



It's About You: Getting Insights from Young Women with Metastatic Breast Cancer

Taking the Survey

YSC knows that young women living with metastatic breast cancer (MBC) are an understudied and underserved population. We know that more information is needed to provide support and resources to you.

Why Another Survey?

We reviewed past surveys completed by women (and sometimes just young women) living with MBC which provided good, but repetitive and incomplete information.

Why Is Ours Different?

Our survey is designed to dig deeper about your unique needs and challenges and what, so far, you've identified as helpful solutions (or not). We consider it "the next layer" of questions. The survey is crafted based on previous research, surveys and other data collected about and from the young and MBC population.

What Will YSC Do with the Survey Results?

We will share these results in public forums and scientific meetings so researchers may rely on this information and other organizations can help as well. And, we will share the results with you. Your answers, of course, are anonymous.



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Thank you for your willingness to share your knowledge and experience with YSC!

It's Long. We Know It.

It will take some time to complete. It is in multiple sections. You will have the option to opt out of sections that may not apply to you. You can save your results and return to it later. Just click the “Save I Need to Come Back” button in the top right hand corner of the survey. (Please note that some users have experienced an inability to save responses and return when taking the survey on a mobile phone.) Again, your answers are anonymous. Thank you for hanging in there to help us help you.

A Little Something – No Really!

Let us thank you! When you finish the survey, you can request and receive a YSC gift and be entered for a chance to win one of three pairs of Oakley sunglasses! Nice!

* 1. How did you find out about this survey? (select one)

- YSC Email/newsletter
- Facebook
- Twitter
- Other Social Media (please specify)
- Someone forwarded a YSC email to me
- Someone emailed me a link
- Web search (Google, Yahoo, Bing etc.)
- Word of mouth
- Other breast cancer or metastatic breast cancer organization (please list below)
- US Mail
- Numerous sources
- Other (please specify)

* 2. Are you a young woman living with metastatic breast cancer (MBC)?

- Yes
- No
- Not sure



* 3. Were you diagnosed with any stage of breast cancer before or at the age of 41?

Yes

No



* 4. Please indicate your age when you were first diagnosed with breast cancer:



* 5. Year of initial breast cancer diagnosis:

* 6. Stage at initial diagnosis (We are using the definitions of "stage" as described here: <http://www.breastcancer.org/symptoms/diagnosis/staging>)

* 7. What year(s) were you diagnosed with metastatic disease?

* 8. What is the location(s) of your metastases?

* 9. How old were you when you were diagnosed with metastatic disease?



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Please share how you identify yourself by race and or ethnicity:

* 10. What is your race:

* 11. What is your ethnicity (based on categories provided from the National Center for Education Statistics <http://nces.ed.gov/ipeds/reic/definitions.asp>):



* 12. Please share your City and State

City/Town:

State/Province:

* 13. How would you describe the area where you live:

- Rural Urban Suburban Other



* 14. Please describe your relationship status:

- Single
 Married
 Partnered/Committed Relationship
 Divorced
 Other (please specify)



* 15. Do you have children? If not, please type the number "0" in the first box. If so, please share their year(s) of birth:

No children

Child 1

Child 2

Child 3

Child 4

Child 5

More than 5 children



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* 16. I have an email address:

Yes

No

* 17. I have a computer:

Yes

No

* 18. I have a cell phone:

Yes

No

* 19. I have a cell phone/smartphone that can connect to the internet:

- Yes
- No

* 20. I can send/receive text messages using my cell phone:

- Yes
- No

* 21. I prefer to receive information by:

	1st preference	2nd preference	3rd preference
Email	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Cell Phone	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Postal Mail	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



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Your Diagnosis, Disease and Treatment Information

* 22. Is it important to you to learn more about metastatic breast cancer (MBC), treatment options, and prognosis?

- Yes
- No



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* 23. How important is it to you to gain knowledge about MBC, treatment options, and prognosis?

- Very Important Somewhat Important Not important at all

* 24. Have you sought information about MBC, treatment options, and prognosis?

- Yes
 No



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* 25. What sources have you consulted for information on MBC, treatment options, and prognosis? Please check all that apply:

- | | |
|---|---|
| <input type="checkbox"/> None | <input type="checkbox"/> Magazines/newspapers |
| <input type="checkbox"/> Online - YSC website | <input type="checkbox"/> Books |
| <input type="checkbox"/> Online - Other breast cancer organization's website(s) | <input type="checkbox"/> Other women with MBC |
| <input type="checkbox"/> Online - Other general resources (wikipedia, Google, etc.) | <input type="checkbox"/> Healthcare provider |
| <input type="checkbox"/> Online - Government websites (NCI, NIH, etc.) | <input type="checkbox"/> Social media |
| <input type="checkbox"/> Online - hospital websites | <input type="checkbox"/> Webinar/conference call(s) |
| <input type="checkbox"/> Online - newsletters | <input type="checkbox"/> In-person conference(s) |
| <input type="checkbox"/> Online community boards/peer support | <input type="checkbox"/> Helpline/Hotline |
| <input type="checkbox"/> Pamphlets | |
| <input type="checkbox"/> Other (please specify) | |

26. Of the sources you used which were the most helpful? Please list all that apply

27. Which were the least helpful? Please include why:

* 28. How easy was it to find the information you wanted/needed?

- N/A
- Very easy
- Somewhat easy
- Not easy at all

29. What could have made it easier?

* 30. Was there any information you were unable to find that you wanted/needed?

- N/A
- No
- Yes (if so, what?)



* 31. Who do you talk with on your Healthcare Provider team about MBC, treatment, and your prognosis?

- | | |
|---|---|
| <input type="checkbox"/> No one, I don't discuss it | <input type="checkbox"/> Social Worker |
| <input type="checkbox"/> Surgical Oncologist | <input type="checkbox"/> Nurse |
| <input type="checkbox"/> Plastic Surgeon | <input type="checkbox"/> Patient Navigator |
| <input type="checkbox"/> Medical Oncologist | <input type="checkbox"/> Nurse Navigator |
| <input type="checkbox"/> Radiation Oncologist | <input type="checkbox"/> Primary Care Physician |
| <input type="checkbox"/> Other (please specify) | |



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* 32. Have you looked for information about how long young women are living with MBC?

- Yes
- No



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33. If yes, did you find the information and where?

* 34. Would information on how long young metastatic women are living be helpful to you?

- Yes
- No

* 35. What options would you utilize, if available, to learn more about MBC, treatment options, and prognosis? Please check all that apply:

- | | |
|---|--|
| <input type="checkbox"/> Conference call(s) | <input type="checkbox"/> Podcasts |
| <input type="checkbox"/> Webinar | <input type="checkbox"/> Printed materials |
| <input type="checkbox"/> Newsletter for young women living with MBC | <input type="checkbox"/> YSC written tools |
| <input type="checkbox"/> Websites | <input type="checkbox"/> YSC online tools |
| <input type="checkbox"/> In-person conference(s) | <input type="checkbox"/> Social media |
| <input type="checkbox"/> Other young women with MBC | <input type="checkbox"/> Bulletin boards/online community(ies) |
| <input type="checkbox"/> Webpage(s) for young women with MBC | <input type="checkbox"/> Online guide |
| <input type="checkbox"/> Apps | |
| <input type="checkbox"/> Other (please specify) | |



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Sub-topic: Clinical Trials

* 36. Are clinical trials important to you?

- Yes
- No
- I don't know what "clinical trials" are



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* 37. How important is it to you to learn about the availability of clinical trials?

- Very important
- Somewhat important
- Not important at all

* 38. Have you sought information about clinical trials?

- Yes
- No



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* 39. What sources have you consulted for information on clinical trials? Please check all that apply:

- | | |
|--|---|
| <input type="checkbox"/> Online: YSC webpage on clinical trials | <input type="checkbox"/> Magazines/newspapers |
| <input type="checkbox"/> Online: website clinicaltrials.gov | <input type="checkbox"/> Books |
| <input type="checkbox"/> Online: other breast cancer organizations' website(s) (please list below) | <input type="checkbox"/> Other women with MBC |
| <input type="checkbox"/> Online: general cancer organizations | <input type="checkbox"/> Healthcare provider |
| <input type="checkbox"/> Online: general resources (Wikipedia, Google) | <input type="checkbox"/> Social media |
| <input type="checkbox"/> Online: government websites (NCI, NIH, etc.) | <input type="checkbox"/> Webinar/conference call |
| <input type="checkbox"/> Online: hospital websites | <input type="checkbox"/> In-person conference(s) |
| <input type="checkbox"/> Online: other | <input type="checkbox"/> Helpline |
| <input type="checkbox"/> Newsletters | <input type="checkbox"/> Online community boards/peer support |
| <input type="checkbox"/> Pamphlets | <input type="checkbox"/> None |
| <input type="checkbox"/> Other (please specify) | |

40. Of the sources you consulted which were the most helpful? Please list all that apply:

41. Which clinical trial resources were the least helpful? Please include why.

* 42. How easy was it to find the information you wanted?

- Very easy
- N/A
- Somewhat easy
- Not easy at all

43. What would have made it easier to find clinical trial resources?

44. Was there any information that you wanted/needed that you were unable to find?

- No
- Yes (If so, what?)



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* 45. Who do you talk with on your Healthcare Provider team about clinical trials? Please check all that apply:

- No one, I don't discuss it
- Surgical Oncologist
- Plastic Surgeon
- Medical Oncologist
- Radiation Oncologist
- Social Worker
- Nurse
- Patient Navigator
- Nurse Navigator
- Primary Care Physician
- Other (please specify)



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* 46. What options would you utilize, if available, to learn more about and help you decide whether to participate in clinical trials? Please check all that apply:

- Conference call
- Webinar
- Newsletter for young women living with MBC
- Websites
- In-person conferences
- Other young women with MBC
- Webpage for young women with MBC
- Apps
- Podcasts
- Printed materials
- YSC written tools
- YSC online tools
- Social media
- Bulletin boards/online communities
- Online guide
- Other (please specify)



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* 47. Have you participated in a Phase I, II, or III Clinical Trial?

