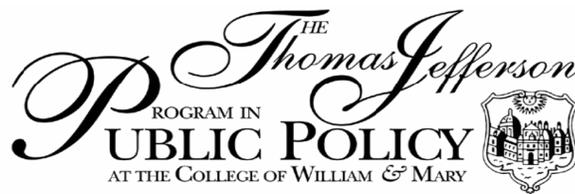




**Beyond Boobs! Program Participation and Changes in Quality of Life  
Final Report  
Ashley Gray, Jane Miller, and Jordan Whitaker  
Research Assistants: Erin Faltermeir and Grace Elizabeth Oxley**



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## **1. Introduction**

Beyond Boobs! is a 501(c)(3) nonprofit organization that offers support groups, programs and events for premenopausal women diagnosed with breast cancer. The organization also provides educational materials designed to inform their members, known as Boobers, and the public about breast cancer, the importance of early detection and healthy lifestyles to create a positive, lasting impact in the lives of those diagnosed with breast cancer, as well as their friends and families. Beyond Boobs! has a presence in several communities in Virginia, North Carolina, and South Carolina, where women have the opportunity to take part the Not Your Typical Support Group (NYTSG), a close-knit, intimate support group that meets monthly in the homes of fellow Boobers. Beyond Boobs! founders and staff deliver these services and programs with humor and positivity.

The goal of this project is to assess the impact of Beyond Boobs! programs and events on the Boobers they serve and to identify the potential benefits associated with participation. The results of the assessment will be used for future interactions with key stakeholders (i.e. corporations, non-profit affiliates and community groups) who may partner with or donate to the organization. To reach this goal, a literature review was performed to identify ways to measure the influence of participation in breast cancer support groups on the health and lives of participants. This led to the development of an online survey that measured changes in respondent quality of life before and after participating in Beyond Boobs! programs. The survey also asked respondents to provide their perceptions of the programs' efficacy, and respondents were offered the opportunity to provide feedback on the organization. In addition to the assessment, the clients, Co-Founder Mary Beth Gibson and Director of Operations Chris Schwab, requested two main deliverables: 1) the development of organizational fact sheets for key stakeholders and 2) a strategy for expansion that recognizes best practices from other breast cancer support group organizations and examines their methods of expansion. Ultimately, the creation of these deliverables was followed by concluding recommendations and questions that Beyond Boobs! staff will need to consider should they expand the organization in the future.

## **2. Literature Review: Executive Summary**

With the exception of skin cancer, breast cancer has the highest rates of diagnosis and mortality in women.<sup>1</sup> Since 1989, age-adjusted breast cancer death rates for women in the United States declined at an average annual rate of 2-3.3 percent, due in part to earlier detection and improved courses of treatment. Thus, an increasing number of women who have been diagnosed with breast cancer are living today. Despite this decrease in mortality rates from breast cancer, diagnosis rates are still high and have a significant impact on the wellbeing of those diagnosed. By 2015, an estimated 3.4 million women living in the United States will have been diagnosed with breast cancer at some point during their life, fueling public health efforts to improve medical treatment and the quality of life (QOL) of women diagnosed with breast cancer.

Many studies find the diagnosis of cancer to have both immediate and long-term impacts on the mental health status of the diagnosed individual. Research indicates that psychological distress may diminish with time, though the degree of the distress may vary. In some cases, survivors three years post-diagnosis may exhibit the same level of distress as individuals three months post-diagnosis.[5] While most studies note impacts on mental health status, a differential impact upon wellbeing by the age of the patient is also noted.[6] Prior literature suggests that younger women diagnosed with or receiving treatment for breast cancer should be considered at elevated risk for quality of life disruption, making targeted interventions for this cohort a priority to reduce the potential for significant clinical distress. Furthermore, coping methods available to women diagnosed with breast cancer vary widely, including social support group therapy, psychological counseling, psychiatric intervention, and more.

Long term depression and anxiety in women diagnosed with breast cancer are associated with previous psychological trauma, lack of an intimate confiding relationship, younger age, and severely stressful non-cancer-related life experiences. This suggests that breast cancer organizations should target their resources towards women who are already at-risk for depression, such as chronically ill women and those in poverty, as well as younger women and those most susceptible to recurrence of breast cancer. The research suggests that breast cancer support organizations could be more effective in their outreach efforts by targeting women who, because of life circumstances, lack the knowledge or inclination to join support organizations. For the purpose of this study, previous literature was reviewed to determine the influences of social support group therapy and educational awareness on the age-based differential QOL impact of breast cancer patients to determine whether social support through breast cancer support groups improves the quality of life for women diagnosed with breast cancer.

Previous studies have found that social support positively influences quality of life in breast cancer patients. Increased social support confers a number of benefits that range in level of impact depending on the nature of the support and the factors surrounding the life of the diagnosed individual. Some factors of social support include the degree of isolation, size of the social support network, and type of care. Studies suggest these factors are meaningful and important when considering provision of services and post-diagnosis support. With regards to the degree of isolation, studies have largely demonstrated that social isolation produces adverse

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<sup>1</sup> Please see *Appendix A*, "Formal Literature Review and Survey Instruments Referenced" for this review in its entirety, as well as a list of references cited in *Appendix B*.

effects on QOL. An individual's wellbeing and ability to maintain functionality, such as performing a variety of day-to-day activities, diminishes with more isolation, whereas being more socially integrated helps to preserve QOL after diagnosis.

Social support networks vary in size and social interventions via support groups have the potential to solidify a pre-existing, strong network, as well as expand the networks of individuals without adequate support providers. Studies have repeatedly shown that social support group therapy can broaden a patient's social network, improve their level of social integration, and expose the individual to more options for personal and emotional assistance as a natural byproduct of a secure social support network. Organizations and support groups are better positioned to provide an array of services than are traditional support structures comprised solely of friends and family, and are also able to do so in a more personal, intimate manner which may be absent from conventional medical and psychiatric therapy. Support group therapy provides participants with an understanding of coping mechanisms and symptom management, as well as the setting and/or tools with which to cope and overcome their symptoms.

Support group effectiveness may differ across patients with similar diagnoses but differing psychosocial support levels. A Carnegie Mellon study found that women diagnosed with breast cancer who were already receiving support at home gained no benefit from participating in breast cancer support groups. This indicates that breast health organizations should consider focusing their efforts on those women who have relatively less social capital or lack other means (familial, community, etc.) of support. Support groups may also be effective in ways that extend beyond emotional and psychological health. For example, they may help patients follow their medical treatment plans more rigorously. Again, it stands to reason that these benefits will accrue to women in more precarious economic or social situations.

In addition to targeting at-risk women, breast health organizations should consider offering support groups that deliver a holistic range of services. One model, the Duke Cancer Institute-affiliated Pathfinders for Cancer program, provides patient support, community resources and advocacy, as well as an evidence based curriculum of coping strategies. Patients meet at least once a month with a licensed clinical social worker who helps develop patient coping skills, awareness of inner strengths, and a self-care plan. In the program's pilot study, patients improved in a number of areas, such as coping skills and social support.

Breast health organizations often engage in non-social support group activities, including aromatherapy, art therapy, humor therapy, music therapy, psychotherapy, and yoga. While none of those activities have been proven to increase cancer survival rates, they can improve patient quality of life. In particular, yoga offers the prospect of a combination of physical, emotional, and social benefits. A study by the Albert Einstein College of Medicine found that breast cancer patients randomly assigned to a twelve-week yoga program saw favorable outcomes in quality of life, distressed mood, and emotional, social, and spiritual well-being, and, when compared with patients in the control group. Since yoga programs are relatively easy and inexpensive to set up or contract out, and also serve as a social activity, breast cancer support groups should consider offering yoga as an activity for participating patients and survivors.

While the links between support and QOL are repeatedly illustrated, groups and organizations should take care in claiming the extent of their impacts. Although several studies have evaluated the links between QOL and risk of mortality, medical science has yet to reach a definitive consensus surrounding the existence of an effect of support on mortality rates. The impact of support on QOL, in many cases, may not be immediately clear or easily measured. However, social support networks are capable of building reliable relationships to alleviate physical stresses (such as difficulty picking up a prescription), emotional distress (such as difficulty coping with depression following a diagnosis), and social stresses (such as not having a spouse, children, and friends and loved ones to count on). Support groups may help to fill a void in these instances, which are commonly faced by those diagnosed with breast cancer. It follows that programs and organizations that are focused on helping individuals through support group therapy and seek to build a support community of similarly-situated individuals can achieve notable gains in the QOL of those diagnosed with breast cancer. Furthermore, receiving support from these organizations and social support mechanisms as quickly as possible post-diagnosis can deter more significant disruptions to QOL and help those with diminished QOL regain more favorable quality of life measurements.

### **3. Methods of Survey Design and Implementation**

Based on the review of previous literature, self-assessment performed by support group participants is necessary to evaluate the potential benefits of participating in breast cancer support groups and alternative support mechanisms. Understanding the experiences of Boobers is critical to identifying the effect of their involvement in Beyond Boobs! programs and events on their health and wellbeing. Not only do the respondents' self-assessments provide essential data to identify benefits but they also allow an evaluation of the efficacy of the many programs and events offered by Beyond Boobs!.

Studies conducted to evaluate breast cancer survivorship, the impact of support groups, and observations of quality of life highlighted the most frequently used and validated survey instruments. After compiling a list of potential survey instruments from those found in the literature review, measures were selected that identified potential benefits from participation in breast cancer support groups. Essentially, these studies provided a basis to select variables that were best measured by the available survey instruments. It was determined that quality of life assessments based on the wellbeing categories of functional, physical, emotional, and social health were among the most useful and proven measures. Physical wellbeing is defined as the "capacity to perform a variety of physical activities (e.g. sports, carrying groceries, climbing stairs, and walking)." Functional wellbeing relates to fulfilling role behaviors and the "extent to which health interferes with usual daily activity such as work, housework, or school." Emotional wellbeing consists of both mental health and health perceptions, accounting for "general mood or affect, including depression, anxiety, and positive wellbeing" and "overall ratings of current health in general." Social wellbeing regards the "extent to which health interferes with normal social activities such as visiting with friends or group activities." The following surveys offered a number of questions that measure the aforementioned wellbeing categories: 1) Berkman-Syme Social Network Index (SNI, L.F. Berkman & S.L. Syme); 2) Comprehensive Care Survey (University of California, San Francisco); 3) Mindfulness and Quality of Life Among Breast Cancer Survivors (Allison Forti, University of North Carolina at Greensboro); and 4) Short-Form 36 Health Survey (SF-36, Medical Outcomes Trust).<sup>2</sup>

Our initial survey was intended to be a "kitchen-sink" draft, providing a strong foundation from which subsequent vetting could guarantee a collection of particularly targeted questions. Furthermore, drawing on a variety of surveys allowed us to incorporate the questions most applicable for this project. By using questions based on 5-point Likert scales, ranking and free-response, the Beyond Boobs! survey questions were less time-consuming and identified general shifts or changes in wellbeing. The final survey question set resulted from a lengthy review process in which each wellbeing category was measured by no more than three questions.

Given the nature of our project, a baseline established under proper pre-test conditions was not possible. To compensate, the survey was completed anonymously and respondents were asked to answer survey questions by recalling how they felt after diagnosis, before their involvement with Beyond Boobs! and presently, after their involvement with Beyond Boobs!. Though this method necessarily entails a level of inaccuracy and recall bias, the respondents

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<sup>2</sup> For more information regarding these survey instruments including the purpose of the instrument, a summary of its content, and recommended further reading, please see *Appendix C*, "Survey."

were instructed to provide answers to the best of their ability. The survey began with questions to evaluate demographic information and general population characteristics before delving into the questions that measured each wellbeing category. To better serve the needs of the clients, program efficacy and free response questions formed the concluding section in which participants were asked to reflect on the strengths and weaknesses of Beyond Boobs! services and their perceptions of the influence of the organization on their own health and wellbeing.

The survey was administered through SurveyMonkey, an on-line platform where surveys can be hosted and analyzed. Conventional mailing would have been difficult to administer and response rates would have been reduced because of the short time frame in which the survey could be implemented. The survey was sent to over 450 program participants whose contact information was provided by the clients and who communicate through social media and received regularly e-mailed newsletters. Additionally, SurveyMonkey had a mechanism to provide regular reminders to individuals who had not completed the survey, enhancing the response rate. The survey was available for Boobers to complete for approximately one month, at which time the survey was closed and results gathered for analysis.

## **4. Analysis of Results**

### *Demographic Profile of Respondents*

Beyond Boobs! aims to help women, especially premenopausal women, cope with a breast cancer diagnosis, treatment, and with recovery post-treatment. In the Western world, the average age of menopause is 51, with a typical age range spanning 40-61 years. The average age among survey respondents was 47 years, while average time since last treatment for breast cancer was 2.9 years. This suggests Beyond Boobs! is on target in its goal of reaching premenopausal women in particular.

The survey respondents were scattered among Beyond Boobs!'s operating area: 31 percent of respondents live in Greater Williamsburg, 19 percent in Hampton/Newport News, 15 percent in Virginia Beach, 15 percent in south Hampton Roads outside of Virginia Beach, 12 percent in the Richmond area, with the remaining respondents residing in northeastern North Carolina or the Middle Peninsula. The density of respondents in Greater Williamsburg suggests that while that area remains the population center of Beyond Boobs!, there are opportunities for growth in other areas where the organization currently operates.

Beyond Boobs! draws support from women who have faced a variety of breast cancer diagnoses, as 37 percent of respondents were diagnosed with Stage I breast cancer, while 41 percent were diagnosed with Stage II, 16 percent were diagnosed with Stage III and 7 percent with Stage IV. 12 percent of respondents have seen a recurrence of breast cancer following treatment. A majority of respondents underwent breast cancer treatment via (in descending order) surgery, chemotherapy, radiation, and hormone therapy.

Beyond Boobs! draws a disproportionately high number of white participants, and a disproportionately low number of participants from other races when compared with the racial demographics of Hampton Roads and Virginia as a whole. The survey found that 81 percent of survey respondents were white, as opposed to 13 percent who were African-American, 4 percent who were Hispanic, and 2 percent who are Asian. This is concerning for two reasons. First, it suggests Beyond Boobs! is potentially underserving members of minority communities. Second, African-Americans and Hispanics are less likely to have insurance and have lower incomes and net wealth on average than whites, and therefore may have a systematically higher risk for health or financial difficulties resulting from a breast cancer diagnosis.

Beyond Boobs! program participants may have more financial resources or higher levels of social capital on average than the United States population as a whole, which would indicate that especially at-risk women diagnosed with cancer are underrepresented within the organization. With respect to educational attainment, 56 percent of survey respondents had completed a bachelor's degree or higher, compared with 34 percent of all Virginians age 25 and older.

The magnitude of these seeming disparities may be influenced by a higher survey response rate on the part of Boobers from wealthier socioeconomic backgrounds. In addition, there are differences in the incidence of breast cancer across racial groups, with Asian and

Hispanic women less likely than whites and African-Americans to have the disease. However, these two considerations are probably not the primary drivers of the disparities seen in the survey results.

### *Program Participation by Respondents*

Among the methods in which survey respondents learned of the organization, the most common were from “another Boober,” “nurse navigator/nurse coordinator,” and “word of mouth.” This suggests the organization is doing a good job in promoting its efforts via a diverse range of community and medical stakeholders, and that Boobers are speaking positively of the organization.

The majority of respondents, approximately 57 percent, became involved with the organization in the six months following their diagnosis. This is unsurprising, as the shock and fear caused by a diagnosis is an understandably strong impetus towards joining a support group. A question Beyond Boobs! may wish to address is whether and to what extent it makes sense to target support services towards women who are undergoing treatment versus women who are years past their most recent treatment, and how those services might differ, if at all.

The overwhelming majority of respondents relied on close family members, friends and confidants in the time since their diagnosis. This is obviously very good news for those individuals in question. However it is a near certainty that there are at least some women with little to no familial or other types of social support who could benefit from their involvement with Beyond Boobs!. However, they may be less likely to seek out the organization, making outreach to them a challenge.

Participation in the Not Your Typical Support Group among respondents was fairly mixed. Approximately 7 percent of respondents currently attend NYTSG meetings, while 38 percent used to attend and 15 percent never attended. Those Boobers who currently attend support group meetings report attending an average of 8 meetings a year, while those who previously attended support group meetings reported attending only 3.5 a year. The results suggest that the first handful of meetings that new Boobers attend are particularly important in whether that individual persists with the group.

### *Physical Wellbeing*

To gauge changes in physical wellbeing, two questions were developed to investigate energy level changes and problems with completing work and regular daily activities faced by respondents. To evaluate changes in energy level, respondents were asked to assess how often they felt the following conditions, both “after diagnosis, but before Beyond Boobs!” and “after Beyond Boobs!”: 1) a lot of energy and pep; and, 2) worn out and tired. Respondents were asked to rank the frequency with which they experienced these conditions (i.e. none of the time, a little of the time, some of the time, most of the time, and all of the time). Several major changes in energy level were noted among respondents. In particular, the number of respondents who felt they experienced a lot of energy and pep “a little” or “none of the time” decreased by approximately 50 percent. The number of respondents who felt a lot of energy and pep “most of

the time” increased significantly, by 160 percent. These results demonstrate that respondents, in general, experienced positive changes in the frequency with which they felt a lot of energy and pep after they participated in the support group program offered by Beyond Boobs!.

Not only did respondents more frequently feel a lot of energy and pep after their involvement with Beyond Boobs!, but respondents decreasingly felt worn out or tired. Respondents who felt worn out and tired “all of the time,” “most of the time” and “some of the time” experienced declines in frequency by 46, 37, and 14 percent, respectively. The decline in frequency of reduced energy again suggests that participation in Beyond Boobs! programs may be influential in enhancing energy level and physical wellbeing.

The second question asked respondents to assess if they experienced interruptions to their work or regular daily activities as a result of physical health. The scenarios respondents were asked to evaluate included whether they: 1) cut down the amount of time spent on work or other activities, resulting in accomplishing less than they would like, 2) were limited in the kind of work or other activities they performed, 3) had difficulty performing work or other activities, or 4) experienced none of the above difficulties. Across the board, fewer respondents reported encountering these difficulties. Furthermore, the number of respondents who did not feel any of these impediments increased by approximately 30 percent, reinforcing the finding that participation in Beyond Boobs! programs may positively influence physical wellbeing.

### *Social Wellbeing*

Beyond Boobs! program participants were asked to respond to a series of questions regarding key aspects of their social life. Respondents were asked to identify how their physical health and emotional difficulties had impacted their normal social activities with family, friends, neighbors, or groups in which they are involved. Following diagnosis but before receiving Beyond Boobs! services, normal social activities were found to be largely interfered with. After having received Beyond Boobs! services, responses shifted toward less severe self-assessments of social interference, as evidenced by the 30 percent decline in respondents reporting moderate or greater interference.

Another question assessed to what degree respondents felt there were people available whom they could count on to listen to them when they needed to talk. After diagnosis but before receiving Beyond Boobs! services, a large number of respondents felt they did not have strong social support networks. As with physical health, the trend of positive changes after receiving Beyond Boobs! services continued. Approximately 37 percent fewer respondents felt they did not have a reliable social network. It is important to note that the number of respondents who felt as though they had no one they could talk to decreased to zero, suggesting that participation in Beyond Boobs! helped some individuals build a social support network.

### *Emotional Wellbeing*

Approximately 58 percent of respondents reported that emotional difficulties, such as anxiety and depression stemming from their breast cancer diagnosis, led them to reduce their participation in work and daily activities following their diagnosis. Ultimately, 40 percent of

Boobers report currently having problems with work or daily activities as a result of emotional difficulties, suggesting improvement after involvement with Beyond Boobs!.

