

Research Participant Perception Survey Sp

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.

1.2 Would you recommend joining a research study to your family and friends? 1.3 To find out more about my disease

- | | | | |
|-------------------------------------|--------------------------------------|------------------------------------------|--------------------------------------------|
| <input type="radio"/> Definitely no | <input type="radio"/> Probably no | <input type="radio"/> Very important | <input type="radio"/> Somewhat important |
| <input type="radio"/> Probably yes | <input type="radio"/> Definitely yes | <input type="radio"/> Not very important | <input type="radio"/> Not important at all |

1.4 Because no other medical options were available

- | | |
|------------------------------------------|--------------------------------------------|
| <input type="radio"/> Very important | <input type="radio"/> Somewhat important |
| <input type="radio"/> Not very important | <input type="radio"/> Not important at all |

1.5 To gain access to new treatment/therapy

- | | |
|------------------------------------------|--------------------------------------------|
| <input type="radio"/> Very important | <input type="radio"/> Somewhat important |
| <input type="radio"/> Not very important | <input type="radio"/> Not important at all |

1.6 To obtain free healthcare

- | | |
|------------------------------------------|--------------------------------------------|
| <input type="radio"/> Very important | <input type="radio"/> Somewhat important |
| <input type="radio"/> Not very important | <input type="radio"/> Not important at all |

1.7 To help others

- | | |
|------------------------------------------|--------------------------------------------|
| <input type="radio"/> Very important | <input type="radio"/> Somewhat important |
| <input type="radio"/> Not very important | <input type="radio"/> Not important at all |



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1.8 Because of the Research/Health Center's reputation

- | | |
|------------------------------------------|--------------------------------------------|
| <input type="radio"/> Very important | <input type="radio"/> Somewhat important |
| <input type="radio"/> Not very important | <input type="radio"/> Not important at all |

1.9 Because I am concerned about the topic of study

- | | |
|------------------------------------------|--------------------------------------------|
| <input type="radio"/> Very important | <input type="radio"/> Somewhat important |
| <input type="radio"/> Not very important | <input type="radio"/> Not important at all |

1.10 To obtain education and learning

- | | |
|------------------------------------------|--------------------------------------------|
| <input type="radio"/> Very important | <input type="radio"/> Somewhat important |
| <input type="radio"/> Not very important | <input type="radio"/> Not important at all |

1.11 Because of a positive experience in another study

- | | |
|------------------------------------------|--------------------------------------------|
| <input type="radio"/> Very important | <input type="radio"/> Somewhat important |
| <input type="radio"/> Not very important | <input type="radio"/> Not important at all |

1.12 Because of family influence/involvement

- | | |
|------------------------------------------|--------------------------------------------|
| <input type="radio"/> Very important | <input type="radio"/> Somewhat important |
| <input type="radio"/> Not very important | <input type="radio"/> Not important at all |

1.13 To earn money/payment

- | | |
|------------------------------------------|--------------------------------------------|
| <input type="radio"/> Very important | <input type="radio"/> Somewhat important |
| <input type="radio"/> Not very important | <input type="radio"/> Not important at all |

1.14 Because my caregiver encouraged me

- | | |
|------------------------------------------|--------------------------------------------|
| <input type="radio"/> Very important | <input type="radio"/> Somewhat important |
| <input type="radio"/> Not very important | <input type="radio"/> Not important at all |

1.15 Other reasons

- | | |
|------------------------------------------|--------------------------------------------|
| <input type="radio"/> Very important | <input type="radio"/> Somewhat important |
| <input type="radio"/> Not very important | <input type="radio"/> Not important at all |

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

- | | |
|---------------------------|--------------------------|
| <input type="radio"/> Yes | <input type="radio"/> No |
|---------------------------|--------------------------|

1.17 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?

- | | |
|--------------------------------|--------------------------|
| <input type="radio"/> Yes | <input type="radio"/> No |
| <input type="radio"/> Not sure | |

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

- | | |
|------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------|
| <input type="radio"/> Simple (for example: a few visits or simple tests or surveys) | <input type="radio"/> Moderate (for example: multiple visits or a short inpatient stay; only a few procedures, not risky or intense) |
| <input type="radio"/> Intense (for example: long or multiple inpatient stays or many visits; procedure(s) that are intense, risky, or complex) | |



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1.19 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

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

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

1.21 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

1.22 Did the research team members listen carefully to you?

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

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

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

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

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

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

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

1.26 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

1.27 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



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

- | | |
|-------------------------------|---------------------------------|
| <input type="radio"/> Never | <input type="radio"/> Sometimes |
| <input type="radio"/> Usually | <input type="radio"/> Always |

