Empowering the Participant Voice:
Implementing the Research Participant Perceptions Survey at Duke

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Why a Research Participant Experience Survey?
Duke University School of Medicine: Core Values

• Excellence in education, research and patient care
• Respect for and inclusion of people from all backgrounds
• Commitment to service, solving real world problems
• Sense of urgency in transforming discoveries into improved human health
• Professionalism and integrity demonstrated in all aspects of performance and effort

https://medschool.duke.edu/about-us
Patient Care

• We participate in a nationwide survey to help us ensure that patients are pleased with their treatment
  • Press Ganey HCAHPS (Hospital Consumer Assessment of Healthcare Providers and Systems) includes questions about different aspects of the patient's care experience
Example

Likelihood of Recommending Hospital

Why ask about the research participant experience?

The effectiveness of practices designed on behalf of participants should be judged, at least in part, by the experiences of the participants themselves.
The Suite of RPPS Surveys

- Validated long version [2012]; 5,000 respondents from 15 CTSAs

- Validated shorter versions [2018]
  - Research Participant Perception Survey – Short-Plus
  - Research Participant Perception Survey – Ultrashort-Plus
  - Research Participant Perception Survey – Short-Plus – Spanish
  - Research Participant Perception Survey – Ultrashort-Plus – Spanish
RPPS-Short Survey Asks About...

- **Motivations** to join, stay, or leave research
- Informed consent
- Listening, courtesy, respect
- Feeling valued
- Language, culture, privacy
- Communication with team
- **Overall research experience**
- **Willingness to recommend to friends and family**
- Demographics
RPPS Ultra-Short Survey Questions

• Would you recommend joining a research study to your family and friends?
• Please use the scale below to rate your overall experience in the research study, where 0 is the worst possible experience, and 10 is the best possible experience.
• 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?
• Did the research team members listen carefully to you?
• Did the research team members treat you with courtesy and respect?
• When you were not at the research site did you know how to reach the research team if you had a question?
• When you were not at the research site and you needed to reach a member of the research team, were you able to reach him/her as soon as you wanted?
How to use the RPPS?

Intentionally…

• Cross sectional survey
• Comparative
• Pre/Post intervention or change
Comparative Research Experience Rating for 3 Research Groups over Three Years
Comparative

"Felt like a valued partner"

Percent responses of "Always"

Sem 2 2017 | Sem 1 2018 | Sem 2 2018 | Sem 1 2019 | Sem 2 2019

Males | Females
Figure 1

RPPS: How well did the information and discussions you had prepare you for what to expect during participation?

- Pre/Post

- Percent responding "completely"

- Video

- All labs
- Lab under study

- Jan-Jun 2016
- Jul-Dec 2016
- Jan-Jun 2017
- Jul-Dec 2017
- Jan-Jun 2018
- Jul-Dec 2018
Why aren’t we using it already?

Common challenges:
• Which survey?
• Cost and logistics of sending survey
• Managing data
• Analyzing data
• Visualizing data
• Deciding what the data means and how to use it to drive change
Specific Aims of U01 grant

1. **Develop** a novel Research Participant Perception Survey/REDCap (RPPS/REDCap) collaborative infrastructure and standard implementation models

2. **Demonstrate** that the collaborative RPPS/REDCap infrastructure and implementation model is an effective approach to collect institutional benchmarks and actionable data

3. **Disseminate** the infrastructure, catalyze research-on-research, and transform evaluation by empowering the participant voice
Use Cases as the Foundation

Supported in part by NIH/NCATS Grants U01TR003206 & UL1TR001866
Use Cases as the Foundation

USE CASE #3 (Multiple Research Projects, Unit Level, Temporal Benchmarking) --- Intrainstitution Aggregation

Database Connections
METADATA Information

RPPS Project Data
RPPS Project Level METADATA

Data

Project Context
Sharing Context (what, when)

#1 Research Project Coordinator - or -
#2 Institution Project Coordinator

REDCap Plug-In Visualization Tool

#1 Research Project Coordinator - or -
#2 Institution Project Coordinator

Supported in part by NIH/NCATS Grants U01TR003206 & UL1TR001866
Data Flow

- Data collected from participants using REDCap
- Intra-Institution dashboards hosted locally
- Inter-Institution dashboard

