



**It's about You:**  
**Getting Insights from Young Women with Metastatic Breast Cancer**  
(survey open from August 2013 through February 2014)

**Results**  
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**Respondents.** Six hundred seven women started the survey with 470 participants meeting the inclusion criteria. Three hundred sixty women completed the survey. The number of women answering each question varied. For example, 604 women answered the first question while other questions had significantly less as women could opt to answer or not answer most questions.

Thirty-nine percent of respondents were between the ages of 34 and 37 at initial diagnosis (any stage), and 31% had MBC at initial diagnosis. Age at diagnosis of MBC ranged from 21 to over 50 with the highest percentages at age 42-45 (10%), 37 (9.6%) and 36 (9.2%). The majority of respondents were Caucasian (82%), from the United States (91%), living in a suburban area (53%), married (65%) and had one or more child (65%). Forty-five percent of respondents reported having no children.

Of the 437 women who answered the question about the location of their metastatic disease, 63% reported having bone metastasis. Remaining locations of metastasis included: liver (34%), lungs (26%), brain (8%), gastrointestinal system or colon (4%), pleural (3%), skin (2%), ovaries (2%), chest wall (1%) and other (16%). Forty-one percent had metastasis in more than one organ. If a YW reported metastases in multiple bones, it was counted as metastatic in one “organ.”

When asked how they learned about the survey, 36.4% said from YSC email/newsletter and 38.2% indicated from Facebook. Ninety-nine percent of respondents reported having an email account and a cell phone. When asked whether they preferred to receive information via email, cell phone or postal mail, 87% identified email as their first choice.

**MBC, Treatment, Options and Prognosis.** (n=401) respondents who sought information on this topic (95%). Consulting HCPs (78%) was highest followed by online (other breast cancer organizations’ websites) (74%), other women with MBC (63%), other general webpages like Wiki and Google (62%) and online community boards/peer support (60%). Sixty-three percent indicated that information was “somewhat” easy to find.

When asked what resources were least helpful (open-ended questions), there were comments about outdated information, “no hope” and “scary statistics.” ***Pamphlets, books and other printed materials were deemed as the least helpful resources.*** Respondents complained that there was not enough accurate data that was easy to understand and provided support (e.g. citations, studies). They shared that news reports seemed to “spin” information which may or may not be accurate. Information respondents found was stated as being too generic and general rather than being specific to their situation. They stated that they had to judge the accuracy of the information found.

When asked what could have made the search for information easier, responses indicated ***a need for one centralized location*** to find information relevant to MBC with easier terminology, a bank of current research and more information overall that is easy to find and access. It was noted that a focus on YW was also needed.

Asked if there was any information they could not find, 50% said no and 33% said yes. Information found lacking included prognosis statistics, treatment and side effect information,

updates on new treatment and medical advances, information on different types and locations of metastases, as well as clinical trial information. Seventy-six percent of respondents looked for information for how long YW are living with MBC, and 80% said this information would be helpful.

When asked with whom respondents talk on the HCP team about MBC, treatment and prognosis, the three most frequent responses were: medical oncologist (94%); nurse (42%); and radiation oncologist (29%). When asked what they would utilize to learn more about MBC, treatment options and prognosis, the top four responses were: websites (73%); other YW with MBC (73%); newsletter for YW with MBC (66%); and webpage for YW with MBC (64%).

***Clinical Trials.*** Seventy-two percent (n=327) indicated it was “very important” to learn about the availability of clinical trials, and 69% previously sought information about clinical trials. ***It was the 4<sup>th</sup> highest ranked topic for which participants searched for information.*** Respondents sought information through: HCPs (69%); clinicaltrials.gov (44%); online government websites (39.5%); and online (hospital websites) (33%). Breastcancertrials.org was regularly cited as a source of information. Some reported finding clinicaltrials.gov helpful, but others complained about it being outdated or too much information to analyze. Other comments indicated feelings of frustration because after spending time searching for clinical trials, respondents found none for which they would qualify. In response to with whom on the HCP team they inquired about clinical trials, 77% said a medical oncologist; 20% said no one; and 15% said a nurse.

The majority of respondents reported that information on clinical trials was “somewhat” easy to find (53%). They stated that the following would have made for easier personal research:

- o Better search engines;
- o Easier to read and understand;
- o Someone with whom to speak on the phone to help navigate through trial information and filter out inapplicable trials;
- o Up-to-date information;
- o One clear resource instead of multiple sources; and
- o Listings for just MBC.

