



Perceptions & Insights Study

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



PARTICIPATION EXPERIENCES

Introduction

The 2025 Perceptions & Insights Study collected information on the experiences of over 4,400 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.



PARTICIPATION EXPERIENCES

BEFORE PARTICIPATION

- About 1 in 4 **learned about their clinical study online**, most often through **social media**.
- As in past years, **altruistic motivators** (helping advance science, helping others) remain top drivers of participation.
- **Electronic informed consent forms** continue to be perceived as the **easiest to understand**.

DURING PARTICIPATION

- **Logistical factors** (e.g., travel, time requirements) continue to be among the **top sources of burden and disruption** during clinical study participation.
- **Those who experienced tech issues most often contacted the study staff** to help resolve technical difficulties.
- **1 in 3 received no compensation or reimbursement**, with nearly half of those in Europe receiving no compensation/reimbursement.

AFTER PARTICIPATION

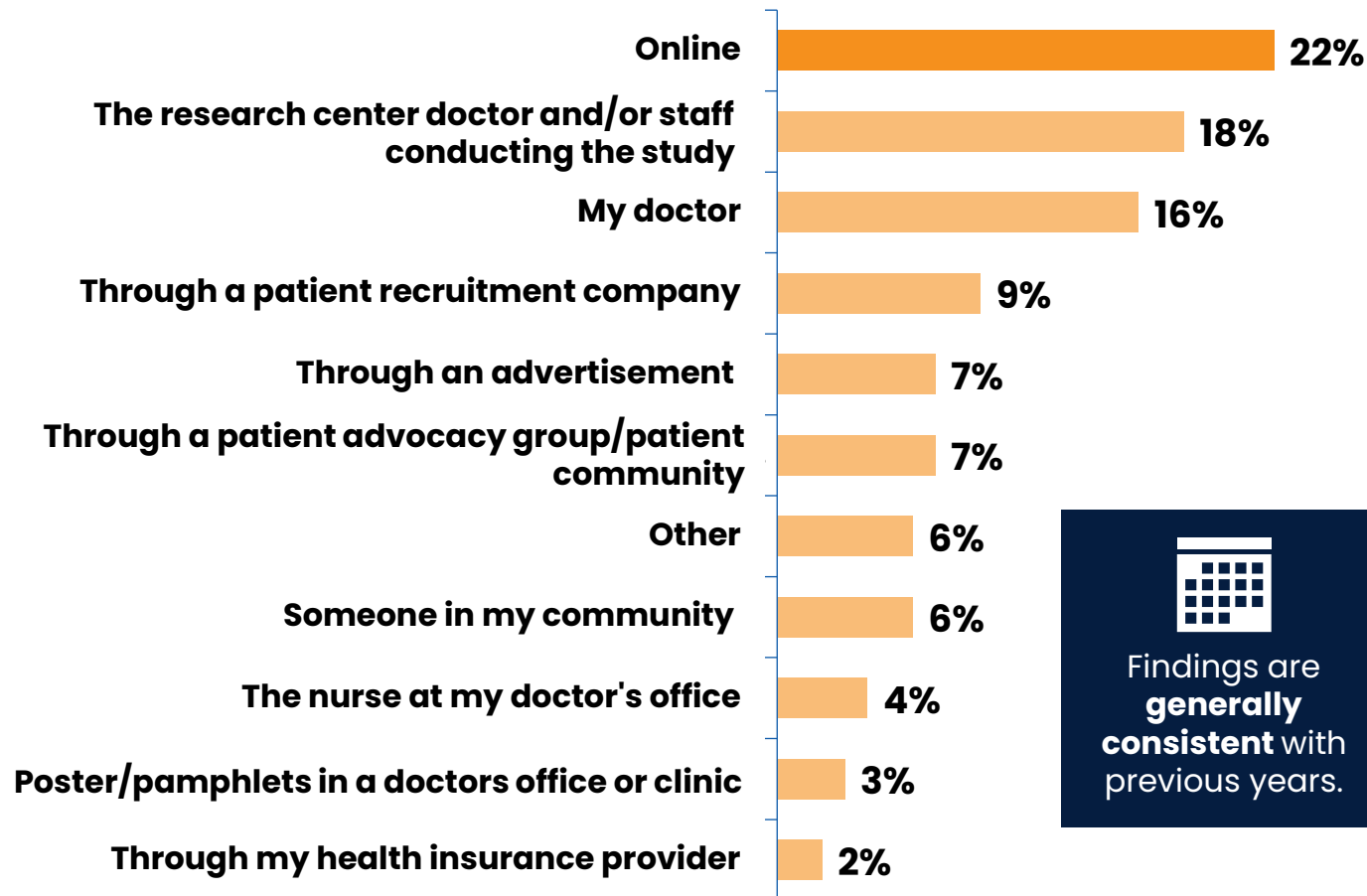
- About **1 in 3 respondents received updates following completion of the study**, which increased slightly from 2023. Additionally, compared to prior years, **fewer participants report that they ‘never heard back from anyone’** after participation ends.
- Participants continue to report **high levels of satisfaction with their participation experience**.



BEFORE PARTICIPATION

About 1 in 4 Learned About Their Clinical Study Online, Most Often Through Social Media

Where did you first learn about the clinical research study?



Findings are generally consistent with previous years.

Sample Size = 4,415 | Base: Those who participated in a clinical study



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

Top mentions

- Through social media (48%)
Of those who found out about their clinical study on social media (n=458), the majority learned on Facebook (80%)
- Through an online advertisement (18%)
- Through a government clinical studies registry/database (10%)
- From an online news article (10%)

Sample Size = 955 | Base: Those who first learned about a clinical research study online



Where did you see or hear the advertisement where you first learned about the clinical research study?

Top mention

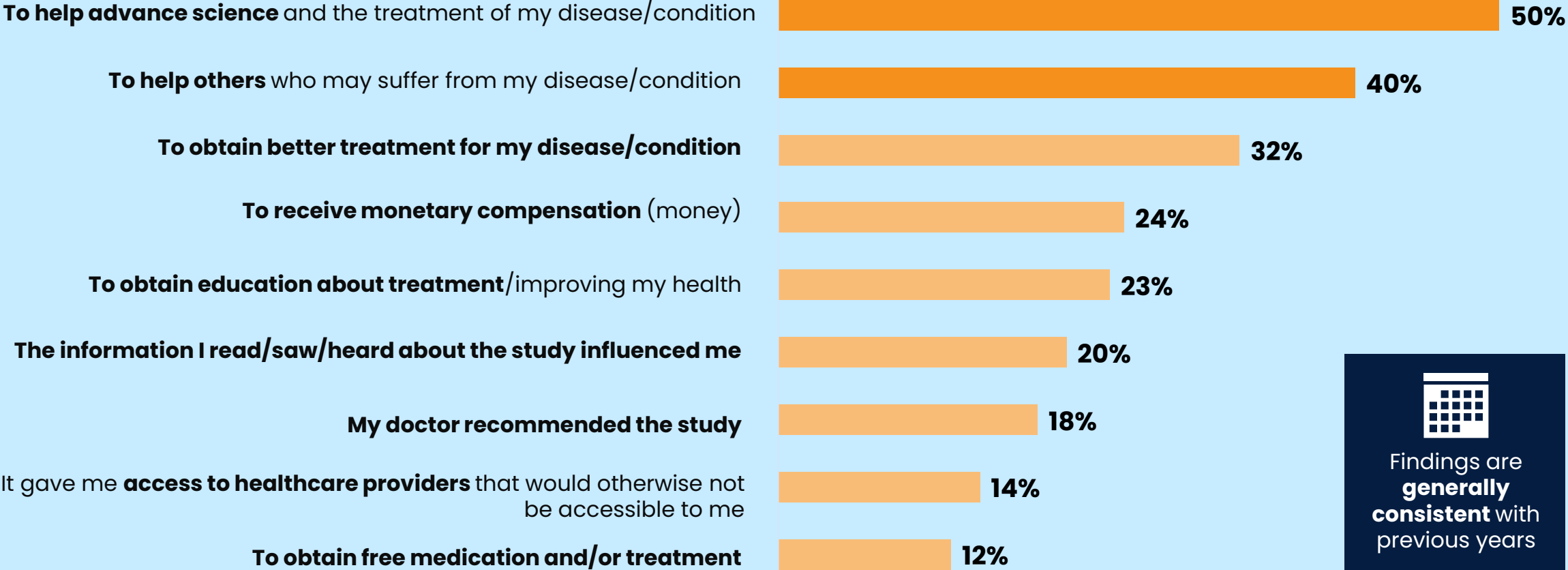
46%

Saw a newspaper or magazine ad

Sample Size = 295 | Base: Those who first learned about their clinical research study through an advertisement

