

A 2024 “HRPP Innovations” Webinar:

**We Asked Participants
About Their Experience...
What Did They Say?
What Should We Do?**

July 9, 2024; 1:00 pm – 2:30 pm ET



Format for 2024



Attendee Hub

Livestreamed Content
Live Q&A
Chat/Discussions



Webinar Sessions

Three Webinars: March,
July, November
One Attendee Hub
Please Complete the
Survey Afterward!



Community

Continue Discussions
after Webinars Conclude
Check Upcoming
AAHRPP Events
Resources from Speakers



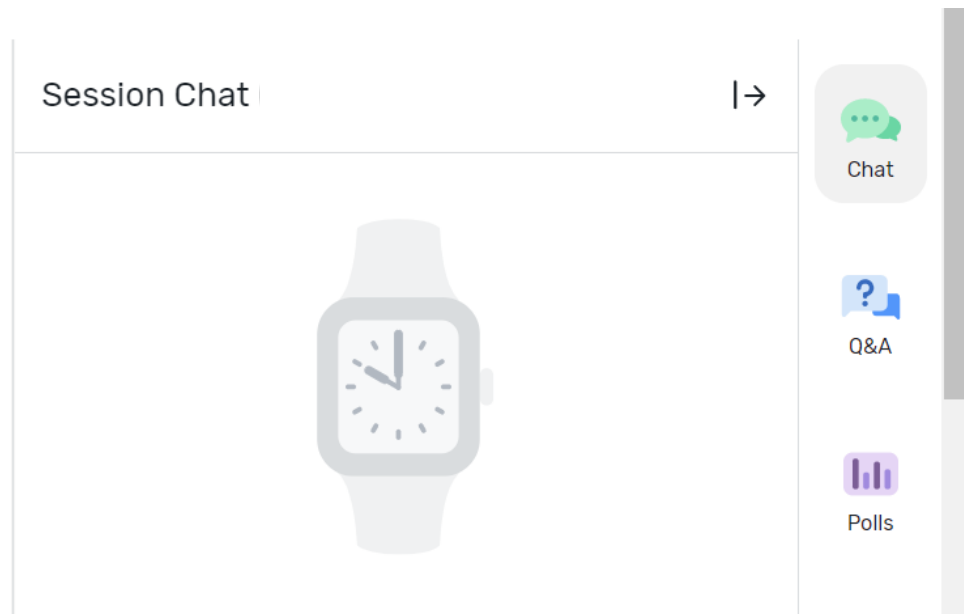
On-Demand Content

Webinar Recordings on
Hub
Available for the
Whole Year



Chat Feature

To chat with your colleagues before and after the session, or if you have technical questions, use the “Chat” icon



Questions

To ask questions about the topic for the presenters,
please use the “Q&A” icon:

Live Q&A

Q&A hasn't started yet

Ask a question

Pending Approved Answered Declined

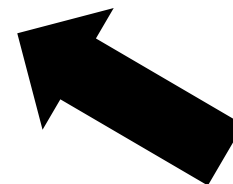
No one has asked any questions yet
Get things started by asking a few questions of your own!

Chat

Q&A

Polls

Survey



Upcoming Webinars



Save these dates for the remaining
2024 "Ask AAHRPP" webinars:

- August 13, 2024
- October 8, 2024
- December 10, 2024



**HRPP
Innovations**
Webinar Series



Save these dates for the remaining
2024 "HRPP Innovations" webinar:

- November 12, 2024

Visit [Webinars \(aahrpp.org\)](https://aahrpp.org) for more information and registration links



2025 AAHRPP Annual Conference

Visit AAHRPP's [Annual Conference](#) page
for more information

 **AAHRPP**[®]


**SAVE THE
DATE!**

2025 AAHRPP ANNUAL CONFERENCE:
***HRPP Dedication, Dialogue and
Discovery in Denver***

MAY 20-22, 2025 |  **GRAND HYATT DENVER**
1750 WELTON STREET
DENVER, CO 80202

Presenter Introductions





Nichelle Cobb
AAHRPP





Sana Khoury-Shakour
University of California, Santa Cruz





Rhonda Kost
The Rockefeller University





Joseph Andrews
Wake Forest University School of Medicine



We asked research participants about their experiences... What did they say? What should we do?

Sana Khoury-Shakour PhD/Director, Office of Research Compliance
Administration, Office of Research, University of California, Santa Cruz

Rhonda G. Kost MD/Clinical Research Officer/Center for Clinical Translational
Research, The Rockefeller University

Joseph Andrews PhD/Associate Vice President & Assistant Dean, Regulatory
Affairs and Research Integrity at Wake Forest School of Medicine



Support

Empowering the Participant Voice: Collaborative Infrastructure and Validated Tools for Collecting Participant Feedback to Improve the Clinical Research Enterprise is supported in part by a

- Collaborative Innovation Award from the National Center for Accelerating Translational Science U01TR003206 to the Rockefeller University, and:
- Clinical Translational Science Awards:
 - UL1TR001866 (Rockefeller University),
 - UL1TR002553 (Duke University),
 - UL1TR003098 (Johns Hopkins University),
 - UL1TR002001 (University of Rochester),
 - UL1TR002243 (Vanderbilt University),
 - UL1TR001420 (Wake Forest Health Sciences University).

EVP adoption is supported in part by

- UM1TR004404 (Michigan University)
- UL1TR001873 (Columbia University).

Dr. Kost, Dr. Andrews, and Dr. Khoury-Shakour have no conflicts to disclose.

Research Participant Feedback is Important for IRBs/HRPPs

Understanding research participant experience is an integral part of conducting and reviewing high-quality human subjects research and aligns with the common principles, guidance, and standards for HRPPs.

Research Participant Feedback is Important for IRBs/HRPPs

Belmont Report

Respect for persons:

- Upholds participants autonomy and rights to be heard
- Ensures that informed consent is clear and comprehensive

Beneficence:

- Identifies discomfort experienced by participants and work to minimize it in future studies
- Enhances benefits through participant-driven insights

Justice:

- Ensure that benefits and burdens of research are distributed fairly through diverse feedback
- Promotes equitable selection and inclusive practices

Research Participant Feedback is Important for IRBs/HRPPs AAHRPP Perspective

Institution (Domain I)

- Ensures that the HRPP is responsive to participant needs
- Drives improvements based on participant experience
 - Enhance education/training efforts tailored to specific needs
- Demonstrates leadership commitment
- Guides resource allocation
- Fosters public trust

Research Participant Feedback is Important for IRBs/HRPPs AAHRPP Perspective

IRB (Domain II)

- Inform IRB members about the real-world implications of research studies, leading to more a more informed and balanced decision-making
- Adjust IRB guidelines and procedures to ensure that they are more attuned to participant experiences and concerns
- Refine Informed Consent documents to improve informed consent decision making

Research Participant Feedback is Important for IRBs/HRPPs AAHRPP Perspective

Researchers and Research Staff (Domain III)

- Provide practical insights into the feasibility and acceptability of study procedures, leading to better-designed and more participant friendly research protocols
- Refine the informed consent process
- Improve retention
- Enhance recruitment practices

Reactive vs. Proactive Approach

Responding to complaints
and addressing issues only
after they have negatively
impacted participants and
have been brought to
researcher and HRPP
attention



Gathering participant
perceptions and anticipating
potential issues through
broad insights before they
become problems

Research Participant Feedback is Important for IRBs/HRPPs

- Protection of research participants is a primary function of HRPP/IRBs, making it essential to have an insight into their experience and satisfaction
- Generally, research participant perception is an area that has not received adequate attention as an HRPP quality measure
- Information about research participant perceptions gathered systematically can be a marker to help us identify areas that need to be addressed

Why develop measures of the participant experience?

- Volunteers are central to clinical research.
- *Experiences matter.*
- Informed consent is a core value of ethical research.
- Respect, autonomy, feeling valued, barriers/facilitators.
- Small group engagement is valuable, specific, and limited.
- Validated measures are needed for scale and generalizability and to evaluate experiences within and across groups and over time.
- Measures enable data-driven decision-making, segmentation, benchmarking, and assessment of impact.