Over 28% stated being unable to find information including how to enroll in clinical trials, if they were eligible for clinical trials, logistics of participating and whether or not trials could be accessed locally.

When asked what sources they would use if available, the highest-ranking responses were: websites (61%); webpage for YW with MBC (59%); other YW with MBC (58%); and newsletter for YW with MBC (46%). Twenty-two percent said an app would be helpful.

Despite acknowledging the importance of clinical trials, 74% stated never participating in one. Reasons included: being unaware of any in which they could participate (33%); “HCP didn’t tell me about any” (22%); HCP advised against participation (7%); “I did not want to” (6%); and “I tried to participate but was declined” (7%). Individual comments indicated that they chose not to

participate in clinical trials because they were stable and did not need to participate, some trials were too far away or they did not qualify. Some respondents complained about the medical oncologist not being aware of clinical trials.

**Management of Treatment and Side Effects.** Respondents (87%) indicated that this topic was “very important,” and 88% sought information on this topic. ***It was the second highest category for which respondents sought information.*** Top sources consulted were: HCP (70%); other MBC women (54%); online: other breast cancer organizations (42%); and online: general cancer organizations (41%); and online: general resources like Google (40%). The nonprofit organization Breastcancer.org was mentioned frequently in comments as a source of information.

The majority of respondents (63%) indicated that information on this topic was “somewhat easy” to find. Twenty-two percent reported there was information that they researched but could not find. This included information on how to treat/manage side effects especially rare side effects, alternative therapies to manage side effects, consolidated listing of all treatments and their effectiveness and side effects and use of vitamins during treatment.

When asked what tools they would use to learn more about management of treatment and side effects, if available, the top four responses were: other YW with MBC (68%); websites (64%); webpage for YW with MBC (55%); and a newsletter for YW MBC (50%). On their healthcare team, women primarily spoke with the medical oncologist (94%) and with a nurse (54%). In response to a question asking whether the HCP spent time explaining the treatment regimen and possible side effects, they responded: “yes, every time” (66%); “yes sometimes” (22%); “yes but only when I ask” (10%); and no (3%).

**Complementary Alternative Medicine (CAM) and Hospice.** Fifty-two percent (n=287) stated that they did not use **CAM**, and 48% reported they did. Top CAM choices were: yoga (56%); meditation (48%); diet changes (50%); supplements (46%); acupuncture (41%); and herbal products (40%). Massage, although not offered as a choice, was listed frequently in the comments section. Reasons given for using CAM included: to manage or relieve side effects, to fight the disease and to support emotional wellbeing. Comments indicated concern about the cost of CAM, how to pay for it if insurance did not as well as making time for additional appointments. Thirty-four percent of respondents reported that the use of CAM helped “a lot,” and 55% said it helped “somewhat.”

When asked if the HCP was aware of their CAM use, 83% said yes, and 51% indicated that the HCP was included in decision making about their use. Seventy-four percent of respondents said that the HCP supported their use of CAM. Eighty-seven percent reported currently using CAM along with the traditional standard of care.

Eighty-eight percent (n=283) indicated that **hospice** had not been discussed with them, and 1.4% said they did not know what the term hospice meant. Sixty-two percent reported that they knew what hospice is and its benefits. A majority of respondents (56%) did not believe that it was important to learn about hospice.

***Hospice was the least searched for topic.*** Eighty-six percent had not sought any information about hospice. Of those who did, the sources consulted varied greatly with HCPs in the lead at 41% and hospice websites at 35%. Fifty-nine percent indicated that information on hospice was “somewhat easy” to find. In response to open-ended questions a theme that arose multiple times was when to start hospice. If available, YW living with MBC indicated that they would use the following option to learn more about hospice: other YW with MBC (58%); websites (57%); webpage for YW with MBC (57%); and a newsletter for YW with MBC (42%).

***Anticipatory Grief.*** Anticipatory grief was a term used in the survey to describe feelings and emotions that YW with MBC may be experiencing about a loss which has not yet occurred. For example, a young mother with MBC may be fearful that her children will grow up without her or be concerned about their wellbeing in the future if she is not around. Eighty-two percent stated that anticipatory grief was a topic of importance to them. Sixty-four percent reported that it was “very important” to receive information on how to manage it. YW reported the following kinds of anticipatory grief: loss of life cut short (86%); loss of leaving spouse without a partner (75%); loss of leaving kids without a parent (67%); loss of identity (38%); loss of career (29%); and loss of leaving the world without having had children (25%). Other losses specified in comments included: missing important events in the lives of family members, feeling that there was more they wanted to do with their life, never getting married or finding love, leaving behind family and friends and dying before their parents.

