Research Participant Satisfaction

Current Results from the July 2019 Survey
Research Participant Satisfaction Survey

• In July 2019, 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, 119 participants responded
Overall Experience in Research Study

0 (Worst) 1 2 3 4 5 6 7 8 9 10 (Best)
Would you recommend joining a research study to your family and friends?

- Yes: 100%
- No: 0%
Importance of Reasons for Joining Study

- To find out more about my disease: 90% very important/somewhat important, 10% not very important/not important at all
- No other medical options were available: 80% very important/somewhat important, 20% not very important/not important at all
- To gain access to new treatment/therapy: 70% very important/somewhat important, 30% not very important/not important at all
- To obtain free healthcare: 60% very important/somewhat important, 40% not very important/not important at all
- To help others: 50% very important/somewhat important, 50% not very important/not important at all
- Because of the research/health center's reputation: 40% very important/somewhat important, 60% not very important/not important at all
- Because I am concerned about the topic of study: 30% very important/somewhat important, 70% not very important/not important at all
- To obtain education and learning: 20% very important/somewhat important, 80% not very important/not important at all
- Because of a positive experience in another study: 10% very important/somewhat important, 90% not very important/not important at all
- Because of family influence/movement: 5% very important/somewhat important, 95% not very important/not important at all
- To earn money/payment: 20% very important/somewhat important, 80% not very important/not important at all
- Because my caregiver encouraged me: 40% very important/somewhat important, 60% not very important/not important at all
- Other reasons: 30% very important/somewhat important, 70% not very important/not important at all
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

Never
Sometimes
Usually
Always
Did you ever have to wait too long for your visit to begin?

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

Did you ever have to wait too long between tests at your visit?
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
- Family/work issues unrelated to the study
- Interaction with 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
Not very important/Not important at all
Reasons for staying in a research study

- To find out more about my disease
- To gain access to new treatments/they are available
- To obtain free healthcare
- To help others
- To learn about the topic of study
- To obtain education and training
- 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

0% - 100%
Very important/Somewhat important
Not very important/Not important at all
Things that would be important for participants in a future study

- Access to computer, internet, and television
- Access to comfortable bed
- Payment/More
- 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