



Languages:

- English
- Español

Welcome!

The purpose of this survey is to collect feedback about research participant experiences.

The results will help us understand how to improve the experience in the future.

This survey is being used nationwide as part of the Empowering the Participant Voice project.

The survey will take 5-7 minutes to complete.

Survey responses are analyzed as a group. We do not share any individual survey responses to staff or research teams or in any reports or publications.

Your participation is voluntary.

Have you participated in a research study in the past six months? (It does not matter whether you completed, withdrew, or are still enrolled in the study, as long as it involved more than an on-line survey)

Yes
 No

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.

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

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

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

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

- Yes
- No

Did the study involve taking a drug or a supplement or the use of a new medical device, or undergoing a new medical procedure?

- Yes
- No
- Not sure

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)

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 discussion with the study team before joining the study
- I do not remember

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

- No
- Yes - somewhat
- Yes - mostly
- Yes - completely

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

Did the research team members listen carefully to you?

- Never
- Sometimes
- Usually
- Always

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

- Never
- Sometimes
- Usually
- Always

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

- Never
- Sometimes
- Usually
- Always

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

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

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

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

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

- Never
- Sometimes
- Usually
- Always

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

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

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

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

- Never
- Sometimes
- Usually
- Always

Were you ever concerned about your safety and health during the study?
(this question was retired as of 2022.04.14)

- Never
- Sometimes
- Usually
- Always

I feel comfortable discussing any concerns about the safety of the way the study is being conducted with the research team.

- Never
- Sometimes
- Usually
- Always

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

What is your age?

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

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

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

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

What is your sex?

- Female
- Male
- Intersex

How would you describe your gender identity?

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

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

Which of the following things would be important for you in a future study? Please check all that apply.

- 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)

Please specify other important things:

Thank you for completing the survey. 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 NIH.