Although an important topic, 71% had not sought information about anticipatory grief or how to manage it. For those who had, 53% said it was “somewhat easy” to find. The most frequent sources of information were HCP (51%) and other YW with MBC (46%). Forty-six percent answered “other” which primarily indicated therapy and counseling.

Many (42%) spoke to no one and had not discussed it. The next highest responses were: “other” (29%); medical oncologist (22%); social worker (17%); and nurse (13%). Respondents indicated that “other” included counselors, psychologists, family and support groups. When asked what they would use to learn more about anticipatory grief and how to manage it, frequent responses were: other YW with MBC (62%); a web page for YW with MBC (50%); a newsletter for YW with MBC (46%); and websites (45%).

This section also asked about the effect of MBC on their family and friends as well as what specific things they may have done or currently doing to manage feelings of anticipatory grief. ***Seventy-one percent said that they thought their family/friends/loved ones also struggled with anticipatory grief issues.*** The majority (81%) had discussed their prognosis with family/friends/loved ones. For those who had not, reasons included their family and friends’ fear/avoidance of the topic, discomfort in discussing and that it was not necessary because they were doing well. Several respondents claimed that their families were in denial.

***Stress and Emotional Wellbeing.*** Respondents indicated that their stress level is worse (31%) or varies with some days stressful and some not (56%). The majority responded that their emotional wellbeing is worse (57%), had not changed much (26%) or improved (16%). Emotional wellbeing was impacted as follows: anxiety (71.5%); trouble sleeping (61%); depression (45%); withdrawal from things they once liked to do (31%); and withdrawal from friends (24%); and other (17%). Comments indicated that the “other” included sadness, anger, more easily irritated, loss of security, loss of faith in the “goodness of life,” lack of appetite and fear.

Sixty-nine percent stated that it was “very important” to gain knowledge about stress and emotional wellbeing, and 60% had sought information. The top two sources consulted were HCPs (57%) and other women with MBC (55%). In addition to these two sources, therapy/counseling was also mentioned as a helpful source. Sixty-two percent said it was “somewhat” easy to find information on stress and emotional wellbeing. Suggestions for what could make finding information easier included easy to find information on-line, directed to MBC and YW and physician referrals to support including social workers. Responses regarding who on the healthcare team, those included: medical oncologist (44%); “no one, I don’t discuss it” (26%); nurse (23%); social worker (22%); and other (22%). “Other” included psychologists, counselors and therapists. Respondents indicated that they would use the following sources, if available, to learn how to improve their stress and emotional wellbeing: other YW with MBC (64%); newsletter for YW with MBC (43%); websites (40.5%); webpage for YW with MBC (41%); in-person conferences (31%); and YSC online tools (29%).

We asked how respondents managed stress prior to cancer, whether they continued to do those things and what pre-existing conditions may have been present that would impact their emotional wellbeing. We asked whether they continue to do the same things they did before to support themselves, and 66% said yes while 34% said no. Those who responded no said that they did not do so because of pain, physical inability to do so, lack of time and desire to spend time with family and fatigue. Eighty-two percent said they take time to rest. The 14% who did not said they did not rest because of guilt, kids, work obligations, they were too busy or had no time for themselves. When asked if they were able to take time to do nothing, 75% said yes while 25% said no. Those who said no indicated that kids, work and “too much to do” precluded it. Some responded that they did not take time to do nothing because they wanted to stay busy. One-third of respondents said that they were not comfortable asking for help or assistance. They stated it was hard to ask, that they are too independent, too stubborn, that it feels like a burden and/or have too much pride or felt too vulnerable to ask.

***Before their breast cancer diagnosis, 60% of respondents reported having no psychosocial concerns.*** Twenty-eight percent of respondents reported having anxiety, while 24% reported having depression, 7% reported trauma, and 6% reported feelings of isolation. Sixty-one percent of those YW with identified issues sought professional help. Forty-eight percent sought professional psychosocial help related to their MBC (n=236). Typical responses from those who had not sought help were that there was “no need” or their issues were “not serious enough.” Lack of money, fear and seeing enough doctors already were also listed as reasons. For those who did seek help, they

indicated that therapy/counseling, medication and talking with others were most beneficial. Forty-one percent were taking or had taken prescription medication, and 91% reported being compliant in taking them.