Respondents were also asked to assess the degree to which they felt they were able to count on a person for emotional support. Almost 80 percent of survey respondents were able to count on a person for emotional support to at least a moderate extent at the time of their diagnosis. It is possible that people with strong social support networks are systematically more likely to become Beyond Boobs! participants. After involvement with Beyond Boobs!, that number increases to 90 percent.

Finally, respondents were asked if they had as much contact as they would like with a person they felt close to and in whom they could trust and confide. Most respondents felt satisfied with their level of contact with their confidants, while 24 percent of respondents did not feel they had reliable access to their confidants. After receiving Beyond Boobs! services, another favorable shift occurred. Even more individuals expressed satisfaction with their level of contact and even fewer respondents reported the absence of reliable access to their confidants.

#### *Respondent Perceptions of Beyond Boobs! Program Efficacy*

Three questions were developed to evaluate respondent's perception of the efficacy of Beyond Boobs! programs and events. The first of these asked respondents to consider how influential the organization was in improving their treatment and/or recovery. On a scale of 1 to 10, with 1 being "not at all" and 10 being "as much as possible," respondents believed that the programs and events they participated in did improve their treatment and recovery. The question had an average rating score of 7.12 and approximately 70 percent of the respondents ranked the program as 7 or higher in efficacy.

The remaining two questions asked respondents to individually rate the efficacy of a list of programs and events on a rating scale of 1, "not at all effective," to 10, "as effective as possible." The six events highlighted included the Breast Ball Golf Tournament, Breast Fest, the Pink Carpet Gala, Petal for the Cure, 10K Run for the Hills, and Starlets of Dance. The only event to have an average rating higher than 7 was the Pink Carpet Gala (7.54). Closely following this event, respondents found the 10K and Starlets of Dance events to be effective with average rating score 5.96 and 5.49 respectively. The remaining events had average scores below 5.

While Beyond Boobs! events were typically not found to be effective at promoting wellbeing or enhancing treatment and/or recovery, the organization's programs had comparatively higher average rating scores. The services listed in the question included the Not Your Typical Support Group, H.I.P. Chicks, Vital Connections, annual Retreat, and Hope in a Tote. The highest rated service was the support group (8.41) followed by the annual retreat (7.98), H.I.P. Chicks (7.88), Vital Connections (7.60) and Hope in a Tote (7.06). The responses to these questions suggest that the services Beyond Boobs! offers to members are more effective at promoting wellbeing and enhancing treatment and/or recovery than the events hosted by Beyond Boobs!.

### *Free Response Section*

Survey participants were asked to provide feedback through a variety of free response questions. The free response section is intended to capture the feelings and thoughts of Beyond Boobs! members and to provide information for crafting future strategies for the organization. Given the nature of free response, the content of the feedback was varied, but several distinguishable and persistent themes were evident.

Respondents identified many central aspects of what they feel makes Beyond Boobs! services effective, such as being able to express themselves in a safe and understanding environment while feeling empowered and uplifted. Participants also identified some aspects of the services they found ineffective, such as being limited in their ability to participate in events and programs due to financial or scheduling constraints. Overall, most individuals who responded expressed feelings of connectedness, family-like ties, sisterhood, and camaraderie, which they personally felt was essential for their support and prevented them from feeling alone.

Respondents made recommendations for the improvement of Beyond Boobs! services. Recommendations highlighted the communication structure of Beyond Boobs! and the need for the creation of new positions such as a full-time fundraiser. Recommendations and further comments also cited the need for improved descriptions of services, primarily “Hope in a Tote,” as well as the need to address individuals feelings of being unwelcome, perhaps by implementing a mentoring and matching program for new members, which would link them with individuals of similar background and stage in life.

A major overarching theme throughout the free responses was the respondents’ desire to balance growing as an organization with the desire to keep Beyond Boobs! from growing too quickly. Several respondents highlighted the small size and personal, close-knit nature of the NYTSGs and organization as a key strength of Beyond Boobs! culture. Some respondents did advocate for expansion, but this was split between two camps. One small subset of respondents wished to see more programs, events, and general services offered, and another small subset supported geographic expansion and more groups/group meetings in areas of current operation (such as Richmond).

Respondents who chose not to participate in support group meetings also provided feedback. Reasons for non-participation ranged from not feeling welcome by facilitators to not being contacted by the group/organization to being afraid to open up / preferring to not talk about their condition. These respondents recommended instituting a mentoring program, citing mentors as a potential way to engage new members in a friendly way while assisting in the navigation of Beyond Boobs! services and culture. Many of these respondents expressed the concern for what they perceived as “cliques” forming in the groups, which create an exclusionary environment for outsiders and members who are disliked by facilitators. Respondents recommended that the facilitator and group-leader role be a rotating position to avoid clique-forming and mission stray. Finally, some respondents expressed uncertainty as to how money raised from fundraising events is used to help women with breast cancer.

## **5. Methods of Fact Sheet Design**

Among the deliverables requested by the Beyond Boobs! clients was the development of a fact sheet for relevant stakeholders, namely corporate and individual donors, community group sponsors, and potential affiliate non-profit groups. After the survey results were analyzed, a bank of fact sheet content was developed to convey fundamental information about Beyond Boobs! to potential sponsors or donors interested in the organization. In order to illustrate the organization's profile and membership and the impact of Beyond Boobs! on members' wellbeing, a mix of background information and survey results were collected. The fact sheet information bank captured organization and participant information (i.e. number of women served and demographics) and the influence of participation in the Not Your Typical Support Group and other programs and events on members' physical, emotional and social wellbeing. The presentation of key findings from the survey will provide stakeholders with an idea of the groups of women participating in the events and programs offered by Beyond Boobs! and the potential benefits offered to the women served by the organization. Not only will the content in the fact sheet bank briefly overview the organization, but it will demonstrate the efficacy of Beyond Boobs! programs and the stakeholders' potential return on investment. The fact sheet information content can be found in *Appendix E: Fact Sheet Information Bank*.

## **6. Methods of Breast Health Organizational Model Research**

A preliminary list of breast health organizations was composed using Wikipedia and a search on Google<sup>3</sup>. The initial goal was to develop a bank of forty organizations to evaluate. Ultimately, thirty-seven breast health organizations were reviewed. The project's research assistants wrote brief descriptions of the programs offered by the organizations, which were later grouped into different general activity types. The frequency of those types of services offered were counted and included in Appendix F. To help Beyond Boobs! craft a strategy for organizational expansion, broad themes about the structure and goals of each organization was compiled and also listed in Appendix F. The single most pervasive theme throughout this exercise was a dichotomy between national organizations, which tended to focus on education, fundraising, or easily replicable but narrow services, and local or regional organizations, which offered an array of services, including in-person support groups similar to those offered by Beyond Boobs!

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<sup>3</sup> [http://en.wikipedia.org/wiki/Category:Breast\\_cancer\\_organizations](http://en.wikipedia.org/wiki/Category:Breast_cancer_organizations)

## **7. Breast Health Organizations: National vs. Regional Models**

After examining thirty-seven breast health organizations for their education, program, and event offerings, it is apparent that there are two main types of organizational models: national and regional.

National organizations often focus primarily on education, raising awareness about breast cancer, and providing information on prevention. They may focus on raising money for breast cancer research, or on grantmaking to other, locally based organizations. These large organizations provide programs and services that are easily replicable across the country and lack the intimate, small-group feel found in Beyond Boobs! programs and events. While some multistate and national breast health organizations do offer in-person support, few offer in-person support groups with the geographic density, meeting frequency, or personal connection delivered by Beyond Boobs!.

Regional organizations narrowly tailor their support efforts and financial resources to provide programs and events in a specific community or region. Their support efforts were largely centered on support group meetings in which members of the organization met with one another at a defined location, with regular frequency. Moreover, this model provides more intimate, in-person interaction among members in a manner similar to that of Beyond Boobs!.

### *National Organizations*

A minority of the national or multistate organizations offered support services for their members. A noteworthy example is ABCD: After Breast Cancer Diagnosis. ABCD focused their support efforts through one-on-one support through mentors, pairing mentees with their mentors by demographic profile and diagnosis. This pairing process allows women to connect better and focus on working through their diagnosis, treatment, family issues, professional concerns and general anxiety. By creating a social network of women experienced with the diagnosis and treatment of breast cancer, and by making it widely available to women across states by limiting support to one-on-one situations, ABCD is able to provide narrowly tailored support on a large scale.

The majority of multistate or national breast cancer support organizations offer educational programs, outreach, and financial and/or legal assistance. Avva Health, a breast cancer support group started by doctors from Stanford University, is organized to provide women recently diagnosed with breast cancer with a mobile app containing relevant health, prevention, diagnosis, and treatment information. The app offers information to help women navigate from diagnosis to survivorship by providing medically and emotionally relevant information and a network of health providers capable of meeting the varying needs of these women. Other organizations offer similar information and networks via webpages and speaking engagements like Boarding for Breast Cancer, a non-profit group organized for young women diagnosed with breast cancer. In particular, this organization offers the “It’s Personal Campaign,” a forum for women to tell their stories and connect with others. The Breast Cancer Network Australia (BCNA) provides women diagnosed with breast cancer and their families with the best information, treatment, care and support possible by offering financial assistance,

research grants, educational awareness, and representing women's voices and positions with policymakers and health care providers. Both Boarding for Breast Cancer and BCNA are fairly large organizations that operate on a national level in the United States and Australia, respectively.

Other national groups, such as Look Good Feel Better, engage with women through in-person support by providing information and workshops to help patients and survivors cope with physical appearance needs. However, Look Good Feel Better's in-person's workshops last two hours, a very different scope of time than Beyond Boobs! support groups. Another quasi-national organizations, Living Beyond Breast Cancer, pursues a hybrid education/support model, with conferences on different breast cancer topics held mostly in the Philadelphia region, but also at varying sites nationally. While women no doubt gain support from attendance at those conferences, they are less personal and less frequent than Not Your Typical Support Group meetings. In sum, most national breast cancer organizations do not have support groups as a main focus. Direct, in-person support offered by national groups is almost always more targeted and less comprehensive than Not Your Typical Support Group.

### *Regional Organizations*

By contrast, several regionally focused breast health organizations offer a good comparison with Beyond Boobs! and show areas in which Beyond Boobs! might add services. The Linda Creed Epstein Foundation (LCEF), also in Philadelphia, is regionally focused, has a similar organizational structure, and offers a number of different services. Founded in 1987, LCEF was "the first local organization to address breast cancer as a serious and widespread disease threatening the lives of women living in the Delaware Valley." It has a thirteen member Board of Directors, six staff members, and a \$500,000+ yearly operating budget. The foundation offers free mammograms and patient financial assistance, has African-American and LGBT focused support groups, and participates in state-level advocacy as the local grassroots affiliate of the National Breast Cancer Coalition. LCEF can accurately be described as a peer of Beyond Boobs!. However, their advocacy work, more targeted support groups, and focus on free mammograms are activities Beyond Boobs could consider as future directions.

Another regionally based organization that provides support group services is Curemonos, a New Jersey-based community organization "created to help, guide, and educate medically-underserved women (especially Latina women) who are facing a breast cancer diagnosis." Curemonos works to educate individuals in already high mortality populations about the dangers of breast cancer, as well as to educate health professionals about the challenges of serving individuals in those communities. The group also provides Spanish language support, education, and social gathering events, and day-long programs that focus on wellness.

Beyond Boobs! is at or beyond the level and diversity of services offered by the two above breast health organizations. However, the examples of LCEF and Curemonos show that Beyond Boobs! could consider expanding services offered and activities undertaken within its current geographic footprint. For example, the group could pursue grants to fund free mammograms. Beyond Boobs! could increase its educational outreach to health professionals,

drawing on the experience of women who have undergone breast cancer treatment. Beyond Boobs! could also make concerted efforts to expand outreach medically underserved populations.

Ultimately, if the types of support groups Beyond Boobs! offers were easy to run, every breast health organization in the United States would offer them. The fact that they do not suggests Beyond Boobs! is offering something unique. Conversely, other groups may have services that Beyond Boobs! could offer in order to strengthen access to breast health resources for women in Richmond, Williamsburg, Hampton Roads, and northeastern North Carolina.

## **8. Recommendations**

The comparison between national and regional breast health organizations outlined two potential approaches Beyond Boobs! may take. Similarly, the comparison of the thirty-seven breast health organizations also provided a view into alternative program offerings, general themes, and questions to consider before expanding the organization's size and programming. The recommendations will be divided into the following categories: Educational Programs, Support Group Methods, Additional Programs, Organizations to Examine, Questions to Consider, and Final Recommendations.

### *Educational Programs*

Despite the Not Your Typical Support Group being the centerpiece of the Beyond Boobs! organizational model, educational programs are important for a number of reasons, including promoting awareness among Boobers and the community, garnering wider sponsor or donor focus, and fulfilling an advocacy role. Numerous multistate or national organizations focused their efforts on educational programs rather than offering specialized or intensive support group programs. A number of organizations utilized public speaking engagements at schools, community groups, and conferences to give breast health talks, showcase their approach to support or programs, and raise their profile. In particular, Breast Cancer Alliance (BCA) developed a Junior BCA program for high school students to mentor their fellow students and friends and promote breast health awareness.

Other organizations leveraged social media and websites to provide information about diagnosis, treatment and recovery options as well as a forum for women to exchange their stories and experiences. Avva Health, a non-profit organization created by physicians who wanted to offer their patients a central location for breast health and support information, created a phone application to showcase useful information for recent diagnosis and treatment stages and information about local support groups and services. By serving as a gatekeeper for support group information, Avva Health is able to enhance the support network of their members while providing medically reliable information to their members. Boarding for Breast Cancer, a national non-profit group started by Olympic gold medalists who lost a friend to breast cancer, offers an online forum for women to exchange their stories to provide support and encouragement for one another and to foster a sense of hope and inspiration for those women with breast cancer who need it.

Finally, the expansion of Beyond Boobs! Advisory Board would add an element of authority to the organization's support and education efforts. In other organizations, the Medical Advisory Board serves a consultant role, establishing medical legitimacy to the support model of the organization and screening documents set forth by the organization. Beyond Boobs! could benefit from the Advisory Board reviewing applications for health grants and adding legitimacy to the Not Your Typical Support Group model and potential benefits to Boobers.

### *Support Group Methods*

Beyond Boobs! Not Your Typical Support Group offers women an opportunity to open up and voice their concerns in an intimate, nurturing environment. Given that the organization is organic in nature and that Boobers fuel the expansion of the support groups by reaching out their friends and family in need of support, there could potentially be unmet demand in certain communities where Beyond Boobs! has not established itself. For those areas where interest is small but growing, it may be helpful to develop a hybrid support program through one-on-one mentoring with trained Boobers who are willing to devote time outside of their monthly support group activities to newcomers interested in becoming Boobers but without the sufficient numbers to organize a support group. Similar to the one-on-one support offered by After Breast Cancer Diagnosis (ABCD), mentors and mentees could be paired together on the basis of similar demographics, stage of diagnosis or treatment type. This program hinges on the availability of Boobers who are located within close geographic proximity to the newcomers or interested women and who are willing to offer their time. A hybrid support group structure such as this could also be narrowly tailored to provide support for specialized groups by race, age, sexuality or more.

### *Additional Programs*

While many organizations offer financial or legal assistance to their members, this service can be cost intensive and drain resources quickly without a large financial base. In order to maintain current offerings while expanding programs or developing new services, it is essential that events or programs that are not well attended or do not meet the needs of Boobers be streamlined to reduce an inefficient allocation of resources and enhance the efficacy of services. In order to expand the social networks and support services offered to Boobers, it may be helpful to affiliate or partner with other breast cancer organizations with a broad funding base like Susan G. Komen or a specialized organization providing specific services like Look Good Feel Better. By affiliating with organizations like these, Boobers would benefit from the expanded services while cutting the resource costs of provision and enhancing the legitimacy of the organization for potential donors and sponsors.

### *Organizations to Examine*

Of the thirty-seven breast health organizations, ten organizations merit a closer look by Beyond Boobs! staff. Each of these organizations has a unique character and pairs their model with programs and events tailored to meet the needs of their focus group or target audience. These organizations are:

1. After Breast Cancer Diagnosis (ABCD)
2. Avva Health
3. Between Women
4. Breast Cancer Alliance (BCA)
5. Linda Creed Breast Cancer Foundation
6. Living Beyond Breast Cancer
7. Look Good Feel Better

8. Rethink Breast Cancer
9. SHARE Cancer Support
10. Young Survival Coalition

Further information about each of these organizations can be found in *Appendix F: Breast Health Organizations*.

### *Questions to Consider*

Beyond Boobs! will need to consider a number of issues before choosing their method of expansion, whether regional or national, and any changes with their service offerings. The following are several questions that the organization should reflect upon when making these decisions:

1. What does Beyond Boobs! want to do in terms of geographic and program expansion?
2. What are the goals for the organization in the coming year? Five years? Ten years?
3. What are the primary goals? What are the secondary goals?
4. What is the organization willing to change about the culture or structure to accomplish these goals?
5. How will Beyond Boobs! engage with their Boobers as the organization expands? What will the messaging be? How will the organization demonstrate it is following its message? Will there be a mechanism to garner feedback from Boobers?
6. Is Beyond Boobs! ready to potentially lose Boobers as a result of the expansion?
7. Is Beyond Boobs! comfortable with aligning their organization's program and services with other organizations to foster a network of affiliations that can supplement each other's programs and draw from their collective target populations? If so, what values, mission and/or vision would Beyond Boobs! like to see in a potential affiliate?
8. Would Beyond Boobs! rather be a more comprehensive breast health organization in Hampton Roads/Richmond/northeastern North Carolina or a more narrowly targeted organization that works over a much greater distance with a less personal, more replicable model?

### *Final Recommendations*

Ultimately, changes to the organizations structure, program offering, and expansion will need to be as transparent as possible. Messaging is key to this transparency. The organization will need to make efforts to ensure Boobers are not going to lose the personal experience they have grown to love during the expansion. The character and quality of Beyond Boobs! programs are quintessential to the organization and Boobers have grown accustomed to it. While changes to the organization are inevitable, Boobers will need to be made aware of the changes coming and where the organization is headed, even if the changes are slight. Other considerations need to be made to ensure that as the organization adapts and evolves its base is not alienated or cut off. Ideally, the organization will need measures of both change and continuity, as new and old Boobers become a part of the organization and allow the organization to truly grow. The following suggestions may prove useful for the organization to follow in the coming years:

1. Implement an annual or biannual survey to evaluate organizational demographics and changes in wellbeing per Boober. In addition to this survey, a newcomer survey will need to be implemented that specifically asks them to evaluate their wellbeing prior to any involvement in Beyond Boobs! programs or services. This will add a proper baseline to the annual survey and allow for stronger comparisons in the future.
2. Create opportunities for Boober feedback on events and programs to determine which are most and least effective. Take these results into consideration with those from the annual survey to guide programming decisions for the future.
3. Create a newcomer form, electronic and hard copy, something that newly interested women can provide basic contact and medical information and a means of contact. It will allow the organization to institute a newcomer survey and the annual survey.
4. Create an anonymous comment box on the Beyond Boobs! website that Boobers can use to provide their feedback on programs, events and services.
5. Create a “Donate Now” button on every page of the Beyond Boobs! website to give stakeholders the opportunity to donate to the organization.
6. Examining the percentage of funds an organization spends on program activities is one of the easiest and most common ways of evaluating the effectiveness of a non-profit organization. It is, for example, one of the main metrics Charity Navigator uses in evaluating charities. By continuing the upward trend in program expenditures as a percentage of overall expenditures, Beyond Boobs! will be better positioned to raise more funds in the future, in addition to delivering more services to Boobers and the public.
7. All else being equal, support group services may especially improve the quality of life for younger women, women who lack other means of social support, and women from more precarious socio-economic circumstances. By broadening its membership among those groups, and among African-American, Hispanic-American, and Asian-American women, Beyond Boobs! will be able to grow its membership within its current geographic footprint, will become more competitive in applying for health grants, and may add even more value per-member than it is currently.
8. The literature review provided in this report will hopefully help the Beyond Boobs! leadership learn more about the existing research on the relationship between breast cancer and quality of life, and between quality of life and the types of services offered by Beyond Boobs! and other breast health organizations. By working with its Advisory Board to continue research on the themes discussed in the literature review, Beyond Boobs! can ensure that it is delivering services that add the most value for breast cancer survivors, and will be even better positioned to document and demonstrate why that is the case. This will in turn make the organization even more competitive for more funding opportunities. In addition, expanding the Advisory Board via increased membership by physicians, psychologists, and hospital administrators will help the organization stay

current on relevant research and develop even stronger ties with organization partners and funders.