Research Participant Perception Survey (RPPS)



Engaged
Stakeholders,
Developed &
Validated
RPPS-Long.
One-time
national
benchmarks
2006-2011

Original Research Participant Survey Team

The Clinical Center at NIH

David Henderson
Laure Lee
Robert Wesley

The Rockefeller University *

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Barry Collier

NRC Picker, Inc

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Baystate Medical Center (Tufts)*

Hal Jensen
Marybeth Kennedy

Vanderbilt University *

Paul Harris
Kirstin Scott
Jan Zolkower

*CTSA institution

Part I - Focus Groups

Stakeholders engaged in developing the RPPS

Focus Groups, n=129



Participants

45% male
50 yrs old (19-86)

58% white
28% African American
2% Asian
2% Native American
9% Not reported

13% ≤ high school
28% some college
31% college graduate
26% graduate education

1-20 protocols
experience

- Participant-centered
- Top Box scores
- Validated in 5,000 research participants
- 17-institutions involved over the course of RPPS development

Kost, et. al., *Clin Transl Sci* 2011 4,403-413

Research Participant Perception Survey – Early work

Assessing Research Participants' Perceptions of their Clinical Research Experiences

Clin Transl Sci 2011

Rhonda G. Kost, M.D.¹, Laura M. Lee, R.N., B.S.N.³, Jennifer Yessis, Ph.D.², Barry S. Collier, M.D.¹, and David K. Henderson, M.D.³, and The Research Participant Perception Survey Focus Group Subcommittee⁴

Development of a Research Participants' Perception Survey to Improve Clinical Research

Clin Transl Sci 2012

Jennifer L. Yessis, Ph.D.¹, Rhonda G. Kost, M.D.², Laura M. Lee, B.S.N.³, Barry S. Collier, M.D.², and David K. Henderson, M.D.³

Assessing Participant-Centered Outcomes to Improve Clinical Research

NEJM 2013

Rhonda G. Kost, M.D., Laura M. Lee, M.S., R.N., Jennifer Yessis, Ph.D., Robert A. Wesley, Ph.D., David K. Henderson, M.D., and Barry S. Collier, M.D.

Research Participant-Centered Outcomes at NIH-Supported Clinical Research Centers

Clin Transl Sci 2014

Rhonda G. Kost, M.D.¹, Laura N. Lee, B.S.N., M.S.², Jennifer L. Yessis, Ph.D.³, Robert Wesley, Ph.D.², Sandra Alfano, Pharm.D.⁴, Steven R. Alexander, M.D.⁵, Sylvia Baedorf Kassis, M.P.H.⁶, Philip Cola, M.A.⁷, Ann Dozier, R.N., Ph.D.⁸, Dan E. Ford, M.D., M.P.H.⁹, Paul A. Harris, Ph.D.¹⁰, Emmelyn Kim, M.A., M.P.H.¹¹, Simon Craddock Lee, Ph.D., M.P.H.¹², Gerri O'Riordan, R.N.⁵, Mary-Tara Roth, R.N., M.S.N., M.P.H.⁶, Kathryn Schuff, M.D.¹³, June Wasser, M.A.¹⁴, David K. Henderson, M.D.², and Barry S. Collier, M.D.¹

Example RPPS Survey Questions

Did the research team members listen carefully to you?

- ☐ Never
- ☐ Sometimes
- ☐ Usually
- ☐ Always

Did the research team members treat you with courtesy and respect?

- ☐ Never
- ☐ Sometimes
- ☐ Usually
- ☐ Always

Do you have confidence and trust in the study team?

- ☐ Never
- ☐ Sometimes
- ☐ Usually
- ☐ Always

During your discussion about the study, did you feel pressure from the research staff to join the study?

- ☐ Never
- ☐ Sometimes
- ☐ Usually
- ☐ Always

72 questions

- Motivation to join
- Recruitment
- Consent
- Experiences during conduct
- Anything unexpected
- Motivation to leave/stay
- After the study
- Joining a future study
- Study characteristics
- Demographics
- Open Text

RPPS-Long: What we learned from 4,960 participants

- Response rate 25-30%, different by group
- 73% of participants gave their experience the top overall ratings
- 66% would recommend research participation to others
- 94% felt no pressure to join
- 78% thought the consent discussion was “completely” understandable
- 67% felt “completely” prepared by the consent process
- 85% wanted to have the study outcomes shared with them
- Motivations to join, leave, stay in research
 - altruism, learning, professionalism, benefit, compensation

Of the 72 questions, 6 were the major drivers of the Overall experience rating:

Respect, Listening, Consent x 2, Knowing how to, and Being able to reach the team

Kost et al N Engl J Med 2013; 369:2179-2181 Dec 5 2013.

Research Participant Perception Survey (RPPS)

Continuous
monthly
surveying at RUH
2012 - present



Engaged
Stakeholders,
Developed
Validated
RPPS-Long
One-time
national
benchmarks
2008-2011

How to use the RPPS?

Intentionally...

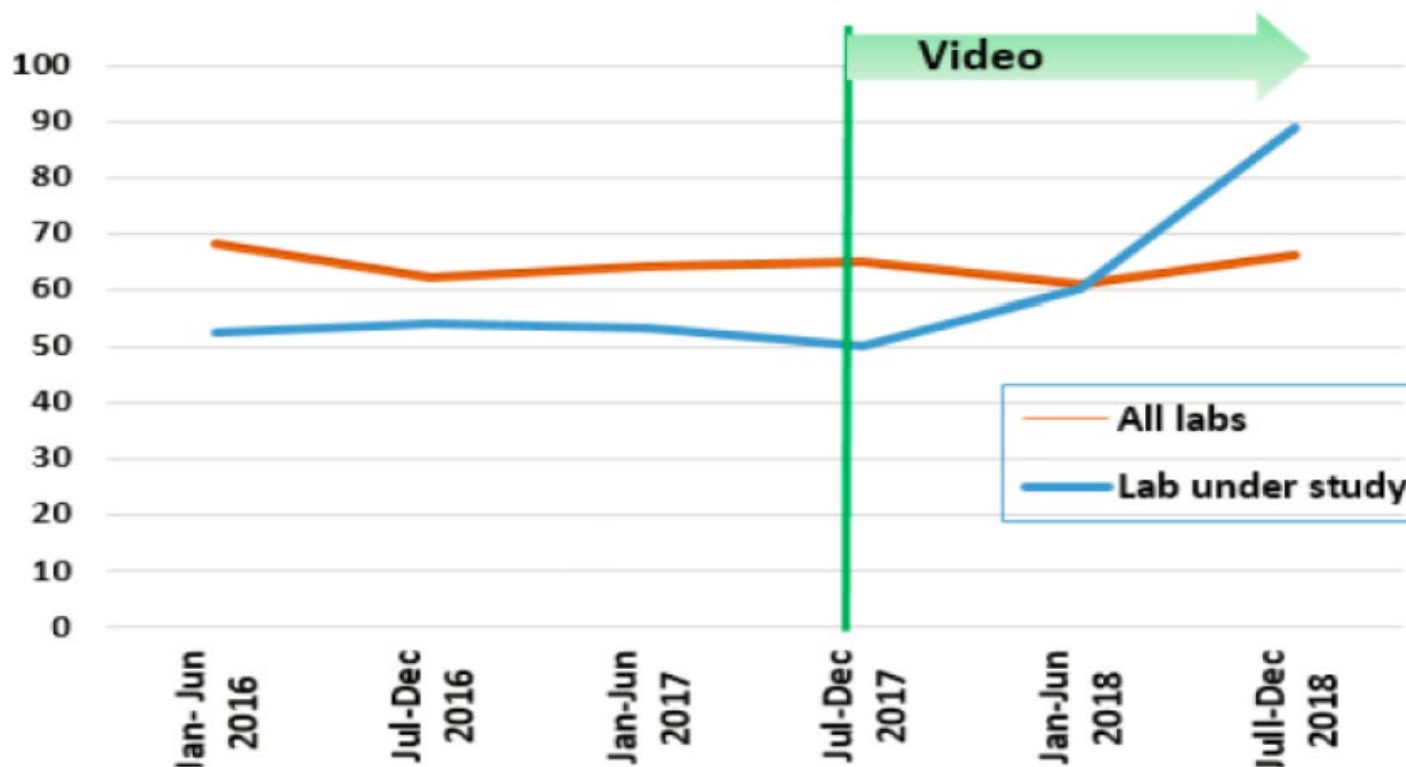
- Cross sectional survey
 - Take a pulse
 - Filter – experiences of groups
 - Identify opportunities
 - Conduct research
- Pre/Post
 - Compare research experience before & after innovations
 - Compare RPPS results across groups/interventions/sites
 - Conduct research