Altruistic Motivators Remain Top Drivers for Participation

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

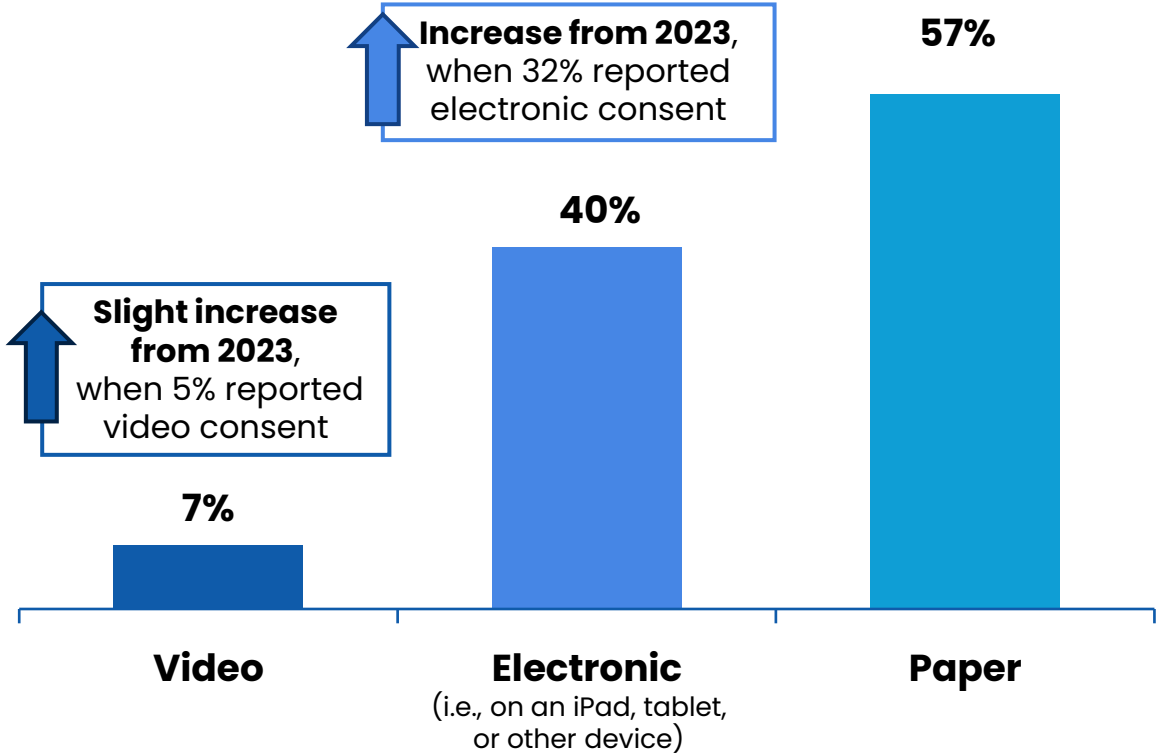



Findings are generally consistent with previous years

Sample Size = 4,415 | Base: Those who participated in a clinical study

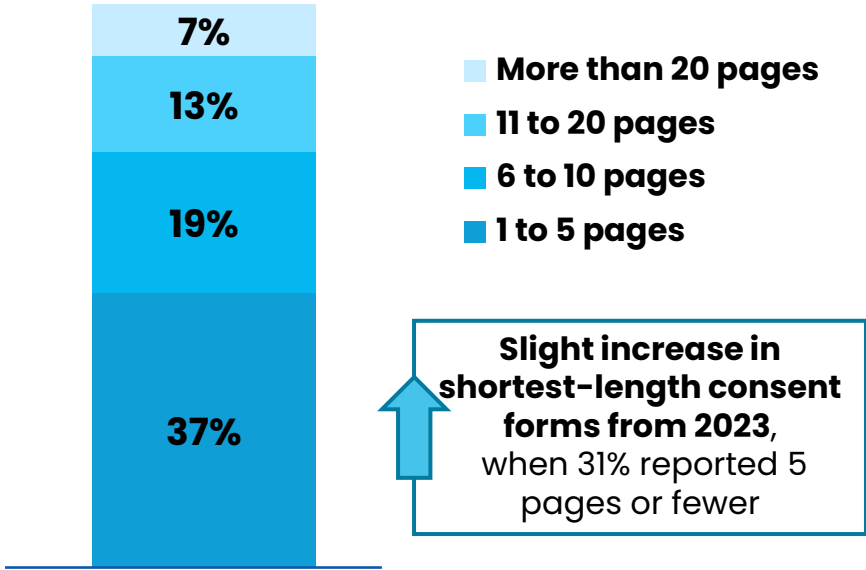
Slight Increase in Electronic and Video Informed Consent

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



Sample Size = 4,415 | Base: Those who have participated in a clinical study, excludes, 'I don't remember'

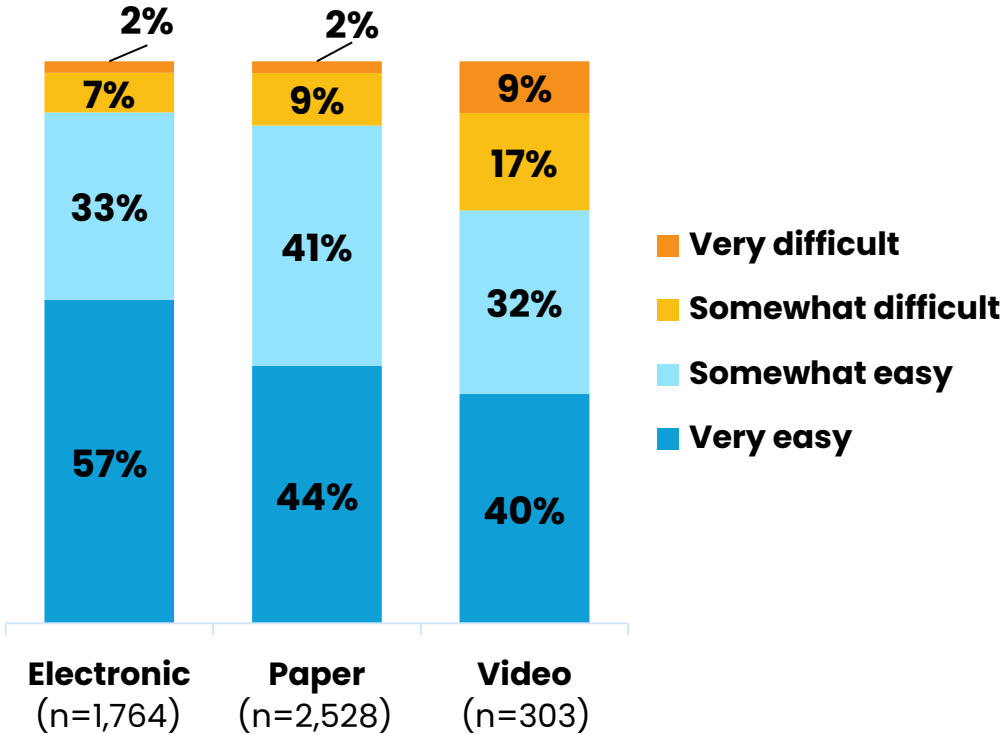
About how many pages was the informed consent form for your most recent study?
(Paper only)



