What if you knew what participants were thinking?

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Collaborative Infrastructure and Validated Tools for Collecting Participant Feedback to Improve the Clinical Research Enterprise
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Overview

1. What is the Research Participant Perception Survey (RPPS)?
2. What is the Empowering Participant Voice project about?
3. Plans, Progress, What’s Next...
4. How will the tools be shared beyond the EPV collaborators?
5. How might the EPV tools to test an innovation in a TIN trial?
What is the Research Participant Perception Survey (RPPS)?
Research Participant Perception Survey – Validated Measures of the Research Participant Experience

Part I

Focus Groups
• Participants & stakeholders (n=129) identify themes of positive and negative research experiences

Survey Draft
• “Actionable” question design
• Face/Content Validation – by participants and other stakeholders

Fielding
• Broad Sampling – representative of research population*

Analysis
• Psychometric Analyses
• Instrument Reliability, validation
• Local & Aggregate Outcomes

Plan, Execute, Remeasure, Review
• Benchmarking, improvement cycles

Part II

Part III

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RPPS survey asks about...

- Motivations to join, stay, leave research
- Informed consent
- Listening/courtesy/respect
- Feeling valued
- Language/culture/privacy
- Communication with team
- Rate the Overall research experience
- Would you recommend to friends and family
- Demographics

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Motivation to join
1. Would you recommend joining a research study to your family and friends?
2. Did the study require that you already have a disease or condition in order to enroll?
3. Did the study involve taking a drug or a supplement or the use of a new medical device, or undergoing a new medical procedure?
4. Did the Informed consent form prepare you for what to expect during the study?
5. Did the information and discussions you had before participating in the research study prepare you for your experience in the study?
6. Did the research team members listen carefully to you?
7. Did the research team members treat you with courtesy and respect?
8. During your discussion about the study, did you feel pressure from the research staff to join?
9. When you were not at the research site did you know how to reach the research team if you needed to?
10. 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?
11. Did you feel you were a valued partner in the research process?
12. If you considered leaving the study, did you feel pressure from the Research Team to stay?
13. Did the research staff respect your cultural background (e.g. language, religion, ethnic group)?
14. Did the research staff do everything possible to provide assistance with any language difference you might have?
15. Did you have enough physical privacy while you were in the study?

Motivation to leave
16. 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. Scale from (Worst)0.......9,10 (Best)
17. How much did the study demand of you? (Pick the answer that most closely describes your experience)
18. Demographic questions
19. Is there anything else you would like to share about your experience in the study you most recently joined?

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RPPS Surveys

RPPS – Long survey, aggregate scores, from 15 CTSA centers (~5000 responses)

• 73% gave their overall experience the Top (9 or 10) rating (61-82% across sites)
• 66% Would Recommend research participation to friends and family completely (46-87% across sites)
• Overall rating correlated with feeling valued, respected, listened to (completely); understanding consent (completely), and being able to reach the research team (always) when needed.
• Participants who answered that they trusted the research team completely were the participants who felt they were always treated with courtesy and respect (99%) and always listened to (93%) (p<0.001)

Motivation insights:
• Participants stayed in research when they felt valued and perceive benefit.
• 85% said they would have liked to receive results of the study
• 72% said receiving results would be a factor in deciding about future participation

RPPS – Short and Ultrashort surveys

• Capture all the important drivers of overall research rating in a handful of questions (+ demographics)
• Increase response rates to 60-75%

Link to RPPS surveys and related publications
Evaluation - Causal Pathway

INPUTS → ACTIVITIES → OUTPUTS → EFFECTS → IMPACT

Facilitate Translational Science to Improve Human Health

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Evaluation - Causal Pathway

**Inputs**
- RPPS Surveys
- Recruitment expertise
- Community engagement expertise
- Cultural competence
- Studios
- CABs
- Patient panels
- Research team expertise

**Activities**
- Assess participant experiences during research
- Patient engagement
- Community engagement
- CEnR
- Recruitment outreach
- Aligning incentives
- Participant experience data
- Data-driven Patient-centered design
- Pragmatic /adaptive design
- Responsive design

**Outputs**
Better participant experiences
More...:
- Trust
- Sense of partnership
- Patient & Community-centeredness
- Communication
- Respect
- Felt listened to

**Effects**
Faster study completion
Results applicable to affected populations
Best practices

**Impact**
Facilitate Translational Science to Improve Human Health

**Functionalized Knowledge**
Improve Human Health
Reduce Health Disparity
How to use the RPPS?

- Complementary to face-to-face initiatives
- Informed by stakeholder input before and after implementation
- Intentionally...
  - Take a pulse
  - Comparative
  - Pre/Post

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Cross Sectional - “Take a pulse”

Satisfaction with Research Team

https://ictr.johnshopkins.edu/programs_resources/research-participant-satisfaction-survey-results/
Comparative

Research Experience Rating for 3 Research Groups over Three Years

Percent Responses of 9 or 10 (Best)

- Lab A
- Lab B
- Lab C

2017 2018 2019
"Felt like a valued partner"

Comparative

Percent responses of "Always"

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

Males  |  Females

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Pre/Post

Figure 1

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

Percent responding "completely"

Study, plan, execute, remeasure

All labs

Lab under study

Jan-Jun 2016  Jul-Dec 2016  Jan-Jun 2017
Pre/Post

Figure 1

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

Percent responding "completely"

- Orange line: All labs
- Blue line: Lab under study

Video

If you could deploy the RPPS survey right now:

What would you want to learn from the survey?
Which participants would you send it to?
With whom would you share results?
Why isn’t the RPPS used more broadly

Common challenges.....

