

# **Empowering the Participant Voice:**

## **Implementing the Research Participant Perceptions Survey at Duke**

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# Why a Research Participant Experience Survey?



# Duke University School of Medicine: Core Values

- Excellence in education, research and patient care
- Respect for and inclusion of people from all backgrounds
- Commitment to service, solving real world problems
- Sense of urgency in transforming discoveries into improved human health
- Professionalism and integrity demonstrated in all aspects of performance and effort

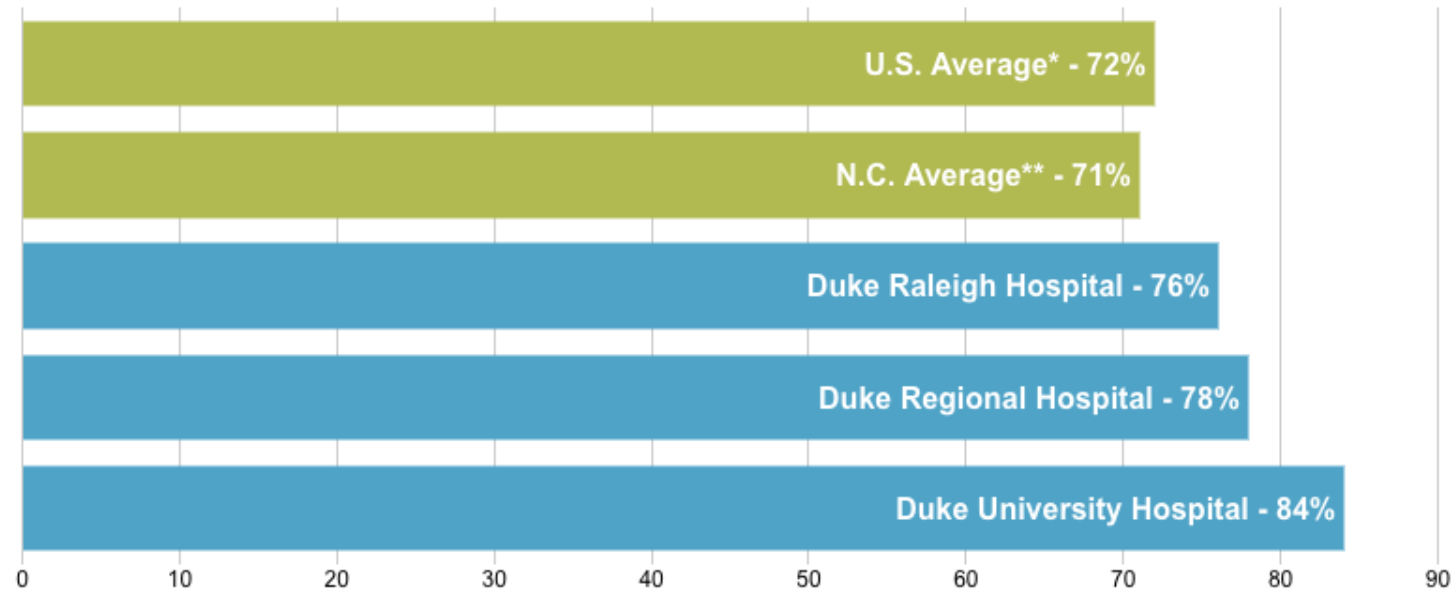
<https://medschool.duke.edu/about-us>

# Patient Care

- We participate in a nationwide survey to help us ensure that patients are pleased with their treatment
  - Press Ganey HCAHPS (Hospital Consumer Assessment of Healthcare Providers and Systems) includes questions about different aspects of the patient's care experience

# Example

## Likelihood of Recommending Hospital



Source: <https://www.dukehealth.org/quality-and-safety/patient-satisfaction-quality-scores/recommend-hospital>

# Why ask about the research participant experience?

The effectiveness of practices designed on behalf of participants should be judged, at least in part, *by the experiences of the participants themselves.*



# The Suite of RPPS Surveys

- Validated long version [2012]; 5,000 respondents from 15 CTSAAs
- Validated shorter versions [2018]
  - Research Participant Perception Survey – Short-Plus
  - Research Participant Perception Survey – Ultrashort-Plus
  - Research Participant Perception Survey – Short-Plus – Spanish
  - Research Participant Perception Survey – Ultrashort-Plus – Spanish

# RPPS-Short Survey Asks About...

- ***Motivations*** to join, stay, or leave research
- Informed consent
- Listening, courtesy, respect
- Feeling valued
- Language, culture, privacy
- Communication with team
- ***Overall research experience***
- ***Willingness to recommend to friends and family***
- Demographics