Supported in part by NIH/NCATS Grant # U01TR003206
EPV At-a-Glance Dashboard

Demo
### At-A-Glance Dashboard - Empowering the Participant Voice

#### % Responding Very or Somewhat Important

<table>
<thead>
<tr>
<th>Reason</th>
<th>Total</th>
<th>Asian</th>
<th>African American</th>
<th>White</th>
<th>Native American</th>
<th>Black or African American</th>
<th>Hispanic or Latino</th>
<th>Other</th>
<th>Multi-racial</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain or discomfort related to participation</td>
<td>55</td>
<td>44</td>
<td>56</td>
<td>68</td>
<td>100</td>
<td>52</td>
<td>80</td>
<td>45</td>
<td></td>
</tr>
<tr>
<td>Worried about risks of treatment</td>
<td>55</td>
<td>56</td>
<td>67</td>
<td>68</td>
<td>100</td>
<td>52</td>
<td>70</td>
<td>55</td>
<td></td>
</tr>
<tr>
<td>Side effects that occurred during the study</td>
<td>54</td>
<td>56</td>
<td>67</td>
<td>63</td>
<td>100</td>
<td>52</td>
<td>70</td>
<td>64</td>
<td></td>
</tr>
<tr>
<td>Invasion of privacy</td>
<td>35</td>
<td>63</td>
<td>33</td>
<td>42</td>
<td>0</td>
<td>32</td>
<td>56</td>
<td>36</td>
<td></td>
</tr>
<tr>
<td>Too much time spent waiting around</td>
<td>35</td>
<td>56</td>
<td>33</td>
<td>37</td>
<td>0</td>
<td>34</td>
<td>56</td>
<td>36</td>
<td></td>
</tr>
<tr>
<td>Time commitment required</td>
<td>48</td>
<td>78</td>
<td>44</td>
<td>47</td>
<td>50</td>
<td>45</td>
<td>78</td>
<td>36</td>
<td></td>
</tr>
<tr>
<td>Family/work issues unrelated to the study</td>
<td>37</td>
<td>56</td>
<td>22</td>
<td>47</td>
<td>50</td>
<td>35</td>
<td>33</td>
<td>27</td>
<td></td>
</tr>
<tr>
<td>Interactions with research team</td>
<td>34</td>
<td>33</td>
<td>22</td>
<td>53</td>
<td>100</td>
<td>32</td>
<td>33</td>
<td>36</td>
<td></td>
</tr>
<tr>
<td>Not getting test results</td>
<td>33</td>
<td>67</td>
<td>33</td>
<td>53</td>
<td>100</td>
<td>29</td>
<td>33</td>
<td>45</td>
<td></td>
</tr>
<tr>
<td>Undue pressure to stay in study</td>
<td>24</td>
<td>33</td>
<td>11</td>
<td>53</td>
<td>0</td>
<td>20</td>
<td>33</td>
<td>18</td>
<td></td>
</tr>
<tr>
<td>Problems with study payments</td>
<td>30</td>
<td>44</td>
<td>33</td>
<td>58</td>
<td>0</td>
<td>26</td>
<td>50</td>
<td>45</td>
<td></td>
</tr>
<tr>
<td>Unexpected tests and procedures that occurred during the study</td>
<td>32</td>
<td>44</td>
<td>38</td>
<td>50</td>
<td>50</td>
<td>29</td>
<td>40</td>
<td>36</td>
<td></td>
</tr>
<tr>
<td>Transportation/parking</td>
<td>30</td>
<td>44</td>
<td>33</td>
<td>42</td>
<td>0</td>
<td>28</td>
<td>44</td>
<td>36</td>
<td></td>
</tr>
</tbody>
</table>
Did the information and discussions you had before participating in the research study prepare you for your experience in the study?

[Graph showing trends over time for different age groups.]
Duke Implementation of EPV/RPPS
Duke Use Cases

• Inclusive of all study types
  • Interventional
  • Observational
  • Population health based
  • University based

Row level metadata

• Study type
  • Observational/interventional
  • Organization Unit: Onc/Non-Onc
  • Management Group: Primary (CRU), Secondary (Tier, other)

• Randomization
• Summary accrual
Framework for Survey Delivery

- CURRENT: Email, MyChart (studies using OnCore accrual)
- FUTURE: Postal mail – to be as inclusive as possible
- FUTURE: Twilio (texting)

OASIS and OnCore Teams working together:

- Pull necessary data to allow survey distribution to participants in pilot studies
- Test data integrity and workflow
- Ensure no participants surveyed more than once/year
Implementation Efforts

• April 2020: Initial Project IRB approval (exempt)
• September 2021: Implementation IRB approval as QI Project
• Quarterly Stakeholder meetings
• Centralization of survey distribution in RIC/DOCR
• Identify Current RPPS Users (pre-pilot):
  • Psychology and Behavioral Health PIs (2) (tobacco use studies)
  • School of Nursing PI (1) working with LatinX community
• Data extract integrity & workflow test: late August
• Full thread test: late September
• Identify pilot studies
• Test survey with/without motivation questions in one study population
Next Steps

• Full thread test in late September
• Randomize 60-100 PERT study participants to receive survey with/without motivation questions – is there a differential response and/or completion rate?
• Identify volunteer pilot studies willing to allow US to survey their participants.
• Interested? https://duke.qualtrics.com/jfe/form/SV_0jjH5R7quNhPQTc
Thank You!

Would you like to learn more?
Visit: https://www.rockefeller.edu/research/epv/

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