

Patients' Perspectives on Genomic Data and Individualized Cancer Therapy



CANCER AND BLOOD DISORDERS CENTER

Study ID: _____

This questionnaire includes many questions about you, your cancer diagnosis, and your experiences so far with the iCat research study, a study looking at specialized genetic testing of pediatric tumors. Some of these questions may seem more important to you than other questions, but please do your best to answer as many of the questions as possible. All of your responses will be kept confidential. Your oncologist will NOT be given any information about your answers to this questionnaire.

The purpose of this questionnaire is to help doctors and scientists learn about patients' and families' experiences with genetic testing of tumors as well as how patients and families respond to hearing the test results. The information from this study will help oncologists understand more about patients' and families' perspectives on testing like this and to better care for adolescents like you in the future.

Study ID: _____

Experience with Genetics and Genetic Testing

Please answer the following questions about your personal experience with genetics and genetic testing.

1. Other than the testing that was done for this research study, have you or anyone in your immediate family ever undergone genetic or genomic testing?

- Yes
- No
- I am not sure

2. Do you have regular exposure to genetics or experience with genetics and/or genetic information (such as a job in genetics or a similar field)?

- Yes
- No

3. Have you ever taken any classes (such as in high school or college) on genes or genetics, or have you been to any talks or lectures on genes or genetics?

- Yes
- No

Genetic Information

We are hoping to learn more about what patients understand about genetics and genetic information. For each of the following statements about genetics, please indicate whether you feel the statement is true or false by circling the appropriate response.

Once a genetic marker for a disorder is identified in a person, the disorder can be prevented or cured.	True	False
If a person has a genetic marker for a disorder, the person will always get the disorder.	True	False
Only mothers can pass on genetic disorders.	True	False
People who have a genetic marker for a disease are unhealthy.	True	False

Study ID: _____

Patient Cancer Information

Please answer the following questions about your cancer and your cancer treatment.

4. Are you currently receiving treatment for your cancer?

- Yes
- No

5. How would you rate your current state of overall health?

- Excellent
- Very good
- Good
- Fair
- Poor

6. How likely do you feel that you are to be cured of your cancer?

- Very likely to be cured (Greater than 80%)
- Likely to be cured (60-80%)
- Possible to be cured (40-59%)
- Unlikely to be cured (20-39%)
- Very unlikely to be cured but still possible (Less than 20%)
- No chance of cure

7. What do you think your chance of being cured of your cancer is, compared to other young adults with the same cancer diagnosis?

- My chance of being cured is much greater than others with the same diagnosis.
- My chance of being cured is somewhat greater than others with the same diagnosis.
- My chance of being cured is about the same as others with the same diagnosis.
- My chance of being cured is somewhat less than others with the same diagnosis.
- My chance of being cured is much less than others with the same diagnosis.

Study ID: _____

Understanding of Testing and Purpose of Testing

We are trying to understand how well patients understand the purpose of testing tumors for genetic changes (“mutations”). Please think back to when you enrolled on the iCat research study, and answer the following questions about your thoughts about the study and what you expected from it.

8. Do you remember signing up to participate in the iCat research study to test your tumor for changes in its genes (“mutations”)?

- Yes
- No

9. How well do you remember the conversation(s) you had with your doctor about the iCat research study and the genetic testing involved in it?

- Extremely well
- Well
- Moderately
- Poorly
- Extremely poorly

10. How well did you understand the information you were told about this research study and the genetic testing involved in it?

- Extremely well
- Well
- Moderately
- Poorly
- Extremely poorly

Study ID: _____

Understanding of Testing and Purpose of Testing (continued)

11. When you first agreed to participate in this research study, how likely did you think it was that the genetic testing of your tumor would show that there was a change in the genes (“mutation”)?

- Very likely to find a mutation
- Likely to find a mutation
- Somewhat likely to find a mutation
- Unlikely to find a mutation
- Very unlikely to find a mutation

12. When you first agreed to participate in this research study, how likely did you think it was that the genetic testing of your tumor would find a change in the genes (“mutation”) that would suggest a new treatment option for you?

- Very likely to suggest a new treatment or medicine
- Likely to suggest a new treatment or medicine
- Somewhat likely to suggest a new treatment or medicine
- Unlikely to suggest a new treatment or medicine
- Very unlikely to suggest a new treatment or medicine

13. If the results from the genetic testing of your tumor showed that there **WAS** a change in the genes (“mutation”) that suggested a new treatment option, how did you think this would change your chances of being cured?

- Much more likely to be cured
- Slightly more likely to be cured
- No change
- Slightly less likely to be cured
- Much less likely to be cured

14. If the results from the genetic testing of your tumor showed that there **WAS NOT** a change in the genes (“mutation”) that suggested a new treatment option, how did you think this would change your chances of being cured?