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

- | | |
|----------------------------------------------------------|---------------------------------|
| <input type="radio"/> Never | <input type="radio"/> Sometimes |
| <input type="radio"/> Usually | <input type="radio"/> Always |
| <input type="radio"/> Did not consider leaving the study | |

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

- | | |
|------------------------------------------|---------------------------------|
| <input type="radio"/> Never | <input type="radio"/> Sometimes |
| <input type="radio"/> Usually | <input type="radio"/> Always |
| <input type="radio"/> No cultural issues | |

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

- | | |
|-------------------------------|---------------------------------|
| <input type="radio"/> Never | <input type="radio"/> Sometimes |
| <input type="radio"/> Usually | <input type="radio"/> Always |

1.32 Pain or discomfort related to participation

- | | |
|------------------------------------------|--------------------------------------------|
| <input type="radio"/> Very important | <input type="radio"/> Somewhat important |
| <input type="radio"/> Not very important | <input type="radio"/> Not important at all |

1.33 Worried about risks of treatment

- | | |
|------------------------------------------|--------------------------------------------|
| <input type="radio"/> Very important | <input type="radio"/> Somewhat important |
| <input type="radio"/> Not very important | <input type="radio"/> Not important at all |

1.34 Side effects that occurred during the study

- | | |
|------------------------------------------|--------------------------------------------|
| <input type="radio"/> Very important | <input type="radio"/> Somewhat important |
| <input type="radio"/> Not very important | <input type="radio"/> Not important at all |

1.35 Invasion of privacy

- | | |
|------------------------------------------|--------------------------------------------|
| <input type="radio"/> Very important | <input type="radio"/> Somewhat important |
| <input type="radio"/> Not very important | <input type="radio"/> Not important at all |

1.36 Too much time spent waiting around

- | | |
|------------------------------------------|--------------------------------------------|
| <input type="radio"/> Very important | <input type="radio"/> Somewhat important |
| <input type="radio"/> Not very important | <input type="radio"/> Not important at all |

1.37 Time commitment required

- | | |
|------------------------------------------|--------------------------------------------|
| <input type="radio"/> Very important | <input type="radio"/> Somewhat important |
| <input type="radio"/> Not very important | <input type="radio"/> Not important at all |

1.38 Family/work issues unrelated to the study

- | | |
|------------------------------------------|--------------------------------------------|
| <input type="radio"/> Very important | <input type="radio"/> Somewhat important |
| <input type="radio"/> Not very important | <input type="radio"/> Not important at all |

1.39 Interactions with research team

- | | |
|------------------------------------------|--------------------------------------------|
| <input type="radio"/> Very important | <input type="radio"/> Somewhat important |
| <input type="radio"/> Not very important | <input type="radio"/> Not important at all |



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1.40 Not getting test results

- ☐ Very important
☐ Not very important

- ☐ Somewhat important
☐ Not important at all

1.41 Undue pressure to stay in study

- ☐ Very important
☐ Not very important

- ☐ Somewhat important
☐ Not important at all

1.42 Problems with study payments

- ☐ Very important
☐ Not very important

- ☐ Somewhat important
☐ Not important at all

1.43 Unexpected tests and procedures that occurred during the study

- ☐ Very important
☐ Not very important

- ☐ Somewhat important
☐ Not important at all

1.44 Transportation/parking

- ☐ Very important
☐ Not very important

- ☐ Somewhat important
☐ Not important at all

1.45 Other reasons

- ☐ Very important
☐ Not very important

- ☐ Somewhat important
☐ Not important at all

1.46 To find out more about my disease

- ☐ Very important
☐ Not very important

- ☐ Somewhat important
☐ Not important at all

1.47 Because no other medical options were available

- ☐ Very important
☐ Not very important

- ☐ Somewhat important
☐ Not important at all

1.48 To gain access to new treatment/therapy

- ☐ Very important
☐ Not very important

- ☐ Somewhat important
☐ Not important at all

1.49 To obtain free healthcare

- ☐ Very important
☐ Not very important

- ☐ Somewhat important
☐ Not important at all

1.50 To help others

- ☐ Very important
☐ Not very important

- ☐ Somewhat important
☐ Not important at all

1.51 Because of the Research/Health Center's reputation

- ☐ Very important
☐ Not very important

- ☐ Somewhat important
☐ Not important at all



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1.52 Because I am concerned about the topic of study

- | | |
|------------------------------------------|--------------------------------------------|
| <input type="radio"/> Very important | <input type="radio"/> Somewhat important |
| <input type="radio"/> Not very important | <input type="radio"/> Not important at all |

