

This questionnaire is evaluated automatically. Please use a pen to fill in your answers as follows:

- ☐ Multiple-choice (select all applicable options)
☐ Single-choice (select only one option)



Selected
Selected



Undo select
Undo select

1 Questions

1.1 Survey Date and Time

Welcome! 1. This page provides information you may want before deciding whether to complete this survey. The same questionnaire is being used nationwide to learn from research participants' feedback (Empowering the Participant Voice*). a. The survey that follows is part of a research study conducted by [INSERT PI] at [INSERT INSTITUTION]. The purpose of the research is to understand research participants' experiences and enhance them. b. The survey that follows is part of our quality assurance program conducted by [INSTITUTION] University. 2. Participation involves completing the survey. The survey asks about you and your most recent research experience. It will take 5-7 minutes to complete the survey. For your answers to be saved, you must click "Done" at the end of the survey. Plan to complete the survey in one sitting. 3. There are no direct benefits to you. However, the survey results may help us understand how to improve the research participation experience at this research center and others across the country. 4. We will do our best to protect your information, but there is always a small risk of loss of confidentiality. To further minimize the risks to confidentiality, we do NOT ask for any details about your prior research studies, doctors, hospitals, or any diagnoses. 5. Survey responses are analyzed as a group to identify areas of excellence and opportunities for improvement. We will NOT reveal any individual survey responses to staff or research teams nor in our publications. 6. There is no compensation for completing the survey. 7. Your participation is voluntary and you can change your mind. Your answers will not be recorded until you click "Done" at the end of the survey.

Please answer the questions below regarding the research study you enrolled in within the past year. If you enrolled in more than one study, answer for the most recent study.

When the survey questions refer to "the study," we are asking about your experiences enrolled in that clinical research study, not this online survey study.

1.2 Would you recommend joining a research study to your family and friends?

- ☐ Definitely no
☐ Probably no
☐ Probably yes
☐ Definitely yes



Research Participant Perception Survey - SP

1.3 Below is a list of possible reasons for joining a research study. When you considered joining the study, how important were these reasons for you?

	Very important	Somewhat important	Not very important	Not important at all
To find out more about my disease	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because no other medical options were available	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
To gain access to new treatment/therapy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
To obtain free healthcare	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
To help others	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because of the Research/Health Center's reputation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because I am concerned about the topic of study	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
To obtain education and learning	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because of a positive experience in another study	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because of family influence/involvement	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
To earn money/payment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because my caregiver encouraged me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other reasons	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

1.4 Did the study require that you already have a disease or condition in order to enroll?

- ☐ Yes
☐ No

1.5 Did the study involve taking a drug or a supplement, the use of a new medical device, undergoing a new medical procedure, or a change in lifestyle, behavior, or counseling?

- ☐ Yes
☐ No
☐ Not sure

1.6 How much did the study demand of you? (Pick the answer that most closely describes your experience)

- ☐ Simple (for example: a few visits or simple tests or surveys)
☐ Moderate (for example: multiple visits or a short inpatient stay; only a few procedures, not risky or intense)
☐ Intense (for example: long or multiple inpatient stays or many visits; procedure(s) that are intense, risky, or complex)



1.7 Before you joined the study, how did the study team discuss the details of the study with you?

- ☐ Mostly through the email or video or telephone conversations
- ☐ Mostly while physically in the same place with a member of the study team
- ☐ A mix of conversations taking place both physically in the same place and over telephone/video/computer)
- ☐ No discussions with the study team before joining the study
- ☐ I do not remember

1.8 Did the Informed consent form prepare you for what to expect during the study?

- ☐ No
- ☐ Yes, somewhat
- ☐ Yes, mostly
- ☐ Yes, completely

1.9 Did the information and discussions you had before participating in the research study prepare you for your experience in the study?