9. Raising funds from health grantmakers would give Beyond Boobs! more money with which to provide services to Boobers, would diversify the organization's base of financial support, and would further increase the organization's standing in the health care community.
10. Virginia-based hospital and insurance companies are unique in that they have an interest in improving health outcomes for women with breast cancer, especially in the state, have important institutional knowledge and resources, and have a financial base from which to fund health organizations like Beyond Boobs!. Few other organizations are so ideally positioned at that equilibrium. As a result, working with those companies could be key in expanding Beyond Boobs! and in continuing to improve services delivered.
11. Organizations with large donor-bases and nationally recognizable names tend to engage the public regularly. Separate from the services provided to their members, these organizations hold events specifically intended to raise their public visibility, thereby attracting more donors and creating opportunities for sponsorship of these events. Beyond Boobs! should continue to engage in public speaking events to raise the profile of the organization and achieve the same effect.
12. Finally, Beyond Boobs! has been working towards maintaining strong, well-functioning support groups, and the survey results provide a rationale for continuing these efforts. In order to retain as many Boobers as possible and increase successful recruitment, NYTSGs must be led in such a way that the culture of Beyond Boobs! is readily felt. This will ensure there is a consistently welcoming environment for new and current members and will prevent the formation of exclusionary "cliques."

## **Appendix A: Formal Literature Review**

### *Introduction*

With the exception of skin cancer, breast cancer has the highest rates of diagnosis and mortality in women.[1] Since 1989, age-adjusted cancer death rates for women in the United States declined at an average annual rate of 2-3.3 percent, due in part to earlier detection and improved courses of treatment.[2] Thus, an increasing number of women who have been diagnosed with breast cancer are living today. Despite this decrease in mortality rates from breast cancer, diagnosis rates are still high and have a significant impact on the wellbeing of those diagnosed. By 2015, an estimated 3.4 million women living in the United States will have been diagnosed with breast cancer at some point during their life, fueling public health efforts to improve medical treatment and the quality of life (QOL) of women diagnosed with breast cancer.[3]

### *The Impact of Cancer Diagnosis on Quality of Life*

Many studies find the diagnosis of cancer to have both immediate and long-term impacts on the mental health status of the diagnosed individual.[4] Research indicates that psychological distress may diminish with time, though the degree of the distress may vary. In some cases, survivors three years post-diagnosis may exhibit the same level of distress as individuals three months post-diagnosis.[5] While most studies note impacts on mental health status, a differential impact upon wellbeing by the age of the patient is also noted.[6] A longitudinal study conducted by Vinokur et al., using a sample of 274 breast cancer patients during their first year after diagnosis, examined changes in patient physical and emotional functioning and identified factors that support the recovery process.[7] The study found that younger age had a significant influence on the impairment of mental health, and that younger patients who were seriously impaired had significantly deteriorated physical and emotional wellbeing as compared to their older counterparts. More recently, a study with a sample of 304 breast carcinoma patients comparing the quality of life of younger (50 years or younger) versus older (older than 50 years) women at the end of their treatment, using the Functional Assessment of Cancer Therapy-Breast (FACT-B) instrument, found that younger women reported significantly greater QOL deterioration, especially in terms of their emotional wellbeing.[8]

Prior literature suggests that younger women diagnosed with or receiving treatment for breast cancer should be considered at elevated risk for quality of life disruption, making targeted interventions for this cohort a priority to reduce the potential for significant clinical distress. Furthermore, coping methods available to women diagnosed with breast cancer vary widely, including social support group therapy, psychological counseling, psychiatric intervention, and more. Prior literature recommends that younger women diagnosed with or receiving treatment for breast cancer be considered a high risk group for quality of life disruption, making targeted interventions for this cohort a priority to reduce the potential for significant clinical distress. For the purpose of this study, we will review previous literature to determine the influences of social support group therapy and educational awareness on the age-based differential QOL impact of breast cancer patients to determine whether social support through breast cancer support groups improves the quality of life for younger women diagnosed with breast cancer.

In a study conducted by Epplein et al, 2,230 breast cancer survivors aged 20 to 75 years were examined from 2002 to 2004 in an effort to assess QOL as an indicator for the potential of cancer recurrence and the risk of death.[9] In addition to clinical and demographic information, participants were interviewed 6, 18, and 36 months after they had been diagnosed with breast cancer. Of the sample population, only 1,845 women participated in the final, 36<sup>th</sup> month in-person interview and questionnaire. As some women died or were not accessible during the time period of study, the 2,230 participants' initial, 6<sup>th</sup> month interview results and the 36<sup>th</sup> month's 1,845 participants are taken together to form the basis of analysis for this study. The primary instrument utilized by researchers was the General Quality of Life Inventory-74, a tool that assesses QOL along a number of wellbeing categories including physical, psychological, and social wellbeing. The study found that social wellbeing had the strongest relationship of the four dimensions to mortality. Results demonstrated that higher rates of social wellbeing were statistically significant and associated with a lower risk of cancer recurrence and mortality.

Despite seemingly substantial decreases in risks of recurrence and mortality associated with increased social wellbeing, no single or combined dimension of QOL was found to be statistically significant at the 36<sup>th</sup> month interview. Researchers suggested that the social "facets of marriage and family, social support, and interpersonal relationships caused reduced risk of recurrence of 43%...40%...and 35% [respectively]." It is important to note these same facets were significantly associated at the 6<sup>th</sup> month interview, sooner after diagnosis, suggesting that social support immediately after diagnosis may help reduce the risk of recurrence and/or mortality. Although these results were not statistically significant, further research could better define the promising relationship between QOL and decreases in recurrence and mortality. Indeed, the researchers proceed to discuss a 2009 study, highlighting how many studies have found that larger social networks and increased social support resulted in significant and meaningful increases in survival when compared to women who may be classified as "socially isolated."

The study by Epplein et al. supports the theory that social intervention sooner after diagnosis can result in higher QOL, potentially decreasing the risk of recurrence and mortality. This finding may be important for health care providers and the support group community to help promote cost-effective and widely accessible care for outpatients. Furthermore, this cost-effective treatment could potentially increase survival rates, as "one's social wellbeing is potentially modifiable."

Depression is widely noted as a potential side effect of breast cancer diagnosis. Over the years, several studies have attempted to determine the prevalence of depression among women diagnosed with breast cancer. A study from the United Kingdom [10] found that "nearly 50% of the women with stage I or II breast cancer had depression, anxiety, or both in the year after diagnosis, 25% in the second, third, and fourth years, and 15% in the fifth year." Of the women who experience a recurrence of breast cancer, 45% experienced depression, anxiety, or both within three months of the diagnosis. Previous psychological treatment predicted depression, anxiety, or both in the period around diagnosis (one month before diagnosis to four months after diagnosis). Long term depression and anxiety were associated with previous psychological treatment, lack of an intimate confiding relationship, younger age, and severely stressful non-

cancer-related life experiences. This suggests that breast cancer organizations should target their resources towards women who are already at-risk for depression, such as chronically ill women and those in poverty, as well as younger women and those most susceptible to reoccurrence of breast cancer. As a result, the research suggests that breast cancer support organizations could be more effective in their outreach efforts by targeting women who, because of life circumstances, lack the knowledge or inclination to join support organizations.

The healthcare needs of more recent survivors may also be different and more acute than those whose breast cancer occurred further in the past. A French study [11] found that patients who were assessed at five and ten years post-diagnosis demonstrated diminished physical and emotional functioning as compared to the control group. However, survivors who were fifteen years removed from their diagnosis “were generally not different than controls.” This finding suggests that breast cancer organizations may optimize the efficacy of their services by targeting their efforts at newly or recently diagnosed patients rather than those who are more than a decade past their original diagnosis.

### *Age-Based Differential Impact on Quality of Life*

A 2010 study conducted by Kwan et al. evaluated the quality of life of women diagnosed with breast cancer immediately after diagnosis.[2] Using the Functional Assessment of Cancer Therapy-Breast Cancer (FACT-B), the authors evaluated the functional, emotional and physical wellbeing of a sample of 950 women and found that youth was associated with a diminished quality of life relative to older women. The authors also found that higher levels of social support were associated with higher quality of life in patients following diagnosis. The women with higher levels of social support tended to be older, suggesting that younger women with lower levels of social support are especially in need of intervention to preserve or enhance their quality of life after breast cancer diagnosis.

In a study by Chou et al., researchers investigated linkages between support mechanisms and survival rates in young patients.[12] Emphasizing a targeted approach, the researchers sampled women ages 50 or younger, taking into account “disease severity, treatment, socio-demographic factors, and health status,” and focusing on “the structural and emotional aspects of social support by examining the effect of changes in social contact on survival in the early months after diagnosis, capturing a snapshot at a point of time that may be the most vulnerable for breast cancer patients.” Unlike other studies, the authors tracked changes in social support over time and also examined how survival was influenced by factors like the type of social network and the nature of the contact with supporters.

Researchers conducted in-person interviews with a sample of 584 women within seven months of diagnosis in order to gather demographic information, clinical information, and social characteristics. The selected women participated in the study for 12.5 years, ending in December 2006. Four types of measures were recorded as part of the study survival analysis, including socio-demographic characteristics, disease and treatment characteristics, health status, and social support. Registries provided most basic patient information, while self-assessments utilizing the Medical Outcomes Study (MOS SF-36) and Berkman-Syme Social Network Index (SNI) provided insight into participants’ general health and social support, respectively. General health

included mental health, self-perception of current health, health outlook, and resistance to illness, whereas social support was comprised of both the frequency and quality of contact with others. Social support quality depended on the participants' perception of having received affection and care from those identified as providers of emotional support, as well as their ability to confide in them. Measuring survival status as a dependent variable, it was found that increases in contact with an individual's social support network from a given level corresponded with increased survival rates as compared to those who kept the same frequency of contact. The size of the social network was not found to be a significant factor.

On the whole, the frequency of contact and the level of emotional support significantly impacted the likelihood of survival. This suggests that social support groups and mechanisms play an important role in increasing survival rates in breast cancer patients. The types of support these groups offer alleviates stresses associated with the disease, "benefit[ing] the women's survival by enhancing their coping skills, providing additional support, and increasing opportunities for obtaining cancer-related information." The researchers also noted that social support takes various forms and can occur in both formal and informal settings between groups, within the family, and from health care providers. Managing stress, alleviating anxiety, and forging "social 'connectedness' functions as an informal network where information is exchanged and decisions are supported." This enables diagnosed individuals to have better responses to their circumstances (such as managing depression) while forming a communal bond and lessening self-perceived burdens. Another study, conducted by Bloom and Spiegel,[13] found that limitations on a woman's social participation ability negatively impacted her social network, which may explain why the Chou et al. study revealed no difference in survivability for those with constant or decreasing social networks after diagnosis.

### *Social Support and Quality of Life*

Numerous studies have found that social support positively influences quality of life in breast cancer patients. In a 2002 study conducted by Michael et al., the authors examined the impact of social networks on quality of life in breast cancer survivors.[14] Using the Nurses' Health Study (NHS) to select their sample group, researchers surveyed women who were free of breast cancer at the time and those who had developed cancer within a four-year follow up window, using the SF-36 and CARES-SF to evaluate QOL, as well as the Berkman-Syme Social Network Index to evaluate social integration. The results demonstrated that socially isolated women were more likely to experience adverse effects on their QOL and wellbeing following a breast cancer diagnosis. In particular they experienced a significant level of diminished role function, vitality, and physical function compared to women considered socially integrated. "Prediagnosis level of social integration" explained more of the variation in health related QOL than treatment type or tumor characteristics.

A similar study conducted by Kroenke et al. in 2006 evaluated the influence of social ties on survival, specifically examining whether mortality increased or decreased after diagnosis of breast cancer.[15] Using a sample of 2,835 women from the Nurses' Health Study between 1992 and 2002, the authors assessed the strength of each participant's social network in 1992, 1996, and 2000. The results demonstrated that women who had smaller social networks before diagnosis had an increased rate of mortality compared to those who were more socially

integrated. This suggests that social support group therapy that increases patients' levels of social integration and overall level of social support *could* be positively associated gains in health. However, the existing literature as a whole has not found a scientifically provable link between support group participation and decreases in mortality. Even if there is a link between strength of social networks and mortality, the link might only exist with respect to levels of social support before diagnosis.

The study examined a sample of 2,835 women from 1992 to 2002 in order to assess the impact of social support on survival rates after diagnosis. The measurement of "social support" was divided into a social network aspect and a social-emotional support aspect. The social network aspect was measured by the Berkman-Syme Social Networks Index (SNI), which evaluates participants based on marital status, regularity of social interaction with close relatives and friends, religious affiliation, and affiliation with other community organizations. According to their response patterns, respondents were categorized as socially isolated, moderately isolated, moderately integrated, or socially integrated. The social-emotional support aspect was defined as "the presence and availability of a confidant." Researchers tested this dimension by interviewing participants about the availability and frequency of interaction with a close confidant.

The results found that socially isolated women were more likely to die from both breast cancer and "any cause" than socially integrated women. However, the elevated risk of death was exclusive to those with the highest degree of isolation, suggesting that decreases in isolation can improve the chances for survival. Measurements of social networks through the SNI seem to support this trend. Although no relationship was found between survival and either marital status or group membership, the absence of close family, other relatives, and friends was found to significantly increase the risk of death in women diagnosed with breast cancer. Women lacking close relatives faced a higher risk of overall mortality when compared to women with ten or more close relatives. Those with no close relatives were shown to have an even higher risk (approximates a 165 percent increased risk) of breast cancer death under the same comparison. For women with no close friends, a higher risk of all-cause mortality was found in comparison to women with ten or more close friends. Breast cancer mortality rate increased by 306 percent under the same comparison. The same trend holds true for women with no living children as compared to women with six or more living children, as women without any living children have about 562 percent increased risk of dying from breast cancer. However, it is important to note that the risk of breast cancer mortality, as well as mortality in general, is higher when the participant is absent living children rather than absent close friends. The same risk is also greater for women absent of close friends than for those without relatives. Across all cases, women who were absent any single type of support were at much greater risk of mortality, while the frequency of contact with any type of support appeared to be a weakly related factor.

The findings of these studies suggest that expanding patient social networks and increasing social integration may increase quality of life for breast cancer survivors. Social support group therapy can broaden patients' social networks, improving levels of social integration and overall level of social support. Furthermore, these studies find support from other research with similar outcomes. Caregivers fulfill a critical role in outpatient care, as the risk of mortality, especially from breast cancer, is significantly increased in the absence of a

caregiver. Although marital status and group belonging were found to have no significant implications for survival rates of patients diagnosed with breast cancer, those who were able to rely on family and friends benefitted. “Individuals who have someone available to actively provide...care may be protected from more adverse outcomes.” This suggests that efforts to promote social support group intervention may provide meaningful contributions to recovery for those diagnosed with breast cancer.

### *Social Support Group Therapy and Quality of Life*

Evaluation of breast cancer treatment methods remains in continuous development. Although traditional care for diagnosed individuals and survivors receives a great amount of attention throughout contemporary research and appraisal, some aspects of care have yet to be explored in great detail. The purpose of our work, therefore, is to illuminate these relatively under-explored aspects, principally the benefits of support groups for individuals diagnosed with breast cancer and for survivors. Although the physical, psychological, and social benefits derived from group interaction and support oriented activities are difficult to quantify, numerous sources offer a solid foundation on which to base analyses and contribute to a greater understanding of the impact of support groups.

It is important that breast cancer support groups not oversell the potential benefits of their services, as the research evidencing the benefits of support groups is uncertain. In one of the most noteworthy studies on the effectiveness of support groups [16], Dr. David Spiegel of Stanford University “reported that support groups helped women with breast cancer cope and live longer.” “In Dr. Spiegel’s 1989 clinical trial, the group of women with metastatic breast cancer who took part in supportive group therapy lived eighteen months longer than women who didn’t.” However, this study had “used average survival rather than median survival to compare the groups,” which can be misleading. “When Spiegel’s groups are looked at using the median survival, which gives a clearer picture, there is no significant survival difference between those who did and did not take part in the support group.” In 2007, Dr. Spiegel attempted to replicate his study, and found that support group participants experienced no difference in survival than the control group, while the intervention group did report having better quality of life. In this way support group activity has been clearly linked to higher quality of life, but the strength of the relationship between support group activity and prolonged life remains uncertain.

The American Cancer Society reports that many forms of support groups, including group therapy, “can enhance quality of life.” However, “available scientific evidence does not support claims that support groups can actually extend the survival time of people with cancer.” They expand on this by stating; “The scientific community in general believes that support groups can enhance quality of life for many people with cancer...by providing information and practical support to manage feelings of aloneness and helplessness that sometimes result from a cancer diagnosis. Research has shown that people with cancer are better able to deal with their disease when supported by others in similar situations.”[16] These statements further reflect how the scientific community has accepted support groups as an effective tool to increase quality of life in cancer patients, yet continue to question whether group participation can actually promote survival.

With the high prevalence of psychosocial morbidity accompanying breast cancer diagnoses, a number of methods have been created to address individual wellbeing and promote mental health in diagnosed individuals. Among these methods, supportive-expressive group therapy (or simply, breast cancer support groups) was developed to “help patients with cancer face and adjust to their existential concerns express and managed disease-related emotions, increase social support, enhance relationships with family and physicians, and improve symptom control.”[17] The goal of this group therapy is to support patients and aid in coping behaviors in order to mitigate the effect of the psychosocial distress that negatively impacts patient wellbeing. In a study conducted by Classen et al., 125 women with metastatic breast cancer were randomly assigned to a control or an intervention group, and received either educational materials or a year of weekly supportive-expressive group therapy in addition to the educational materials.[17] Measuring mood disturbance and traumatic stress symptoms, the authors found that this therapy helped patients to cope with their conditions and treatments and reduced psychosocial distress. In doing so, the group therapy improved the emotional wellbeing of patients within the intervention group.

The next study, conducted by Kroenke, Kwan, et al., used a sample of 3,139, breast cancer diagnosed women selected from the Pathways Study.[18] Participant quality of life was assessed through their responses to social network questions derived from the Arizona Activity Frequency Questionnaire (AAFQ, applied in this case to determine participants’ spouse/intimate partner status, number of close friends and relatives, and their religious, social, and community ties), the Berkman-Syme Social Network Index (SNI, or B-SNI, to assess participants’ social network components), the Medical Outcomes Study (MOS) Social Support Survey (which provided emotional/informational support, tangible support, positive social interaction, and affectionate support, forming an aggregate “perceived social support”), and the Functional Assessment of Cancer Therapy-Breast Cancer (FACT-B) Version 3 (for the purpose of assessing QOL in terms of physical, functional, emotional, and social wellbeing).

