Research Participant Satisfaction

Results from the July 2016 Survey
The Institute of Clinical and Translational Research randomly selected 500 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.

The response rate was 34%.
Survey Sample

- N=170
- 50% Female, 50% Male
- 91% White, 7% African American, 2% Asian, 1% American Indian or Alaska Native
- Education:
  - 8th grade or less: 1%
  - High school graduate or GED: 7%
  - Some college or 2 year degree: 26%
  - 4-year college graduate or more: 56%
- Age:
  - 18-34: 3%
  - 35-44: 7%
  - 45-54: 19%
  - 55-64: 23%
  - 65+: 48%
Would you recommend joining a research study to your family and friends?
Importance of Possible Reasons for Joining a Research Study
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
Reasons for leaving a research study

- Pain/discomfort from participation
- Worry about risk of tx.
- 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

[Bar chart showing reasons for leaving a research study]
Reasons for staying in a research study

- Find out more about my disease
- Gain access to new tx
- Obtain free healthcare
- To help others
- Concern about study topic
- Obtain education and learning
- Positive experience in another study
- Family influence/involvement
- Earn money/payment
- Caregiver encouraged me
- Relationship with research team
- Feeling valued as a participant
- Improved health or QOL
What would be important for participants in a future study

<table>
<thead>
<tr>
<th>% of Responses</th>
<th>Access to computer, internet, and television</th>
<th>Access to comfortable bed</th>
<th>Payment/More payment</th>
<th>Support groups</th>
<th>Volunteer appreciation</th>
<th>Flexible schedule</th>
<th>Accessible parking/location</th>
<th>Planned d/c &amp; proper goodbye to team</th>
<th>Summary of overall research results shared with me</th>
<th>Results of personal lab tests shared with me or my doctor</th>
</tr>
</thead>
<tbody>
<tr>
<td>0%</td>
<td>20%</td>
<td>10%</td>
<td>5%</td>
<td>10%</td>
<td>5%</td>
<td>40%</td>
<td>30%</td>
<td>5%</td>
<td>80%</td>
<td>60%</td>
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