

# Empowering the Participant Voice

## Wouldn't you like to know what your participants are thinking?

Rhonda G. Kost MD<sup>1</sup>, Joseph Andrews PhD<sup>2</sup>, Raneer Chatterjee MD<sup>3</sup>, MPH, Alex Cheng PhD<sup>4</sup>, Ann Dozier PhD<sup>5</sup>, Daniel Ford MD MPH<sup>6</sup>, Paul A. Harris PhD<sup>4</sup>, & EPV Consortium

<sup>1</sup>The Rockefeller University, <sup>2</sup>Wake Forest School of Medicine, <sup>3</sup>Duke University, <sup>4</sup>Vanderbilt University, <sup>5</sup>University of Rochester, <sup>6</sup>Johns Hopkins University



### Introduction

#### WHAT?

**Empowering the Participant Voice (EPV)** is a Rockefeller-led six-CTSA collaboration to *DEVELOP, DEMONSTRATE, and DISSEMINATE* shared infrastructure to collect participants' feedback about their research participation, analyze the results, and improve research.

Table 1 Value Proposition

Value to your Clinical Research Enterprise
Build participant trust
Assess informed consent
Tailor approach to participants
Improve experience of underrepresented groups
Identify best practices
Improve recruitment and retention
Identify high and low performing teams
Understand COVID impact
Establish benchmarks
Develop participant-centered evidence base

#### HOW?

- DEVELOP RPPS/REDCap tools that streamline fielding the Research Participant Perception Survey and enable local and national benchmarking
- DEMONSTRATE impact and ease of use through locally configured site Use Cases
- DISSEMINATE tools to Consortium & REDCap community

#### WHY?

- Participant feedback adds Value to your Clinical Research Enterprise.
- Analytic capability of infrastructure provides evidence-base for decisions.

