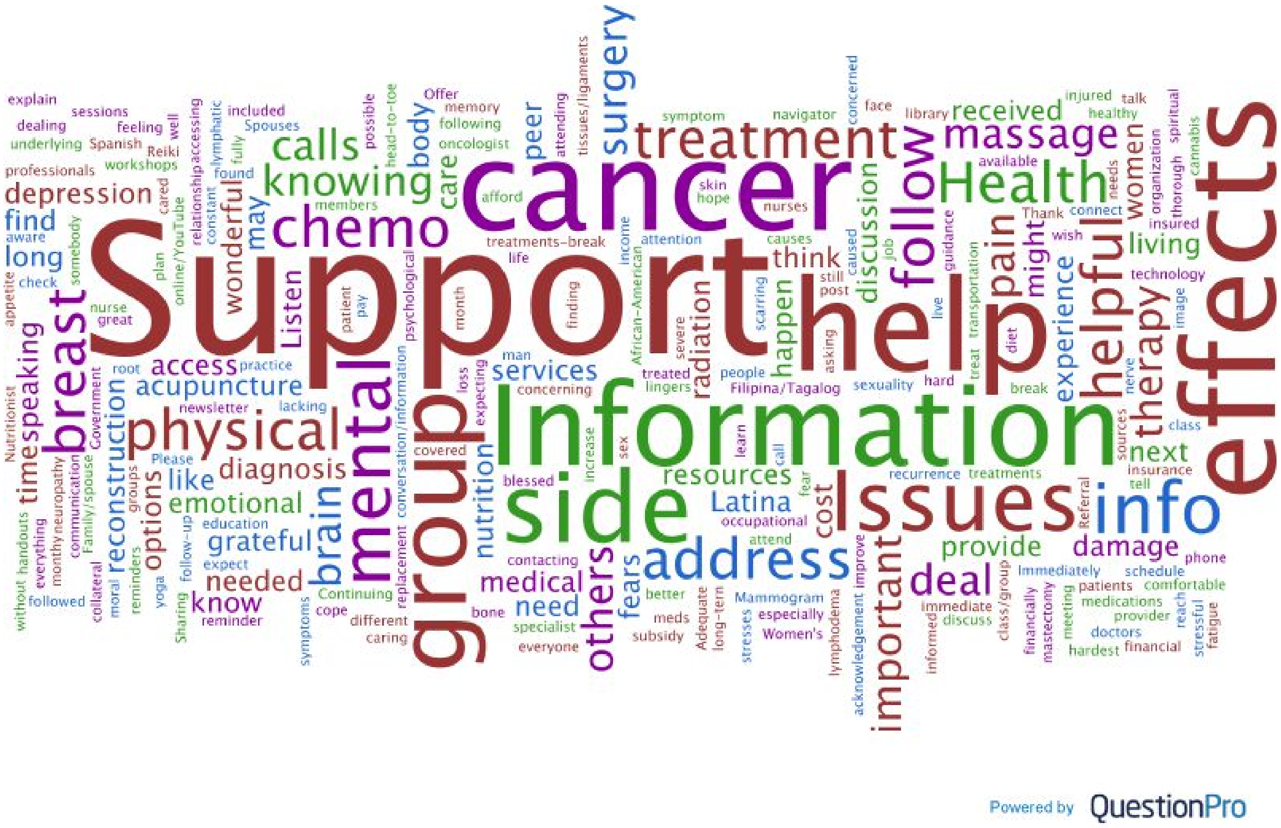
San Francisco Bay Area & Northern California
Breast Cancer Survivorship Navigation Project

SUMMARY REPORT ON BREAST CANCER SURVIVOR NEEDS AND ENGAGEMENT

For Survey Participants and Everyone Interested in Improving Breast Cancer Survival