# RPPS Ultra-Short Survey Questions

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

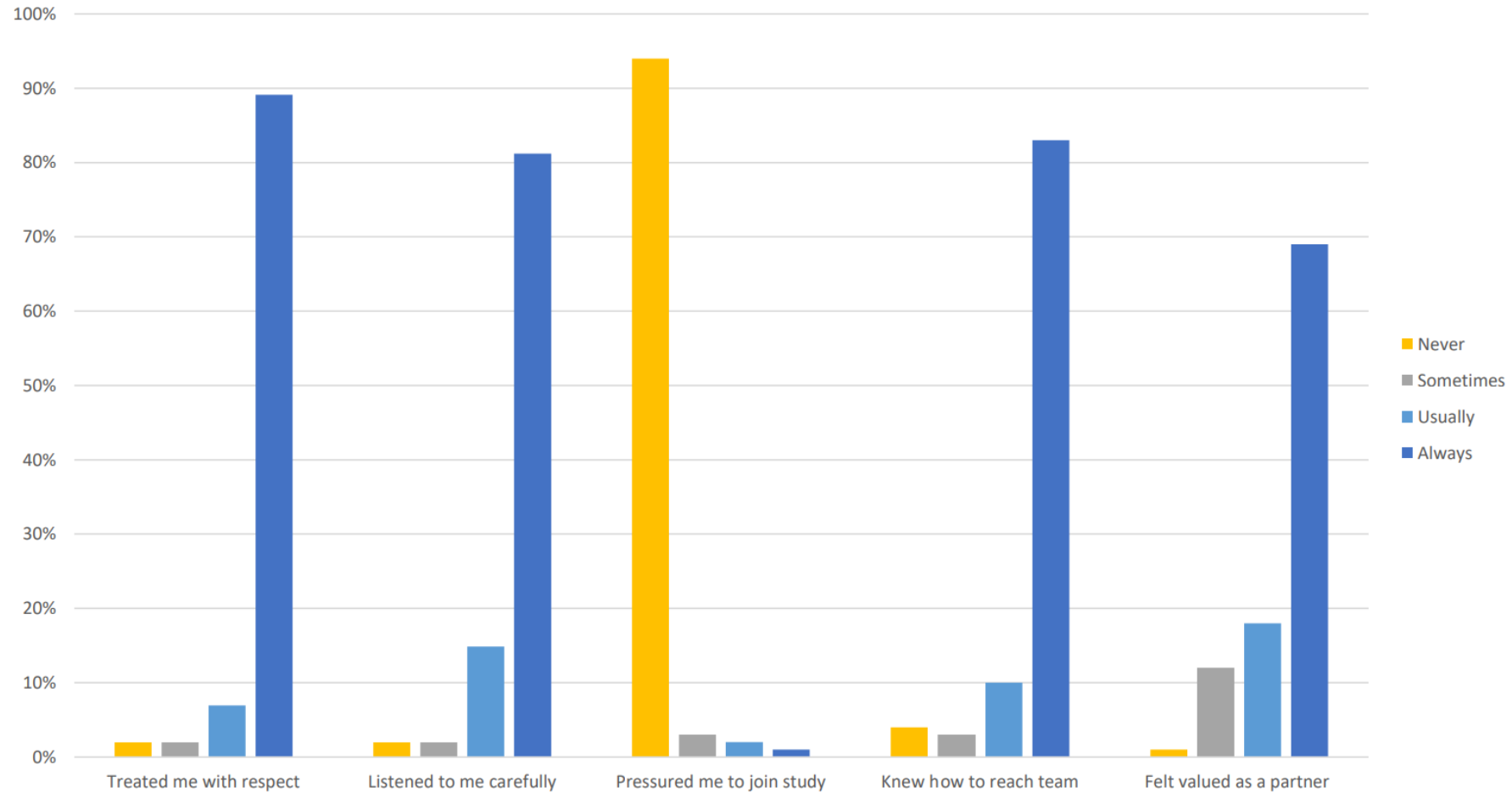
# How to use the RPPS?

Intentionally...

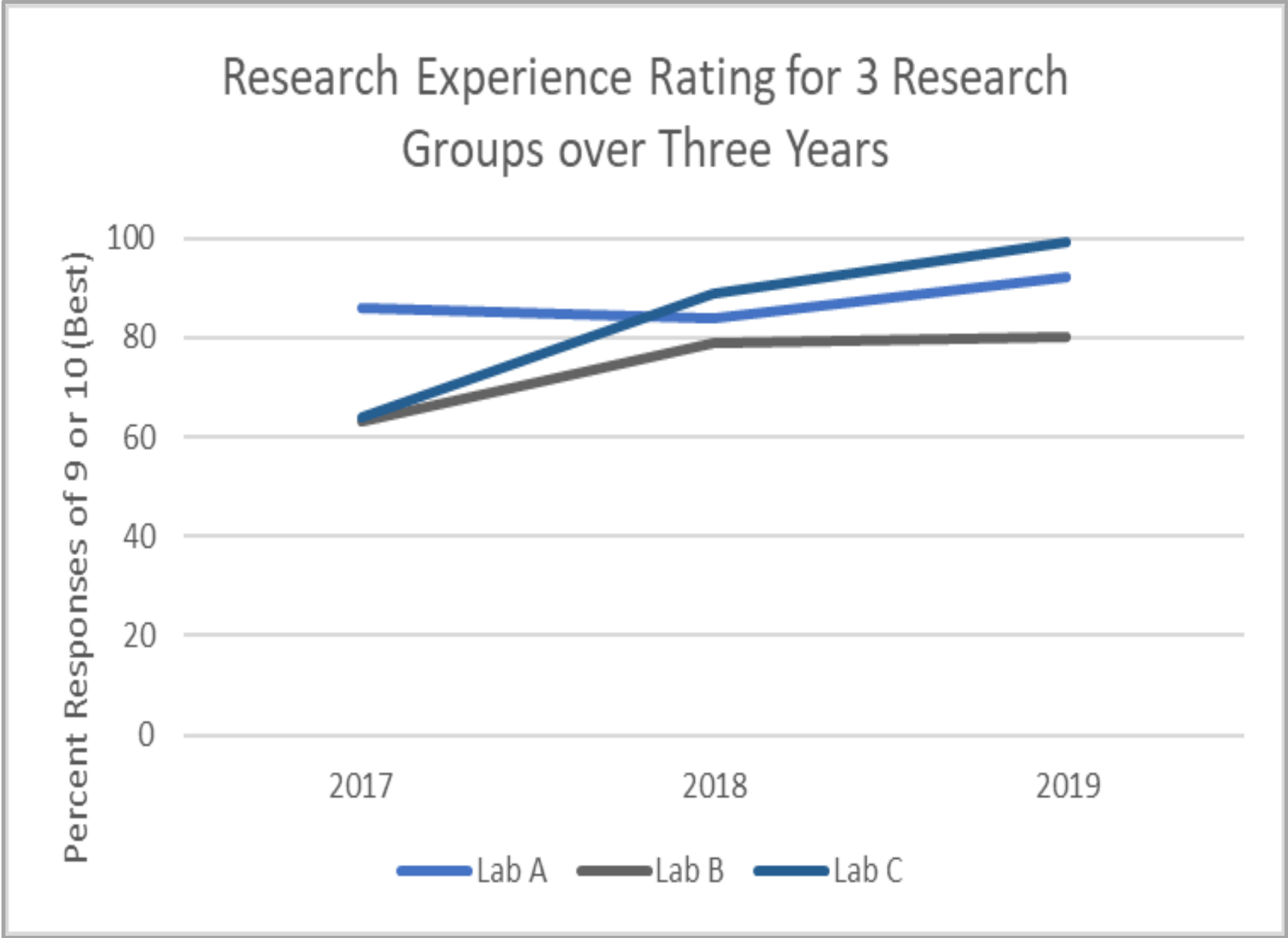
- Cross sectional survey
- Comparative
- Pre/Post intervention or change