Socially integrated women were found to enjoy a higher QOL score, whereas socially isolated women “were significantly more likely to have lower than median QOL scores in both minimally and multiply adjusted models.” Higher numbers of close friends and relatives also correlated with improved QOL. In accordance with previous studies in which Kroenke was involved, larger social networks corresponded with increased QOL for breast cancer survivors, higher levels of emotional/informational support resulted in increased social and emotional wellbeing, physical wellbeing was improved with increased tangible support, and positive social interaction was shown to have increased all aspects of QOL. While the study acknowledges that there is a substantial body of prior research pointing to significant positive associations between the size of a social network and QOL, their study is unique in that “these findings are the first to examine social support mechanisms in helping to understand why larger social networks are related to better QOL outcomes in breast cancer survivors.”

The study importantly notes that among their observations, the strongest association appears between positive social interaction and QOL, leading the researchers to conclude that “it is possible that positive social interaction may enable women to forget for a while the distress of being a cancer patient, and the physiologic effects last beyond the actual interaction.” Seemingly almost counterintuitive to their findings, the data also shows that increased affection is related to

lower QOL in participants with late-stage cancer. The authors speculate that there could be an associated burden that accompanies affection such that women may feel the need to constantly appear brave, or that some distancing or avoidance may result from overbearing but otherwise helpful individuals and groups. Strengths of this study were the ability to conduct evaluations during treatment periods (as opposed to solely post-treatment) and the broader array of social support and QOL aspects assessed, including cancer-specific QOL components. Our own study will be limited in this regard because post-Beyond Boobs! assessments are the only sort of assessment that we may feasibly conduct, and also because the multitude of support types and aspects of QOL cannot be effectively implemented as part of our work.

On the whole, breast cancer patients supported by larger social networks were found to have enjoyed a higher QOL. Additionally, results indicate that social interventions may be more successful if the provided support has a broad focus, accounting for more than just social-emotional support. For example, incorporation of tangible, physical support such as providing an individual with a car ride to pick up their prescriptions lends an often-overlooked dimension of support. It is important to provide these supports with the individual's personal set of conditions in mind. In continuing the previous example, late-stage women may need more help in the burden of going to pick up prescriptions. In these ways, research on support groups may be practically applied to provide services that increase quality of life in those diagnosed with breast cancer.

Researchers Kroenke, Quesenberry, et al., conducted another study seeking to clarify the impact of support for those diagnosed with breast cancer. This study focuses on levels of support as well as on the social burden in relationships.[19] Drawing on "2,264 women diagnosed with early-stage, invasive breast cancer from the...(LACE) Study," the researchers hypothesized that "larger social network size would be related to lower mortality in women with breast cancer," and, "that associations would differ by levels of support and social burden in relationships." The researchers used similar survey instruments and questionnaires as other studies, including the Arizona Activity Frequency Questionnaire, the Berkman-Syme Social Network Index, and the FACT-B. The combined use of these instruments provided information of the social relationships of participants. Information about the quality of these relationships was further ascertained by asking participants about their status regarding "a spouse or intimate partner, number of first-degree female relatives (living mother, number of biological daughters, number of full sisters), friendship ties, religious/social ties, and community ties," as well as "whether they were providing caregiving to an infant, a child, or an elderly person or disabled person." Those providing care comprised 34 percent of the study population and were designated as "caregivers."

The greatest risk for all-cause mortality within the study population occurred among participants who had lower levels of support and less substantial social networks. Among those classified as "caregivers," higher social integration was found to correspond to a decreased risk of all-cause mortality. Having a spouse or intimate partner was also found to decrease caregivers' risk of all-cause mortality. Involvement in volunteer work also decreased mortality in caretakers. However, these trends in caregivers were either not significant or weaker in significance than those among women who were not classified as caregivers.

In sum, social network size and participation in social activities was found to increase survivability for those diagnosed with breast cancer. This study revealed the importance of varying levels of social support and the nuances of having a “burden,” as is demonstrated through the experience of caregivers. It therefore follows that the quality of relationships may be an additional relevant factor. This insight provides an important contribution to the research which already supports the beneficial impact of sizeable social networks. This research suggests that one need not have an expansive social network to achieve the benefits of social interventions, and that high levels of support from a small group can increase survivability for those diagnosed with breast cancer. Support serves a variety of purposes in helping those diagnosed overcome stresses and burdens, which has important implications for health care aimed at positively impacting quality of life. The benefits conveyed here are based on participants joining support groups or activities relatively shortly after diagnosis, but the benefits may also extend into the longer-term. Close-knit support groups similar to Beyond Boobs!, and others that are made readily available soon after diagnosis therefore have the very real potential to be a positive factor in people’s lives.

Furthermore, support groups may have different effects on women in different life circumstances. For example, a Carnegie Mellon University study “found that educational groups helped women adjust to a diagnosis of early-stage breast cancer.” However, “some studies of support groups showed limited benefits” while others showed no measurable help. The Carnegie Mellon study reported that women already receiving help at home did not benefit from participating in the group. This provides more support to the argument that breast cancer support groups could add more value if they are targeted towards women who lack existing social support resources.[10]

In addition to offering the potential to “help reduce tension, anxiety, and tiredness (fatigue), and the risk of depression,” support groups may also be helpful to patients “with keeping doctors' appointments, and teaching them about their treatment during group meetings may help them follow their treatment plan as well as reduce stress. Keeping doctor appointments and taking cancer treatments as prescribed may help people live longer, but this type of support is more medical and practical rather than emotional.” It stands to reason that these benefits may be more likely to accrue to women without health insurance or those toward the lower end of the income spectrum, as they may not otherwise have access to these necessary resources. One unique model of cancer support is the Pathfinders program, a non-profit, psychosocial support program for cancer and chronically ill patients.[20] The program is based out of Aspen, Colorado and Duke Cancer Institute in North Carolina. “The program combines patient support, community resources and advocacy with an evidence based curriculum of coping strategies called, The Seven Pillars of Personal Recovery (hope, balance, inner strength, self care, support, spirit, life review).” Researchers conducted a study based on a pilot version of the program, and found that “participation in the Pathfinders program was associated with reductions in distress and despair and improvements in quality of life among advanced breast cancer patients.” In the study, “participants met at least monthly with a licensed clinical social worker who administered the Pathfinders intervention, which focused on strengthening adaptive coping skills, identifying inner strengths, and developing a self-care plan.” As a result, “changes in pre-defined Pathfinders targets such as coping skills, social support, self-efficacy, spirituality, and optimism correlated with improvements in patient-reported outcomes.” This suggests that programs with

holistic strategies similar to that of the Pathfinder program may result in improved quality of life among women diagnosed with breast cancer.

### *Non-social support breast health group activities*

The American Cancer Society (ACS) has examined the literature on other forms of support offered by breast cancer non-profits, including aroma therapy, art therapy, humor therapy, music therapy, psychotherapy, and yoga. According to the ACS, none of these forms of support have been clinically proven to increase the cancer survival rate. However, in terms of benefits, they do demonstrate potential to increase quality of life among cancer survivors.[21] Many breast cancer support groups host yoga, Zumba, or other similar programs that combine physical activity and meditation. There is evidence that doing so could improve the quality of life of patients with breast cancer.

A study produced by researchers at the Albert Einstein College of Medicine randomly assigned patients to a twelve-week waitlist control group or to a twelve-week yoga program that featured physical poses, breathing, and meditation exercises.[22] Patient quality of life was measured before random assignment and three months after the yoga and waitlist programs ended. “Regression analyses indicated that the control group had a greater decrease in social wellbeing compared with the intervention group after controlling for baseline social wellbeing.” Yoga intervention group patients that did not receive chemotherapy saw favorable outcomes in quality of life, emotional, social, spiritual wellbeing, and in-distressed mood, when compared with patients in the control group. As a result, this analysis “suggests that yoga is associated with beneficial effects on social functioning among a medically diverse sample of breast cancer survivors. Among patients not receiving chemotherapy, yoga appears to enhance emotional wellbeing and mood and may serve to buffer deterioration in both overall and specific domains of QOL.” Since yoga programs are relatively easy and inexpensive to set up and because they can also serve as a social activity, these results suggest that breast cancer support groups should consider offering yoga as an activity for participating patients and survivors.

While the links between support and QOL are repeatedly illustrated, groups and organizations should take care in claiming the extent of their impacts. Although several studies have evaluated the links between QOL and risk of mortality, medical science has yet to reach a definitive consensus surrounding the existence of an effect of support on mortality rates. The impact of support on QOL, in many cases, may not be immediately clear or easily measured. However, social support networks are capable of building reliable relationships to alleviate physical stresses (such as difficulty picking up a prescription), emotional distress (such as difficulty coping with depression following a diagnosis), and social stresses (such as not having a spouse, children, and friends and loved ones to count on). Support groups may help to fill a void in these instances, which are commonly faced by those diagnosed with breast cancer. It follows that programs and organizations that are focused on helping individuals through support group therapy and seek to build a support community of similarly-situated individuals can achieve notable gains in the QOL of those diagnosed with breast cancer. Furthermore, receiving support from these organizations and social support mechanisms as quickly as possible post-diagnosis can deter more significant disruptions to QOL and help those with diminished QOL regain more favorable quality of life measurements.

## *Survey Instruments Referenced*

### 1. Berkman-Syme Social Networks Index, or “SNI”

This is a tool used by researchers to understand the degree of social integration or isolation of the respondent. Information about the social characteristics of the respondent is derived from a self-assessment. This questionnaire involves four “types of social connections: marital status (married versus not); sociability (number and frequency of contacts with children, close relatives, and close friends); church group membership (yes versus no); and membership in other community organizations (yes versus no)...allow[ing] researchers to categorize individual into four levels of social connection: socially isolated (individuals with low intimate contacts – not marries, fewer than six friend or relatives, and no membership in either church or community groups), moderately isolated, moderately integrated, and socially integrated” (PhenX Toolkit Supplemental Information, Oct. 21, 2009).

Please see the following source for a description of Berkman-Syme SNI and an example questionnaire:

[https://www.phenx.org/Portals/0/phenx-content/consensus/social\\_environments/18a\\_SocSupport-SNI.pdf](https://www.phenx.org/Portals/0/phenx-content/consensus/social_environments/18a_SocSupport-SNI.pdf)

### 2. The Short Form 36 Health Survey, or “SF-36”

This is a 36-item questionnaire designed to provide researchers with a concise but useful measure of general health. The collected responses help to inform researchers of the level of health, broadly summarized in terms of physical and mental functionality and integrity of the respondent. Most importantly, “as opposed to one that targets a specific age, disease, or treatment group...SF-36 has proven useful in surveys of general and specific populations, comparing the relative burden of diseases, and in differentiating the health benefits produced by a wide range of different treatments” (Ware, n.d.).

Please see the following source for an in-depth description of the scale of measurement, validity of the instrument, interpretation of results, and supplemental SF-36 information, as SF-36 is a registered trademark of the Medical Outcomes Trust:

<http://www.sf-36.org/tools/SF36.shtml>

### 3. Functional Assessment of Cancer Therapy-B, or “FACT-B”

From the Functional Assessment of Chronic Illness Treatment (FACIT) Measurement system, owned and copyrighted by David Cella, Ph.D., FACT-B is a questionnaire used by researchers to understand the quality of life specifically in Breast Cancer patients. There are several other validated instruments of FACIT which measure quality of life for other chronic ailments, beyond cancer, as well. The FACT-Breast Symptom Index (FBSI) and National Comprehensive Cancer Network-FACT FBSI 16 (NCCN-FACT FBSI-16) are both supplemental question sets which further ascertain quality of life.

Please see the following source for the questionnaires (FACT-B, FBSI, and NCCN-FACT FBSI-16), as well a description of the questionnaire origins, terms of use, and proprietary rights.

<http://www.facit.org/FACITOrg/Questionnaires>

4. Medical Outcomes Study (MOS)

“The Medical Outcomes Study: Measures of Quality of Life Core Survey (MOS) was a two-year study of patients with chronic conditions. The 116-item MOS core survey measures of quality of life include physical, mental, and general health” (RAND, May 9, 2013). Of the studies in the Literature Review, the MOS Social Support Survey and MOS SF-36

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# Appendix C - Beyond Boobs! Participant Survey

## Survey Information

This survey is being conducted for Beyond Boobs! by graduate students in the Master of Public Policy program at the College of William and Mary. The survey involves answering questions about your experience as a Boober and how Beyond Boobs! has influenced your life. This survey is estimated to take 8-15 minutes to complete.

Although this survey does ask for some identifying information, the information collected in this survey will be reported in aggregate form. In particular, individuals will not be identified in the final report, and individual responses will not be shared with Beyond Boobs! Copies of the final report will be posted in January, 2014 on the following website: <http://www.wm.edu/as/publicpolicy/graduate/research/index.php>

Participation in this survey is voluntary. By beginning the survey, you acknowledge that you have read this information and agree to participate in this research, with the knowledge that you are free to withdraw your participation at any time without penalty.

If you have any questions about the survey or the research project, please contact Professor Sarah Stafford, Director of the Thomas Jefferson Program in Public Policy, College of William and Mary at [slstaf@wm.edu](mailto:slstaf@wm.edu) or (757) 221-1317.

# Appendix C - Beyond Boobs! Participant Survey

## Personal Information

### 1. What is your age?

- 18-22
- 23-27
- 28-32
- 33-37
- 38-42
- 43-47
- 48-52
- 53-57
- 58-62
- 63-67
- 71-75
- 76-80
- 81+

### 2. What is your sex?

- Female
- Male

### 3. What is your race / ethnicity (check all that apply)?

- African American
- American Indian or Alaskan Native
- Asian American or Pacific Islander
- Hispanic or Latin American
- White non-Hispanic
- Other

### 4. What is your city and state?

## Appendix C - Beyond Boobs! Participant Survey

### 5. What is the highest level of education or degree you have completed? (If currently enrolled, highest degree received.)

- No schooling completed
- Nursery school to 8th grade
- Some high school, no diploma
- High school graduate, diploma or the equivalent (such as GED)
- Some college credit, no degree
- Trade/technical/vocational training
- Associate degree
- Bachelor's degree
- Master's degree
- Professional degree
- Doctorate degree

## Appendix C - Beyond Boobs! Participant Survey

### General Information

**6. Have you been diagnosed with breast cancer?**

- Yes
- No

**7. How long ago was your initial breast cancer diagnosis?**

Years:

**8. Has your breast cancer re-occurred following treatment?**

- Yes
- No

## Appendix C - Beyond Boobs! Participant Survey

### 9. How long ago was your your most recent breast cancer diagnosis?

Years:

### 10. At what stage was your breast cancer upon diagnosis?

- Stage I
- Stage II
- Stage III
- Stage IV

### 11. Did you have/receive any of the following? (Check all that apply.)

- Surgery to treat your breast cancer
- Radiation to treat your breast cancer
- Chemotherapy to treat your breast cancer
- Hormone therapy to treat your breast cancer

### 12. How many years ago was your last treatment for breast cancer?

Years:

### 13. How did you learn about Beyond Boobs!? (Check all that apply.)

- Another Boober
- Word of mouth (not from a Boober)
- Oncologist's office
- Radiologist's office
- Surgeon's office
- Mastectomy boutique
- Nurse navigator / nurse coordinator (a designated health professional who provided you with health care and/or treatment guidance)
- Hospital support services
- Website/Twitter/Facebook

Other (please specify)

## Appendix C - Beyond Boobs! Participant Survey

### 14. How soon after your diagnosis did you become involved with Beyond Boobs!?

- 0-6 months
- 7-12 months
- 13-18 months
- 19-24 months
- More than two years

### 15. Since your diagnosis, have you received emotional or psychological support from any of the following types of providers outside of Beyond Boobs!? (Check all that apply.)

- Close family members
- Friends/confidants
- Counselors (including psychological or psychiatric counselors)
- Other social groups
- Religious/spiritual organizations

# Appendix C - Beyond Boobs! Participant Survey

## Your Involvement with Beyond Boobs!

### 16. With which of the following Beyond Boobs! events have you been involved? (Check all that apply.)

	Participant / Attendee	Volunteer
Breast Ball Golf Tournament	<input type="checkbox"/>	<input type="checkbox"/>
Breast Fest – A Party for the Health of It	<input type="checkbox"/>	<input type="checkbox"/>
Pink Carpet Gala – Premiere of the calendar models and A Calendar To Live By	<input type="checkbox"/>	<input type="checkbox"/>
Petals for the Cure	<input type="checkbox"/>	<input type="checkbox"/>
10K – A Run for the Hills	<input type="checkbox"/>	<input type="checkbox"/>
Starlets of Dance	<input type="checkbox"/>	<input type="checkbox"/>
Other (please specify)		

### 17. With which of the following Beyond Boobs! programs have you been involved? (Check all that apply.)

- Not Your Typical Support Group - support group meeting
- H.I.P. Chicks on the Town - group social outings
- Vital Connections - phone, in-person, or online connections with another Boober facilitated by BB!
- Renew Restore Retreat - weekend or daylong retreats for young survivors
- Hope in a Tote - a BB! provided bag containing gifts and items that will help ease the physical and emotional challenges of newly diagnosed women
- None

Other (please specify)

## Appendix C - Beyond Boobs! Participant Survey

### Your Involvement with Beyond Boobs!

#### 18. Do you attend Beyond Boobs! support group meetings?

- Yes, currently attend
- No, used to attend
- Never attended

## Appendix C - Beyond Boobs! Participant Survey

### Your Involvement with Beyond Boobs!

**19. On average, how many Beyond Boobs! support group meetings do you attend a year?**

- 0
- 1
- 2
- 3
- 4
- 5
- 6
- 7
- 8
- 9
- 10
- 11
- 12
- More than 12

## Appendix C - Beyond Boobs! Participant Survey

### Your Involvement with Beyond Boobs!

**20. On average, how many Beyond Boobs! support group meetings did you attend a year?**

- 0
- 1
- 2
- 3
- 4
- 5
- 6
- 7
- 8
- 9
- 10
- 11
- 12
- More than 12

# Appendix C - Beyond Boobs! Participant Survey

## About Your Wellbeing

For the following question, please base your responses on what you believe best reflects your feelings before being diagnosed with breast cancer.

### **21. How would you describe your general well-being prior to being diagnosed with breast cancer?**

- Very good
- Good
- Fair
- Poor
- Very poor

## Appendix C - Beyond Boobs! Participant Survey

### About Your Wellbeing: Before Beyond Boobs!

For each of the following questions, please base your responses on what you believe best reflects your feelings after being diagnosed with breast cancer, but before your involvement with Beyond Boobs!

**22. After diagnosis, but before your participation with Beyond Boobs!, how often did you feel the following:**

	None of the time	A little of the time	Some of the time	Most of the time	All of the time
A lot of energy and pep	<input type="radio"/>				
Worn out and tired	<input type="radio"/>				

**23. After diagnosis, but before your participation with Beyond Boobs!, did you have any of the following problems with your work or other regular daily activities as a result of your physical health? (Check all that apply.)**

- Cut down the amount of time you spent on work or other activities, causing you to accomplish less than you would like
- Were limited in the kind of work or other activities
- Had difficulty performing work or other activities (for example, it took extra time)
- None of the above

# Appendix C - Beyond Boobs! Participant Survey

## About Your Wellbeing: Before Beyond Boobs!

For each of the following questions, please base your responses on what you believe best reflects your feelings after being diagnosed with breast cancer, but before your involvement with Beyond Boobs!

### 24. After diagnosis, but before your participation with Beyond Boobs!, how often did you feel the following about your life?

	None of the time	A little of the time	Some of the time	Most of the time	All of the time
Anxious	<input type="radio"/>				
Calm	<input type="radio"/>				
Content	<input type="radio"/>				
Downhearted	<input type="radio"/>				

### 25. After diagnosis, but before your participation with Beyond Boobs!, did you...

	Strongly disagree	Disagree	Neutral	Agree	Strongly Agree
feel unsettled about your future?	<input type="radio"/>				
feel a sense of optimism about the direction in which your life was heading?	<input type="radio"/>				
believe there was some real purpose for your life?	<input type="radio"/>				

### 26. After diagnosis, but before your participation with Beyond Boobs!, did you have any of the following problems with your work or other regular daily activities as a result of any emotional difficulties (such as feeling depressed or anxious)? (Check all that apply.)