Sample Size = 2,528 | Base: Those who have participated in a clinical study, paper informed consent, excludes 'I don't remember'

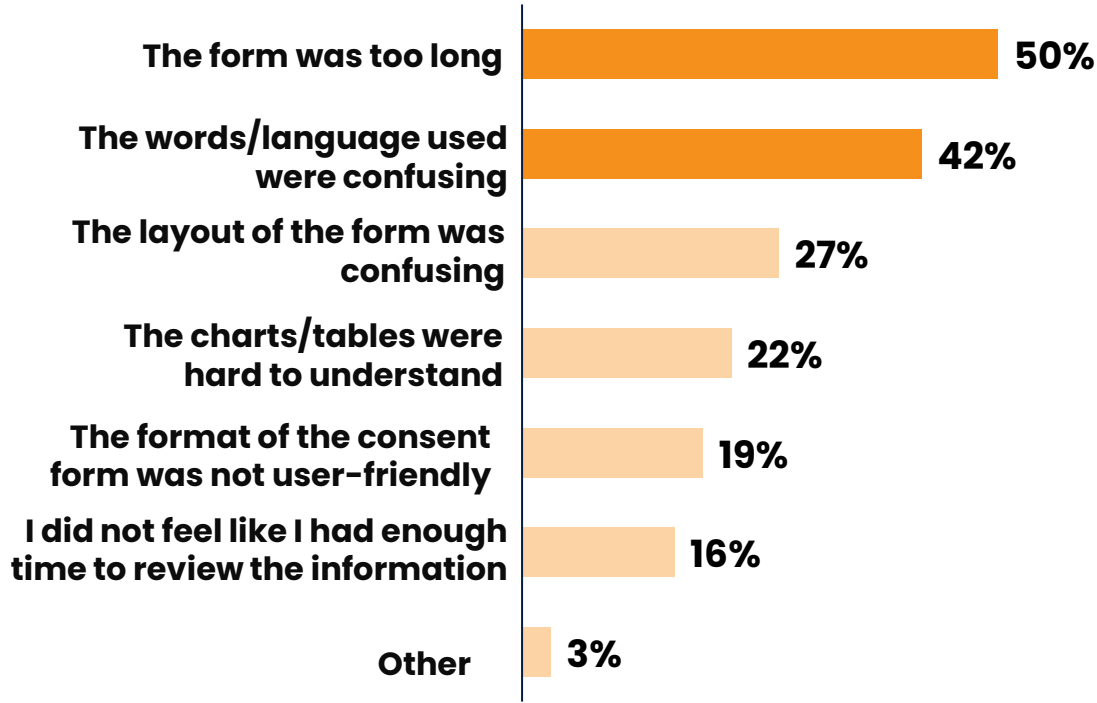
Electronic Consent Perceived as Easiest to Understand

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



Base: Those who participated in a clinical study, excludes, 'I don't remember'

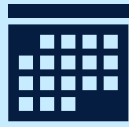
(If difficult) Why was the informed consent form difficult to understand? (Select all that apply)



Sample Size = 437 | Base: Those who found the informed consent form difficult to understand



The majority (75%) reviewed and signed their ICF in **one hour or less.**



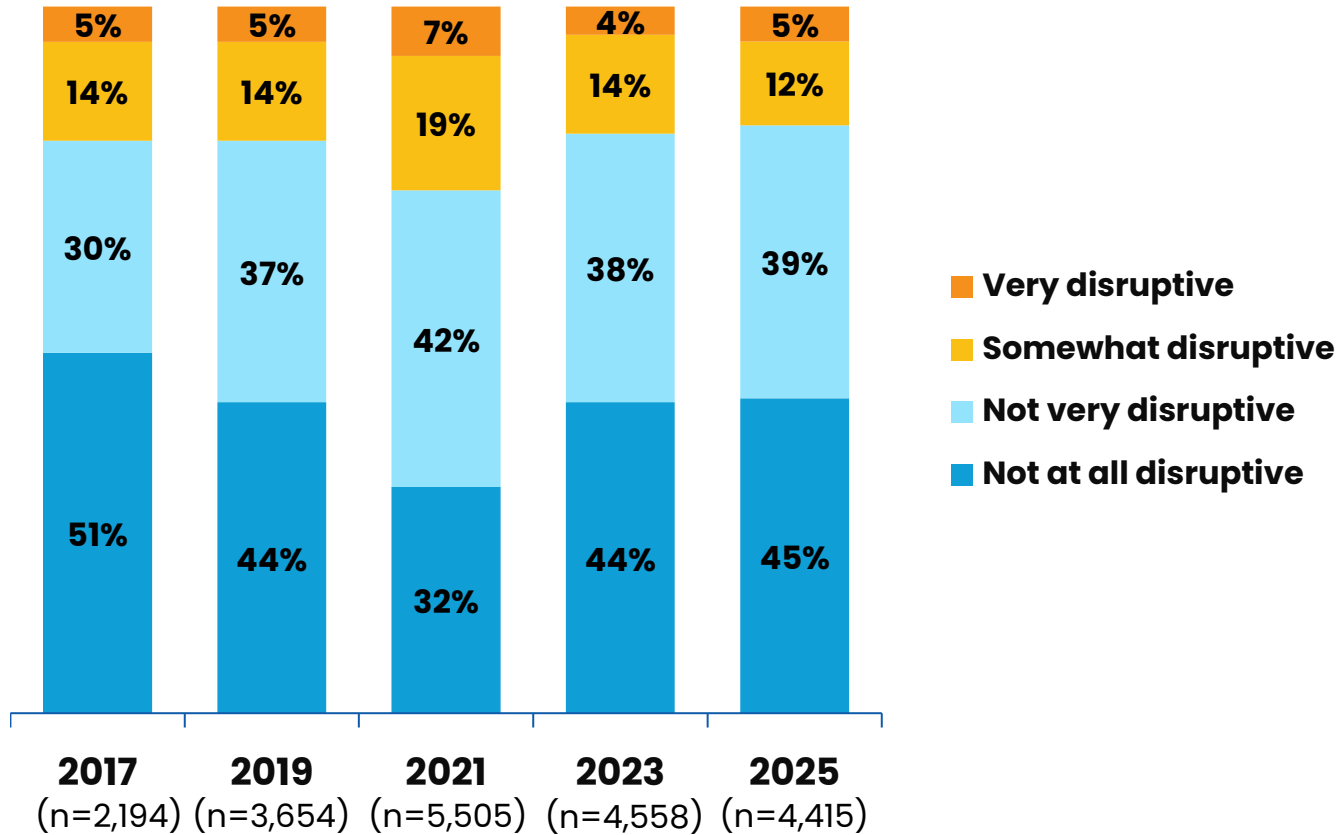
Slight decrease in overall ICF understanding compared to 2023



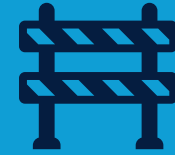
DURING PARTICIPATION

Travel and Time Requirements Continue to be Top Mentioned Sources of Disruption to Daily Routine

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



Base: Those who have participated in a clinical study



What made your participation in the clinical research study disruptive?

Top mentions

- **Having to travel** to the study clinic (**49%**)
- **Too much time required** (**30%**)
- **Completing study requirements at home** (such as completing questionnaires) (**29%**)
- **Missing work** or not getting paid (**25%**)
- **Having to use technology** (such as a smartphone, tablet, etc.) (**21%**)

Sample Size = 716 | Base: Those who reported 'Somewhat' or 'Very disruptive'



Top sources of disruption are **consistent with previous years**

Logistical Factors Continue to be Among the Top Sources of Burden and Disruption

How burdensome was each of the following?