- ☐ No
- ☐ Yes, somewhat
- ☐ Yes, mostly
- ☐ Yes, completely

1.10 Did the research team members listen carefully to you?

- ☐ Never
- ☐ Sometimes
- ☐ Usually
- ☐ Always
- ☐ No Research Team Member Involved

1.11 Did the research team members treat you with courtesy and respect?

- ☐ Never
- ☐ Sometimes
- ☐ Usually
- ☐ Always
- ☐ No Research Team Member Involved

1.12 During your discussion about the study, did you feel pressure from the research staff to join the study?

- ☐ Never
- ☐ Sometimes
- ☐ Usually
- ☐ Always

1.13 Did the research staff do everything possible to provide assistance with any language difference you might have?

- ☐ Never
- ☐ Sometimes
- ☐ Usually
- ☐ Always
- ☐ No language difference



Research Participant Perception Survey - SP

1.14 When you were not at the research site did you know how to reach the research team if you had a question?

- ☐ Never
- ☐ Sometimes
- ☐ Usually
- ☐ Always

1.15 When you were not at the research site and you needed to reach a member of the research team, were you able to reach him/her as soon as you wanted?

- ☐ Never
- ☐ Sometimes
- ☐ Usually
- ☐ Always
- ☐ Did not need to reach the research team

1.16 Did you feel you were a valued partner in the research process?

- ☐ Never
- ☐ Sometimes
- ☐ Usually
- ☐ Always

1.17 If you considered leaving the study, did you feel pressure from the Research Team to stay?

- ☐ Never
- ☐ Sometimes
- ☐ Usually
- ☐ Always
- ☐ Did not consider leaving the study

1.18 Did the research staff respect your cultural background (e.g. language, religion, ethnic group)?

- ☐ Never
- ☐ Sometimes
- ☐ Usually
- ☐ Always
- ☐ No cultural issues

1.19 Did you have enough physical privacy while you were in the study?

- ☐ Never
- ☐ Sometimes
- ☐ Usually
- ☐ Always



Research Participant Perception Survey - SP

1.20 Below is a list of possible reasons for leaving a research study. How important were these reasons for you in considering leaving the study?

	Very important	Somewhat important	Not very important	Not important at all
Pain or discomfort related to participation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Worried about risks of treatment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Side effects that occurred during the study	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Invasion of privacy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Too much time spent waiting around	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Time commitment required	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Family/work issues unrelated to the study	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Interactions with research team	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Not getting test results	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Undue pressure to stay in study	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Problems with study payments	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Unexpected tests and procedures that occurred during the study	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Transportation/parking	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other reasons	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
To find out more about my disease	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because no other medical options were available	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
To gain access to new treatment/therapy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
To obtain free healthcare	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
To help others	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because of the Research/Health Center's reputation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because I am concerned about the topic of study	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



Research Participant Perception Survey - SP

	Very important	Somewhat important	Not very important	Not important at all
To obtain education and learning	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because of a positive experience in another study	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because of family influence/involvement	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
To earn money/payment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because my caregiver encouraged me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because of my relationship with the research team	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Feeling valued as a research participant	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Improved health or quality of life	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other reasons	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

1.21 Which of the following things would be important for you in a future study?

- ☐ Access to computer, internet, and television
- ☐ Access to comfortable bed
- ☐ Payment/More Payment
- ☐ Support groups
- ☐ Volunteer appreciation
- ☐ Flexible Schedule
- ☐ Accessible parking and study location
- ☐ Planned discharge and proper goodbye to research team
- ☐ Summary of overall research results shared with me
- ☐ Results of personal lab tests shared with me or my doctor
- ☐ Other (please specify)

1.22 Please specify other important things:



Research Participant Perception Survey - SP

1.23 Please use the scale below to rate your overall experience in the research study, where 0 is the worst possible experience, and 10 is the best possible experience.

- ☐ 0 worst
- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ 5
- ☐ 6
- ☐ 7
- ☐ 8
- ☐ 9
- ☐ 10 best

1.24 What is the highest grade or level of school that you have completed?

- ☐ 8th grade or less
- ☐ Some high school, did not graduate
- ☐ High school graduate or GED
- ☐ Some college or 2-year degree
- ☐ 4-year college graduate
- ☐ More than 4-year college degree

1.25 What is your age?

- ☐ 18-34
- ☐ 35-44
- ☐ 45-54
- ☐ 55-64
- ☐ 65-74
- ☐ 75 and over

1.26 What is your race? (Please choose one or more)

- ☐ American Indian or Alaska Native
- ☐ Asian
- ☐ Black or African American
- ☐ Native Hawaiian or other Pacific Islander
- ☐ White