- No
- Yes, please list trial(s)

* 48. If you have not participated in any clinical trials, please share why not:

- Not aware of any that I could participate in
- My healthcare providers didn't tell me about any
- My healthcare providers advised against it
- I did not want to
- I tried to participate, but was declined
- Other (please specify)

49. If you would like to expand upon your clinical trial participation or lack of participation, please do so here:



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* 50. Have you visited the YSC webpage on clinical trials?

- Yes
- No



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* 51. If yes, was it useful?

- Yes
- No
- Unsure
- Don't recall
- Have not seen it

52. What could YSC do to improve the clinical trials webpages?



* 53. Is the management of treatment and its side effects important to you?

- Yes
- No



* 54. How important is it to you to obtain information about managing your treatment, the side effects that may arise, and how to manage those side effects?

- Very important
- Somewhat important
- Not important at all

* 55. Have you sought information about managing your treatment and possible side effects?

- Yes
- No



* 56. What sources have you consulted for information on management of treatment and side effects? Check all that apply:

- Online: YSC website
- Online: other breast cancer organization website (please list below)
- Online: general cancer organizations
- Online: general resources (Wikipedia, Google)
- Online: government websites (NCI, NIH, etc.)
- Online: hospital websites
- Online: other
- Newsletters
- Pamphlets Magazines/newspapers
- Books
- Other women with MBC
- Healthcare provider
- Social media
- Webinar/conference call
- In-person conference
- Helpline/Hotline
- None
- Other (please specify)



57. Of the sources you consulted which were the most helpful? Please list all that apply:

58. Of the sources you consulted which were the least helpful? Please include why.

59. How easy was it to find the information you wanted/needed?

- Very easy
- Somewhat easy
- Not easy at all

60. What could have made it easier to find the information?

61. Was there any information you were unable to find that you wanted/needed?

- No
- Yes, please specify



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* 62. Who do you talk with on your Healthcare Provider team about management of treatment and side effects? Please check all that apply:

- No one, I don't discuss it
- Surgical Oncologist
- Plastic Surgeon
- Medical Oncologist
- Radiation Oncologist
- Social Worker
- Nurse
- Patient Navigator
- Nurse Navigator
- Primary Care Physician
- Other (please specify)

* 63. Do your Healthcare Providers spend time explaining your treatment regimen and possible side effects?

- Yes, every time
- Yes, sometimes
- Yes, but only when I ask
- No, they do not



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* 64. What options would you utilize, if available, to learn more about management of treatment and side effects? Please check all that apply:

- Conference call
- Webinar
- Newsletter for young women living with MBC
- Websites
- In-person conferences
- Other young women with MBC
- Webpage for young women with MBC
- Apps
- Podcasts
- Printed materials
- YSC written tools
- YSC online tools
- Social media
- Bulletin boards/online communities
- Online guide
- Other (please specify)



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Complementary and Alternative Medicine (CAM)

* 65. Have you used complementary and alternative medicine (CAM) to help manage your MBC or treatment side effects (for example acupuncture or meditation)?

- No
- Yes



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* 66. If yes, please check all approached that you've tried:

- Herbal Products
- Supplements
- Dietary Changes
- Meditation
- Yoga
- Acupuncture
- Reiki/Energy Work
- None
- Other (please list)

67. Why/for what purpose did you use these CAM methods?



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* 68. Did the CAM approach(es) help?

- Yes, a lot
- Yes, somewhat
- No, didn't help at all
- I haven't used CAM

* 69. Are you currently utilizing a complementary and/or alternative approach?

- Yes
- No, please tell us why?



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* 70. Did you make your Healthcare Providers aware that you are/were utilizing CAM?

- Yes
- No
- I haven't used CAM

* 71. Did you include your Healthcare Providers in the making of your decision to use CAM?

- Yes
- No
- N/A

* 72. Did your Healthcare Providers support your decision to use CAM?

- Yes
- No
- N/A



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* 73. Are/were you utilizing CAM along with traditional, standard of care treatment (for example chemotherapy, radiation)?

- Yes
- No



Hospice Care

* 74. Hospice care is often an option discussed with those with MBC. Has Hospice been discussed with you?

- No
- I don't know what Hospice is
- Yes, who discussed this with you?

* 75. Do you feel that you understand what hospice is and its benefits?

- Yes
- No, not really

* 76. Is it important to you to learn more about hospice care?

- Yes
- No

* 77. How important is it to you to gain knowledge about hospice care?

- Very important
- Somewhat important
- Not important at all



* 78. Have you sought information about hospice care?

- Yes
- No



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* 79. What sources have you consulted for information on hospice care? Please check all that apply:

- | | |
|--|--|
| <input type="checkbox"/> Online: YSC website | <input type="checkbox"/> Magazines/newspapers |
| <input type="checkbox"/> Online: other breast cancer organization websites (please list below) | <input type="checkbox"/> Books |
| <input type="checkbox"/> Online: general cancer organizations | <input type="checkbox"/> Other women with MBC |
| <input type="checkbox"/> Online: general resources (Wikipedia, Google) | <input type="checkbox"/> Healthcare provider |
| <input type="checkbox"/> Online: government websites (NCI, NIH, etc.) | <input type="checkbox"/> Social media |
| <input type="checkbox"/> Online: hospital websites | <input type="checkbox"/> Webinar/conference call |
| <input type="checkbox"/> Online: hospice websites | <input type="checkbox"/> In-person conference |
| <input type="checkbox"/> Online: other | <input type="checkbox"/> Helpline |
| <input type="checkbox"/> Newsletters | <input type="checkbox"/> None |
| <input type="checkbox"/> Pamphlets | |
| <input type="checkbox"/> Other (please specify) | |

80. Of the sources you consulted which were the most helpful? Please list all that apply:

81. Which hospice resources were the least helpful? Please include why:



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* 82. How easy was it to find the information you wanted?

- Very easy
- Somewhat easy
- Not easy at all

83. What could have made it easier?

84. Was there any hospice care information that you were unable to find that you wanted/needed?

- No
- Yes, please tell us what?

* 85. What options would you utilize, if available, to learn more about hospice care? Please check all that apply:

- | | |
|---|---|
| <input type="checkbox"/> Conference call | <input type="checkbox"/> Podcasts |
| <input type="checkbox"/> Webinar | <input type="checkbox"/> Printed materials |
| <input type="checkbox"/> Newsletter for young women living with MBC | <input type="checkbox"/> YSC written tools |
| <input type="checkbox"/> Websites | <input type="checkbox"/> YSC online tools |
| <input type="checkbox"/> In-person conferences | <input type="checkbox"/> Social media |
| <input type="checkbox"/> Other young women with MBC | <input type="checkbox"/> Bulletin boards/online communities |
| <input type="checkbox"/> Webpage for young women with MBC | <input type="checkbox"/> Online guide |
| <input type="checkbox"/> Apps | |
| <input type="checkbox"/> Other (please specify) | |



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Anticipatory Grief

Anticipatory Grief is defined as “grappling with or grieving a loss before it completely unfolds.”
(http://www.helpguide.org/harvard/dealing_serious_illness.htm)

In the setting of MBC, examples of anticipatory grief could include whether or not one will be able to have children, will see her children grow, will die too young. Another example is the uncertainty of life as she knew it.

* 86. Is anticipatory grief a topic of importance to you?

- Yes
- No



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* 87. If yes, Please check all that apply:

- Loss of life cut short
- Loss of leaving spouse/partner/significant other
- Loss of leaving this earth without having had kids
- Loss of leaving children without their mother
- Loss of career
- Loss of identity
- Other (please explain)

* 88. How important is it to you to gain knowledge about managing anticipatory grief?

- Very important
- Somewhat important
- Not important at all



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* 89. Have you sought information about anticipatory grief or managing it?

Yes

No



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* 90. What sources have you consulted for information on anticipatory grief? Please check all that apply:

Online: YSC website

Magazines/newspapers

Online: other breast cancer organization websites (please list below)

Books

Online: general cancer organizations

Other women with MBC

Online: general resources (Wikipedia, Google)

Healthcare provider

Online: government websites (NCI, NIH, etc.)

Social media

Online: hospital websites

Webinar/conference call

Online: other

In-person conference

Newsletters

Helpline

Pamphlets

None

Other (please specify)



91. Of the sources you consulted which were the most helpful? Please list all that apply:

92. Which sources were the least helpful and why?

* 93. How easy was it to find the anticipatory grief information you wanted?

- Very easy
- Somewhat easy
- Not easy at all

94. What could have made it easier?

95. Was there any information you were unable to find that you wanted/needed?



* 96. Who do you talk with on your Healthcare Provider team about anticipatory grief issues? Please check all that apply:

- No one, I don't discuss it
- Surgical Oncologist
- Plastic Surgeon
- Medical Oncologist
- Radiation Oncologist
- Social Worker
- Nurse
- Patient Navigator
- Nurse Navigator
- Primary Care Physician
- Other (please specify)

* 97. What options would you utilize, if available, to learn more about anticipatory grief and how to manage it? Please check all that apply:

- | | |
|---|--|
| <input type="checkbox"/> Conference call | <input type="checkbox"/> Podcasts |
| <input type="checkbox"/> Webinar | <input type="checkbox"/> Printed materials |
| <input type="checkbox"/> Newsletter for young women living with MBC | <input type="checkbox"/> YSC written tools |
| <input type="checkbox"/> Websites | <input type="checkbox"/> YSC online tools |
| <input type="checkbox"/> In-person conferences | <input type="checkbox"/> Social media |
| <input type="checkbox"/> Other young women with MBC | <input type="checkbox"/> Bulletin boards/online communities |
| <input type="checkbox"/> Webpage for young women with MBC | <input type="checkbox"/> Online guide |
| <input type="checkbox"/> Apps | <input type="checkbox"/> Educational efforts for caregivers and significant others |
| <input type="checkbox"/> Other (please specify) | |



* 98. Given the definition of anticipatory grief discussed above, do you feel that your family/friends/loved ones also struggle with anticipatory grief issues?

