Empowering the Participant Voice (EPV): Participant Feedback to Improve the Clinical Research Enterprise

Joseph Andrews PhD1, Ranee Chatterjee MD2, MPH, Alex Cheng PhD3, Ann Dozier PhD4, Daniel Ford MD MPH5, Paul A. Harris PhD3, Rhonda G. Kost MD6
1Wake Forest School of Medicine, 2Duke University, 3Vanderbilt University, University of Rochester, Johns Hopkins University, 5The Rockefeller University

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Introduction

WHY?
- A critical piece of translation that often remains unexamined is the actual research participation experience. How do participants characterize that experience? Do they feel adequately prepared? Do they feel pressured? Do they feel respected? Do they feel like partners? What went well? What could have been done better?

- Enabling participants from diverse populations to speak directly to the Clinical Research Enterprise about their experiences helps build trust.

- The resulting data provide an evidence-base for hypothesis-generation and testing to drive the development of research processes that are more participant-centered and more effective.

HOW?
- A validated tool for participant feedback: Research Participant Perception Survey (RPPS) is participant-centered, free, validated in thousands of participants, and takes 2-3 minutes to complete.

- Common institutional challenges to fielding RPPS include missing infrastructure, standards, guidance, expertise and benchmarks to facilitate success.

The Innovation:
- Empowering the Participant Voice (EPV) is a six-CTSA collaboration to DEVELOP RPPS/REDCap infrastructure and tools that streamline RPPS fielding and enable local and national benchmarking.

- DEMONSTRATE ease of use and impact through Use Cases, and DISSEMINATE to the Consortium & REDCap community.

Here we report the successful development of the EPV RPPS/REDCap infrastructure, and early results from Use Cases at the collaborating sites.

Table 1 Use Cases at Collaborating Sites: Early Implementation

<table>
<thead>
<tr>
<th>Site</th>
<th>Sampling method</th>
<th>Sample size</th>
<th>Special features</th>
<th>RPPS features</th>
<th>Find data to improve participant experience</th>
</tr>
</thead>
<tbody>
<tr>
<td>Study level</td>
<td>Institution level</td>
<td>Enterprise Survey Projects</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>1</td>
<td>Random, multiple clients</td>
<td>20%</td>
<td>Adherence evaluation questions on adherence satisfaction</td>
<td>23%</td>
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<tr>
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<td>Adherence evaluation questions on adherence satisfaction</td>
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<tr>
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<td>Adherence evaluation questions on adherence satisfaction</td>
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<tr>
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<td>Adherence evaluation questions on adherence satisfaction</td>
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<tr>
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<td>Random, multiple clients</td>
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<tr>
<td>6</td>
<td>Random, multiple clients</td>
<td>20%</td>
<td>Adherence evaluation questions on adherence satisfaction</td>
<td>23%</td>
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</tr>
</tbody>
</table>

Results

Figure 1. Study level + Institution level (Enterprise) Survey Projects

Figure 2. Flow of information for Aggregation (for national benchmarking)

Figure 3. At-a-Glance Dashboard - Visual Analytics External Module for Total and Filtered analysis of Survey Outcomes

Conclusion - Closing a translational gap: Direct feedback from representative populations about their experiences in research is essential to understand and improve barriers to broad participation in research. We created streamlined RPPS/REDCap infrastructure that provides a platform for collecting participant feedback at scale, local evaluation, and national benchmarking.