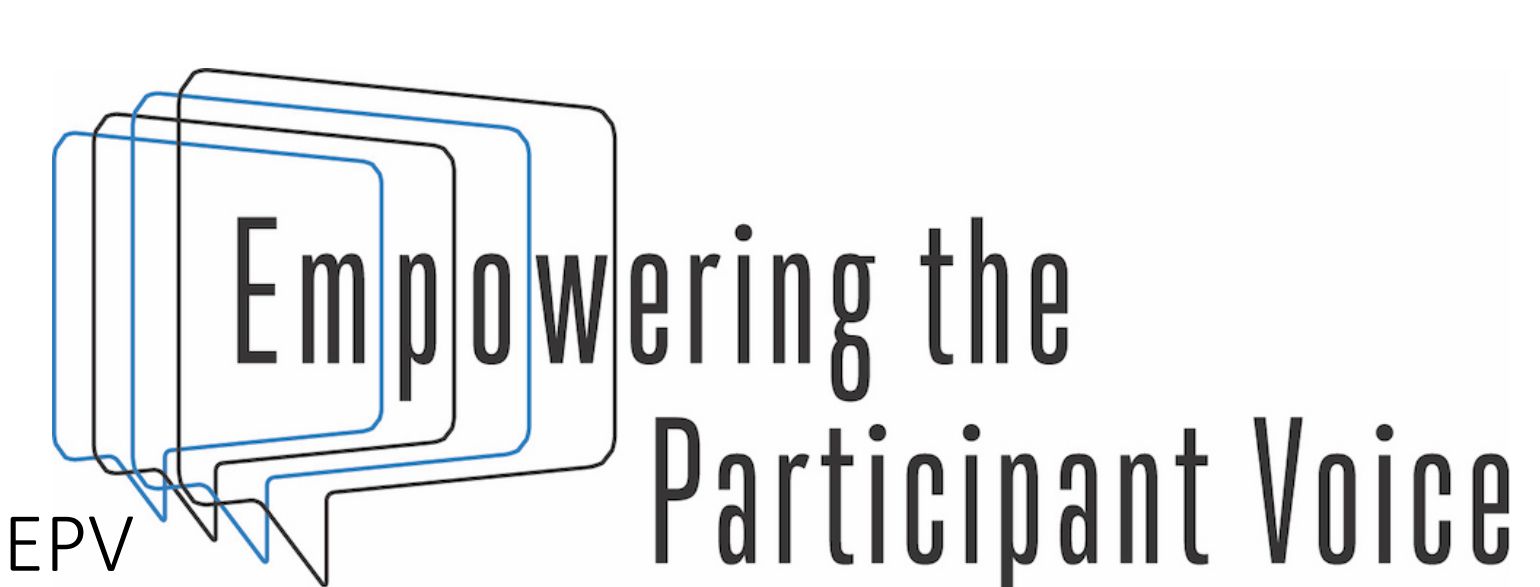




# Placing Participant Experiences at the Center of Improving Research by:



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## INTRODUCTION & AIMS

The Empowering the Participant Voice (EPV) project (2020 – 2024) leveraged the validated Research Participant Perception Survey and the REDCap platform to

**1) DEVELOP, 2) DEMONSTRATE, and 3) DISSEMINATE** infrastructure to collect participants' feedback about their research experiences, creating an evidence base to analyze and compare results and improve research.

## METHODS

**Develop:** EPV Learning Collaborative, engaged diverse stakeholders, standards for data comparability, created RPPS/REDCap tools that streamline fielding and analysis of the Research Participant Perception Survey, and enabled benchmarking. Sites designed Use Cases reflecting local priorities.

**Demonstrate:** Sites implemented Use Cases using the same survey, [EPV project setup file, tools, and standards](#). Sites iterated to improve survey reach and developed an Implementation Guide. Sites analyzed local findings with stakeholders and benchmarked with peers.

**Disseminate** – Shared results to participants, public, CTSA's, OHRP, agencies, others. Implementation Guide, tools, infrastructure available free of charge via [website](#); Operational and technical advice for Early Adopters, aggregate data.

## RESULTS

### Who answered the survey?

**Total:** By March 2024, 5020 surveys were returned; response rate 19% (Site range: 12-53%). **Gender:** Woman 59%; Man 35%, Non-binary 1% None of these terms describe me, or Prefer not to say 5%. **Race:** Asian 2.5%, American Indian or Alaska Native 1.1%, Black or African American 14.9%, Native Hawaiian and Pacific Islander 0.2%, White 83.4%. **Ethnicity:** Spanish or Hispanic or Latino/a/x origin/descent: 6.1%.

