

Demographics and general information

Opening Screen:

We request information about your gender, menopausal status, race, and geographic information.

Question	Explanation	Answer Options
1. What is your gender?		Female Male X (includes trans, non-binary, and other)
2. What is your menopausal status?		Pre-menopausal Post-menopausal
3. Are you of Hispanic, Latino, or Spanish origin?		Yes No
4. What is your race? Please select all that apply.		American Indian or Alaska Native Asian Black or African American Native Hawaiian or other Pacific Islander White Other
5. Please describe your race?		Free text answer
6. In what country do you live?		United States Portugal Spain Sweden United Kingdom
7. What is the postal code/zip code where you receive your primary care and treatment for MBC?		Free text answer
8. Are you currently participating or have you ever participated in any other MBC registries?		Yes No

<p><b>9. Which other registries are you participating in or have you participated in? Please select all that apply.</b></p>		<p>AURORA  CSC Cancer Experience Registry  Dr. Susan Love Research Foundation's The Health of Women (HOW) Study®  Dr. Susan Love Research Foundation's Metastatic Breast Cancer Collateral Damage Project  MBC Initiative (Dr. Monica Bertagnolli)  MBC Project (Dr. Nikhil Wagle)  NCI Exceptional Responders Initiative/NCT02243592  University of Wisconsin/Exceptional Survivors Study (Dr. Mark Burkard)  Other</p>
<p><b>10. Please tell us what other registries you are participating in or have participated in.</b></p>		<p>Free text answer</p>
<p><b>11. Please tell us anything you would like us to know about yourself or your cancer. (optional)</b></p>		<p>Free text answer</p>

## Disease history

### Opening Screen:

We request information about both your primary and metastatic breast cancer including breast cancer markers, as well as where the disease has spread outside the breast. You may refer to your medical records if you have them. An open-ended question about your main concerns about living with MBC is at the end of the survey.

Question	Explanation	Answer Options
<p><b>1. What stage was your breast cancer when you received your initial diagnosis?</b></p>	<p><i>An initial diagnosis of Stage IV means the cancer has already spread outside the breast (i.e., de novo)</i></p>	<p>Stage 0  Stage I  Stage II  Stage III  Stage IV  Not sure/I don't remember</p>
<p><b>2. When were you first diagnosed with primary breast cancer?</b></p>		<p>Date selection answer</p>
<p><b>3. What was the estrogen receptor status of your primary breast cancer?</b></p>	<p><i>If your primary breast cancer was triple negative, please check ER-.</i></p>	<p>Estrogen Receptor Positive (ER+)  Estrogen Receptor Negative (ER-)  Not sure/I don't remember</p>
<p><b>4. What was the progesterone receptor status of your primary breast cancer?</b></p>	<p><i>If your primary breast cancer was triple negative, please check PR-.</i></p>	<p>Progesterone Receptor Positive (PR+)  Progesterone Receptor Negative (PR-)  Not sure/I don't remember</p>

<p><b>5. What was the HER2 status of your primary breast cancer?</b></p>	<p><i>If your primary breast cancer was triple negative, please check HER2-.</i></p>	<p>HER2 Positive (HER2+) HER2 Negative (HER2-) Not sure/I don't remember</p>
<p><b>6. What type(s) of primary breast cancer did you have? Please select all that apply.</b></p>	<p><i>Breast cancer is categorized by the cell type in the breast where it started. It can start in the cells of the milk duct (ductal) or in the lobes where the milk is made (lobular).</i></p>	<p>Invasive Lobular Invasive Ductal Ductal Carcinoma in situ (DCIS) Inflammatory breast cancer (IBC) Other Not determined Not sure/I don't remember</p>
<p><b>7. Please describe the type of primary breast cancer you had.</b></p>		<p>Free text answer</p>
<p><b>8. At your initial MBC diagnosis, where had your disease spread outside of the breast? Please select all that apply.</b></p>		<p>Bone Brain Liver Lung Lymph nodes Skin Other Not sure/I don't remember</p>
<p><b>9. Where has your disease spread outside of the breast?</b></p>		<p>Free text answer</p>
<p><b>10. What are the sites of your metastatic disease today? Please select all that apply.</b></p>		<p>Bone Brain Liver Lung Lymph nodes Skin My scans show that I am NED (No evidence of disease) Other Not sure/I don't remember</p>
<p><b>11. Where has your disease spread outside of the breast at this time?</b></p>		<p>Free text answer</p>
<p><b>12. Did you have a biopsy for your metastatic disease?</b></p>		<p>Yes No</p>

<p><b>13. From what part of the body was the biopsy taken? Please select all that apply.</b></p>		<p>Brain Bone Liver Lung Lymph nodes Skin Other Not sure/I don't remember</p>
<p><b>14. From what part of the body was the biopsy taken?</b></p>		<p>Free text answer</p>
<p><b>15. What is the estrogen receptor status of your metastatic breast cancer? Please select all that apply.</b></p>	<p><i>If your metastatic breast cancer is triple negative, please check ER-.</i></p>	<p>Estrogen Receptor Positive (ER+) Estrogen Receptor Negative (ER-) Not sure/I don't remember</p>
<p><b>16. What is the progesterone receptor status of your metastatic breast cancer? Please select all that apply.</b></p>	<p><i>If your metastatic breast cancer is triple negative, please check PR-.</i></p>	<p>Progesterone Receptor Positive (PR+) Progesterone Receptor Negative (PR-) Not sure/I don't remember</p>
<p><b>17. What is the HER2 status of your metastatic breast cancer? Please select all that apply.</b></p>	<p><i>If your metastatic breast cancer is triple negative, please check HER2-.</i></p>	<p>HER2 Positive (HER2+) HER2 Negative (HER2-) Not sure/I don't remember</p>
<p><b>18. What type(s) of metastatic breast cancer do you have? Please select all that apply.</b></p>	<p><i>Breast cancer is categorized by the cell type in the breast where it started. It can start in the cells of the milk duct (ductal) or in the lobes where the milk is made (lobular).</i></p>	<p>Invasive Lobular Invasive Ductal Inflammatory breast cancer (IBC) Other Not determined Not sure/I don't remember</p>
<p><b>19. Please describe the type of metastatic breast cancer you have.</b></p>		<p>Free text answer</p>
<p><b>20. Please tell us your main concern about having metastatic breast cancer. (optional)</b></p>		<p>Free text answer</p>

