Executive Summary

Participants' experiences in research studies influence how they feel about current and future participation, as well as what they say to others about participating in research. Listening and responding to participants' feedback about their research experiences can add **Value to your Clinical Research Enterprise**, e.g., it can help improve clinical study recruitment and retention, assure a robust informed consent process, and foster trust with participants and communities.

Participants who feel like partners in research give high ratings to their experiences. Participants who feel overlooked, cannot reach their teams, encounter unprofessional interactions, or don't understand what they signed up for, rate their experiences less positively. Data drives positive change.

Volunteers from different demographic groups may have different experiences, and the experience with various research teams or protocols can differ widely. Identifying opportunities for improvement, making changes to enhance the research experience, then measuring the impact of those changes, can benefit everyone in the research community.

**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

"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

Participants who feel like partners in research give high ratings to their experiences. Participants who feel overlooked, cannot reach their teams, encounter unprofessional interactions, or don't understand what they signed up for, rate their experiences less positively. Data drives positive change.

Volunteers from different demographic groups may have different experiences, and the experience with various research teams or protocols can differ widely. Identifying opportunities for improvement, making changes to enhance the research experience, then measuring the impact of those changes, can benefit everyone in the research community.

"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

Supported in part by NIH/National Center for Advancing Clinical Translational Science (NCATS) Collaborative Innovation Award U01TR003206, and CTSA awards UL1TR002553 UL1TR003098, UL1TR002001, UL1TR001866, UL1TR002243, and UL1TR001420.
The Empowering the Participant Voice (EPV) project provides free infrastructure to institutions to enable them to collect feedback from participants at scale. EPV provides streamlined tools for **Implementing the Research Participant Perception Survey (RPPS)** within a suite of REDCap-compatible tools.

The EPV team has validated the survey, built and tested the infrastructure, designed the tools, and standardized key elements of the process to make the process robust, comparison-ready, and reproducible.

Implemented by an institution’s own team, the EPV RPPS data can be used to evaluate key aspects of research participation. RPPS data provides opportunities within and across institutions to test innovations in alignment with institutional priorities and initiatives.

We created an **At-a-Glance Dashboard** for each site and for the Consortium to present the high-level results, conditionally formatted and filterable, without the need for data manipulation.

Five major academic medical center CTSAs have completed successful demonstration projects. Each Use Case was configured to accommodate local priorities, specific organizational and technical configurations, and to afford autonomy and flexibility in implementation. Sites are discovering benefits for the institution as well as for study teams and participants.
As sites weigh whether to join the EPV Consortium to field the RPPS, there are some Top Considerations associated with streamlined, successful implementations for most sites. Alternative configurations may offer advantages as well as trade-offs in some local contexts (details in Guide).

Top Considerations

- **Securing buy-in from top CTSA and/or institutional leadership** is essential to message priority and alignment, assure support, and foster engagement of diverse and interdisciplinary stakeholders.

- **Leveraging existing institutional, clinical research, and community stakeholders**, including IRB, faculty, research staff, Community Advisory Boards, engagement and outreach teams, and liaisons, taps established structures, resources, and familiarity with institutional initiatives, contributing to trust and sustainability.

- **Integrating the survey activities into existing institutional initiatives** such as Diversity, Outreach, Engagement, research protections, QA, performance improvement, and patient satisfaction aligns with institutional incentives and goals, and leverages existing workflow, mission, buy-in from stakeholders, and visibility for sustainability.

- **Including managers, specialists, and stakeholders on the EPV team**, such as PI, project manager, REDCap specialist, EHR/CTMS data analyst, and engagement/participant expert, enables smooth survey implementation.

- **Implementing the survey at the enterprise level** leverages institutional resources to increase scale and sustainability, minimizes duplication of effort, and assures an adequate response sample size.

- **Surveying a sufficient sample of eligible research participants** results in fuller representation of participants and studies, produces a meaningful data set, and minimizes bias.

- **Sharing (de-identified) survey response data with the EPV Consortium (DUA)** affords site confidentiality, builds trust with the community and consortium through transparency, develops the evidence base for benchmarking for sites to level set, and serves as a source of hypothesis generation and testing for innovation and best practices.

- **Joining the EPV Consortium as an early adopter** enables CTSA-CTSA collaboration, early access to innovative survey and analysis tools for collecting and acting on participant feedback, Research Learning Collaborative membership for peer and technical support, and the opportunity to impact design decisions.

“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. Participant desire to receive final results of the research is a top stakeholder issue.” - EPV Site Team 2

**To Start the Process:**

The first steps in implementing the EPV RPPS are to meet with your own institution’s leadership and key stakeholders to gauge interest and share the value proposition. Contact Dr. Rhonda Kost, Project Principal Investigator, at kostr@rockefeller.edu for an exploration of feasibility, effort, interest, and value for your institution and the EPV Consortium.