# Cross-Sectional

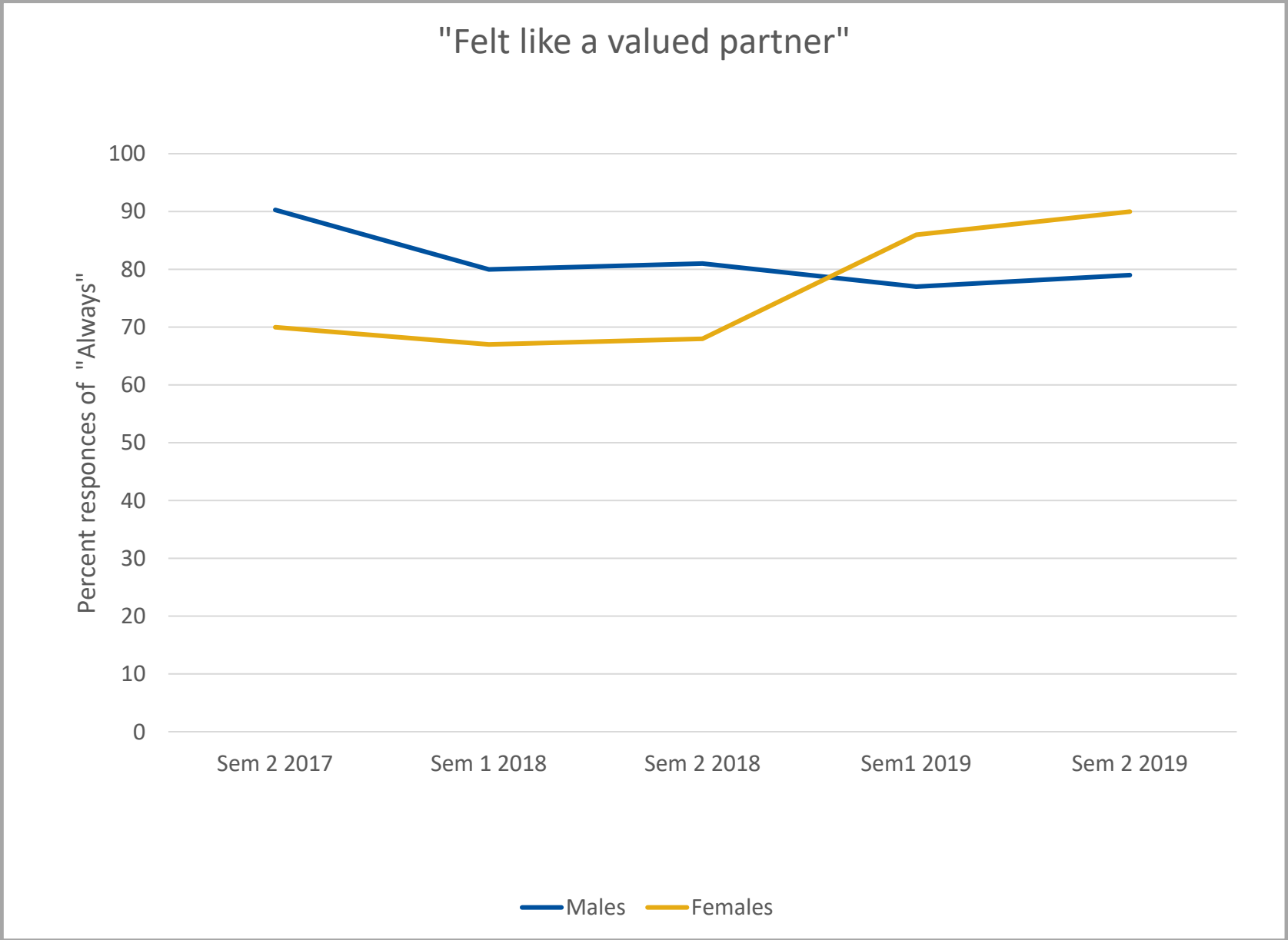
## Satisfaction with Research Team



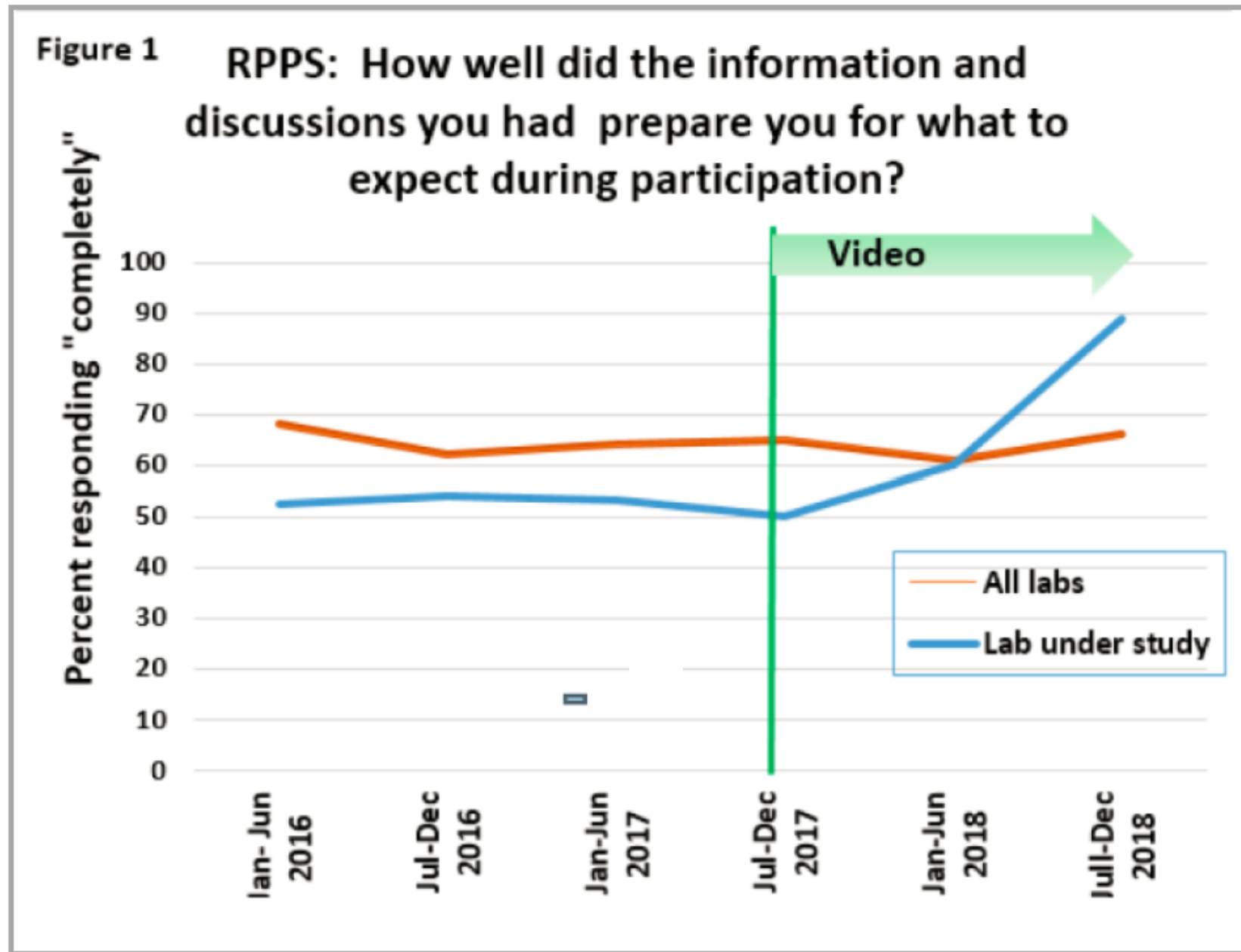
# Comparative



# Comparative



# Pre/Post



# Why aren't we using it already?

## Common challenges:

- Which survey?
- Cost and logistics of sending survey
- Managing data
- Analyzing data
- Visualizing data
- Deciding what the data means and how to use it to drive change