- Reduced the amount of time you were able to spend on work or other activities, or spent longer than usual to perform the same tasks?
- Accomplished less than you would like
- Didn't do work or other activities as carefully as usual
- None of the above

Other (please specify)

## Appendix C - Beyond Boobs! Participant Survey

### About Your Wellbeing: Before Beyond Boobs!

For each of the following questions, please base your responses on what you believe best reflects your feelings after being diagnosed with breast cancer, but before your involvement with Beyond Boobs!

**27. After diagnosis, but before your participation with Beyond Boobs!, to what extent did your physical health or emotional difficulties interfere with your normal social activities with family, friends, neighbors, or groups?**

- Not at all
- Slightly
- Moderately
- Quite a bit
- Completely

**28. After diagnosis, but before your participation with Beyond Boobs!, to what extent did you feel like there were people available to you whom you could count on to listen to you when you needed to talk?**

- Not at all
- Slightly
- Moderately
- Quite a bit
- Completely

**29. After diagnosis, but before your participation with Beyond Boobs!, were you able to count on a person or persons to provide you with emotional support (such as talking over problems or helping you make a difficult decision)?**

- Not at all
- Slightly
- Moderately
- Quite a bit
- Completely

## Appendix C - Beyond Boobs! Participant Survey

**30. After diagnosis, but before your participation with Beyond Boobs!, did you have as much contact as you would like with a person or persons you felt close to, in whom you could trust and confide?**

- Not at all
- Slightly
- Moderately
- Quite a bit
- Completely

# Appendix C - Beyond Boobs! Participant Survey

## About Your Wellbeing: After Beyond Boobs!

For each of the following questions, please base your responses on what you believe best reflects your feelings at the present and after having been involved with Beyond Boobs!

### 31. Currently, would you say your general wellbeing is:

- Very good
- Good
- Fair
- Poor
- Very poor

### 32. Currently, how often do you feel the following:

	None of the time	A little of the time	Some of the time	Most of the time	All of the time
A lot of energy and pep	<input type="radio"/>				
Worn out and tired	<input type="radio"/>				

### 33. Currently, do you have any of the following problems with your work or other regular daily activities as a result of your physical health? (Check all that apply.)

- Cut down the amount of time you spent on work or other activities, causing you to accomplish less than you would like
- Were limited in the kind of work or other activities
- Had difficulty performing work or other activities (for example, it took extra time)
- None of the above

Other (please specify)

# Appendix C - Beyond Boobs! Participant Survey

## About Your Wellbeing: After Beyond Boobs!

For each of the following questions, please base your responses on what you believe best reflects your feelings at the present and after having been involved with Beyond Boobs!

### 34. Currently, how often do you feel the following about your life:

	None of the time	A little of the time	Some of the time	Most of the time	All of the time
Anxious	<input type="radio"/>				
Calm	<input type="radio"/>				
Content	<input type="radio"/>				
Downhearted	<input type="radio"/>				

### 35. Currently, do you...

	Strongly disagree	Disagree	Neutral	Agree	Strongly Agree
feel unsettled about your future?	<input type="radio"/>				
feel a sense of optimism about the direction in which your life is heading?	<input type="radio"/>				
believe there is some real purpose for your life?	<input type="radio"/>				

### 36. Currently, do you have any of the following problems with your work or other regular daily activities as a result of any emotional difficulties (such as feeling depressed or anxious)? (Check all that apply.)

- Reduced the amount of time you were able to spend on work or other activities, or spent longer than usual to perform the same tasks?
- Accomplished less than you would like
- Didn't do work or other activities as carefully as usual
- None of the above

Other (please specify)

## Appendix C - Beyond Boobs! Participant Survey

### About Your Wellbeing: After Beyond Boobs!

For each of the following questions, please base your responses on what you believe best reflects your feelings at the present and after having been involved with Beyond Boobs!

**37. Currently, to what extent do physical or emotional challenges interfere with your normal social activities with family, friends, neighbors, or groups?**

- Not at all
- Slightly
- Moderately
- Quite a bit
- Completely

**38. Currently, is there someone available to you whom you can count on to listen to you when you need to talk?**

- Not at all
- Slightly
- Moderately
- Quite a bit
- Completely

**39. Currently, are you able to count on a person or persons to provide you with emotional support (such as talking over problems or helping you make a difficult decision)?**

- Not at all
- Slightly
- Moderately
- Quite a bit
- Completely

## Appendix C - Beyond Boobs! Participant Survey

**40. Currently, do you have as much contact as you would like with a person or persons you feel close to, in whom you can trust and confide?**

- Not at all
- Slightly
- Moderately
- Quite a bit
- Completely

# Appendix C - Beyond Boobs! Participant Survey

## About Your Wellbeing: After Beyond Boobs!

For each of the following questions, please base your responses on what you believe best reflects your feelings at the present and after having been involved with Beyond Boobs!

### 41. Please rate the following phrases as they apply to you:

	Strongly Agree	Agree	Not Sure	Disagree	Strongly Disagree
I am as healthy as anybody I know.	<input type="radio"/>				
I expect my health to get worse.	<input type="radio"/>				
My health is excellent.	<input type="radio"/>				

# Appendix C - Beyond Boobs! Participant Survey

## Feedback

**42. To what extent do you feel your treatment and/or recovery was improved by Beyond Boobs! services?**

1 - Not At All	2	3	4	5	6	7	8	9	10 - As Much As Possible
<input type="radio"/>									

**43. Do you feel the following events were an integral part of promoting your well-being or enhancing your treatment and/or recovery? Please evaluate the effectiveness of these services in your experience.**

	1 - Not at all effective	2	3	4	5	6	7	8	9	10 - As Effective As Possible
Breast Ball Golf Tournament	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Breast Fest – A Party for the Health of It	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Pink Carpet Gala – Premiere of the calendar models and A Calendar To Live By	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Petals for the Cure	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10K – A Run for the Hills	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Starlets of Dance	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

# Appendix C - Beyond Boobs! Participant Survey

**44. Do you feel the following services you received were an integral part of promoting your well-being or enhancing your treatment and/or recovery? Please evaluate the effectiveness of these services in your experience.**

	1 - Not At All Effective	2	3	4	5	6	7	8	9	10 - As Effective As Possible	N/A
Not Your Typical Support Group - support group meeting	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
H.I.P. Chicks on the Town - group social outings	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Vital Connections - phone, in-person, or online connections with another Boober facilitated by BB!	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Renew Restore Retreat - weekend or daylong retreats for young survivors	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Hope in a Tote - a BB! provided bag containing gifts and items that will help ease the physical and emotional challenges of newly diagnosed women	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Other (please specify)

**45. What do you feel makes these services effective or ineffective?**

**46. What recommendations would you make to improve the services offered by Beyond Boobs!?**

**47. Are there any comments or additional information you would like to add which may be helpful for our evaluation of Beyond Boobs!?**

## Appendix C - Beyond Boobs! Participant Survey

### Feedback

**48. Why did you choose not to attend or participate in support group meetings?**

**49. What recommendations would you make to improve the services offered by Beyond Boobs!?**

**50. Is there any additional information or comments you would like to add which may be helpful for our evaluation of Beyond Boobs!?**

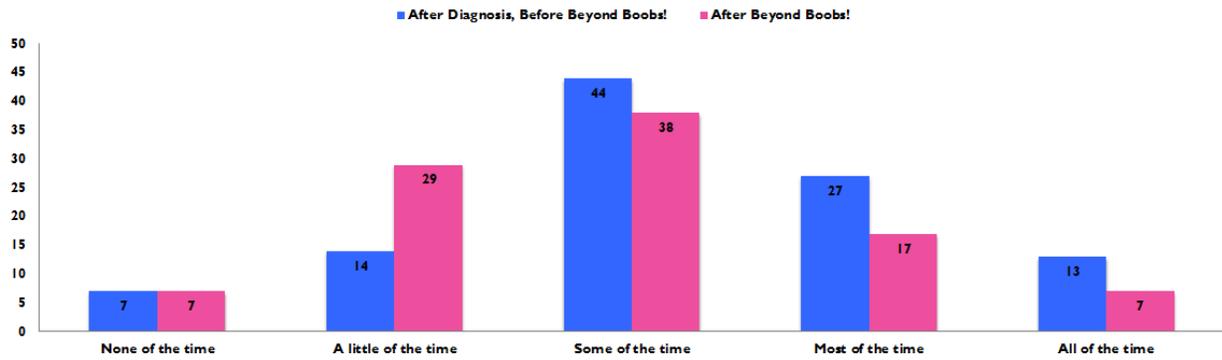
# Appendix C - Beyond Boobs! Participant Survey

## Survey Conclusion

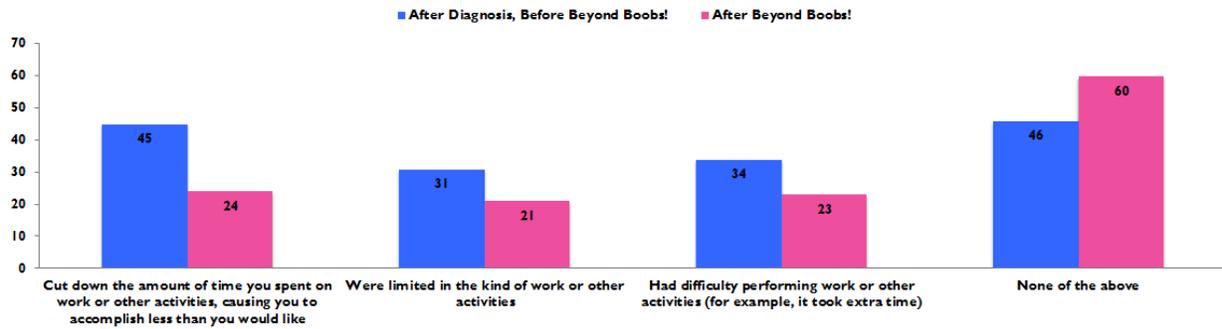
Thank you for your time and participation in our survey! Please look for our final report at <http://www.wm.edu/as/publicpolicy/graduate/research/index.php> in January 2014.

## Appendix D: Charts and Tables

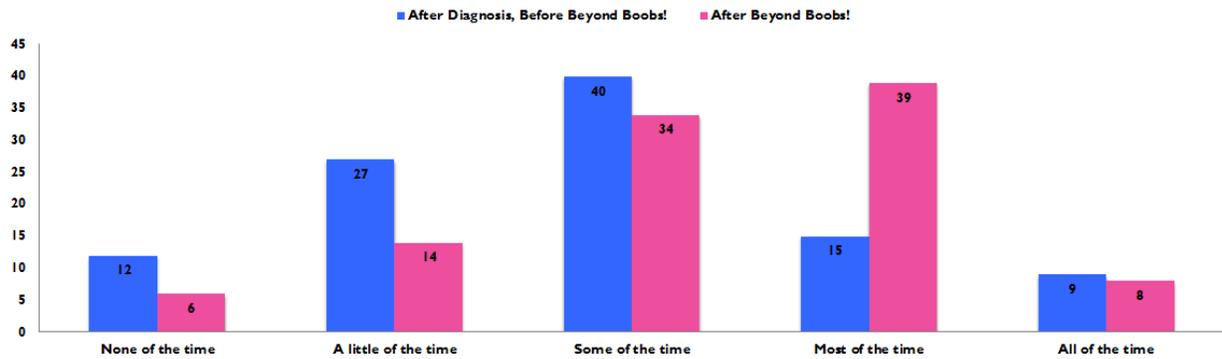
### How often do you feel worn out and tired?



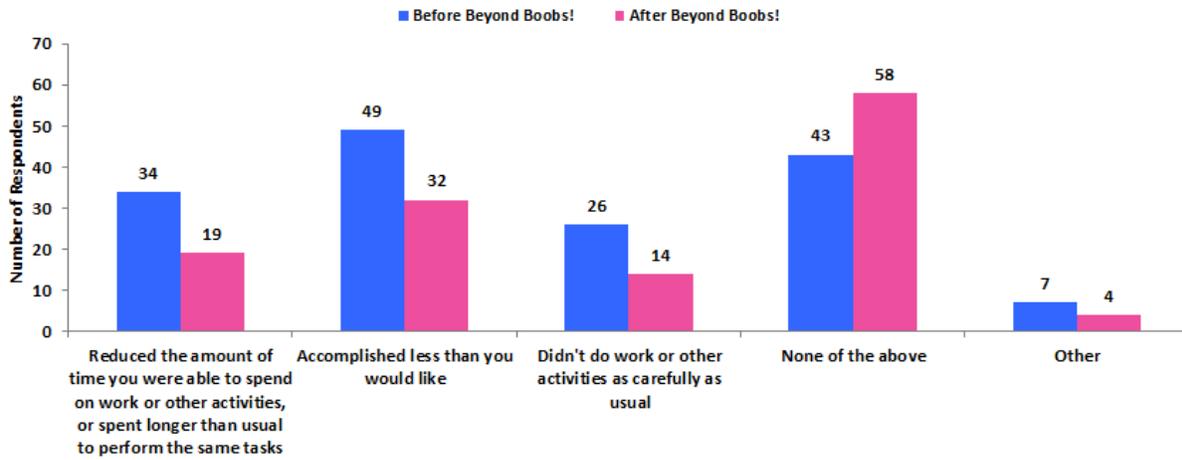
### Did you have any of the following problems with your work or other regular daily activities as a result of your physical health?



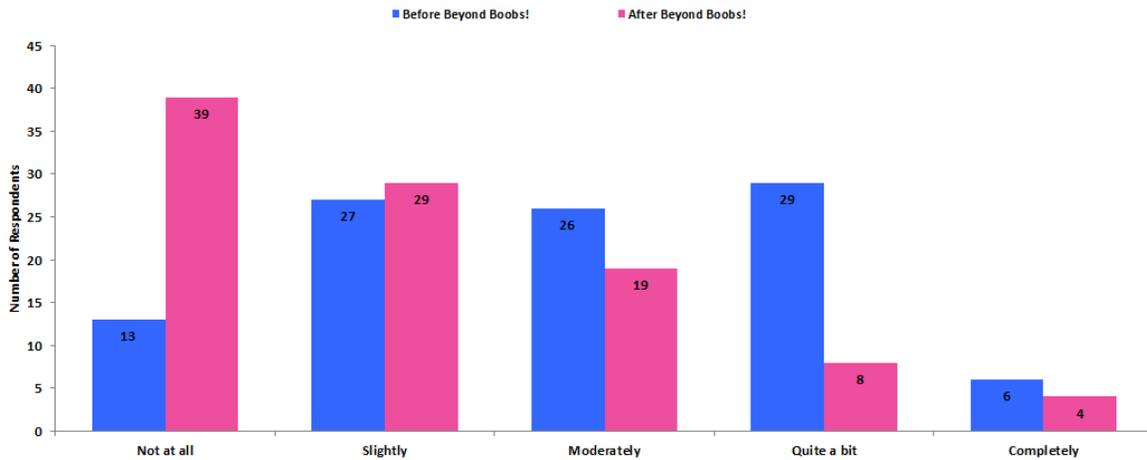
### How often do you feel a lot of energy and pep?



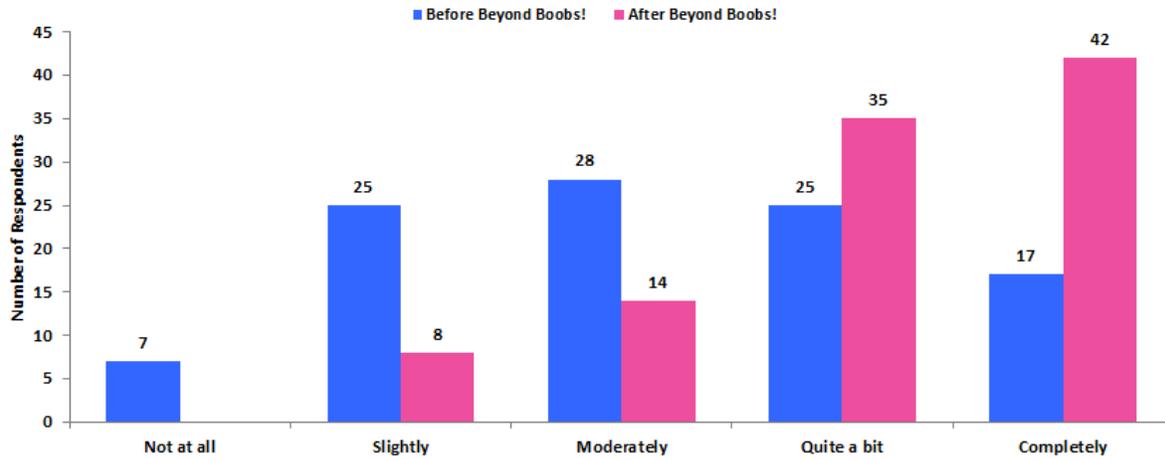
**Emotional Wellbeing: Did you have any of the following problems with your work or other regular daily activities as a result of any emotional difficulties?**



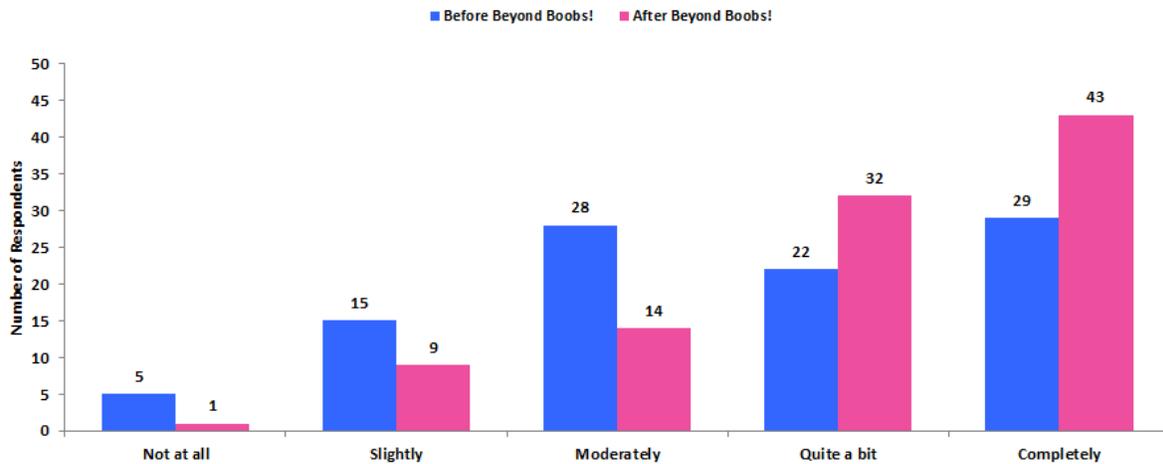
**Social Wellbeing: To what extent did your physical health or emotional difficulties interfere with your normal social activities with family, friends, neighbors, or groups?**



