

Survey: About you

Please tell us more about you by answering the questions below. As you fill out the questions, the answers will be automatically saved. If you would like to leave the survey and complete it at another time, it will be available in the Dashboard.

You can reach us by emailing info@osproject.org if you have any questions.

If you would like to withdraw from the project, you can contact the team at info@osproject.org at any time. Any information that has already been entered into the system cannot be withdrawn, however no additional data will be generated.

1. What sex were you assigned at birth?

Sex assigned at birth is the assignment and classification of people as male, female, or intersex based on a combination of external anatomy, internal anatomy, hormones, and chromosomes.

- ☐ Male
- ☐ Female
- ☐ Intersex
- ☐ Prefer not to answer

2. What is your gender identity? Select all that apply

Gender identity is a term to describe a person's inner sense of being male, female, both, neither or some other gender. It can correspond to or differ from a person's sex assigned at birth.

- ☐ Man
- ☐ Woman
- ☐ Transgender ⓘ
- ☐ Nonbinary ⓘ
- ☐ Genderqueer ⓘ
- ☐ Genderfluid ⓘ
- ☐ Agender ⓘ
- ☐ Two-spirit ⓘ
- ☐ Questioning or unsure of gender identity
- ☐ None of these fully describe me
- ☐ Prefer not to answer

3. Which of the following categories best describes you?

Select all that apply. Note you may select more than one group.

- ☐ American Indian or Alaska Native
(For example: Aztec, Blackfeet Tribe, Mayan, Navajo Nation, Native Village of Barrow (Utiqagvik) Inupiat Traditional Government, Nome Eskimo Community, etc.)
- ☐ Asian
(For example: Asian Indian, Chinese, Filipino, Japanese, Korean, Vietnamese, etc.)
- ☐ Black, African American, or African
(For example: African American, Ethiopian, Haitian, Jamaican, Nigerian, Somali, etc.)
- ☐ Hispanic, Latino, or Spanish
(For example: Colombian, Cuban, Dominican, Mexican or Mexican American, Puerto Rican, Salvadoran, etc.)
- ☐ Middle Eastern or North African
(For example: Algerian, Egyptian, Iranian, Lebanese, Moroccan, Syrian, etc.)
- ☐ Native Hawaiian or other Pacific Islander
(For example: Chamorro, Fijian, Marshallese, Native Hawaiian, Tongan, etc.)
- ☐ White
(For example: English, European, French, German, Irish, Italian, Polish, etc.)
- ☐ None of these fully describe me
- ☐ Prefer not to answer

4. Tell us anything else you would like about yourself or your cancer.

5. How did you hear about the project?

- ☐ Social media (Facebook, Twitter, Instagram, etc.)
- ☐ General internet/Online sources (search engines, patient advocacy group website, blogs, online newsletter, etc.)
- ☐ Media (news media program, print or digital advertisement, promotional video, article in magazine or newspaper, radio or podcasts, brochure, etc.)
- ☐ Advocacy Group (Cancer patient advocacy group, Cancer related-nonprofit, Other Patient Organizations)
- ☐ Word of mouth (friend/family, study staff, study participants, patient, support group, etc.)
- ☐ Doctor/Clinical care center (physician, doctor's office, hospital or medical institution, treatment center, etc.)
- ☐ Event (patient conference, science or research symposium, networking event, etc.)
- ☐ Other

Instructions: Answer the following three questions thinking about yourself. For example, if you are a parent registering a child for Count Me In, please answer these questions about yourself.

6. How often do you have someone (like a family member, friend, hospital/clinic worker or caregiver) help you read hospital materials?

- ☐ All of the time
- ☐ Most of the time
- ☐ Some of the time
- ☐ A little of the time
- ☐ None of the time

7. How often do you have problems learning about your medical condition because of difficulty understanding written information?

- ☐ All of the time
- ☐ Most of the time
- ☐ Some of the time
- ☐ A little of the time
- ☐ None of the time

8. How confident are you filling out forms by yourself?

- ☐ Always
- ☐ Often
- ☐ Sometimes
- ☐ Occasionally
- ☐ Never

9. What is the highest level of school you have completed? Please check one.

- ☐ 8th grade or less
- ☐ Some high school
- ☐ High school graduate or equivalent
- ☐ Some college or technical school
- ☐ College graduate (Associates or Bachelors)
- ☐ Graduate or professional school (for example Masters, PhD, MD, JD/LLB)

10. What language do you speak at home?

- ☐ English

☐ Spanish

☐ Other

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Submit

Survey questions 3, 3a, 3b, and 3c use 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. Diversity and inclusion for the All of Us research program: A scoping review. *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) <https://www.pewresearch.org/social-trends/2015/06/11/multiracial-in-america/>

Survey questions 6-9: Chew LD, et al. *Journal of general internal medicine*. May 2008;23(5):561-566.

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The Osteosarcoma Project is part of **Count Me In**, a research initiative that brings together patients and scientists as partners to speed up discoveries in cancer research.

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Count Me In
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Survey: About Your Osteosarcoma

Please tell us more about your experience with osteosarcoma by answering the questions below. As you fill out the questions, the answers will be automatically saved. If you would like to leave the survey and complete it at another time, it will be available in the Dashboard. You can reach us by emailing info@osproject.org if you have any questions.



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After completing these questions, we will ask a few additional questions to understand more about you.

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.

2. When were you first diagnosed with osteosarcoma?

Choose month... 
 Choose year... 

3. When did you first experience symptoms from osteosarcoma?

Choose timeframe... 

4. When you were first diagnosed with osteosarcoma, where in your body was it found? Select all that apply.

- ☐ Leg -- above the knee (femur)
- ☐ Leg -- below the knee (tibia/fibula)
- ☐ Upper arm (humerus)
- ☐ Pelvis
- ☐ Jaw
- ☐ Spine
- ☐ Lung (one)
- ☐ Lung (both)
- ☐ Other
- ☐ I don't know

5. Please select all the places in your body that you currently have osteosarcoma, select all that apply. If you do not have evidence of disease, please select "No Evidence of Disease (NED)."

- ☐ Leg -- above the knee (femur)
- ☐ Leg -- below the knee (tibia/fibula)
- ☐ Upper arm (humerus)
- ☐ Pelvis
- ☐ Jaw
- ☐ Spine
- ☐ Lung (one)
- ☐ Lung (both)
- ☐ Other

☐ No Evidence of Disease (NED)

☐ I don't know

6. Have you had radiation as a treatment for osteosarcoma?

☐ Yes

☐ No

☐ I don't know

7. Please check the therapies that you have ever received for osteosarcoma (select all that apply). If you do not remember the names of your therapies we can obtain this information from your medical records.

☐ Methotrexate

☐ Cisplatin

☐ Doxorubicin

☐ Ifosfamide

☐ Etoposide

☐ Gemcitabine

☐ Docetaxel

☐ Pazopanib

☐ Sorafenib

☐ Regorafenib

☐ Cabozantinib

☐ Cyclophosphamide

☐ Carboplatin

☐ Other

8. Has your osteosarcoma ever relapsed?

☐ Yes

☐ No

☐ I don't know

9. Are you currently being treated for osteosarcoma?

☐ Yes

☐ No

☐ I don't know

10. Have you ever been diagnosed with any other cancer(s)?

☐ Yes

☐ No

☐ I don't know

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Back

Submit



Count
Me
In

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