Acting on results

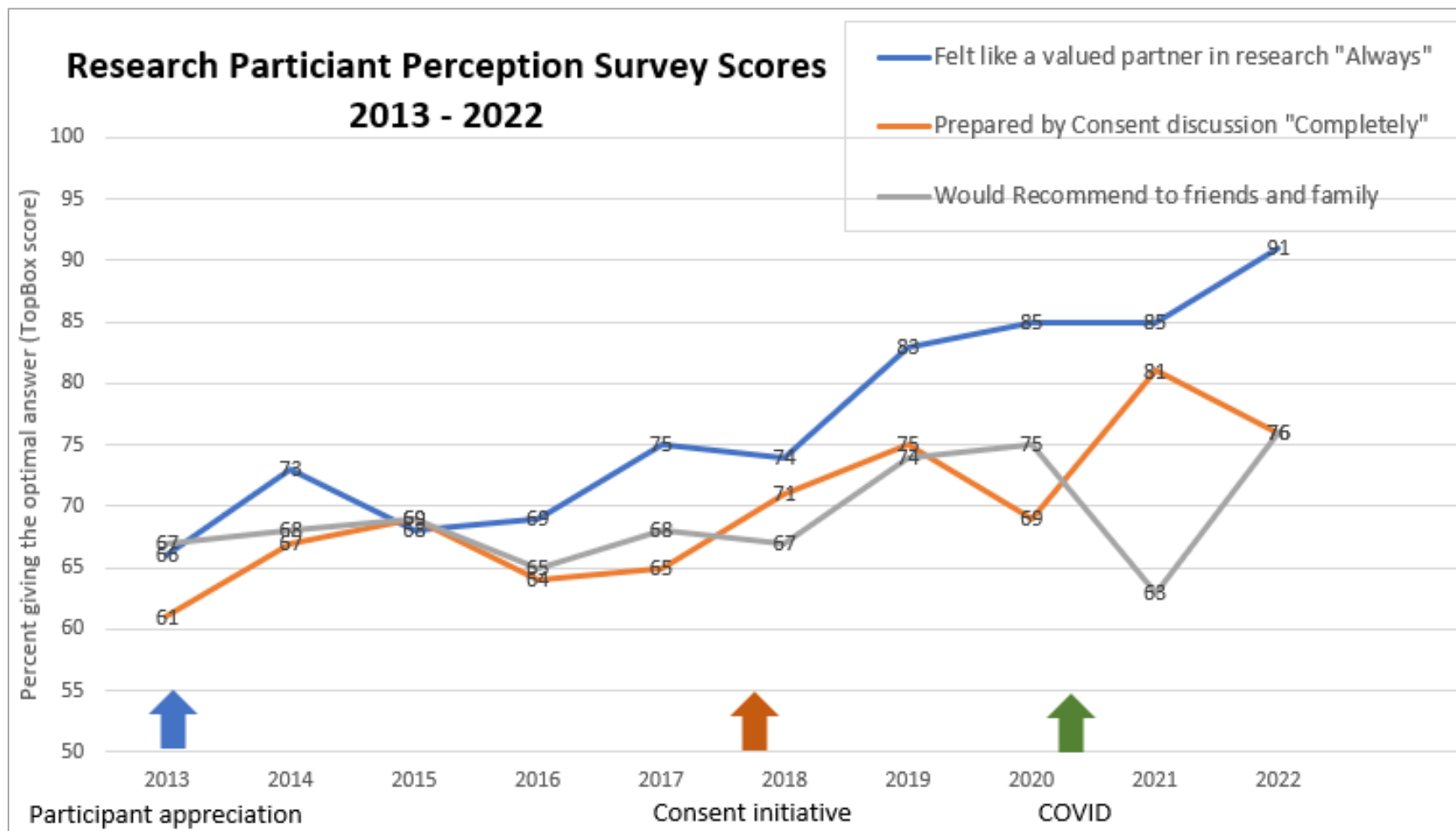
Figure 1

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

Percent responding "completely"



Acting on results



Continuous
monthly
surveying at RUH
2012 - present

Developed
Shorter validated
RPPS-S
2018

TIN Collaboration
Webinar
Prep-to-grant
February 25, 2019

Empowering the
Participant Voice

2020 →

2024

Engaged
Stakeholders,
Developed
Validated
RPPS-Long
One-time national
benchmarks
2008-2011

Empowering the Participant Voice (EPV) - Aims



- 1. Develop** a novel Research Participant Perception Survey/REDCap (RPPS/REDCap) collaborative infrastructure, tools, and standard implementation models.
- 2. Demonstrate** that the collaborative RPPS/REDCap infrastructure and implementation model is an effective approach to collect local and national benchmarks and actionable data.
- 3. Disseminate** the infrastructure, catalyze research-on-research and transform evaluation by empowering the participant voice.



EPV - Research Participant Survey Team 2020-2024

The Rockefeller University

Rhonda Kost
Natalie Schlesinger
Cameron Coffran
Adam Qureshi
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Sameer Cheema
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Alex Cheng
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Eva Bascompte-Moragas
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Nan Kennedy

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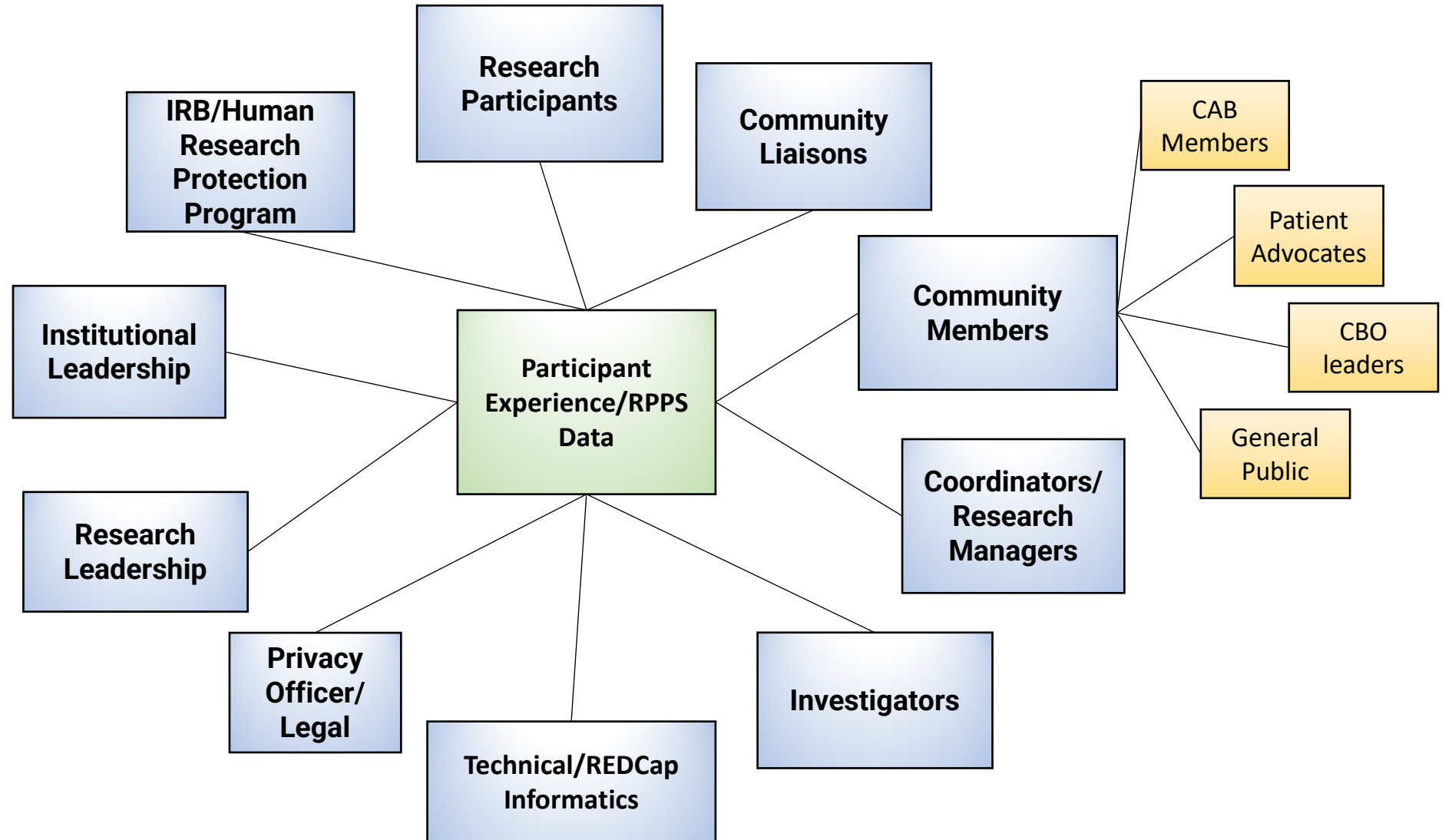
Nancy Green
Karen Marder
Siddiq Mohamed
Sheila O'Byrne

Engaging Stakeholders

Engaging Stakeholders

Engaging Stakeholders

**Perspectives
were sought
widely
throughout
EPV**



Kost et al JCTS 2024, PMID: 38476242

Value Proposition, Concerns, and Solutions

Anticipated Value	Concerns	Solutions
Validated measures	What about custom questions?	Core survey; local flexibility to add content
Evaluate consent experience	Apples to oranges? Stubborn low scores?	Variables for filtering data; iterative QI
Benchmark with peers	Confidentiality? Reputational harm?	Local data governance; Blinded aggregation
Examine group differences	Participant confidentiality, group harms?	Local data governance; no PHI per DUA
Evidence-driven QI	What is actionable? Who can act on findings?	Develop local workflow, use existing organization
Measure impact of solutions	Apples to oranges, resources for QI	Filters, Learning Collaborative, local autonomy, institutional commitment
Participants feel heard	Expectations, transparency, reputational impact	Engage stakeholders, Local sharing decisions
Increase trust with participants	Groups with historically low trust may not participate;	Virtuous cycle – engage, assess, share, demonstrate accountability

Standards and Considerations



Timing

- Administer post-consent, end-of-study, annually



Sampling

- Census sampling recommended for broader reach and representation



Scope of Implementation

- Enterprise-wide increases scale and sustainability



Metadata

- Incorporate variables to link response data to the study, unit, investigator, disease, etc.