- Much more likely to be cured
- Slightly more likely to be cured
- No change
- Slightly less likely to be cured
- Much less likely to be cured

Study ID: _____

Understanding of Testing and Purpose of Testing (continued)

Please think back to when you enrolled on the iCat research study and what you understood about the research study at that time. For each of the following, please indicate whether you agree with the statement, disagree with the statement, or are unsure about the statement by circling the appropriate response.

By participating in this study, I was helping the doctors and scientists learn information that may benefit me.	Disagree	Unsure	Agree
By participating in this study, I was helping doctors and scientists learn information that may benefit future cancer patients.	Disagree	Unsure	Agree
The main reason this study was done was to improve my treatment.	Disagree	Unsure	Agree
The main reason this study was done was to improve the treatment of future cancer patients.	Disagree	Unsure	Agree
There may not have been direct medical benefit to me from participating in this study.	Disagree	Unsure	Agree
I can be sure that participating in this study provided me the best chance of cure.	Disagree	Unsure	Agree
Participating in this study means that new treatments may be suggested that could be helpful in treating my cancer.	Disagree	Unsure	Agree
Treatment recommendations from this study are certain to be effective for patients that receive them.	Disagree	Unsure	Agree
Any treatment recommendations from this study are standard for my type of cancer.	Disagree	Unsure	Agree
All patients participating in this research study received a treatment recommendation.	Disagree	Unsure	Agree

Study ID: _____

Hopes for Testing

Please indicate how much you agree with the following statements about why you chose to participate in this research study. Choose how true each statement was for you at the time you signed up to take part in the iCat research study.

	Extremely true	Very true	Somewhat true	A little true	Not at all true
I hoped it would increase my chance of being cured.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I hoped that doing this testing would provide me with peace of mind.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I hoped it would help find cures for future patients.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I hoped it would help provide information to me and my doctor about my cancer.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I hoped it would teach me about my genes.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I hoped it would teach me about my family's genes.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I hoped it would give me a greater number of treatment options.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I hoped to help doctors and scientists learn more about the genes involved in cancer.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My doctor recommended the study.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Participating in this research study gave me hope.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I did not expect any benefit to me or my family from this research.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Study ID: _____

Hopes for Testing (continued)

Please answer the following questions about the hopes and expectations you had at the time you enrolled in this research study.

15. Who did you expect to benefit most from the genetic testing of your tumor? *Please choose one.*

- Me
- My family members
- Future patients
- Doctors and scientists
- Other (please specify: _____)

16. Which of the following did you **MOST HOPE WOULD HAPPEN** because of your participation in this research study? *Please choose only one.*

- I would have a better chance of being cured.
- Doing this testing would give me peace of mind.
- Doctors would be better able to find cures for future patients.
- My doctors would be able to learn more about my cancer.
- I would learn about my genes.
- I would learn about my family's genes.
- I would have a greater number of treatment options.
- I did not hope anything would happen as a result of this research.
- Other (please specify: _____)

17. Which of the following did you think was **MOST LIKELY TO HAPPEN** because of your participation in this research study? *Please choose only one.*

- I would have a better chance of being cured.
- Doing this testing would give me peace of mind.
- Doctors would be better able to find cures for future patients.
- My doctors would be able to learn more about my cancer.
- I would learn about my genes.
- I would learn about my family's genes.
- I would have a greater number of treatment options.
- I did not think anything was likely to happen as a result of this research.
- Other (please specify: _____)

Study ID: _____

Concerns about Testing

Please indicate how much you agree with each of the following statements about concerns you had about participating in this research study. Choose how true each statement was for you at the time you signed up to take part in the iCat research study.

	Extremely true	Very true	Somewhat true	A little true	Not at all true
I worried that I would learn information about my cancer that would be stressful or cause anxiety.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I worried that I would learn information about my genes that would be stressful or cause anxiety.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I worried that I would learn information about my family that would be stressful or cause anxiety.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I worried that I would learn that my cancer was less treatable or more aggressive than previously thought.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I worried that the information learned in this research study would not be kept private.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I worried that the information learned could have hurt my family's ability to get insurance.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I worried that the information learned could have hurt my family's ability to get or keep a job.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I worried that the results would take a long time to come back.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I worried that no new information would be found to help me, causing me and my family to be disappointed.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I did not have any worries or concerns about this research.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Study ID: _____

Concerns about Testing (continued)

Please answer the following questions about the concerns you had at the time you enrolled in this research study.