% 'Somewhat' or 'Very Burdensome'

2025

(n=4,415)

Biopsy procedures (n=1,832)	34%
Traveling to clinic (n=3,738)	28%
Diagnostic tests (n=2,884)	24%
Taking the study medicine (n=2,895)	21%
Length of study visits (n=4,012)	20%
Lab work (n=3,519)	18%
Health questionnaires (n=4,164)	17%

Base: Clinical study participants, excludes 'Not Applicable'



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

- ✓ 15 minutes or less: 13%
- ✓ 15 to 30 minutes: 27%
- ✓ 30 minutes to 1 hour: 35%
- ✓ 1 to 2 hours: 16%
- ✓ 2 to 3 hours: 4%
- ✓ More than 3 hours: 4%

Sample Size = 3,677 | Base: Clinical study participants, excludes not having to travel and 'I don't remember'

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 (35%)
- **Receiving compensation** (money) for my time (31%)
- **Having a study nurse or doctor come to my home** for some of my study visits (28%)
- **Having help/assistance traveling** to and from the study (25%)
- **Virtual study visits/telehealth** (25%)
- **Shorter study visits** (21%)

Sample Size = 716 | Base: Those who reported that their participation in a clinical research study was 'Somewhat' or 'Very disruptive' to their daily routine



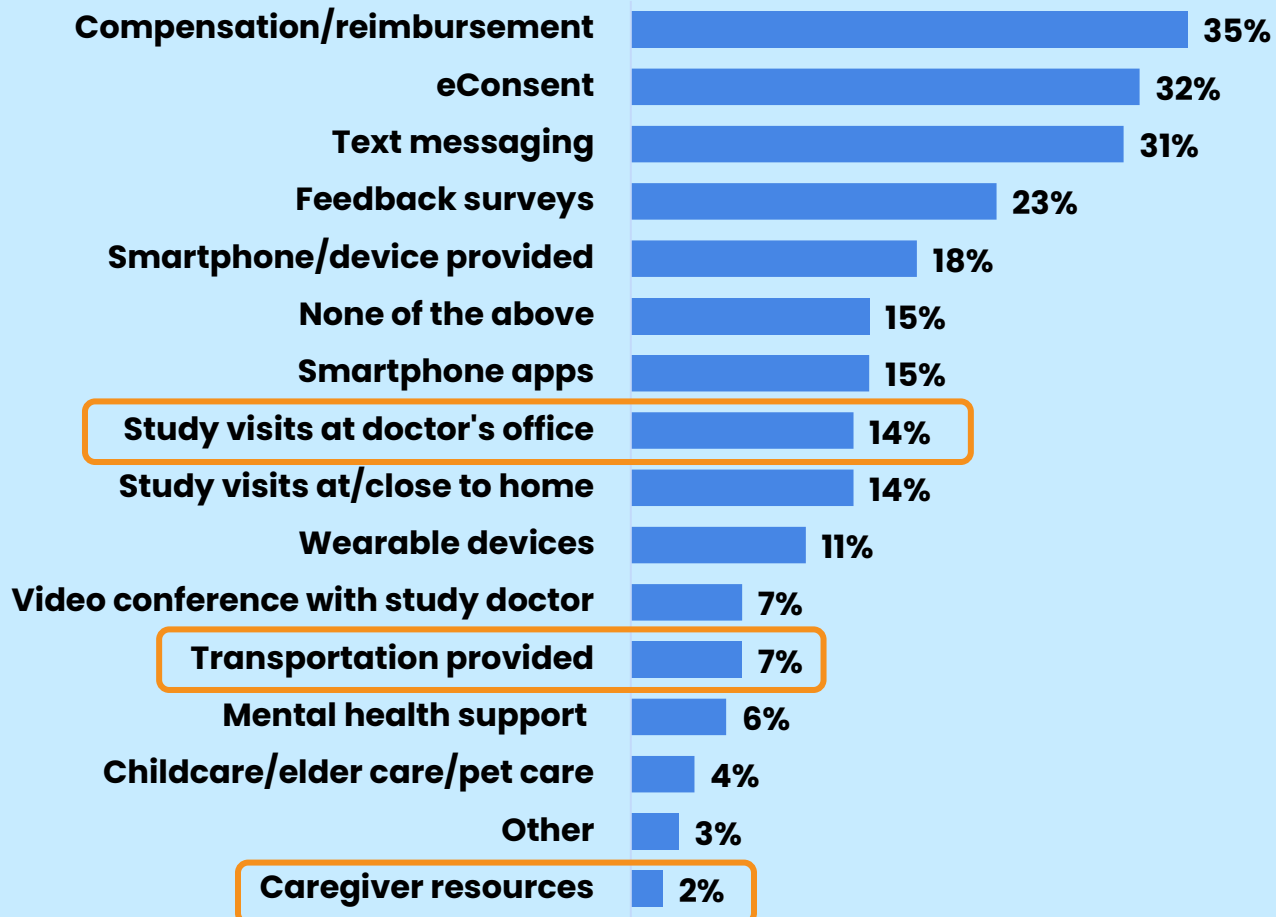
How much time, on average, did you spend at each study visit, not including travel to and from the study clinic?

- ✓ 15 minutes or less: 12%
- ✓ 15 to 30 minutes: 20%
- ✓ 30 minutes to 1 hour: 30%
- ✓ 1 to 2 hours: 21%
- ✓ 2 to 3 hours: 9%
- ✓ More than 3 hours: 7%

Sample Size = 4,068 | Base: Clinical study participants, excludes 'I don't remember'

Logistical Supportive Services and Caregiver Resources Rated as Most Helpful

Which of the following services were used during your clinical research study?



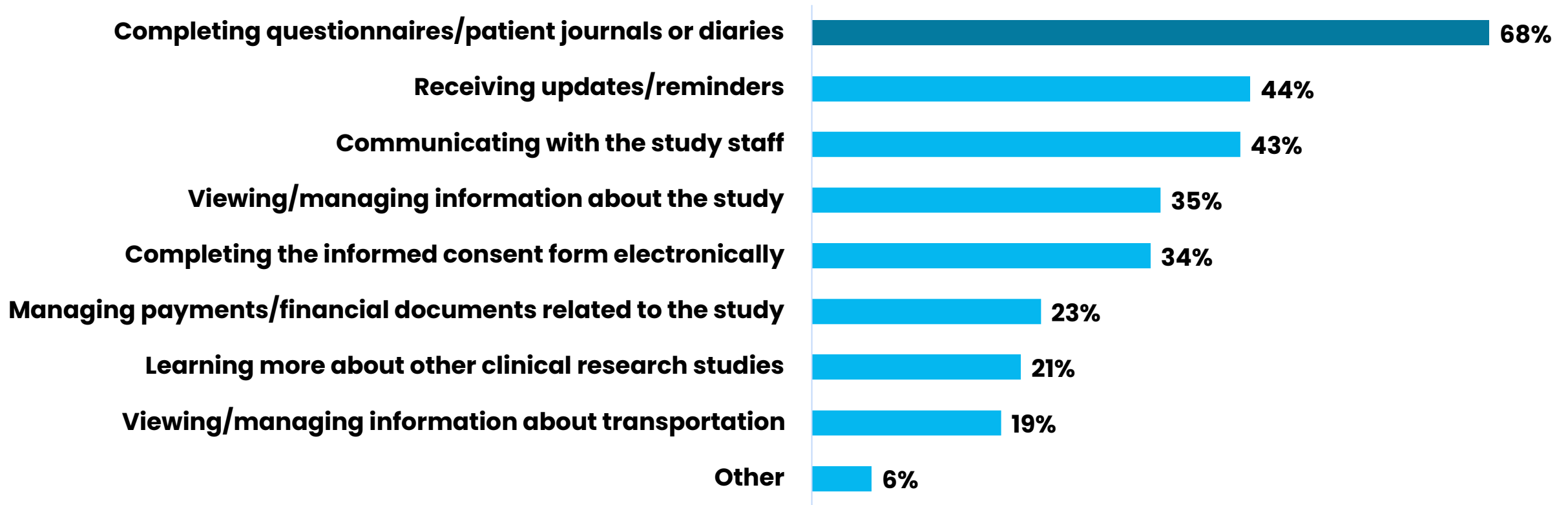
How helpful or not were each of these services?