- Yes
- No
- I am not sure

If yes, please explain:

* 99. Have you discussed your prognosis with your family/friends/loved ones?

- Yes
- No, please share why?



100. If yes, tell us how/where/when you had these discussions.



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* 101. Have you taken any steps to leave or create memories for family and friends?

- Yes
- It is not important to me
- No



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102. Please share what you did. Were there tools, resources, you found to do so? If yes, please list:

* 103. Would tools to communicate about your disease and prognosis be helpful?

- Yes
- No

* 104. What options would you utilize, if available, to leave or create memories for family and friends?

- Scrapbooking templates
- Letter templates
- Special occasion templates
- Legacy projects (video your life history for example)
- Blog templates
- Other (please specify)



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Stress & Emotional Well-Being

* 105. Are the topics of stress and emotional well-being important to you?

- Yes
- No



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* 106. Since my diagnosis of MBC my stress level is about:

- The same
- Better
- Worse
- It varies, some days are stressful; some days are not

107. If you answered the above question as “worse” or “it varies,” share with us how it is worse or how it varies:



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* 108. Since my diagnosis of MBC, my emotional well-being has:

- Improved
- Has not changed much
- Worsened

* 109. In what ways has your emotional well-being been impacted since your diagnosis of MBC? Check all that apply:

- | | |
|--|--|
| <input type="checkbox"/> No change | <input type="checkbox"/> Withdrawal from family |
| <input type="checkbox"/> Improved | <input type="checkbox"/> Withdrawal from friends |
| <input type="checkbox"/> Anxiety | <input type="checkbox"/> Trouble sleeping |
| <input type="checkbox"/> Depression | <input type="checkbox"/> Sleeping all the time |
| <input type="checkbox"/> Withdrawal from things you once liked to do | |
| <input type="checkbox"/> Other (please explain) | |

* 110. How important is it to you to gain knowledge about stress and emotional well-being?

- Very important
- Somewhat important
- Not important at all



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* 111. Have you sought information about stress or emotional well-being (including any of the issues identified in the previous question(s))?

- Yes
- No



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* 112. What sources have you consulted for information about stress or emotional well-being (including any of the issues identified in previous questions)? Please check all that apply:

- Online: YSC website
- Online: other breast cancer organization websites (please list below)
- Online: general cancer organizations
- Online: general resources (Wikipedia, Google)
- Online: government websites (NCI, NIH, etc.)
- Online: hospital websites
- Online: other
- Newsletters
- Pamphlets
- Other (please specify)
- Magazines/newspapers
- Books
- Other women with MBC
- Healthcare provider
- Social media
- Webinar/conference call
- In-person conference
- Helpline/Hotline
- None

113. Of the sources you consulted which were the most helpful? Please list all that apply:

114. Which sources about stress and emotional well-being were the least helpful? Please include why:



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* 115. How easy was it to find the information you wanted?

- Very easy
- Somewhat easy
- Not easy at all

116. What could have made it easier?



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* 117. Who do you talk with on your Healthcare Provider team about your stress and emotional well-being?

Please check all that apply:

- | | |
|---|---|
| <input type="checkbox"/> No one, I don't discuss it | <input type="checkbox"/> Social Worker |
| <input type="checkbox"/> Surgical Oncologist | <input type="checkbox"/> Nurse |
| <input type="checkbox"/> Plastic Surgeon | <input type="checkbox"/> Patient Navigator |
| <input type="checkbox"/> Medical Oncologist | <input type="checkbox"/> Nurse Navigator |
| <input type="checkbox"/> Radiation Oncologist | <input type="checkbox"/> Primary Care Physician |
| <input type="checkbox"/> Other (please specify) | |

* 118. What options would you utilize, if available, to learn more about and to manage stress and emotional well-being? Please check all that apply:

- | | |
|---|--|
| <input type="checkbox"/> Conference call | <input type="checkbox"/> Podcasts |
| <input type="checkbox"/> Webinar | <input type="checkbox"/> Printed materials |
| <input type="checkbox"/> Newsletter for young women living with MBC | <input type="checkbox"/> YSC written tools |
| <input type="checkbox"/> Websites | <input type="checkbox"/> YSC online tools |
| <input type="checkbox"/> In-person conferences | <input type="checkbox"/> Social media |
| <input type="checkbox"/> Other young women with MBC | <input type="checkbox"/> Bulletin boards/online communities |
| <input type="checkbox"/> Webpage for young women with MBC | <input type="checkbox"/> Online guide |
| <input type="checkbox"/> Apps | <input type="checkbox"/> Educational materials for caregivers and significant others |
| <input type="checkbox"/> Other (please specify) | |



* 119. Before MBC, how have you previously managed stress and emotional well-being?

* 120. Do you continue to do these things?

Yes

No, please tell us why not?



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* 121. Before you were diagnosed with breast cancer (any stage), did you have a history of any of the following? Please check all that apply:

- Anxiety
- Depression
- Trauma
- Feelings of isolation
- None of these
- Other (please specify)

122. Did you seek help/treatment for the issues identified in the previous question?

No, why not:

Yes, please share what help/treatment

* 123. Have you sought professional psycho-social help or support related to your MBC?

- Yes
- No



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124. If your response was "no," why not?

125. If your response to the question was "yes," what about professional assistance helped?



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* 126. Did the professional assistance include taking prescription medicine?

- Yes
- No



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* 127. Were you/are you compliant with these prescription medications?

- Yes
- No



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* 128. How do you take time for yourself?

* 129. Do you take time to rest?

- Yes

No, please share why not?

* 130. Are you able take time to do nothing?

- Yes
- No, please tell us why not?

* 131. Are you comfortable asking for help or assistance?

- Yes
- No, please tell us why not?



It's About You: Getting Insights from Young Women with Metastatic Breast Cancer

Working, Not Working and/or Disability

* 132. Has your MBC diagnosis affected your ability to work and earn a living?

- Yes
- No

* 133. Were you working at the time of your MBC diagnosis?

- Yes
- No

* 134. Are you working now?

- Yes
- No

* 135. Is the topic working/not working and/or disability important to you?

- Yes
- No



It's About You: Getting Insights from Young Women with Metastatic Breast Cancer

* 136. Does/did your employer know that you have been diagnosed with MBC?

- Yes
- No
- N/A

* 137. Do/did your co-workers know?

- Yes
- No
- N/A



It's About You: Getting Insights from Young Women with Metastatic Breast Cancer

* 138. What kind of leave do/did your work benefits include?

- | | |
|---|--|
| <input type="checkbox"/> Paid Time Off | <input type="checkbox"/> Short Term disability |
| <input type="checkbox"/> Sick Leave | <input type="checkbox"/> Long Term disability |
| <input type="checkbox"/> Family Medical Leave Act | <input type="checkbox"/> None |
| <input type="checkbox"/> Other (please specify) | |

* 139. Have you taken leave because of your MBC diagnosis and treatment?

- Yes
- No



It's About You: Getting Insights from Young Women with Metastatic Breast Cancer

* 140. If yes, please specify what kind of leave you have taken. (check all that apply)

- Paid Time Off
- Sick Leave
- Family Medical Leave Act
- Short Term disability
- Long Term disability
- None
- Other (please specify)

* 141. Have you exhausted your leave?

- Yes
- No
- N/A



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* 142. Has your employment been terminated since your diagnosis of MBC?

- Yes
- No



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143. If yes, what reason were you given for being terminated?

* 144. If you have worked since your MBC diagnosis, has your employer made any accommodations for you (flexible work schedule, work from home, part-time, etc.)?

- Yes
- No
- N/A

145. If yes, please explain.



It's About You: Getting Insights from Young Women with Metastatic Breast Cancer

* 146. At the time of your diagnosis with MBC, did anyone provide information about your rights to work, or possible disability benefits?

- Yes
- No



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147. If yes, who discussed your rights or disability with you?

* 148. Have you applied for SSDI (Social Security Disability Income)?

- Yes
- No

* 149. Do you know your rights concerning SSDI and the Compassionate Allowance?

- Yes
- No

* 150. How important is it to you to gain knowledge about working and disability options?

- Very important
- Somewhat important
- Not important at all



It's About You: Getting Insights from Young Women with Metastatic Breast Cancer

* 151. Have you sought information about working/not working/disability?

- Yes
- No



It's About You: Getting Insights from Young Women with Metastatic Breast Cancer

* 152. What sources have you consulted for information about working/not working/disability? Please check all that apply:

- | | |
|---|--|
| <input type="checkbox"/> Online: YSC website | <input type="checkbox"/> Magazines/newspapers |
| <input type="checkbox"/> Online: other breast cancer organization website | <input type="checkbox"/> Books |
| <input type="checkbox"/> Online: general cancer organizations | <input type="checkbox"/> Other women with MBC |
| <input type="checkbox"/> Online: general resources (Wikipedia, Google) | <input type="checkbox"/> Healthcare provider |
| <input type="checkbox"/> Online: government websites (NCI, NIH, etc.) | <input type="checkbox"/> Social media |
| <input type="checkbox"/> Online: hospital websites | <input type="checkbox"/> Webinar/conference call |
| <input type="checkbox"/> Online: other | <input type="checkbox"/> In-person conference |
| <input type="checkbox"/> Newsletters | <input type="checkbox"/> Helpline/Hotline |
| <input type="checkbox"/> Pamphlets | <input type="checkbox"/> None |
| <input type="checkbox"/> Other (please specify) | |

153. Of the sources you consulted which were the most helpful? Please list all that apply:

154. Which sources were the least helpful? Please include why:



It's About You: Getting Insights from Young Women with Metastatic Breast Cancer

* 155. How easy was it to find the information you needed/wanted?