18. Which of these statements best describes which you **MOST WORRIED WOULD HAPPEN** because of your participation in this research study? *Please choose only one.*

- I worried that I would learn information about my cancer that would cause me anxiety.
- I worried that I would learn information about my genes that would cause me anxiety.
- I worried that I would learn information about my family that would cause me anxiety.
- I could have learned that my cancer was less treatable or more aggressive than previously thought.
- I worried that the information learned in this research study would not be kept private.
- I worried that the information learned could have hurt my family's ability to get insurance.
- I worried that the information learned could have hurt my family's ability to get or keep a job.
- I worried that the results would take a long time to come back.
- I worried that no new information would be found, causing me and my family to be disappointed.
- I did not have any worries or concerns about this research.
- Other (please specify: _____)

19. Which of these statements best describes which you thought was **MOST LIKELY TO HAPPEN** because of your participation in this research study? *Please choose only one.*

- I could have learned information about my cancer that would cause me anxiety.
- I could have learned information about my genes that would cause me anxiety.
- I could have learned information about my family that would cause me anxiety.
- I could have learned that my cancer was less treatable or more aggressive than previously thought.
- The information learned in this research study might not be kept private.
- The information learned could have hurt my family's ability to get insurance.
- The information learned could have hurt my family's ability to get or keep a job.
- The results would take a long time to come back.
- No new information would be found, causing me and my family to be disappointed.
- I did not have any concerns or worries that were likely to result from this research.
- Other (please specify: _____)

Study ID: _____

Reporting of Cancer and Medication Results

We are looking to learn about what types of information patients want to receive from studies such as this. Please again think back to when you enrolled on the iCat research study. For each of the following, please choose if you would have wanted or would not have wanted each type of information reported back to you.

	Would have wanted	Would not have wanted
Information that told doctors that you were MORE likely to be cured of your cancer	<input type="checkbox"/>	<input type="checkbox"/>
Information that told doctors that you were LESS likely to be cured of your cancer	<input type="checkbox"/>	<input type="checkbox"/>
Information that directed doctors toward a treatment option that might be beneficial to you based on the genetic changes (“mutations”) found in your tumor	<input type="checkbox"/>	<input type="checkbox"/>
Information that told doctors about genetic changes (“mutations”) in your tumor but these changes did not suggest a new treatment	<input type="checkbox"/>	<input type="checkbox"/>

Reporting of Other Results

We are looking to learn about what types of information patients want to receive from studies such as this. Please again think back to when you enrolled on the iCat research study. For each of the following, please choose if you would have wanted or would not have wanted each type of information reported back to you.

	Would have wanted	Would not have wanted
Information that told doctors that you and others in your family might be at an increased risk of developing certain types of cancers	<input type="checkbox"/>	<input type="checkbox"/>
Information that told doctors about a change in your genes that could be passed onto your own children and cause an illness or condition other than cancer (even if you do not have that condition)	<input type="checkbox"/>	<input type="checkbox"/>
Information about your or your family’s genes or health that could allow doctors to screen for or prevent certain illnesses or conditions	<input type="checkbox"/>	<input type="checkbox"/>
Information about your or your family’s genes or health, but there was nothing that doctors could do to screen for or prevent these illnesses or conditions	<input type="checkbox"/>	<input type="checkbox"/>
Information about your or your family’s genes or health, but doctors did not know if this would cause any illnesses or conditions	<input type="checkbox"/>	<input type="checkbox"/>

Study ID: _____

Research Study Requirements

We are also trying to better understand what requirements are reasonable for research studies involving cancer and genetics. Please answer the following questions about requirements for research studies.

20. If a research study such as iCat required you to have another tumor biopsy that you would not get otherwise, do you think that you would choose to enroll in the research study and have the biopsy?

- Yes
- No

21. If a research study such as iCat required you to have another tumor biopsy that you would not get otherwise but your doctor recommended it, do you think that you would choose to enroll?

- Yes
- No

22. If a research study such as iCat required you to have another tumor biopsy that you would not get otherwise and this biopsy had a moderate-high (>50%) chance of injury, infection, or other negative effect, do you think that you would choose to enroll in the research study and have the biopsy?

- Yes
- No

Study ID: _____

Follow-up of Results

Please answer the following questions about the results and information you received as part of this research study.

23. Did the genetic testing of your tumor find any changes in the genes (“mutations”) that were reported back to you and your doctors?

- Yes
- No
- I do not know

24. As part of this research study, was a treatment recommendation reported back to you and your doctors?

- Yes —————→ *Go to Question 25*
- No —————→
- I do not know —————→ *Go to Question 25*

24a. Why did you not receive a treatment recommendation reported back to you? Please check all that apply.

- No changes in the genes (“mutations”) were found that suggested a new treatment for me.
- There was not enough tumor sample to do the necessary testing.
- I did not want to have the results of the testing reported back to me and my doctors.
- I did not receive a treatment recommendation but I do not know why.