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

### Support

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### Approach

Figure 1. Overview of Implementation

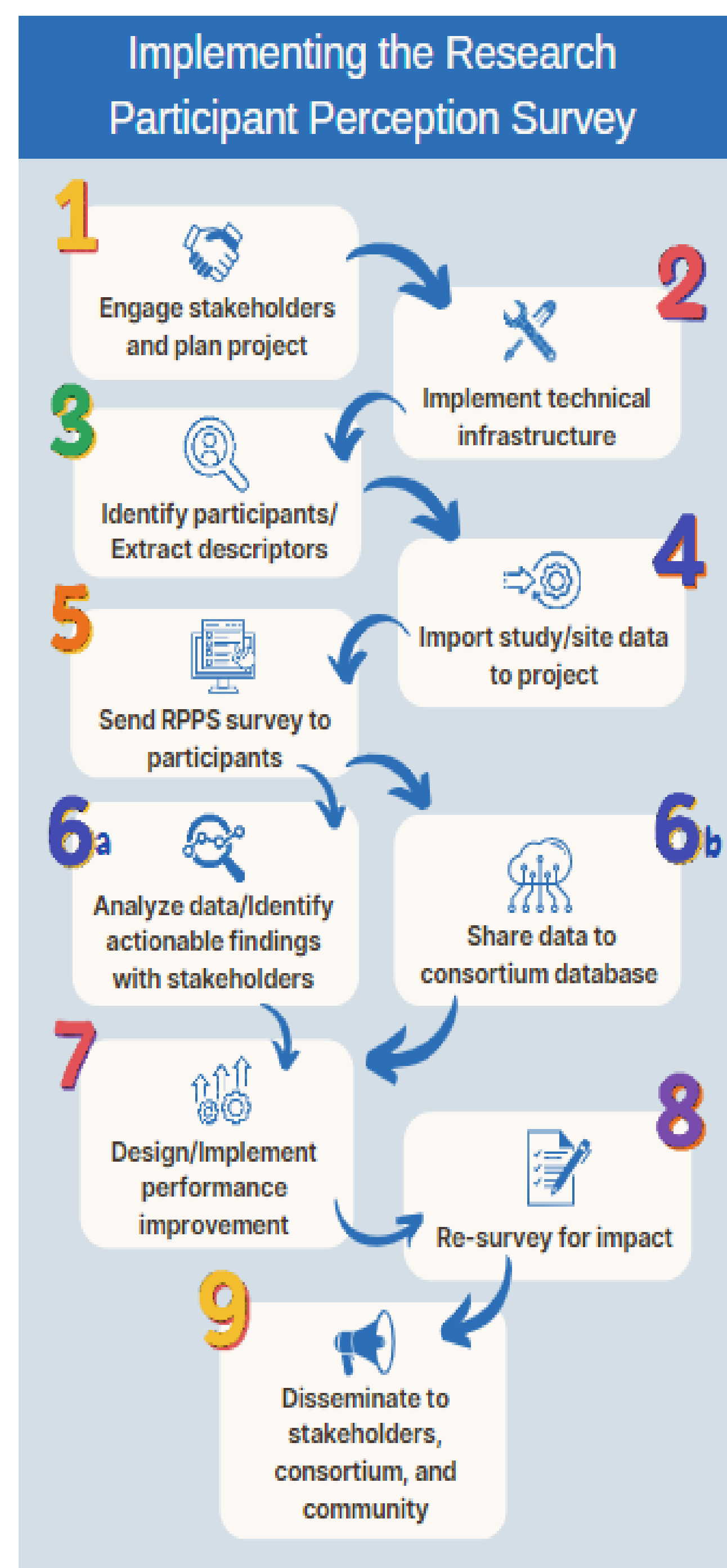


Figure 2. At-a-Glance Dashboard - Visual Analytics and Filters

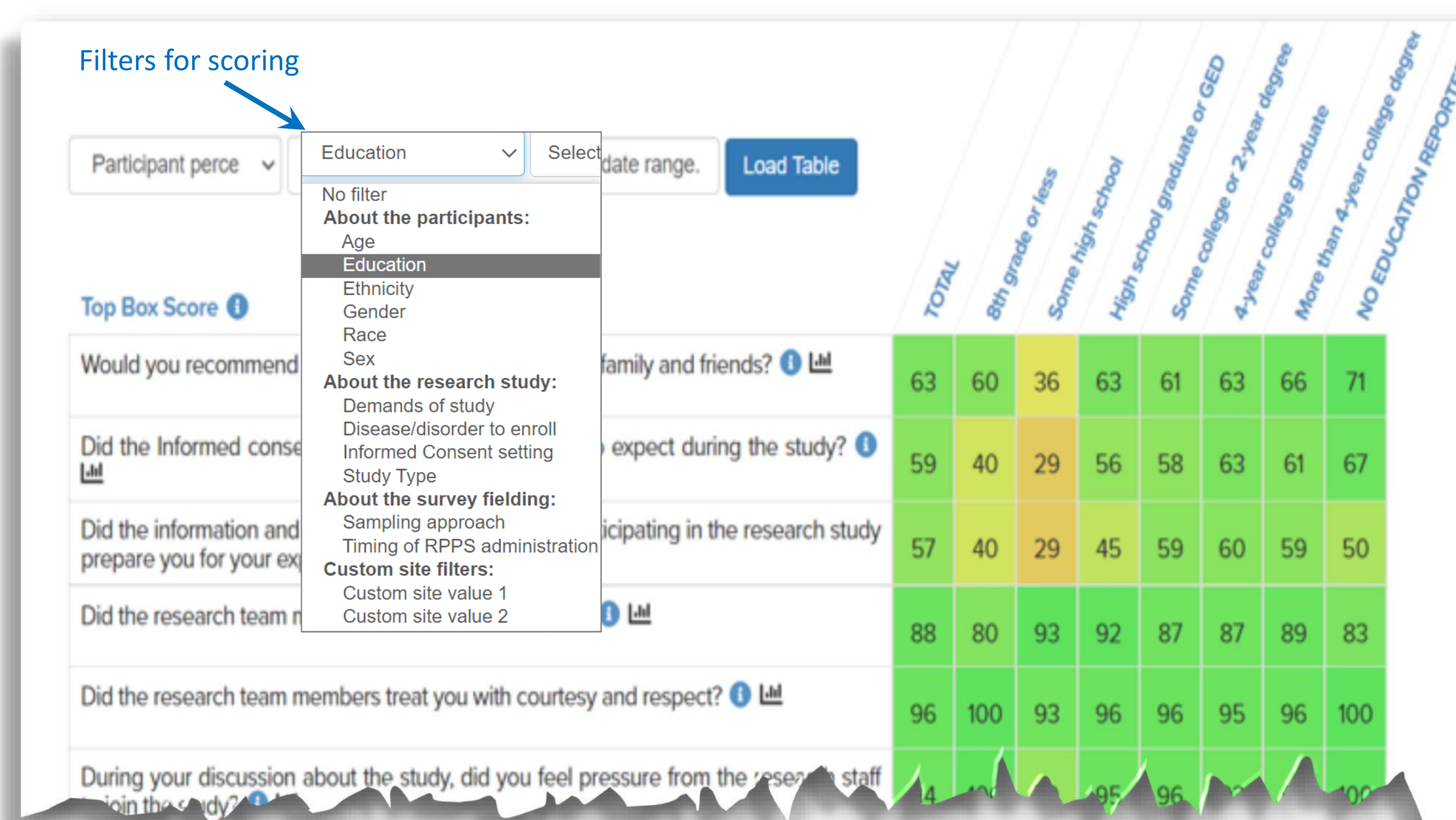
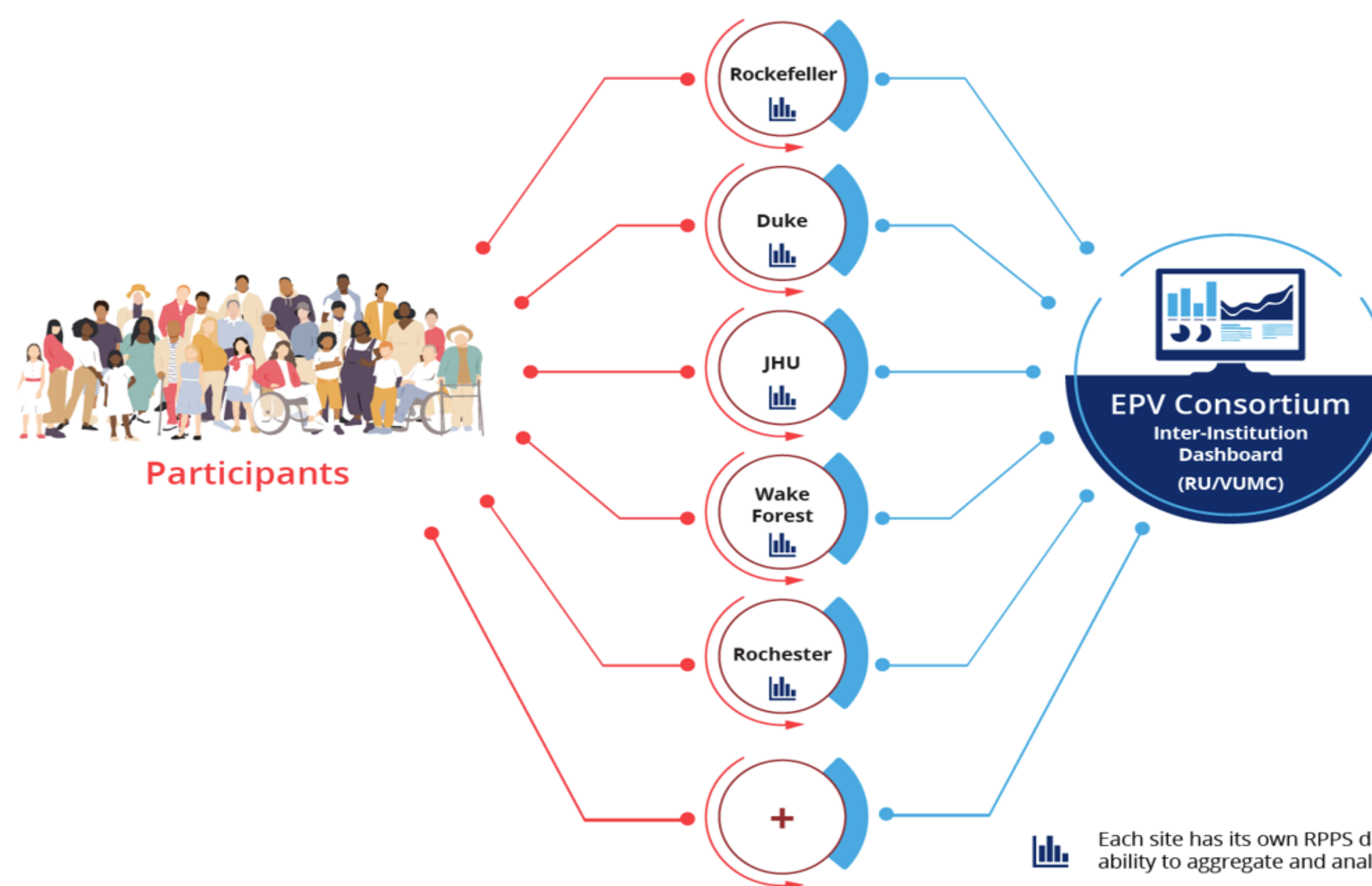