**Work.** At the time of diagnosis, 82% of YW were working, but only 44% were working at the time they took the survey. Sixty-three percent said that MBC has impacted their ability to work and earn a living. The majority of respondents indicated that their employer (84%) and co-workers (79%) are aware of their MBC diagnosis.

Sixty-eight percent of YW with MBC have taken leave from work. The types of leave taken varied: sick leave (42%); paid time off (40%); short-term disability (39%); Family and Medical Leave Act (FMLA) (34%); and long-term disability (31%). Eighteen percent said “other,” and their comments indicated that was unpaid leave. Thirty-one percent of respondents had exhausted all leave, and 22% had been terminated. Forty-two percent said that their employer made accommodations for them. Accommodations included flexible work schedules, part-time hours, working remotely and decreased physical demands.

At the time of MBC diagnosis, 63% said that no one gave them information on their rights to work or available disability benefits. For those who were made aware, they learned the information from their human relations department, social worker, HCP or insurance company. Forty-two percent of respondents have applied for [Social Security Disability Insurance](#) (SSDI), and 63% said they did not know their rights to SSDI and the [Compassionate Allowance](#). Information was minimal about how disability benefits were calculated, the timeline and application process and the tax implications of receiving benefits.

Obtaining information on working and disability options was “very important” to 68% of respondents. Fifty-seven percent consulted resources, and the top three sources were: online government resources (51%); other women with MBC (34%); and other (35%). Responses indicated that the “other” included Social Security, social worker, employer and disability insurance carrier. Thirty-two percent reported that it was “not easy” to find information on working and disability options. What could have made it easier included being given information by HCPs when diagnosed with MBC, better coordination of information between state or federal governments and the hospital, easier to find online information, information specifically for MBC patients and someone to help navigate the process. On the healthcare team, respondents discussed working/disability with no one (44%) or the medical oncologist (42%). If available, respondents would use the following options to learn more about working and disability: websites (50%); other YW with MBC (43%); webpage for YW with MBC (39%); newsletter for YW with MBC (36%); and printed materials (36%).

**Interpersonal Relationships.** Interpersonal relationships was a topic subdivided into five areas: (1) connecting with other YW with MBC; (2) single/dating; (3) having kids/adoption; (4) family

and friends; and (5) children. For each sub-topic, respondents were asked questions to determine if that section applied to them and they could opt out if not interested or applicable.

#### 1. Connecting with other YW with MBC

Ninety-one percent of YW with MBC stated it was important to connect with other YW with MBC. Sixty percent said it was “very” important, and 40% said “somewhat.” Seventy-two percent tried to connect or sought information about how to make such a connection with sources used including: other women with MBC (61%); social media (41%); YSC website (41%); online: other breast cancer organization website (36%); in-person conference (21%); and other (29%). Connections were attempted through: online support group (47%); message boards (39%); social media (32.5%); and in-person support, all ages and all stages of breast cancer (32.5%). The most helpful support was found through online support groups for YW with MBC (including the YSC discussion boards), in-person support groups and social media. Least helpful were general cancer support groups for all stages and in-person support groups where women were typically much older than YW seeking support.

Respondents indicated that it was “somewhat” easy to find connections (51%) with other answers split between “very” (25%) and “not” easy (25%). Thirty-one percent said there was information or connections that they could not find with remarks indicating a lack of in-person support for YW and difficulty finding women under 30 with MBC.

When asked who on the healthcare team they speak with about connecting with other YW with MBC, they answered: no one (52%); medical oncologist (21%); social worker (18.5%); and nurse (18%). If available, YW with MBC would use the following options to connect: other YW with MBC (76%); a web page for YW with MBC (59%); in-person conference (52%); newsletter for YW with MBC (48%); social media (47%); and websites (47%).

More specific questions were asked in this section to learn why connections are not made or what other programs or initiatives would be of interest to this population. When asked whether they were afraid to become close to another young woman with MBC, 72.5% said no. Seventy percent read anecdotes/blogs by YW with MBC.