*Top 10 Most Helpful Services:
(% indicating 'Very helpful')*

- 1) Study visits at home or close to home (76%)
- 2) Transportation to/from study center (72%)
- 3) Supportive services for caregivers (70%)
- 4) Compensation for time/expenses (68%)
- 5) Video conference with study doctor (67%)
- 6) Text messaging for reminders/instructions (66%)
- 7) Smartphone apps for data collection (63%)
- 8) Mental health support (60%)
- 9) Wearable devices (59%)
- 10) Informed consent on an electronic tablet (52%)

Smartphone Apps were Most Often Used to Complete Questionnaires

What did you use the smartphone app for during participation?



Sample Size = 653 | Base: Respondents who used smartphone apps for study collection, excludes 'I don't know/ I don't remember'

When Faced with Technical Difficulties, Patients Most Often Contacted Sites



What problems, if any, did you experience with using technologies as part of your participation in a clinical study?

- I did not experience any problems: 72%
- The device did not operate the way it was supposed to: 11%
- It was difficult to wear the device 24/7: 10%
- The instructions on how to use the device were unclear: 10%
- I could not reach anyone at the study clinic to help me with the device: 8%
- I could not connect the device to the internet: 7%
- Other: 4%

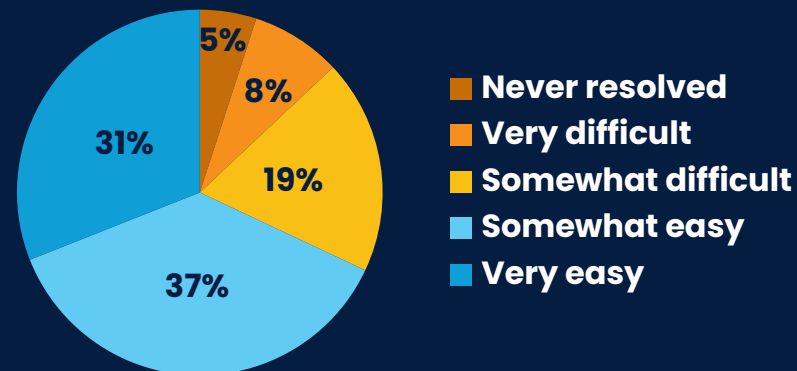
Sample Size = 2,545 | Base: Those who used technology as part of clinical study participation, excludes, 'I don't know/ I don't remember'

Who did you contact about the technical difficulties you experienced?



Sample Size = 717 | Base: Those who experienced one or more problems using technologies during participation, excludes 'I don't remember'

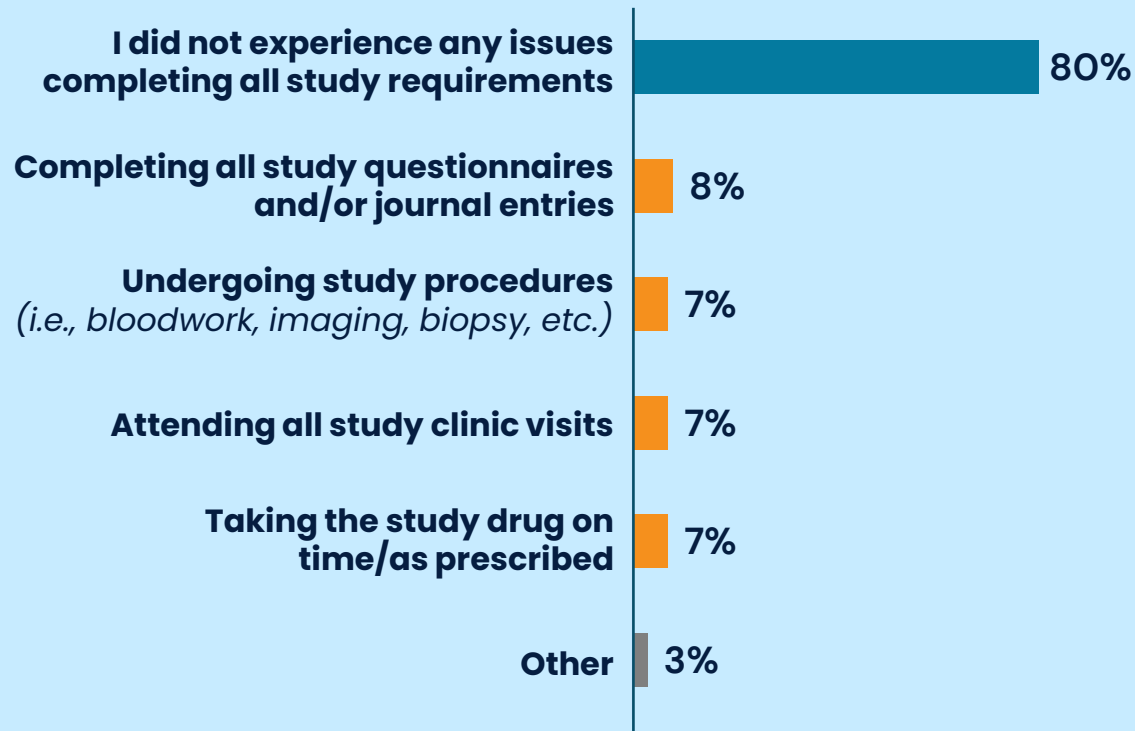
In general, how easy or difficult was it to fix any technical difficulties?



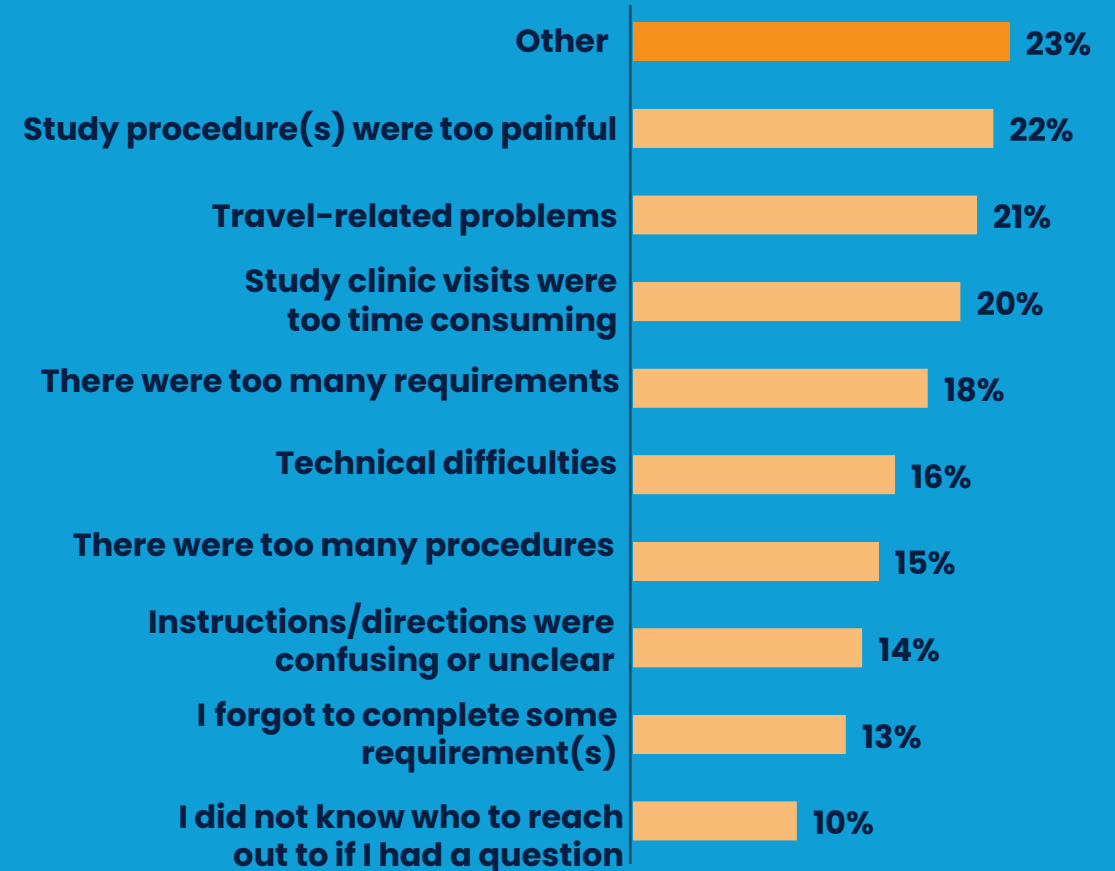
Sample Size = 770 | Base: Those who experienced one or more problems using technologies

Most Interventional Clinical Study Participants Reported No Problems Completing All Study Requirements

Did you experience problems with any of the below requirements?