# Specific Aims of U01 grant

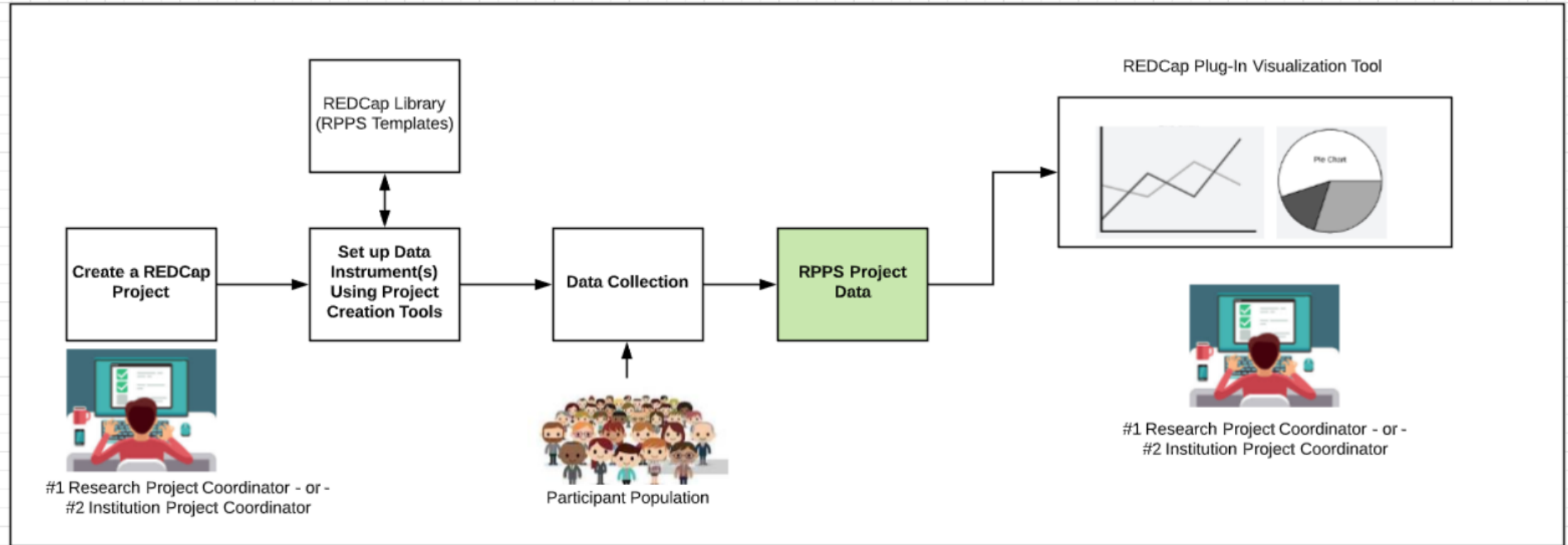
1. **Develop** a novel Research Participant Perception Survey/REDCap (RPPS/REDCap) collaborative infrastructure and standard implementation models
2. **Demonstrate** that the collaborative RPPS/REDCap infrastructure and implementation model is an effective approach to collect institutional benchmarks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



# Use Cases as the Foundation

Supported in part by NIH/NCATS Grants  
U01TR003206 & UL1TR001866

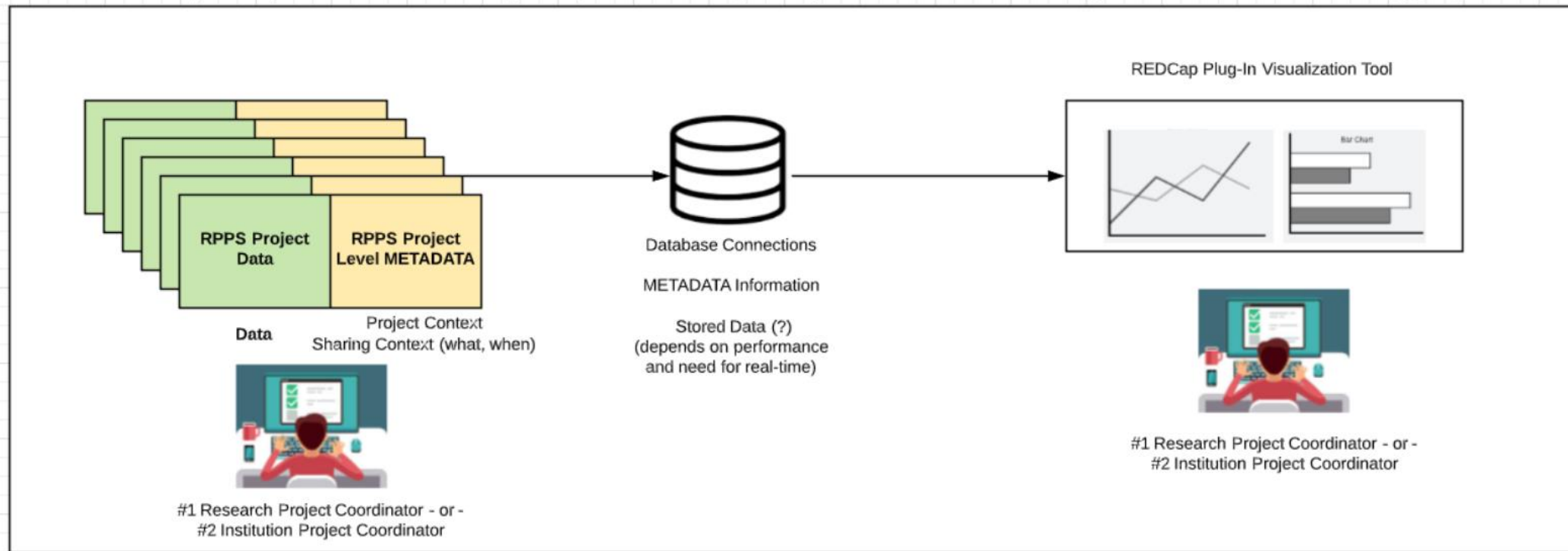
## USE CASE #1 (Project Collection) + USE CASE #2 (Institutional Benchmarking) --- Single Capture



