Research Participant Satisfaction
Current Results from the July 2018 Survey
Research Participant Satisfaction Survey

• In July 2018, 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, 135 participants responded
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
Preparation for Study

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
Satisfaction with Research Process

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?

Did you ever have to wait too long for your visit to begin?
Reasons for leaving a research study

- Pain or discomfort related to participation
- Worried about risk of treatment
- Side effects that occurred during the study
- Too much time spent waiting around
- Time commitment required unrelated to the study
- Interactions 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

[Bar chart showing reasons for staying in a research study with corresponding percentages for 'Very important/Somewhat important' and 'Not very important/Not important at all'].

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

Reasons:
- To find out more about my disease
- To gain access to new treatment/therapy
- To obtain free healthcare
- To help others
- To obtain free healthcare
- To obtain education and learning
- 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