Why did you experience a problem completing this study requirement?
(Select all that apply)

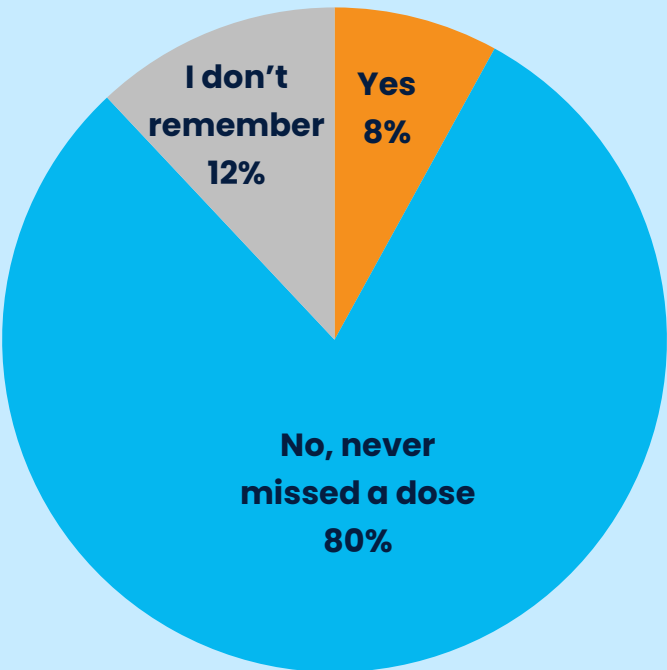


Sample Size = 2,430 | Base: Those who have participated in an interventional clinical study

Sample Size = 439 | Base: Those who experienced a problem completing one or more study requirements. **Note:** 'Other' responses included mentions of side effects, lack of efficacy, placebo concerns, risky or painful procedures, logistical challenges, and poor communication with the study site, in addition to other problems.

Forgetting to Take the Study Drug was the Top Reason for Missed Doses

Did you ever miss a dose of the investigational study drug?



Sample Size = 2,766 | Base: Those who received compensation and/or reimbursement as part of their participation in a clinical study

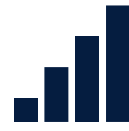
Which of the following best describes the reasons that you missed a dose?

- **I forgot** (40%)
- I experienced **side effects** or was afraid of potential side effects (16%)
- **Other** (13%)
- There was a **delay** or problem with getting the investigational study drug (e.g., shipping delay) (12%)
- I had a **problem with a medical device** (e.g., medical equipment was broken) (11%)
- The **instructions** for taking the investigational study drug were **unclear** (10%)

Sample Size = 200 | Base: Those who indicated that they missed a dose



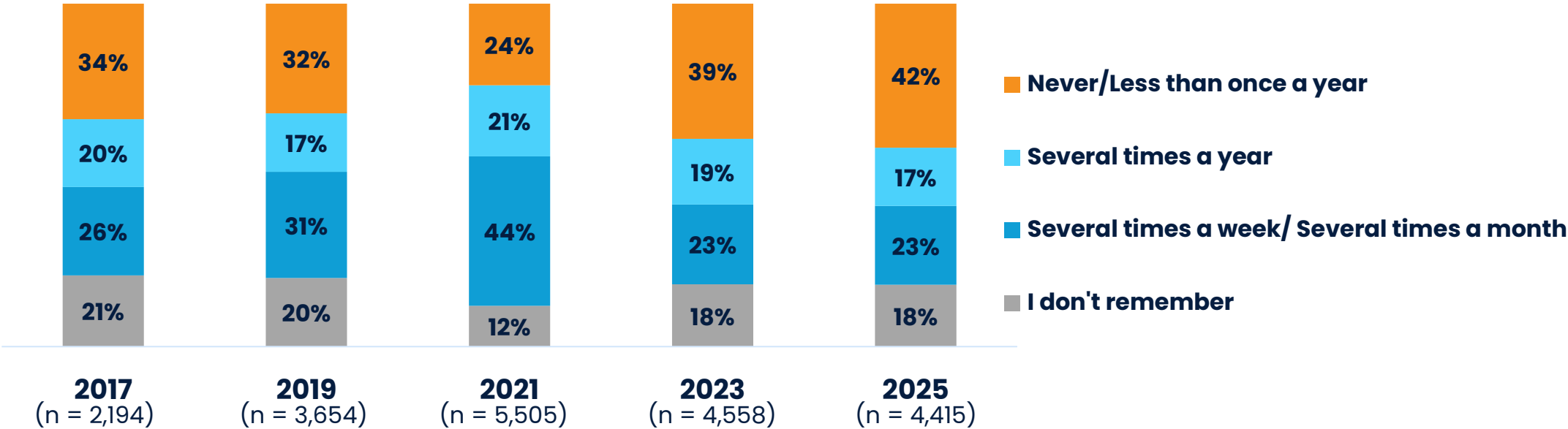
Those who participated in remote/virtual studies were more likely to indicate missing a dose of the study drug (19%) compared to those who participated in hybrid (13%) or traditional in-person study models (7%).



As a general trend, younger respondents were more likely to indicate that they had missed a dose of the study drug.

Frequency of Study Updates During Participation Continues to Decline

How often did you receive updates about the study while you were enrolled in it?



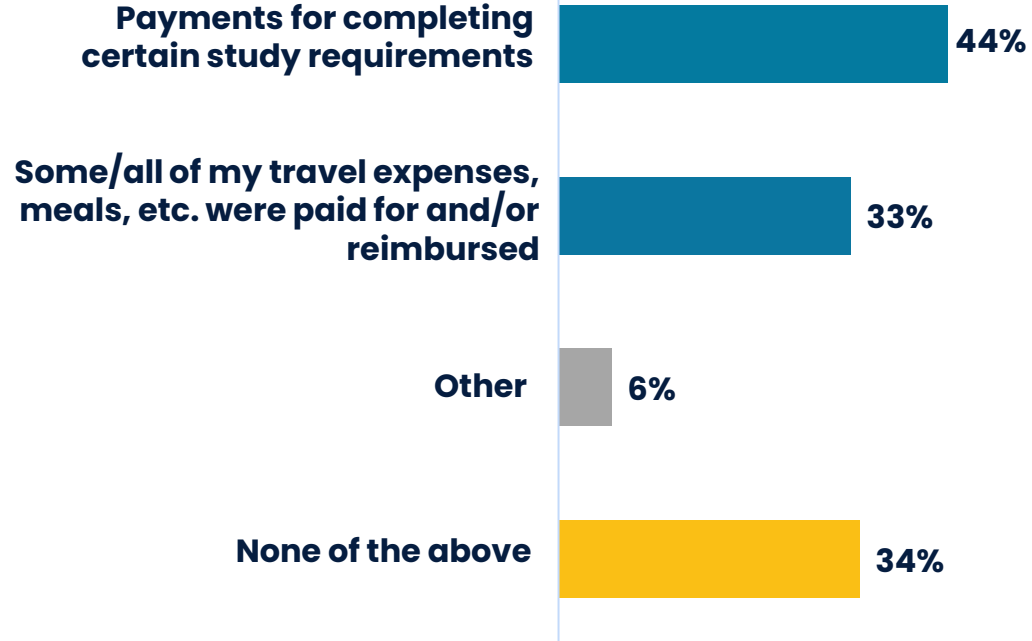
Base: Those who have participated in a clinical study



As in past years, those participating in **hybrid/remote** studies were more likely to receive **frequent updates**, while those participating in a **traditional clinical research study** were **least likely to receive frequent updates**. **29% of those in traditional studies reported never receiving updates while enrolled**, compared to 22% in hybrid studies and 21% in remote studies.