October 2018



Introduction

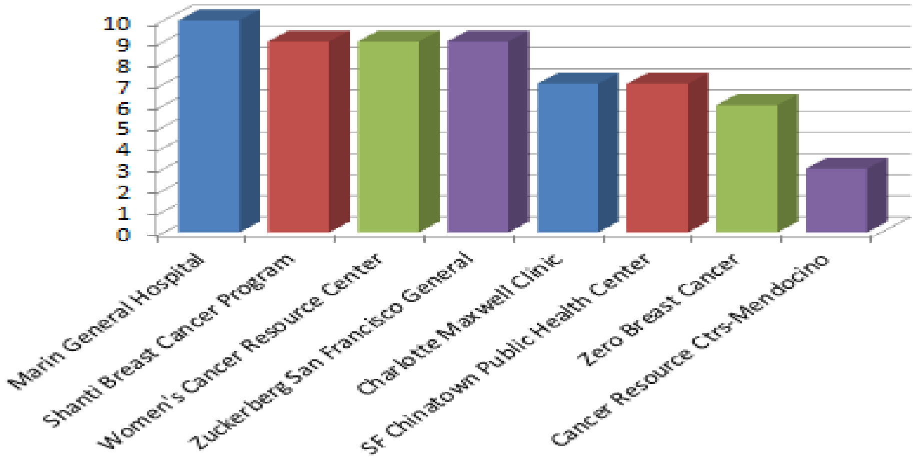
We started the Breast Cancer Survivorship Navigation Project (BCSNP) to understand and address needs and gaps experienced by people from under-served groups who had breast cancer. We define “survivor” as anyone who has ever been diagnosed with breast cancer. However, for this project, we focused on people who were treated with curative intent for initial cancer and who completed any surgery, radiation, chemo and adjuvant therapy other than long-term hormonal therapy.

The BCSNP team includes survivors, patient navigators, clinicians, advocates and researchers. We represent non-profit, health care, academic and service organizations around the San Francisco Bay Area serving people with cancer who are racially and ethnically diverse, gender and sexual minorities and have lower incomes (see list at end of report.)

In 2017, we created a list of questions to help us better understand the needs of the breast cancer survivors we serve. This survey was distributed by BCSNP members and our colleagues. We received a total of 63 complete responses. All but one of the respondents had a diagnosis of breast cancer; that person’s answers were removed (for consistency) for a total of 62 responses.

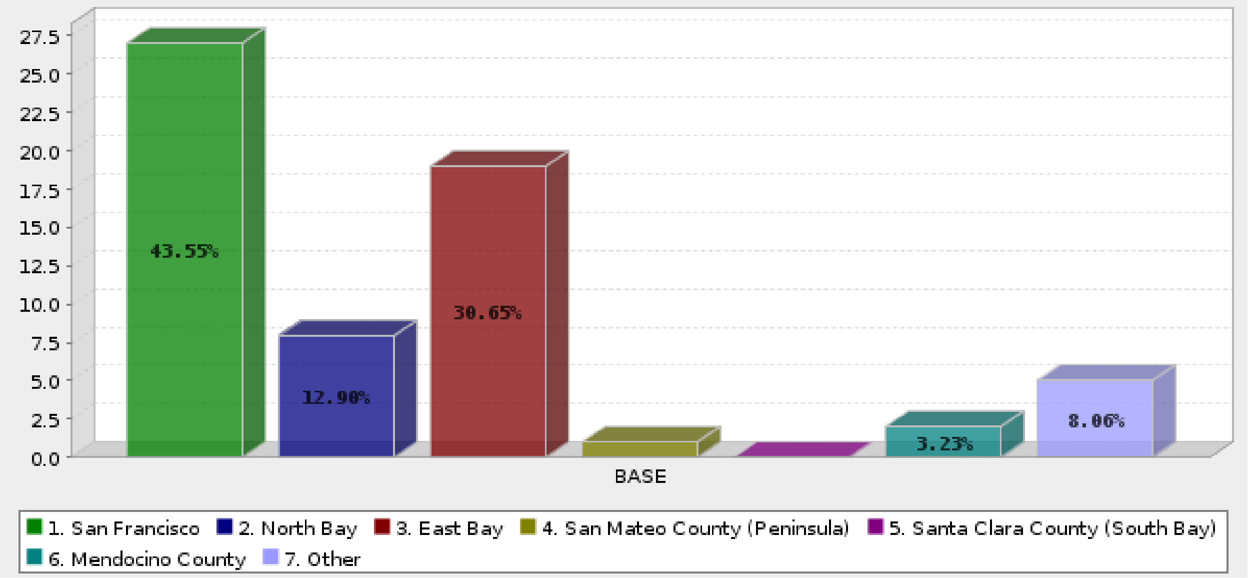
We greatly appreciate the help of our colleagues and responses from our communities. Following is a summary of results and future steps.

