

## Join the movement: tell us about yourself

Thank you for providing your contact information. The Metastatic Breast Cancer Project is open to patients in the United States or Canada. Please help us understand more about your metastatic breast cancer by answering the questions below. As you fill out the questions below, your answers will be automatically saved. If you've previously entered information here and want to pick up where you left off, please use the link we sent you via email to return to this page. If you decide not to complete this form and would like the information entered below to be deleted from the database, now or in the future, you can email info@mbcproject.org to request that your responses be removed. About You Please fill out as much as you can. All questions are optional. You can return at any time with the link sent to you by email. When were you first diagnosed with breast cancer? Choose year... Choose month... When were you first diagnosed with metastatic breast cancer (also known as advanced or stage IV breast cancer)? Choose month... Choose year... 3. At any time, was your breast cancer found to be hormone

receptor positive (HR+, ER+ and/or PR+)? O Yes O No O I don't know 4. At any time, was your breast cancer found to be HER2 positive (HER2+)? O Yes O No O I don't know 5. At any time, was your breast cancer found to be triple negative (e.g, NOT ER+, PR+ or HER2+)? O Yes O No O I don't know 6. At any time, were you diagnosed with inflammatory breast cancer? O Yes O No O I don't know 7. Since your diagnosis with metastatic breast cancer, have you been on any of your cancer therapies for more than 2 years? O Yes O No O I don't know Have any of your therapies worked extraordinarily well made your cancer disappear completely (resulting in no evidence of disease, NED) or resulted in a dramatic reduction in tumor size - for any period of time? O Yes O No O I don't know 9. If you have had an extraordinary response to therapy, tell us more about it. Describe response/therapy

10. When was your most recent biopsy of your cancer?
Choose month...
Choose year...
Tell us anything else you would like to about yourself or your cancer.

Choose year...

What country do you live in? \*

Choose country...

In what year were you born?

What is your ZIP or postal code?

Zip Code

Man

■ Woman

☐ Transgender

5. Which categories describe you? Select all that apply. Note, you may select more than one group.

American Indian or Alaskan Native

Asian

Black, African American, or African

Hispanic, Latino, or Spanish

Middle Eastern or North African

Native Hawaiian or other Pacific Islander

White

None of these fully describe me

Prefer not to answer

What is your gender identity? Select all that apply

Nonbinary
A gender not listed here
Prefer not to answer

17. What sex were you assigned at birth?

Male
Female
Intersex
Prefer not to answer

18. How did you hear about the MBCproject?

I understand that the information I entered here will be stored in a

Metastatic Breast Cancer Project. If I am in the USA or Canada, I

I understand that if I do not sign the research consent form to

I understand that if I sign the research consent form and would

like to withdraw from the research study, I can contact the study

team at info@mbcproject.org at any time, although any of my

secure database for research studies conducted by the

agree to be contacted about possibly participating in the

participate in the Metastatic Breast Cancer Project and would like the information entered above to be deleted from the database, now or in the future, I can email info@mbcproject.org to request

Metastatic Breast Cancer Project.

that my information be removed.

information that has already been entered into the system cannot be withdrawn. My information would be removed from future studies.

Citation information for race & ethnicity questions

Survey question 15 uses some of the language developed for race & ethnicity questions and responses created either as part of

the *All of Us* Research Program from the National Institutes of Health or as part of the Pew Research Center 2014 National Survey of Latinos. Below is the citation information for these questions:

Cronin RM, Jerome RN, Mapes B, Andrade R, Johnston R, Ayala J,

Schlundt D, Bonnet K, Kripalani S, Goggins K, Wallston KA, Couper MP, Elliott MR, Harris P, Begale M, Munoz F, Lopez-Class M, Cella D, Condon D, AuYoung M, Mazor KM, Mikita S, Manganiello M, Borselli N, Fowler S, Rutter JL, Denny JC, Karlson EW, Ahmedani BK, O'Donnell CJ; Vanderbilt University Medical Center Pilot Team, and the Participant Provided Information Committee.

Development of the Initial Surveys for the All of Us Research
Program. Epidemiology. 2019 Jul;30(4):597-608. doi:
10.1097/EDE.0000000000001028. PMID: 31045611; PMCID:
PMC6548672.

Mapes BM, Foster CS, Kusnoor SV, Epelbaum MI, AuYoung M,
Jenkins G, Lopez-Class M, Richardson-Heron D, Elmi A, Surkan K,

Cronin RM, Wilkins CH, Pérez-Stable EJ, Dishman E, Denny JC,

Rutter JL; All of Us Research Program. <u>Diversity and inclusion for the All of Us research program: A scoping review.</u> PLoS One. 2020 Jul 1;15(7):e0234962. doi: 10.1371/journal.pone.0234962. PMID: 32609747; PMCID: PMC7329113.

"Multiracial in America." Pew Research Center, Washington, D.C. (June 11, 2015). <a href="https://www.pewresearch.org/social-trends">https://www.pewresearch.org/social-trends</a>

/2015/06/11/multiracial-in-america

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Count Me In