1.53 To obtain education and learning

- | | |
|------------------------------------------|--------------------------------------------|
| <input type="radio"/> Very important | <input type="radio"/> Somewhat important |
| <input type="radio"/> Not very important | <input type="radio"/> Not important at all |

1.54 Because of a positive experience in another study

- | | |
|------------------------------------------|--------------------------------------------|
| <input type="radio"/> Very important | <input type="radio"/> Somewhat important |
| <input type="radio"/> Not very important | <input type="radio"/> Not important at all |

1.55 Because of family influence/involvement

- | | |
|------------------------------------------|--------------------------------------------|
| <input type="radio"/> Very important | <input type="radio"/> Somewhat important |
| <input type="radio"/> Not very important | <input type="radio"/> Not important at all |

1.56 To earn money/payment

- | | |
|------------------------------------------|--------------------------------------------|
| <input type="radio"/> Very important | <input type="radio"/> Somewhat important |
| <input type="radio"/> Not very important | <input type="radio"/> Not important at all |

1.57 Because my caregiver encouraged me

- | | |
|------------------------------------------|--------------------------------------------|
| <input type="radio"/> Very important | <input type="radio"/> Somewhat important |
| <input type="radio"/> Not very important | <input type="radio"/> Not important at all |

1.58 Because of my relationship with the research team

- | | |
|------------------------------------------|--------------------------------------------|
| <input type="radio"/> Very important | <input type="radio"/> Somewhat important |
| <input type="radio"/> Not very important | <input type="radio"/> Not important at all |

1.59 Feeling valued as a research participant

- | | |
|------------------------------------------|--------------------------------------------|
| <input type="radio"/> Very important | <input type="radio"/> Somewhat important |
| <input type="radio"/> Not very important | <input type="radio"/> Not important at all |

1.60 Improved health or quality of life

- | | |
|------------------------------------------|--------------------------------------------|
| <input type="radio"/> Very important | <input type="radio"/> Somewhat important |
| <input type="radio"/> Not very important | <input type="radio"/> Not important at all |

1.61 Other reasons

- | | |
|------------------------------------------|--------------------------------------------|
| <input type="radio"/> Very important | <input type="radio"/> Somewhat important |
| <input type="radio"/> Not very important | <input type="radio"/> Not important at all |

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

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



1.63 Please specify other important things::

1.64 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.

- | | |
|-------------------------------|-------------------------|
| <input type="radio"/> 0 worst | <input type="radio"/> 1 |
| <input type="radio"/> 2 | <input type="radio"/> 3 |
| <input type="radio"/> 4 | <input type="radio"/> 5 |
| <input type="radio"/> 6 | <input type="radio"/> 7 |
| <input type="radio"/> 8 | <input type="radio"/> 9 |
| <input type="radio"/> 10 best | |

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

- | | |
|---------------------------------------------------|----------------------------------------------------------|
| <input type="radio"/> 8th grade or less | <input type="radio"/> Some high school, did not graduate |
| <input type="radio"/> High school graduate or GED | <input type="radio"/> Some college or 2-year degree |
| <input type="radio"/> 4-year college graduate | <input type="radio"/> More than 4-year college degree |

1.66 What is your age?

- | | |
|-----------------------------|-----------------------------------|
| <input type="radio"/> 18-34 | <input type="radio"/> 35-44 |
| <input type="radio"/> 45-54 | <input type="radio"/> 55-64 |
| <input type="radio"/> 65-74 | <input type="radio"/> 75 and over |

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

- | | |
|-----------------------------------------------------------|--------------------------------------------------------------------|
| <input type="checkbox"/> American Indian or Alaska Native | <input type="checkbox"/> Asian |
| <input type="checkbox"/> Black or African American | <input type="checkbox"/> Native Hawaiian or other Pacific Islander |
| <input type="checkbox"/> White | |

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

- | | |
|---------------------------------------------------------------|------------------------------------------|
| <input type="radio"/> No - not Spanish/Hispanic/Latino/a/x | <input type="radio"/> Yes - Puerto Rican |
| <input type="radio"/> Yes - Mexican/Mexican American/Chicano | <input type="radio"/> Yes - Cuban |
| <input type="radio"/> Yes - other Spanish/Hispanic/Latino/a/x | |

1.69 What is your sex?

- | | |
|--------------------------------|----------------------------|
| <input type="radio"/> Female | <input type="radio"/> Male |
| <input type="radio"/> Intersex | |

1.70 How would you describe your gender identity?

- | | |
|------------------------------------------------------------|--------------------------------------------------------|
| <input type="radio"/> Female (including transgender women) | <input type="radio"/> Male (including transgender men) |
| <input type="radio"/> Non-binary/gender-fluid/agender | <input type="radio"/> Prefer not to say |



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

DRAFT

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

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