1.27 Are you of Spanish or Hispanic or Latino/a/x origin or descent?

- ☐ No - not Spanish/Hispanic/Latino/a/x
- ☐ Yes - Puerto Rican
- ☐ Yes - Mexican/Mexican American/Chicano
- ☐ Yes - Cuban
- ☐ Yes - other Spanish/Hispanic/Latino/a/x

1.28 What is your sex?

- ☐ Female
- ☐ Male
- ☐ Intersex



1.29 How would you describe your gender identity?

- ☐ Female (including transgender women)
- ☐ Male (including transgender men)
- ☐ Non-binary/gender-fluid/agender
- ☐ Prefer not to say

1.30 Is there anything else you would like to share about your experience in the study you most recently joined?

Thank you for your interest and the investment of your time. Your responses will help us to improve the research experience for participants.

Empowering the Participant Voice is supported in part by a grant from the National Center for Accelerating Translational Science U01TR003026 to The Rockefeller University, and Clinical Translational Science Awards UL1TR002553 (Duke University), UL1TR003098 (Johns Hopkins University), UL1TR002001 (University of Rochester), UL1TR001866 (Rockefeller University), UL1TR002243 (Vanderbilt), and UL1TR001420 (Wake Forest University Health Sciences).



This questionnaire is evaluated automatically. Please use a pen to fill in your answers as follows:

- ☐ Multiple-choice (select all applicable options)
☐ Single-choice (select only one option)



Selected
Selected



Undo select
Undo select

1 Questions

1.1 Survey Date and Time

Welcome! 1. This page provides information you may want before deciding whether to complete this survey. The same questionnaire is being used nationwide to learn from research participants' feedback (Empowering the Participant Voice*). a. The survey that follows is part of a research study conducted by [INSERT PI] at [INSERT INSTITUTION]. The purpose of the research is to understand research participants' experiences and enhance them. b. The survey that follows is part of our quality assurance program conducted by [INSTITUTION] University. 2. Participation involves completing the survey. The survey asks about you and your most recent research experience. It will take 5-7 minutes to complete the survey. For your answers to be saved, you must click "Done" at the end of the survey. Plan to complete the survey in one sitting. 3. There are no direct benefits to you. However, the survey results may help us understand how to improve the research participation experience at this research center and others across the country. 4. We will do our best to protect your information, but there is always a small risk of loss of confidentiality. To further minimize the risks to confidentiality, we do NOT ask for any details about your prior research studies, doctors, hospitals, or any diagnoses. 5. Survey responses are analyzed as a group to identify areas of excellence and opportunities for improvement. We will NOT reveal any individual survey responses to staff or research teams nor in our publications. 6. There is no compensation for completing the survey. 7. Your participation is voluntary and you can change your mind. Your answers will not be recorded until you click "Done" at the end of the survey.

Please answer the questions below regarding the research study you enrolled in within the past year. If you enrolled in more than one study, answer for the most recent study.

When the survey questions refer to "the study," we are asking about your experiences enrolled in that clinical research study, not this online survey study.

1.2 Would you recommend joining a research study to your family and friends?

- ☐ Definitely no
☐ Probably no
☐ Probably yes
☐ Definitely yes



Research Participant Perception Survey - SP

1.3 Below is a list of possible reasons for joining a research study. When you considered joining the study, how important were these reasons for you?

	Very important	Somewhat important	Not very important	Not important at all
To find out more about my disease	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because no other medical options were available	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
To gain access to new treatment/therapy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
To obtain free healthcare	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
To help others	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because of the Research/Health Center's reputation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because I am concerned about the topic of study	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
To obtain education and learning	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because of a positive experience in another study	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because of family influence/involvement	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
To earn money/payment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because my caregiver encouraged me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other reasons	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

1.4 Did the study require that you already have a disease or condition in order to enroll?

- ☐ Yes
☐ No

1.5 Did the study involve taking a drug or a supplement, the use of a new medical device, undergoing a new medical procedure, or a change in lifestyle, behavior, or counseling?