# Use Cases as the Foundation

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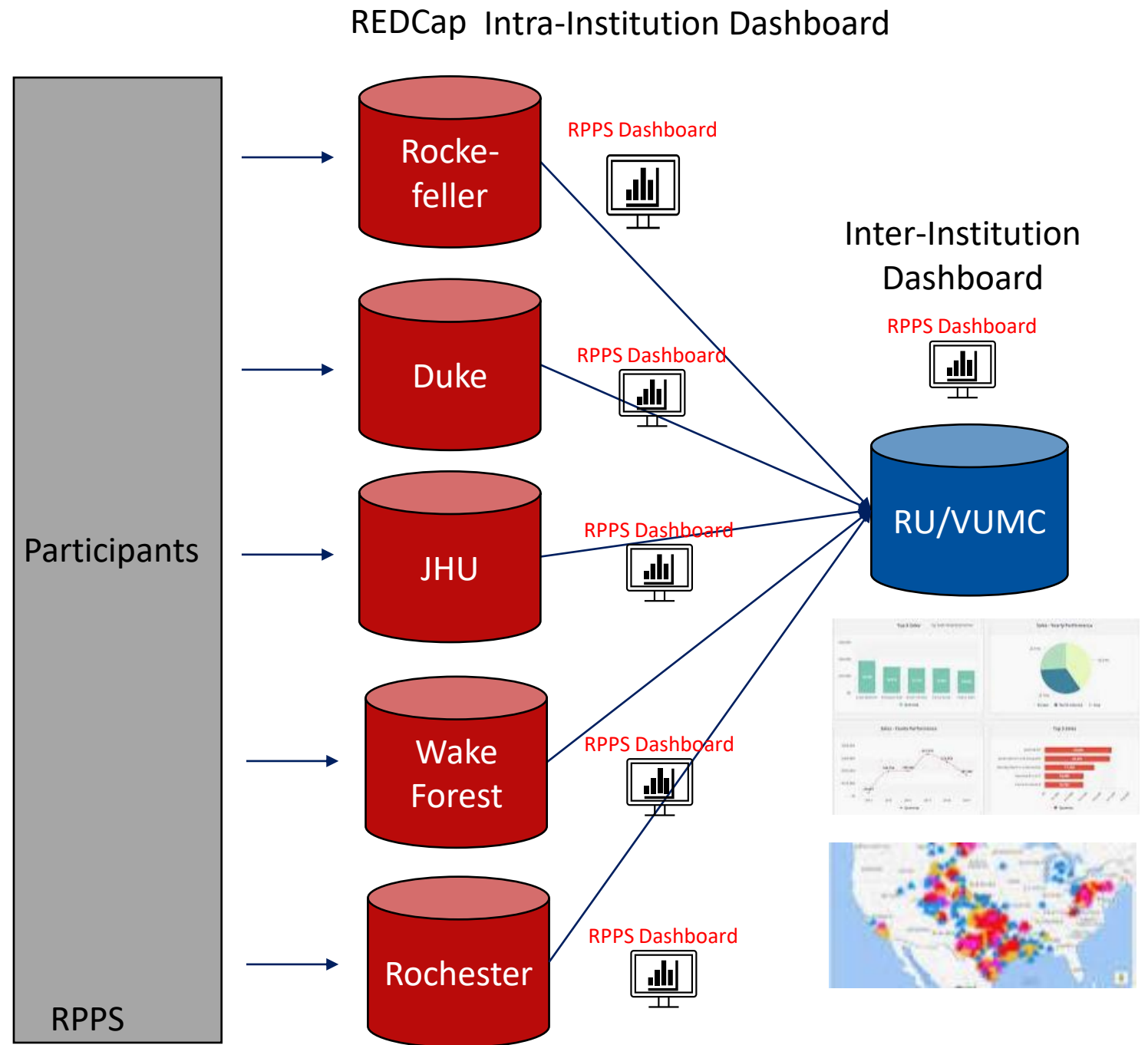
## USE CASE #3 (Multiple Research Projects, Unit Level, Temporal Benchmarking) --- Intrainstitution Aggregation



# Data Flow

- Data collected from participants using REDCap
- **Intra-Institution dashboards hosted locally**
- **Inter-Institution dashboard**

Supported in part by NIH/NCATS  
Grant # U01TR003206



# EPV At-a-Glance Dashboard

Demo



**Duke** Clinical & Translational  
Science Institute

[ctsi.duke.edu](https://ctsi.duke.edu)

