



THE PATIENT PERSPECTIVE ON CLINICAL TRIALS

A COLLABORATIVE SURVEY REPORT BROUGHT TO YOU BY:



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EXECUTIVE SUMMARY

Despite the clinical research industry's continual search for solutions to the challenges posed by inadequate clinical trial recruitment and retention, an easy path to finding qualified study participants in a timely fashion continues to elude the industry.

Many single-focused solutions have been proposed; from artificial intelligence and electronic health records to identify patients, to mHealth wearables and virtual trials to engage participants. These solutions have attempted to turn around the dynamic between clinical research and patients — all from the perspective of the industry.

More recently, a movement toward a broader ecosystem has been underway, based on a collaboration between multiple stakeholders, including sponsors, clinical researchers, regulatory authorities, health systems, physicians and patients.

What this approach purports to do, and what many previous methods failed to do, is to connect with patients in a real way — not just as subjects needed to fill a trial, but as people who have a right to be in the driver's seat where their own health is concerned.

For this approach to be successful, making these connections will be vital. To begin this work, the industry needs a continual flow of better information about what motivates patients to participate, what they hope to gain from clinical research and where they hope to get information about clinical trials. Insight like this can guide the industry to decide how to focus its recruitment efforts in a way that proves efficient for these companies and meaningful for patients.

This report seeks to add to the body of information necessary to make these decisions.

Fielded in June, July and August 2018, this survey was conducted by SCORR Marketing, a marketing firm dedicated to the life sciences, in partnership with Antidote Technologies, a digital health company that helps connect patients to clinical trials.

The survey provides insight into the perspectives of people who are living with some of the most common diseases affecting Americans today: diabetes, kidney disease, cancer and multiple sclerosis. These are people whose health understandably takes on a big role in their lives. Because these are people who have more motivation to participate in research than the general population, these are the people that the clinical research industry cannot afford not to reach.

While providing information about patients, this report also raises important questions for the industry to face. Here are a few:

- A little more than a quarter of the respondents in this survey have participated in a trial, which, as expected, is a higher participation rate than the 18% of respondents in another survey who reported that they or a family member had participated in clinical research.¹ But, given that this is a survey of people afflicted with a particular health condition, why is it that three-quarters have never participated in a trial and one-third have never even given trial participation a thought?
- Nearly one in five of these patients said that a person had to be close to a major hospital in order to participate in research. Why were remote trials not even considered a possibility by these respondents?
- Getting better care and improving their own quality of life were reasons cited in this survey for participating in research. The top reason, however, was altruistic, which raises the question: Should the industry be working harder to educate Americans about how clinical research can improve the health of future generations?
- Only one-third of these respondents have ever talked about research with their doctor — which is higher, but not significantly so, than other research that indicates that 19% of the general population have had this discussion with their physician.² This finding should have the clinical research industry asking itself a slew of questions, starting with why? Do physicians not know or not understand the importance of research? Do they see no value for their patients? Or, are other reasons involved?

For the industry to truly develop a new ecosystem that focuses on collaboration between all the stakeholders involved, including patients, it is valuable for researchers to continually ask questions like these. No survey provides all the answers, but by taking a deep look into the insights provided in this survey, the industry may be one step closer to making better decisions that truly embrace the people whom research is all about.

In the following pages, SCORR and Antidote present general findings from the survey. More detailed information — results broken down by demographics and disease as well as additional questions and responses — will be provided in the full report, which will be available later this year from SCORR Marketing. Some key conclusions are outlined on page 24. This report concludes with a comparison of some of this survey's results with those from another survey taken in 2017 of clinical research participants

The survey results provide a variety of insights about patients based on their disease, more of which will be explored in the full report.

Survey respondents with cancer (lung cancer or melanoma) are more likely to be very familiar with clinical trials than are respondents with any of the other therapeutic conditions. Participants with lung cancer are also the most likely of all patients surveyed to have joined a clinical trial. Patients with gastrointestinal disease are the least likely.

In addition, melanoma and lung cancer patients who joined clinical trials were primarily concerned with extending their own lives. Those with lupus or kidney disease were more interested in helping future patients.

Patients with lung cancer or melanoma reported the primary way of getting information about clinical trials is through their doctor's office. Lung cancer and melanoma patients are also most likely to deem it very important that their doctor supports their decision to join a clinical trial. For those with Type 1 diabetes, the primary source of information about clinical trials comes from advocacy groups.

Kidney disease and multiple sclerosis patients place a higher priority on logistical factors than do patients with other conditions. Oncology patients are the least inclined to be concerned with financial considerations, while allergy/asthma patients are more than twice as likely than melanoma or lung cancer patients to believe payment for participation would be a motivator.