Frequency

- Deploy survey at least semi-annually for efficient use of effort



EPV Implementation
Guide

Implementation Guide: Considerations



Institutional Support

- Align with Institutional initiatives



Team

- Dedicated project team to manage EPV



Engage stakeholders

- Leverage established structures and resources



Privacy

- De-identified data shared with Consortium



Scope of Implementation

- Enterprise-wide increases scale and sustainability



Sampling

- Census sampling recommended for broader reach and representation



Timing

- Administer post-consent, end-of-study, annually



Platform

- REDCap based infrastructure + email, EMR portal, SMS (Twilio)



Frequency

- Deploy survey at least semi-annually for efficient use of effort



Site Use Case Configurations

- All sites using the same core EPV/RPPS-short
- All sites using the same EPV project setup file, tools, standards
- Surveys sent at: End-of-study (5), After consent (2), non-specific timing (opt)

- Wake Forest – **Enterprise**, census, 6-monthly, delivery via patient portal
- Rochester – **Enterprise**, census, 2-monthly, compensation raffle, public results page
- Johns Hopkins – **Enterprise**, random sample, 6 monthly, public results page
- Rockefeller – **Enterprise**, census, 2-monthly, long-term data, public results page
- Duke – **Study-level** implementation, incremental, contact card intervention.
- Columbia – **Modified**, 3 research units, census, continuous, pilot sample 1500 responses
- Michigan – **Enterprise**, random sample, 6-monthly, recent adopter

- As of June 2024, 28,111 surveys sent, **5420 surveys returned** (89% complete + 11% >50% complete)

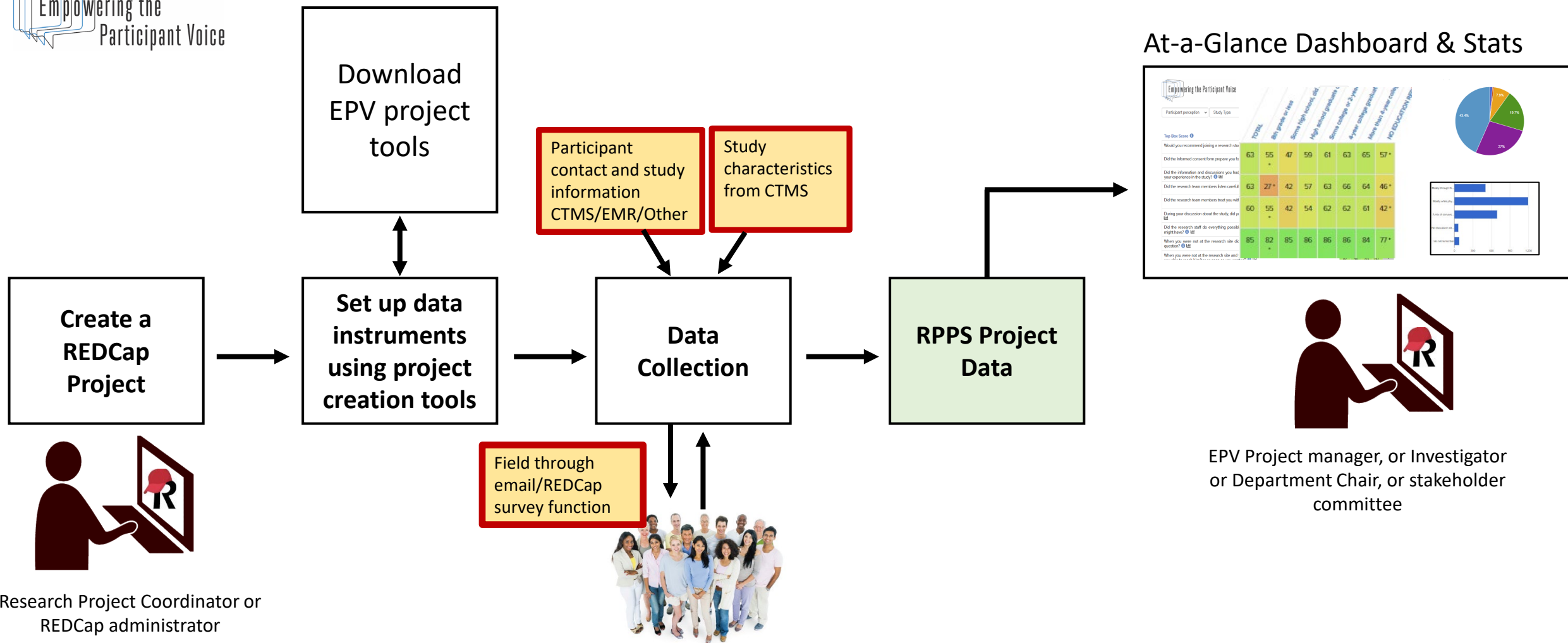
Research Participant Survey (RPPS-Short-EPV)

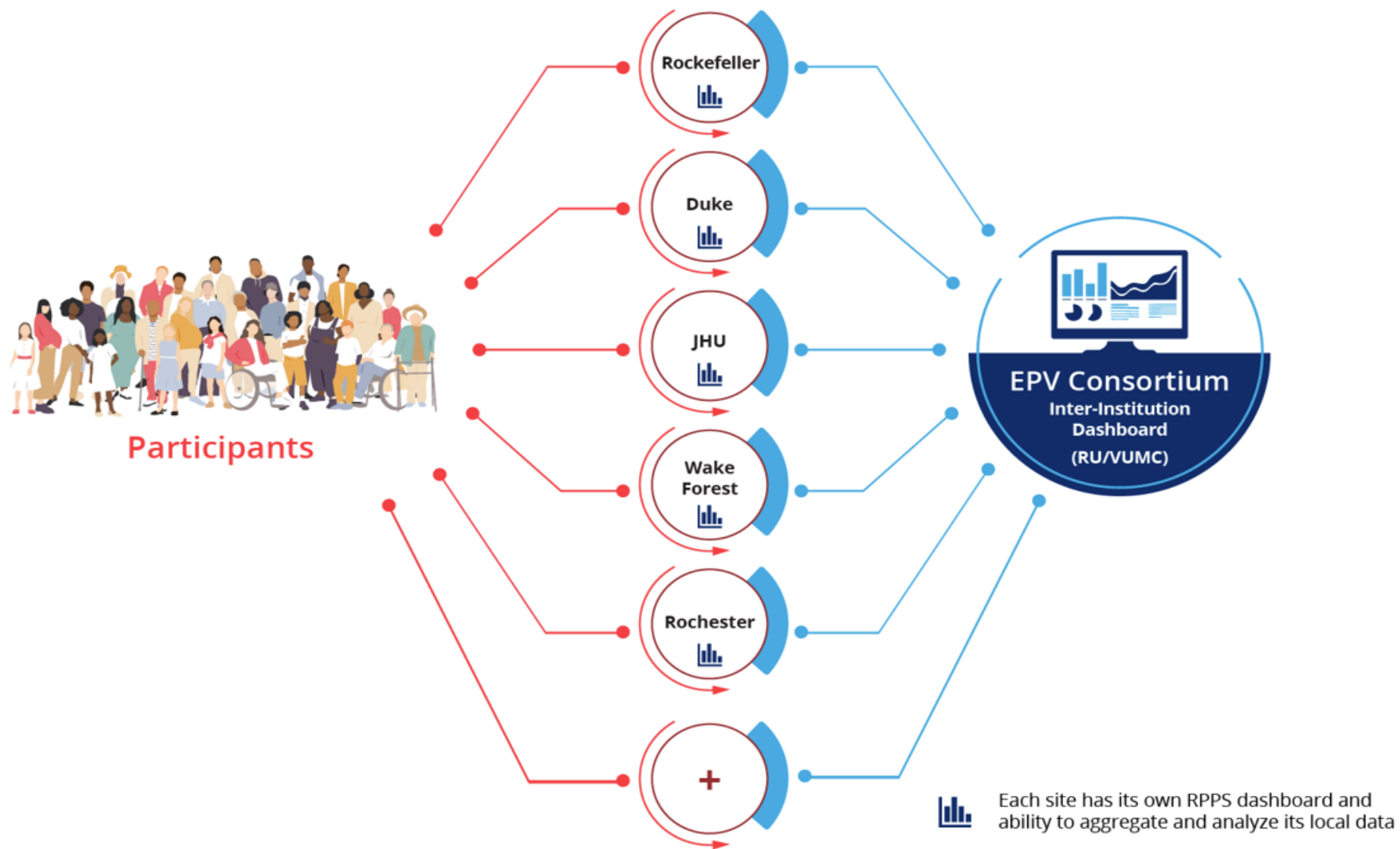
Asks about:

