CISCRP

2023

Perceptions & Insights Study

Global trends in public and patient attitudes about, and experience with, clinical research.

PARTICIPATION EXPERIENCE

Introduction

The 2023 Perceptions & Insights Study collected information on the experiences of over 4,500 clinical research participants—highlighting the most burdensome aspects of participation and ways to best overcome these challenges.

In this report, CISCRP provides a summary of participation experiences at critical time points: before, during, and after participation. Learnings can help guide best practices for future clinical research studies.

Study participants are still **learning about their study through various sources**, including online channels, as well as via the study doctor/staff or their clinical care doctors.

Compared to 2021, **participation** was perceived to be somewhat **less disruptive** and more in line with 2019 levels, highlighting the potential impact of the pandemic. However, logistical factors were still perceived as most burdensome.

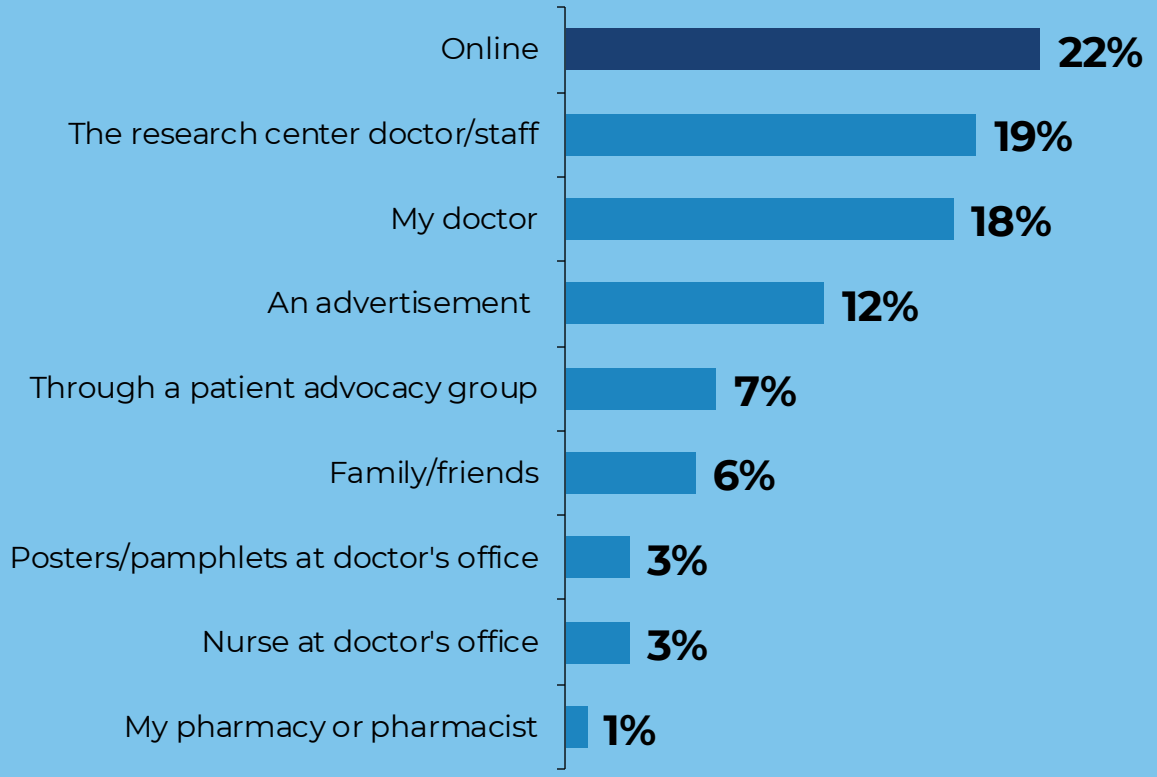
Text messaging, **smartphone apps**, **home nursing visits**, and **supportive services** were viewed as most helpful in **optimizing experiences**.

There was a **decreased frequency in updates** provided while enrolled compared to 2021, as well as **less communication after participation**.

Learning About Clinical Research Studies

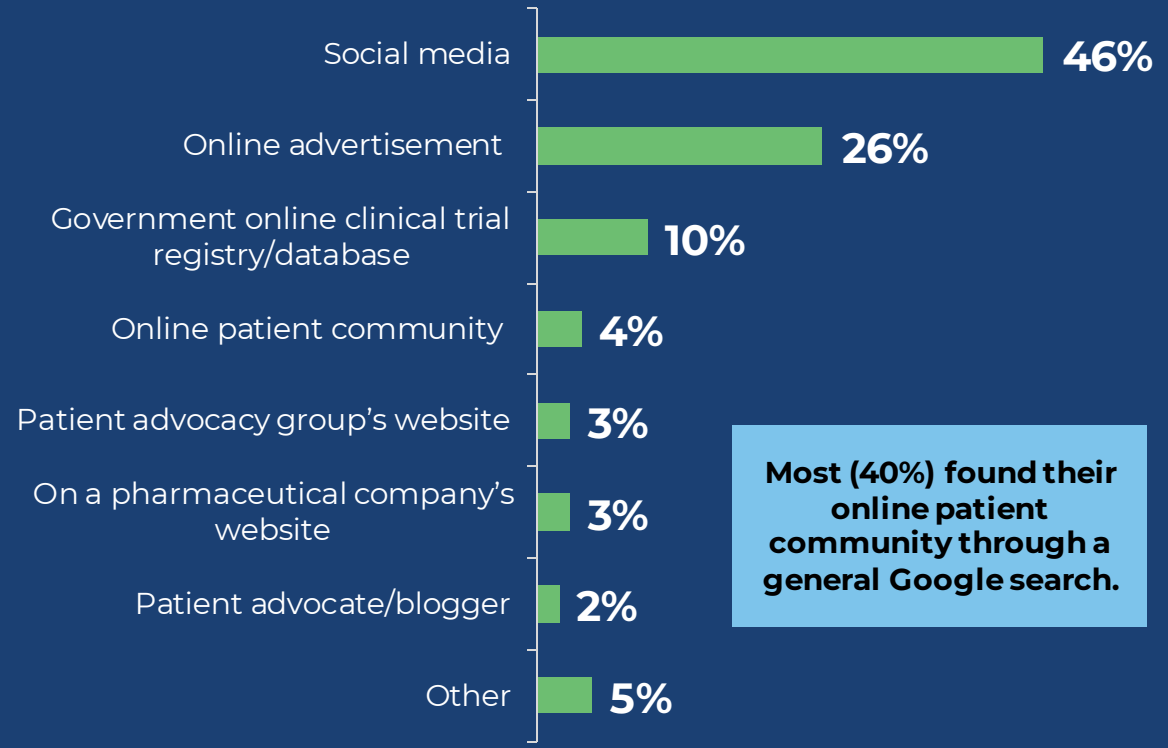
Participants first learn about clinical research studies through multiple sources including online channels (such as social media and online advertisements), as well as via the study doctor/staff or their clinical care doctors.

