

Be The Match Post - CT Survey Questions

Summary: This survey will be used to improve potential donor experience, commitment and ultimately workup availability. The electronic survey will be sent via email to a sub-set of donors post Confirmatory Testing release. The survey questions helped determine what information potential donors need to remain connected, engaged and informed about the donation process.

Proposed Survey Questions:

These questions will be pre-populated in the survey distribution system:

Gender : Male or Female

Donor Age

Donor Race: White, Asian, Multiple Race, Black or African American, Hispanic/Latino, American Indian or Alaska Native, Native Hawaiian or Other Pacific Islander

Donor Ethnicity: Not Hispanic or Latino, not answered, Hispanic or Latino

CT Release Code: Send Letter A, Send Letter B, Send Letter C, Send Letter D

CT Appointment date

Donor consent date

DC Number

DID

State

The below questions would be answered by the donor through the survey distribution system:

1. Overall, how would you rate your most recent experience with Be The Match? very good, good, neutral, poor, very poor
2. How would you rate each of these following activities associated with your recent confirmatory typing (CT) process?
 - a. Initial Contact: very good, good, neutral, poor, very poor, I do not remember
 - b. Health Assessment: very good, good, neutral, poor, very poor, I do not remember
 - c. Appointment plans: very good, good, neutral, poor, very poor, I do not remember
 - d. Blood Draw accommodations: very good, good, neutral, poor, very poor, I do not remember
 - e. Resolution communication: very good, good, neutral, poor, very poor, I do not remember
 - f. Resolution timeframe: very good, good, neutral, poor, very poor, I do not remember
3. Based on the materials provided to you, were you left with any unanswered questions? Yes, no
 - a. If "yes" please tell us what questions you still had after reviewing the materials. Free text
4. Why did you decide to go in for confirmatory typing: (select all that apply)
 - a. I am a committed registry member and wanted to follow through with what I signed up for when I joined.
 - b. I felt pressured by my family and/or friends

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- c. I felt pressured by my donor contact representative
 - d. Someone I know needs or needed a transplant
 - e. I could save someone's life
 - f. It is consistent with my values, morals or religious beliefs
 - g. Other
 - i. If "other" what was that reason? Free text
5. If you are selected for confirmatory typing for another patient in the future, how likely is it that you would go through with the process again? very likely, likely, neutral, unlikely, very unlikely
6. Experience with the blood draw accommodations:
- a. The wait time for the blood draw was appropriate. True, false
 - b. The location of the blood draw facility was convenient. True, false
 - c. The appointment options offered by the facility were accommodating. True, false
 - d. The professionalism of the staff at the blood draw location was suitable. True, false
 - e. I was treated well at the blood draw location. True, false
7. Working with the Donor Contact Representative:
- a. I was well informed about the process and next steps. True, false
 - b. I felt comfortable asking the donor contact representative questions True, false
 - c. The donor contact representative was knowledgeable. True, false
 - d. I felt appreciated by the donor contact representative. True, false
 - e. I was informed that a decision could take up to 60 days (2 months) True, false
 - f. I would have liked to have communication with the donor contact representative while I was waiting to find out if I was the best match. True, false
 - g. Was there anything during the interaction with the contact rep that we could improve to make your experience better? Free text
8. Time for blood draw appointment.
- a. I had enough time to decide if I wanted to provide a blood sample. True, false
 - b. Time away from school, work, or other activities for the blood draw was reasonable. True, false
9. Bone Marrow or stem cell donation procedure:
- a. I believe donating bone marrow or stem cells is safe. True, false
 - b. My family or friends believe that donating bone marrow or stem cells is safe. True, false
 - c. If "false" to either question above: What was it about your beliefs that made you feel unsafe? Free text
10. If you are selected as the best match for a patient, the total time commitment for phone calls, appointments, further testing and actual donation could take approximately 20-30 hours over a period of 4-6 weeks. Knowing this time frame how likely are you to commit to donating. very likely, likely, neutral, unlikely, very unlikely
11. Donor would only answer this question if they answered neutral, unlikely or very unlikely to Q20: Below is a list of possible factors that may have contributed to the indication that you would be neutral, unlikely or very unlikely to move forward with

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stem cell donation if requested to do so for a patient in the future. We would appreciate your feedback if any of these factors contributed to that indication

- a. Time commitment associated with being a donor. Yes, no
 - b. Concerns about the donation process. Yes, no
 - c. Potential travel involved with being a donor. Yes, no
 - d. Support from family and/or friends. Yes, no
 - e. Personal health concerns. Yes, no
 - f. Additional reasons not listed above. Free text
12. Is there anything else you would like to tell us? Free text

Thank you

Public Burden Statement: An agency may not conduct or sponsor, and a person is not required to respond to, a collection of information unless it displays a currently valid OMB control number. The OMB control number for this project is 0915-0212. Public reporting burden for this collection of information is estimated to average .25 hours per response, including the time for reviewing instructions, searching existing data sources, and completing and reviewing the collection of information. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden, to HRSA Reports Clearance Officer, 5600 Fishers Lane, Room 10C-03I, Rockville, Maryland, 20857.