Surveys Completed by Organization



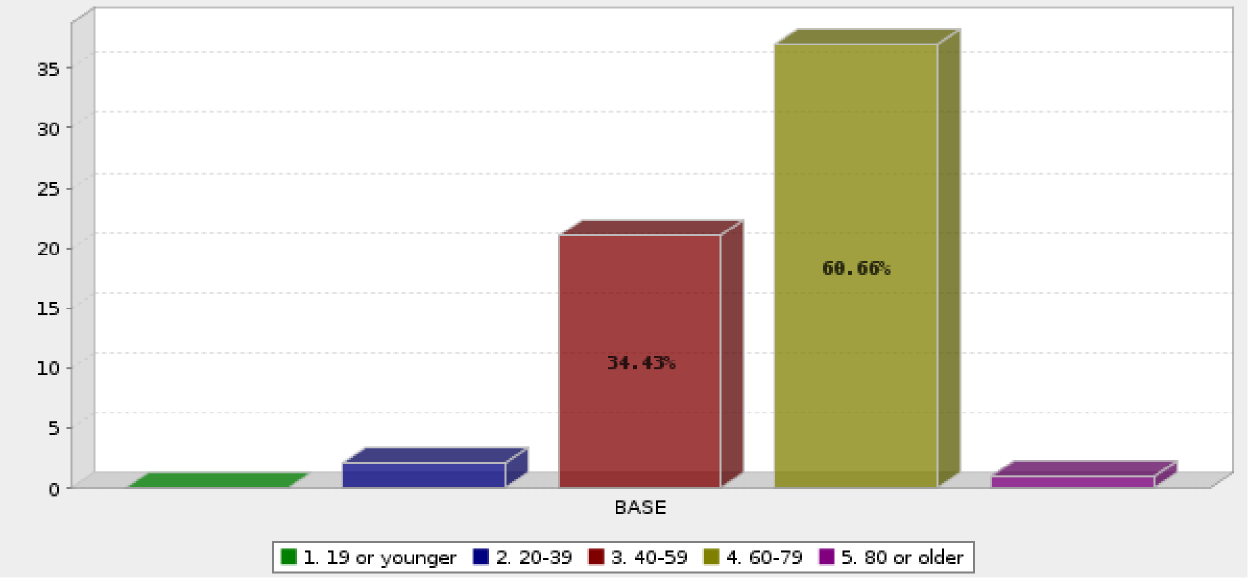
Participants were recruited by 8 organizations, including Marin General Hospital (17%), Shanti’s Women’s Cancer Program (15%), Women’s Cancer Resource Center (15%), Zuckerberg San Francisco General (15%), Charlotte Maxwell Clinic (12%), San Francisco Chinatown Public Health Center (12%), Zero Breast Cancer (with Kaiser Permanente) (10%) and Cancer Resource Centers of Mendocino (5%).