Where did you first learn about the clinical research study? (2023)



Sample Size = 4,558 | Base: Those who have participated in a clinical trial, 2023

Where online did you first learn about the clinical research study?



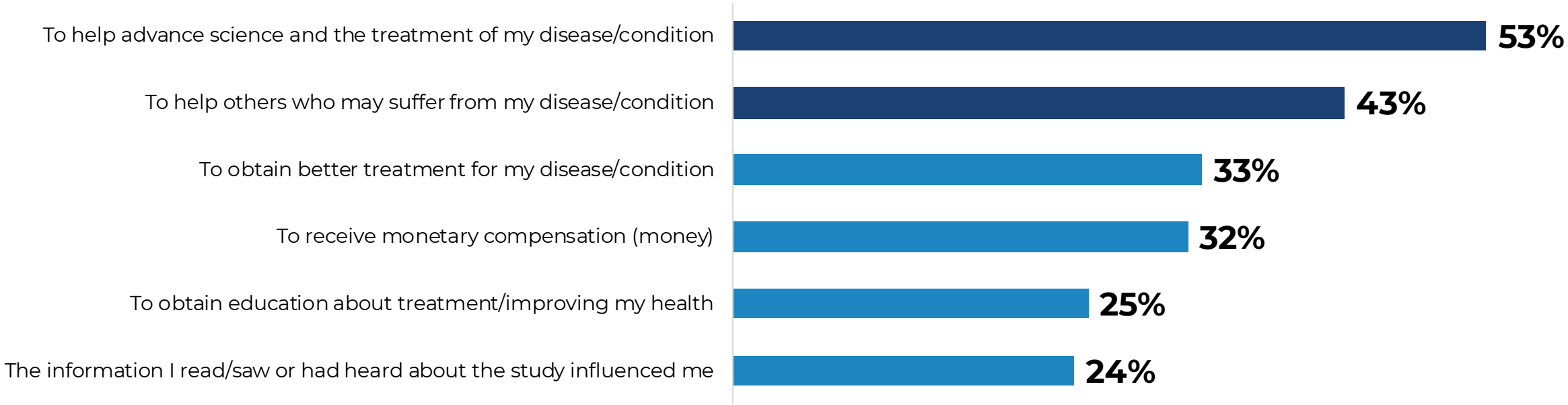
Most (40%) found their online patient community through a general Google search.

Sample Size = 1,008 | Base: Those who learned about study online, 2023

Participation Drivers

Altruistic motivations remain top drivers for participation.

Please indicate which of the following are reasons you decided to participate in a clinical research study?
(% Mentioning)



Sample Size = 4,558 | Base: Those who have participated in a clinical trial, 2023

Top motivators were consistent with 2021 findings.

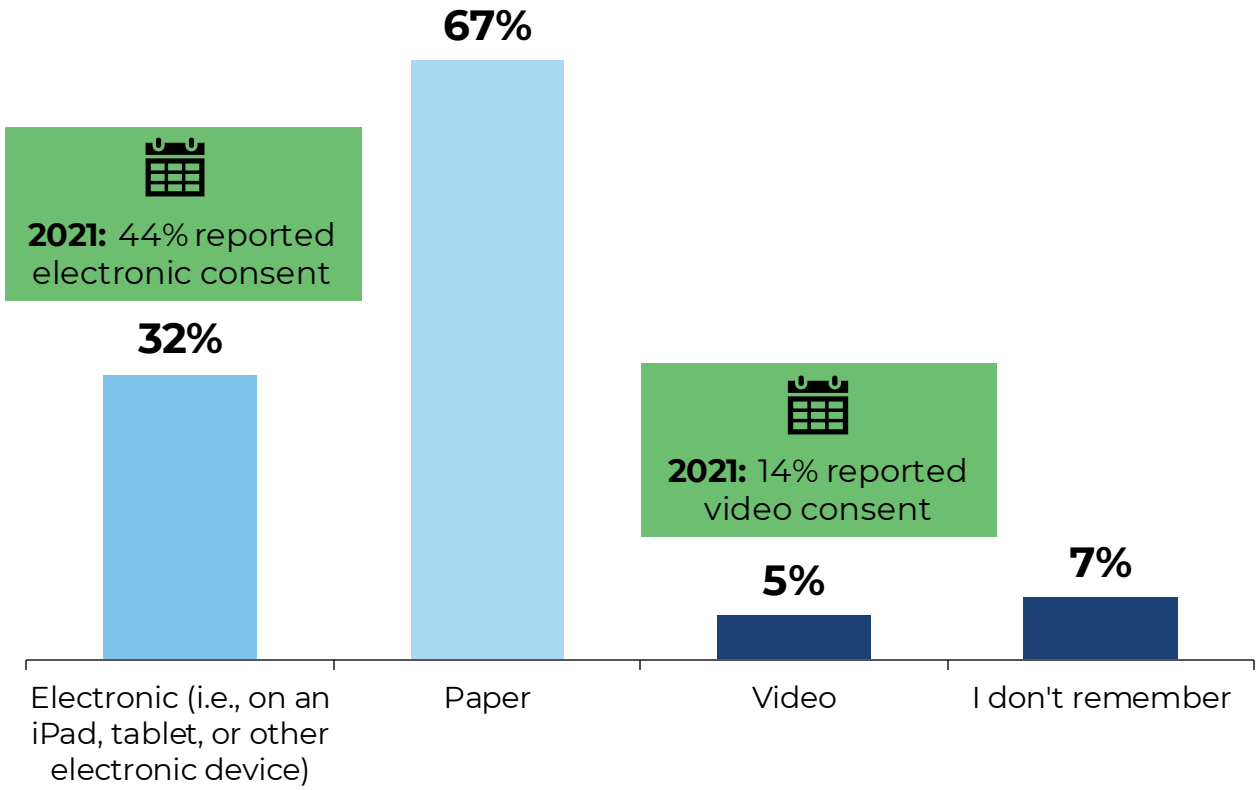
Non-Hispanic respondents were more likely than Hispanic respondents to cite 'help advance science' (55% vs. 44%) and 'to help others' (45% vs. 34%).

As a general trend, older populations were more likely to cite 'help advance science' than younger populations, while younger populations were more likely to cite 'family/friend recommendation'.

Informed Consent Formats

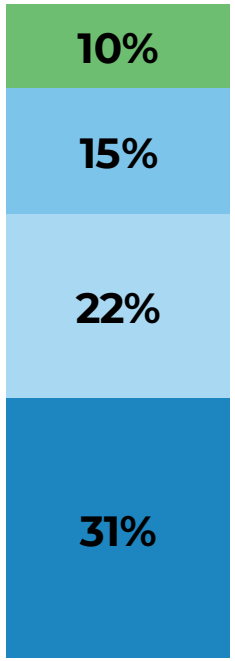
Compared to 2021, there was a decrease in the use of electronic and video consent formats.