Respondents with melanoma, kidney disease or lung cancer are most likely to say the opinions of their families and friends are essential or matter quite a bit in their decision to join a clinical trial. The input of their families and friends matters the least for those with gastrointestinal disease or allergies/asthma.

In terms of patients reporting confidence in making well-informed health decisions, kidney disease patients feel the most confident and patients with Type 1 diabetes patients express the least, an interesting finding due to the causal relationship between diabetes and kidney disease.

More than any other patient group, patients with lupus indicate that being consulted about what they want from a treatment would motivate them to participate in clinical research. Similarly, being given explanations about why joining a clinical trial is important or the effect on them if people don't participate is more important to patients with lupus than the other survey respondents.

RESPONDENT PROFILE

There are 3,987 survey respondents (all from the U.S.) who responded to an online survey between June 18, 2018, and August 21, 2018, representing a range of separate therapeutic conditions.

Survey participants were recruited through Antidote’s partner network and included a diverse group of patients and caregivers connected to the following organizations:

- American Kidney Fund
- Allergy & Asthma Network
- Healthline
- JDRF
- Lung Cancer Alliance
- Lupus Research Alliance
- Melanoma Research Alliance
- Multiple Sclerosis Association of America

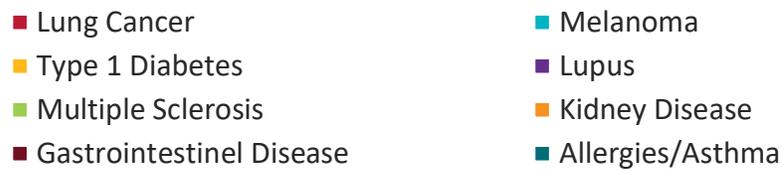
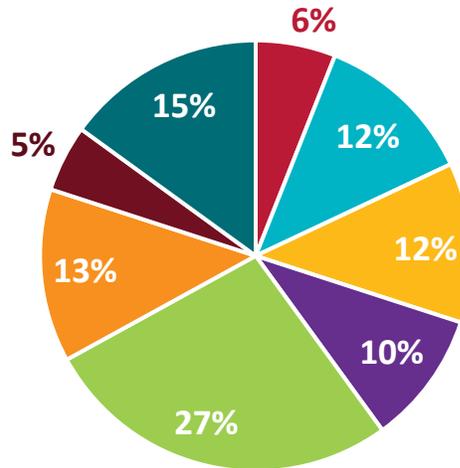
A majority of respondents were white, female patients. The high numbers of female respondents is consistent with the research on how gender influences online behaviors related to health information,³ and it is also supportive of the notion that mothers largely fill the role of “chief medical officer” for their families.⁴

About a quarter of respondents reported they have participated in clinical trials.