\*Some sites do not share demographic data for all surveys sent (36% missing), essential for calculating representativeness.

### At-a-Glance Dashboard: Multi-site Aggregate TopBox Scores. Filters to view experiences by demographics



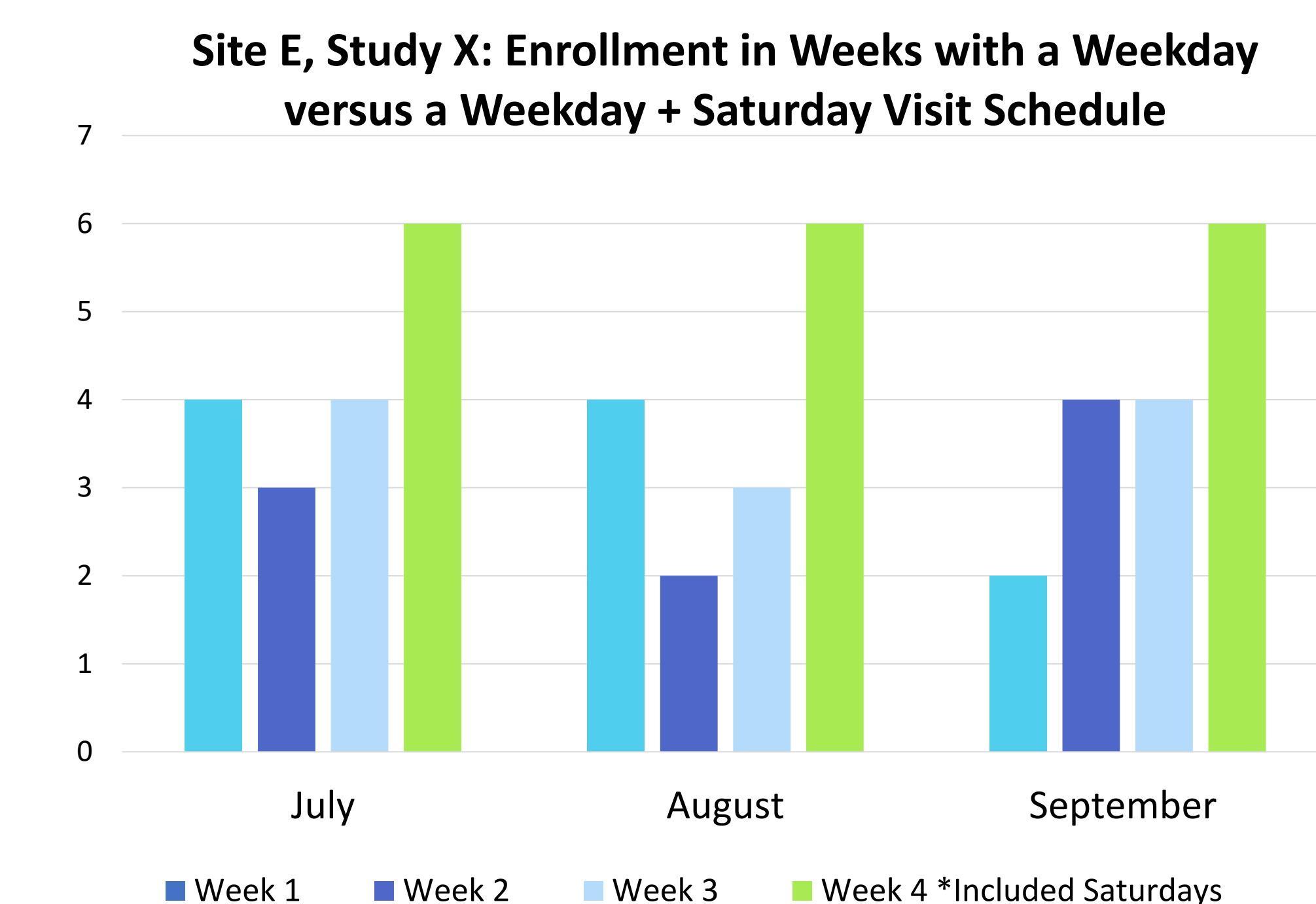
### Value Proposition

| 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 & low performing teams          |
| Understand COVID impact                       |
| Establish benchmarks                          |
| Develop participant-centered evidence base    |