In what format did you receive the informed consent form for your most recent study?
(Select all that apply)



Sample Size = 5,505 | Base: Those who have participated in a clinical trial

About how many pages was the informed consent form for your most recent study?
(Paper Only)



- More than 20 pages
- 11 to 20 pages
- 6 to 10 pages
- 1 to 5 pages

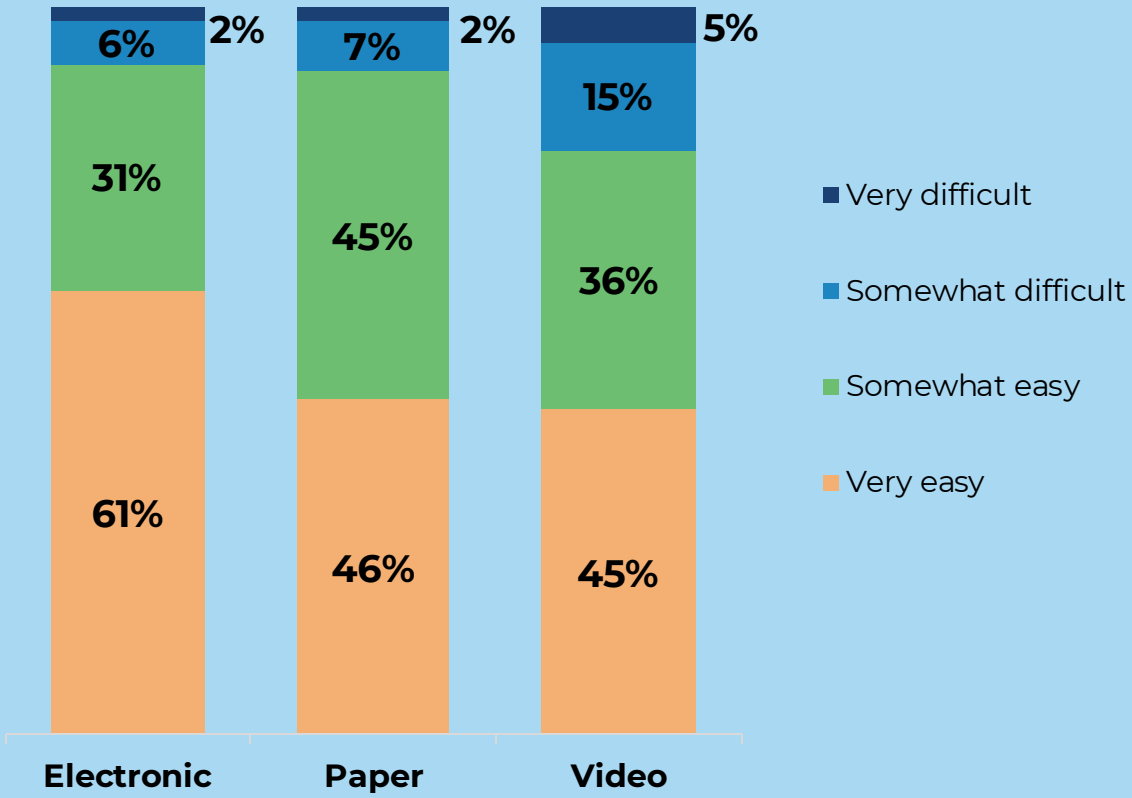
In 2021, 65% of paper consents were 10 pages or less.

Sample Size = 2,265 | Base: Those who have participated in a clinical trial, paper information consent; excludes 'I don't remember'

Understanding the Informed Consent Form

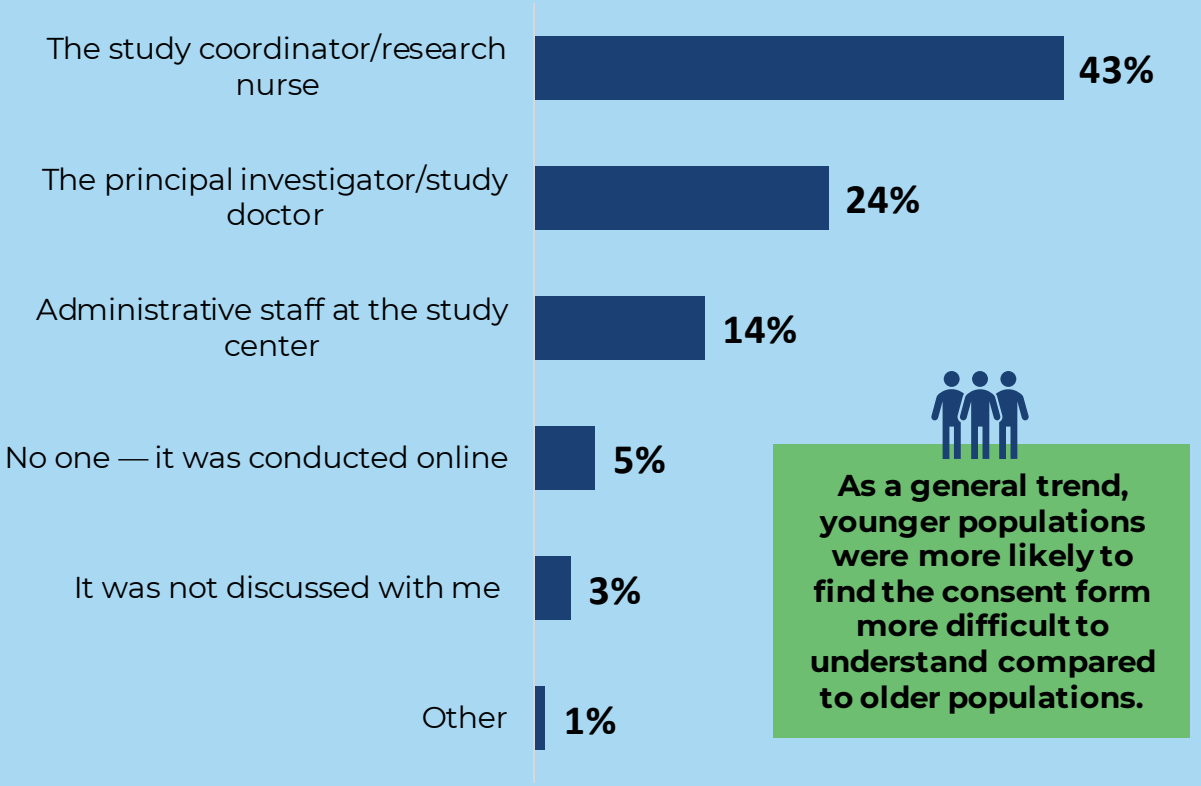
The electronic consent form is perceived to be the easiest to understand as compared to other formats.

In general, how easy or difficult was it to understand your informed consent form?



Sample Size = 4,085 | Base: Those who have participated in a clinical trial; excludes 'I don't remember'

What member of the study team reviewed the informed consent form with you?