Residence Location



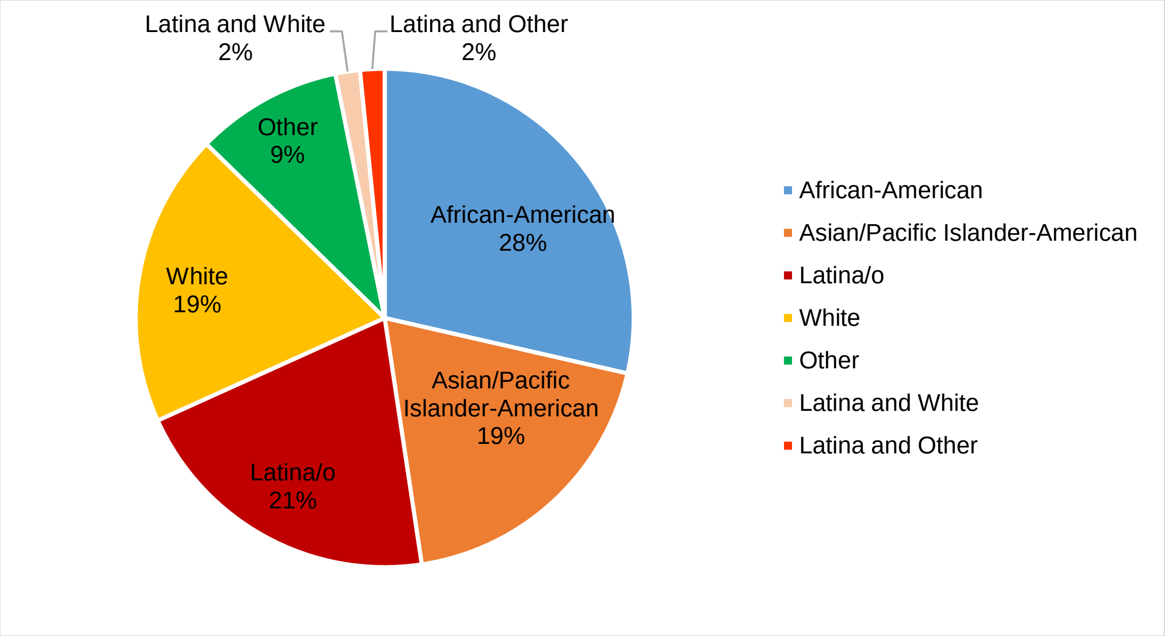
The vast majority of respondents lived in cities in the San Francisco Bay Area (SFBA). The majority of respondents lived in San Francisco (43.6%), followed by the East Bay (30.7%), North Bay (12.9%), Other (8.1%), Mendocino County (3.2%) and San Mateo County (1.6%). Those who chose "Other" lived near the SFBA or had moved out of the area after completing breast cancer treatment.

Age of Respondents



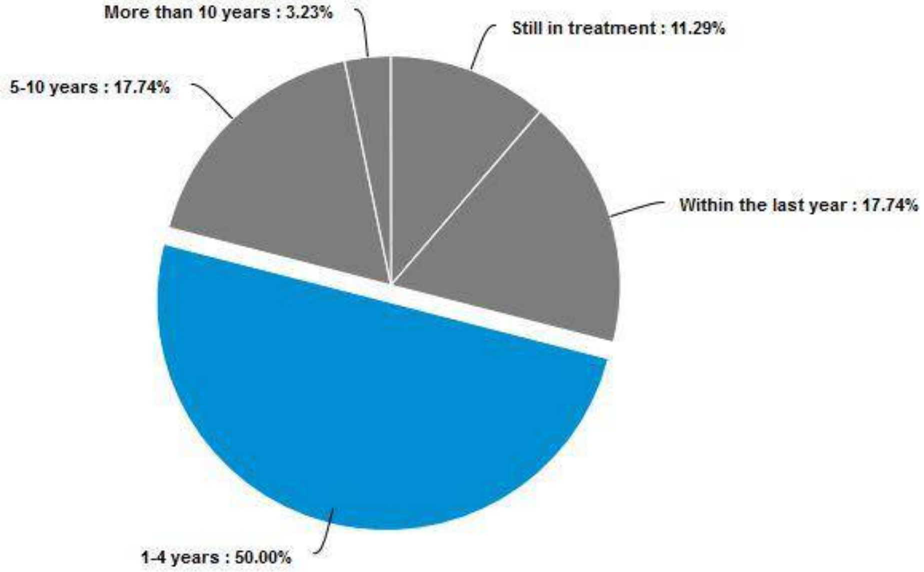
The majority of resondents were in the age group of 60-79 years (61%), followed by 40-59 years (34%), 20-39 years (3%) and 80 or older (2%).