## At-A-Glance Dashboard - Empowering the Participant Voice

Reasons for leaving a study



Race



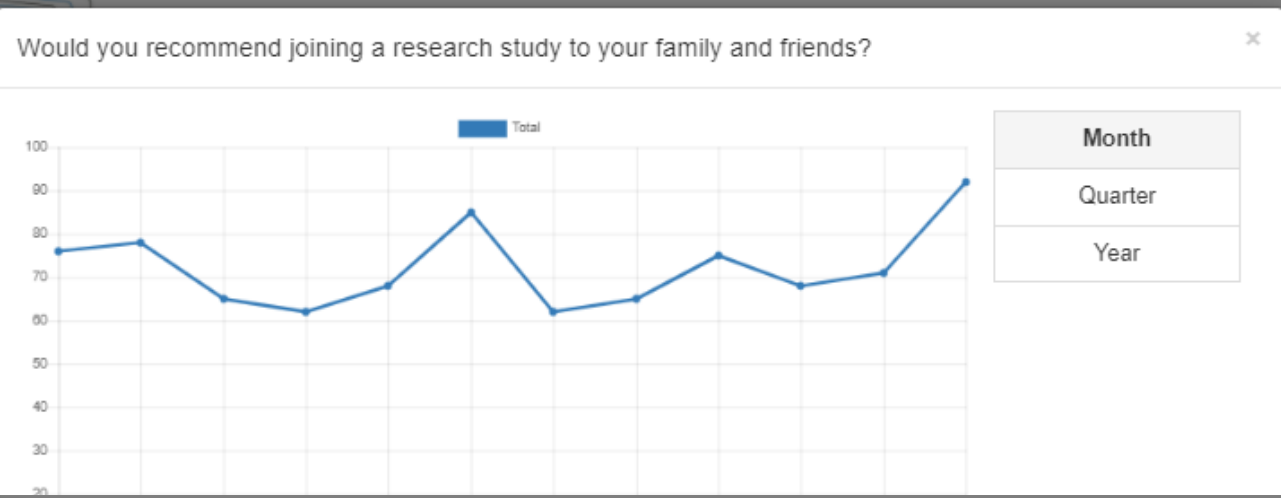
Load Table

% Responding Very or Somewhat Important	TOTAL	Asian	American Indian or A	Black or African Ame	Native Hawaiian or o	White	NO RACE REPORTED	MULTIPLE
Pain or discomfort related to participation	55	44	56	68	100	52	80	45
Worried about risks of treatment	55	56	67	68	100	52	70	55
Side effects that occurred during the study	54	56	67	63	100	52	70	64
Invasion of privacy	35	63	33	42	0	32	56	36
Too much time spent waiting around	35	56	33	37	0	34	56	36
Time commitment required	48	78	44	47	50	45	78	45
Family/work issues unrelated to the study	37	56	22	47	50	35	33	27
Interactions with research team	34	33	22	53	100	32	33	36
Not getting test results	33	67	33	53	100	29	33	45
Undue pressure to stay in study	24	33	11	53	0	20	33	18
Problems with study payments	30	44	33	58	0	26	50	45
Unexpected tests and procedures that occurred during the study	32	44	38	50	50	29	40	36
Transportation/parking	30	44	33	42	0	28	44	36

Participant perception ▼ No filter ▼ Select a date range... Load Table

Top Box Score ?

	TOTAL
Would you recommend joining a research study to your family and friends? <span>?</span> <span>📊</span>	71
Did the informed consent form prepare you for what to expect during the study? <span>?</span> <span>📊</span>	67
Did the information and discussions you had before participating in the research study prepare you for your experience in the study? <span>?</span> <span>📊</span>	57
Did the research team members listen carefully to you? <span>?</span> <span>📊</span>	80
Did the research team members treat you with courtesy and respect? <span>?</span> <span>📊</span>	80
During your discussion about the study, did you feel pressure from the research staff to join the study? <span>?</span> <span>📊</span>	87
Did the research staff do everything possible to provide assistance with any language difference you might have? <span>?</span> <span>📊</span>	-
When you were not at the research site did you know how to reach the research team if you had a question? <span>?</span> <span>📊</span>	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? <span>?</span> <span>📊</span>	45
Did you feel you were a valued partner in the research process? <span>?</span> <span>📊</span>	61
If you considered leaving the study, did you feel pressure from the Research Team to stay? <span>?</span> <span>📊</span>	80
Did the research staff respect your cultural background (e.g. language, religion, ethnic group)? <span>?</span> <span>📊</span>	-



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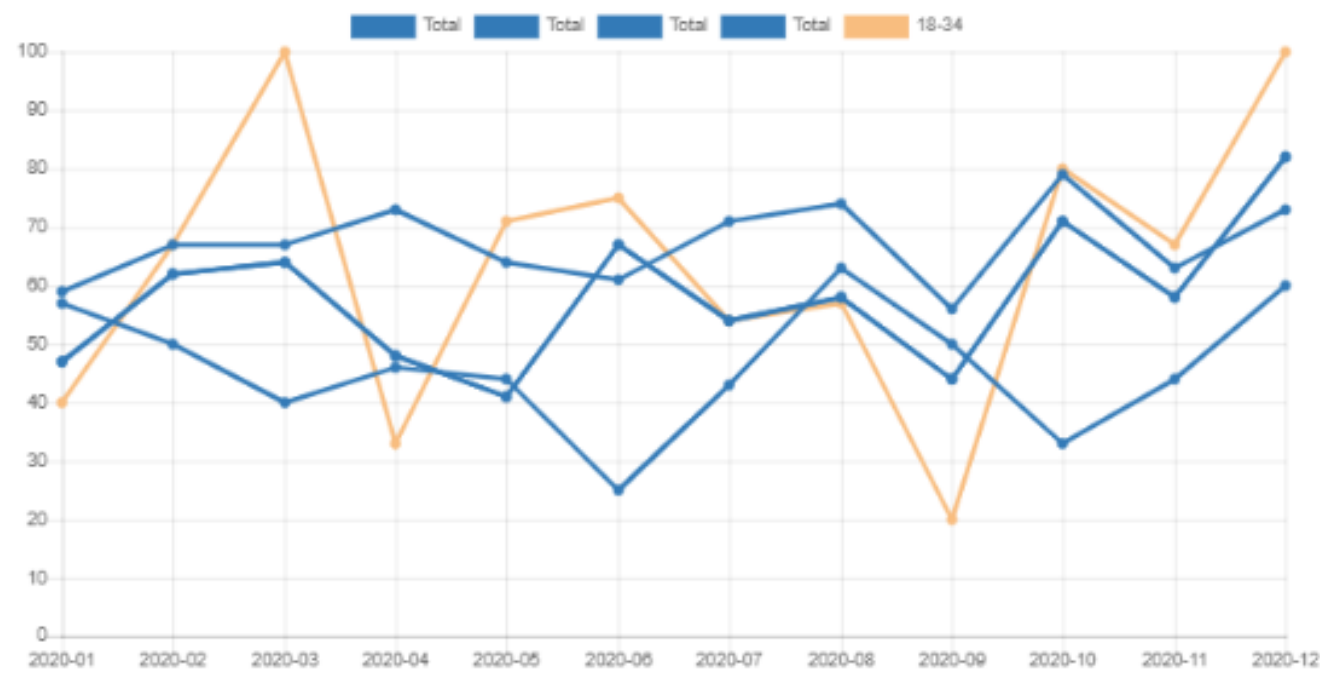
Close