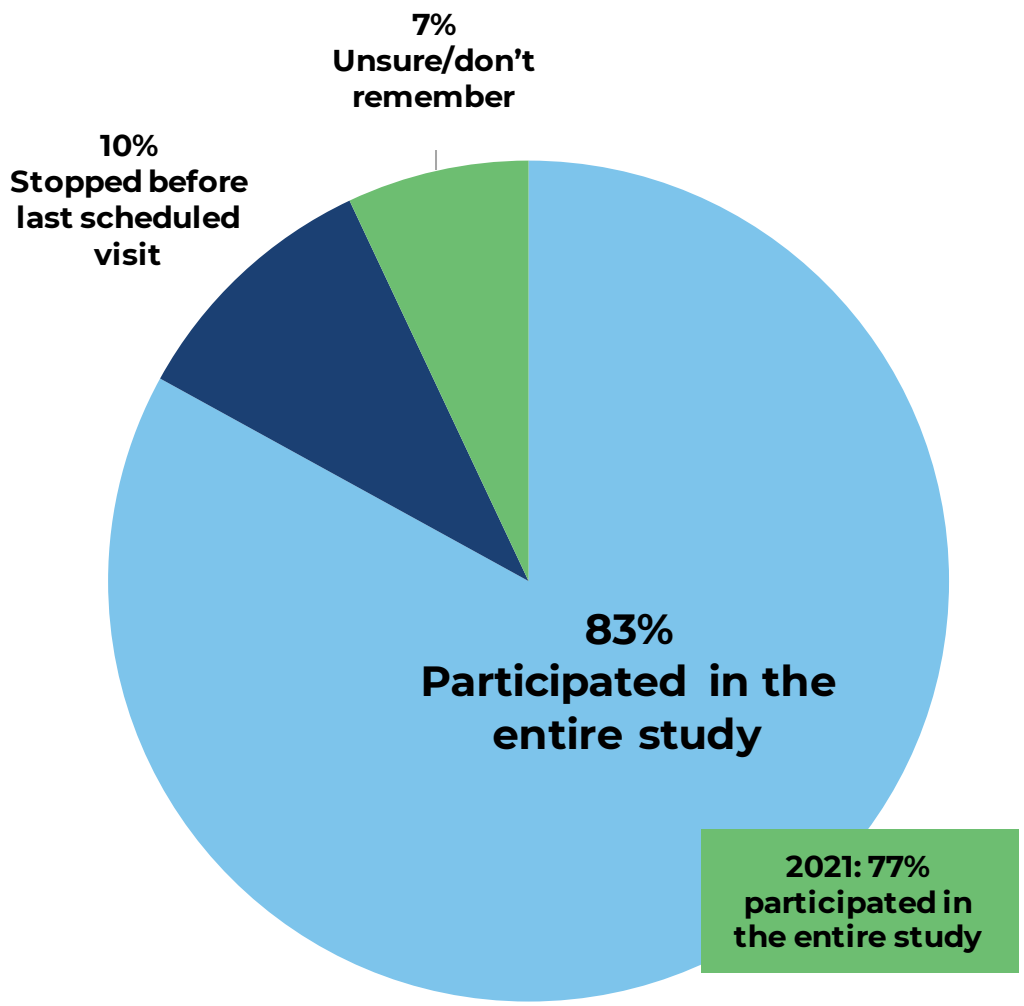
As a general trend, younger populations were more likely to find the consent form more difficult to understand compared to older populations.

Sample Size = 4,558 | Base: Those who have participated in a clinical trial; excludes 'I don't remember'

Stopping Participation

Side effects and study location are top drivers for stopping study participation.

Did you participate in the entire research study or did you stop before your last scheduled study visit?



Sample Size = 4,558 | Base: Those who have participated in a clinical trial

Why did you stop your participation in the clinical research study?

Top Mentions:

- The side effects of the study drug (15%)
- The location of the study center (14%)
- There was poor communication with the study center (12%)
- The procedures during my study visits were too cumbersome (12%)
- There was no virtual option (12%)

Which of the following would have encouraged you to stay in the clinical research study?

Top Mentions:

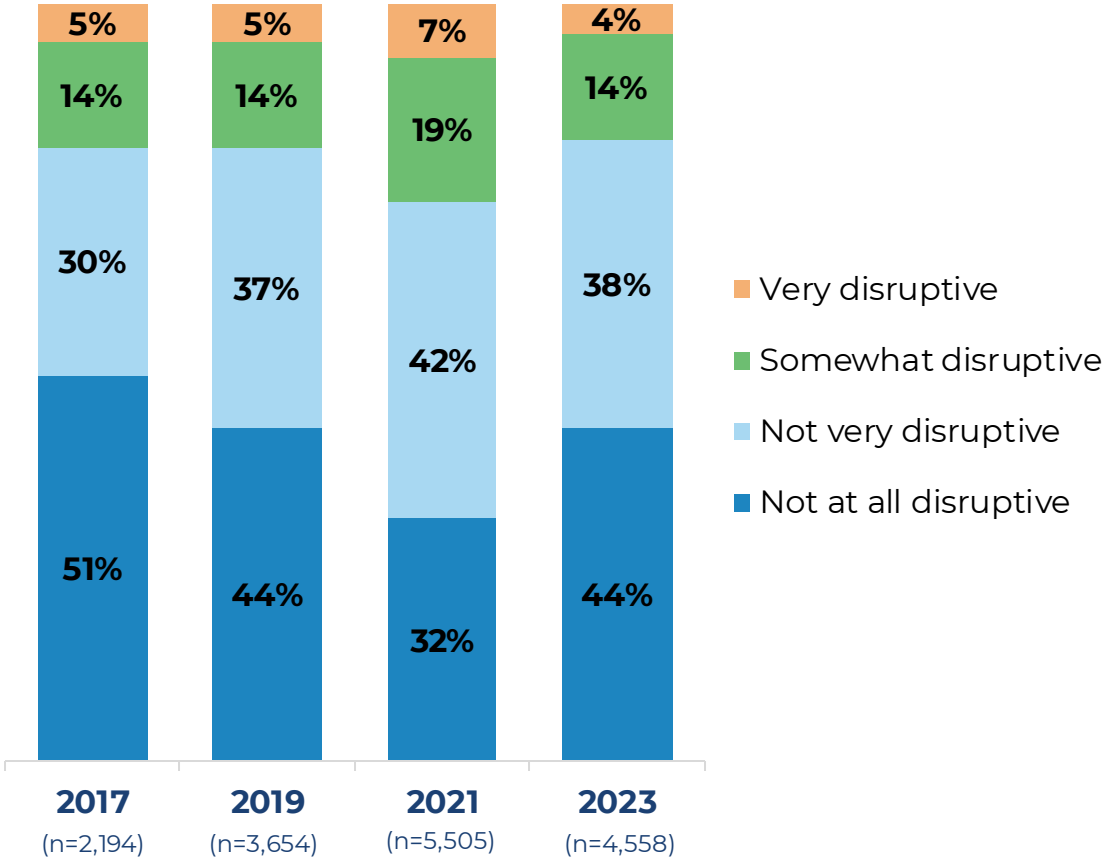
- Nothing (28%)
- More virtual visits (18%)
- Being provided supportive services (18%)
- Reduced amount of time for each in-person study visit (16%)

Sample Size = 444 | Base: Those who stopped participation in a clinical trial

Stopping Participation

Compared to 2021, there was a decreased disruption to daily routines. However, travel to the study clinic and time required to participate continue to be the top causes of disruptions.