- Informed consent
- Listening/courtesy/respect
- Feeling valued
- Language/Culture/Privacy
- Communication with the research team
- Rate the Overall Research Experience
- Demands of the Study
- Demographics
- Factors affecting the decision to join future research
- Open text field

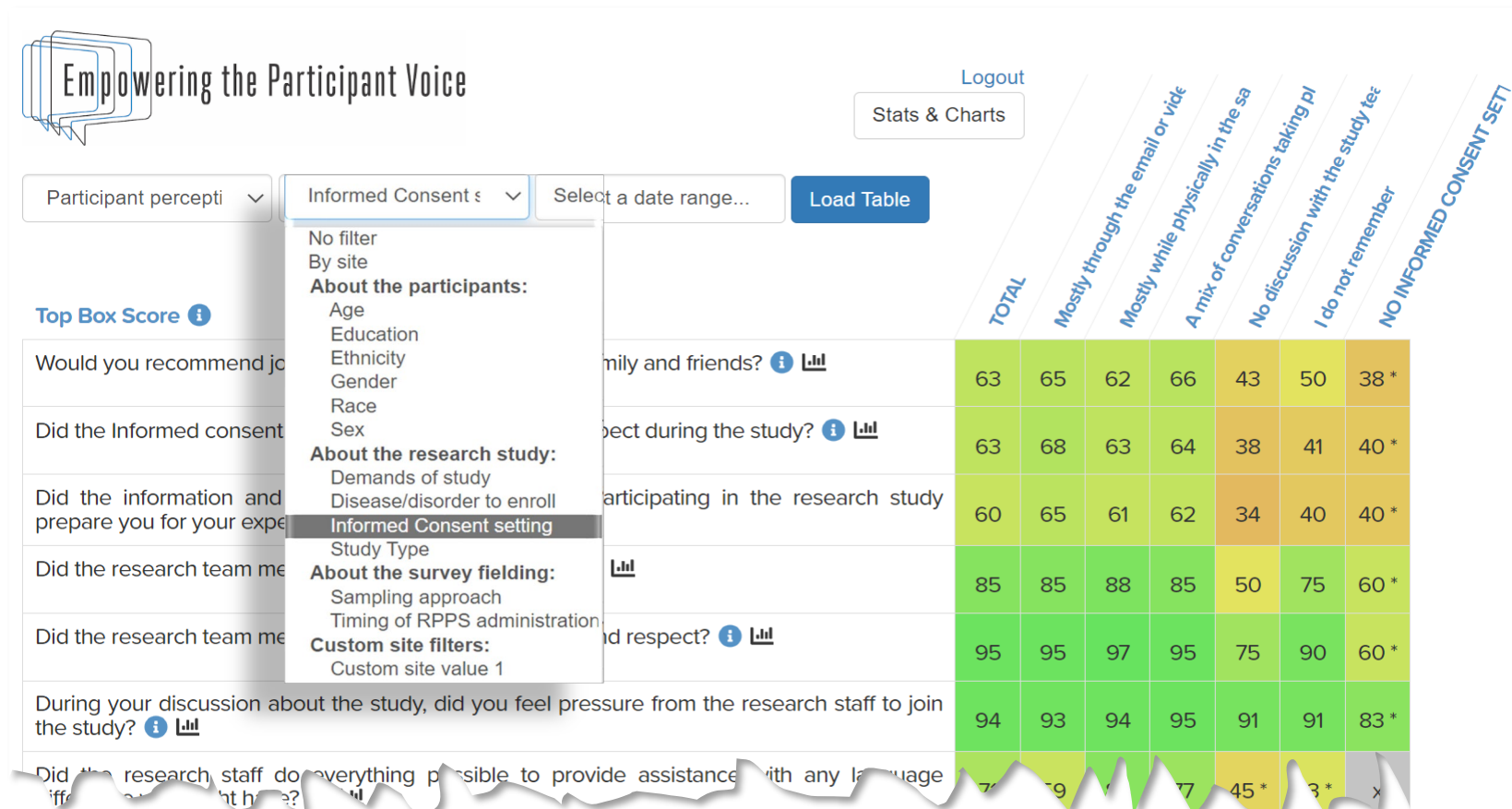
Top Box Scoring

Data Flow model

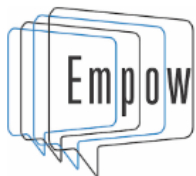




At-A-Glance-Dashboard



[Links to a Dashboard video demo, and Hands-on-test-dashboard](#)







Participant perception



No filter



Load Table

Top Box Score



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.  


Would you recommend joining a research study to your family and friends?  



Did the Informed consent form prepare you for what to expect during the study?  

Did the information and discussions you had before participating in the research study prepare you for your experience in the study?  

Did the research team members listen carefully to you?  

Did the research team members treat you with courtesy and respect?  

During your discussion about the study, did you feel pressure from the research staff to join the study?  

Did the research staff do everything possible to provide assistance with any language difference you might have?  

When you were not at the research site did you know how to reach the research team if you had a question?  

TOTAL

69

61

63

60

84

94

94

78

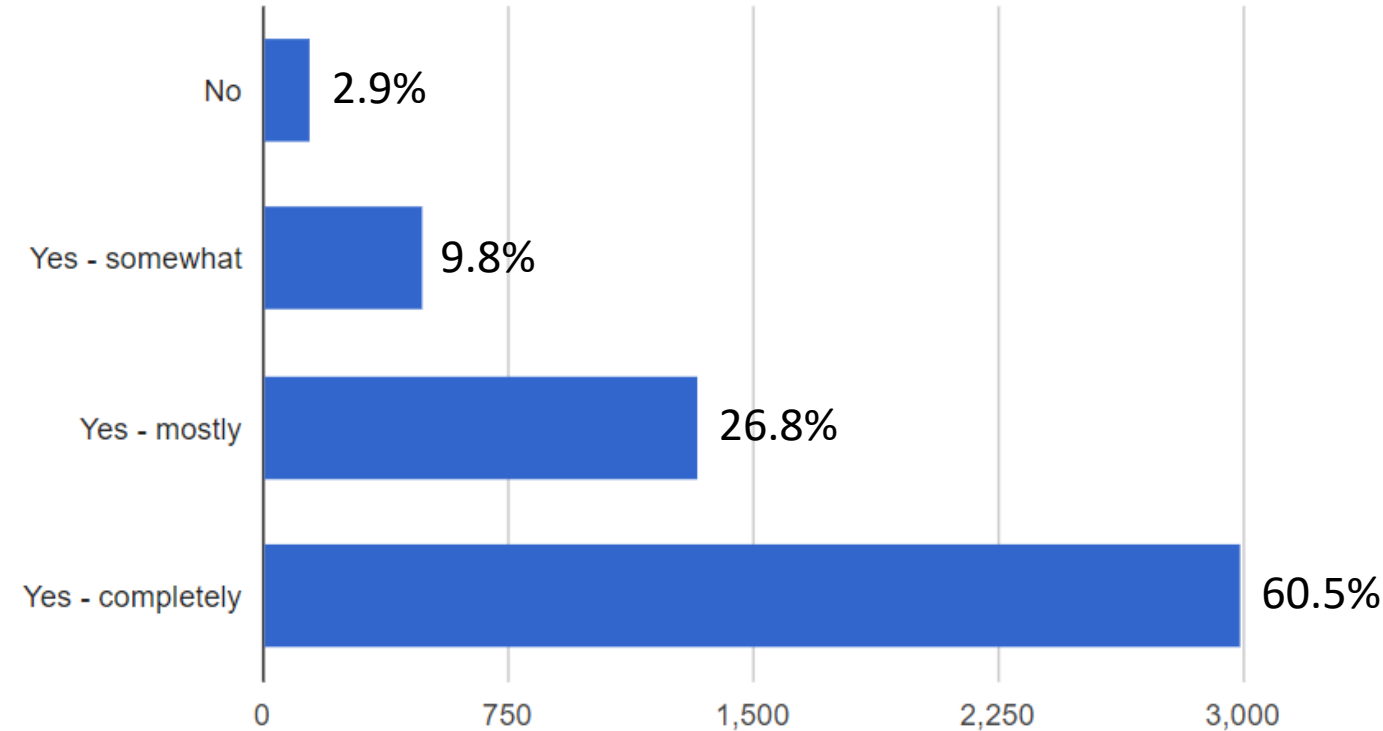
74

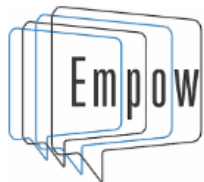
Did the information and discussions you had before participating in the research study prepare you for your experience in the study?