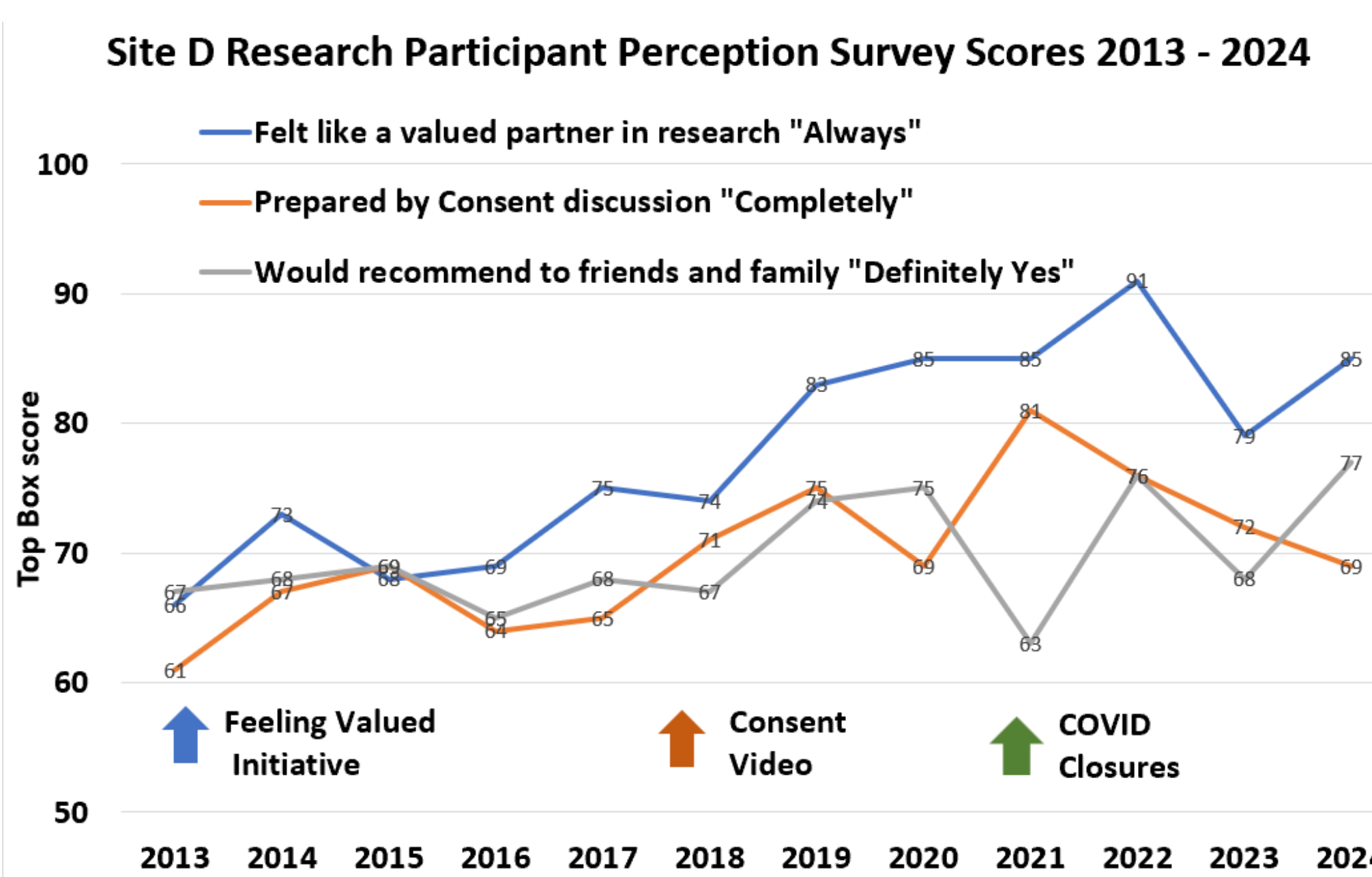
## RESULTS (cont.)

### Acting on Findings

| Site | RPPS Finding   | Action  | Evaluation/Impact                                   |
|------|--|---|---|
| A    | Disparities in receiving adequate language assistance                                      | Created Research Equity Council   | Pending   |
| B    | Complaints about payment delays<br>Strong preference to receive study results              | Implemented Greenphire<br>Planned return of results trial<br>RPPS results returned publicly   | Pending<br>Implemented                              |
| C    | Interest from Cancer Center leadership in comparing outcome data with other centers        | Multi-site project action: developed Cancer Center variable to filter responses from Cancer Center study participants                     | Pending implementation                              |
| D    | 37% respondents left free text comments<br>Recent decline in Overall rating/consent scores | Response/analysis committee<br>Study-specific actions address c/o<br>Reviewed with PI<br>Revision to consent training curriculum underway | Vendor<br>Change Protocol procedure                 |
| E    | Participants requested weekend study visits  | Saturday visits 1 week/month (one team)   | 60% increase in enrollment on wks w/saturday visits |