How much did your participation in the clinical research study affect your general daily routine?



Base: Those who have participated in a clinical trial

What made your participation in the clinical research study disruptive?

Top Mentions:

- Having to travel to the study clinic (56%)
- Too much time required (31%)
- Missing work and/or not getting paid (29%)
- Having to complete study requirements at home (such as completing questionnaires) (20%)
- Having to use technology (such as a smartphone, tablet, etc.) (18%)

Sample Size = 814 | Base: Those who reported 'somewhat' or 'very' disruptive

Participation Burdens

Logistical factors create the most burden.

How burdensome was each of the following? *% 'Somewhat' or 'Very' Burdensome*	2023 (n=4,558)
Traveling to the study clinic	**29%**
The length of the study visits	**23%**
Undergoing diagnostic tests (e.g., x-rays, MRIs)	**16%**
Lab work (e.g., blood tests, urine)	**16%**
Completing health questionnaires	**15%**
Taking the clinical study medicine	**12%**

How long did it take you to travel to the clinic (one-way)?*

- ✓ 15 minutes or less: 10%
- ✓ 15 to 30 minutes: 26%
- ✓ 30 minutes to 1 hour: 35%
- ✓ 1 to 2 hours: 18%
- ✓ 2 to 3 hours: 5%
- ✓ More than 3 hours: 6%

**Base: Excludes not having to travel and don't remember*

How much time, on average, did you spend at each study visit, not including travel to and from the study clinic?

- ✓ 15 minutes or less: 8%
- ✓ 15 to 30 minutes: 16%
- ✓ 30 minutes to 1 hour: 32%
- ✓ 1 to 2 hours: 27%
- ✓ 2 to 3 hours: 9%
- ✓ More than 3 hours: 9%

What could have made your participation in the clinical research study less disruptive?

Top Mentions:

- Not having to travel as far to get to my study visits (36%)
- Receiving compensation (money) for my time (34%)
- Virtual study visits (32%)
- Having a study nurse or doctor come to my home for some of my study visits (23%)
- Receiving a pre-paid debit card for study-related expenses (21%)
- Having help/assistance traveling to and from the study (15%)

Sample Size = 4,558 | Base: Those who have participated in a clinical trial

Post-Participation Communication

Compared to 2021, there is a decreased frequency in updates provided after participation.

Did you receive any reports or updates on the results of the study once you finished the clinical research study?

2023: Yes (31%) No (53%)

2021: Yes (43%) No (44%)

2019: Yes (32%) No (51%)

2017: Yes (30%) No (53%)

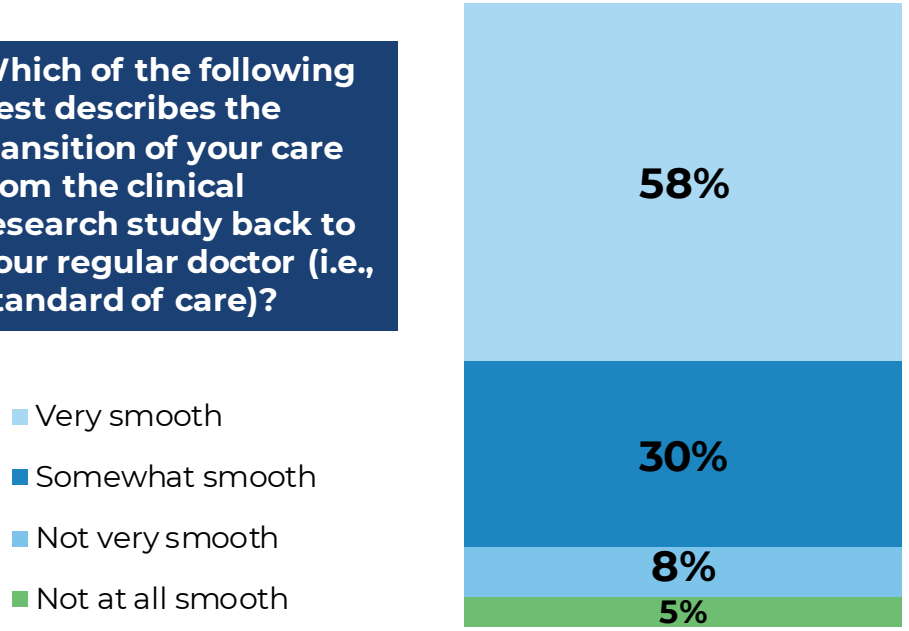
What information did you receive?	% Mentioning	% Indicating "Very" Helpful
A summary of the study results	**59%**	**48%**
My individual study results (i.e., procedures and test results)	**46%**	**58%**
Whether I received the study drug or a placebo	**24%**	**65%**
Information about upcoming clinical research studies	**23%**	**47%**
Information about scientific publications	**20%**	**44%**
The brand name for the study drug	**19%**	**50%**
Drug approval status by the regulatory agency in your country	**17%**	**61%**

Sample Size = 2,194 in 2017; 3,654 in 2019; 5,505 in 2021; 4,558 in 2023
Base: Respondents who participated in a clinical trial; excludes 'I don't remember'

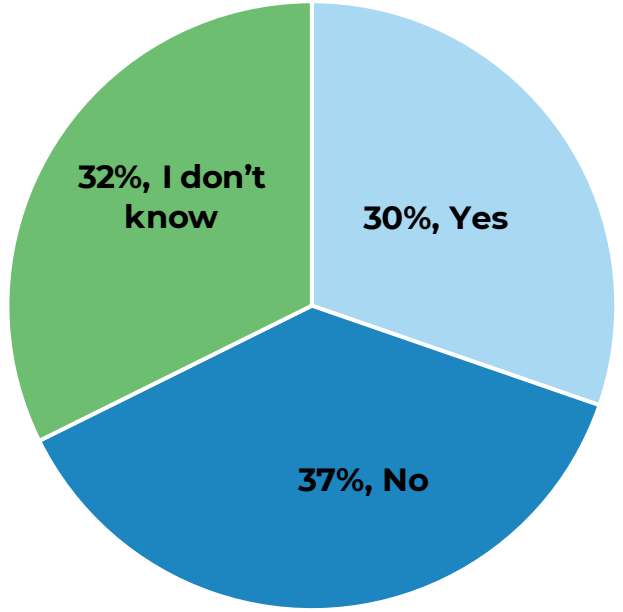
Post-Participation Coordination and Communication

While transition to standard of care after participation is perceived as generally smooth, communication could be improved among healthcare providers.

Which of the following best describes the transition of your care from the clinical research study back to your regular doctor (i.e., standard of care)?



