Research Participant Satisfaction
Results from the December 2016-January 2017 Survey
In December 2016, 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, a second set of invitations was sent January 18th.
Would you recommend joining a research study to your family and friends?
Importance of Possible Reasons for Joining a Research Study

- Find out more about my disease
- No other medical options available
- Gain access to new treatment
- Obtain free healthcare
- Help others
- 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?

- Yes: 90%
- No: 10%

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

- Yes: 100%
- No: 0%
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

Options: Never, Sometimes, Usually, Always
Reasons for leaving a research study

- Pain/discomfort related to participation
- Worried about risks of treatment
- Side effects during study
- Invasion of privacy
- Too much time
- Family/work issues unrelated to study
- Interactions with research team
- Not getting test results
- Undue pressure to stay in study
- Unexpected tests/procedures during study
- Transportation

Not Important at all/Not very important
Somewhat/very important
Reasons for staying in a research study
What 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/location
- Planned d/c & proper goodbye to team
- Summary of overall research results shared with me
- Results of personal lab tests shared with me or my doctor
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