Respondents reported being interested in an in-person, MBC-focused retreat for YW, and 68% said they would attend one hosted by YSC. The top topics of interest for such a retreat included coping, research updates, how to communicate with family members and children about their disease, resources to assist them and quality of life. The most important elements for them to be able to attend were cost, location and topics of interest.

It was also asked whether or not it made a difference to YW with MBC if in-person support was focused solely on YW with MBC. Sixty-five and a half percent responded yes. The survey also asked if respondents had attended an in-person support group not focused solely on MBC and whether they felt welcomed. Forty-five percent said they did not feel welcomed. As one person stated, “I quickly realized my story was everyone’s biggest fear. I was uncomfortable.” Similar comments

about scaring non-MBC participants were made. Seventy-seven percent connect through Facebook or other social media with YW with MBC (31 responded to this question).

## 2. Single/Dating

Only 29% of respondents indicated that they were single or dating, and responses to this section were low. Of those who responded, 67% indicated that it was important to learn or dialogue about dating (n=54) with 56% saying it was “very” important. Only 22% sought information about being single and dating while living with MBC with online sources and other YW with MBC (37.5%) as the top resources. For those who sought information, 73% said such information was not easy to find. ***Single/dating was one of only two topic areas where “not easy” was the most frequent response to how easy it was to find certain categories of information.*** Responses indicated a particular lack of information for lesbians with MBC.

Eighty-one percent of respondents did not discuss this topic with anyone on the healthcare team. The next closest ranking answers were medical oncologist, primary care physician or other (elaborated on as including friends, family and therapist) (8%). If available, respondents would use the following options to learn more about being single/dating with MBC: other YW with MBC (64%); newsletter for YW with MBC (56%); webpage for YW with MBC (50%); and websites (47%). Forty-four percent have dated or currently are dating, and 81% have discussed their diagnosis with potential partners. For those who had not had a discussion, fear of rejection was the most common reason.

## 3. Having Kids/Adoption

Seventy percent said that they were not interested in learning more about having biological children and/or adoption. The 41 women who were interested indicated that they sought information from: other YW with MBC (60%); HCPs (60%); and the resource Fertile Hope (60%). If available, they would use the following options to learn more: other YW with MBC (87.5%); a web page for YW with MBC (69%); a newsletter for YW with MBC (62.5%); websites (56%); and an online guide (50%). On the HCP team, respondents spoke about this topic with no one (62.5%); medical oncologist (31%); and OB-GYN (25%). Five respondents (31%) have taken steps to have children, biological or adopted.

The inclusion of the topic of having biological children or adopting became controversial. Some women living with MBC felt that this is an ignored topic for their population even though some women with MBC can live with their disease for quite some time. Others found the topic inappropriate especially if they were not able to conceive or have been told that they should not. Some reported that they strongly believe that YW with MBC should not have or adopt children no matter their prognosis. YSC decided to include this topic area because it may be a topic of importance to this population, and it is not our place to decide what is or is not appropriate for another. Of note, there was one response indicating that some survey respondents felt that the topic and questions were insensitive.

#### 4. Family and Friends

Questions in this section were often skipped with 53 people responding which dropped off as the section progressed. Sixty-four percent reported that family and friends was a topic of importance to them while 62% stated it was “very” important. When asked whether they sought information to help family and friends cope with their disease, 65% said no. For those who did seek information, 50% received information from the HCP, 33% from an online general cancer website, 33% from online other (non-YSC) breast cancer organization websites and 25% from books, online general resources (Google) and “other.” Half of the respondents indicated that information for family and friends was not easy to find. ***This was one of only two topic areas where “not easy” was the most frequent response.*** If available, respondents would use the following to help family and friends: websites (47%); printed materials (47%); webpage for YW with MBC (41%); other YW with MBC (41%); and a newsletter for YW with MBC (41%).

Sixty-eight percent of respondents reported that they do not speak to HCPs about this topic. The next highest response was the medical oncologist (18%). Forty-four percent did not know if their family and friends sought information about MBC, and 23% said that their family and friends had done so.

When asked if respondents had given friends specific tasks when they asked what they could do to help, 58% said yes with requests including rides to appointments, childcare help, meals and errands. Forty-two percent said no. One-half of respondents said support of family and/or friends had decreased over time. Fifty-five percent had not reached out to family and/or friends to let them know that help and support was still needed. Reasons included a lack of need for such help, fear of being turned down, they didn’t want to be a “bother” and they have a hard time asking for help. Twenty-six percent have used websites like CaringBridge, My LifeLine, and Lotsa Helping Hands to keep family and friends updated. Those who had not did not know of these resources or they preferred to keep their lives private.