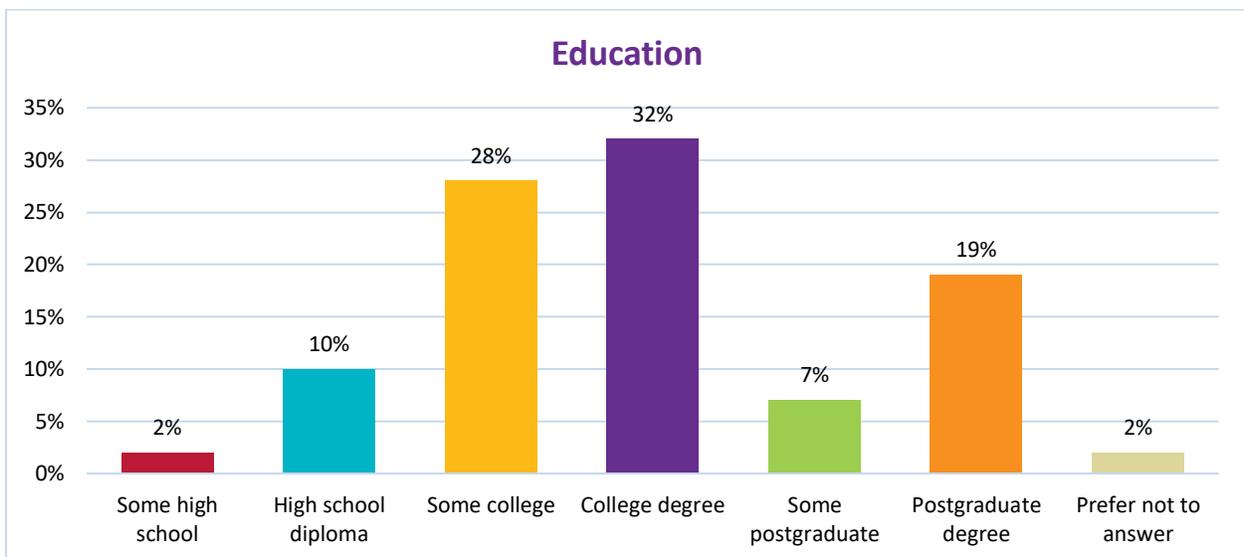


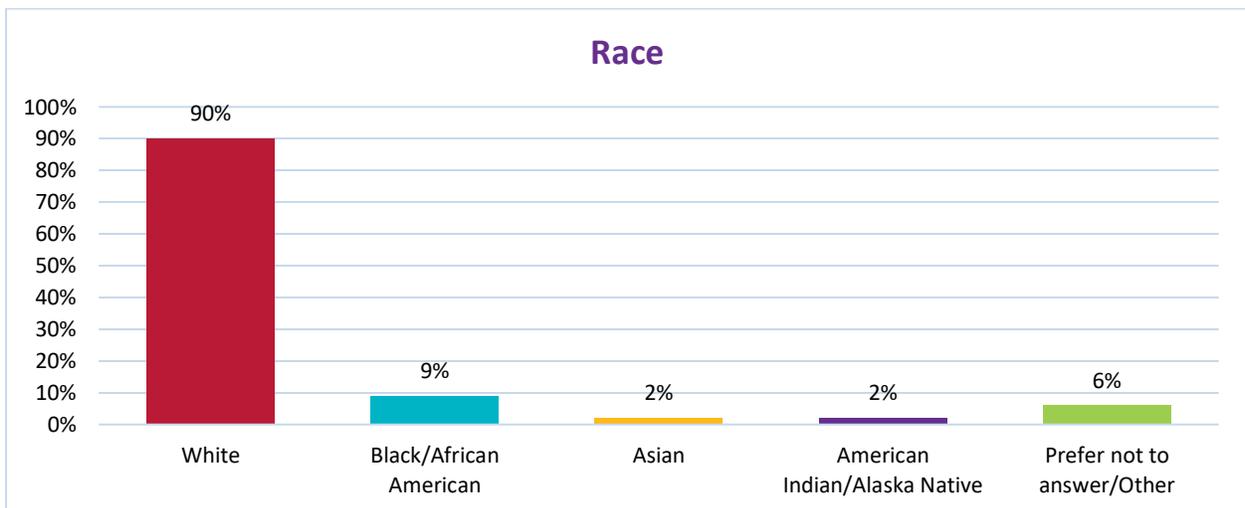
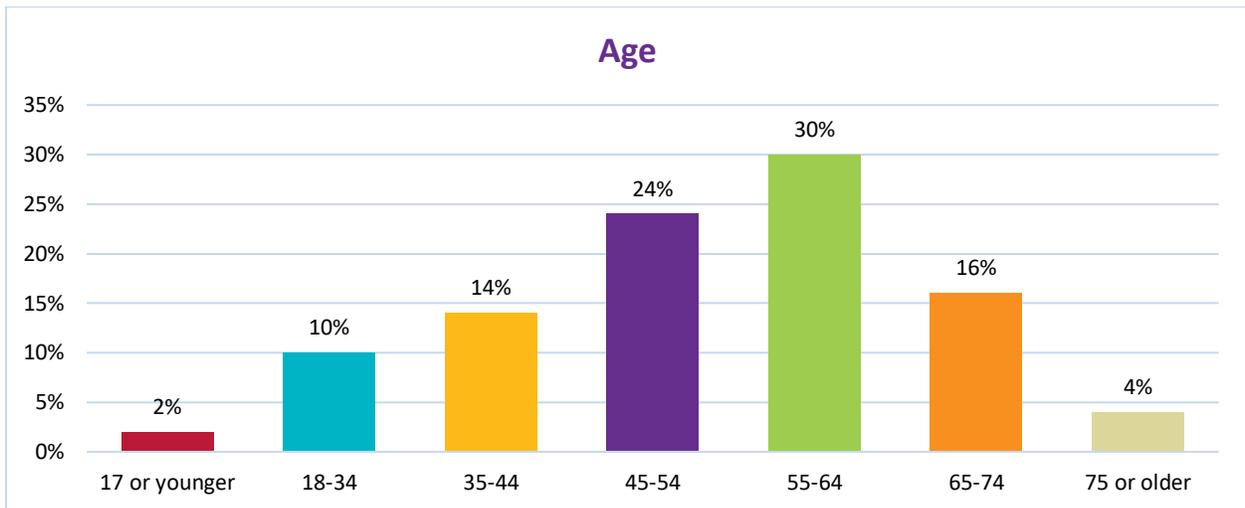
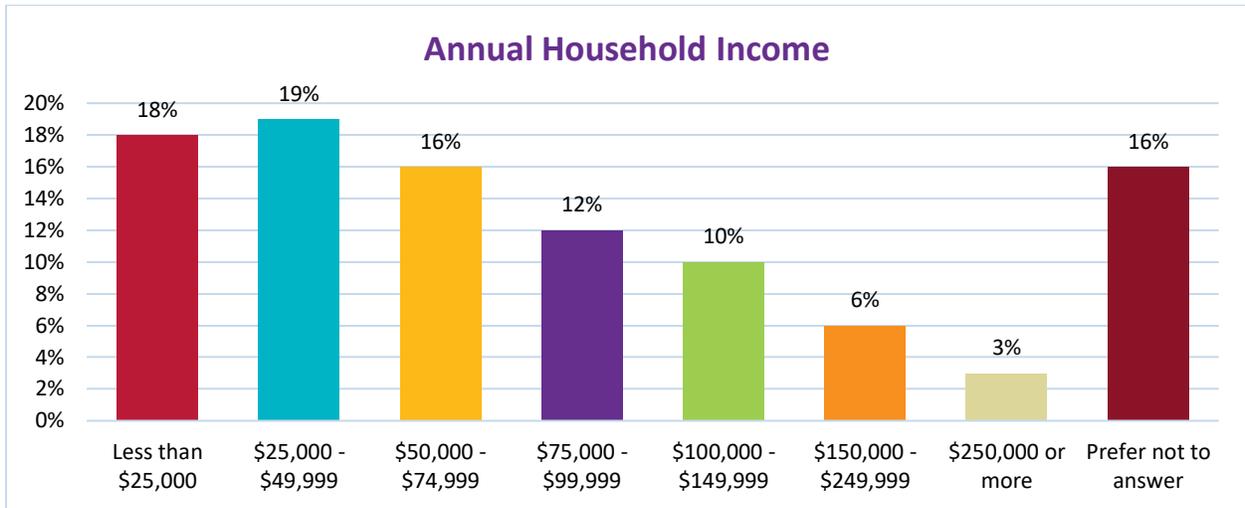
RESPONDENT DEMOGRAPHICS