(rpps_s_q18) [Refresh Plot](#) | [View as Bar Chart](#) ▼

Total Count (N)	Missing*	Unique
4,949	22162 (81.7%)	4

Counts/frequency: No (142, 2.9%), Yes - somewhat (487, 9.8%), Yes - mostly (1328, 26.8%), Yes - completely (2992, 60.5%)





Empowering the Participant Voice

[Logout](#)[Stats & Charts](#)

Participant perception

No filter

Load Table

Top Box Score



Please use the scale below to rate your experience, and 10 is the best possible



Would you recommend joining a


Did the Informed consent form provide

Did the information and discussion about the study?  

Did the research team members

Did the research team members treat you with courtesy and respect?  

During your discussion about the study, did you feel pressure from the research staff to join the study?  

Did the research staff do everything possible to provide assistance with any language difference you might have?  

No filter

By site

About the participants:

Age

Education

Ethnicity

Gender

Race

Sex

About the research study:

Demands of study

Disease/disorder to enroll

Informed Consent setting

Study Type

About the survey fielding:



Sampling approach



Timing of RPPS administration

Custom site filters:

Custom site value 1

the research study, where 0 is the worst possible

friends?  

ing the study?  

h the research study prepare you for your experience

TOTAL

69

61

63

60

84

94


94


70


Participant percepti ▼


Informed Consent s ▼
[Load Table](#)

Top Box Score ?


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. ? 


Would you recommend joining a research study to your family and friends? ? 

Did the Informed consent form prepare you for what to expect during the study? ? 

Did the information and discussions you had before participating in the research study prepare you for your experience in the study? ? 

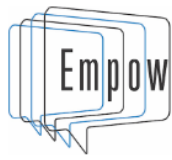
Did the research team members listen carefully to you? ? 

Did the research team members treat you with courtesy and respect? ? 

During your discussion about the study, did you feel pressure from the research staff to join the study? ? 

TOTAL	Mostly through the email or vide	Mostly while physically in the sa	A mix of conversations taking pl	No discussion with the study tes	I do not remember	NO INFORMED CONSENT SETT
69	71	70	71	54	58	68
61	65	59	65	42	48	61
63	68	63	67	34	37	62
60	67	60	63	29	35	60
84	86	87	86	53	69	82
94	96	96	96	72	86	91
94	94	95	95	91	89	94

Informed Consent Setting



Participant percepti

Informed Consent s

[Load Table](#)

Informed Consent Setting

Top Box Score

	TOTAL	Mostly through the email or vide	Mostly while physically in the sa	A mix of conversations taking pl	No discussion with the study tea	I do not remember	NO INFORMED CONSENT SET
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.	69	71	70	71	54	58	68
Would you recommend joining a research study to your family and friends?	61	65	59	65	42	48	61
Did the Informed consent form prepare you for what to expect during the study?	63	68	63	67	34	37	62
Did the information and discussions you had before participating in the research study prepare you for your experience in the study?	60	67	60	63	29	35	60
Did the research team members listen carefully to you?	84	86	87	86	53	69	82
Did the research team members treat you with courtesy and respect?	94	96	96	96	72	86	91
During your discussion about the study, did you feel pressure from the research staff to join the study?	94	94	95	95	91	89	94
Did the research staff do everything possible to provide assistance with any language difference you might have?	78	66	79	76	27	48	87
When you were not at the research site did you know how to reach the research team if you had a question?	74	76	74	78	49	51	72
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?	63	65	65	65	36	43	59
Did you feel you were a valued partner in the research process?	74	78	74	80	50	53	69
If you considered leaving the study, did you feel pressure from the Research Team to stay?							


Participant perception ▾



Demands of study ▾



Load Table



Top Box Score



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.  



Would you recommend joining a research study to your family and friends?  



Did the Informed consent form prepare you for what to expect during the study?  



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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?  

Did you feel you were a valued partner in the research process?  

TOTAL

Simple (for example: a few visits)

Moderate (for example: multiple)

Intense (for example: long or mu

NO DEMANDS OF STUDY REPY

70	70	66	31	75
62	61	65	38	63
66	72	55	38	61
65	71	47	38	63
85	87	80	77	85
94	96	93	69	93
95	95	93	85	96
67	70	60	-	-
73	70	76	85	75
67	66	76	80	65
73	76	74	38	71

Demands of the Study



Filtered by Site

Participant percepti



By site



Load Table



Top Box Score


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.  



Would you recommend joining a research study to your family and friends?  



Did the Informed consent form prepare you for what to expect during the study?  



Did the information and discussions you had before participating in the research study prepare you for your experience in the study?  



Did the research team members listen carefully to you?  

Did the research team members treat you with courtesy and respect?  



During your discussion about the study, did you feel pressure from the research staff to join the study?  



Did the research staff do everything possible to provide assistance with any language difference you might have?  



When you were not at the research site did you know how to reach the research team if you had a question?  

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?  

Did you feel you were a valued partner in the research process?  

If you considered leaving the study, did you feel pressure from the Research Team to stay?  

Did the research staff respect your cultural background (e.g. language, religion, ethnic group)?  

Did you have enough physical privacy while you were in the study?  

TOTAL

16 18 19 22 25 28

69	66	72	80	68	61	67
61	58	62	73	60	62	59
63	60	63	77	67	64	57
60	59	59	74	68	60	54
84	83	83	91	85	80	88
94	94	95	94	95	90	96
94	95	94	92	96	93	94
78	79	63	73	67	88	72
74	74	72	85	68	69	83
63	64	57	86	57	55	74
74	70	76	86	73	69	75
89	93	86	88	94	88	88
91	92	89	93	89	91	95
93	91	94	94	94	-	91

Selected Local RPPS Findings/Actions/Impact

Findings	Actions	Impacts
(A) 53% of respondents said a flexible visit schedule very Important for future studies	Add Saturday appts one week out of each month	✓ Enrollment increased 60% in weeks with Saturday appointments (from 3.6 to 6 /wk)
(A) 74% of respondents were able to reach the study team when needed	Distribute contact cards at POC	✓ 83% of respondents were able to reach the study team when needed
(B) Multiple complaints about delays to study compensation	Took data to the committee reviewing whether to invest in debit card system	✓ Committee passed debit card proposal & proceeded with implementation
(C) Scores for consent from respondents in cancer center studies << than others	Mandatory consent training for CC investigators; request for CC variable	- Impact pending on scores; CC variable implemented in EPV 2024
(D) Comments about specific interactions, study procedures	Shared w/ clinical leadership; staff retraining; revision to vendor contract	✓ No related complaints in ensuing 11 months
(E) Informed consent and language assistance disparities	Formation of Equity in Research Committee to address findings	- Institutional response
(F) Low response rate from Latino/x population (significant % of participants)	Developed lower literacy materials in English and Spanish, including RPPS	✓ 40% of response cohort Latino/x (compared to aggregate 6%).



Empowering the Participant Voice

2023 Annual Report

The Empowering the Participant Voice survey is a critical tool for researchers to understand the experiences of participants in their studies. Only studies that are approved by the Institutional Review Board (IRB) are eligible to participate in the survey. The survey is conducted annually, from January 1 to April 2023. The survey is designed to be completed by participants in a study, and the results are used to improve the research process and the experience of participants.

Demographics of respondents

Younger adults and persons from historically underserved populations were less likely to complete the survey.

Table 1: Demographics of respondents

Demographic category	Percentage
Age	18-24: 15%, 25-34: 25%, 35-44: 20%, 45-54: 15%, 55-64: 10%, 65+: 15%
Ethnicity	White: 45%, Black: 25%, Hispanic: 15%, Asian: 10%, Other: 5%
Sex	Male: 45%, Female: 55%
Race	White: 45%, Black: 25%, Hispanic: 15%, Asian: 10%, Other: 5%

Overall experience of participants

Participants were asked to score their overall experiences on a scale of one to 10. The average score for all participants was 8.7. For Hispanic participants the average score was 7.8. For Black/African American participants the average score was 6.9.

Table 2: Rating of Overall Experience (10 being best)

Rating	Percentage
1	1%
2	0%
3	0%
4	1%
5	2%
6	5%
7	10%
8	21%
9	47%
10	1%

Participants rated several areas highly:

- Our participants felt listened to.
- They were treated with courtesy and respect.
- They felt they had enough privacy.
- They felt their cultural background and their language differences were respected.

These are areas of the research experience where improvements should be made:

- We should improve communication about the study at the beginning and throughout the study.
- We should create ways to help our participants feel valued.
- We should evaluate our informed consent process so patients know better what to expect in a study.

[University of Rochester Survey Results website](#)

Johns Hopkins University Survey Results Website

Research Participant Satisfaction Survey

Johns Hopkins Medicine is committed to making the experience of being a research participant as positive as possible.

117 respondents completed the survey

The respondents of the survey reflected the diversity of Johns Hopkins patients. They were usually older, being 55 or above, and 20.2% of the respondents did not report as White.