- Very easy
- Somewhat easy
- Not easy at all

156. What would have made it easier?

157. Was there any information you were unable to find that you wanted/needed?

- No
- Yes, please specify



It's About You: Getting Insights from Young Women with Metastatic Breast Cancer

* 158. Who do you talk with on your Healthcare Provider team about working/not working/disability? Please check all that apply:

- | | |
|---|---|
| <input type="checkbox"/> No one, I don't discuss it | <input type="checkbox"/> Social Worker |
| <input type="checkbox"/> Surgical Oncologist | <input type="checkbox"/> Nurse |
| <input type="checkbox"/> Plastic Surgeon | <input type="checkbox"/> Patient Navigator |
| <input type="checkbox"/> Medical Oncologist | <input type="checkbox"/> Nurse Navigator |
| <input type="checkbox"/> Radiation Oncologist | <input type="checkbox"/> Primary Care Physician |
| <input type="checkbox"/> Other (please specify) | |

* 159. What options would you utilize, if available, to learn more about working/not working/disability? Please check all that apply:

- | | |
|---|---|
| <input type="checkbox"/> Conference call | <input type="checkbox"/> Podcasts |
| <input type="checkbox"/> Webinar | <input type="checkbox"/> Printed materials |
| <input type="checkbox"/> Newsletter for young women living with MBC | <input type="checkbox"/> YSC written tools |
| <input type="checkbox"/> Websites | <input type="checkbox"/> YSC online tools |
| <input type="checkbox"/> In-person conferences | <input type="checkbox"/> Social media |
| <input type="checkbox"/> Other young women with MBC | <input type="checkbox"/> Bulletin boards/online communities |
| <input type="checkbox"/> Webpage for young women with MBC | <input type="checkbox"/> Online guide |
| <input type="checkbox"/> Apps | <input type="checkbox"/> None |
| <input type="checkbox"/> Other (please specify) | |



It's About You: Getting Insights from Young Women with Metastatic Breast Cancer

Relationships: Connecting with Other Young Women; Single/Dating; Childless/Adoption; Family/Friends

* 160. Is the topic of interpersonal relationships important to you? Note: if you answer “no” to this question, you will be skipped to the next section. If you answer yes, you will have the opportunity to opt out of subsections less relevant to you.

Yes

No



It's About You: Getting Insights from Young Women with Metastatic Breast Cancer

Connecting with other Young Women with MBC

* 161. Is it important to you to connect, or to learn how to connect, with other young women with MBC?

Yes

No



It's About You: Getting Insights from Young Women with Metastatic Breast Cancer

* 162. How important is it to you to connect, or to learn how to connect, with other young women with MBC?

Very important

Somewhat important

Not important at all

* 163. Have you tried to connect, or sought information on how to connect, with other young women with MBC?

- Yes
- No



It's About You: Getting Insights from Young Women with Metastatic Breast Cancer

* 164. What sources have you consulted for information on connecting with other young women living with MBC? Please check all that apply:

- | | |
|--|--|
| <input type="checkbox"/> Online: YSC website | <input type="checkbox"/> Magazines/newspapers |
| <input type="checkbox"/> Online: other breast cancer organization websites (please list below) | <input type="checkbox"/> Books |
| <input type="checkbox"/> Online: general cancer organizations | <input type="checkbox"/> Other women with MBC |
| <input type="checkbox"/> Online: general resources (Wikipedia, Google) | <input type="checkbox"/> Healthcare provider |
| <input type="checkbox"/> Online: government websites (NCI, NIH, etc.) | <input type="checkbox"/> Social media |
| <input type="checkbox"/> Online: hospital websites | <input type="checkbox"/> Webinar/conference call |
| <input type="checkbox"/> Online: other | <input type="checkbox"/> In-person conference |
| <input type="checkbox"/> Newsletters | <input type="checkbox"/> Helpline/Hotline |
| <input type="checkbox"/> Pamphlets | <input type="checkbox"/> None |
| <input type="checkbox"/> Other (please specify) | |



* 165. What have you done so far to try to connect with young women with MBC? Please check all that apply:

- In person support group (all ages, all stages)
- In-person young women's support group (all stages) I
- In-person young MBC support group I
- In-person MBC support group (all ages)
- Online support group
- Support group by telephone
- One to one peer match
- Message boards
- YSC bulletin boards
- Social media
- Nothing
- Other (please specify)



166. Of the sources you consulted or connections you attempted, which were the most helpful? Please list all that apply:

167. Which sources or connections were the least helpful? Please share why:



It's About You: Getting Insights from Young Women with Metastatic Breast Cancer

* 168. How easy was it to find the information/connections you wanted?

- Very easy
- Somewhat easy
- Not easy at all

169. What would have made it easier?

170. Was there any information/connection you were unable to find that you wanted/needed?

- No
- Yes, please specify



It's About You: Getting Insights from Young Women with Metastatic Breast Cancer

* 171. Who do you talk with on your Healthcare Provider team about connecting with other young women with MBC? Please check all that apply:

- No one, I don't discuss it
- Surgical Oncologist
- Plastic Surgeon
- Medical Oncologist
- Radiation Oncologist
- Social Worker
- Nurse
- Patient Navigator
- Nurse Navigator
- Primary Care Physician
- Other (please specify)

* 172. What options would you utilize, if available, to learn about connecting or to connect with young women with MBC? Please check all that apply:

- | | |
|---|---|
| <input type="checkbox"/> Conference call | <input type="checkbox"/> Podcasts |
| <input type="checkbox"/> Webinar | <input type="checkbox"/> Printed materials |
| <input type="checkbox"/> Newsletter for young women living with MBC | <input type="checkbox"/> YSC written tools |
| <input type="checkbox"/> Websites | <input type="checkbox"/> YSC online tools |
| <input type="checkbox"/> In-person conferences | <input type="checkbox"/> Social media |
| <input type="checkbox"/> Other young women with MBC | <input type="checkbox"/> Bulletin boards/online communities |
| <input type="checkbox"/> Webpage for young women with MBC | <input type="checkbox"/> Online guide |
| <input type="checkbox"/> Apps | <input type="checkbox"/> Skype |
| <input type="checkbox"/> Other (please specify) | |



It's About You: Getting Insights from Young Women with Metastatic Breast Cancer

* 173. Are you afraid to become close to another young women living with MBC?

- No
- Yes, please indicate why:

* 174. Do you read blogs or anecdotes about other young women living with MBC?

- Yes
- No

* 175. Have you attended the Conference for Young Women (C4YW)? Please note that we will ask more questions on C4YW in a later section.

- Yes
- No



It's About You: Getting Insights from Young Women with Metastatic Breast Cancer

* 176. If YSC were to host a MBC Retreat, would you strongly consider attending?

- Yes
- No
- Unsure



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* 177. If yes or unsure, what would be the most important elements for you to attend?

* 178. What topics or activities would you like to see offered at a MBC Retreat?



It's About You: Getting Insights from Young Women with Metastatic Breast Cancer

* 179. In considering whether to attend an in-person support group, does it matter to you if the group is focused solely on YOUNG women living with MBC?

Yes, please comment

No, please comment

* 180. If you've attended an in-person support group NOT focused solely on MBC, have you been welcomed by the other participants in the group?

Yes

Somewhat

No, please describe your experience:



It's About You: Getting Insights from Young Women with Metastatic Breast Cancer

YSC Face to Face (F2F) groups

YSC Face to Face (F2F) groups are local groups of young women affected by breast cancer meeting where and when they want in a relaxed, supportive environment. <http://www.youngsurvival.org/get-involved/f2f/>

* 181. Do you know about YSC F2F groups?

Yes

No

* 182. Are you aware of YSC F2F groups in/around your area?

Yes

No

183. Have you participated in a F2F in your area?

Yes, please share your experience

No, why not?

* 184. Would you be interested in learning more about YSC F2Fs and the possibility of starting a F2F in your area?

Yes

No



It's About You: Getting Insights from Young Women with Metastatic Breast Cancer

* 185. Are you aware that YSC hosts a monthly teleconference for young women with MBC?
<http://www.youngsurvival.org/programs/connect/metslink/>

Yes

No



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* 186. Have you participated in YSC's monthly MetsLink calls?

Yes, tell us about your experience:

No, please tell us why not:



It's About You: Getting Insights from Young Women with Metastatic Breast Cancer

* 187. Have you requested to be peer-matched (connected) with another young woman through YSC's SurvivorLink program <http://www.youngsurvival.org/programs/connect/survivorlink/> ?

Yes

No



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* 188. Were you matched?

Yes, please tell us about your experience

No, please tell us why you weren't matched



It's About You: Getting Insights from Young Women with Metastatic Breast Cancer

* 189. Have you connected with other young women with MBC on YSC's community boards?

Yes

No



It's About You: Getting Insights from Young Women with Metastatic Breast Cancer

190. If you've connected on community boards please, tell us in which forums have you participated?

191. If you do participate, do you find the community boards to be supportive and helpful?

Yes, please explain:

No, please explain:



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192. Have you connected with other young women with MBC through Facebook or other social media?

- Yes
- No



It's About You: Getting Insights from Young Women with Metastatic Breast Cancer

* 193. What is most important to you? Please rank in order of importance.

	Most important	Important	Least important
Being connected with other young women with MBC	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Being connected with other women of any age with MBC	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Being connected with other young women with breast cancer of any stage	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



It's About You: Getting Insights from Young Women with Metastatic Breast Cancer

Single - Dating

* 194. Since your diagnosis of MBC have you been or are you currently single?

Yes

No



It's About You: Getting Insights from Young Women with Metastatic Breast Cancer

* 195. Is it important to you to learn or dialog more about dating?

Yes

No



It's About You: Getting Insights from Young Women with Metastatic Breast Cancer

* 196. How important is it to you to learn more dating while living with MBC?

- Very important
- Somewhat important
- Not important at all



It's About You: Getting Insights from Young Women with Metastatic Breast Cancer

* 197. Have you sought information about being single and dating while living with MBC?

- Yes
- No



It's About You: Getting Insights from Young Women with Metastatic Breast Cancer

* 198. What sources have you consulted for information on dating? Please check all that apply:

- Online: YSC website
- Online: other breast cancer organization websites (please list below)
- Online: general cancer organizations
- Online: general resources (Wikipedia, Google)
- Online: government websites (NCI, NIH, etc.)
- Online: hospital websites
- Online: other
- Newsletters
- Pamphlets
- Magazines/newspapers
- Books
- Other women with MBC
- Healthcare provider
- Social media
- Webinar/conference call
- In-person conference
- Helpline/Hotline
- Other (please specify)

199. Of the sources you consulted which were the most helpful? Please list all that apply:

200. Which were the least helpful? Please include why:



It's About You: Getting Insights from Young Women with Metastatic Breast Cancer

* 201. How easy was it to find the information you wanted?