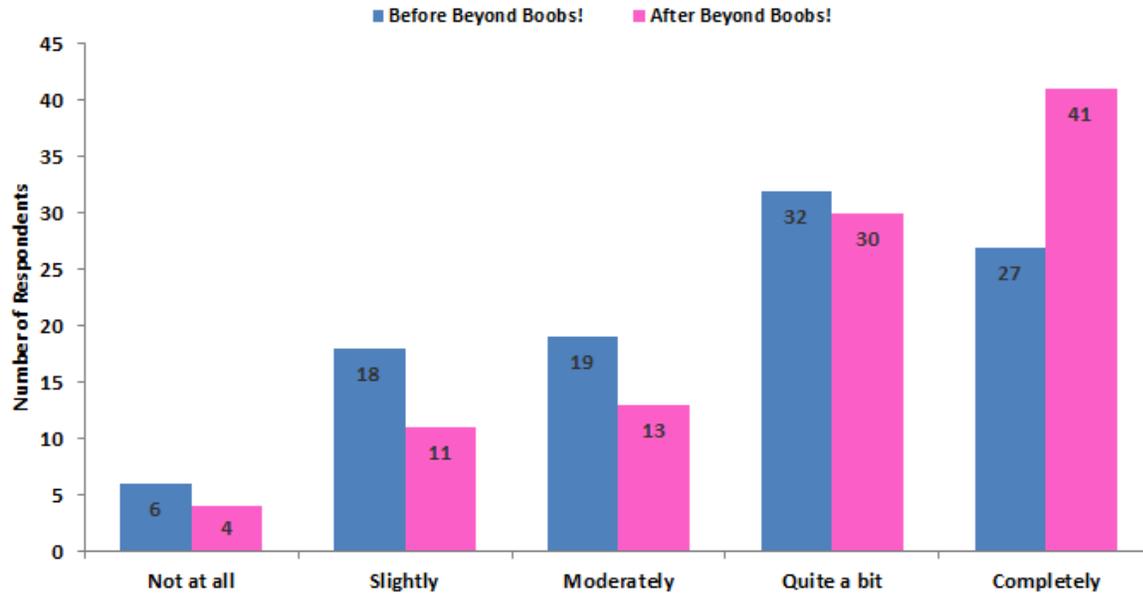
**Social Wellbeing: To what extent did you feel like there were people available to you whom you could count on to listen to you when you needed to talk?**



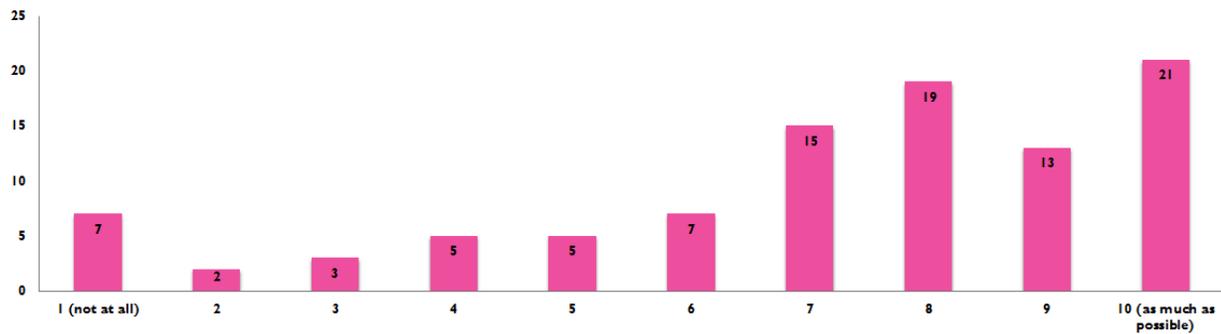
**Social Wellbeing: Were you able to count on a person or persons to provide you with emotional support (such as talking over problems or helping you make a difficult decision)?**



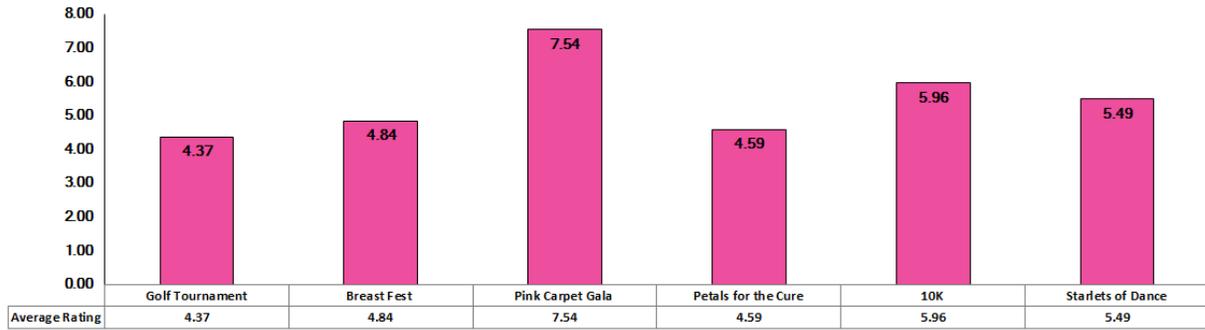
## Social Wellbeing: Did you have as much contact as you would like with a person or persons you felt close to, in whom you could trust and confide?



## To what extent do you feel your treatment and/or recovery was improved by Beyond Boobs!



**Do you feel the following events were an integral part of promoting your well-being or enhancing your treatment and/or recovery?**



**Do you feel the following services you received were an integral part of promoting your well-being or enhancing your treatment and/or recovery?**



## Appendix E: Fact Sheet Information Bank

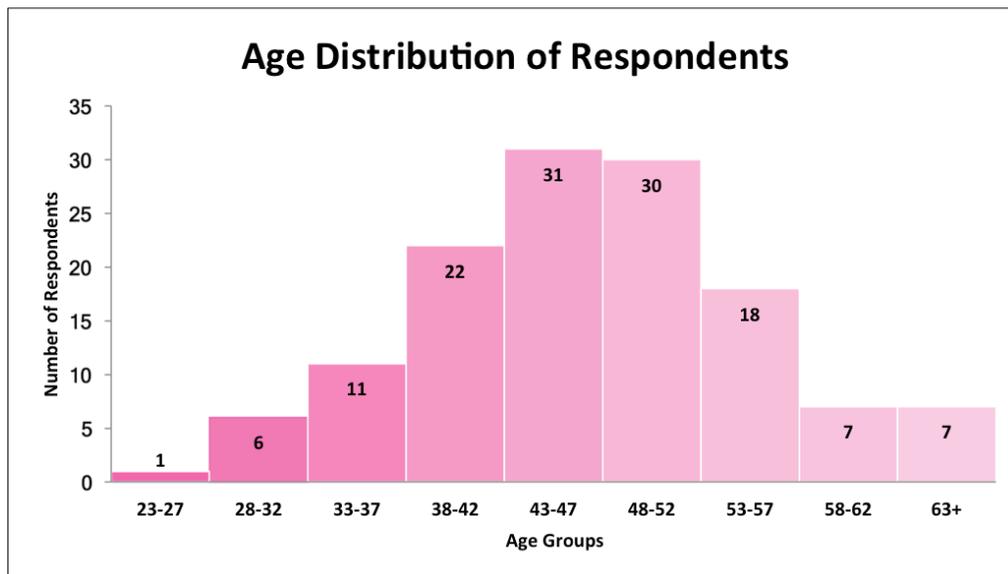
Across the board, the information contained within the fact sheets should be consistent. Stakeholders will likely be interested in:

- the demographics of Boobers;
- the types of events and organizations they most frequently participate in; and,
- the influence of Beyond Boobs! support group activities on the lives of Boobers.

The following list of graphics and their respective descriptions will provide a framework for the information contained within the fact sheets.

### *Demographics: Age of Respondents*

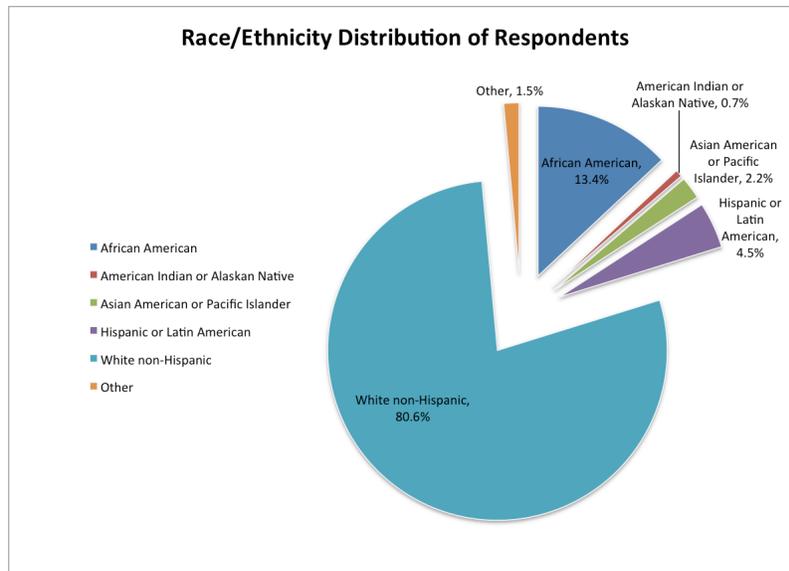
While the survey did not capture the age of all Boobers, the response rate provides a good idea to relevant stakeholders of the relative ages of Boobers. For this particular graphic, the bar graph demonstrates the range of ages and the frequency of respondents within those age groups.



***Interpretation:*** The majority of Boobers who participate in the Not Your Typical Support Group and other programs or events are premenopausal women (younger than 52 years of age). Approximately 75 percent of the Boobers who participated in the survey conducted by the College of William and Mary were 52 years old or younger.

*Demographics: Racial/Ethnic Breakdown*

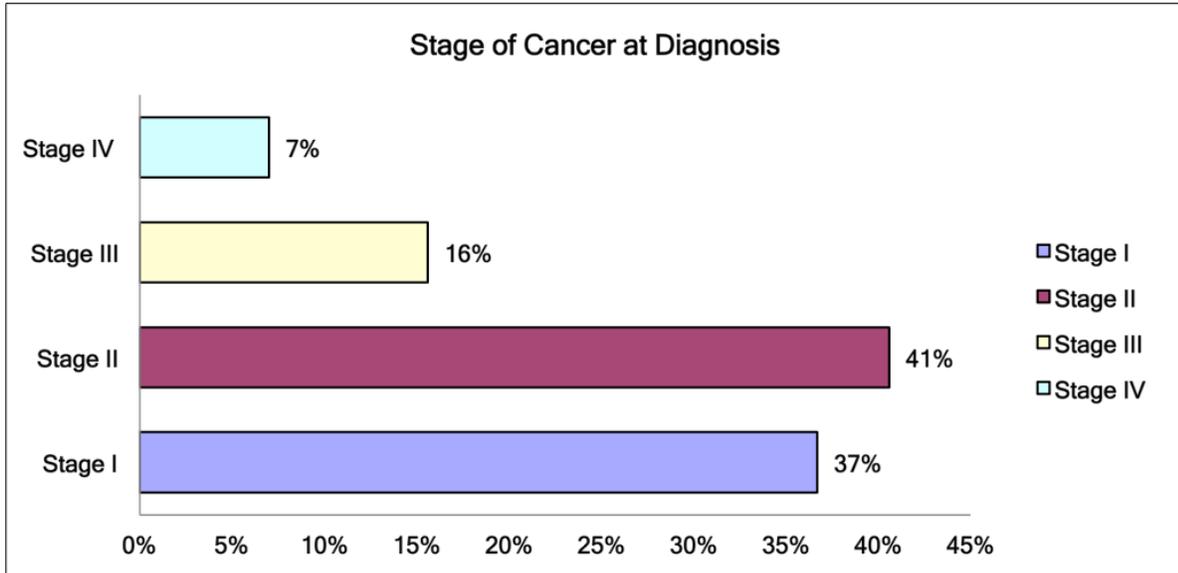
Diversity in an organization’s membership may be an important factor that stakeholders consider when deciding to donate or sponsor non-profit groups. In order to convey the diversity of organization, the pie chart of survey respondent racial or ethnic backgrounds would be effective.



**Interpretation:** Beyond Boobs! hosts a range of program and services that draw women from a variety of racial and ethnic backgrounds. A survey conducted by the College of William and Mary found that 13.4 percent of Boobers are African American, 4.5 percent are Hispanic or Latin American, and 2.2 percent are Asian American or Pacific Islander.

*Demographics: Stage of Cancer at Diagnosis*

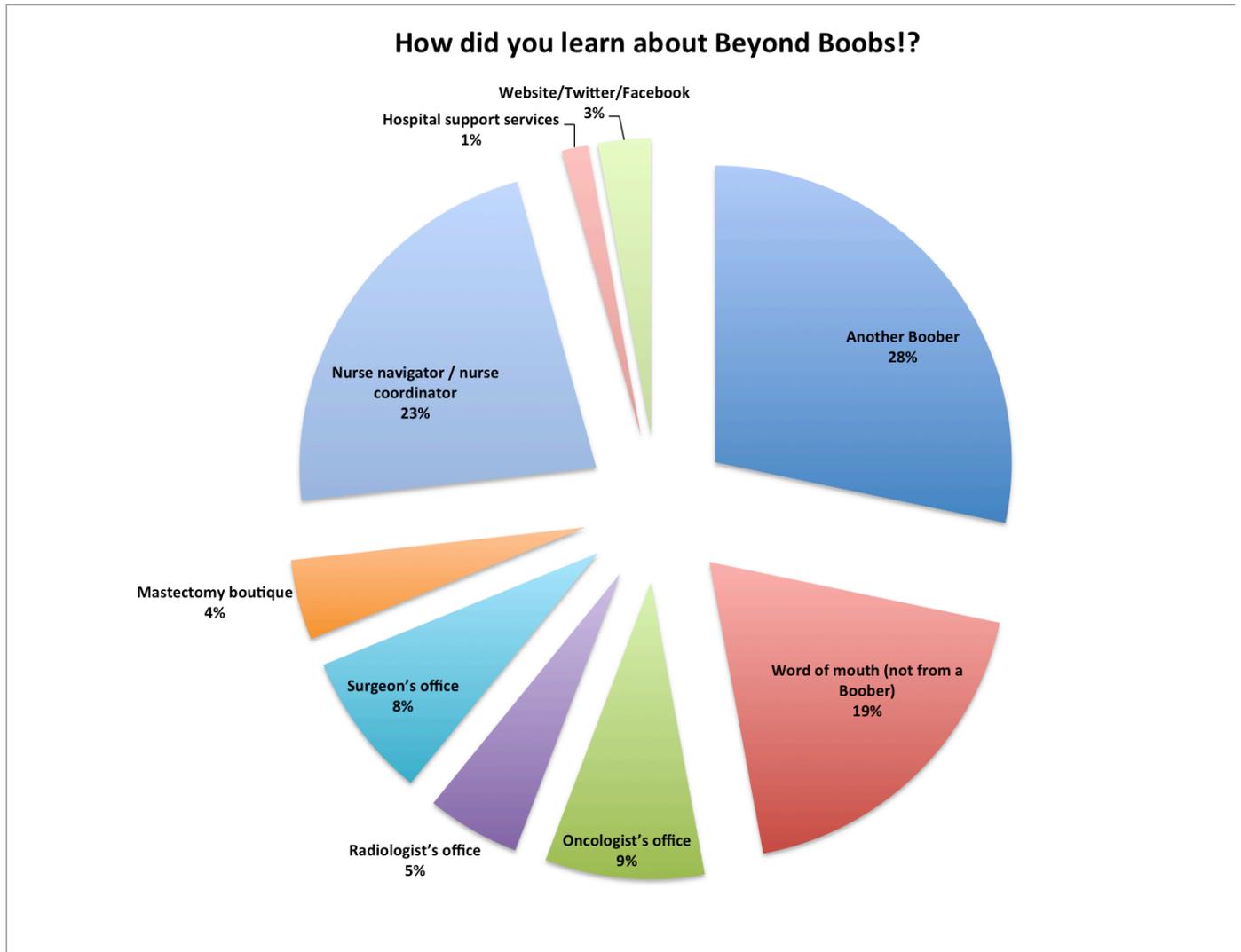
Certain stakeholder groups, in particular other non-profit groups, may like to know the prevalence of each stage of cancer at the time of diagnosis for Boobers. Perhaps, in combination with the aforementioned demographic indicators, the stakeholders may have a better idea of the populations being served by Beyond Boobs!



**Interpretation:** According to the survey conducted by the College of William and Mary, the majority (approximately 78 percent) of Beyond Boobs! members were diagnosed in the early stages of breast cancer. The remaining Boobers were diagnosed at Stage III and Stage IV, 16 percent and 7 percent respectively.

*How did you learn about Beyond Boobs!?*

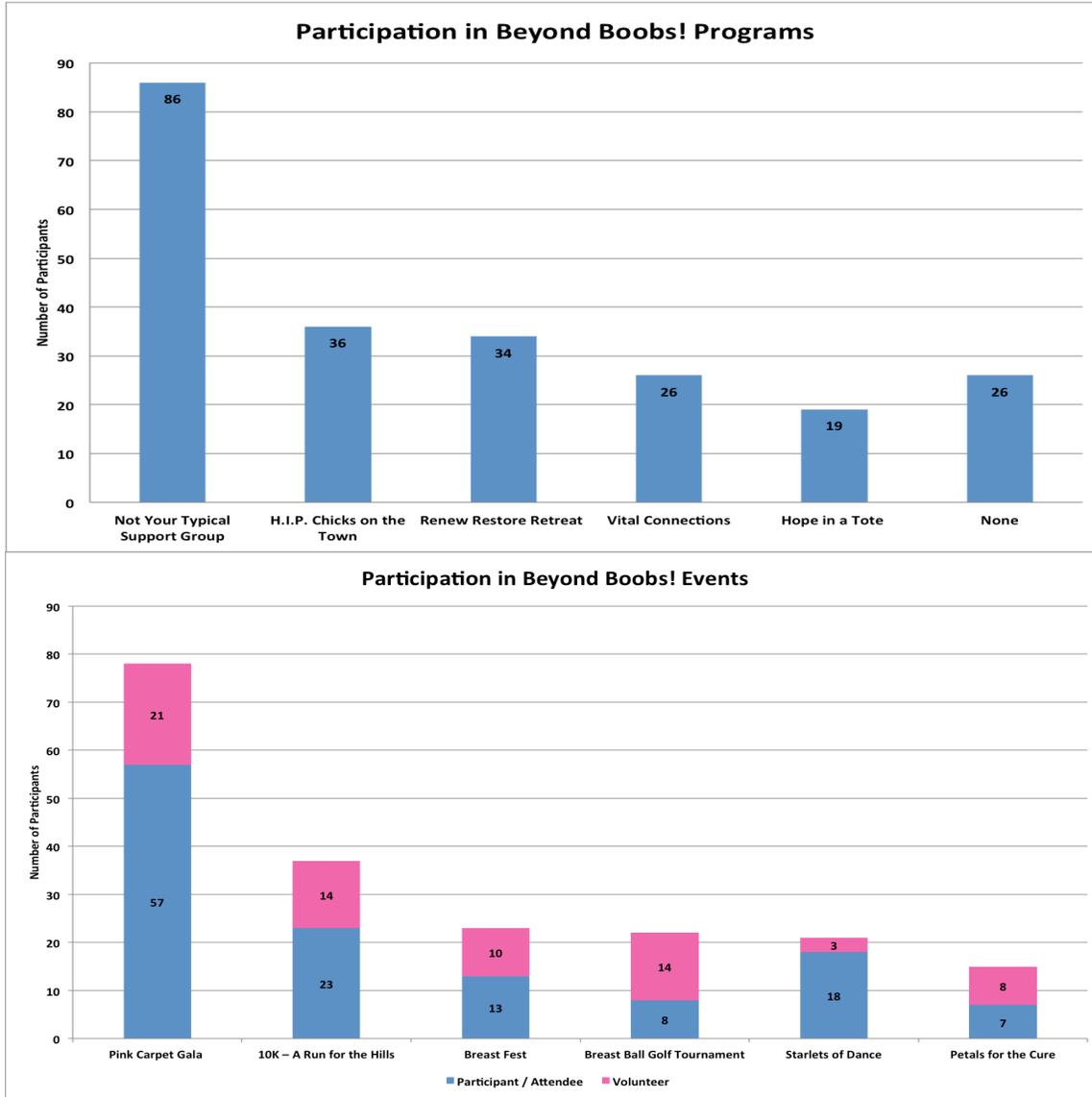
Stakeholders may look positively upon organizations that employ a number of tactics to promote awareness of the organization and services, perhaps demonstrating versatility in the organization and the depth of the organization's connections with the community, doctors and more.