1 in 3 Received No Compensation or Reimbursement

Which of the following types of compensation and/or reimbursement did you receive during participation, if any?

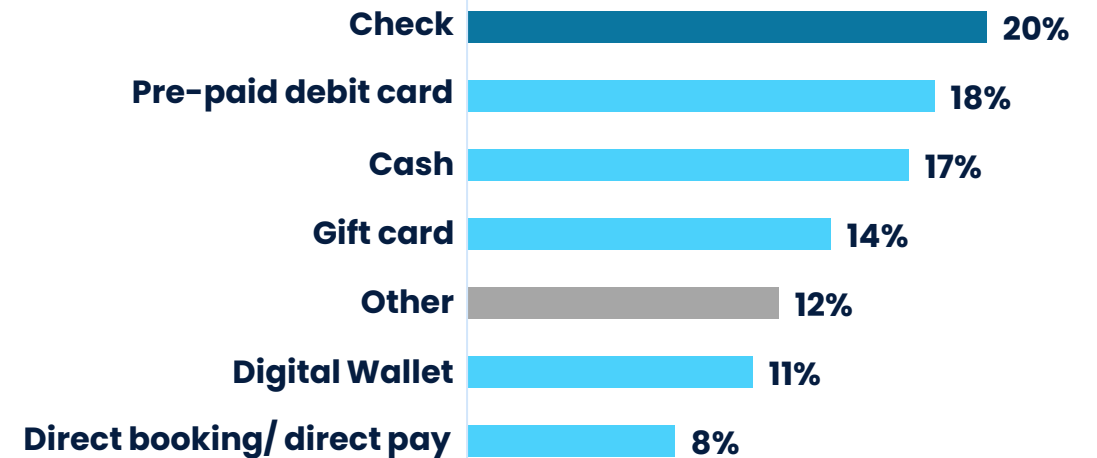


Sample Size = 4,157 | Base: Those who have participated in a clinical study, excludes 'I don't know/ I don't remember'



Compensation/reimbursement varied widely by world region and was least common in Europe. Nearly half (49%) of those in Europe received no compensation or reimbursement, compared to just 13%-20% in other world regions.

What was the primary way you received your compensation and/or reimbursement?

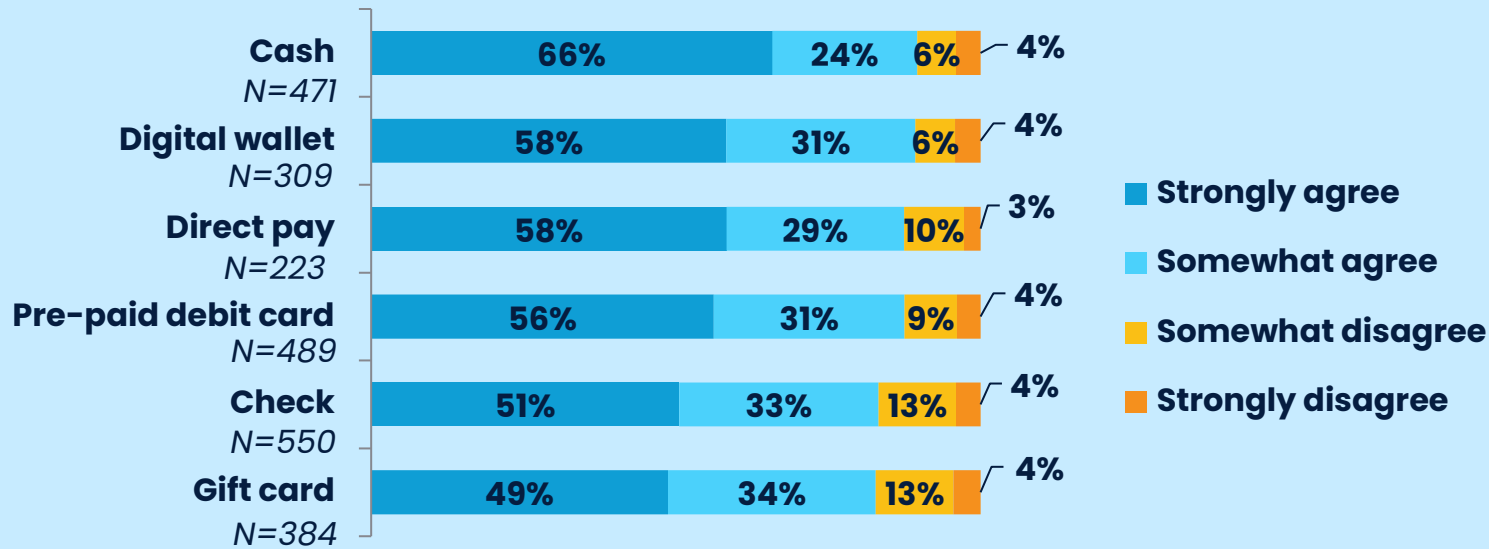


Sample Size = 2,766 | Base: Those who received compensation and/or reimbursement as part of their participation in a clinical study

Cash, Digital Wallets, and Direct Pay Perceived as Most Convenient

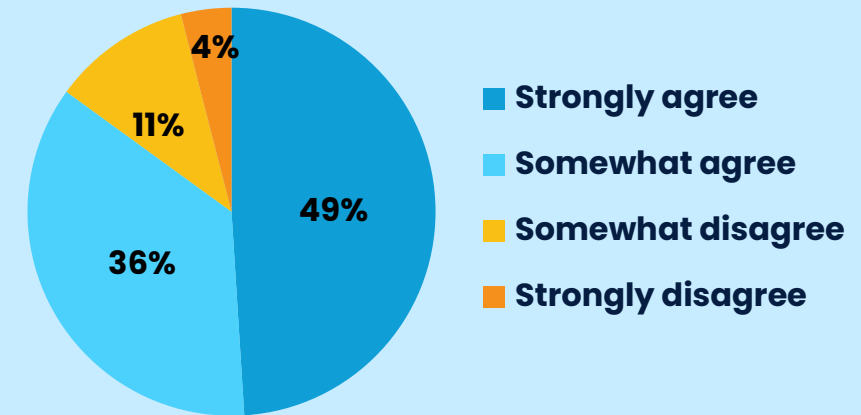
Among those who received compensation or reimbursement as part of their participation in a clinical study, **cash, digital wallets, and direct pay** (i.e., the clinical study paying for travel/lodging expenses directly, rather than reimbursing expenses later) were perceived as the **most convenient** compensation/reimbursement methods. While most 'somewhat' or 'strongly' agreed that the amount provided was fair and enough to cover costs, there is some room for improvement as **15% felt the amount of compensation was not fair or enough to cover costs**.

The method of payment was convenient for me.



Base: Those who received compensation and/or reimbursement as part of their participation in a clinical study. Excludes 'Other.'

The amount of compensation and/or reimbursement provided was fair and enough to cover my costs.



Sample Size = 2,766 | Base: Those who received compensation and/or reimbursement as part of their participation in a clinical study.

79% Completed Participation in the Entire Study

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



- I participated in the entire clinical research study
- I stopped before my last scheduled study visit
- I am not sure/I do not remember



Slight decrease in study completion rate compared to 2023, when 83% participated in the entire study

Sample Size = 4,415 | Base: Those who participated in a clinical study



Why did you stop participation in the clinical research study?

