

Research Participant Perception Survey **Rockefeller University RESULTS 2023-2024**



The Research Participant Perception Survey (RPPS) was created with broad participant input and validated by a Rockefeller-led multi-site collaboration.

At the Rockefeller University, we ask every research participant for feedback about their research experiences. Hearing about our participants' experiences helps us learn what is working well and what could be better. We use what you tell us to improve how we conduct research.

We ask for feedback using the Research Participant Perception Survey (RPPS). The survey was developed with input from more than 100 research participants, investigators, coordinators, and others. It has been tested and revised with input from thousands of research participants.

The survey takes 2-3 minutes to complete and asks about the following topics:

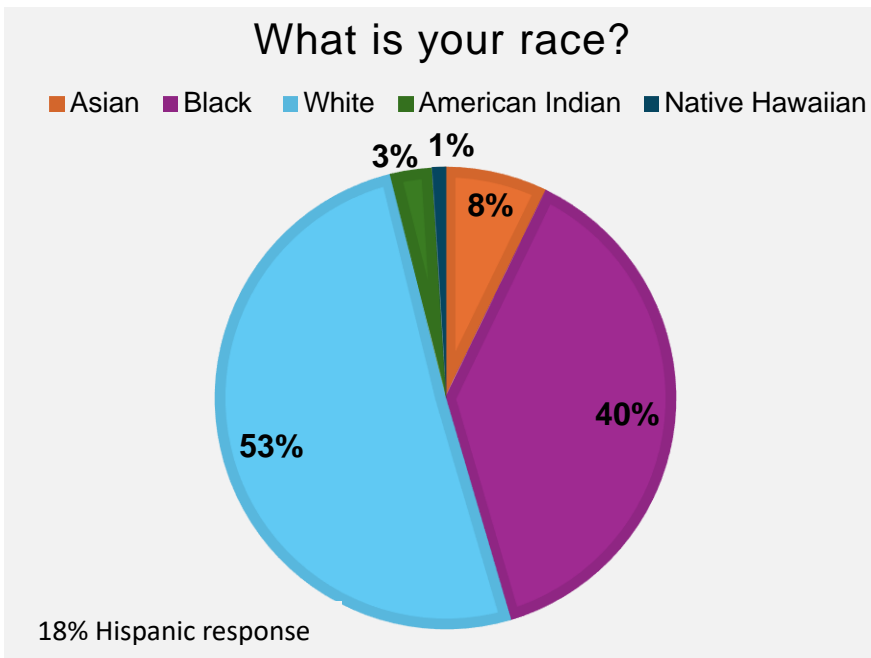
- Informed Consent
- Feeling listened to, respected, and valued
- Communication with the team
- Language, culture, and privacy accommodations
- Overall research experience
- Demands of the study
- Demographics
- Anything else you would like to share about your experience

Who received a survey?

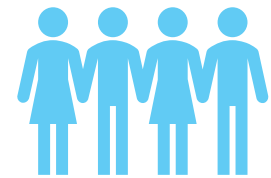
Everyone! Participants who are 18 or older, and recently signed informed consent, or completed participation received an invite by email. For longer studies, participants receive surveys annually. We send surveys out every other month.

Who Responded?

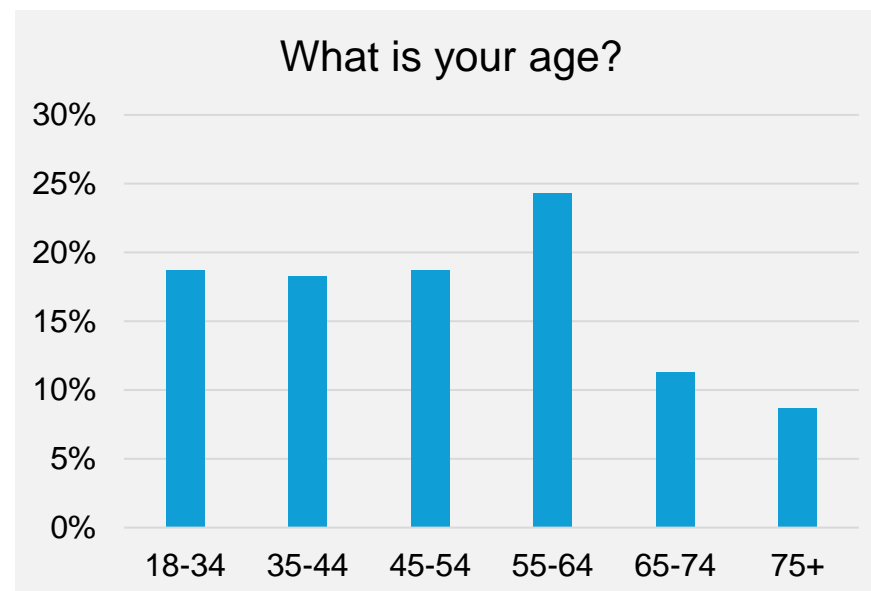
From June 2023 – October 2024, we sent 332 surveys and received responses from 77 participants. Below are some of the characteristics of the participants who returned the survey.



