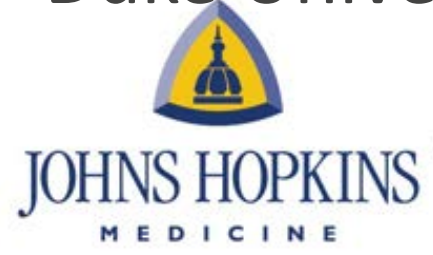


# Empowering the Participant Voice

## Empowering the Participant Voice (EPV): Participant Feedback to Improve the Clinical Research Enterprise

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### Introduction

#### WHY?

- A critical piece of translation that often remains unexamined is the actual research participation experience. *How do participants characterize that experience? Do they feel adequately prepared? Do they feel pressured? Do they feel respected? Do they feel like partners? What went well? What could have been done better?*
- Enabling participants from diverse populations to speak directly to the Clinical Research Enterprise about their experiences helps build trust.
- The resulting data provide an evidence-base for hypothesis-generation and testing to drive the development of research processes that are more participant-centered and more effective.

#### HOW?

##### A validated tool for participant feedback:

- Research Participant Perception Survey (RPPS) is participant-centered, free, validated in thousands of participants, and takes 2-3 minutes to complete.
- Common institutional challenges to fielding RPPS include missing infrastructure, standards, guidance, expertise and benchmarks to facilitate success.

##### The Innovation:

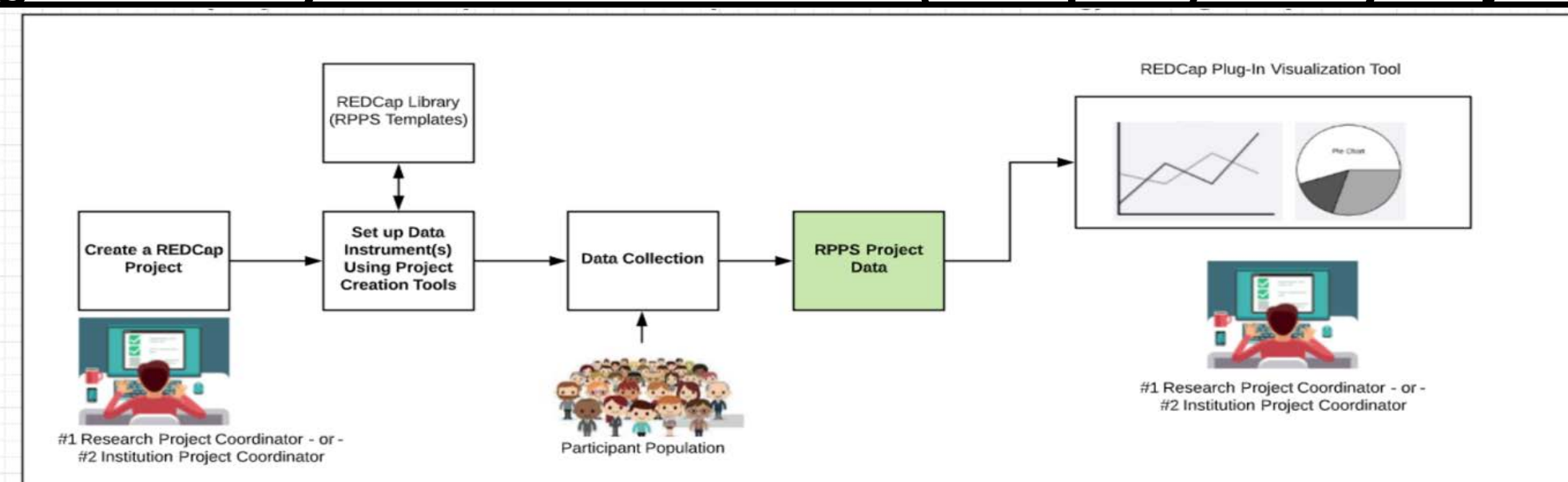
- Empowering the Participant Voice (EPV)** is a six-CTSA collaboration to **DEVELOP** RPPS/REDCap infrastructure and tools that streamline RPPS fielding and enable local and national benchmarking, **DEMONSTRATE** ease of use and impact through Use Cases, and **DISSEMINATE** to the Consortium & REDCap community.

Here we report the successful development of the EPV RPPS/REDCap infrastructure, and early results from Use Cases at the collaborating sites.