## Quality of Life

### Opening Screen:

We realize that living with MBC is more than just a medical experience. We request information about other diseases you have, diets or supplements you consume, complementary medicine practices, your social support network, and your ability to do daily activities. An open-ended question about how MBC is affecting your health and life is at the end of the survey.

Question	Explanation	Answer Options
1. <b>What is the current status of your health and physical activity?</b>		Fully active, able to carry on all pre-diagnosis of MBC activities without restriction Restricted in physically strenuous activity, but able to walk and carry out light work, e.g., light house work, office work Capable of all self care and normal activities more than 50% of waking hours, but unable to carry out any work activities Capable of only limited self care; confined to a bed or chair more than 50% of waking hours Completely disabled; cannot carry on any self care; totally confined to a bed or chair
2. <b>Other than breast cancer, do you have or have you ever had any other cancers?</b>		Yes No
3. <b>Please tell us the other type(s) of cancer.</b>		Free text answer
4. <b>Do you have other illnesses that are chronic?</b>		Yes No
5. <b>Please select all chronic illnesses that apply.</b>		Autoimmune disease (examples: multiple sclerosis, rheumatoid arthritis, lupus, Graves disease, Hashimoto thyroiditis, others) Diabetes Heart disease High blood pressure High cholesterol Psychiatric disorders (examples: major depressive disorder, bipolar, others) Other
6. <b>Please tell us what chronic illness(es) you have.</b>		Free text answer
7. <b>Do you take any regular supplements or consume a specific type of diet?</b>		Yes No

8. Please select all supplements or diets that apply.		Vitamin D Aspirin Vegan diet Vegetarian diet Gluten-free diet Other vitamins, supplements, or diets
9. Please tell us about other vitamins or supplements you take or diets you follow.		Free text answer
10. Do you engage in additional therapies such as yoga, meditation, acupuncture, etc.?		Yes No
11. Please select all practices that apply.		Acupuncture Massage Meditation Yoga Other
12. Please tell us about other practices you follow.		Free text answer
13. Do you feel that you have a strong social/family support network?		Yes No
14. Please share how MBC and your treatments are affecting your overall quality of life. (optional)		Free text answer

## Genetics and tumor mutations (4-7 questions)

### Opening Screen:

We will ask about a family history of breast cancer and genetic testing of your tumor(s). You may refer to your medical records if you have them.

Question	Explanation	Answer Options
1. Do you have a family history of breast or other cancer?		Yes No
2. Have you been tested for inherited genetic mutations associated with hereditary breast cancer such as BRCA1 or BRCA2?		Yes No Not sure/I don't remember

3. Did any gene(s) show a mutation?		Yes I underwent testing, but no mutations were found Not sure/I don't remember
4. What genes showed a mutation? Please select all that apply.		BRCA1 BRCA2 tp53 ATM CHEK PALB2 Other
5. What other gene(s) showed a mutation?		Free text answer
6. Has your tumor or blood been tested for acquired (not inherited) mutations? (e.g., Tests from Foundation Medicine, Guardant Health, Tempus, or another company)?	<i>In addition to the genes and mutations you inherit from your parents, the cells in your body can acquire additional mutations over time for various reasons. Many diagnostic tests can analyze your tumor for mutations in multiple genes.</i>	Yes No Not sure/I don't remember
7. Please tell us why you did or did not undergo genetic testing. (optional)		Free text answer

## Clinical Trials

### Opening Screen:

If you have participated in a clinical trial, we will ask about your experience in the trial(s) and for details about your treatment, which will be entered in the treatment profile tab on the app or website you are using. You may refer to any records you have. If you have not participated in a trial, we would like to learn why not.

Question	Explanation	Answer Options
1. Have you ever participated in a clinical trial for your metastatic breast cancer?	<i>If your answer is yes, please provide details regarding your trial(s) on the Treatment Profile tab.</i>	Yes No
2. Have you considered participating in a clinical trial for your metastatic breast cancer but did not participate?		Yes No

<p><b>3. If you have not been part of a clinical trial for metastatic breast cancer, please check the reason(s) why you did not participate. Please select all that apply.</b></p>		<p>No one mentioned clinical trials to me.  I had trouble finding or selecting a trial that was right for me.  I didn't want to leave my current doctor.  I was interested in a clinical trial but did not meet the criteria.  I wasn't sure of the best time in my disease course to enroll.  I was concerned about travel time, child care, or lost work time  I was concerned about costs.  I was concerned about being treated like a "guinea pig".  I was concerned I would get a placebo.  I was concerned I would not benefit.  I was concerned about possible side effects.  I was concerned that a clinical trial was a last resort.  I did not want to undergo extra procedures (e.g., biopsy).  Other</p>
<p><b>4. Please tell us any other reason you chose not to participate.</b></p>		<p>Free text answer</p>