#### 5. Kids

One hundred sixteen YW responded to this section. Seventy-five percent stated that their children are aware of their MBC diagnosis, and 54% said that their children expressed fear about their MBC diagnosis and prognosis. They have tried to relieve their fear by talking openly, telling them about the good care they are receiving (medicines and doctors), assuring them that they are doing all they can to fight the disease as well as providing love and support. Some utilized counselors, child support groups and spiritual leaders. Seventy-seven percent had asked their kids about their feelings. For those who had not, the main reason was that their children were too young. When asked to rate on a scale of 1 to 10 how difficult it has been to parent while managing MBC diagnosis and treatment, with 10 being the most difficult, 6.58 was the average rating. Comments included fears of leaving kids without a mother, being too tired to play or participate in family activities, inability to make long-term plans, the effect of MBC on the kids’ anxiety level and sense of security, as well as the difficulties of juggling their schedules along with MBC treatment. The struggles of being a single mom with MBC was also shared. “Being a parent is a 24/7 job and

so is being a patient,” was a comment by one respondent about the difficulties of parenting with dealing with MBC.

Only 34% have sought information on parenting with MBC. Top sources were books (44%) and other YW with MBC (41%). When asked how easy it was to find information, the majority said it was “somewhat” easy (56%), but one-third (33%) said it was not. One respondent commented “I was looking for a conference for us to attend as a family. There are none!” Respondents noted that, if available, they would use the following sources and tools: other YW with MBC (65%); a newsletter for YW with MBC (54%); websites (47%); webpage for YW with MBC (47%); and printed materials (41%). When given a list of possible programs for kids, 63% were not aware of them. [Camp Kesem](#), a free camp for kids whose parent has cancer, was the most well-known (17%) and listed as a “most helpful” resource.

The majority (54%) did not discuss parenting while living with MBC with HCPs. The next closest responses were social worker (22%), medical oncologist (19%), and “other” (18%). Responses indicated that most “others” was a therapist or counselor.

**Sexuality and Intimacy.** Ninety percent of respondents stated that their diagnosis has impacted their sexuality, femininity and/or body image. Reasons included lack of sex drive, fatigue, painful sex, vaginal dryness, discomfort with physical appearance, did not feel attractive (due to scarring loss of hair, loss of body parts and weight gain), feel years older than their chronological age and concern about injury during sex. ***Prior to cancer, 87% did not have difficulties with sex and/or intimacy, and 67% did not have body image issues.*** Seventy percent had spoken with their significant other about sex, but only half (50%) make time for intimacy. Reasons included fatigue, young children, lack of motivation, other priorities and an unwilling partner as reasons. Comments included, “I feel like a thing....a patient. Not like a wife or partner or me.” “When diagnosed with MBC, you lose your carefree. Sex fell into that category, and intimacy has taken other forms. It is sad.” A common theme was that “I feel my body has betrayed me.”

When asked how important it is to gain knowledge on this topic, 46.5% said it was “somewhat” important, and 39% said “very” important. Thirty-eight percent sought information on sexuality and intimacy. The most common sources were: other YW with MBC (42%); HCP (38%); other (variety of answers in comments) (33%); other (non-YSC) online breast cancer organizations (31%); general cancer online organizations (30%); and an in-person conference (25%). Information on this topic was “somewhat” easy to find for the majority (58%). If available, YW would use the following to learn more about sexuality and intimacy: other YW with MBC (46.5%); websites (42%); a web page for YW with MBC (39%); and a newsletter for YW with MBC (39%).

Over half (61%) did not speak with HCPs about sexuality and intimacy. Twenty-one percent spoke with the medical oncologist on the topic, 12% to the ob-gyn and 10% to a nurse.

**Legal Matters/End of Life Planning.** Sixty-seven percent said that the topics legal matters and end of life planning was important. Sixty-eight percent said it was “very” important. Fifty-seven percent

sought information on the topic with the most common sources being: other MBC women (28%); other (non-YSC) online sites (28%); HCP (20%); and in-person conferences (20%). Fifty-nine percent said information was “somewhat” easy to find, and 22% said it was not. When asked about the most helpful source of information, the most frequent response was an attorney. Information would have been easier to find if respondents had checklists, templates, cancer- specific tools and step-by-step guides. If available, YW with MBC would use the following to learn more about legal and end of life planning: websites (59%); webpage for YW with MBC (56%); other YW with MBC (46%); newsletter for YW with MBC (45%); printed materials (43%); in-person conference (41%); online guide (39%); and YSC online tools (37%).