• Cost and logistics of sending surveys
• Managing data
• Analyzing data
• Visualizing data
• What does it mean?
What is the *Empowering Participant Voice* project about?
Specific Aims:

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

www.Rockefeller.edu/research/epv

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## Study Timeline

<table>
<thead>
<tr>
<th>Milestones</th>
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<th>Year 3</th>
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- **Program Development:**
- **Milestones Aim 1:**
- **Milestones Aim 2:**
- **Milestones Aim 3:**

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Engaging stakeholders

• Institutional Leadership
• IRB/Privacy Officer
• Investigators
• Clinical Research Managers
• Research Coordinators/Research Nurses
• Community members/liaisons
• Patient/Participants
• Sponsor/NIH
• Other Consortium hubs

• Understand expectations, concerns
• Refine the value proposition
• Define the questions
• Input on implementation
• Reach hard-to-reach populations
• Plan how to share & analyze results, design interventions, measure impact, returning results to the community
• Foster trust, participation, impact
Standards, Data, Metadata

**Survey Response Data**
- Participant-provided, de-identified, RPPS-Short response data
- Demographics

**Project Level Metadata** - Survey project characteristics
- Timing (end of study, post-consent, other)
- Sampling approach (census, random, targeted, bias)

**Study Level Metadata** - Study characteristics
- Interventional /observational
- Domain (disease, trial design)- MeSH*
- Compensation yes/no
- Investigator, Coordinator
- Department, Unit

**Evaluation Metadata**
- Measures of ease of implementation and impact
Data flow model: Use Cases 1 & 2

# USE CASE #1 (Project Collection) + USE CASE #2 (Institutional Benchmarking) --- Single Capture

1. Create a REDCap Project
2. Set up Data Instrument(s) Using Project Creation Tools
3. Data Collection
4. REDCap Library (RPPS Templates)
5. RPPS Project Data
6. REDCap Plug-In Visualization Tool
7. #1 Research Project Coordinator - or - #2 Institution Project Coordinator
8. Study characteristics from CTMS
9. Field through email/REDCap survey fxn
10. CTMS/EMR/Other
11. Participant information

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Data Flow Model: Use Cases 3 & 4

USE CASE #3 (Multiple Research Projects, Unit Level, Temporal Benchmarking) --- Intrainstitution Aggregation
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- **Program Development**: Milestones Aim 1;
- **Milestones Aim 1**: Milestones Aim 2;
- **Milestones Aim 2**: Milestones Aim 3

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EPV At-a-Glance Dashboard
<table>
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<th>Question</th>
<th>TOTAL</th>
<th>Asian</th>
<th>African American</th>
<th>Native American or other Native</th>
<th>Black or African American</th>
<th>White</th>
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<tr>
<td>Would you recommend joining a research study to your family and friends?</td>
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<td>56</td>
<td>56</td>
<td>62</td>
<td>50</td>
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<td>Did the informed consent form prepare you for what to expect during the study?</td>
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<td>67</td>
<td>44</td>
<td>57</td>
<td>50</td>
<td>72</td>
<td>52</td>
<td>64</td>
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<tr>
<td>Did the information and discussions you had before participating in the research study prepare you for your experience in the study?</td>
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<td>56</td>
<td>56</td>
<td>52</td>
<td>50</td>
<td>60</td>
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<tr>
<td>Did the research team members listen carefully to you?</td>
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<td>88</td>
<td>78</td>
<td>76</td>
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<td>83</td>
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<td>Did the research team members treat you with courtesy and respect?</td>
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<td>88</td>
<td>78</td>
<td>76</td>
<td>100</td>
<td>83</td>
<td>54</td>
<td>73</td>
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<td>During your discussion about the study, did you feel pressure from the research staff to join the study?</td>
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<td>100</td>
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<td>Did the research staff do everything possible to provide assistance with any language difference you might have?</td>
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<td>When you were not at the research site did you know how to reach the research team if you had a question?</td>
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<td>44</td>
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<td>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?</td>
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<td>Did you feel you were a valued partner in the research process?</td>
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<tr>
<td>If you considered leaving the study, did you feel pressure from the Research Team to stay?</td>
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<td>92</td>
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<td>79</td>
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<td>Did the research staff respect your cultural background e.g. language, religion, ethnic group?</td>
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<td>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.</td>
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<td>27</td>
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Plans, Progress, What’s next

