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

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INTRODUCTION

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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 experience, analyze and compare the results, and improve research.

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Table 2. Site configurations and early impact

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MEDICAL CENTER

Configuration Model	Method of Administration	Response rate	Finding	Impact Leveraging survey results to recognize study team and staff efforts			
A- Enterprise level – census, tracks to study	Email	20%	Positive trend identified in participant scores for feeling like a valued partner in the research process over 8+ years.				
B- Enterprise level – sampled, no study linkage	Email and Text message	18%	Participant Dissatisfaction with timing of reimbursement for study participation	Institution-wide change to alternative payment vendor			
C- Enterprise level – CTMS only, tracks to study	Email and Paper	20%	Cancer center participants gave lower than average ratings on measures of Informed Consent	Leadership implemented additional informed consent trainings for Investigators			
D- Enterprise level – census, tracks to study	Patient Portal	20%	Participants indicated difficulty with language assistance in languages other than English and Spanish	Institution gathering stakeholder feedback to determine which language services to offer			
E- Study level – with aggregation	Email	27%	Only 75% of participants in one study indicated that they knew how to reach the study team when they were not onsite	Study team distributed contact cards to participants. Positive change in communication scores			

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SPECIFIC AIMS

> **DEVELOP** RPPS/REDcap tools that streamline fielding the Research Participant Perception Survey and enable local and national benchmarking (2020-2021) > **DEMONSTRATE** impact & ease of use through locally configured Use Cases (2021 - 2023)

Now:

> **DISSEMINATE** tools to the Consortium & REDCap community to expand reach and impact. (2022- present)