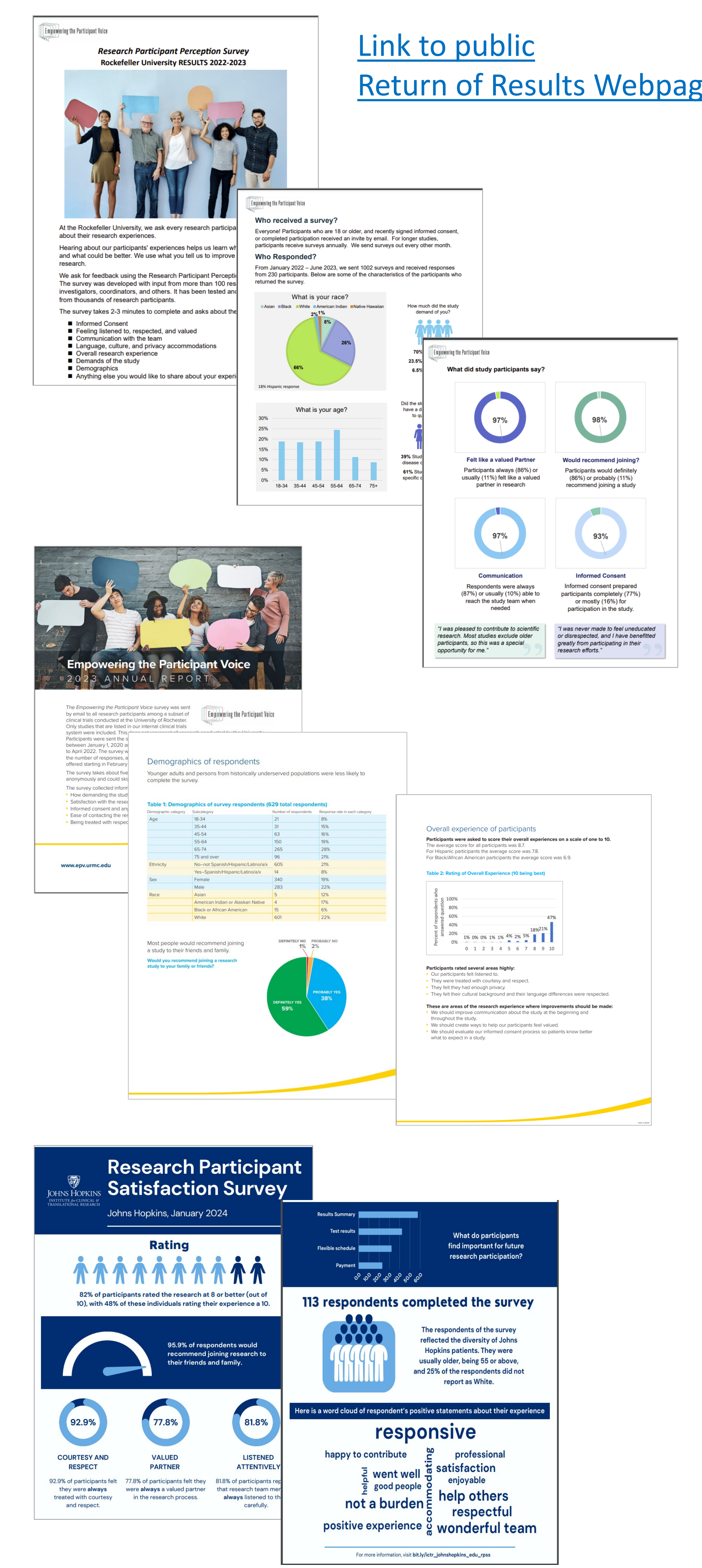


### Listening to participant feedback over time



## DISSEMINATION

TIN, OHRP, AAHRP Webinars, CABs, research teams, participants, community. Two early adopter sites live; others considering uptake.



[Link to public Return of Results Webpages](#)

## CONCLUSIONS

- Five sites fielded the RPPS using EPV tools for 2 years; the dashboard, data aggregation and selective filters enable insights locally and at scale.
- Overall, most participants (85-95%) awarded the highest rating to their experiences of feeling listened to, respected, and free from pressure.
- Fewer participants (60-74%) rated their experiences highly regarding consent, language, communication, overall rating & recommending research to others.
- Filters reveal group disparities /inequities in research experiences.
- **The data reveal differences in site and group experiences that present opportunities for collaboration, performance improvement, identification of best practices, and improving/accelerating research.**
- Next steps: Using RPPS to evaluate performance improvement initiatives in areas of need (consent, language) and designed for scale and generalizability.