**Interpretation:** The three most popular methods of communicating about Beyond Boobs! to potential new Boobers were from: Another Boober (28 percent), Nurse Navigator/Nurse Coordinator (23 percent), and Word of Mouth (not a Boober) (19 percent). Additionally, Beyond Boobs was recommended to newly diagnosed women and those undergoing treatment by a number of medical providers, including Oncologists (9 percent), Breast Surgeons (8 percent), and Radiologists (5 percent).

*Participation in Programs and Events*

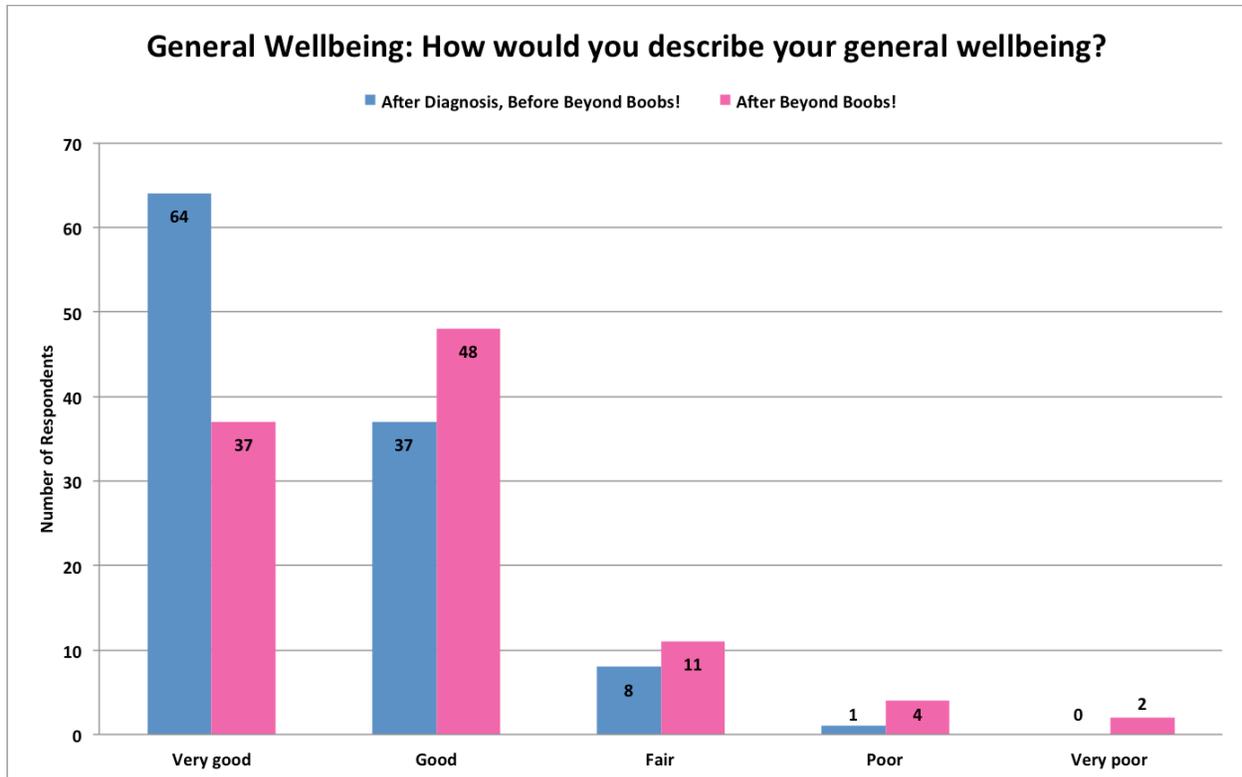
Stakeholders may be dually interested in the programs and events offered by the organization and the participation rates as well. Potentially, these graphics and statistics can demonstrate the organization is reaching a number of members and including a number of community volunteers, which organizations are most important to the organization and members, and may cater to the preferences and interests of the stakeholder.



**Interpretation:** The most popular programs offered by the organization to Boobers are: the Not Your Typical Support Group, H.I.P. Chicks on the Town, and Renew Restore and Retreat. Similarly, the most popular events among Boobers are: the Pink Carpet Gala, 10K – A Run for the Hills, and Breast Fest. On the other hand, the events most popular among volunteers are: the Pink Carpet Gala, Breast Ball Golf Tournament, and Breast Fest.

### *The Influence of Beyond Boobs!: General Wellbeing*

While the survey included general and granular measures of wellbeing, to aid in the efficiency of presenting facts on the document, it may be better to recognize improvements in general wellbeing. General wellbeing in the context of health is defined as, “a broad multidimensional concept that usually includes subjective evaluations of both positive and negative aspects of life,” in light of a person’s diagnosis, treatment or medical condition.<sup>4</sup> Since this category captures the physical, function, emotional, and social wellbeing categories further explored in the survey, it would be a good way to briefly encapsulate the study’s findings and highlight the role the support group plays in improving Boobers’ wellbeing.

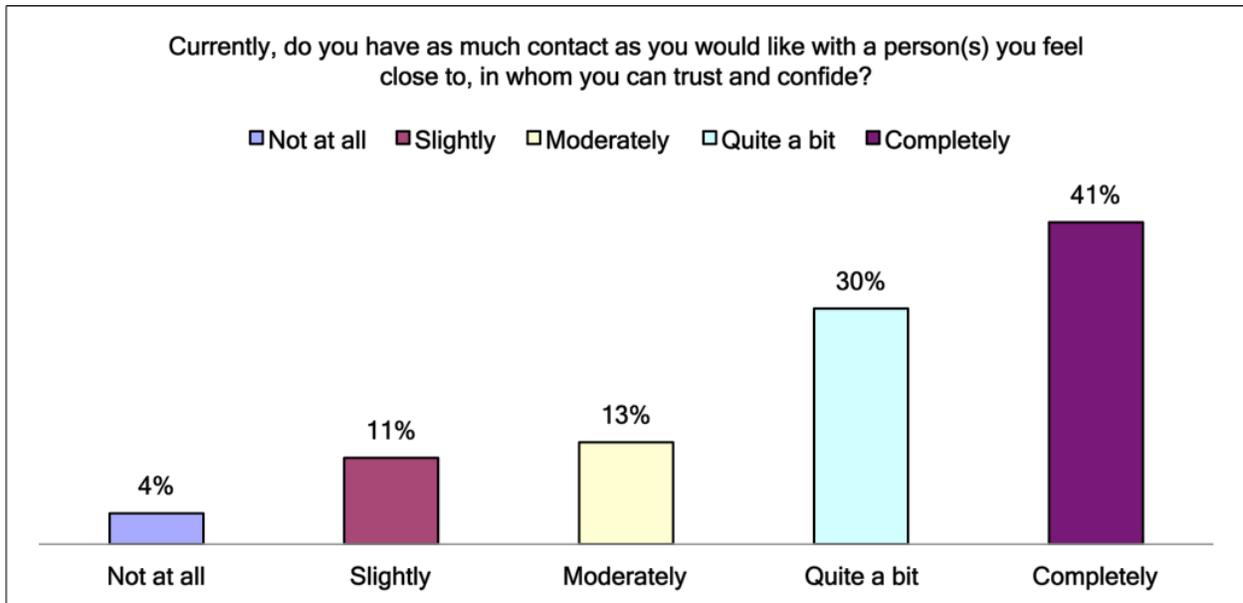


**Interpretation:** According to a study conducted by the College of William and Mary, participation in the Not Your Typical Support Group is positively associated with improvement in general wellbeing. While a number of factors influence wellbeing, including the stage of cancer at diagnosis, treatment type, and length of time in recovery, Boobers typically demonstrated improvement in physical, functional, emotional and social wellbeing.

<sup>4</sup> <http://www.cdc.gov/hrqol/concept.htm>

*Do you have as much support as you would like?*

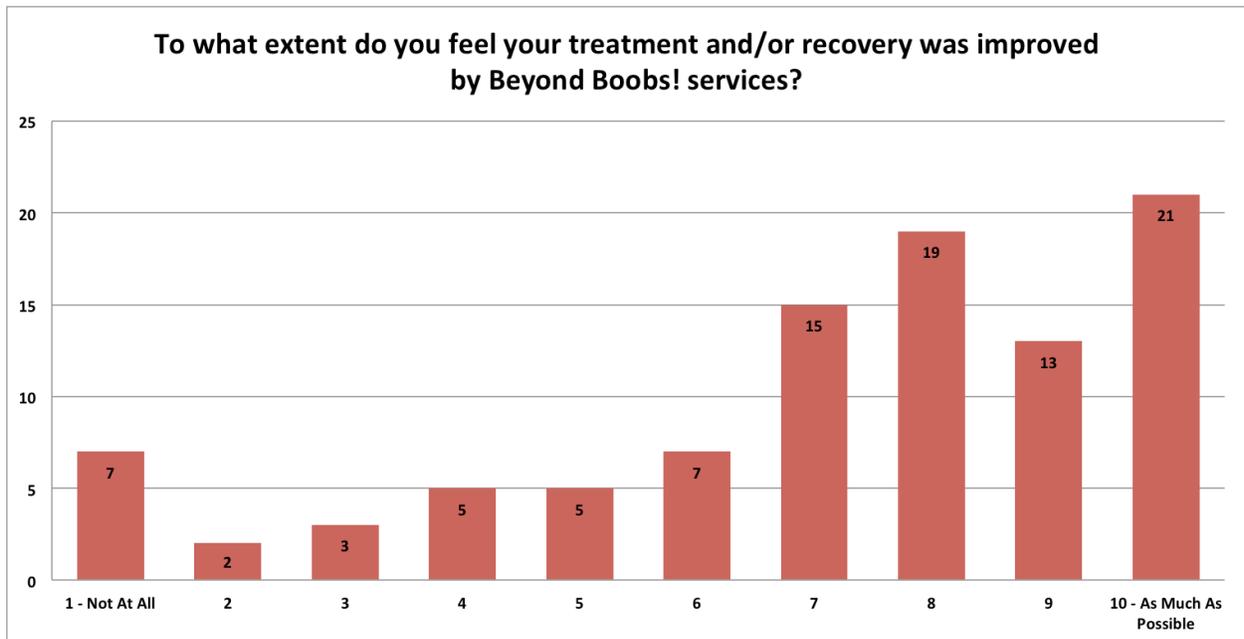
Stakeholders may value a glimpse into the satisfaction of the population served with the programs and services offered. The quintessential service and benefit that Beyond Boobs! provides is support. It necessarily follows that Boober satisfaction with the amount of support provided would demonstrate the organization is meeting the needs and level of demand of its target audience.



**Interpretation:** According to the study conducted by the College of William and Mary, over 70 percent of respondents felt that they completely or mostly received as much contact with the person(s) they were close to, in whom they could trust and confide.

*To What Extent Beyond Boobs! Improved Recovery and Treatment?*

Perhaps one of the most important metrics in valuing the benefits that Beyond Boobs! extends to Boobers is their perception of the influence of the organization on their treatment and recovery. This particular aspect of the organization’s interaction with Boobers would provide stakeholders an assessment of the value the organization’s target audience places upon the support offered to them.



**Interpretation:** The study conducted by the College of William and Mary found that the majority of Boobers believed the organization’s program and services improved their treatment and recovery. On average, respondents ranked their perceptions as to the organization’s efficacy at 7.12 on a scale of 1 (not at all) to 10 (as much as possible).

## Appendix F: Breast Health Organizations

### **ABCD: After Breast Cancer Diagnosis**

- **Background:** Started as a small group founded by a breast cancer survivor.
- **Mission and Target Audience:** This organization is based on the belief that the most valuable information and support come from others in similar life circumstances with similar experiences with the disease. They offer free personalized information and 1x1 support (via mentors) to patients, families and friends. Targets all women diagnosed with breast cancer. The primary focus is on timely diagnosis, treatment, managing family issues, addressing professional concerns, and helping women to cope with general anxiety. Mentors are paired with women of similar diagnosis and demographic profiles.
- **Structure:** Board of Directors, Medical and Community Advisory Board. Has an affiliation with Komen.

### **Avva Health**

- **Background:** Medical Professionals from the Stanford University Cancer Center came together to provide an organizational tool for women newly diagnosed with breast cancer or undergoing treatment after viewing firsthand the complexities of the treatment process.
- **Mission and Target Audience:** The focus is on helping to navigate women from diagnosis to survivorship, medically and emotionally. The organization targets women who are in the process of treatment. The organization provides an Application for smartphones containing information readily accessible for those newly diagnosed or undergoing treatment to provide a more streamlined patient experience.
- **Structure:** Avva was designed by a team of current and former Stanford and Harvard students, and is led by an Advisory Board composed of cancer survivors and faculty of prestigious medical schools. The organization actively seeks partnerships with individual medical professionals.

### **Between Women**

- **Background:** Founded by Linda Cady in 1997 to help other women affected by breast cancer through the treatment process with dignity and hope.
- **Mission and Target Audience:** The organization targets uninsured or under-insured women at risk for breast cancer or recently diagnosed in local areas. Provides educational awareness and materials for Latinas and high school students, access to mammography services, and support services for newly diagnosed women
- **Structure:** Led by a Board of Advisors and an Advisory Council. The organization is one of 600 members of the National Breast Cancer Coalition. This organization operates locally in the Imperial Valley.

### **Boarding for Breast Cancer**

- **Background:** Created in 1996 by four young women (two professional snowboarders) after their friend died from breast cancer.
- **Mission and Target:** The organization targets a young demographic, providing education, prevention services, and support for young women diagnosed with cancer. They seek to provide a model of inspiration and emphasize the pursuit of healthy

lifestyles. The organization has a program called the “It’s Personal Campaign” which is a forum for stories of survivors.

- **Structure:** Led by a five person Board of Directors. Enjoys sponsorship and event support from a variety of skating corporations.

### **Breast Cancer Alliance**

- **Background:** Founded in 1996 by Mary Waterman after receiving a Stage IV breast cancer diagnosis. She wanted to use her limited remaining time to leave a legacy of hope for other women affected by the disease. She founded Breast Cancer Alliance (BCA) with five friends who continued the work after her death.
- **Mission and Target:** Invests in innovative research, breast surgery fellowships, regional education, dignified support and screening for the uninsured and underserved. The organization also offers a Junior BCA program and engages in the mentoring of high school students and educating peers about breast cancer.
- **Structure:** Complex hierarchy with a Board of Directors, Advisory Board, Medical Advisory Board, Founders Board, and Leadership Circle.

### **Breast Cancer Angels**

- **Background:** Founded by two survivors in 2000. The organization began with six individuals (“Angels”) sending in \$20 a month
- **Mission and Target Audience:** Breast Cancer Angels provide financial, emotional and spiritual assistance for women and their families as they are going through breast cancer treatment in Southern California. Services include food program assistance, housing assistance, and clothing and medical costs.
- **Structure:** Individual donors (“Angels”) contribute funds that are almost entirely passed on to patients, and a corporate sponsor covers overhead costs.

### **Breast Cancer Network Australia**

- **Background:** This organization is the largest breast cancer organization in Australia, having been founded in 1998 by Lyn Swinburne to impact the Australian communities burdened by breast cancer diagnosis.
- **Mission and Target Audience:** Breast Cancer Network Australia (BCNA) works to ensure that women diagnosed with breast cancer, and their families, receive the very best information, treatment, care and support possible. The organization targets all Australian women at risk for, suffering from, or having survived breast cancer, as well as all those touched by the disease. In addition to engaging in educational awareness efforts, the group seeks to represent women’s voices and positions with policymakers and health care providers. Members link together by sharing stories on the website.
- **Structure:** BCNA is a national network with more than 85,000 individual members and 310 member groups. The organization is led by a CEO, patron, and governing Board.

### **Breast Cancer Recovery**

- **Background:** Breast Cancer survivor Ann Haney founded BCR in 1997 to facilitate emotional recovery for breast cancer survivors.
- **Mission and Target:** The primary focus of this organization is to provide rejuvenating retreats for female breast cancer survivors.

- **Structure:** The organization is headed by an Executive Committee and a Board of Directors and has five full time staff members. Retreats are subsidized but participants still pay a fee to participate. This organization receives grants from Komen.

### **Breast Cancer Support (Japan)**

- **Background:** This organization has been providing hospital visits since 1993, and now seeks to promote a positive outlook on living with breast cancer in Japan.
- **Mission and Target Audience:** To provide support and education for all Japanese women affected by breast cancer.
- **Structure:** The Association covers all of Japan with over 40,000 members in over 30 local branches.

### **Cancer Care**

- **Background:** Cancer Care (CC) was founded in New York in 1944, and today provides services to more than 1,000,000 people annually.
- **Mission and Target:** CC has an extremely wide target and array of services, seeking to provide aid to patients of all ages, races, and socioeconomic status affected by all types of cancer. Services offered include one-on-one counseling, support groups, education, publications, and financial assistance with medical costs.
- **Structure:** The organization is led by a Chief Operating Officer and has a large, fulltime staff. CC had revenue of \$18.3 million in 2012, with 55 percent of funds generated from corporations and foundations.

### **Cancer Support Community**

- **Background:** In 2009 The Wellness Community and Gilda's Club Worldwide combined to form the Cancer Support Community.
- **Mission:** Provides supportive environments to cancer patients and survivors by providing education and support services to patients, survivors, and caregivers. Provide professional psychosocial oncology mental health support services through a network of professionally led community-based centers, hospitals, community oncology practices and online. The organization has over 50 local branches and 100 satellite locations online.
- **Structure:** CSC has a complex hierarchy with a Headquarters Staff, an Honorary Board, a Young Leadership Council, a Board of Directors, a President's Council, and a Professional Advisory Board. Partners with over 20 national organizations, including ACS and Komen.

### **Cleaning For a Reason**

- Founded in 2005 by Debbie Sadone, owner of Buckets and Bows Cleaning Service, after giving a price quote to a woman who couldn't afford cleaning services because she was undergoing cancer treatment. Debbie decided from that time on to provide cleaning services free of charge to all women undergoing breast cancer treatment.
- **Mission and Target Audience:** Relieve stress in Breast cancer patients by providing complementary services. This organization has provided services to over 13,000 women. Provides free housecleaning services to women with cancer using professional cleaning

services. Targets all women with breast cancer, particularly those responsible for their own homes.

- **Structure:** Services are contracted out in the United States and Canada. The organization is governed by a large Board of Visitors and employs seven fulltime employees and seven part time employees.

### **Crickett's Answer for Cancer**

- **Background:** Crickett's Answer for Cancer (CAC) was formed in 2006 in the memory of breast cancer victim Crickett Julius.
- **Mission and Target Audience:** CAC provides no cost wigs, mastectomy and lymphedema products, massage, facials, and other pampering services to women diagnosed with breast cancer. Seeks to restore a sense of identity and self-esteem in women suffering from breast cancer.
- **Structure:** Run by founders Bonnie Julius and Carl Trone. Relies on small donations and reportedly gives 100 percent of donations to patients.

### **Curemonos**

- **Background:** Breast cancer survivor Dora Arias founded Curémonos in 2007 in order to provide educational and support community similar to that of Beyond Boobs! while also raising awareness among healthcare providers about the barriers medically-underserved women face in the healthcare system.
- **Mission and Target:** Targeted towards medically underserved and uninsured women, also especially focused on the Latino community.
- **Structure:** Headed by founder Dors Arias. This organization receives Komen grants.

