

Research Participant Perception Survey (RPPS)

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Learning Objectives

- Describe the importance of surveying research subjects about study experience
- Identify facilitators and barriers to surveying research subjects at an enterprise-wide level
- Provide feedback on the current CTSI plan for implementing the Research Participant Perception Survey

Current mechanisms to assess participant rights and safety

- High quality research relies on enrolling and retaining participants
- Regulations and ethics protect participant rights and safety
- Current mechanisms to assess if researchers achieve this are
 - Appropriate consent processes were documented
 - Informed consent forms signed
 - Regulatory guidelines followed
 - AAHRP requires processes for responding to participants' concerns

Goals of direct assessment of participant perceptions of research

- Provide robust, actionable information about processes
- Improve understanding of participant experience
 - Autonomy
 - Safety
 - Satisfaction
- Can help with
 - Enhancement of human subject protection
 - Recruitment and retention
 - Quality of research processes
 - Increase public trust in research

First step in development of RPPS

- CTSA program effort led by Rhonda Kost, PhD at Rockefeller and included NIH Clinical Center and NRC Picker, Inc.
- 22 focus groups each focused on different topic
 - 12 research participant focus groups
 - Study coordinators selected good candidates
 - Role of incentives, informed consent, reasons people drop out
 - 11 Research professional focus groups
 - IRB members, research nurses and coordinators, investigators
 - Perceived participant concerns, retention, barriers for participants

Themes used to develop survey

- Themes were identified from all focus groups
- Examples
 - Reasons identified by subjects for participating in research
 - Research professional's view of informed consent process important to subjects
 - Factors associated with positive or negative participant experience

Validation of survey

- Draft survey sent to 67 people at 34 academic research institutions for feedback
- Conducted semi-structured interview with 19 research participants
- Original survey 76 questions, 115 responses
 - Designed like HCAHPS
 - Readability assessed using Flesch-Kincaid
 - grade 6-8
- 15 research centers fielded and validated final survey
- NRC Picker collected and analyzed data

Testing of first version of survey

- Mailed to 18,890 adult participants
- Participants chosen by each institution
- Response rate 29%
- Demographics
 - 85% white
 - 12 % Black or African American
 - 5% Hispanic
 - 32% older adults >65
 - Education level, characteristics of study

Results (con't)

- Questions had strong internal consistency
- Similar question sensitivity for different subpopulations
- All but 4 questions correlated with the overall satisfaction score question
- Variation across institutions
- Changes to the survey included
 - revision of 3 of the questions that started “after the study was over,” by adding response options indicating ongoing enrolment
 - deletion of 2 of the “after the study was over” questions that were unfocused
 - Deletion of 3 questions that performed poorly in more than one of the analyses conducted

76 questions? Yikes!

- Used 6 key questions that predicated overall rating score
- Developed short (25 questions), ultrashort surveys (13 questions)
- Given to 2,228 participants
- Shorter the survey higher the response rate
- All were reliable
- Shortest survey had highest re-test reliability
- Compensation increased short complete rate from 54% to 71%

New Multi-institutional Collaborative Grant (NIH/NCATS funded)

- 4 year grant- June 2020 to May 2024
- Rockefeller, Rochester, Vanderbilt, Duke, Wake Forest and Johns Hopkins
- Develop a novel RPPS/REDCap collaborative infrastructure (dashboard) and instructions on how to implement the infrastructure
- Demonstrate that the collaborative RPPS/REDCap infrastructure and implementation is an effective approach to collect institutional benchmarks and actionable data
- Disseminate how to implement REDCap dashboard at other institutions

Survey Features- Short Version

- Anonymous, send by email (10% response rate) or mail (22% response rate)
- 5-10 minutes
- Given to research subjects enrolled in a study
 - Early on or at completion of participation
- Collects information about
 - Experience
 - Motivations for participation
 - Satisfaction with the research experience
 - General subject demographics
- Rochester involved in survey's development
- Can be administered by the research team or centrally
- What is missing: how best to structure and disseminate data, inter/intra institutional benchmarking

UR CTSI Plan for Implementation

- Collect 500 survey responses per year
 - Send survey to a random selection of 2000 subjects each year
- Sent centrally by the CTSI – Office of Clinical Research
- De-identified data shared with Vanderbilt for inclusion in interactive dashboard
- Use dashboard to compare results across institutions and within an institution

How can SCORE help?

Study coordinators are important stakeholders to the research enterprise

- What would coordinators want to learn from this survey?
- What is your perspective on how the data should or could be used?
- How should we disseminate the results to study teams?
- Do you have ideas for increasing response rates?

Collaboration Survey

- Purpose: to get feedback about how I am doing with collaborating/communicating you on this project
- It will be emailed to all attendees after this meeting

References

1. Kost RG, Lee LM, Yessis J, Collier BS, Henderson DK, Research Participant Perception Survey Focus Group S. Assessing research participants' perceptions of their clinical research experiences. *Clinical and translational science* 2011;4:403-413.
2. Yessis JL, Kost RG, Lee LM, Collier BS, Henderson DK. Development of a research participants' perception survey to improve clinical research. *Clinical and translational science* 2012;5:452-460.
3. 1. Kelly-Pumarol IJ, Henderson PQ, Rushing JT, Andrews JE, Kost RG, Wagenknecht LE. Delivery of the research participant perception survey through the patient portal. *J Clin Transl Sci* 2018;2:163-168.