- Very easy
- Somewhat easy
- Not easy at all

202. What would have made it easier?

203. Was there any information you were unable to find that you wanted/needed?

- No
- Yes, please indicate what:



It's About You: Getting Insights from Young Women with Metastatic Breast Cancer

* 204. Who do you talk with on your Healthcare Provider team about being single and dating? Please check all that apply:

No one, I don't discuss it

Surgical Oncologist

Plastic Surgeon

Medical Oncologist

Radiation Oncologist

Social Worker

Nurse

Patient Navigator

Nurse Navigator

Primary Care Physician

Other (please specify)

* 205. What options would you utilize, if available, to learn more about and/or to help you date while living with MBC? Please check all that apply:

- Conference call
- Webinar
- Newsletter for young women living with MBC
- Websites
- In-person conferences
- Other young women with MBC
- Webpage for young women with MBC
- Apps
- Podcasts
- Printed materials
- YSC written tools
- YSC online tools
- Social media
- Bulletin boards/online communities
- Online guide
- Skype
- Other (please specify)



It's About You: Getting Insights from Young Women with Metastatic Breast Cancer

* 206. Have you entered the dating arena since your MBC diagnosis?

Yes

No



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* 207. If yes, what helped you "dip your toe back into the water?"



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* 208. Have you discussed your diagnosis with potential partners?

Yes

No

209. At what point did you have that discussion?

210. What was the reaction of potential partner(s)?

211. If you haven't discussed your diagnosis, tell us more about your hesitation?



It's About You: Getting Insights from Young Women with Metastatic Breast Cancer

Having Children/Adoption

* 212. Do you have children?

Yes

No

* 213. Is it important to you to learn more about having biological children and/or adoption?

Yes

No



It's About You: Getting Insights from Young Women with Metastatic Breast Cancer

* 214. How important is it to you to gain knowledge about having biological children and/or adoption?

- Very important
- Somewhat important
- Not important at all



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* 215. Have you sought information about having children and/or adoption?

- Yes
- No



It's About You: Getting Insights from Young Women with Metastatic Breast Cancer

* 216. What sources have you consulted for information on having children and/or adoption? Please check all that apply:

- | | |
|--|--|
| <input type="checkbox"/> Online: YSC website | <input type="checkbox"/> Books |
| <input type="checkbox"/> Online: other breast cancer organization websites (please list below) | <input type="checkbox"/> Other women with MBC |
| <input type="checkbox"/> Online: general cancer organizations | <input type="checkbox"/> Healthcare provider |
| <input type="checkbox"/> Online: general resources (Wikipedia, Google) | <input type="checkbox"/> Social media |
| <input type="checkbox"/> Online: government websites (NCI, NIH, etc.) | <input type="checkbox"/> Fertile Hope |
| <input type="checkbox"/> Online: hospital websites | <input type="checkbox"/> Webinar/conference call |
| <input type="checkbox"/> Online: other | <input type="checkbox"/> In-person conference |
| <input type="checkbox"/> Newsletters | <input type="checkbox"/> Helpline/Hotline |
| <input type="checkbox"/> Pamphlets | <input type="checkbox"/> None |
| <input type="checkbox"/> Magazines/newspapers | |
| <input type="checkbox"/> Other (please specify) | |

217. Of the sources you consulted which were the most helpful? Please list all that apply:

218. Which were the least helpful? Please include why:



* 219. How easy was it to find the information you wanted?

- Very easy
- Somewhat easy
- Not easy at all

220. What would have made it easier?

221. Was there any information you were unable to find that you wanted/needed?

- No
- Yes, please indicate what:



It's About You: Getting Insights from Young Women with Metastatic Breast Cancer

* 222. Who do you talk with on your Healthcare Provider team about having children/adoption? Please check all that apply:

- No one, I don't discuss it
- Surgical Oncologist
- Plastic Surgeon
- Medical Oncologist
- Radiation Oncologist
- Social Worker
- Nurse
- Patient Navigator
- Nurse Navigator
- Primary Care Physician
- Reproductive Endocrinologist
- Genetic Counselor
- OB-GYN
- Other (please specify)

* 223. What options would you utilize, if available, to learn more about having children/adoption? Please check all that apply:

- Conference call
- Webinar
- Newsletter for young women living with MBC
- Websites
- In-person conferences
- Other young women with MBC
- Webpage for young women with MBC
- Apps
- Podcasts
- Printed materials
- YSC written tools
- YSC online tools
- Social media
- Bulletin boards/online communities
- Online guide
- Skype
- Other (please specify)



It's About You: Getting Insights from Young Women with Metastatic Breast Cancer

* 224. Have you taken steps to have children, biological or adopted?

- Yes
- No

225. If you answered yes to the previous question, please share what difficulties, if any, you experienced:



It's About You: Getting Insights from Young Women with Metastatic Breast Cancer

Family and Friend Relationships

In this section we are addressing family and friends generally. Please note that there will be a separate sub-section on children.

* 226. Is it important to you to learn more about and to find resources to help your family and friends cope with and understand your MBC diagnosis?

- Yes
- No



It's About You: Getting Insights from Young Women with Metastatic Breast Cancer

* 227. How important is it to you to learn more about and to find resources to help your family and friends cope with and understand your MBC diagnosis?

- Very important
- Somewhat important
- Not important at all

* 228. To the best of your knowledge, how important is it to your family and friends to find resources to help them cope with and understand your MBC diagnosis?

- Very important
- Somewhat important
- Not important at all



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* 229. Have you sought information and resources to help your friends and family cope with and understand your MBC diagnosis?

- Yes
- No



It's About You: Getting Insights from Young Women with Metastatic Breast Cancer

* 230. What sources have you consulted for information and resources on helping your family and friends cope with and understand your MBC diagnosis? Please check all that apply:

- | | |
|--|--|
| <input type="checkbox"/> Online: YSC website | <input type="checkbox"/> Magazines/newspapers |
| <input type="checkbox"/> Online: other breast cancer organization websites (please list below) | <input type="checkbox"/> Books |
| <input type="checkbox"/> Online: general cancer organizations | <input type="checkbox"/> Other women with MBC |
| <input type="checkbox"/> Online: general resources (Wikipedia, Google) | <input type="checkbox"/> Healthcare provider |
| <input type="checkbox"/> Online: government websites (NCI, NIH, etc.) | <input type="checkbox"/> Social media |
| <input type="checkbox"/> Online: hospital websites | <input type="checkbox"/> Webinar/conference call |
| <input type="checkbox"/> Online: other | <input type="checkbox"/> In-person conference |
| <input type="checkbox"/> Newsletters | <input type="checkbox"/> Helpline/Hotline |
| <input type="checkbox"/> Pamphlets | <input type="checkbox"/> None |
| <input type="checkbox"/> Other (please specify) | |

231. Of the sources you consulted which were the most helpful? Please list all that apply

232. Which were the least helpful? Please include why



It's About You: Getting Insights from Young Women with Metastatic Breast Cancer

* 233. How easy was it to find the information you wanted?

- Very easy
- Somewhat easy
- Not easy at all

234. What could have made it easier?

235. Was there any information you were unable to find that you wanted/needed?

- No

Yes (if so, what?)



It's About You: Getting Insights from Young Women with Metastatic Breast Cancer

* 236. Who do you talk with on your Healthcare Provider team about your family and friend relationships and concerns? Please check all that apply:

- No one, I don't discuss it
- Surgical Oncologist
- Plastic Surgeon
- Medical Oncologist
- Radiation Oncologist
- Social Worker
- Nurse
- Patient Navigator
- Nurse Navigator
- Primary Care Physician

Other (please specify)

* 237. What options would you utilize, if available, to help your family and friends cope with and understand your MBC diagnosis? Please check all that apply:

- | | |
|---|---|
| <input type="checkbox"/> Conference call | <input type="checkbox"/> Podcasts |
| <input type="checkbox"/> Webinar | <input type="checkbox"/> Printed materials |
| <input type="checkbox"/> Newsletter for young women living with MBC | <input type="checkbox"/> YSC written tools |
| <input type="checkbox"/> Websites | <input type="checkbox"/> YSC online tools |
| <input type="checkbox"/> In-person conferences | <input type="checkbox"/> Social media |
| <input type="checkbox"/> Other young women with MBC | <input type="checkbox"/> Bulletin boards/online communities |
| <input type="checkbox"/> Webpage for young women with MBC | <input type="checkbox"/> Online guide |
| <input type="checkbox"/> Apps | <input type="checkbox"/> Skype |
| <input type="checkbox"/> Other (please specify) | |



* 238. To the best of your knowledge, have your family and/or friends sought information cope with and understand your MBC diagnosis?

- Yes
- No
- I don't know



* 239. To the best of your knowledge, what sources have your family and/or friends consulted for information on coping with and understanding your MBC diagnosis? Please check all that apply:

- | | |
|--|--|
| <input type="checkbox"/> Online: YSC website | <input type="checkbox"/> Magazines/newspapers |
| <input type="checkbox"/> Online: other breast cancer organization websites (please list below) | <input type="checkbox"/> Books |
| <input type="checkbox"/> Online: general cancer organizations | <input type="checkbox"/> Other women with MBC |
| <input type="checkbox"/> Online: general resources (Wikipedia, Google) | <input type="checkbox"/> Healthcare provider |
| <input type="checkbox"/> Online: government websites (NCI, NIH, etc.) | <input type="checkbox"/> Social media |
| <input type="checkbox"/> Online: hospital websites | <input type="checkbox"/> Webinar/conference call |
| <input type="checkbox"/> Online: other | <input type="checkbox"/> In-person conference |
| <input type="checkbox"/> Newsletters | <input type="checkbox"/> Helpline/Hotline |
| <input type="checkbox"/> Pamphlets | <input type="checkbox"/> I Don't Know |
| <input type="checkbox"/> Other (please specify) | |

240. To the best of your knowledge, of the sources your family and friends consulted which were the most helpful? Please list all that apply

241. To the best of your knowledge, which were the least helpful? Please include why



It's About You: Getting Insights from Young Women with Metastatic Breast Cancer

* 242. To the best of your knowledge, how easy was it for your family and friends to find the information they wanted?