### Approach

- Guiding Principles**
- Engage diverse stakeholders iteratively to inform the value proposition
  - Develop common standards to preserve validity, ability to compile /compare data
  - Respect local autonomy; site implementation reflects institutional priorities
  - Technology: Optimize ease-of-use; plugins, streamline, integrate

#### Figure 1. Study level + Institution level (Enterprise) Survey Projects



### Infrastructure and Implementation

Figure 2. Flow of information for Aggregation (for national benchmarking)

REDCap Intra-Institution Dashboard

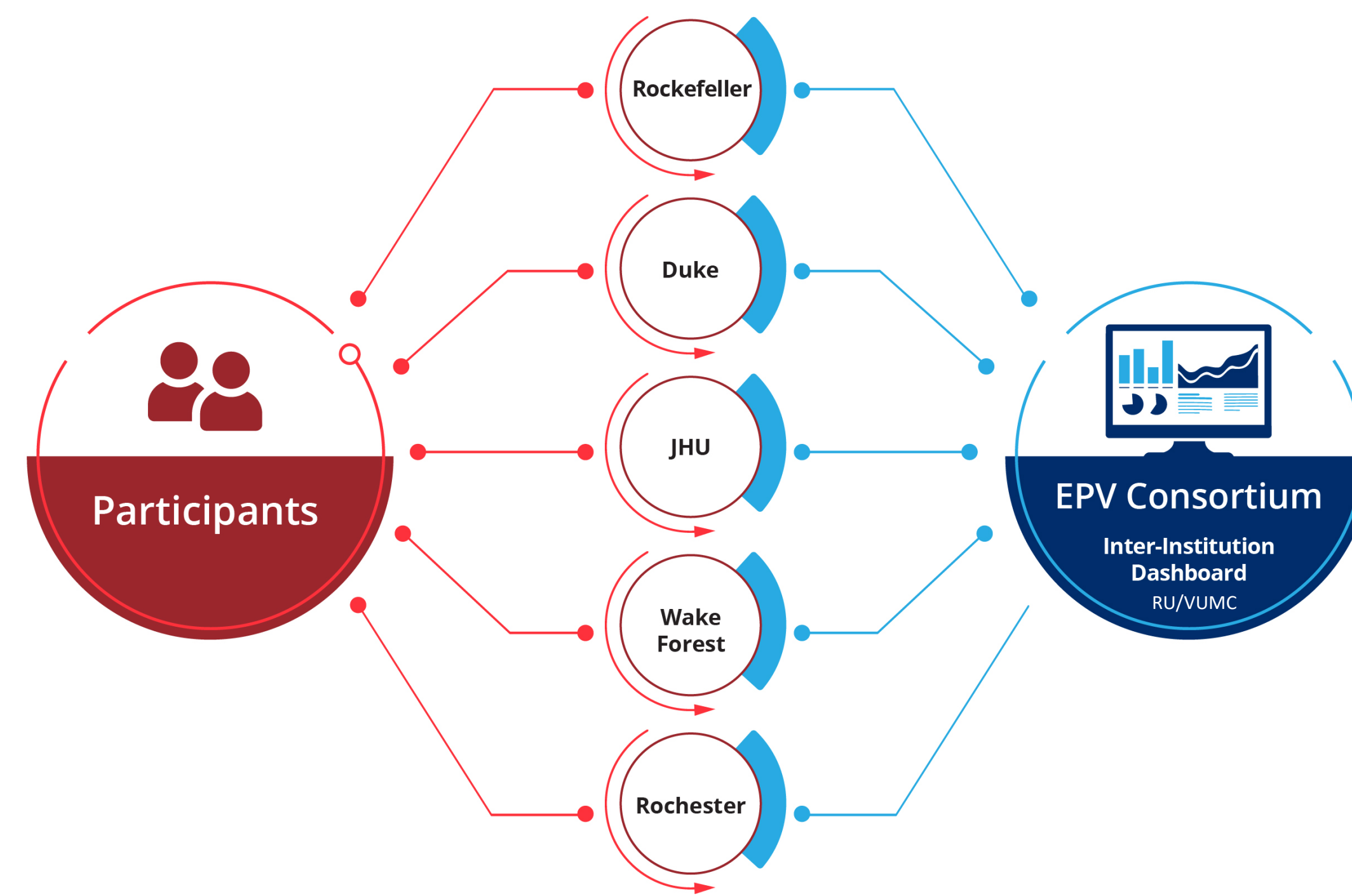


Table 1 Use Cases at Collaborating Sites: Early Implementation

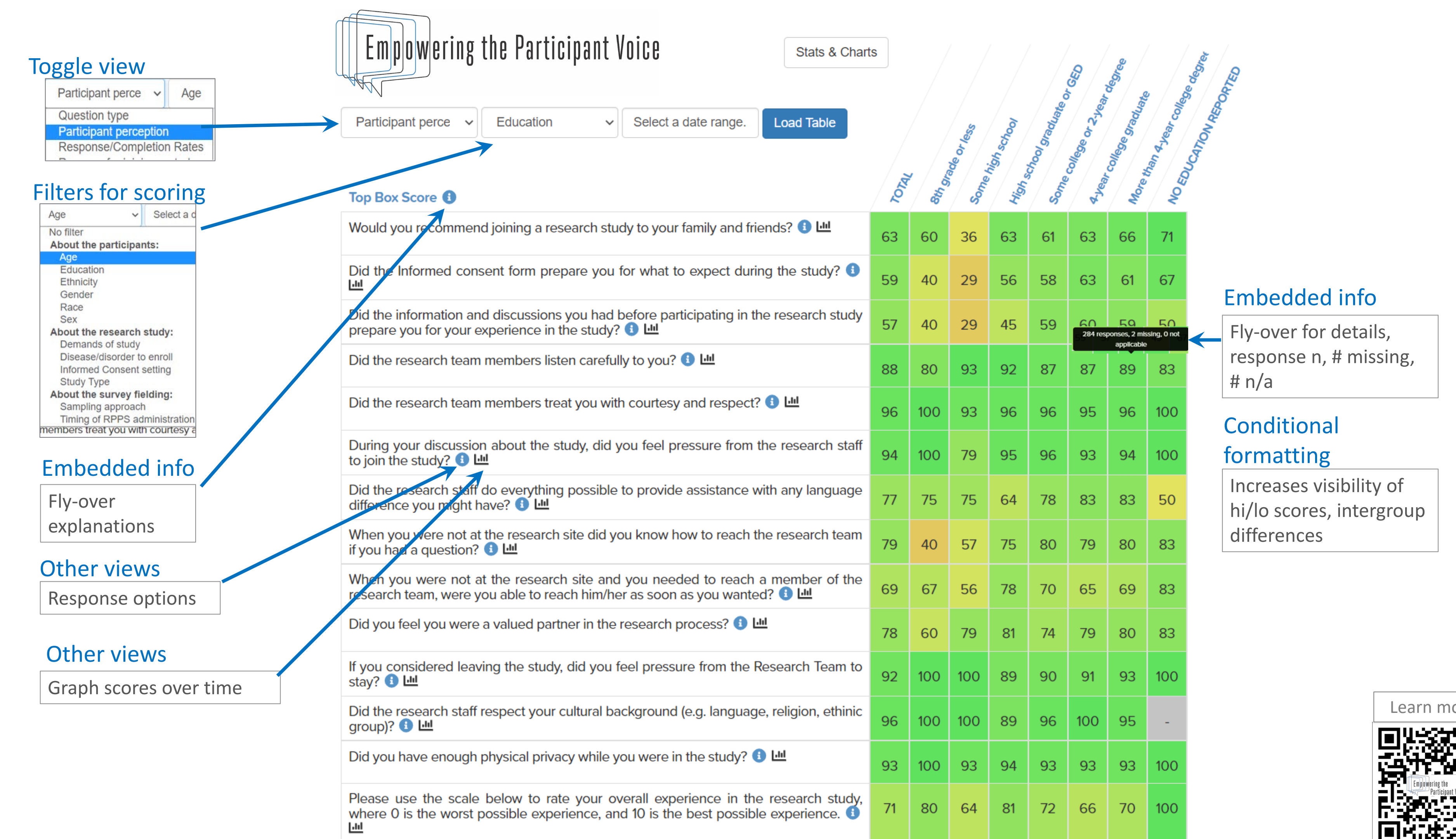
Site	Sampling model	Sample	Timing during study participation	Special feature	Initial Response Rate	First change to implementation
A	Study-level, multiple studies	Census/study, as added	Post-consent, End of study	Spanish language pilot, Pilot motivation questions	26%	Add/remove motivation questions did not affect response rate, Outreach
B	Enterprise** (institution-wide)	Random sample 6-monthly	Post-consent, Random	Return results to community via existing webpage	21%	Testing impact of outgoing message
C	Enterprise	Census monthly	Post-consent	Small changes with each batch	22%	Test financial incentives, timing of invitation; paper surveys for digital divide; Optima Mark Recognition app for upload