- Alignment with institutional priorities and initiatives
- Priorities in Implementation
- Approach to analysis and using the results
1. **RPPS Integration into Institutional Goals**
   - Demonstrating our commitment to participant-centeredness in research;
   - As a mechanism for action to ensure alignment with participant expectations; and
   - Longitudinal measurement of success and evolving needs

2. **Priorities**
   1. Central Approach – reach as many research participants as possible
   2. Use tiered contact methods (EMR Portal; Text Messaging; Mail)

3. **Acting on RPPS findings**
   - Drill down to identify opportunities
   - Stakeholder committee; Research Community; and Leadership – meaningful solutions and reporting back

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• How will RPPS be integrated into your Institutional initiative as a tool to measure progress toward institutional goals?

  o Research Without Walls (Moving research out into the community)
    o RPPS - major evaluation component – assess/improve overall research infrastructure and the clinical research experience with greater use of new technologies and more remote operations

  o Increasing recruitment and retention into clinical research
    o Provide valuable data for Recruitment Innovation Unit and Office of Clinical Research
    o Strengthen engagement key stakeholders (especially community) to advise on paths forward to improve our processes
• **Top priorities in Site Implementation**
  o Build into existing organizational structure (sustainability beyond funding period)
  o Increase survey response rates by research subjects (testing different strategies, i.e. Incentives)

• **Approach to acting on RPPR findings**
  o Systematically obtain feedback from our stakeholder groups on interpretation of findings and recommendations for modifications to survey methods
  o Conduct focus groups to brainstorm solutions/recommendations for changes to research processes
Johns Hopkins has been conducting the Research Participant survey for almost 4 years on an institutional level. We randomly select a group of 500 participants who have signed consent to participate in a clinical trial in the last 6 months and send the survey by email.

Initially, we will continue to follow this plan to implement the EPV at JH so we may draw comparisons of the EPV implementation vs the local RPPS implementation.

**Top 1-3 priorities in site Implementation at JH**

- As little disruption to current surveying as possible
- Assure continued anonymity of participant responses
- Continued communication of findings to all partners
JH will continue current approach to communicate findings with institutional officials, local site personnel and community partners via web posting of results, direct communication with institutional officers and HRRP leaders and dissemination via internal training and meeting opportunities. We also want to focus on racial ethnic disparities in results.

For example: From participant feedback in the past (from open response section) we have contracted with Greenphire to improve participant payments.
Integration at our institution

• Multiple CRUs, some large, some small – lots of QI initiatives ongoing; need to socialize to raise interest and ensure buy-in

• Use-case #s 1 and 2: ID individual study teams willing to volunteer for the pilot as we continue to socialize the program across both the research enterprise and leadership.

• Demonstrate the benefit and value of surveying on a study-by-study basis and sharing the data on an institutional dashboard
  • Consider Use-Case #3 and central deployment of the survey across multiple studies
Priorities in Implementation

- Ensure diversity of research teams and types using program
  - Non-traditional, community-based, one-touch studies
  - RCTs, Observational, University-based (non-clinical)
- Reach traditionally hard to engage populations with multiple survey delivery methods
- Continually engage with our stakeholders to ensure we are using appropriate and effective methods & socializing across the enterprise

Approach to acting on RPPS findings

- Identify 5-7 study teams willing to volunteer for pilot
- Years 3-4: Analyze collected data, define metrics for CRU scorecards, generate hypotheses and interventions to improve scores and/or processes
- Year 4: add metrics to monthly CRU scorecards

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The Rockefeller University
Center for Clinical and Translational Science

Integration at our Institution
• Rockefeller has been fielding the RPPS for more than 10 years
• Aligns with aim to use participant experience data to inform initiatives

Priorities in Implementation
• To reach every participant
• Improve response rates
• Work with stakeholders to integrate CE and RPPS efforts

Approach to Acting on RPPS Findings
• To identify opportunities and develop action plans with stakeholders
• To generate hypotheses and test the impact of specific innovations

Supported in part by NIH/NCATS grant U01TR003206
• How will the tools be disseminated beyond the EPV collaborators?
Project Website www.Rockefeller.edu/research/epv/
- Links to the RPPS surveys in the REDCap Library for download
- Links to publications about RPPS
- In the future, links to External Modules for download
- Articles about how the tools are being used by Collaborating sites
- **SIGN UP** to receive periodic EPV project updates

Future: Aim 3 – Broad sharing, Learning Collaborative, Benchmarking
How might we insert EPV/REDCap tools into a TIN Trial to test an innovation?

• To evaluate the impact of initiatives on participants’ experiences
• To Compare approaches
• To Compare impact of an innovation across populations, sites, studies
• Compare +/- or pre/post innovation in the same study/population
Q & A
research
good
results
questions
enjoyed
think
time
positive
blood
done
follow
go
people
possible
nice
good
first
member
staff
way
like
part
staff
people
continue
come
long
make
still
help
complete
major
contact
back
information
coordinator