Racial/Ethnic Identification



Survey respondents reported their race/ethnicity as African-American (28%) followed by Latina (21%), Asian/Pacific Islander-American (19%), White (19%), Other (9%), Latina and White (2%) and Latina and Other (2%). The respondents that identified “Other” listed *Brazilian, Thai, European/ French* and *Filipina* racial/ethnic identifications.

Time Since Treatment



At the time they participated, half of the respondents had completed their active treatment (this may include surgery, chemotherapy and radiation, hormonal therapy may continue) in the past 1-4 years. There was an equal number of those who finished in the previous year and 5-10 years before (11 or 18% each.) The remainder were still in treatment (7 or 11%) with two people more than 10 years out.

Gender Identity & Identity as LGBTQ

All 62 respondents identified as female. Four respondents (6.8%) identified as LGBTQ.

Financial Status

We asked respondents about their household income and household size. Based upon those answers, we estimated that more than 60% of participants live in households with income below the HHS Poverty Guidelines for 2018.

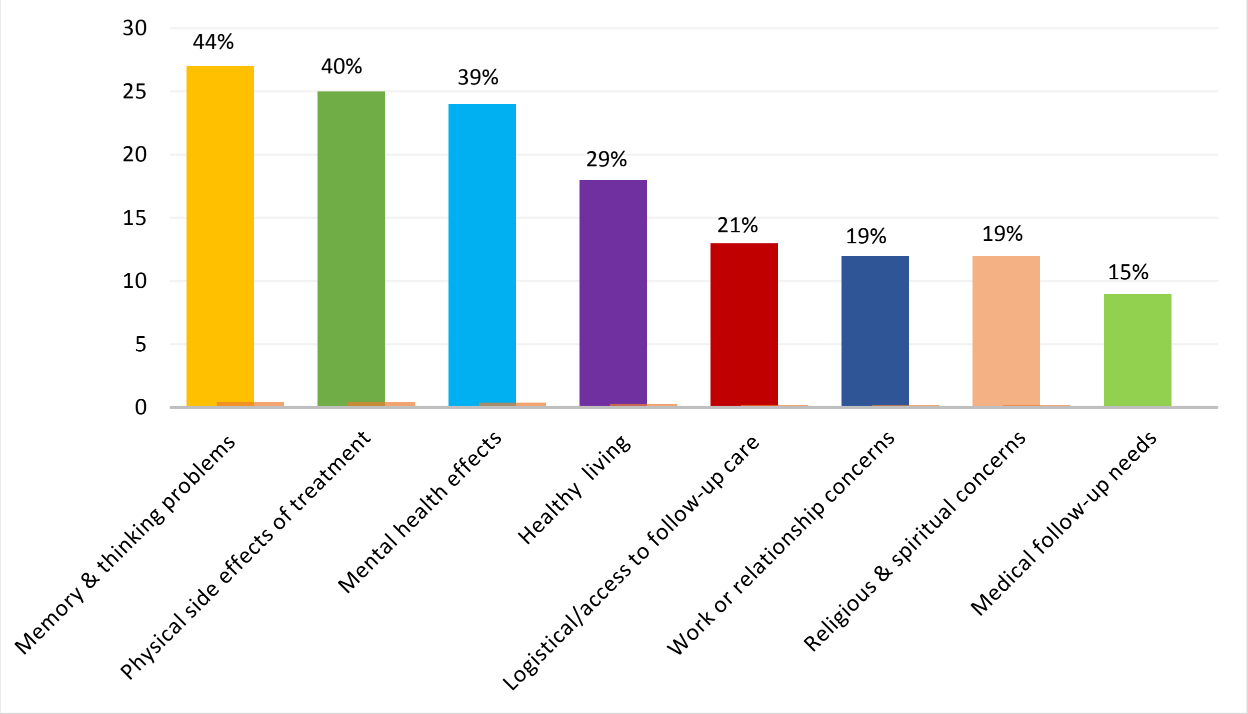
Breast Cancer Support Group Attendance

Most of the respondents (42 or 70%) had attended a breast cancer support group at some point during or after active treatment.

Unmet needs during breast cancer survivorship

Respondents were asked to identify needs that were not met during the year after they completed active treatment. They were offered a list of eight (8) commonly used categories from which to choose. Respondents were able to choose as many answers as they wanted.

The need for more mental health services in breast cancer survivorship was evident; two of the most commonly chosen unmet needs were *Memory and thinking problems (chemo brain)* (44%) and *Mental health effects* (39%).



Many respondents (40%) reported a need for increased attention to *physical side effects of treatment*. Combined with the fact that *medical follow up* needs was the least commonly reported unmet need (15%), this may indicate that routine medical follow up is better addressed than the side effects of cancer treatment.

Results also indicate a need for more support in survivorship on 3 levels: physically, spiritually and socially. More than one quarter of respondents reported unmet needs related to *healthy living (nutrition, stress management, exercise, etc.*) (29%), and almost 1 in 5 for *religious & spiritual concerns* and for *work or relationship concerns* (19% each).