To your knowledge, did the study doctor or the study nurse ever contact your regular doctor?



How did your regular doctor learn about the results of your clinical research study?

% Mentioning

- I provided the results directly to him/her (24%)
- I don't know (24%)
- Does not apply — my regular doctor never learned about the results of my clinical research study (22%)
- The study team and/or sponsor of the study sent the results directly to him/her (19%)
- He/she accessed the results online (e.g., ClinicalTrials.gov, portal, etc.) (10%)

Sample Size = 2,348 | Base: Those who have participated in a clinical trial; excludes does not apply, 2023

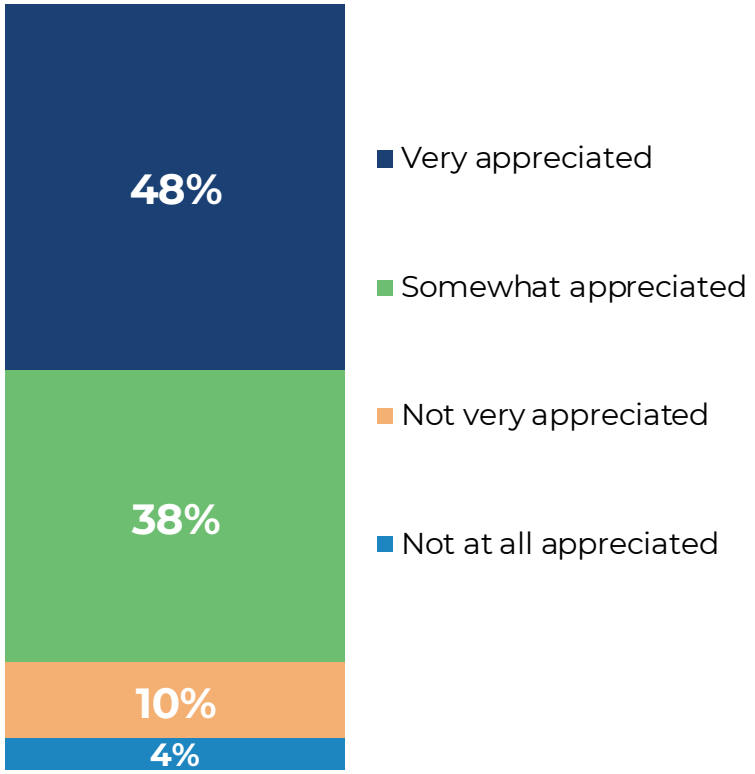
Study Participant Appreciation

Most feel appreciated while enrolled in the study, and study staff play a crucial role in conveying appreciation. About a third report not receiving anything.

As part of your clinical research study participation, which of the following did you receive, if any?	% Mentioning Receiving	% Indicating 'Very' Helpful
Words of appreciation from the study staff	**51%**	**49%**
Thank You card	**16%**	**38%**
Invitation to participate in a satisfaction survey	**15%**	**40%**
An item to support my participation (e.g., blanket, notebook, water bottle)	**11%**	**39%**
Birthday card	**5%**	**41%**
Sympathy/condolence card	**4%**	**41%**
Holiday card	**4%**	**43%**
A certificate to commemorate/recognize my participation	**3%**	**52%**
None of the above	**32%**	**N/A**

Sample Size = 4,558 | Base: Those who have participated in a clinical trial, 2023

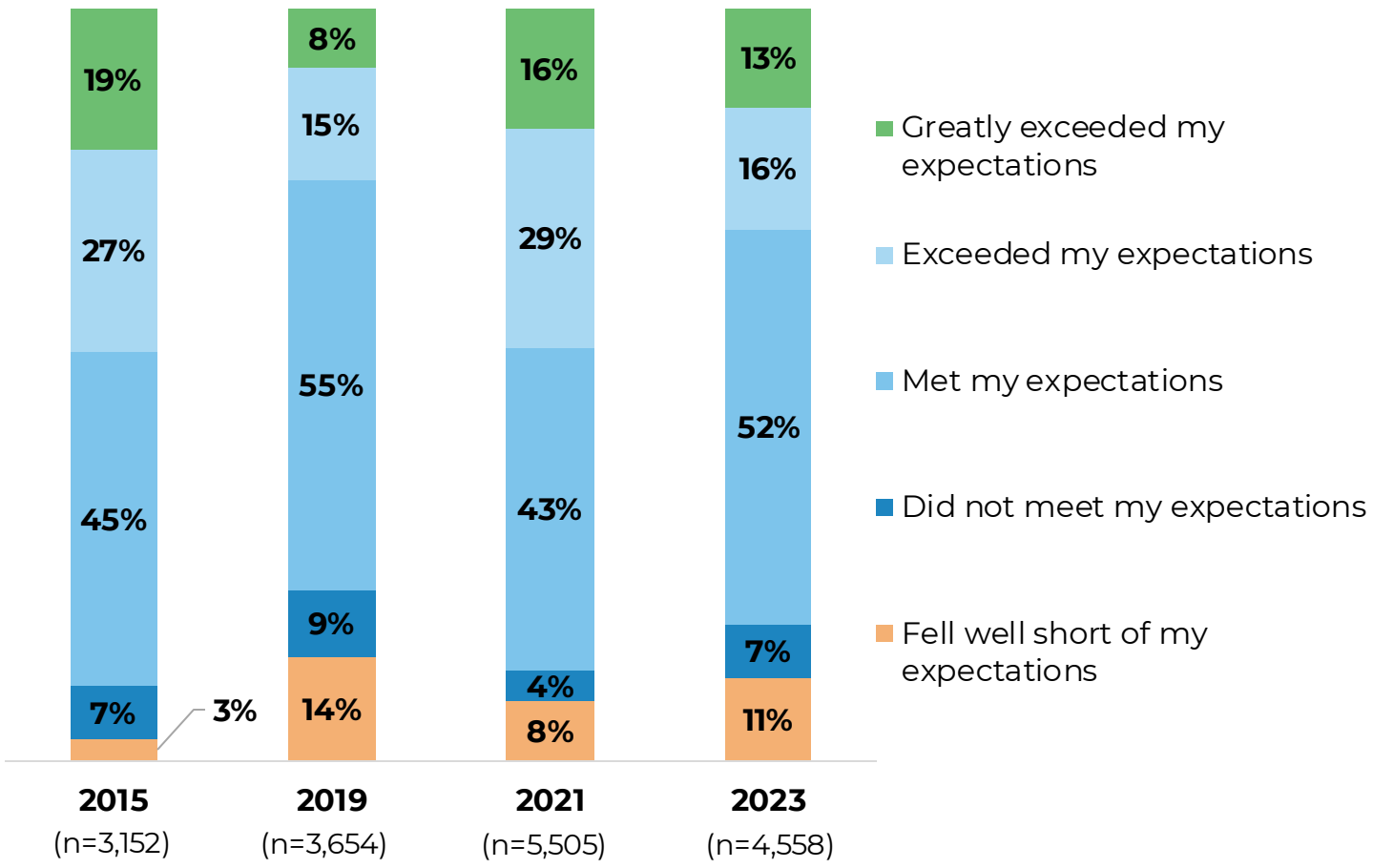
How appreciated did you feel during your clinical research study?



