Research Participant Satisfaction Survey

• In January 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, 129 participants responded
Would you recommend joining a research study to your family and friends?

Yes: 100%
No: 0%
Importance of Possible Reasons for Joining a Research Study

- Find out more about my disease
- Gain access to new treatment
- Obtain free healthcare
- Help others
- Health Center’s reputation
- Concern about study topic
- Obtain education and learning
- Positive experience in another study
- Family influence/involvement
- Earn money/payment
- Caregiver encouraged me

- Not Important at all/Not very important
- Somewhat important/Very important
Preparation for Study

Were you told 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 Members

- Listened carefully to me
- Treated me with respect
- Pressured me to join study
- Knew how to reach team
- Felt I was a valued partner

Categorization:
- Never
- Sometimes
- Usually
- Always
Reasons for leaving a research study
Reasons for staying in a research study

- Find out more about my disease
- Gain access to new tx
- To help others
- Health Center’s Reputation
- Concern about study topic
- Obtain education and learning
- Positive experience and involvement
- Family influence and involvement
- Earn money/payment
- Caregiver encouraged me
- Relationship with research team
- Feeling valued as a participant
- Improved health or QOL

Not Important at all/Not very important
Somewhat important/Very important
Rate your overall experience in the research study (0 is the worst and 10 is the best)
What would be important for participants in a future study

- Access to computer, internet, & tv: 5%
- Access to comfortable bed: 10%
- Payment/More payment: 15%
- Support groups: 20%
- Volunteer appreciation: 25%
- Flexible schedule: 20%
- Accessible parking/location: 15%
- Planned d/c & proper goodbye to...: 10%
- Summary of overall research: 5%
- Results of personal lab tests shared: 0%
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