How much did the study demand of you?



- 48%** Simple study
- 40%** Moderate study
- 12%** Intense study

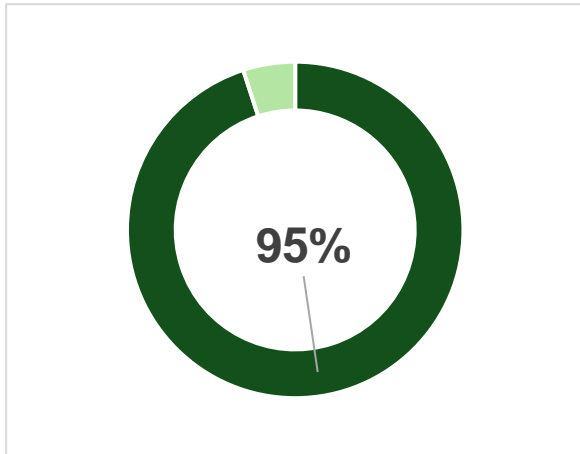


Did the study require that you have a disease or condition to qualify to enroll?



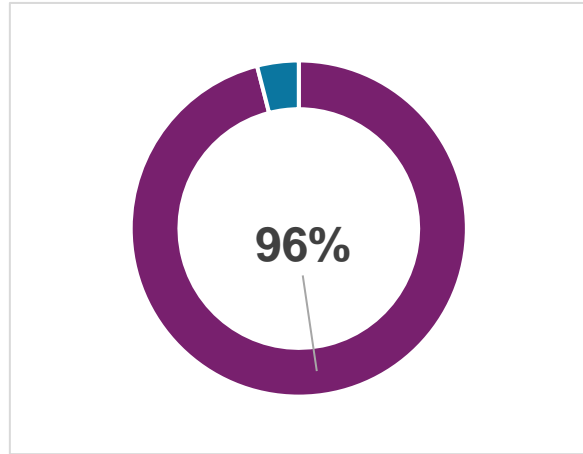
- 56%** Study required a specific disease or condition to enroll
- 44%** Study did not require a specific disease or condition to enroll

What did study participants say?



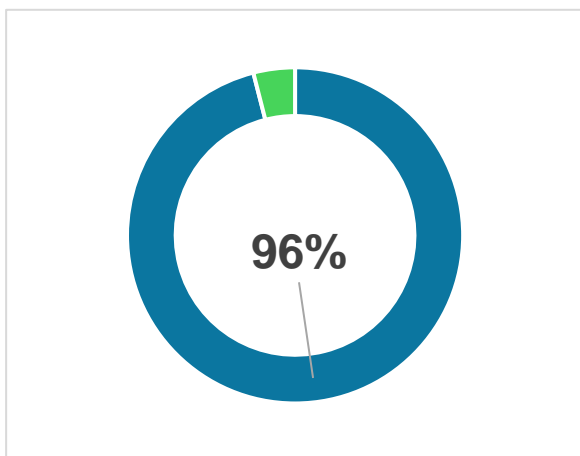
Felt like a valued Partner

Participants always (86%) or usually (9%) felt like a valued partner in research



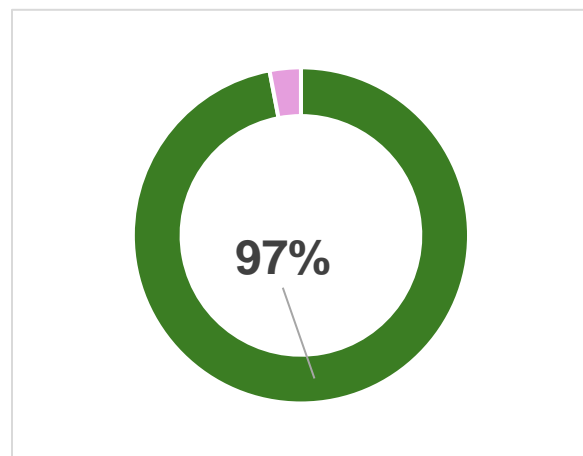
Would recommend joining?

Participants would definitely (73%) or probably (23%) recommend joining a study



Communication

Respondents were always (80%) or usually (16%) able to reach the study team when needed



Informed Consent

Informed consent prepared participants completely (78%) or mostly (19%) for participation in the study.

Everyone I have interacted with during my experience, on all levels, has been phenomenal. I always feel cared for and welcomed at my study visits.

I had a great experience, and I really appreciated how promptly I received compensation.

What else did participants say? 36% of participants who returned a survey included additional comments about their experience. Some praised staff, some described glitches in their visits and constructive suggestions for improvement.

“All the staff has been really excellent--attentive, compassionate, responsive to my needs and questions and always with a sense of humor that made me feel very comfortable. Thank you!!”

“Thank you for including me in this study and I hope a cure is found!”

“Courteous, polite and knowledgeable staff. Never had to wait around.”

What's next?

- Thank you to the research participants who took the time to tell us about your experience. We take your feedback to heart.
- If you receive an experience survey from Rockefeller, please tell us about your experience.