### **Diva for a Day**

- **Background:** Founded by two breast cancer survivors in 2012 who had previously worked together for the American Cancer Society.
- **Mission and Target Audience:** Provides women diagnosed with breast cancer complementary spa days to help patients escape the daily stresses of living with breast cancer. This organization targets all women affected by breast cancer.
- **Structure:** Run by a three-woman Board of Directors. This organization relies on small contributions and professional sponsors to donate services.

### **Keep a Breast**

- **Background:** Young artists founded Keep a Breast (KAB) in 2000 after a friend was diagnosed with breast cancer. The founders sought to reach out to community members in need through the arts by providing educational services and therapeutic activities for survivors.
- **Mission:** Seeks to provide services to a very young demographic. The focus of the organization is on art therapy and youthful activities for their members.
- **Structure:** KAB is headed by a Board of Directors, a Medical Advisory Board, and a Survivor Advisory Board. KAB partners with many skating companies.

### **Linda Creed Epstein Breast Cancer Foundation**

- **Background:** Started in 1987 by friends and family of Linda Creed Epstein, after the singer-songwriter had passed away from a long battle against breast cancer.
- **Mission and Target Audience:** Women of all backgrounds, diagnosed or not, within the community, as well as those who are uninsured in the Delaware Valley and Pennsylvania.
- **Structure:** Has an operating budget of \$500,000, all raised from grants and private sources. Was the first free-standing breast health organization in Pennsylvania, and they've worked to expand across the Delaware Valley. They have strong education, free screening, and diagnostic support elements, as well as support groups targeted at African-American and LGBT women. They also engage in legislative advocacy.

### **Living Beyond Breast Cancer**

- **Background:** Founded in 1991 by Marisa C. Weiss, MD, after a woman had expressed her need for breast-cancer related information, connection, and support after completing treatment.
- **Mission and Target Audience:** According to their website, "LBBC has expanded to assist women at all stages of diagnosis, treatment, and recovery. Our mission includes offering specialized programs and services for the newly diagnosed, young women, women with advanced breast cancer, women at high risk for developing the disease, and African-American and Latina women. We also offer programs for caregivers and healthcare professionals to help them better meet the needs of women affected by breast cancer."  
Mostly operates out of the Philadelphia area, but has conferences elsewhere, such as in Florida and Texas.
- **Structure:** Pursues a hybrid support/education model, with specifically targeted education programs focused on women with breast cancer. Consists of a National Board of Directors, a Medical Advisory Board, and a dedicated staff as well as numerous breast cancer experts who donate their time and experience in a variety of capacities.

### **Look Good Feel Better**

- **Background:** Formed in 1987 by Personal Care Products Council President Ed Kavanaugh.
- **Mission and Target Audience:** Look Good, Feel Better seeks to provide cosmetic support for those diagnosed in order to have a beneficial impact on their outlook, improving quality of life.
- **Structure:** Combines education on how to deal with physical appearance changes caused by cancer with locally hosted workshops (the website lists upcoming programs at Sentara Hampton, Sentara Williamsburg, Riverside Gloucester, and Riverside Newport News) via a network of affiliates. Partners with numerous cosmetic and fashion corporations, as well as the American Cancer Society.

### **Lump to Laughter**

- **Background:** While there is no specific date listed on their website, this group was founded by two friends who had navigated the breast cancer diagnosis, treatment process, and recovery together.

- **Mission and Target Audience:** This is a Christian oriented group, and the founders' experience motivated them to help others with their journey. They seek to assist all women in their journey, as well as helping women to “get in touch with the God that created them.”
- **Structure:** Their main focus is on having patients diagnosed with cancer share their stories. Of the groups examined, this one was the least clear in terms of what they actually did.

### **Men Against Breast Cancer**

- **Background:** Founded in 1999 by Mr. Marc Heyison, after having spent several years helping support his mother, Gloria Heyison, after her diagnosis in 1992. Mr. Heyison also created another nonprofit group – the Gloria Heyison Breast Cancer Foundation.
- **Mission and Target Audience:** Another very targeted group, the focus is on educating men about breast cancer and what to expect as their significant others go through the process. They seek to strengthen the capabilities of caregivers (including women caregivers) in addition to helping “low-income, uninsured and underserved women” get free mammography screenings.
- **Structure:** Their key event is the “Partners in Survival” workshop, which they have in person and online. This program is intended to be educational for caregivers, as well as helping individuals manage relationships and form supportive connections with their loved ones, with the goal being an increased quality of life for the diagnosed individual and their families/friends.

### **Mothers Supporting Daughters**

- **Background:** Formally “Mothers Supporting Daughters with Breast Cancer,” this organization was founded in 1995 by Charmayne Dierker and her daughter Lillie Shockney, following Lillie's diagnosis in 1992.
- **Mission and Target Audience:** In response to the lack of support group and educational materials available to Lillie when she was diagnosed, the co-founders seek to provide women of all backgrounds with the support that they need, building support networks and providing basic medical information as part of their primary focus.
- **Structure:** The organization matches women with breast cancer with “mother volunteers” whose daughters were diagnosed with the same type of cancer and underwent the same type of treatment, and who completed their treatment. The organization also provides education for ways mothers of daughters facing breast cancer can help. The organization is headquartered in Maryland but because its program is based around mentoring, does not seem locked into operating in just one geographic region.

### **National Breast Cancer Foundation**

- **Background:** Founded in 1991 by Janelle Hail, who was diagnosed at age 34 in the 1980s.
- **Mission and Target Audience:** Owing to the fact that Janelle had little support and assistance, as well as little education on the risks and recommended early detection procedures, Janelle emphasized extending the availability of support and knowledge so that the needs of others could be more fully addressed. All women, especially the uninsured, are supported by the organization.

- **Structure:** Has an education and support mission, much like Beyond Boobs! The support programs include providing mammograms for women with financial need, funding cancer research at the Cleveland Clinic and other research institutions, a patient navigator program, and an online support group community. Education components include basic facts about breast cancer, diagnosis, stages, types, treatments, and myths. The group is headquartered in Texas. Their local efforts mostly include funding other programs throughout the United States, including research and mammograms.

#### **Patient's Friends Society – Jerusalem**

- **Background:** This group was founded in 1980 by Palestinian academics and health professionals. It is also a member of the Union for International Cancer Control (UICC).
- **Mission and Target Audience:** Works with women in Palestine. Provides education on a host of issues, not just cancer, or breast cancer.
- **Structure:** Has a hybrid support/education group called the Sunrise Group that provides breast health education for the general population and support for women with breast cancer. Team leaders serve as advocates and teachers in their communities (schools & other organizations) – attending lectures & workshops while speaking at them as well. Each group has an elected representative, who coordinates with a staff member at the central office. Each group organizes their own sub-set of fundraising events. Events and support activities are done with the cooperation of local clubs and media outlets to promote awareness. The organization incorporates government, private, and non-profit sectors and is also associated with grant-making foundations. The group also operates a telephone line providing support and information about breast cancer, and the group has professionals who offer psychosocial support to women diagnosed with breast cancer as well.

#### **Pennsylvania Breast Cancer Coalition**

- **Background:** Founded in 1993 by a group of breast cancer survivors who united under the goal of finding a cure for breast cancer.
- **Mission and Target Audience:** At its core, this organization is a small, Beyond Boobs!-like group which focuses on advancing the search for a cure and supporting those diagnosed as well as their families.
- **Structure:** The group is engaged in statewide educational programming, legislative advocacy, and breast cancer research grants. The president of group also has been appointed to the Pennsylvania Cancer Advisory Board by the state Governor. The group has a component which targets private/public for funds for cancer research/researchers. The group hosts annual statewide conference, inviting national scholars, researchers, and health providers. Interestingly, the group also offers free online courses (sponsors helped) for credit for nurses and social workers (approved by major national education and nursing groups). Finally, this group discusses insurance (inadequate or lack of) and how people with limited time and resources can manage handling treatment costs, insurance complications, prescriptions, legal advice, and general financial pointers that help people navigate the complicated processes (heavily emphasizes patients' rights in the workplace – Family and Medical Leave Act <http://www.dol.gov/whd/fmla/index.htm>).

### **Rethink Breast Cancer**

- **Background:** Founded in 2001, this Canadian organization was created to create a new approach to handling all aspects of breast cancer treatment, prevention, and education.
- **Mission and Target Audience:** This has a variety of focuses, primarily targeting under-40 aged women for support and education (who the group views as at high-risk and as chronically underserved), but having a large emphasis on building a youth movement. This involves targeting teens as part of their education effort, and incorporating all people (regardless of sex and gender) so that everyone can play a part in understanding breast cancer, provide support for one another, and become knowledgeable of early detection mechanisms.
- **Structure:** Has a youth movement which focuses on teen education and raising a new generation of supporters and learned individuals. The group is well-organized, having specific directors for such things as donor development and organization development, as well as a research council made up of medical professionals. Support groups have professionally-led (and well-trained) counseling leaders, and the support group service is offered to entire families, as well as those diagnosed with breast cancer. The organization partners with like-minded organizations. The organization has a “one-on-one” program which matches people with members who were similarly situated at that stage of their life/circumstance, making use of peer support in the process. This is an effective way to use experience and understanding which has already been developed.

### **SHARE Cancer Support**

- **Background:** This organization was founded in 1978, having its origins in an idea by Dr. Eugene Thiessen (a doctor specializing in breast cancer), who believed that survivors could support each other and gathered a group in 1976.
- **Mission and Target Audience:** The group emphasizes supporting both women and men who are impacted by breast cancer in one way or another. The group evolved to have a Latina-focused component which could increase the comfort levels for those preferring Spanish-language services, as well as a branch of SHARE which helps women dealing with ovarian cancer.
- **Structure:** Support groups (including a hotline service), educational programs, and advocacy efforts are central activities the group is engaged in to achieve this end. The group is also working to help fund researchers. To better concentrate their efforts, SHARE created the SHARE Ambassadors to do targeted outreach – visit communities and community subsets (specific populations such as underserved and Latino/Hispanic groups). These representatives are well-educated and able to administer support services and assist in the sharing of education for all.

### **Sharsheret**

- **Background:** Founded in 2001 by Rochelle Shoretz, who was diagnosed at age 28 and understood that there were few culturally sensitive support group options for young Jewish women who were diagnosed with breast cancer.
- **Mission and Target Audience:** The focus is on young, Jewish women – they seek to provide support in a culturally relevant way and believe that support and education for young women “should be targeted; women need to perceive information as personally relevant to women in their age group and culture.”

- **Structure:** Sharsheret has components which are actively involved in helping to connect individuals with organizations that specialize in financial assistance. They have over 250 educational programs across the US, and has franchise-like structure, where communities are provided with resources for their own event planning, hosting of events and outreach, and initiating support groups in the local area of operation. Donorship includes grants from family foundations, individuals and corporations, and the organization relies on their various Advisory Boards, comprised of the organization's leaders and a Medical Advisory Board.

### **Sisters Network Inc.**

- **Background:** Founded in 1994 by Karen Eubanks Jackson, a breast cancer survivor who recognized the need for creating more of a "sisterhood" style of supporting those diagnosed with breast cancer.
- **Mission and Target Audience:** The organization is focused on providing support, education, and enhanced awareness of breast cancer, targeting primarily African American women who are subjected to both higher than average mortality rates and fewer support options which are culturally sensitive.
- **Structure:** The large, annual Breast Cancer Conference to address the impact of breast cancer on their target population has enabled rapid expansion of the group as it is nationally observed and publically visible, rallying the sisterhood and the African American community across the U.S. There is an emphasis on getting federal funding to complement corporate partnerships and private contributions, and this enables the group to hold sponsored, major events. At the lower level, this organization is split into subsets identified as "chapters." To achieve this highly replicable model, each chapter has a facilitator style manual and specifications for starting your own chapter. There is not a lot of programs which offer direct support, but the vast sponsorship supports this group's tendency to focus heavily on large program events and high-profile activities.

### **Survivor's Foundation**

- **Background:** Founded in 2008 by Antoinette Starr, who was diagnosed at the age of 35 and brought with her the understanding of common hardships which accompany diagnosis and treatment, but also the challenges faced by those with few resources and little support.
- **Mission and Target Audience:** With the needs of underserved women in mind, this group has a focus on the financial aspects of breast cancer support. Another primary focus is helping women diagnosed with breast cancer by providing emotional support, although the group's website provides little detail as to their activities.
- **Structure:** There is a half-dozen events which the group hosts which are geared toward fundraising and awareness. Most clearly communicated on their website is their educational materials (which promote self-testing and early detection), breast cancer facts, and their dedication to helping those with few resources through such things as offering scholarships and helping individuals with insurance issues and little resources understand the services and options available to them.

### **Taiwan Breast Cancer Alliance**

- **Background:** Founded in 2002, by Gloria, Wei-Chieh Lin.
- **Mission and Target Audience:** With the core values of love, sharing, energy, and passion, this organization seeks to have a strong, positive impact on the lives of those diagnosed by using an inclusive approach – patients, patient volunteers (survivor peers), and the families of patients are the main focus of the group’s work.
- **Structure:** The organization places a heavy emphasis on using the already experienced and knowledgeable patients and survivors to continue providing relevant assistance and perform organization functions – patients lead patients; volunteers train volunteers. The organization seeks to invite as high a profile professionals as possible to give lectures and help raise the profile of the group. The Alliance also offers a lot of classroom courses to help their members and people they want to train to help future members. Group/organization leaders are encouraged to pursue educational opportunities and management education/certification to assist in stronger leadership within the group, and the group is also engaged in advocacy efforts. Finally, the organization reaches out and has started initiatives in hospitals and with collegiate systems to increase their presence and spread awareness.

### **The Gathering Place**

- **Background:** Founded in 2000, this organization was created due to the lack of breast cancer support in the greater Cleveland community.
- **Mission and Target Audience:** According to the website, “the mission of The Gathering Place is to support, educate and empower individuals and families touched by cancer through programs and services provided free of charge.”
- **Structure:** The organization has two education centers (including library facilities with educational material), support groups to assist in the emotional difficulties of diagnosis, exercise and gentle movement classes, nutrition classes and dietary counseling (with healthy cooking classes), and age-appropriate support groups which assist in care and education for children and caregivers, as well as all members of the family. The organization also attends health fairs, engages in speaking engagements and presentations in a variety of settings (schools, churches, businesses, institutions), and offers their speaking services as an education source to complement their library education resources.

### **Willow Breast Cancer Support Canada**

- **Background:** Founded in 1994, this organization was established by a group of women who understand the need for support and information for those diagnosed with breast cancer.
- **Mission and Target Audience:** According to their website, Willow’s vision is that all those diagnosed with breast cancer in Canada will “have timely access to unbiased information and compassionate support services to help those living with breast cancer.” Their formally stated mission is “to provide peer support and information to people affected by breast cancer, including those at high risk.”
- **Structure:** Willow is primarily focused on connecting people to groups and peers who lead support groups. These support groups are recreated by motivated survivors as the group offers the resources and knowledge which enable individuals to bring Willow’s style of support structures to their local community. Education and the sharing of

information is a critical feature, and their booklets, information services, and translation (numerous languages available) are made available free of charge to members.

### **You Can Thrive! Foundation**

- **Background:** This organization was founded in 2005 by Laura DeAngelis, who wished to extend her knowledge of navigating the process of diagnosis and recovery as she herself had been diagnosed at age 35.
- **Mission and Target Audience:** Working for all those diagnosed, this organization seeks to impact the community with a holistic approach, improving quality of life through a spiritual but non-religious method of reducing the pain and distress experienced by women. The services which the organization provides are implemented with the under-served and under-resourced individual in mind, making their services affordable and accessible to those in New York City.
- **Structure:** The organization developed their programs around ease of replicable-ability. This allows for easy reapplication and a clear vision of their intended impact. Services range from nutritional education to meditation activities and retreats, to exercise programs and various types of physical therapy to alleviate stress and reduce the severity of members' symptoms. The organization is also involved with assisting in the patient navigation services, using professional volunteers and well-trained individuals to both deliver services and spread awareness to other professionals in the medical community. Advocacy is also a central component to their organization, and they have received a grant from the Avon Foundation for Women.

### **Young Survival Coalition**

- **Background:** This organization was founded in 1998 by a group of individuals who were all diagnosed before the age of 35 – all of whom recognized that young women needed access to more support, better information, and further research concerning the aspects of breast cancer which surround young women.
- **Mission and Target Audience:** Young, premenopausal women are the focus of the organization, and the primary goals are to unite the globe to increase advocacy and research for young women and breast cancer, extend education and information outreach to young women, and provide support to this largely under-served demographic.
- **Structure:** The Young Survival Coalition and Living Beyond Breast Cancer host the Conference for Young Women (C4YW), the international conference for women under the age of 45. This one-of-a-kind event features educational programming for survivors, caregivers, families and healthcare professionals focused on every phase of a young woman's breast cancer. Beyond Boobs! is keenly aware of this Conference. This organization also has a Medical Advisory Board to complement their support staff and Board of Directors. The Young Survival Coalition uses their nationwide presence to organize their efforts in terms of four regions, having field offices throughout these regions and deliver a range of support services, education materials, advocacy and awareness events, and fundraising events.

## Appendix G: Breast Health Organization Activities

Service	Category
Acupuncture, massage, reflexology, aromatherapy	<b>1. Acupuncture, massage, reflexology, aromatherapy</b>
African-American outreach	<b>2. Targeted support groups</b>
Bilingual support group	
Chemotherapy support group	
DCIS support	
LGBT outreach	
Newly diagnosed support	
Parent of survivor mentorship program	
Partner's survival program for husbands of breast cancer patients	
Post-treatment support	
Reoccurrence workshop	
Senior support group	
Stage IV support	
Young mother's support group	
Young women's support group	
Annual conference	<b>3. Social events</b>
Annual party	
Annual social gathering	
Art sessions	<b>4. Art therapy</b>
Body art therapy	
Beauty makeover	<b>5. Physical appearance support</b>
Breast reconstruction support	
Glamour photography session	
Wig clinics	
Care package	<b>6. Care package</b>
Post-surgery supply kit	
Counseling	<b>7. General support groups</b>
Group retreat	
Meditation	
Mentoring / peer support	
Online blog / storytelling	
Online support group	
Peer support	
Phone helpline	
Small group health program	
Spa days	
Support group (general)	
Educational materials	<b>8. Educational materials</b>
Environmental risk-factor education	
Nutritional resources	
Patient navigator	
Smartphone app	
Exercise sessions	<b>9. Exercise sessions</b>
House cleaning	<b>10. Financial and logistical support</b>
Medical related financial assistance	
Housing needs assistance	
Non-medical financial assistance	
Yoga, Zumba, reiki	<b>11. Yoga, Zumba, reiki</b>

## **Appendix H: Funding and Partnership Possibilities**

The following are organizations and institutions with whom Beyond Boobs! could partner in service delivery and research and/or seek out for financial support.

### Breast Health Organizations

American Cancer Society  
Breast Cancer Alliance  
Breast Cancer Research Foundation  
Susan G. Komen for the Cure

### Academic and Research Institutions

EVMS  
National Cancer Institute  
VCU Health System

### Hospitals

Bon Secours  
Chesapeake Regional Medical Center  
Riverside Health System Foundation  
Sentara Health Foundation

### Health Insurance Providers

Aetna  
Anthem Blue Cross and Blue Shield of VA  
Amerigroup  
CareFirst BlueCross BlueShield  
Coventry Health Care of Virginia  
Humana  
Innovation Health  
Kaiser Mid-Atlantic  
Optima Health Insurance Company  
UnitedHealthOne

### More resources:

The Foundation Center's rankings:

Top 100 Foundations by Total Giving

<http://foundationcenter.org/findfunders/topfunders/top100giving.html>

Top 100 Foundations by Asset Size

<http://foundationcenter.org/findfunders/topfunders/top100assets.html>

Top 50 Corporate Foundations by Total Giving

<http://foundationcenter.org/findfunders/topfunders/top50giving.html>