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