24b. Please consider how the fact that you did not receive a treatment recommendation impacted you. Please check all that apply.

- I was disappointed to have not received a treatment recommendation.
- I was surprised to have not received a treatment recommendation.
- Not receiving a treatment recommendation has significantly impacted my thoughts and feelings about this research study.
- I regret having taken part in this research study because I did not receive a treatment recommendation.
- I am still glad that I took part in the research study despite having not received a treatment recommendation.

Study ID: _____

Follow-up of Results (continued)

25. Have you ever received a treatment that was recommended as part of this research study, either now or in the past?

- Does not apply; no treatment recommendation was made → *Go to Question 26*
- Yes → *Go to Question 26*
- No →
- I do not know → *Go to Question 26*

25a. Why have you not received a treatment that was recommended as part of this research study? *Please check all that apply.*

- No treatment recommendation was made.
- I am doing well on standard treatment so we are continuing to use that treatment.
- My doctor did not want to use the recommended treatment.
- My family and I did not want to use the recommended treatment.
- We were unable to get the recommended treatment.
- I have been too sick to receive the recommended treatment.
- I am not receiving the recommended treatment but I do not know why.
- Other (please specify):

- I am doing well off of treatment so I have never started the recommended treatment

26. If you could make the decision again of choosing to participate in this research study, would you choose to participate?

- Yes
- No

27. Do you feel that participating in this research study has been helpful for you?

- Yes
- No

Study ID: _____

Impact of Results

Please consider how strongly you agree with the following statements about the impact that participating in this research study has had on you and your family. Choose one response for each statement to describe how true it is for you.

	Extremely true	Very true	Somewhat true	A little true	Not at all true
Participating in this study gave me more hope that I would be cured.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Participating in this study taught me about my cancer.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Participating in this study taught me about my genes and genetics.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Participating in this study gave me hope that we will be able to cure future patients with cancer.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Participating in this study gave me false hope.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I experienced direct medical benefit from participating in this study.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My family and I benefited from participating in this study.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am glad I chose to participate in this study.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Participating in this study caused me added stress and anxiety.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Waiting for results from this study caused me added stress and anxiety.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Participating in this study caused me added stress and anxiety about my cancer.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Participating in this study caused me added stress and anxiety about my genes.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Participating in this study caused me added stress and anxiety about myself and/or my family.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Participating in this study hurt my family's ability to get or keep insurance.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Study ID: _____

Participating in this study hurt my family's ability to get or keep a job.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I was disappointed with the results that I received as part of this study.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Participating in this study provided me with peace of mind.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Participating in this study gave me the feeling that I had done everything I could for my health.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I feel that I helped myself by participating in this study.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I feel that I helped others by participating in this study.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I feel that I was hurt by participating in this study.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I regret having participated in this study.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

28. Which of the following do you feel was the **MOST POSITIVE IMPACT** on you and your family about your participation in the iCat research study? *Please choose only one.*

- It gave me more hope that I would be cured.
- It gave me hope that we will be able to cure future patients with cancer.
- It taught me about my genes and cancer.
- It provided me with peace of mind that I have done everything I could for my health.
- It directed my doctors to new treatment options for me.
- I experienced direct medical benefit by participating in this study.
- Participating in this research study had no positive impact on me and my family.
- Other (please specify: _____)

29. Which of the following do you feel was the **MOST NEGATIVE IMPACT** on you and your family about your participation in the iCat research study? *Please choose only one.*

- It gave me false hope.
- It caused me added stress and anxiety about my cancer.
- It caused me added stress and anxiety about my genes.
- It caused me added stress and anxiety about myself and/or my family.
- It hurt my family's ability to get or keep insurance.
- It hurt my family's ability to get or keep a job.
- Waiting for results from the study caused me added stress and anxiety.
- Participating in this research study had no negative impact on me and my family.
- Other (please specify: _____)

Study ID: _____

Demographic Information

Please answer the following questions about yourself to help us understand more about who is participating in this research study.

30. How old are you?

- Less than 20 years old
- 20-29 years old
- 30-39 years old
- 40-49 years old
- 50 years old or older

31. What is the highest level of school you have completed?

- 8th grade or less
- Some high school
- High school graduate or equivalent
- Some college or technical school
- College graduate (either associate or bachelor's degree)
- Graduate or professional school (e.g., MD, PhD, JD, MA, MS)

32. What is your gender?

- Male
- Female

33. Which group best describes your racial/ethnic background?

- White
- Black/African-American
- Hispanic/Latino
- Asian/Pacific Islander
- Native American
- Other

Study ID: _____

You have reached the end of our questions. Thank you very much for participating. If you have other comments about your experiences with the iCat research study that you would like to share, please feel free to write them in below.