Therapeutic Condition

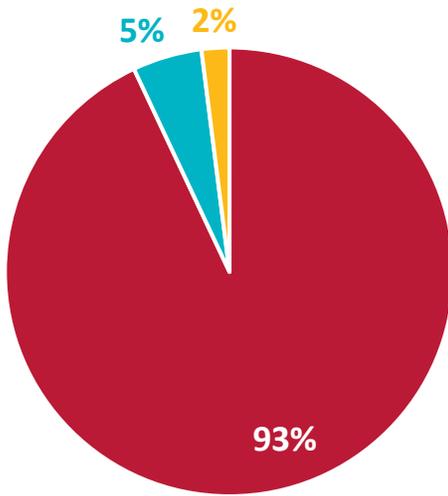


Education



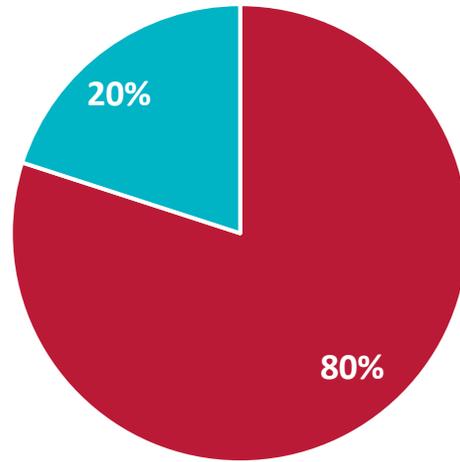


Ethnicity



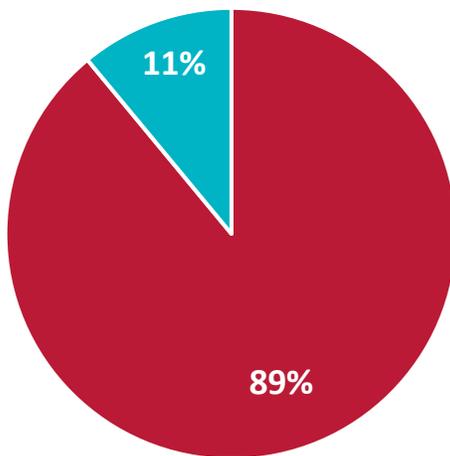
- Non-hispanic
- Hispanic/Latinx
- Prefer not to answer