In an open-ended question, respondents were asked to suggest types of services or information that might have helped with their unmet needs. The words used in response to this question are the basis for the word cloud on the cover of this summary. Again, mental health support was in the forefront as respondents frequently cited support groups, mental health and therapy as needed services. One respondent wrote, "Listen to others and take their info so you are informed. Do not go on line/You Tube …it may be too traumatizing."

Services/Information Suggested (in order of frequency)
Treatment education
Complementary care
Support group
Mental health/therapy
Fear
Financial assistance
Side effects
Transportation
Body Image

Increased treatment education was included in many responses. One respondent wrote, "More conversation/information concerning what I might experience or expect after treatment. Not knowing can be stressful." Another wrote, "Immediately after diagnosis, have patient attend a breast cancer information class/group to explain what will happen, what options are available for reconstruction and treatment."

The need for services to mitigate short and long-term side effects, pain and chemo brain was frequently listed including complimentary care (acupuncture, nutrition, diet, massage, lymphatic massage and services for sexual issues). Several women wrote about the need for logistical and material assistance, especially transportation, financial support and help accessing technology.

Finally, the fear of recurrence and the future was included in several responses; one woman cautioned, "Don't treat cancer as the boogey man." At the Report-back meeting, a participant noted that some need more than a doctor's reassurance.

Future Engagement

The BCSNP team was pleased that the majority of the respondents (82%) want to receive project updates and/or are willing to participate in the future. The most common ways they would like to engage are taking additional surveys (30%), attending in person meetings (28%), online discussions (16%) and helping to share information (13%).

The BCSNP Steering Committee invited all participants interested in updates who provided an email or mailing address to a meeting on July 18, 2018 to discuss a draft of this report, along with colleagues, including those who administered the survey. Attendees suggested creating an interactive site for sharing information moving forward, such as a Google group or forum on Yahoo. For example, a venue specific to breast cancer patient navigators could provide a place to share regional experiences and resources (expanding beyond the current group serving San Francisco).

