

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

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INTRODUCTION

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.

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
Develop participant-centered evidence base

Figure 1. Overview of Implementation

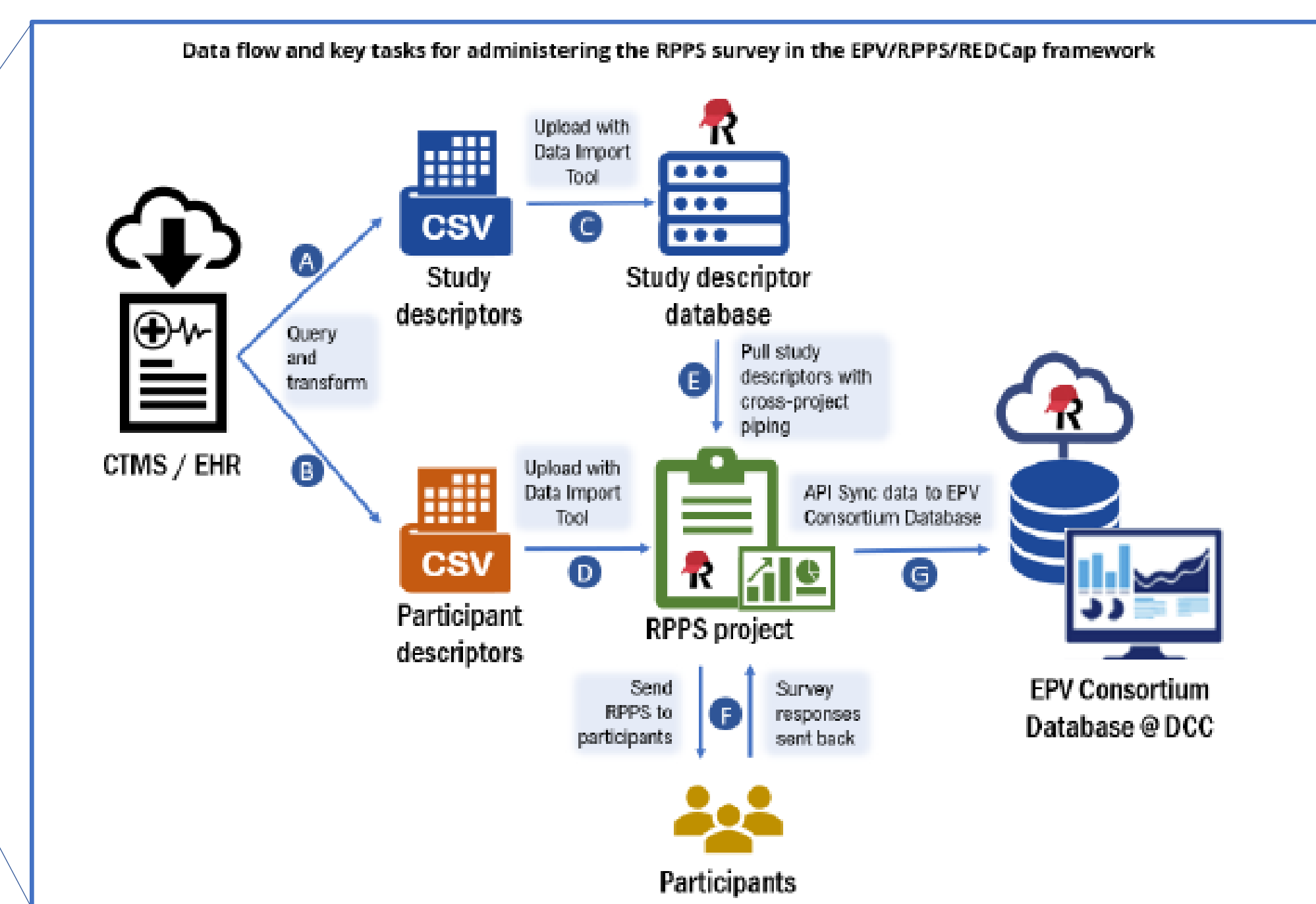
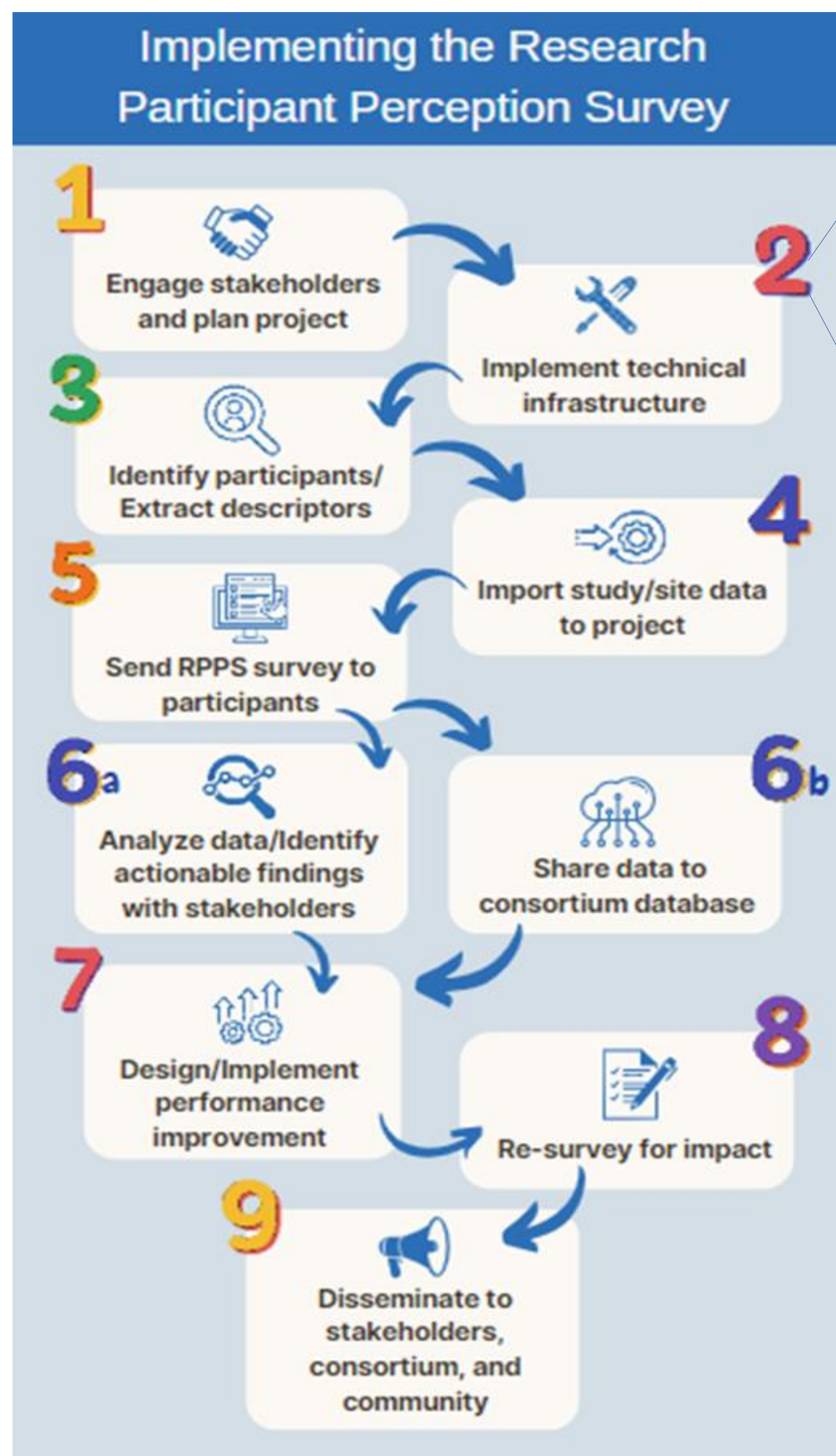