Gender



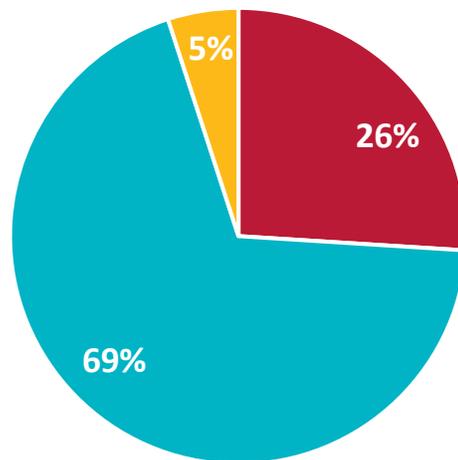
- Female
- Male

Patient or Caregiver



- Patient
- Caregiver

Clinical Trial Participation



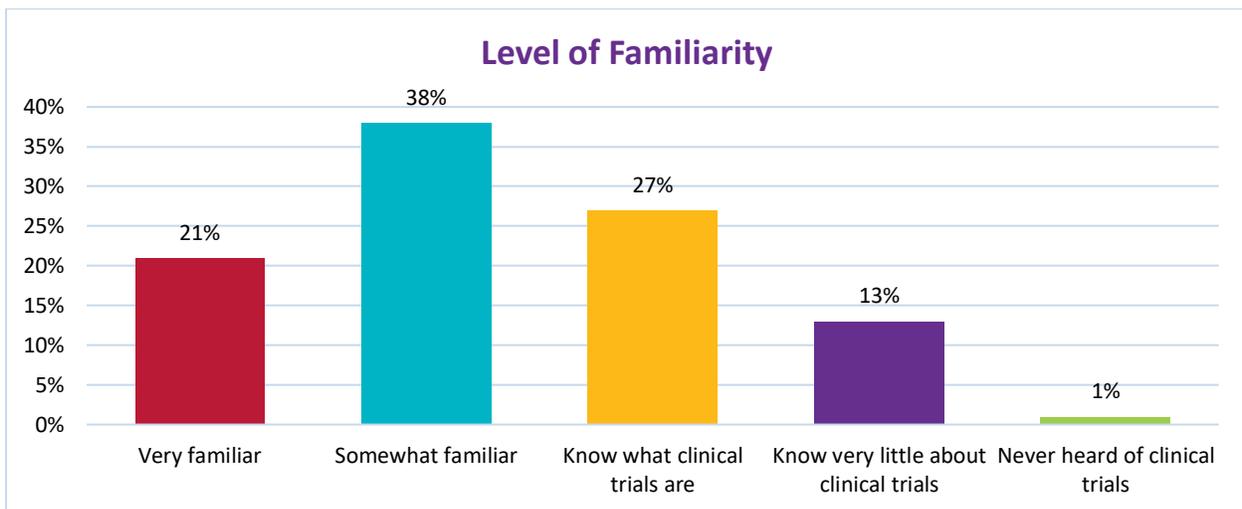
- Has ever joined a clinical trial
- Has not ever joined a clinical trial
- Don't know

PATIENT KNOWLEDGE

Eighty-six percent of these respondents are aware of clinical trials, a rate not significantly more than the general population. (A July 2017 survey indicated that 80% of Americans have heard of a clinical trial.⁵) Respondents self-selected their level of familiarity with clinical trials, and eight true/false questions about clinical research basics were asked to validate the respondents' general knowledge.

- 59% were either very familiar or somewhat familiar with clinical trials and another 27% reported they know what clinical trials are.
- 74% correctly assessed the validity of seven or eight of the eight true/false questions.

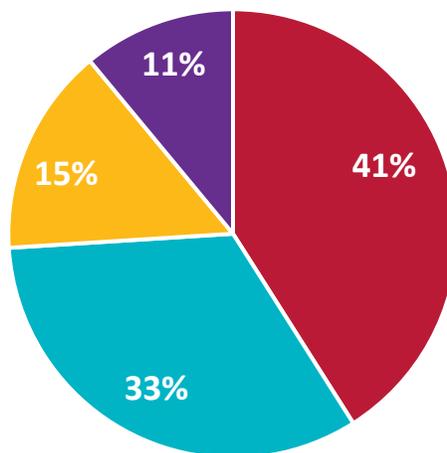
How familiar are you with clinical trials?



True or false? Please answer true or false to the following statements.

