Research Participant Satisfaction

Current Results from the January 2020 Survey
In January 2020, the Institute of Clinical and Translational Research randomly selected participants from the Clinical Research Management Services list to receive a survey by email if they were involved in a research study at Johns Hopkins within the last 6 months. Currently, 108 participants responded.
Demographics of Survey Participants

**Age**
- 18-34: 6%
- 35-44: 7%
- 45-54: 14%
- 55-64: 23%
- 65+: 50%

**Race**
- Asian: 2%
- Black or African American: 2%
- Native Hawaiian or Pacific Islander: 18%
- American Indian or Alaskan Native: 0%
- White: 78%

**Sex**
- Female: 48%
- Male: 52%
Overall Experience in Research Study
Would you recommend joining a research study to your family and friends?
Importance of Reasons for Joining Study

- **Very important/Somewhat important**
- **Not very important/Not important at all**

- To find out more about my disease
- To get access to new treatment/therapy
- To obtain free healthcare
- To help others
- Because of the research/health center's reputation
- Because I am concerned about the topic of study
- Because of a positive experience in another study
- Because of family influence/involvement
- Because my caregiver encouraged me
- Other reasons

- Very important/Somewhat important: [Graph showing percentages]
- Not very important/Not important at all: [Graph showing percentages]
Did the informed consent form prepare you for what to expect during the study?

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

- Treated me with respect
- Listened to me carefully
- Pressured me to join study
- Knew how to reach team
- Felt valued as a partner
Satisfaction with Research Process

Were you ever concerned about your safety or health during the study?

- Always
- Usually
- Sometimes
- Never

Did you ever have to wait too long between tests at your visit?

- Always
- Usually
- Sometimes
- Never

Did you ever have to wait too long for your visit to begin?

- Always
- Usually
- Sometimes
- Never
Consideration of leaving the research study

Did you ever consider leaving the study?

- No: 80%
- Yes, briefly: 10%
- Yes, a great deal: 5%
- Yes, I left the study: 5%

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

- I did not consider leaving: 50%
- Sometimes: 15%
- Usually: 20%
- Always: 10%
Reasons for leaving a research study

- Pain or discomfort related to participation
- Worried about risks of treatment
- Side effects that occurred during the study
- Too much time spent waiting around
- Too much time commitment required
- Interactions with the research team
- Not getting test results
- Undue pressure to stay in study
- Problems with study payments
- Unexpected tests and procedures
- Transportation/parking
- Other reasons

([Very important/Somewhat important] vs [Not very important/Not important at all])
Reasons for staying in a research study

![Bar chart showing reasons for staying in a research study](https://via.placeholder.com/150)

- Very important/Somewhat important
- Not very important/Not important at all

- To find out more about my disease
- No other medical options were available
- To gain access to new treatments/therapies
- To obtain free healthcare
- I am concerned about the topic of study
- A positive experience in another study
- Family influence/involvement
- To earn money/payment
- My caregiver encouraged me
- My relationship with the research team
- Feeling valued as a research participant
- Improved health or quality of life
- Other reasons
Things that would be important for participants 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
- Results of personal lab tests
- Other