Seventy-three percent of respondents do not discuss legal matters/end of life planning HCPs. Those who do speak with the social worker (11%) and the medical oncologist (8%).

Thirty-nine percent had not prepared any legal documents for legal or end of life matters. For those who did, they have prepared the following: beneficiary designations (48%); will (35.5%); power of attorney (35.5%); healthcare power of attorney (33%); living will (31%); do not resuscitate order (21.5%); and guardianship papers (18.3%).

Seventy-one percent thought about but did not start end of life plans. Eighteen percent had made plans (n=93). When asked if a planning tool would be useful, 86% agreed. Comments indicated a step by step guide with checklists, templates, lists of resources as well as definitions and explanations would be helpful.

Sixty-five percent reported they had taken steps to leave or create memories. Examples included pictures, videos, journaling, family time, scrapbooks, letters and vacations.

When asked whether tools to communicate about their disease and prognosis would be helpful, 76% replied that they would. When asked what options they would use to leave or create memories for family and friends (n=216), top answers included: legacy project (video) (57%); letter templates (55%); special occasion templates (47%); scrapbooking templates (51%); and blog templates (40%). Comments included that some YW did not want or need templates because it would just be one more thing for them to do while they already had enough on their plates. Others said templates would not be personal enough.

**Finances.** This section addressed how an MBC diagnosis impacted finances and what specific aspects caused financial hardship. Seventy-six percent (n=237) agreed that MBC has negatively impacted their finances or increased financial concerns. Sixty-eight percent thought it was a very important topic, and 45% sought information about it. Sources consulted included: on-line general cancer organization (40%); online other (non-YSC) breast cancer organization website (34%); online government websites (34%); and HCPs (31%). Fifty-five percent reported financial information “somewhat” easy to find, and 32% said it was “not” easy. The search could have been made easier by someone to guide them, more information in one location and a list of organizations that give financial assistance with detailed information on each program organized

by types of assistance. Forty-one percent stated that there was some aspect of financial information that they were unable to find. Sixty-one percent responded that they do not speak to HCPs about financial concerns. Social worker was the response with the next highest percentage at 21%.

The survey asked what in particular caused financial hardship. Responses included: loss of income due to stopping work (59%); office visit copays (48%); prescription co-pays (42%); travel to treatment (30%); parking (17%); and childcare (11%). Fifteen percent indicated that they had not experienced financial difficulty. Additional comments indicated that COBRA costs, deductibles, insurance premiums, the percentage of medical bills required to be paid (or not covered) as well as healthy food options all contributed to their financial problems. Despite financial struggles, only 32% had applied for grants or financial assistance. Seventy-eight percent said that financial assistance programs would help relieve financial concerns.

**Insurance.** Since being diagnosed with MBC, 88% reported having insurance “but not the entire time.” Four percent reported that they did not have insurance since being diagnosed. Seventy-one percent (n=228) had encountered health insurance problems which included: denials; appeals; coverage; errors in coding or billing; difficulties if had to switch insurers; high cost of insurance; delays; and scans or medications denied even if doctor recommended. Many (89%) reported that they believe that they are receiving appropriate care. Those who disagreed cited insurers’ failure to cover CAM as one reason.

Sixty-one percent stated it was “very important” to gain knowledge about insurance with 31% (n=70) indicating it was “somewhat important.” ***Sixty-one percent sought information about insurance making it the fifth highest topic area in terms of information sought.*** Sources consulted included: HCP (40%); other women with MBC (30%); online other (non-YSC) websites (28%); and government websites (26%). Forty-nine percent stated that finding information was “somewhat easy” with 37% stated it was not easy to find information on insurance. When asked what could have made it easier, a typical response was an insurance company representative who could review cancer-related benefits and processes. Thirty-one percent reported there was insurance information they could not find. Forty-five percent indicated that they did not talk to HCPs about insurance. The next highest responses included: medical oncologist (33%); primary care physician (13%); social worker (13%); nurse (10%); and patient navigator (9%).