Statement	"True"	"False"
Clinical trials help determine the safety and effectiveness of a new drug, therapy, treatment or medical device.	99%	1%
If my doctor doesn't tell me about a clinical trial, I won't be able to join a trial.	12%	88%
You need to live near a major hospital to participate in a clinical trial.	19%	81%
Before a trial starts, a group of unbiased experts reviews the clinical trial to make sure people who volunteer for the trial aren't harmed.	92%	8%
I can ask as many questions as I like about a clinical trial before deciding to participate.	98%	2%
Once I decide to participate in a clinical trial, I can change my mind.	92%	8%
Children cannot participate in clinical trials.	32%	68%
Patients are sometimes paid to participate in clinical trials.	87%	13%

Number of True-False Questions Answered Correctly



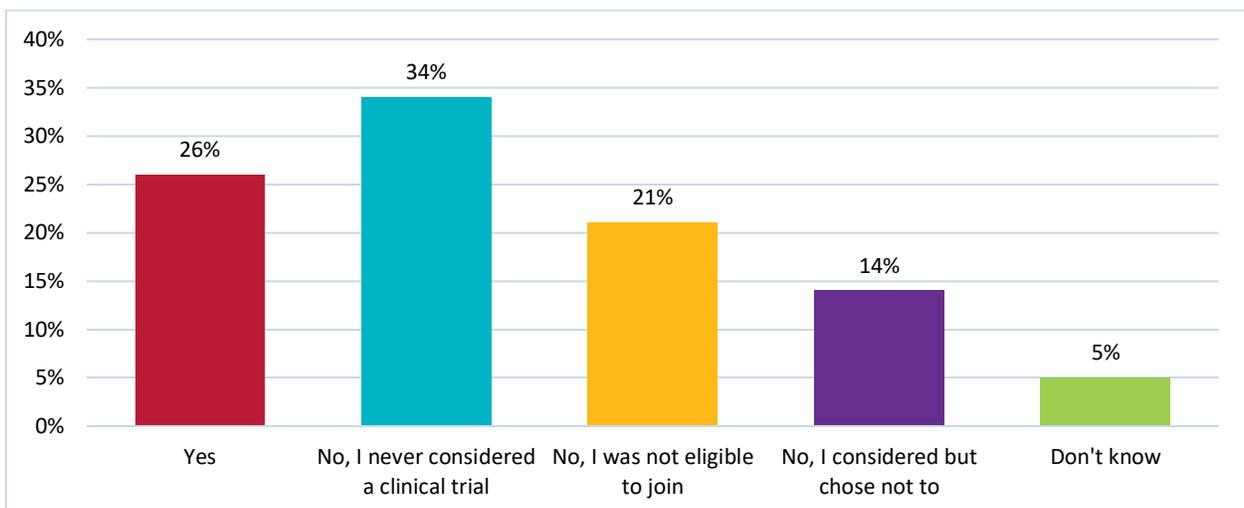
■ 8 ■ 7 ■ 6 ■ 0-5

CLINICAL TRIAL PARTICIPATION

Twenty-six percent of these respondents have joined a clinical trial, while more than one-third never considered the possibility. For those who have participated in clinical research, the reasons varied.

- 75% reported that the major reason or one of the major reasons they joined the clinical trial was to help future patients.
- 69% said they participated to improve their quality of life.
- 63% indicated they were highly motivated to participate in order to receive the best care possible.

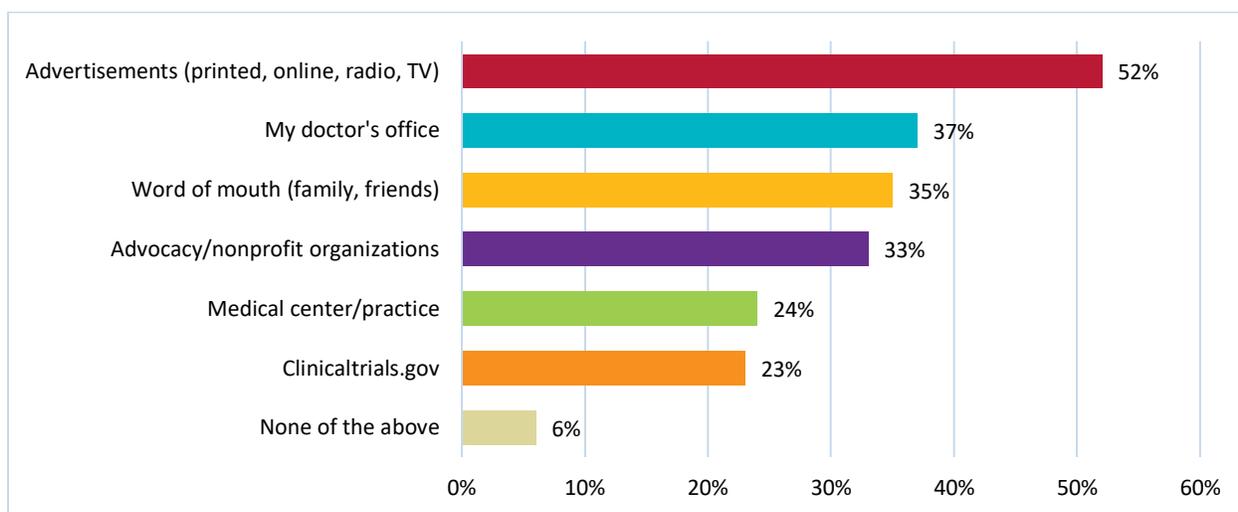
Have you ever joined a clinical trial?