- ☐ Yes
☐ No
☐ Not sure

1.6 How much did the study demand of you? (Pick the answer that most closely describes your experience)

- ☐ Simple (for example: a few visits or simple tests or surveys)
☐ Moderate (for example: multiple visits or a short inpatient stay; only a few procedures, not risky or intense)
☐ Intense (for example: long or multiple inpatient stays or many visits; procedure(s) that are intense, risky, or complex)



1.7 Before you joined the study, how did the study team discuss the details of the study with you?

- ☐ Mostly through the email or video or telephone conversations
- ☐ Mostly while physically in the same place with a member of the study team
- ☐ A mix of conversations taking place both physically in the same place and over telephone/video/computer)
- ☐ No discussions with the study team before joining the study
- ☐ I do not remember

1.8 Did the Informed consent form prepare you for what to expect during the study?

- ☐ No
- ☐ Yes, somewhat
- ☐ Yes, mostly
- ☐ Yes, completely

1.9 Did the information and discussions you had before participating in the research study prepare you for your experience in the study?

- ☐ No
- ☐ Yes, somewhat
- ☐ Yes, mostly
- ☐ Yes, completely

1.10 Did the research team members listen carefully to you?

- ☐ Never
- ☐ Sometimes
- ☐ Usually
- ☐ Always
- ☐ No Research Team Member Involved

1.11 Did the research team members treat you with courtesy and respect?

- ☐ Never
- ☐ Sometimes
- ☐ Usually
- ☐ Always
- ☐ No Research Team Member Involved

1.12 During your discussion about the study, did you feel pressure from the research staff to join the study?

- ☐ Never
- ☐ Sometimes
- ☐ Usually
- ☐ Always

1.13 Did the research staff do everything possible to provide assistance with any language difference you might have?

- ☐ Never
- ☐ Sometimes
- ☐ Usually
- ☐ Always
- ☐ No language difference



Research Participant Perception Survey - SP

1.14 When you were not at the research site did you know how to reach the research team if you had a question?

- ☐ Never
- ☐ Sometimes
- ☐ Usually
- ☐ Always

1.15 When you were not at the research site and you needed to reach a member of the research team, were you able to reach him/her as soon as you wanted?

- ☐ Never
- ☐ Sometimes
- ☐ Usually
- ☐ Always
- ☐ Did not need to reach the research team

1.16 Did you feel you were a valued partner in the research process?

- ☐ Never
- ☐ Sometimes
- ☐ Usually
- ☐ Always

1.17 If you considered leaving the study, did you feel pressure from the Research Team to stay?

- ☐ Never
- ☐ Sometimes
- ☐ Usually
- ☐ Always
- ☐ Did not consider leaving the study

1.18 Did the research staff respect your cultural background (e.g. language, religion, ethnic group)?

- ☐ Never
- ☐ Sometimes
- ☐ Usually
- ☐ Always
- ☐ No cultural issues

1.19 Did you have enough physical privacy while you were in the study?

- ☐ Never
- ☐ Sometimes
- ☐ Usually
- ☐ Always



Research Participant Perception Survey - SP

1.20 Below is a list of possible reasons for leaving a research study. How important were these reasons for you in considering leaving the study?

	Very important	Somewhat important	Not very important	Not important at all
Pain or discomfort related to participation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Worried about risks of treatment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Side effects that occurred during the study	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Invasion of privacy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Too much time spent waiting around	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Time commitment required	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Family/work issues unrelated to the study	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Interactions with research team	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Not getting test results	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Undue pressure to stay in study	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Problems with study payments	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Unexpected tests and procedures that occurred during the study	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Transportation/parking	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other reasons	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
To find out more about my disease	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because no other medical options were available	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
To gain access to new treatment/therapy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
To obtain free healthcare	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
To help others	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because of the Research/Health Center's reputation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because I am concerned about the topic of study	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



Research Participant Perception Survey - SP

	Very important	Somewhat important	Not very important	Not important at all
To obtain education and learning	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because of a positive experience in another study	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because of family influence/involvement	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
To earn money/payment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because my caregiver encouraged me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because of my relationship with the research team	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Feeling valued as a research participant	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Improved health or quality of life	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other reasons	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