Figure 3. Flow of Information for Aggregation (EPV Consortium Dashboard)



### Results

"Our involvement in the (EPV) program and our efforts to share said involvement... has generated significant interest within our CTSI... and across various clinical research units...such that surveying participants about their experiences is being "baked into" new programs and initiatives here.." EPV Site Team 1

"The Institutional value of the survey is already becoming apparent ...Research coordinators and administrators perceived challenges in document translation and language interpretation as a frustration point. The RPPS results illustrate that participants view..(this) as an opportunity for improvement as well. With these data the EPV team has more than anecdotal evidence of the need for process changes and... resources in this area." - EPV Site Team 5

The survey information that we have gathered...is helping us target our efforts to improve the research participant experience as it relates to participant payments, better description of financial burden in the consent process, and return of research results. Participants' desire to receive final results of the research is a top stakeholder issue." - EPV Site Team 2



### Next Steps - DISSEMINATION

- We are ready for Early Adopter institutions who are interested in adopting the EPV RPPS/REDCap infrastructure to collect and learn from their own participants' feedback.
- As the EPV Consortium Database grows, analyze benchmarks, best practices, trends & opportunities.
- Interested sites should meet with institutional leadership and key stakeholders to gauge interest and share the value proposition. Contact Dr. Rhonda Kost, Project Principal Investigator, at [kostr@rockefeller.edu](mailto:kostr@rockefeller.edu) to explore feasibility and value for your institution and the EPV Consortium.

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