Top mentions

- **I was told I did not qualify to participate anymore** (31%)
- **Health reasons** (19%)
- **There was poor communication with the study center** (13%)
- **The location of the study center** (13%)
- **The overall time commitment was too much** (12%)



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

Top mentions

- **None of the above** (32%)
- **More virtual visits offered** (15%)
- **Reimbursement for my out-of-pocket expenses** (14%)
- **Additional information provided on how to manage side effects** (13%)
- **Being provided supportive services** (13%)

Sample Size = 500 | Base: Those who stopped participation in a clinical study




AFTER PARTICIPATION

Slight Increase in Receiving Reports or Updates on Study Results After Participation

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

- 2025: Yes (35%) No (50%)**
- 2023: Yes (31%) No (53%)**
- 2021: Yes (43%) No (44%)**
- 2019: Yes (32%) No (51%)**
- 2017: Yes (30%) No (53%)**

Sample Size = 2,194 in 2017; 3,654 in 2019; 5,505 in 2021; 4,558 in 2023; 4,415 in 2025 | Base: Respondents who participated in clinical study, excludes 'I don't remember'


Those residing in Europe and North America were least likely to receive study results.

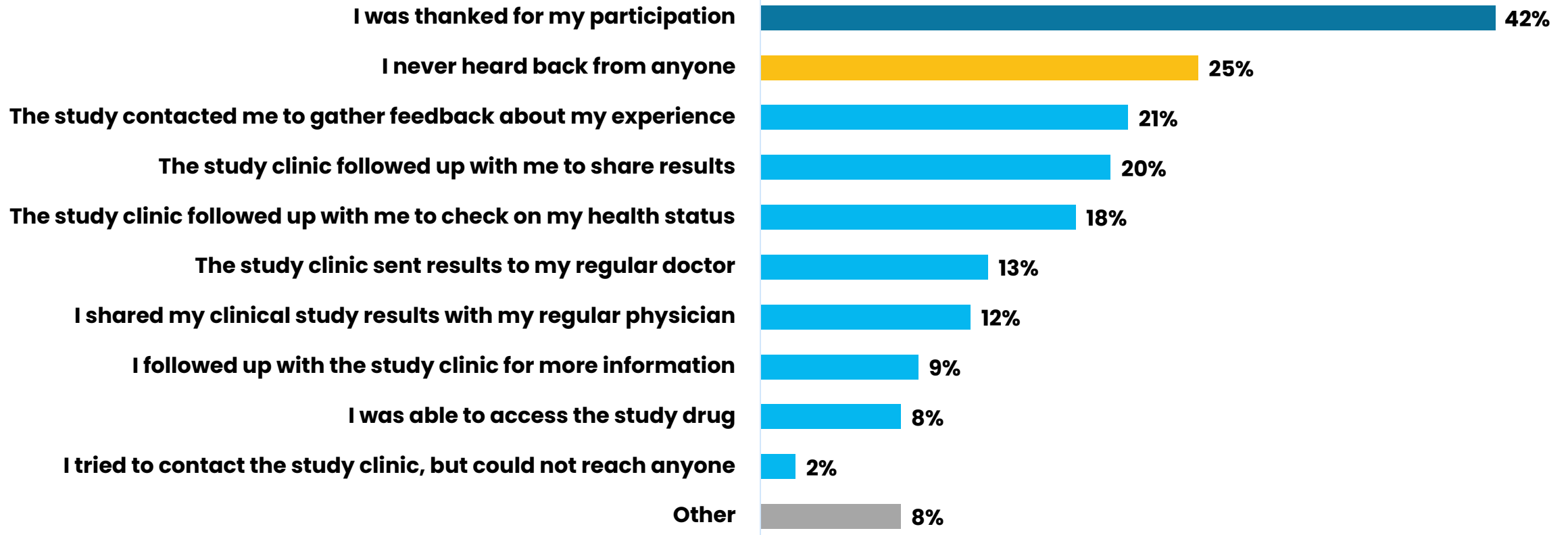

Study results were most often shared via email (50%) or a mailed paper copy (31%).

What information did you receive?	% Mentioning	% Indicating 'Very Helpful'	% Indicating 'Very Easy to Understand'
A summary of the study results	63%	49%	52%
My individual study results (i.e., procedures and test results)	47%	59%	57%
Whether I received the study drug or a placebo	25%	62%	67%
Information about upcoming clinical research studies	25%	53%	55%
Information about scientific publications	20%	46%	45%
Drug approval status by the regulatory agency in your country	18%	55%	55%
The brand name for the study drug	17%	53%	61%

Sample Size = 1,566 | Base: Those who received study reports or updates after participation

Increased Communication Post-Participation

Which of the following happened after you completed your participation in the clinical research study?



Sample Size = 4,415 | Base: Those who participated in a clinical study, 2025

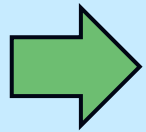


In 2023, 37% never heard back from anyone after participation.

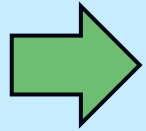


Those in Europe were most likely to never hear back from anyone post-participation compared to all other regions.

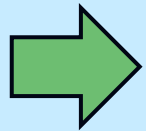
Most Continue to Indicate High Satisfaction Levels



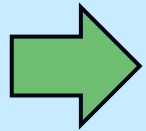
86% felt the study met or exceeded their **overall expectations**



95% believed they received the same or better **care and attention** compared to standard of care



93% would 'probably' or 'definitely' **recommend participation** to family and friends, if a study was appropriate for them



95% would be 'somewhat' or 'very' **willing to participate again** in future clinical research studies - the majority (67%) would be 'very willing'

Sample Size = 4,415 | Base: Those who participated in a clinical study



Findings are **generally consistent** with previous years

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 2025, 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. The survey instrument was reviewed by an ethical review committee. CISCRP collaborated with Clariness, James Lind Care, and Rare Patient Voice to reach and engage respondents.

12,887 Survey Respondents Respondent characteristics are as follows:	Gender	53% Female 46% Male 1% All other genders
	Region	44% North America 5% South America 41% Europe 5% Asia-Pacific 5% Africa
	Age	18% 18–34 years old 16% 35–44 years old 16% 45–54 years old 20% 55–64 years old 31% 65 or older
	Race (top mentions)	76% White 9% Black or African-American 6% Asian
	Ethnicity	86% Non-Hispanic 13% Hispanic
	Incidence of participation in a clinical study	66% have never participated 34% have participated

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

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.

About CISCRP's Research Services

✓ **Patient &
Caregiver
Advisory
Boards**

✓ **Clinical Trial &
Patient Journey
Projects**

✓ **Surveys &
Quantitative
Research
Projects**

✓ **Custom
Research
Projects**

CISCRP's experienced Research Services team is skilled at engaging patients and their support network to obtain meaningful insights for sponsors — including pharmaceutical, biotechnology and medical device companies; contract research organizations; academic and for-profit institutions; foundations; and nonprofit organizations.

Recognized as a trusted leader in the industry, our team brings extensive global experience across therapeutic areas. We excel at facilitating discussions on complex concepts, therapies, and protocols with patients and the public. The findings gathered are transformed into actionable insights designed to drive organizational change.



2025 Perceptions and Insights Study Team

- **Annick de Bruin, Chief Research and Insights Officer**
- **Jasmine Masullo, Senior Director**
- **Shalome Sine, Senior Manager & Quantitative Insights Specialist**
- **Rachel Melloul, Senior Project Manager**
- **Elena Wade, Project Manager**
- **Nicole Weiland, Associate Director Marketing**
- **Lindsey Elliott, Senior Manager, Marketing and Communications**
- **Jasmine Walker, Associate Editor, Health Communication Services**



Thank You

CISCRP thanks the following organizations for their support of the 2025 P&I Study:



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