

# 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
  -

# 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

# 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-

# 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!



# 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.