D	Enterprise	Census monthly	Post-consent, Ongoing, End of Study	8-year experience with RPPS, assess change	25%	Outreach: POC flyers, study team, global ads
E	Enterprise	Census 6-monthly	Post-consent, End of study	Fielding through Epic Portal	21%	Outreach: POC flyers, study team promotion

### Support

Supported in part by NIH/National Center for Advancing Clinical Translational Science (NCATS) Collaborative Innovation Award U01TR003206 (Rockefeller), and Clinical Translational Science Awards UL1TR002553 (Duke University), UL1TR003098 (Johns Hopkins University), UL1TR002001 (University of Rochester), UL1TR001866 (Rockefeller University), UL1TR002243 (Vanderbilt), and UL1TR001420 (Wake Forest University Health Sciences).

### Results

Figure 3. At-a-Glance Dashboard - Visual Analytics External Module for Total and Filtered analysis of Survey Outcomes



**Conclusion - Closing a translational gap:** Direct feedback from representative populations about their experiences in research is essential to understand and improve barriers to broad participation in research. We created streamlined RPPS/REDCap infrastructure that provides a platform for collecting participant feedback at scale, local evaluation, and national benchmarking.

Also on EPV team: Eva Basacompte Moragas, Scott Carey, Cameron Coffran, Carrie Dykes, James Goodrich, Cody Johnson, Schuyler Jones, Issis Kelly-Pumarol, Evelyn Krieter, Cassie Lewis-Land, Sierra Lindo, Liz Martinez, Michael Musty, Pavithra Panjala, Adam Qureshi, Jamie Roberts, Ellis Thomas, R. Vaughan, Lynne Wagenknecht