- Very easy
- Somewhat easy
- Not easy at all

243. What could have made it easier?

244. Was there any information they were unable to find that they wanted/needed?

- No
- Yes, please what:



It's About You: Getting Insights from Young Women with Metastatic Breast Cancer

* 245. To the best of your knowledge, what options would your family and friends utilize, if available, to help them cope with or understand your MBC diagnosis? Please check all that apply:

- | | |
|---|--|
| <input type="checkbox"/> Conference call | <input type="checkbox"/> YSC written tools |
| <input type="checkbox"/> Webinar | <input type="checkbox"/> YSC online tools |
| <input type="checkbox"/> Newsletter for young women living with MBC | <input type="checkbox"/> Social media |
| <input type="checkbox"/> Websites | <input type="checkbox"/> Bulletin boards/online communities |
| <input type="checkbox"/> In-person conferences | <input type="checkbox"/> Online guide |
| <input type="checkbox"/> Other young women with MBC | <input type="checkbox"/> Educational tools/materials for caregivers, family and friends |
| <input type="checkbox"/> Webpage for young women with MBC | <input type="checkbox"/> Educational presentations or materials for caregivers, family and friends |
| <input type="checkbox"/> Apps | <input type="checkbox"/> Therapist at healthcare provider office to meet with family and friends |
| <input type="checkbox"/> Podcasts | <input type="checkbox"/> Therapist in the community |
| <input type="checkbox"/> Printed materials | |

Other (please specify)



It's About You: Getting Insights from Young Women with Metastatic Breast Cancer

* 246. Have you given your friend(s) specific tasks when they ask what they can do to help you?

Yes, please share what you've requested:

No, please share why not:

* 247. Do you believe that the support of your friends and/or family has decreased over time?

Yes, please explain:

No, please explain:

* 248. Have you reached out and let your friends and/or family know that you still need help and support?

No, why not:

Yes, what were the results:

* 249. Have you utilized free web sites like Caring Bridge, MyLifeLine and LotsaHelpingHands to keep family and friends updated and for them to be able to offer their help to support you?

If No, why not?

If yes, please tell us about your experience (good or bad)

250. If no, are you aware that such resources exist?

No

Yes



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Children and Parenting

* 251. Do you have children?

Yes

No



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* 252. Are your children aware of your MBC diagnosis?

Yes

No

* 253. Using a scale of 1 to 10 (one being easy, 10 being the most difficult), how difficult has it been to parent while managing your MBC diagnosis and treatment?

Easy

Middle of
the road

Very difficult

A horizontal scale consisting of ten white circles with black outlines, evenly spaced along a light grey background bar. The circles represent a scale from 1 (Easy) to 10 (Very difficult).

254. Please explain your answer to the previous question:

A large, empty rectangular text box with a thin black border, intended for the respondent to provide a written explanation for their answer to question 253.



It's About You: Getting Insights from Young Women with Metastatic Breast Cancer

* 255. Have your children expressed fear about your MBC diagnosis and prognosis?

Yes

No

256. How have you tried to alleviate their fear?

* 257. Have you asked them about their feelings?

Yes

If no, why not?



It's About You: Getting Insights from Young Women with Metastatic Breast Cancer

* 258. Have you sought information about parenting while living with MBC?

Yes

No



* 259. What sources have you consulted for information on parenting while living with MBC? Please check all that apply:

- Online: YSC website
- Online: other breast cancer organization websites (please list below)
- Online: general cancer organizations
- Online: general resources (Wikipedia, Google)
- Online: government websites (NCI, NIH, etc.)
- Online: hospital websites
- Online: other
- Newsletters
- Pamphlets
- Magazines/newspapers
- Books
- Other women with MBC
- Healthcare provider
- Social media
- Webinar/conference call
- In-person conference
- Helpline/Hotline
- None
- Other (please specify)

260. Of the sources you consulted which were the most helpful? Please list all that apply

261. Which were the least helpful and why?



It's About You: Getting Insights from Young Women with Metastatic Breast Cancer

* 262. How easy was it to find the information you wanted?

- Very easy
- Somewhat easy
- Not easy at all

263. What could have made it easier?

264. Was there any information you were unable to find that you wanted/needed?

- No
- Yes, what were you seeking?



* 265. Who do you talk with on your Healthcare Provider team about parenting while living with MBC? Please check all that apply:

- No one, I don't discuss it
- Surgical Oncologist
- Plastic Surgeon
- Medical Oncologist
- Radiation Oncologist
- Social Worker
- Nurse
- Patient Navigator
- Nurse Navigator
- Primary Care Physician
- Other (please specify)

* 266. What options would you utilize, if available, to learn more about parenting while living with MBC?

- Conference call
- Webinar
- Newsletter for young women living with MBC
- Websites
- In-person conferences
- Other young women with MBC
- Webpage for young women with MBC
- Apps
- Podcasts
- Printed materials for talking with your children
- YSC written tools
- YSC online tools
- Social media
- Bulletin boards/online communities
- Online guide/materials for talking with your children
- Skype



It's About You: Getting Insights from Young Women with Metastatic Breast Cancer

* 267. Are you aware of the any of the following programs for kids and teens? Please check all that apply.

- The Treehouse Gang and its program CLIMB (Children's Lives Include Moments of Bravery)
- WOW! Experience through the Jack and Jill Late Stage Foundation
- Cancer Support Community/Gilda's Club "Noogieland" for kids
- Group Loop for teens
- Camp Kesem
- Printed materials for talking with your children or teens
- Online materials for talking with your children or teens
- Support group for children/teens
- Programs for kids/teens
- I don't know about these programs

268. Have you used any of the above resources for children or teens? If yes, please list:

269. Are there others you have used? Please list:

270. Which do you believe were the most helpful? Please list:

271. Were there any resources you researched for children and teens but could not find? Please share what they were/are:



A. Sex and Intimacy

* 272. Would you like to provide feedback on the subjects sex, intimacy and body image?

- Yes
- No, Note that if you answer "no," you will be moved to the next section.



* 273. Has your diagnosis impacted your sexuality, femininity, and/or body image?

- Yes, if yes, please explain
- No

If yes, please explain:



* 274. Prior to cancer, did you have difficulties with sex and/or intimacy?

- Yes
- No

* 275. Prior to cancer, did you have difficulties with body image?

- Yes
- No



It's About You: Getting Insights from Young Women with Metastatic Breast Cancer

* 276. Have you talked with your spouse/partner/significant other about sex and intimacy concerns?

- Yes, If yes, tell us how it went
- No, If no, why not?
- N/A

Please explain



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* 277. Have you carved out time for one another to create space for intimacy?

- Yes
- No, If no, why not?
- N/A

Please explain



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* 278. How important is it to you to gain knowledge about sexuality, intimacy and body image?

- Very important
- Somewhat important
- Not important at all



It's About You: Getting Insights from Young Women with Metastatic Breast Cancer

* 279. Have you sought out information about sexuality, intimacy and body image?

- Yes
- No



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* 280. What sources have you consulted for information on sexuality, intimacy and body image?

- online: YSC website
- online: other breast cancer organization websites (please list below)
- online: general cancer organizations
- online: general resources (Wikipedia, Google)
- online: government websites (NCI, NIH, etc.)
- online: hospital websites
- online: other
- newsletters
- pamphlets
- Other (please specify)
- magazines/newspapers
- books
- other women with MBC
- healthcare provider
- social media
- webinar/conference call
- in-person conference
- Helpline
- None

281. Of the sources you consulted which were the most helpful? Please list all that apply

282. Which were the least helpful? Please include why.



It's About You: Getting Insights from Young Women with Metastatic Breast Cancer

* 283. How easy was it to find the information you wanted?

- Very easy
- Somewhat easy
- Not easy at all

284. What could have made it easier?



It's About You: Getting Insights from Young Women with Metastatic Breast Cancer

A. Sex and Intimacy

285. Was there any information you were unable to find that you wanted/needed?

Yes, if yes, what?

No

Please explain



It's About You: Getting Insights from Young Women with Metastatic Breast Cancer

* 286. Who do you talk with on your Healthcare Provider team about sexuality, intimacy and body image?

Please check all that apply:

No one, I don't discuss it

Nurse

Surgical Oncologist

Patient Navigator

Plastic Surgeon

Nurse Navigator

Medical Oncologist

Primary Care Physician

Radiation Oncologist

OB-GYN

Social Worker

Other (please specify)

* 287. What options would you utilize, if available, to help with sexuality, intimacy, and body image issues?

Please check all that apply:

- | | |
|---|--|
| <input type="checkbox"/> Conference call | <input type="checkbox"/> YSC online tools |
| <input type="checkbox"/> Webinar | <input type="checkbox"/> Social media |
| <input type="checkbox"/> Newsletter for young women living with MBC | <input type="checkbox"/> Bulletin boards/online communities |
| <input type="checkbox"/> Websites | <input type="checkbox"/> Online guide |
| <input type="checkbox"/> In-person conferences | <input type="checkbox"/> Educational tools/materials directed at partners/significant others |
| <input type="checkbox"/> Other young women with MBC | <input type="checkbox"/> Sex therapist in the community |
| <input type="checkbox"/> Webpage for young women with MBC | <input type="checkbox"/> Sex therapist as part of your Healthcare Provider team |
| <input type="checkbox"/> Apps | <input type="checkbox"/> Erotica |
| <input type="checkbox"/> Podcasts | <input type="checkbox"/> Retreats |
| <input type="checkbox"/> Printed materials | <input type="checkbox"/> Workshops |
| <input type="checkbox"/> YSC written tools | |

Other options (please specify)



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B. Legal Matters/End of Life Plans

* 288. Is it important to you to learn more about legal matters and end of life planning?