Study Participant Satisfaction

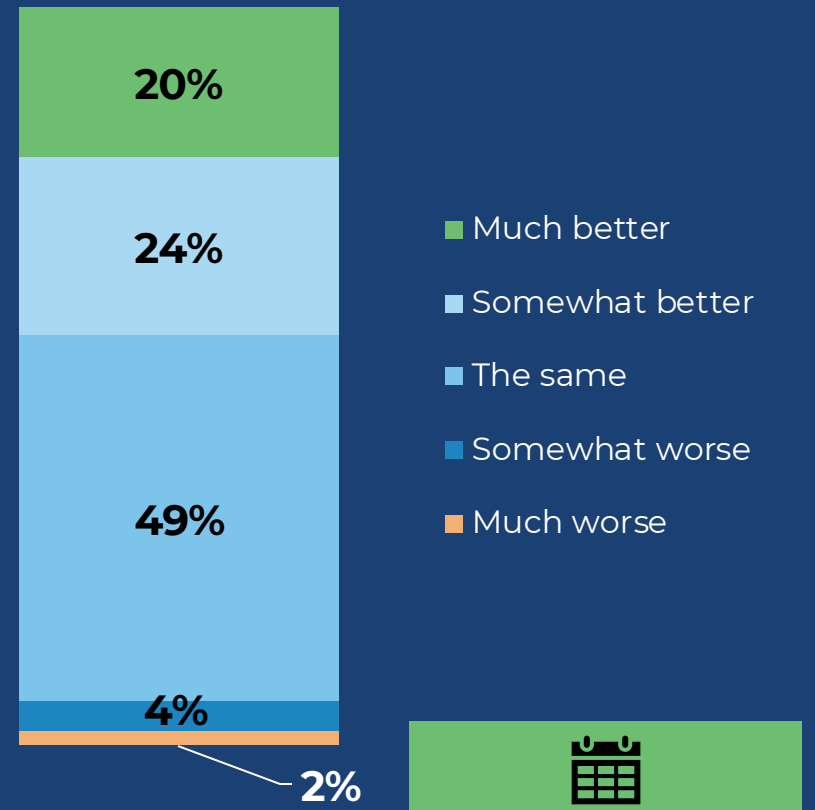
Satisfaction with clinical trial experiences was on par with 2019.

How well did the clinical research study meet your overall expectations?



Base: Those who have participated in a clinical trial

How would you rate the care and attention you received in managing your condition in this clinical research study when compared to the standard care you would have otherwise received?



In 2021, 65% reported 'much' or 'somewhat' better compared to 44% in 2023

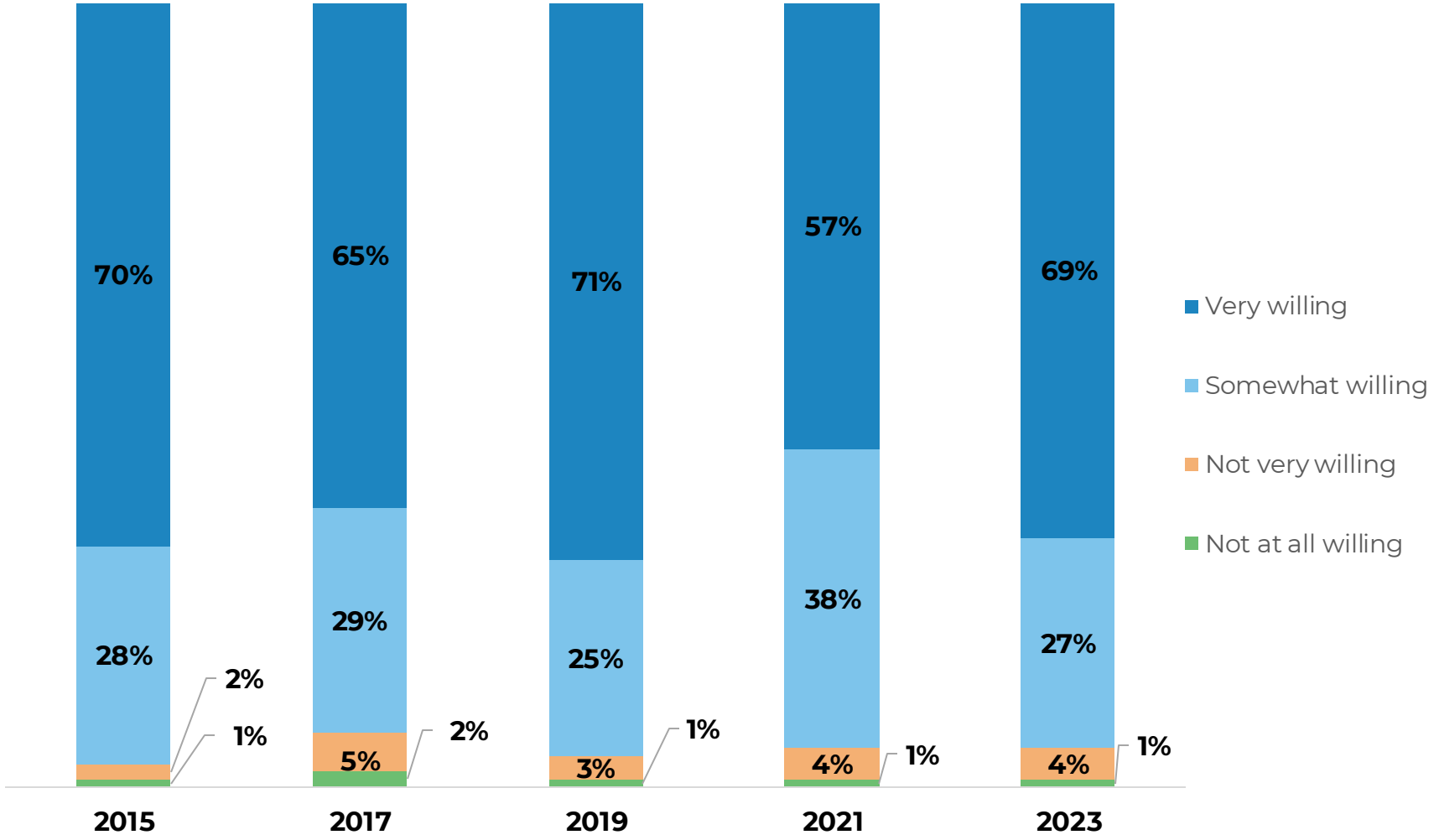
Sample Size = 4,558 | Base: Those who have participated in a clinical trial

Future Participation

Compared to 2021, there was an increase in willingness to participate again.

How willing would you be to participate in another clinical research study in the future?