Why did you join?

Reason	This was the major reason	This was one of the major reasons	Yes, but this wasn't really why	This wasn't really the reason but was a small factor	No, this wasn't the reason
I wanted to help future patients who come after me.	34%	41%	13%	6%	6%
I wanted to improve my quality of life.	33%	36%	12%	7%	12%
I wanted to receive the best care possible.	31%	32%	15%	7%	15%
I wanted to receive the most up-to-date therapies without the high expense.	25%	28%	14%	9%	24%
I joined to extend my life.	20%	21%	10%	11%	38%
I was following my doctor's recommendation.	13%	19%	10%	9%	49%

Where have you heard about clinical trials? (Check all that apply.)



PATIENT MOTIVATORS TO PARTICIPATE IN CLINICAL TRIALS

A variety of questions related to potential health benefits, safety concerns, financial benefits, support and logistical concerns were asked to determine what were important to patients when considering participation in clinical trials. Safety is the biggest factor weighing on these respondents' minds. While logistics and getting paid were less of a concern, these factors should still be considered potential motivators.

Clinical trial information that either explicitly states or reinforces a safety-first message appears to be essential to potential participants; however, to successfully convince a patient to join a trial may require other, non-safety concerning motivators. For example, making it easier to learn about clinical trials and making information readily available about research findings are important factors.

When it came to the likelihood of participating in a clinical trial, more patients preferred the following: participating in a trial to find a cure; a trial that does not involve a drug, therapy, treatment or medical device but seeks to understand how the health of people with a disease changes over time; or a trial to find a better alternative to an existing treatment.

The opinions of friends and family count when a patient considers participating in a clinical trial; 40% reported that their opinions were either essential or influenced the decisions.

If you were considering taking part in a clinical trial, how important would the following be to you?

Reason	Very Important	Important	A Little, Not Very, or Not at All Important
The clinical trial won't interfere with my current treatment or make my current condition worse.	73%	21%	6%
The trial provides me with a drug, therapy, treatment or medical device that potentially could extend or improve the quality of my life.	67%	26%	7%
Someone is available to help me with my questions throughout.	66%	25%	9%
I feel I can complete the entire trial.	59%	36%	5%
I believe the drug, therapy, treatment or medical device being studied has been shown to be safe and effective in previous trials.	59%	30%	11%
I am willing to undergo the medical procedures or tests involved in the study.	58%	35%	7%
I can get to the location of the trial easily.	57%	34%	9%
My doctor supports my decision to participate.	50%	32%	18%
I believe I can attend all the appointments at the trial site for the study.	49%	39%	12%
I can get access to a drug, therapy, treatment or medical device not otherwise available to me.	48%	35%	17%
I am given equipment to track my participation or symptoms (such as a fitness watch) or I can go to a website to enter information.	46%	35%	19%
I won't have to take time away from my job, my school or my other obligations in order to participate.	39%	30%	31%
I can receive health care for free or at a reduced cost.	33%	32%	35%
I am reimbursed for time and travel.	26%	32%	42%
A doctor or nurse comes to my house for some or all of the check-ins that I am required to have in order to participate in the trial.	21%	21%	58%
I am paid to participate.	15%	22%	63%

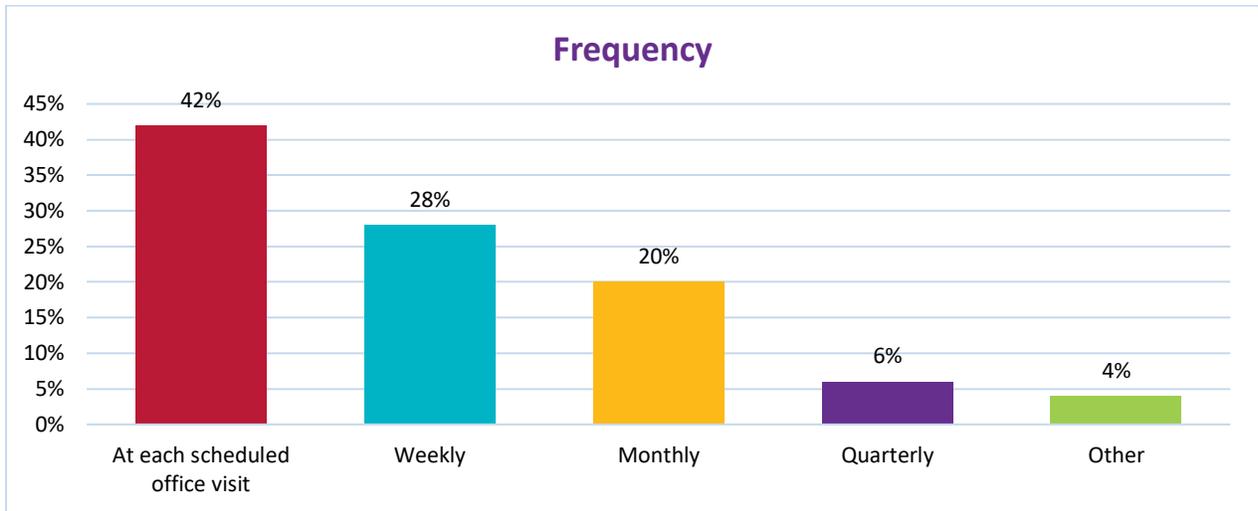
Some researchers work with patients to make it as easy as possible to take part in a clinical trial. Would you be interested in helping with this type of work by _____? (Check all that apply.)