- Yes
 No

* 289. Would you like to provide feedback on legal matters and end of life planning? Note that if you answer "no," you will be skipped to the next section.

- Yes
 No



It's About You: Getting Insights from Young Women with Metastatic Breast Cancer

* 290. How important is it to you to gain knowledge about legal matters and end of life planning?

- Very important
- Somewhat important
- Not important at all



It's About You: Getting Insights from Young Women with Metastatic Breast Cancer

* 291. Have you sought information about legal matters and end of life planning?

- Yes
- No



It's About You: Getting Insights from Young Women with Metastatic Breast Cancer

* 292. What sources have you consulted for information on legal matters and end of life planning? Please check all that apply:

- | | |
|--|--|
| <input type="checkbox"/> online: YSC website | <input type="checkbox"/> magazines/newspapers |
| <input type="checkbox"/> online: other breast cancer organization websites (please list below) | <input type="checkbox"/> books |
| <input type="checkbox"/> online: general cancer organizations | <input type="checkbox"/> other women with MBC |
| <input type="checkbox"/> online: general resources (Wikipedia, Google) | <input type="checkbox"/> healthcare provider |
| <input type="checkbox"/> online: government websites (NCI, NIH, etc.) | <input type="checkbox"/> social media |
| <input type="checkbox"/> online: hospital websites | <input type="checkbox"/> webinar/conference call |
| <input type="checkbox"/> online: other | <input type="checkbox"/> in-person conference |
| <input type="checkbox"/> newsletters | <input type="checkbox"/> Helpline |
| <input type="checkbox"/> pamphlets | <input type="checkbox"/> None |

Other (please specify)

293. Of the sources you consulted which were the most helpful? Please list all that apply

294. Which were the least helpful? Please include why



* 295. How easy was it to find the information you wanted?

- Very easy
- Somewhat easy
- Not easy at all

296. What could have made it easier?

297. Was there any information you were unable to find that you wanted/needed?

- Yes
- No, If so, what?

Explanation



It's About You: Getting Insights from Young Women with Metastatic Breast Cancer

* 298. Who do you talk with on your Healthcare Provider team about and assist in legal matters and end of life planning? Please check all that apply:

- | | |
|---|---|
| <input type="checkbox"/> No one, I don't discuss it | <input type="checkbox"/> Social Worker |
| <input type="checkbox"/> Surgical Oncologist | <input type="checkbox"/> Nurse |
| <input type="checkbox"/> Plastic Surgeon | <input type="checkbox"/> Patient Navigator |
| <input type="checkbox"/> Medical Oncologist | <input type="checkbox"/> Nurse Navigator |
| <input type="checkbox"/> Radiation Oncologist | <input type="checkbox"/> Primary Care Physician |
| <input type="checkbox"/> Other (please specify) | |

* 299. What options would you utilize, if available, to learn more about legal matters and end of life planning?

Please check all that apply:

- | | |
|---|---|
| <input type="checkbox"/> Conference call | <input type="checkbox"/> podcasts |
| <input type="checkbox"/> webinar | <input type="checkbox"/> printed materials |
| <input type="checkbox"/> newsletter for young women living with MBC | <input type="checkbox"/> YSC written tools |
| <input type="checkbox"/> websites | <input type="checkbox"/> YSC online tools |
| <input type="checkbox"/> in-person conferences | <input type="checkbox"/> social media |
| <input type="checkbox"/> other young women with MBC | <input type="checkbox"/> bulletin boards/online communities |
| <input type="checkbox"/> webpage for young women with MBC | <input type="checkbox"/> online guide |
| <input type="checkbox"/> apps | |

Other options(please list)



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* 300. Have you prepared any of the following since your MBC diagnosis:

- a will
- a durable POA (Power of Attorney) (this is a legal document that gives another person the authority to make financial decisions on your behalf)
- a healthcare POA (same as a durable POA but concerns medical decisions only)
- guardianship papers (if you have children)
- beneficiary designations for any retirement accounts, savings, insurance policies
- do not resuscitate (DNR) order
- living will
- none of those listed
- Other (please list)

* 301. Have you made end of life plans?

- Yes
- I think about it, yet have not started making plans
- No



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* 302. If you have made a plan: Does your plan include what kind of service/memorial you would like to have (music, location, readings, etc)?

- Yes
- No



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303. Were there tools that you used to make these plans?

- Yes
- No

304. If yes, what tools did you use to make these plans?

305. How effective were the tools you used?



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306. If you have not made a plan would a planning tool be useful to you?

- Yes
- No

If yes, what would you like this planning tool to include?



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C. Financial Concerns

* 307. . Has your MBC diagnosis negatively impacted your finances and/or increased your financial concerns?

- Yes
- No

* 308. Is it important to you to provide feedback on financial concerns surrounding MBC?

- Yes
- No



It's About You: Getting Insights from Young Women with Metastatic Breast Cancer

* 309. How important is it to you to gain knowledge about financial issues and concerns?

- Very important
- Somewhat important
- Not important at all



It's About You: Getting Insights from Young Women with Metastatic Breast Cancer

* 310. Have you sought information about financial issues and concerns?

- Yes
- No



It's About You: Getting Insights from Young Women with Metastatic Breast Cancer

* 311. What sources have you consulted for information on financial issues and concerns? Please check all that apply:

- | | |
|--|--|
| <input type="checkbox"/> online: YSC website | <input type="checkbox"/> magazines/newspapers |
| <input type="checkbox"/> online: other breast cancer organization websites (please list below) | <input type="checkbox"/> books |
| <input type="checkbox"/> online: general cancer organizations | <input type="checkbox"/> other women with MBC |
| <input type="checkbox"/> online: general resources (Wikipedia, Google) | <input type="checkbox"/> healthcare provider |
| <input type="checkbox"/> online: government websites (NCI, NIH, etc.) | <input type="checkbox"/> social media |
| <input type="checkbox"/> online: hospital websites | <input type="checkbox"/> webinar/conference call |
| <input type="checkbox"/> online: other | <input type="checkbox"/> in-person conference |
| <input type="checkbox"/> newsletters | <input type="checkbox"/> Helpline |
| <input type="checkbox"/> pamphlets | <input type="checkbox"/> None |
| <input type="checkbox"/> Other (please specify) | |

312. Of the sources you consulted which were the most helpful? Please list all that apply

313. Which were the least helpful? Please include why



It's About You: Getting Insights from Young Women with Metastatic Breast Cancer

* 314. How easy was it to find the information you wanted?

- very easy
- somewhat easy
- not easy at all

315. What could have made it easier?

316. Was there any information you were unable to find that you wanted/needed?

- Yes, if so, what?
- No

Please explain



It's About You: Getting Insights from Young Women with Metastatic Breast Cancer

* 317. Who do you talk with on your Healthcare Provider team about financial issues and concerns? Please check all that apply:

- | | |
|---|---|
| <input type="checkbox"/> No one, I don't discuss it | <input type="checkbox"/> Social Worker |
| <input type="checkbox"/> Surgical Oncologist | <input type="checkbox"/> Nurse |
| <input type="checkbox"/> Plastic Surgeon | <input type="checkbox"/> Patient Navigator |
| <input type="checkbox"/> Medical Oncologist | <input type="checkbox"/> Nurse Navigator |
| <input type="checkbox"/> Radiation Oncologist | <input type="checkbox"/> Primary Care Physician |
| <input type="checkbox"/> Other options(please list) | |

* 318. If you have experienced financial difficulty, specifically what expenses are causing that difficulty:

Co-pays for office visits

Parking

Co-pays for medications

Loss of Income due to Stopping Work

Travel to receive treatment

I have not experienced financial difficulty

Childcare

Other (please explain)



It's About You: Getting Insights from Young Women with Metastatic Breast Cancer

* 319. Have you sought grant and/or financial assistance from any organizations?

Yes

No

320. If yes, which ones? Did you receive assistance? Please tell us for what and how it helped.

321. Would financial assistance programs help to relieve your financial concerns?

Yes

No

If yes, please explain:



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D. Insurance

* 322. Have you had insurance coverage since your MBC diagnosis?

- Yes
- Yes, but not the entire time
- No



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* 323. Since your diagnosis of MBC, have you encountered problems with your health insurance?

- Yes
- No

If yes, please explain:



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* 324. Do you believe you are receiving appropriate care for your disease?

- Yes
- No

If not, why? Please provide specific examples.

* 325. Would you like to provide additional feedback on insurance issues?

- Yes
- No



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326. How important is it to you to gain knowledge about insurance issues?

- very important
- somewhat important
- not important at all

* 327. Have you sought information about insurance issues?

- Yes
- No



It's About You: Getting Insights from Young Women with Metastatic Breast Cancer

* 328. What sources have you consulted for information on insurance issues? Please check all that apply:

- | | |
|--|--|
| <input type="checkbox"/> online: YSC website | <input type="checkbox"/> magazines/newspapers |
| <input type="checkbox"/> online: other breast cancer organization websites (please list below) | <input type="checkbox"/> books |
| <input type="checkbox"/> online: general cancer organizations | <input type="checkbox"/> other women with MBC |
| <input type="checkbox"/> online: general resources (Wikipedia, Google) | <input type="checkbox"/> healthcare provider |
| <input type="checkbox"/> online: government websites (NCI, NIH, etc.) | <input type="checkbox"/> social media |
| <input type="checkbox"/> online: hospital websites | <input type="checkbox"/> webinar/conference call |
| <input type="checkbox"/> online: other | <input type="checkbox"/> in-person conference |
| <input type="checkbox"/> newsletters | <input type="checkbox"/> Helpline |
| <input type="checkbox"/> pamphlets | <input type="checkbox"/> None |

Other (please specify)

329. Of the sources you consulted which were the most helpful? Please list all that apply

330. Which were the least helpful? Please include why



It's About You: Getting Insights from Young Women with Metastatic Breast Cancer

* 331. How easy was it to find the information you wanted?

- very easy
- somewhat easy
- not easy at all

332. What could have made it easier?

333. Was there any information you were unable to find that you wanted/needed?

- Yes
- No

If so, what?