When asked what options they would use if available to learn about or assist with insurance issues, responses included: working with a case manager at the insurance company (56.5%); HCPs (46%); websites (39%); other YW with MBC (36%); webpage for YW with MBC (35%); an online guide (33%); monthly billing/statements instead of per treatment or visit (33%); and newsletter for YW with MBC (30%).

Most survey respondents (93%) had not applied to receive their state’s breast and cervical cancer prevention and treatment program. Seven percent applied but were denied. Ninety-six percent had not received any insurance payment assistance through an organization such as the

[Healthwell Foundation](#) or [CancerCare](#) and had not received some form of charity care through HCPs.

***Communicating with HCPs.*** The majority (55%) of respondents stated that it was “very” important to gain knowledge about communicating with HCPs, although only 23% sought such knowledge. Sixty-nine percent reported that finding this information was “somewhat” easy. The most common sources of information were: HCPs (46%); other women with MBC (42%); online other breast cancer organizations (35%); and online general cancer organizations (35%).

If available, respondents (n=112) would use or recommend the following options to aid in communications with HCPs: patient navigator focused on MBC (54.5%); online guide (42%); online tools to organize/plan meeting or appointment (43%); educational presentation/materials to HCPs (40%); newsletter for YW with MBC (36%); and a written guide (33%).

Seventy-four percent are satisfied with HCP communication, although 42% would like additional time with them. Specifically, 91% would like more time with the medical oncologist and 23% with a social worker. ***Comments about the medical oncologist revealed that patients felt rushed or that more time was needed to discuss their issues, questions and concerns in more detail.*** Fifty-six reported that they receive emotional support from HCPs, and 24.5% would like to receive such support. Nineteen percent stated that they did not want emotional support. Specifically, emotional support was sought or received from the medical oncologist (82%), nurse (32%) and social worker (27%). Fifty-one percent stated that they were able to directly email HCPs, and (55%) said that they speak to doctors about quality of life. Most of the respondents who commented on their quality of life conversations said their HCPs were very supportive and understanding.

### ***Needs of MBC Population***

Seventy-seven percent of women reported that they felt overlooked or isolated by traditional breast cancer organizations with 69% stating that they did not feel that they fit into the activities of these organizations. Sixty-nine percent (n=160) reported that they believed that the “pink ribbon” breast cancer awareness movement ignores the issues of MBC patients.

Ninety-two percent reported that public awareness should be raised about MBC at any life stage. There was consensus that few people truly understand what MBC is and that it cannot be cured. A few comments stressed that women with MBC can still sometimes live a “normal” life and that they should not be considered lost causes. Ideas for raising public awareness included: display and use of the [METAvivor](#) ribbon, commercials, media attention, profiles of actual families and patients showing the different faces of MBC and accurate statistics and information about MBC. Similarly, 92% stated that public awareness should be raised about MBC in YW. Many respondents complained about “too much pink,” use of the term “survivor” or “winning the fight.” One respondent said that some organizations treat breast cancer as an “uplifting/inspiring challenge instead of a deathly threat.” One respondent said, “YSC has done a wonderful job regarding young survivors. They could use similar measures for MBC. There are very few of us, but we represent

what would have otherwise been a very productive member of society.” Another said, “Dying is really not pretty, is it? Maybe that is why it is hard to raise public awareness. Pink is pretty.”

Questions about the terminology which should be used to describe YW living with MBC were also asked. Preferences for the following three terms were: survivor (46%); thrivor (21%); and metavior (19%). Comments made in response to these questions indicated a general sense that these YW wanted the truth to be shared not a “pretty name.” Suggestions for other terminology were “living with MBC or stage IV,” or “patient.” “Metster” was a term also mentioned.

This section of the survey elicited many comments and opinions including:

- o “Breast cancer is thought of as a bump in the road. MBC IS the road.”
- o “We’re the boogeyman, the face of death. No one wants us around to remind them that they can’t actually beat breast cancer.”
- o “For me, it’s not about getting through the next year and being cancer-free, it’s about dealing/managing this for the rest of my life.”

Several noted that while 30% of women are diagnosed with metastatic disease, only 2-3% of the money raised goes to MBC research. They also lamented the lack of clinical trials for stage IV disease stating that there seems to be more interest in prevention and mammograms than in MBC. They also said there was little to no information for YW with MBC and no support. They despise hearing that if you find it early, it is cured because, for many of them, this is simply not true.