Figure 2. Site Outreach Materials

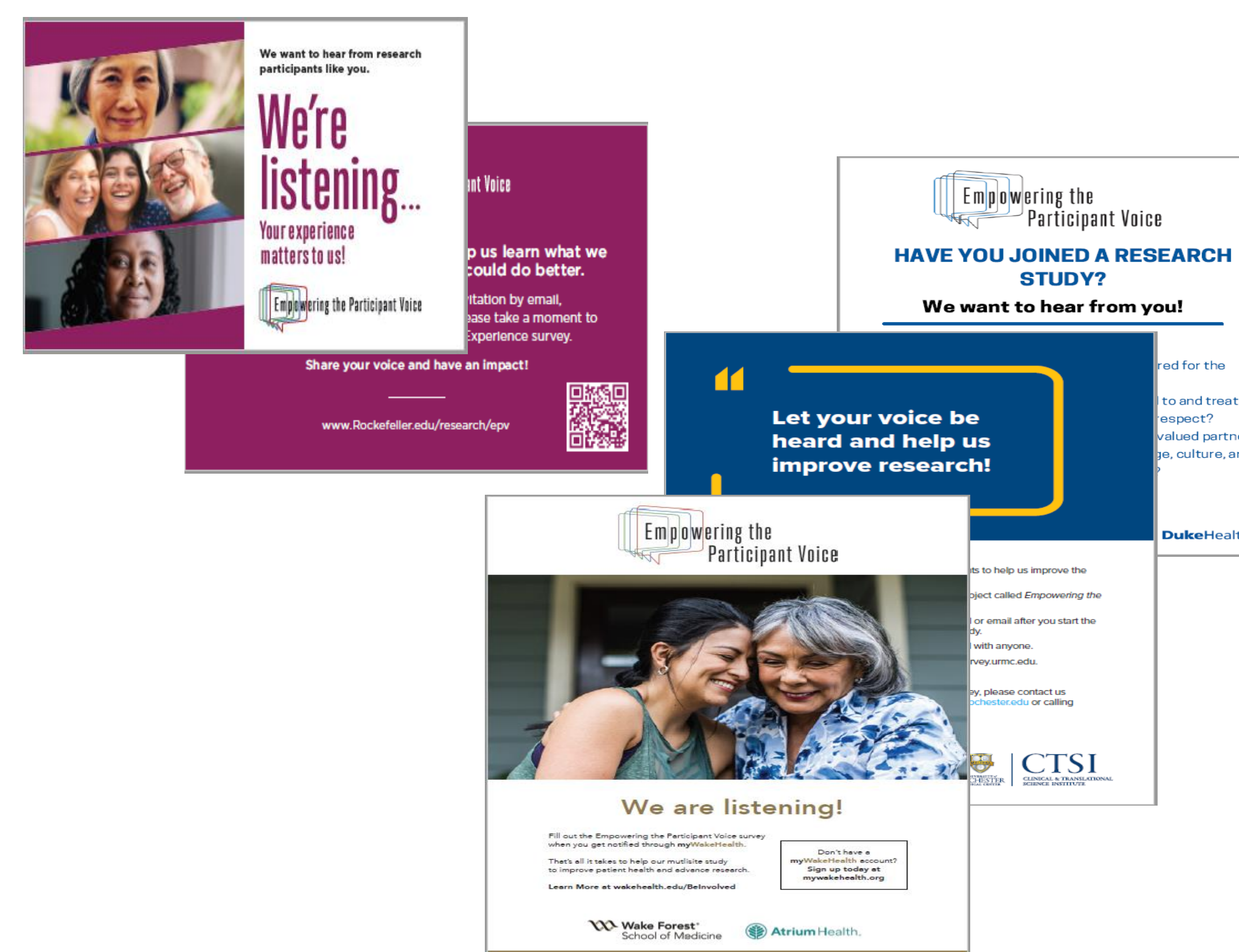
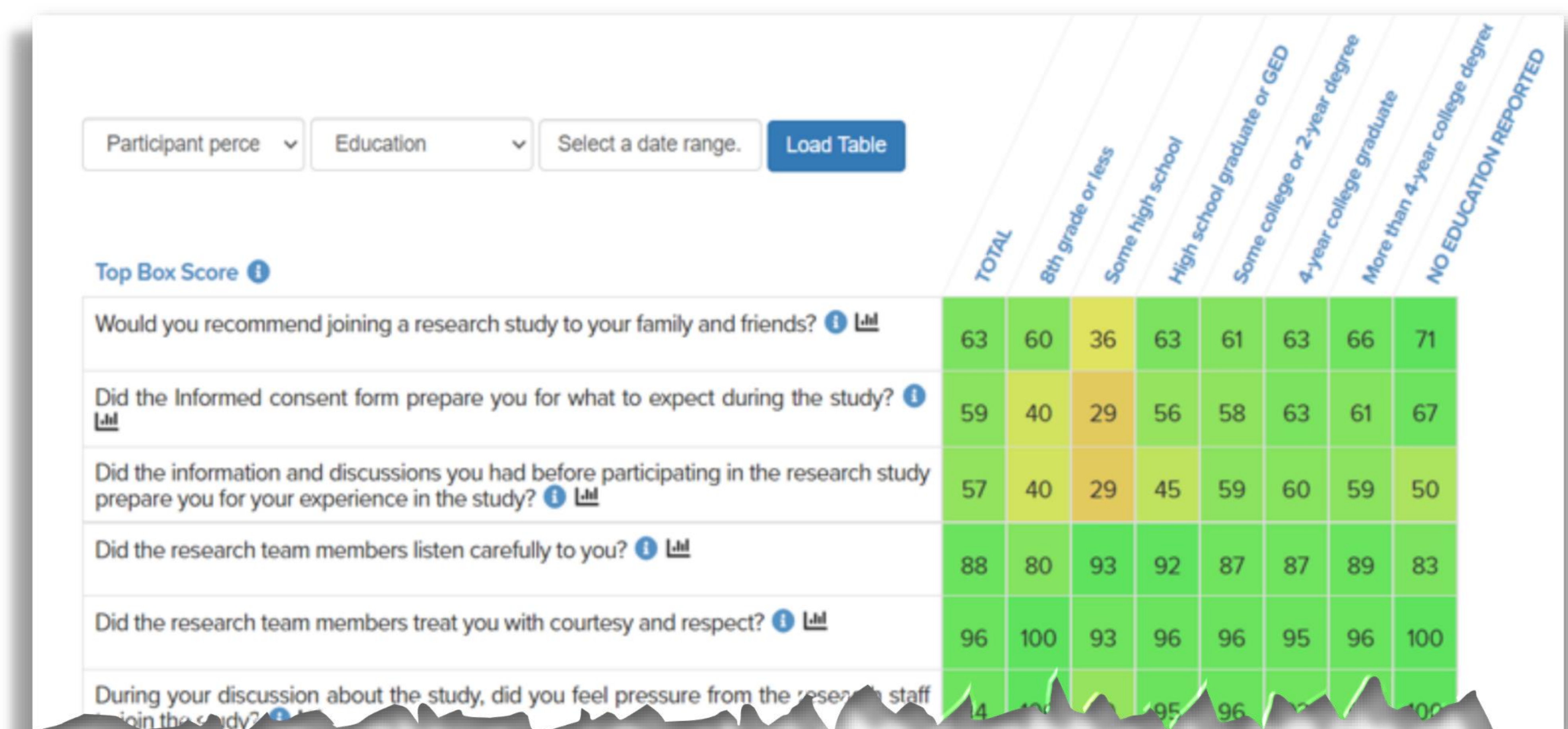


Table 2. Site configurations and early impact

Configuration Model	Method of Administration	Response rate	Finding	Impact
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.	Leveraging survey results to recognize study team and staff efforts
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

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



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 CTSA's 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.