109 respondents completed the survey

98% of respondents reported that their experience in the research study was a "5 or higher".

Here is a word cloud of respondent's statements about their experience

access to result
wonderful
completely comfortable
not ideal timing
polite
rockstars
teams at hopkins
competent
easy to talk to
above and beyond
fantastic experience
timing
no contact
phenomenal support
poor communication
different studies
opportunity
lack of access to result

[Johns Hopkins University Survey Results Website](#)

Rockefeller University Survey Results Website

Research Participant Perception Survey
Rockefeller University RESULTS 2022-2023

At the Rockefeller about their research: Hearing about our research and what could be research.

Who received a survey?

Everyone! Participants who are 18 or older, and recently signed informed consent, or completed participation received an invite by email. For longer studies, participants receive surveys annually. We send surveys out every other month.

Who Responded?

From January 2022 – June 2023, we sent 1002 surveys and received responses from 230 participants. Below are some of the characteristics of the participants who returned the survey.

What is your race?

Asian: 2%, Black: 1%, White: 51%, American Indian: 1%, Native Hawaiian: 1%

How much did the study demand of you?

18-34: 18%, 35-44: 25%, 45-54: 20%, 55-64: 15%, 65+: 10%

What did study participants say?

Felt like a valued Partner
Participants always (86%) or usually (11%) felt like a valued partner in research.

Would recommend joining?
Participants would definitely (86%) or probably (11%) recommend joining a study.

Communication
Respondents were always (87%) or usually (10%) able to reach the study team when needed.

Informed Consent
Informed consent prepared participants completely (77%) or mostly (16%) for participation in the study.

Testimonials:

- "I was pleased to contribute to scientific research. Most studies exclude older participants, so this was a special opportunity for me."
- "I was never made to feel uneducated or disrespected, and I have benefited greatly from participating in their research efforts."

[Rockefeller University Survey Results Website](#)





Value Proposition

- Validated measures
- Evaluate consent experience
- Benchmark with peers
- Examine group differences
- Evidence-driven, participant-centered quality improvement
- Measure impact of interventions
- Participant/communities feel heard
- Increase trust with participants

Interest in RPPS at Wake Forest

Recognized the need to collect participant feedback

- Research was expanding
- Geographic area increasing
- Study types and study populations more diverse
- Need consistent, reliable information on what participants like/dislike about participation in research at WF
- IRB was interested early on



Pilot Study on RPPS Distribution

How to reach people?

- Effective
- Cost efficient

Surveyed 800 adult participants.

- 200 by mail
- 200 by email
- 200 by phone
- 200 by EMR patient portal



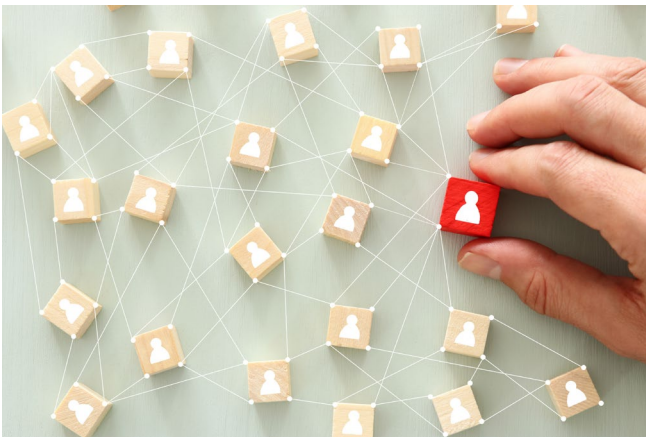
Pilot Results

- Patient portal had the best effectiveness for cost at that time
 - 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 Jun;2(3):163-168. doi: 10.1017/cts.2018.32. Epub 2018 Sep 21. PMID: 30370068; PMCID: PMC6199552.
- Wanted to implement broadly

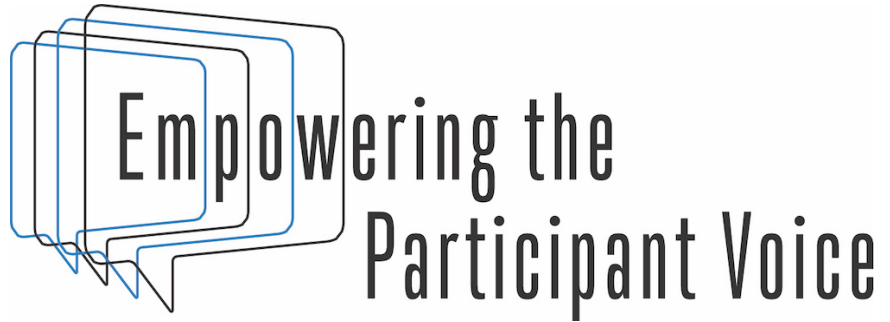


Barriers at WF originally

- Was still a manual process.
- Needed automation for practicality.
 - Working with IT, Privacy, etc.
- Strategic combinations on the horizon



EPV at Wake Forest

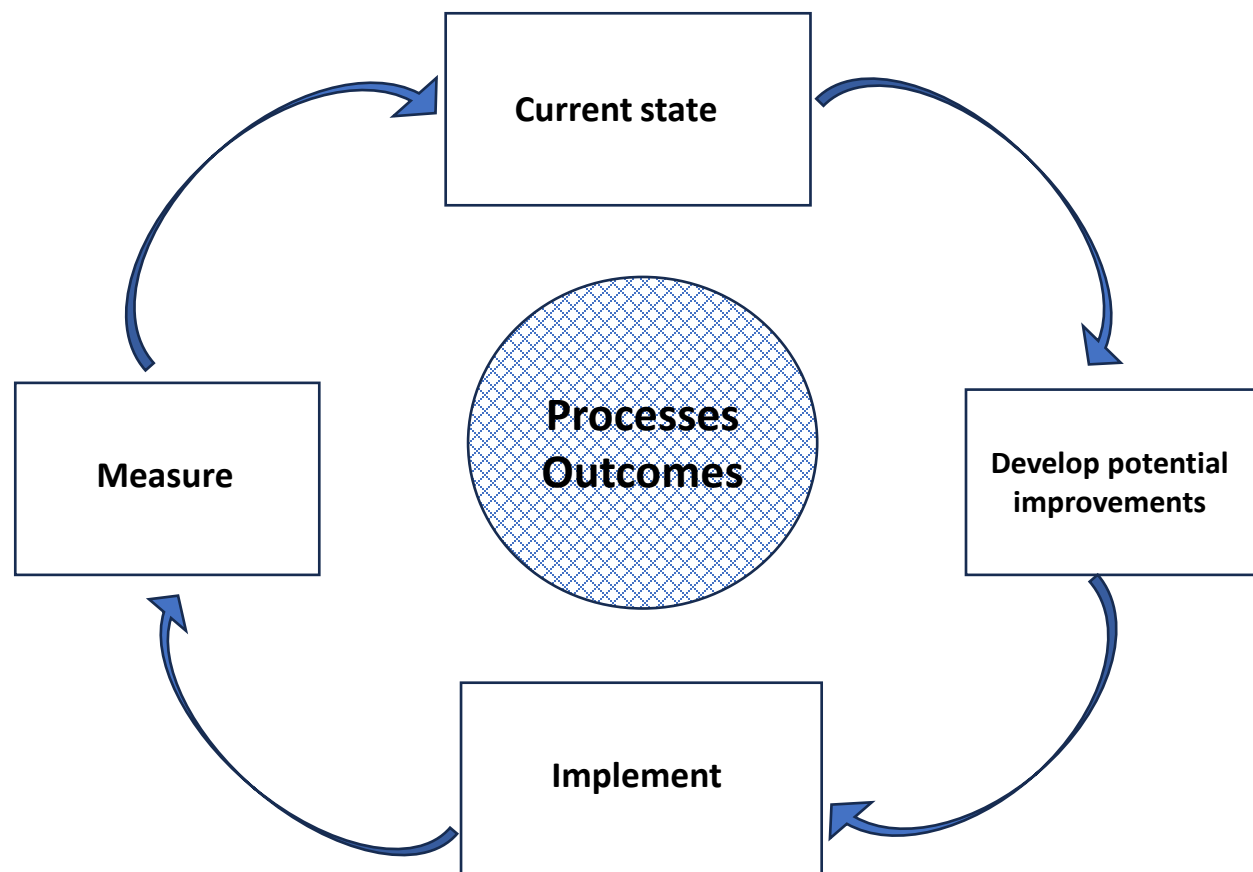


The EPV project:

- Infrastructure for delivery
- Reporting and analysis tools
- The opportunity for consortium comparison
- Institutional goals came into focus
- RPPS Aligned and complimented



Academic Learning Health System



Community Health Outcomes

- Geographic service area changing
 - Broader
 - Urban
 - Rural
 - Diverse population
- Research results representativeness (Justice)
- Community involvement and trust (Autonomy, Beneficence)



