Research Participant Satisfaction

Results of the August 2021 Survey
Research Participant Satisfaction Survey

In August 2021, the Institute of Clinical and Translational Research randomly selected research participants (via the Clinical Research Management Services System) to receive a survey by email.

- Surveys were sent to people who had participated in a research study (specifically a clinical trial) at Johns Hopkins Health System, signed consent for the research in the prior 2-6 months and had a valid email address on file in their electronic medical record.

- A total of 500 emails were sent and 94 people responded, resulting in a response rate of 19%.

- The initial email was delivered on August 17, 2021 and the reminder email (to those who had not responded) was delivered on August 31, 2021.

- The survey was anonymous.
Summary of Findings

Johns Hopkins is committed to systematically assessing the experience of research participants to see how we are doing and where we need to improve.

• The results of our survey in the fall of 2021 confirm that research participants are having a rewarding experience:
  - On a scale of 0-10, 80% rated the experience as a 9 or 10.
  - Over 96% reported the informed consent process and conversations with the research team fully prepared them for the study.
  - Over 98% reported they were always treated with respect by the research team.
  - Over 96% reported they would recommend to family or friends to join a study at Johns Hopkins.

• If you want to learn more about the survey results in more detail, please review the remaining presentation.
Demographics of Survey Responders

Age Category (years)

- 18-34: 10.8%
- 35-44: 14.5%
- 45-54: 7.2%
- 55-64: 26.5%
- ≥65: 41.0%
Demographics of Survey Responders

Race

Sex
Please use the scale below to rate your overall experience in the research study.
Would you recommend joining a research study to your family and friends?
Importance of Reasons for Joining Study

To find out more about my disease

Because no other medical options were available

To gain access to new treatment/therapy

To obtain free healthcare

To help others

Because of the Research/Health Center's reputation

Very Important/Somewhat important

Not very important/Not important
Importance of Reasons for Joining Study

Because I am concerned about the topic of study

To obtain education and learning

Because of a positive experience in another study

Because of family influence/involvement

To earn money/payment

Because my caregiver encouraged me

Percent %

Very Important/Somewhat important
Not very important/Not important
Preparation for Study

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

- Yes: 98.82%  
- No: 1.176%  

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

- Yes: 100.0%  
- No: 0%
Satisfaction with Research Process

Waited too long for study visit/procedures to begin

Waited too long between procedures/tests during visits

Concerned about safety and health during the study
Consideration of leaving the research study

Did you ever consider leaving the study?

- No: 92.9%
- Yes, briefly: 3.5%
- Yes, a great deal: 1.2%
- Yes, I left the study: 2.4%

If you ever considered leaving the study, did you feel pressure from the research team to stay?

- Never: 33.3%
- Sometimes: 1.2%
- Usually: 1.2%
- Always: 64.3%
- Did not consider leaving the study: 0%
Things that would be important to participants in a future study