It's About You: Getting Insights from Young Women with Metastatic Breast Cancer

* 334. Who do you talk with on your Healthcare Provider team about insurance issues? Please check all that apply:

- | | |
|---|---|
| <input type="checkbox"/> No one, I don't discuss it | <input type="checkbox"/> Social Worker |
| <input type="checkbox"/> Surgical Oncologist | <input type="checkbox"/> Nurse |
| <input type="checkbox"/> Plastic Surgeon | <input type="checkbox"/> Patient Navigator |
| <input type="checkbox"/> Medical Oncologist | <input type="checkbox"/> Nurse Navigator |
| <input type="checkbox"/> Radiation Oncologist | <input type="checkbox"/> Primary Care Physician |

Other (please specify)

* 335. What options and tools would you utilize, if available, to learn more about and assist with insurance issues? Please check all that apply:

- | | | |
|---|---|---|
| <input type="checkbox"/> Conference call | <input type="checkbox"/> webpage for young women with MBC | <input type="checkbox"/> social media |
| <input type="checkbox"/> webinar | <input type="checkbox"/> apps | <input type="checkbox"/> bulletin boards/online communities |
| <input type="checkbox"/> newsletter for young women living with MBC | <input type="checkbox"/> podcasts | <input type="checkbox"/> online guide |
| <input type="checkbox"/> websites | <input type="checkbox"/> printed materials | <input type="checkbox"/> healthcare provider assistance |
| <input type="checkbox"/> in-person conferences | <input type="checkbox"/> YSC written tools | <input type="checkbox"/> working with a nurse case manager at insurance company |
| <input type="checkbox"/> other young women with MBC | <input type="checkbox"/> YSC online tools | <input type="checkbox"/> monthly billing/statements instead of per visit or treatment |

Other options (please list)

* 336. Have you received any insurance payment assistance through organizations such as the Healthwell Foundation or CancerCare?

- Yes
 No

If so, which ones?

* 337. Have you applied for and now receive insurance through your state's Women's Health Medicaid program?

Yes

No

* 338. Have you applied for and been denied access to your state's Women's Health Medicaid program?

Yes

No

* 339. Have you received charity care through your Healthcare Provider(s)?

Yes

No



It's About You: Getting Insights from Young Women with Metastatic Breast Cancer

Communicating with Health Care Providers (HCPs)

* 340. Would you like to provide feedback on communicating with your HCPs?

Yes

No



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* 341. How important is it to you to gain knowledge about communicating with your HCPs?

- Very important
- Somewhat important
- Not important at all



It's About You: Getting Insights from Young Women with Metastatic Breast Cancer

* 342. Have you sought information about communicating with your HCPs?

- Yes
- No



It's About You: Getting Insights from Young Women with Metastatic Breast Cancer

* 343. What sources have you consulted for information on communicating with your HCPs? Please check all that apply:

- | | |
|--|--|
| <input type="checkbox"/> Online: YSC website | <input type="checkbox"/> Magazines/newspapers |
| <input type="checkbox"/> Online: other breast cancer organization websites (please list below) | <input type="checkbox"/> Books |
| <input type="checkbox"/> Online: general cancer organizations | <input type="checkbox"/> Other women with MBC |
| <input type="checkbox"/> Online: general resources (Wikipedia, Google) | <input type="checkbox"/> Healthcare provider |
| <input type="checkbox"/> Online: government websites (NCI, NIH, etc.) | <input type="checkbox"/> Social media |
| <input type="checkbox"/> Online: hospital websites | <input type="checkbox"/> Webinar/conference call |
| <input type="checkbox"/> Online: other | <input type="checkbox"/> In-person conference |
| <input type="checkbox"/> Newsletters | <input type="checkbox"/> Helpline/Hotline |
| <input type="checkbox"/> Pamphlets | <input type="checkbox"/> None |
| <input type="checkbox"/> Other (please specify) | |

344. Of the sources you consulted which were the most helpful? Please list all that apply:

345. Which were the least helpful? Please include why:



It's About You: Getting Insights from Young Women with Metastatic Breast Cancer

* 346. How easy was it to find the information you wanted?

- Very easy
- Somewhat easy
- Not easy at all

347. What could have made it easier?

348. Was there any information you were unable to find that you wanted/needed?

- No
- Yes (if so, what?)



It's About You: Getting Insights from Young Women with Metastatic Breast Cancer

* 349. What options, if available, would you use in order to aid communication with your HCPs?

- Conference call
- Webinar
- Newsletter for young women with MBC
- YSC printed materials to organize/plan
- Online tools to organize/plan your meeting/appt
- Educational presentations/materials to HCPs about young women living with MBC
- Written guide for speaking with HCPs
- App for speaking with HCPs
- Online guide for speaking with HCPs
- Patient navigator focused on MBC
- Other (please specify)



It's About You: Getting Insights from Young Women with Metastatic Breast Cancer

* 350. Are you satisfied with the communication you receive from your HCPs?

- Yes
- No

* 351. Would you like additional time with your HCPs

- Yes
- No

352. If you answered yes to the previous question, with which HCPs would you like additional time and why?

Surgical Oncologist	<input type="text"/>
Plastic Surgeon	<input type="text"/>
Medical Oncologist	<input type="text"/>
Radiation Oncologist	<input type="text"/>
Social Worker	<input type="text"/>
Nurse	<input type="text"/>
Patient Navigator	<input type="text"/>
Nurse Navigator	<input type="text"/>
Primary Care Physician	<input type="text"/>

353. Do you want your HCPs to provide you emotional support?

- Yes
- I already receive emotional support from my team
- No

354. If you answered yes to the previous question, from which providers would you like additional support

Surgical Oncologist	<input type="text"/>
Plastic Surgeon	<input type="text"/>
Medical Oncologist	<input type="text"/>
Radiation Oncologist	<input type="text"/>
Social Worker	<input type="text"/>
Nurse	<input type="text"/>
Patient Navigator	<input type="text"/>
Nurse Navigator	<input type="text"/>
Primary Care Physician	<input type="text"/>



It's About You: Getting Insights from Young Women with Metastatic Breast Cancer

* 355. Have you requested that your HCPs spend time reviewing your care plan and treatment options with you?

- Yes
- No

* 356. Have you investigated having an appointment solely to discuss these matters?

- Yes
- No

* 357. Are you able to directly email with your HCPs?

- Yes
- No

* 358. Have you communicated with your HCPs about your quality of life concerns?

- No
- Yes (how did it go?)



It's About You: Getting Insights from Young Women with Metastatic Breast Cancer

We value your feedback, insights and suggestions!

* 359. Would you like to provide feedback on the Conference for Young Women affected by breast cancer (C4YW), a joint effort between YSC and Living Beyond Breast Cancer (LBBC) as well as YSC's Metastatic Resource Kit (MRK)?

Yes

No



It's About You: Getting Insights from Young Women with Metastatic Breast Cancer

* 360. Have you attended C4YW - Annual Conference for young women Affected by Breast Cancer?

No

Yes (how many years?)



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361. If you answered yes to the previous question, do you feel that this conference meets your needs as a young woman with MBC?

Yes, please share how so:

No, please tell us why not:

* 362. What would you most like to see offered at a conference of this type?

* 363. Did you attend the sessions at C4YW focused on MBC?

- No
- Yes (where the sessions helpful?)

* 364. What is your main reason in attending C4YW?

- Medical updates
- To see friends
- Education
- Meet new people
- Connect with other young women with MBC

Other (please specify)



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* 365. Do you feel that C4YW does a good job of including young women with MBC?

- Yes
- Somewhat
- No, please explain

* 366. Did you know that YSC offers tailored resources and programs for young women with metastatic disease?

- Yes
- No

* 367. Have you received a YSC Metastatic Resource Kit (MRK)?

- No
- Yes, please tell us who gave it to you:



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368. If you've received the MRK, was it helpful?

- Yes
- Somewhat
- No

369. Please share your likes and dislikes of the MRK:



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* 370. Were you aware that YSC had a Metastatic Resource Kit (MRK)?

- Yes
- No



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Increase Awareness of Needs of Metastatic Population

We have all heard about "breast cancer awareness" but what does that mean to you?

* 371. Would you like to provide feedback on increasing awareness of needs of the young MBC population?

- Yes
- No



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* 372. Do you, as a young woman with MBC, feel overlooked and/or isolated by traditional breast cancer organizations?

No

Yes, please explain:

* 373. Do you feel that you "fit" into the activities of these organizations?

Yes

No

* 374. Do you feel that the "pink ribbon" breast cancer awareness movement ignores the issues of MBC patients?

No

Yes, please explain:

* 375. Do you think that public awareness should be raised/increased about MBC?

No

Yes, please indicate how:

* 376. Do you think that public awareness should be raised about young women with MBC?

No

Yes, please indicate how:

* 377. What terminology do you prefer, when addressing/referring to another or yourself as a young woman with MBC? Please answer "YES" in one of the first three boxes if that choice is the terminology you prefer, or list the term(s) you prefer in the other boxes. Feedback on each term will be requested in the following question.

Survivor	<input type="text"/>
Thrivor	<input type="text"/>
Metavivor	<input type="text"/>
Other, please indicate	<input type="text"/>
Other, please indicate	<input type="text"/>
Other, please indicate	<input type="text"/>

378. What are your thoughts on the following terms, when referring to yourself or another woman with metastatic breast cancer (feel free to give immediate and honest reactions):

Survivor	<input type="text"/>
Metavivor	<input type="text"/>
Thrivor	<input type="text"/>
Warrior	<input type="text"/>
What others have you heard?	<input type="text"/>



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You did it! Thank you!

We know it was long and we truly appreciate your willingness to be open and honest. YSC is striving for continued improvement with reaching and serving the population of young women with breast cancer. As you noticed we did not ask for your name and contact information - that was intentional. Your answers will remain confidential. We will use the collection of data to better inform our services and others reaching women with breast cancer. And, we will share it with you. Once you click submit, please take the opportunity to allow us to send you a thank you gift. Thank you!!