The Missing Piece

- Do people have differences of opinion about experience?
 - What are they?
 - How can we address them?
 - Is that going to work?
- Academic Learning Health System Model



RPPS Goals

- Better Ensure Equitable Enrollment and Retention
 - Respond to gaps
 - Increase trust by listening/acting
 - Decrease barriers
 - Improve satisfaction



Innovation

- Model – All research participants
- Data Needed
 - EMR flag
 - End of study participation
 - Longer than 10 months
- Challenge
 - Individualized links
 - Solved with method used for telehealth



Results at Wake Forest

- The feedback received helps both institutional leaders and study teams.
 - Comments often positive about team and experience
 - Less than ideal experiences can be described
 - Process for reimbursement
 - Parking, location navigation, contact frustrations
 - Individual experiences
 - Dashboard provides at-a-glance view of scores
 - Consortium comparison



An Identified Gap

- Comparison to consortium
 - *Did the research staff do everything possible to provide assistance with any language difference you might have?*
- Score indicated lower satisfaction
 - Age - over 75
 - Education - some high school or below
 - Gender and Sex - lower for males
 - Informed consent setting – email or video



Developing improvements with IRB

- The EPV team and IRB are working to address this gap through several improvements
 - Age - over 75
 - Education on opening that emphasizes willingness to speak up or provide larger print materials
 - Tools such as amplification headphones and low vision aides
 - Education
 - Reducing the reading level of the consent document
 - Use of AI for assistance with this effort
 - Informed consent setting and Gender
 - Emphasis that study team is happy to take time to have detailed conversation and to answer any questions fully



Future of RPPS at WF

- The survey itself is now a core feature of our research enterprise
 - Rolling out to new regions and service areas as they integrate
- Viewed as important to meeting our ethical obligations
 - Identify and resolve gaps
- Considered critical to the academic Learning Health System model
 - Continuous improvement to research processes
 - Increase our ability to translate ideas into care



Local Decisions and Considerations

A new site perspective

**How to obtain data on
research participants?**

How often should we send the survey?

What should the sample size be?

**Should the data be
linked to individual studies?**

**Should we ask additional questions (in addition to the core
survey questions)?**

With whom should we share the results?

Feasibility

Available data

Experience of peer institutions
similar in size

Feedback from HRPP Advisory groups
and leadership

Implementation Steps and Tips

A new site perspective

- Identify your institution specific goals
 - Ensure that it aligns with current priorities and strategic plans
- Put together an implementation team
- Seek feedback and input from stakeholders
- Design the workflow and test it
- Establish a communication plan

Implementation Steps and Tips

A new site perspective

- Pilot the survey on a smaller sample size prior to full scale implementation
- Take a phased approach in survey implementation
- Consider having a steering committee to promote awareness

Final thoughts..

- RPPS provides valuable data that can enhance human subjects research operations, including IRBs/HRPPs.
- RPPS offers a proactive approach that differs significantly from the reactive approach of responding to participant complaints. Specifically:
 - Systematic data collection
 - Broad range of insights
 - Early identification of trends
- Obtaining participant perception data and acting upon it enhances the participant's sense of value, fosters trust and engagement leading to a **POSITIVE PARTICIPANT EXPERIENCE**

- To contact EPV PI - Dr. Rhonda G. Kost kostr@rockefeller.edu
- EPV website (www.Rockefeller.edu/research/epv)
 - Joining EPV
 - EPV Implementation Guide
 - [EPV sites' Return of Results websites](#)
- Publications –
 - [Bibliography](#) of Research Participation Perception Survey publications (7)

Thank You!



Questions?





Participant percep ▾

Education ▾

Load Table

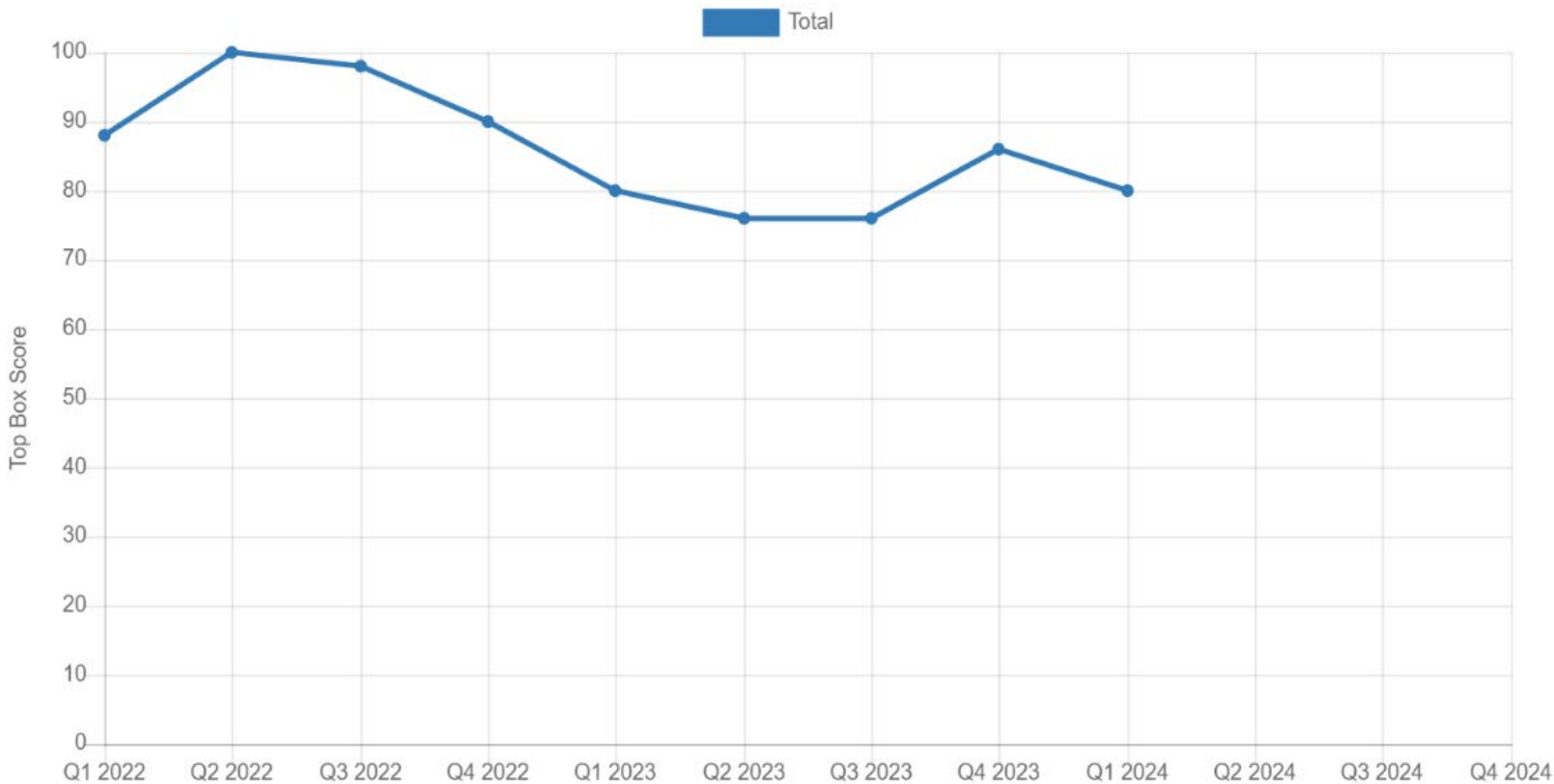
Level of Educational Attainment

Top Box Score ⓘ

	TOTAL	8th grade or less	Some high school, did not grad	High school graduate or GED	Some college or 2-year degree	4-year college graduate	More than 4-year college degree	NO EDUCATION REPORTED
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. ⓘ	69	65	65	73	72	69	66	58
Would you recommend joining a research study to your family and friends? ⓘ	61	51	45	60	59	63	63	37
Did the Informed consent form prepare you for what to expect during the study? ⓘ	63	44	41	60	63	66	64	32
Did the information and discussions you had before participating in the research study prepare you for your experience in the study? ⓘ	60	51	43	59	62	62	60	29
Did the research team members listen carefully to you? ⓘ	84	77	77	85	85	87	83	65
Did the research team members treat you with courtesy and respect? ⓘ	94	91	94	94	94	96	94	84
During your discussion about the study, did you feel pressure from the research staff to join the study? ⓘ	94	91	90	94	95	94	95	91
Did the research staff do everything possible to provide assistance with any language difference you might have? ⓘ	78	45	69	69	80	87	81	29 *
When you were not at the research site did you know how to reach the research team if you had a question? ⓘ	74	66	72	77	75	76	72	63
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? ⓘ	63	70	70	67	63	64	60	71 *
Did you feel you were a valued partner in the research process? ⓘ	74	65	71	76	74	77	72	59

Scores over time

Did you feel you were a valued partner in the research process?



Month
Quarter
Year