Conclusions

The current BCSNP group is very thankful for the input of so many people affected by breast cancer and their willingness to participate in the future. We want to be clear that this is not a scientific study; it represents a snapshot of current concerns and priorities of some of the women that we work with and for. This does not represent all women in the San Francisco Bay Area who have had breast cancer.

While we are presenting overall data here, there are likely differences between groups. For example, clinical practices have changed and the experiences of those who were treated for breast cancer more than 10 years ago is probably not the same as someone who completed treatment within the past year.

Most of the BCSNP organizations provide some type of patient navigation, which may also influence these results. The majority of survey respondents reported taking part in a support group at some time and found it to be very helpful, showing a potential bias in the people invited to participate.

Nonetheless, we believe that the need for information and support from the beginning of treatment to understand what to expect and to build support early on is an important topic for BCSNP focus. A large gap appears to be in providing sufficient resources to address mental and physical impacts of breast cancer and its treatment and to lay a foundation for and support healthy living.

Future Survivorship Work & How You Can Be Involved

Although we no longer have funding, the members as a group are committed to continuing to collaborate on improving survivorship for low-income and diverse people transitioning out of cancer treatment. The group adopted a new name, “Cancer Survivorship Navigation Collaborative” or CSNC, to reflect our broader vision for sharing information and pursue funding for projects to improve (breast) cancer survivorship.

Ideas CSNC members have considered include:

- Supporting and coordinating patient navigator training,
- Building a forum for patient navigators to share across organizations, and
- Testing survivorship patient navigation through community based organizations.

Additional ideas generated at the July 2018 meeting include:

- Organize a speaker series for breast cancer survivors in in harder to reach communities (e.g., rural, speakers of less common languages),
- Create a central “place” for survivors and other volunteers to share their talents across various organizations providing services for those affected by cancer,
- Provide a list of important resources for areas where they are less readily available (e.g., support groups, complementary medicine, etc.),
- Identify affordable training for patient navigators and community health workers (promotores)

We also hope that our member organizations and others will use the information and ideas generated by this survey to improve services, focus resources and/or inform research.

We plan to meet quarterly and share CSNC updates, member experiences and information about resources in an e-newsletter. CSNC membership is open to additional individuals and organizations in the region and the newsletter will be sent to anyone interested with an email address. Please contact one of the people on the list below for more information on how you can work with CSNC to improve life for breast cancer survivors.

BCSNP Steering Committee Members & Organizations Represented

Name	**Organization (location)**
Alison Gause	Marin General Hospital (Greenbrae)
Barbara Cicerelli	Zuckerberg San Francisco General
Carmen Ortiz	Circulo de Vida (San Francisco)
Cassandra Falby	Women’s Cancer Resource Center (Berkeley)
Catherine Thomsen	Zero Breast Cancer (Berkeley, San Rafael)
Gabriella Heinsheimer	Charlotte Maxwell Complementary Clinic (Oakland)
Judith Harkins	Shanti’s Margot Murphy Women’s Cancer Program (SF)
Karen Oslund	Cancer Resource Centers of Mendocino (Ukiah, Mendocino)
Leah Kelley (Advisor)	Marin General Hospital (Greenbrae)
Lei-Chun Fung	SF Department of Public Health, Chinatown Public Health Center
Niharika Dixit	Zuckerberg San Francisco General
Olivia Fe	Latina Breast Cancer Agency (San Francisco)
Priscilla Banks	UC - San Francisco, Comprehensive Cancer Center
Roxanna Bautista	Formerly of Asian Pacific Islander American Health Forum
Sara O'Donnell	Formerly of Cancer Resource Centers of Mendocino
Stacey Tinianov	BAYS (Bay Area Young Survivors)
Ysabel Duron	Latino Cancer Institute (formerly of Latinos Contra Cancer, San Jose)

Special thanks to Anna Nápoles, formerly of UCSF, and Lianna Hartmour of Zero Breast Cancer for their assistance on this project.

This report was originally drafted and presented to participants in July 2018. This revision was published online October 2018.