1.21 Which of the following things would be important for you in a future study?

- ☐ Access to computer, internet, and television
- ☐ Access to comfortable bed
- ☐ Payment/More Payment
- ☐ Support groups
- ☐ Volunteer appreciation
- ☐ Flexible Schedule
- ☐ Accessible parking and study location
- ☐ Planned discharge and proper goodbye to research team
- ☐ Summary of overall research results shared with me
- ☐ Results of personal lab tests shared with me or my doctor
- ☐ Other (please specify)

1.22 Please specify other important things:



Research Participant Perception Survey - SP

1.23 Please use the scale below to rate your overall experience in the research study, where 0 is the worst possible experience, and 10 is the best possible experience.

- ☐ 0 worst
- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ 5
- ☐ 6
- ☐ 7
- ☐ 8
- ☐ 9
- ☐ 10 best

1.24 What is the highest grade or level of school that you have completed?

- ☐ 8th grade or less
- ☐ Some high school, did not graduate
- ☐ High school graduate or GED
- ☐ Some college or 2-year degree
- ☐ 4-year college graduate
- ☐ More than 4-year college degree

1.25 What is your age?

- ☐ 18-34
- ☐ 35-44
- ☐ 45-54
- ☐ 55-64
- ☐ 65-74
- ☐ 75 and over

1.26 What is your race? (Please choose one or more)

- ☐ American Indian or Alaska Native
- ☐ Asian
- ☐ Black or African American
- ☐ Native Hawaiian or other Pacific Islander
- ☐ White

1.27 Are you of Spanish or Hispanic or Latino/a/x origin or descent?

- ☐ No - not Spanish/Hispanic/Latino/a/x
- ☐ Yes - Puerto Rican
- ☐ Yes - Mexican/Mexican American/Chicano
- ☐ Yes - Cuban
- ☐ Yes - other Spanish/Hispanic/Latino/a/x

1.28 What is your sex?

- ☐ Female
- ☐ Male
- ☐ Intersex



1.29 How would you describe your gender identity?

- ☐ Female (including transgender women)
- ☐ Male (including transgender men)
- ☐ Non-binary/gender-fluid/agender
- ☐ Prefer not to say

1.30 Is there anything else you would like to share about your experience in the study you most recently joined?

Thank you for your interest and the investment of your time. Your responses will help us to improve the research experience for participants.

Empowering the Participant Voice is supported in part by a grant from the National Center for Accelerating Translational Science U01TR003026 to The Rockefeller University, and Clinical Translational Science Awards UL1TR002553 (Duke University), UL1TR003098 (Johns Hopkins University), UL1TR002001 (University of Rochester), UL1TR001866 (Rockefeller University), UL1TR002243 (Vanderbilt), and UL1TR001420 (Wake Forest University Health Sciences).



This questionnaire is evaluated automatically. Please use a pen to fill in your answers as follows:

- ☐ Multiple-choice (select all applicable options)
☐ Single-choice (select only one option)



Selected
Selected



Undo select
Undo select

1 Questions

1.1 Survey Date and Time

Welcome! 1. This page provides information you may want before deciding whether to complete this survey. The same questionnaire is being used nationwide to learn from research participants' feedback (Empowering the Participant Voice*). a. The survey that follows is part of a research study conducted by [INSERT PI] at [INSERT INSTITUTION]. The purpose of the research is to understand research participants' experiences and enhance them. b. The survey that follows is part of our quality assurance program conducted by [INSTITUTION] University. 2. Participation involves completing the survey. The survey asks about you and your most recent research experience. It will take 5-7 minutes to complete the survey. For your answers to be saved, you must click "Done" at the end of the survey. Plan to complete the survey in one sitting. 3. There are no direct benefits to you. However, the survey results may help us understand how to improve the research participation experience at this research center and others across the country. 4. We will do our best to protect your information, but there is always a small risk of loss of confidentiality. To further minimize the risks to confidentiality, we do NOT ask for any details about your prior research studies, doctors, hospitals, or any diagnoses. 5. Survey responses are analyzed as a group to identify areas of excellence and opportunities for improvement. We will NOT reveal any individual survey responses to staff or research teams nor in our publications. 6. There is no compensation for completing the survey. 7. Your participation is voluntary and you can change your mind. Your answers will not be recorded until you click "Done" at the end of the survey.