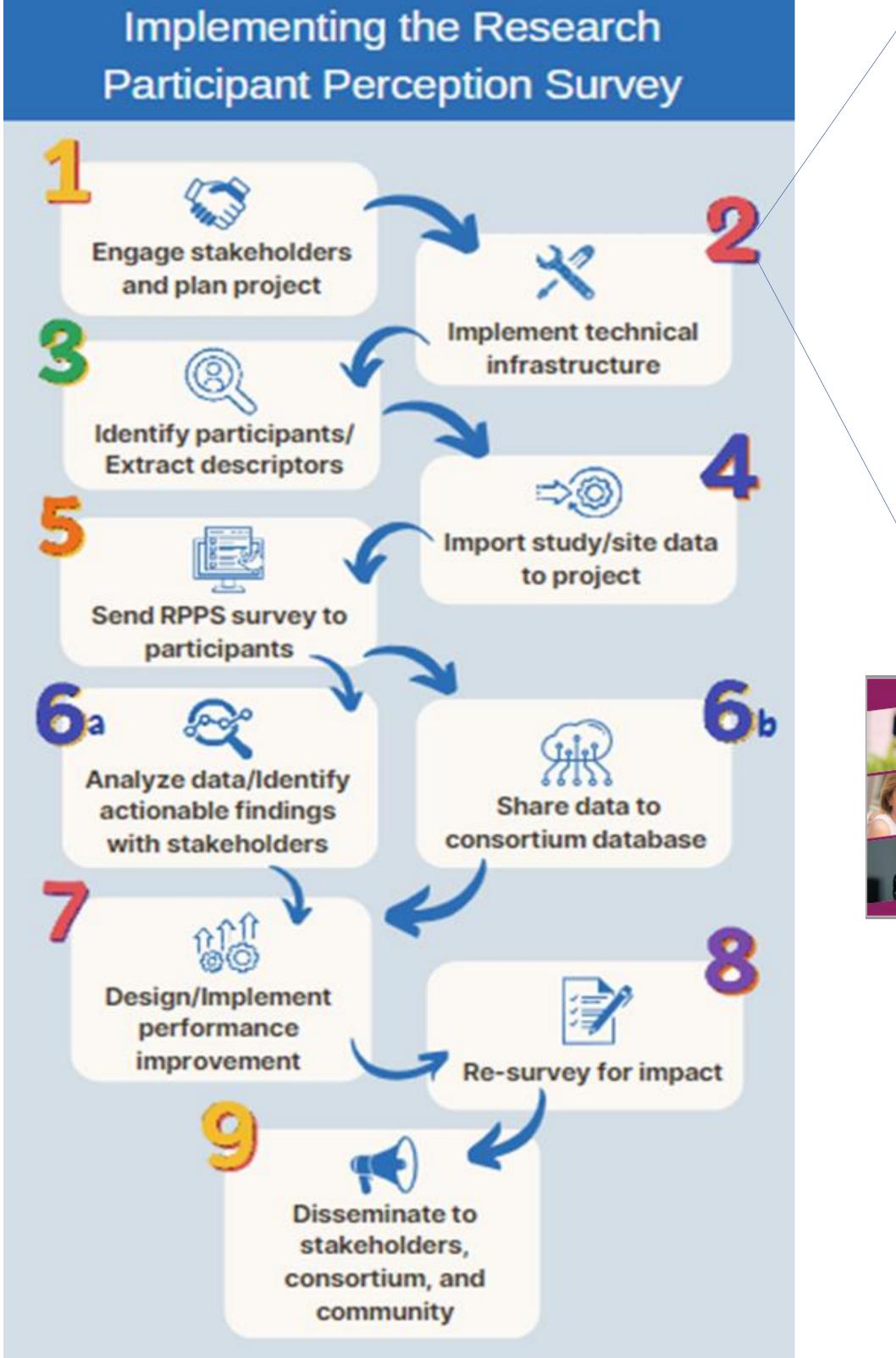
Table 1. Value Proposition

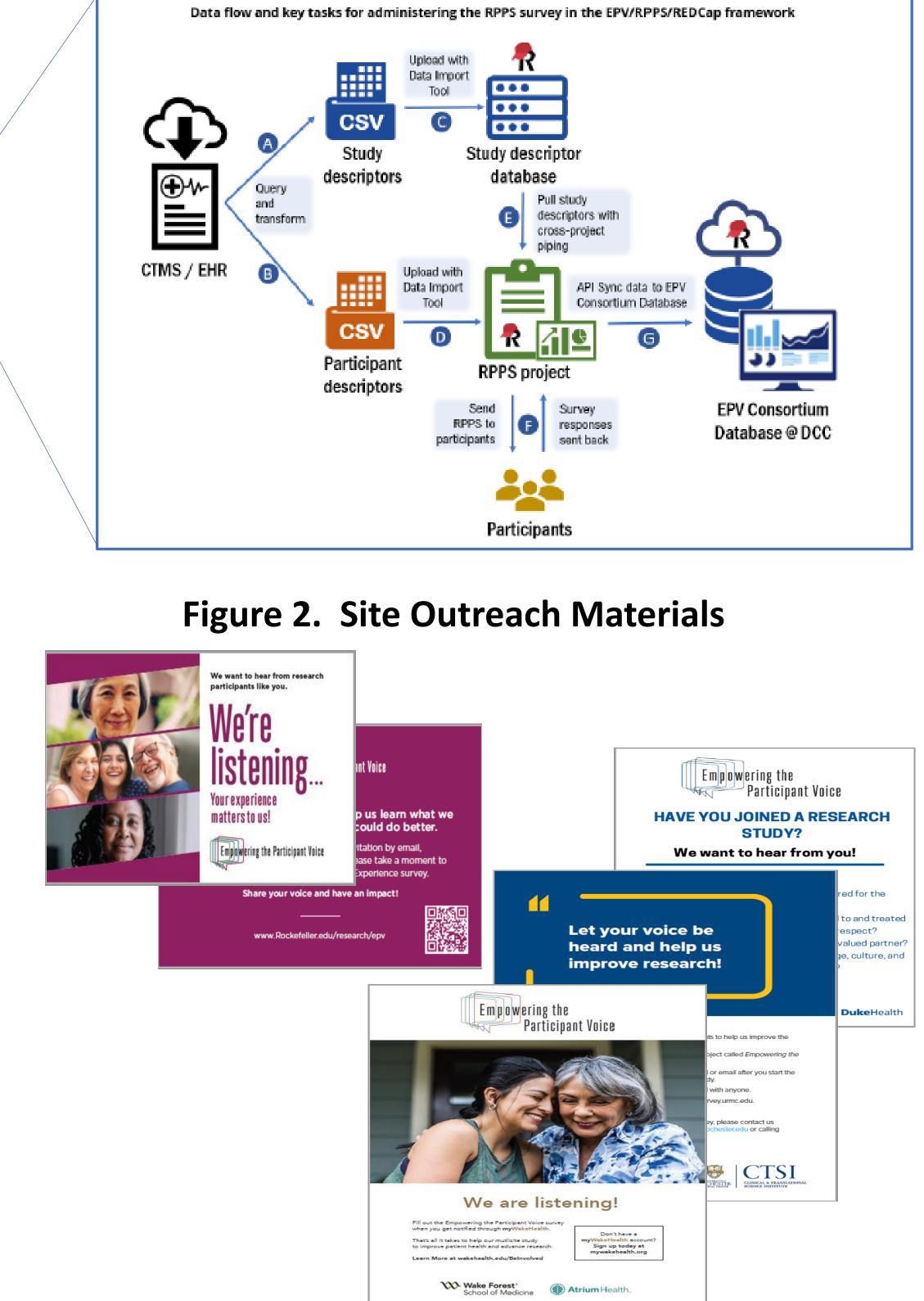
Value to the Clinical Research Enterprise
Build participant trust
Assess informed consent
Tailor approach to participants
Improve experience of underrepresented groups
Identify best practices
Improve recruitment and retention
Identify high and low performing teams
Understand COVID impact
Establish benchmarks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