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

18-34 35-44 45-54 55-64 65 and over

- Top Box Score**
- 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 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 study?
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- When you were not at the research site did you know how to reach 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 members to stay?
- Did the research staff respect your cultural background (e.g. language, religion, ethnic group)?

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



Month  
Quarter  
Year

- Total
- 18-34
- 35-44
- 45-54
- 55-64
- 65 and over
- NO AGE REPORTED

Close

Month  
Quarter  
Year

Month  
Quarter  
Year

Month  
Quarter  
Year

# Duke Implementation of EPV/RPPS

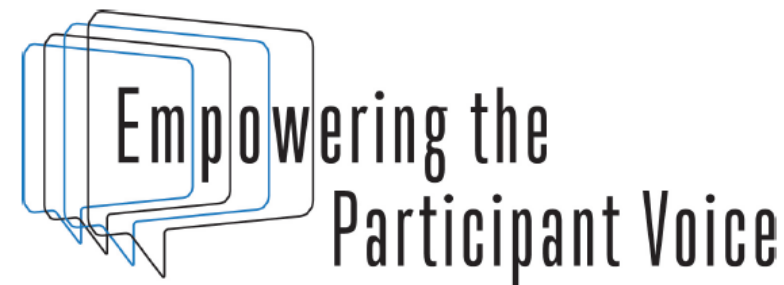


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# Duke Use Cases

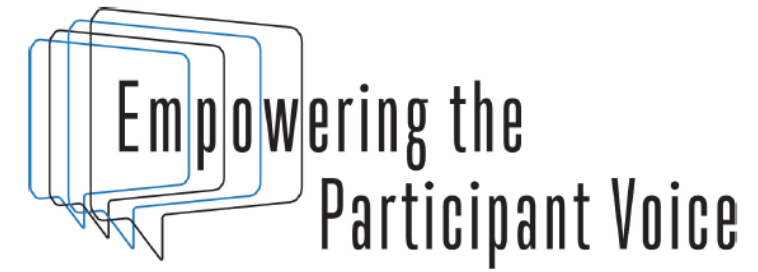


- Inclusive of all study types
  - Interventional
  - Observational
  - Population health based
  - University based

## Row level metadata

- Study type
  - Observational/interventional
  - Organization Unit: Onc/Non-Onc
  - Management Group: Primary (CRU), Secondary (Tier, other)
- Randomization
- Summary accrual

# Framework for Survey Delivery

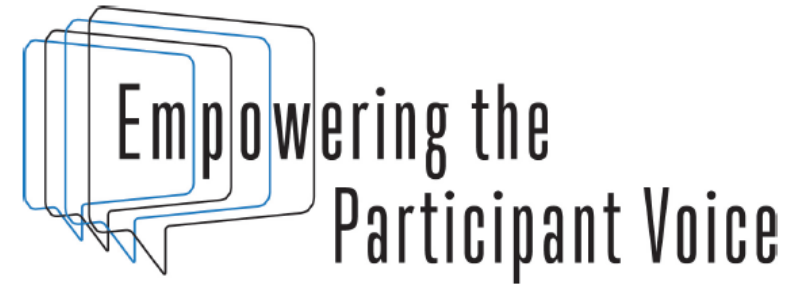


- CURRENT: Email, MyChart (studies using OnCore accrual)
- FUTURE: Postal mail – to be as inclusive as possible
- FUTURE: Twilio (texting)
- OASIS and OnCore Teams working together:
  - Pull necessary data to allow survey distribution to participants in pilot studies
  - Test data integrity and workflow
  - Ensure no participants surveyed more than once/year

# Implementation Efforts



- April 2020: Initial **Project** IRB approval (exempt)
- **September 2021: Implementation** IRB approval as QI Project
- Quarterly Stakeholder meetings
- Centralization of survey distribution in RIC/DOCR
- Identify Current RPPS Users (pre-pilot):
  - Psychology and Behavioral Health PIs (2) (tobacco use studies)
  - School of Nursing PI (1) working with LatinX community
- Data extract integrity & workflow test: late August
- Full thread test: late September
- Identify pilot studies
- Test survey with/without motivation questions in one study population



# Next Steps

- Full thread test in late September
- Randomize 60-100 PERT study participants to receive survey with/without motivation questions – is there a differential response and/or completion rate?
- **Identify volunteer pilot studies willing to allow US to survey their participants.**
- ***Interested?***  
**[https://duke.qualtrics.com/jfe/form/SV\\_0jjH5R7quNhPQTc](https://duke.qualtrics.com/jfe/form/SV_0jjH5R7quNhPQTc)**





***Thank You!***

**Would you like to learn more?**

Visit: <https://www.rockefeller.edu/research/epv/>

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