



# Empowering the Participant Voice

## 2023 ANNUAL REPORT

The *Empowering the Participant Voice* survey was sent by email to all research participants among a subset of clinical trials conducted at the University of Rochester. Only studies that are listed in our internal clinical trials system were included. This does not represent all research conducted by the University. Participants were sent the survey if they enrolled, participated and/or completed a study between January 1, 2020 and March 31, 2022. Data were collected from November 2021 to April 2022. The survey was sent to 3,009 participants; 21% (629) responded. To boost the number of responses, an incentive (\$50 gift card with a 1:25 chance in winning) was offered starting in February 2022.



The survey takes about five to ten minutes. Participants completed the survey anonymously and could skip any question.

The survey collected information about:

- How demanding the study is perceived to be
- Satisfaction with the research experience
- Informed consent and any feelings of coercion
- Ease of contacting the research team
- Being treated with respect and courtesy, and being valued

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## Demographics of respondents

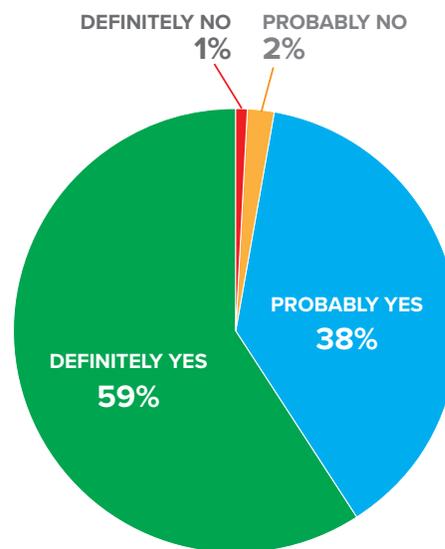
Younger adults and persons from historically underserved populations were less likely to complete the survey.

**Table 1: Demographics of survey respondents (629 total respondents)**

Demographic category	Subcategory	Number of respondents	Response rate in each category
Age	18-34	21	8%
	35-44	31	15%
	45-54	63	16%
	55-64	150	19%
	65-74	265	28%
	75 and over	96	21%
Ethnicity	No—not Spanish/Hispanic/Latino/a/x	605	21%
	Yes—Spanish/Hispanic/Latino/a/x	14	8%
Sex	Female	340	19%
	Male	283	22%
Race	Asian	5	12%
	American Indian or Alaskan Native	4	17%
	Black or African American	15	6%
	White	601	22%

Most people would recommend joining a study to their friends and family.

**Would you recommend joining a research study to your family or friends?**



## Overall experience of participants

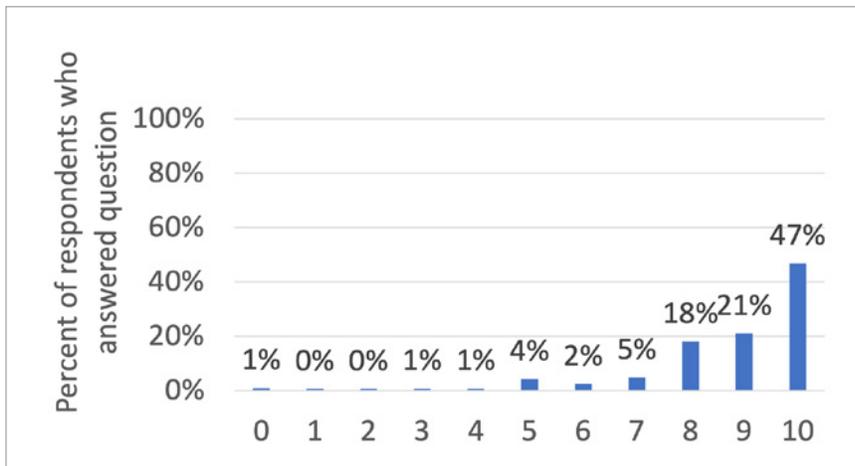
**Participants were asked to score their overall experiences on a scale of one to 10.**

The average score for all participants was 8.7.

For Hispanic participants the average score was 7.8.

For Black/African American participants the average score was 6.9.

**Table 2: Rating of Overall Experience (10 being best)**



### **Participants rated several areas highly:**

- Our participants felt listened to.
- They were treated with courtesy and respect.
- They felt they had enough privacy.
- They felt their cultural background and their language differences were respected.

### **These are areas of the research experience where improvements should be made:**

- We should improve communication about the study at the beginning and throughout the study.
- We should create ways to help our participants feel valued.
- We should evaluate our informed consent process so patients know better what to expect in a study.