Figure 3. At-a-Glance Dashboard - Visual Analytics and Filters

Participant perce Education Select a date range. Load Table Top Box Score	TOTAL	Bth grad	Some L.	High school	Some Some	4 year ollege or 2 year of	More Ollege graduate	NO EDUCATION -
Would you recommend joining a research study to your family and friends? ()			36	63	61	63	66	71
Did the Informed consent form prepare you for what to expect during the study?			29	56	58	63	61	67
Did the information and discussions you had before participating in the research study prepare you for your experience in the study? ① Le	57	40	29	45	59	60	59	50
Did the research team members listen carefully to you? 1	88	80	93	92	87	87	89	83
Did the research team members treat you with courtesy and respect? 🕕 止			93	96	96	95	96	100
During your discussion about the study, did you feel pressure from the research staff								

Figure 1. Overview of Implementation





Top Insights from the Dashboard

- As of March 2023, the EPV Consortium Database has descriptors for 13,981 participants and 2,661 survey responses for a 19% response rate across sites.
- Sites are analyzing results with stakeholders, identifying actionable findings, and designing responsive initiatives
- More about At-a-Glance dashboard in EPV Implementation Guide

Aim 3: Dissemination



We are Disseminating the EPV RPPS/REDCap infrastructure to Early-Adopter institutions. Three CTSAs are actively on-boarding, with 4

more on deck. Contact Dr. Rhonda G. Kost, Project Principal

Investigator, at kostr@rockefeller.edu to explore feasibility and value for your institution and the EPV Consortium.



Included in EPV Consortium: Eva Basacompte Moragas, Ellis Thomas, Lindsay O'Neal, Scott Carey, Cameron Coffran, Natalie Schlesinger, Carrie Dykes, James Goodrich, Issis Kelly-Pumarol, Cassie Lewis-Land, Sierra Lindo, Liz Martinez, Pavithra Panjala, Adam Qureshi, Jamie Roberts, Roger Vaughan, Lynne Wagenknecht. Supported by NIH/National Center for Advancing Clinical Translational Science (NCATS) Collaborative Innovation Award U01TR003206 (Rockefeller), UL1TR002553 (Duke University), UL1TR003098 (Johns Hopkins University), UL1TR002001 (University), UL1TR002001 UL1TR001420 (Wake Forest University Health Sciences).