Please answer the questions below regarding the research study you enrolled in within the past year. If you enrolled in more than one study, answer for the most recent study.

When the survey questions refer to "the study," we are asking about your experiences enrolled in that clinical research study, not this online survey study.

1.2 Would you recommend joining a research study to your family and friends?

- ☐ Definitely no
☐ Probably no
☐ Probably yes
☐ Definitely yes



Research Participant Perception Survey - SP

1.3 Below is a list of possible reasons for joining a research study. When you considered joining the study, how important were these reasons for you?

	Very important	Somewhat important	Not very important	Not important at all
To find out more about my disease	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because no other medical options were available	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
To gain access to new treatment/therapy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
To obtain free healthcare	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
To help others	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because of the Research/Health Center's reputation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because I am concerned about the topic of study	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
To obtain education and learning	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because of a positive experience in another study	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because of family influence/involvement	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
To earn money/payment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because my caregiver encouraged me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other reasons	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

1.4 Did the study require that you already have a disease or condition in order to enroll?

- ☐ Yes
☐ No

1.5 Did the study involve taking a drug or a supplement, the use of a new medical device, undergoing a new medical procedure, or a change in lifestyle, behavior, or counseling?

- ☐ Yes
☐ No
☐ Not sure

1.6 How much did the study demand of you? (Pick the answer that most closely describes your experience)

- ☐ Simple (for example: a few visits or simple tests or surveys)
☐ Moderate (for example: multiple visits or a short inpatient stay; only a few procedures, not risky or intense)
☐ Intense (for example: long or multiple inpatient stays or many visits; procedure(s) that are intense, risky, or complex)



1.7 Before you joined the study, how did the study team discuss the details of the study with you?

- ☐ Mostly through the email or video or telephone conversations
- ☐ Mostly while physically in the same place with a member of the study team
- ☐ A mix of conversations taking place both physically in the same place and over telephone/video/computer)
- ☐ No discussions with the study team before joining the study
- ☐ I do not remember

1.8 Did the Informed consent form prepare you for what to expect during the study?

- ☐ No
- ☐ Yes, somewhat
- ☐ Yes, mostly
- ☐ Yes, completely

1.9 Did the information and discussions you had before participating in the research study prepare you for your experience in the study?

- ☐ No
- ☐ Yes, somewhat
- ☐ Yes, mostly
- ☐ Yes, completely

1.10 Did the research team members listen carefully to you?

- ☐ Never
- ☐ Sometimes
- ☐ Usually
- ☐ Always
- ☐ No Research Team Member Involved

1.11 Did the research team members treat you with courtesy and respect?

- ☐ Never
- ☐ Sometimes
- ☐ Usually
- ☐ Always
- ☐ No Research Team Member Involved

1.12 During your discussion about the study, did you feel pressure from the research staff to join the study?

- ☐ Never
- ☐ Sometimes
- ☐ Usually
- ☐ Always

1.13 Did the research staff do everything possible to provide assistance with any language difference you might have?

- ☐ Never
- ☐ Sometimes
- ☐ Usually
- ☐ Always
- ☐ No language difference



1.14 When you were not at the research site did you know how to reach the research team if you had a question?

- ☐ Never
- ☐ Sometimes
- ☐ Usually
- ☐ Always

1.15 When you were not at the research site and you needed to reach a member of the research team, were you able to reach him/her as soon as you wanted?

- ☐ Never
- ☐ Sometimes
- ☐ Usually
- ☐ Always
- ☐ Did not need to reach the research team

1.16 Did you feel you were a valued partner in the research process?

- ☐ Never
- ☐ Sometimes
- ☐ Usually
- ☐ Always

1.17 If you considered leaving the study, did you feel pressure from the Research Team to stay?

- ☐ Never
- ☐ Sometimes
- ☐ Usually
- ☐ Always
- ☐ Did not consider leaving the study

1.18 Did the research staff respect your cultural background (e.g. language, religion, ethnic group)?

- ☐ Never
- ☐ Sometimes
- ☐ Usually
- ☐ Always
- ☐ No cultural issues

1.19 Did you have enough physical privacy while you were in the study?

- ☐ Never
- ☐ Sometimes
- ☐ Usually
- ☐ Always



Research Participant Perception Survey - SP

1.20 Below is a list of possible reasons for leaving a research study. How important were these reasons for you in considering leaving the study?