Those who participated in a traditional (71%) or hybrid (75%) clinical trial were more likely to report 'very willing' as compared to remote (63%) clinical trial participants.

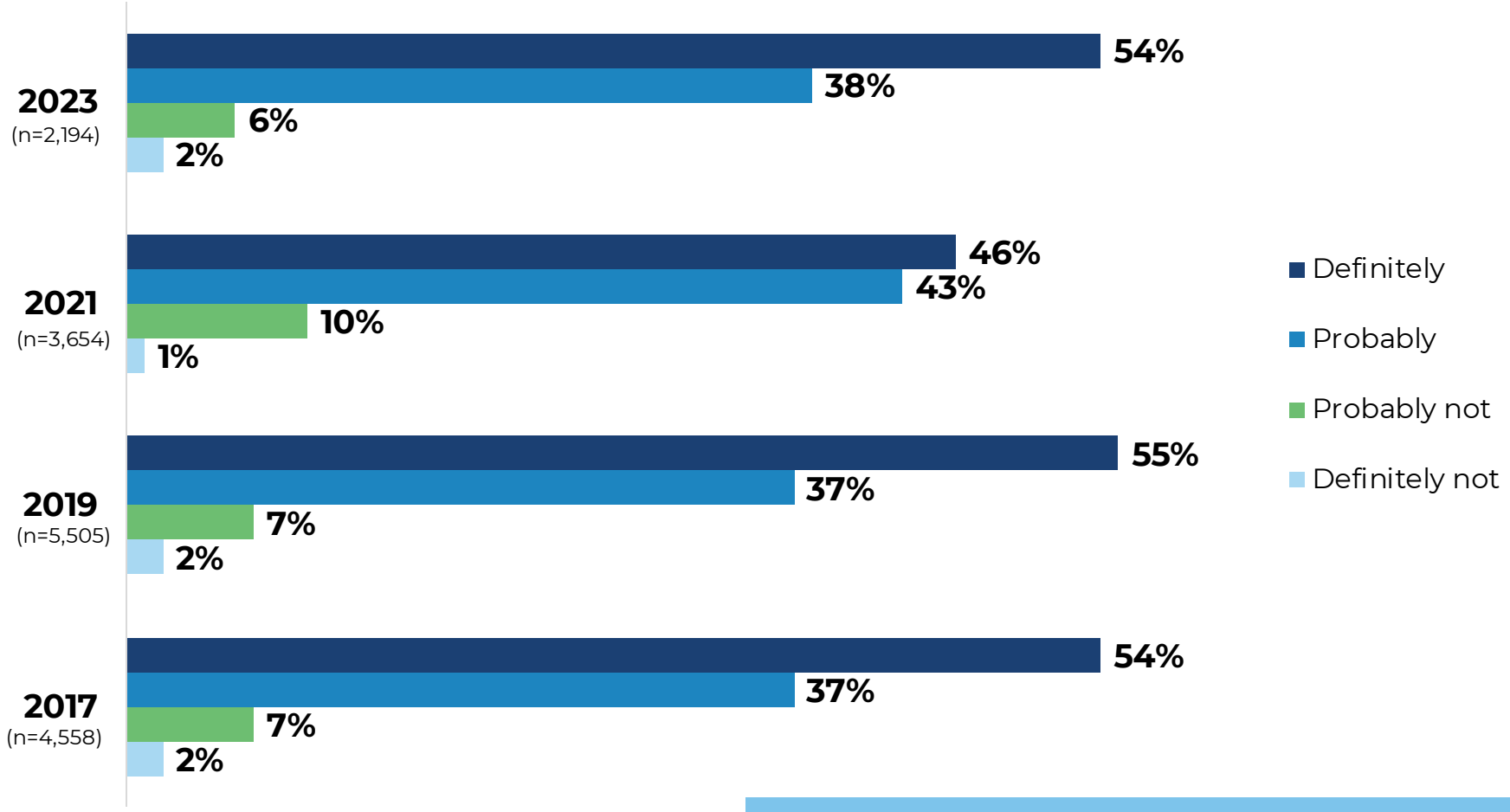


Base: Those who have participated in a clinical trial

Participation Recommendation

Compared to 2021, a higher proportion of respondents would recommend participation to others.

Would you recommend participating in a clinical research study to your family and friends, if the trial was appropriate for them?



Those enrolled in a remote (47%) study were less likely to report they would 'Definitely' recommend, compared to those in a traditional (56%) or hybrid (61%) study.

Base: Those who have participated in a clinical trial

About This Study

The objectives of this study are to establish routine global assessments of public and patient perceptions, motivations, and experiences with clinical research in order to monitor trends and identify opportunities to better inform and engage the public and patients as stakeholders and partners in the clinical research enterprise.

Between April and June 2023, CISCRP conducted an online international survey. The survey instrument was based in part on questions posed in past surveys. CISCRP received input and support from pharmaceutical, biotechnology, and contract research organizations; investigative sites; and patients. The survey instrument was reviewed by an ethical review committee. CISCRP collaborated with Clariness, James Lind Care, Benchmark Research, and Rare Patient Voice to reach and engage respondents.

12,017
Survey Respondents

Respondent characteristics are as follows:

Gender	61% Female | 37% Male | 2% All other genders
Region	47% North America | 2% South America | 46% Europe | 4% Asia-Pacific | 1% Africa
Age	19% 18–34 years old | 18% 35–44 years old | 18% 45–54 years old | 21% 55–64 years old | 24% 65 or older
Race (top mentions)	81% White | 6% Black or African-American | 6% Asian
Ethnicity	85% Non-Hispanic | 15% Hispanic
Incidence of participation in a clinical trial	62% have never participated | 38% have participated

Note: Percentages throughout this report may not total 100 due to rounding

About CISCRP

The Center for Information and Study on Clinical Research Participation (CISCRP) is an internationally recognized non-profit organization dedicated to educating and informing the public and patients about clinical research. CISCRP works to raise awareness, enhance experiences, and strengthen communication and relationships among participants, research professionals, and the public through various services and events.

RESEARCH SERVICES

Insights guiding public and patient engagement in clinical research

- Perceptions & Insights Study
- Patient Advisory Boards
- Patient Clinical Trial Journey Workshops
- Custom Research Projects

COMMUNITY ENGAGEMENT

Educational and engaging events held in local communities to build clinical research awareness and trust

- AWARE-for-All
- Medical Heroes Appreciation 5K
- Journey to Better Health Traveling Exhibit

HEALTH COMMUNICATION SERVICES

Information in plain and easy-to-read language

- Trial Results Summaries
- Educational Brochures
- Review Panels

INTERNATIONAL EDUCATION & AWARENESS

Helpful facts and information about clinical research

- Content Licensing
- Patient Diversity Campaign
- Website Content Development

CISCRP

Thank You

CISCRP thanks the following organizations for their support of the 2023 P&I Study:

abbvie

AMGEN

AstraZeneca

Benchmark Research
Raising the standard.™

Biogen

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Daiichi-Sankyo

EMD SERONO

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