	Very important	Somewhat important	Not very important	Not important at all
Pain or discomfort related to participation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Worried about risks of treatment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Side effects that occurred during the study	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Invasion of privacy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Too much time spent waiting around	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Time commitment required	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Family/work issues unrelated to the study	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Interactions with research team	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Not getting test results	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Undue pressure to stay in study	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Problems with study payments	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Unexpected tests and procedures that occurred during the study	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Transportation/parking	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other reasons	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
To find out more about my disease	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because no other medical options were available	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
To gain access to new treatment/therapy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
To obtain free healthcare	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
To help others	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because of the Research/Health Center's reputation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because I am concerned about the topic of study	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



Research Participant Perception Survey - SP

	Very important	Somewhat important	Not very important	Not important at all
To obtain education and learning	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because of a positive experience in another study	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because of family influence/involvement	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
To earn money/payment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because my caregiver encouraged me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because of my relationship with the research team	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Feeling valued as a research participant	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Improved health or quality of life	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other reasons	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

1.21 Which of the following things would be important for you in a future study?

- ☐ Access to computer, internet, and television
- ☐ Access to comfortable bed
- ☐ Payment/More Payment
- ☐ Support groups
- ☐ Volunteer appreciation
- ☐ Flexible Schedule
- ☐ Accessible parking and study location
- ☐ Planned discharge and proper goodbye to research team
- ☐ Summary of overall research results shared with me
- ☐ Results of personal lab tests shared with me or my doctor
- ☐ Other (please specify)

1.22 Please specify other important things:



Research Participant Perception Survey - SP

1.23 Please use the scale below to rate your overall experience in the research study, where 0 is the worst possible experience, and 10 is the best possible experience.

- ☐ 0 worst
- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ 5
- ☐ 6
- ☐ 7
- ☐ 8
- ☐ 9
- ☐ 10 best

1.24 What is the highest grade or level of school that you have completed?

- ☐ 8th grade or less
- ☐ Some high school, did not graduate
- ☐ High school graduate or GED
- ☐ Some college or 2-year degree
- ☐ 4-year college graduate
- ☐ More than 4-year college degree

1.25 What is your age?

- ☐ 18-34
- ☐ 35-44
- ☐ 45-54
- ☐ 55-64
- ☐ 65-74
- ☐ 75 and over

1.26 What is your race? (Please choose one or more)

- ☐ American Indian or Alaska Native
- ☐ Asian
- ☐ Black or African American
- ☐ Native Hawaiian or other Pacific Islander
- ☐ White

1.27 Are you of Spanish or Hispanic or Latino/a/x origin or descent?

- ☐ No - not Spanish/Hispanic/Latino/a/x
- ☐ Yes - Puerto Rican
- ☐ Yes - Mexican/Mexican American/Chicano
- ☐ Yes - Cuban
- ☐ Yes - other Spanish/Hispanic/Latino/a/x

1.28 What is your sex?

- ☐ Female
- ☐ Male
- ☐ Intersex



1.29 How would you describe your gender identity?

- ☐ Female (including transgender women)
- ☐ Male (including transgender men)
- ☐ Non-binary/gender-fluid/agender
- ☐ Prefer not to say

1.30 Is there anything else you would like to share about your experience in the study you most recently joined?

Thank you for your interest and the investment of your time. Your responses will help us to improve the research experience for participants.

Empowering the Participant Voice is supported in part by a grant from the National Center for Accelerating Translational Science U01TR003026 to The Rockefeller University, and Clinical Translational Science Awards UL1TR002553 (Duke University), UL1TR003098 (Johns Hopkins University), UL1TR002001 (University of Rochester), UL1TR001866 (Rockefeller University), UL1TR002243 (Vanderbilt), and UL1TR001420 (Wake Forest University Health Sciences).