Answer	Percent
Answering online surveys	83%
Participating in individual in-person surveys	64%
Being part of focus groups	62%
Helping researchers in any of these ways (all of the above)	37%
Not helping researchers in any of these ways (none of the above)	10%

What could researchers do to motivate people like you to participate in clinical trials? (Check all that apply.)

Incentive	Percent
Make it easier for me to learn about clinical trials	77%
Make information about findings from clinical trials more readily available	70%
Provide clearer information about the costs that I will incur (time, financial, etc.)	66%
Talk to me earlier about taking part in a clinical trial (not when I have only a few days to decide)	56%
Ask me what I want from a new drug, therapy, treatment or medical device	53%
Explain why it is important for me and people like me to take part in a trial	47%
Pay me to participate	46%
Explain how it impacts me and my treatment options if people like me don't take part in clinical trials	43%
Provide transportation to the clinical trial site	36%

If you were participating in a clinical trial, how often would you want to receive information about how your clinical trial is going?



How likely are you to participate in these trials?

Trial Type	Very Likely	Likely	Maybe	Not Likely	Definitely Not
A trial for a new drug, therapy, treatment or device to find a cure for my condition	65%	22%	11%	1%	1%
A trial that does not involve a drug, therapy, treatment or medical device but that seeks to understand how the health of people living with my condition changes over time	54%	26%	16%	3%	1%
A trial for a new drug, therapy, treatment or device to find a better alternative to an existing treatment	45%	32%	19%	3%	1%
A trial for a new drug, therapy, treatment or device to address my condition	43%	31%	22%	3%	1%
A trial for a new drug, therapy, treatment or device that is intended to lessen a side effect of a treatment I am currently using	37%	31%	24%	6%	2%

How much would the opinions of your family and friends influence your decision to participate in a clinical trial?

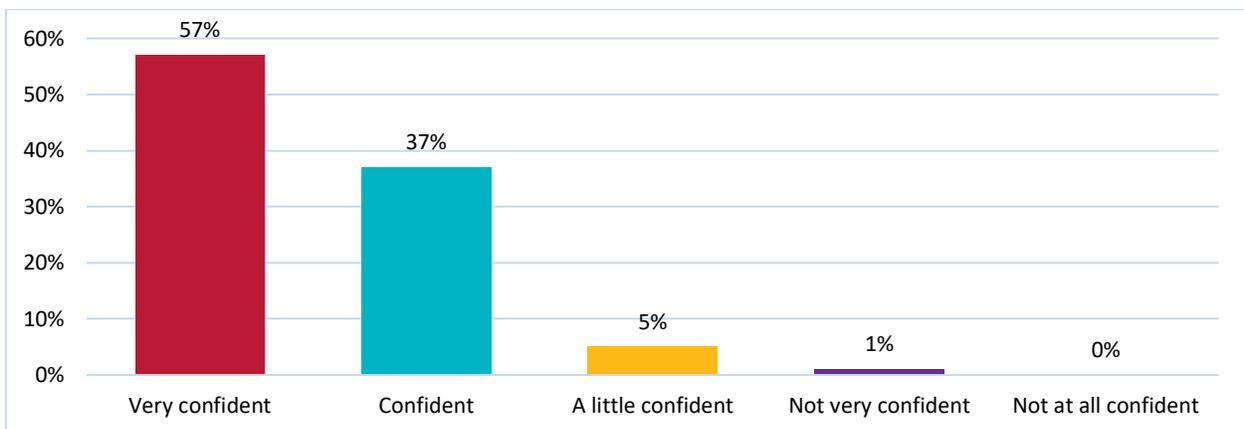
Answer	Percent
Their opinions are essential	13%
Quite a bit	27%
A little	32%
Not very much	18%
Not at all	10%

MAKING PERSONAL HEALTH DECISIONS

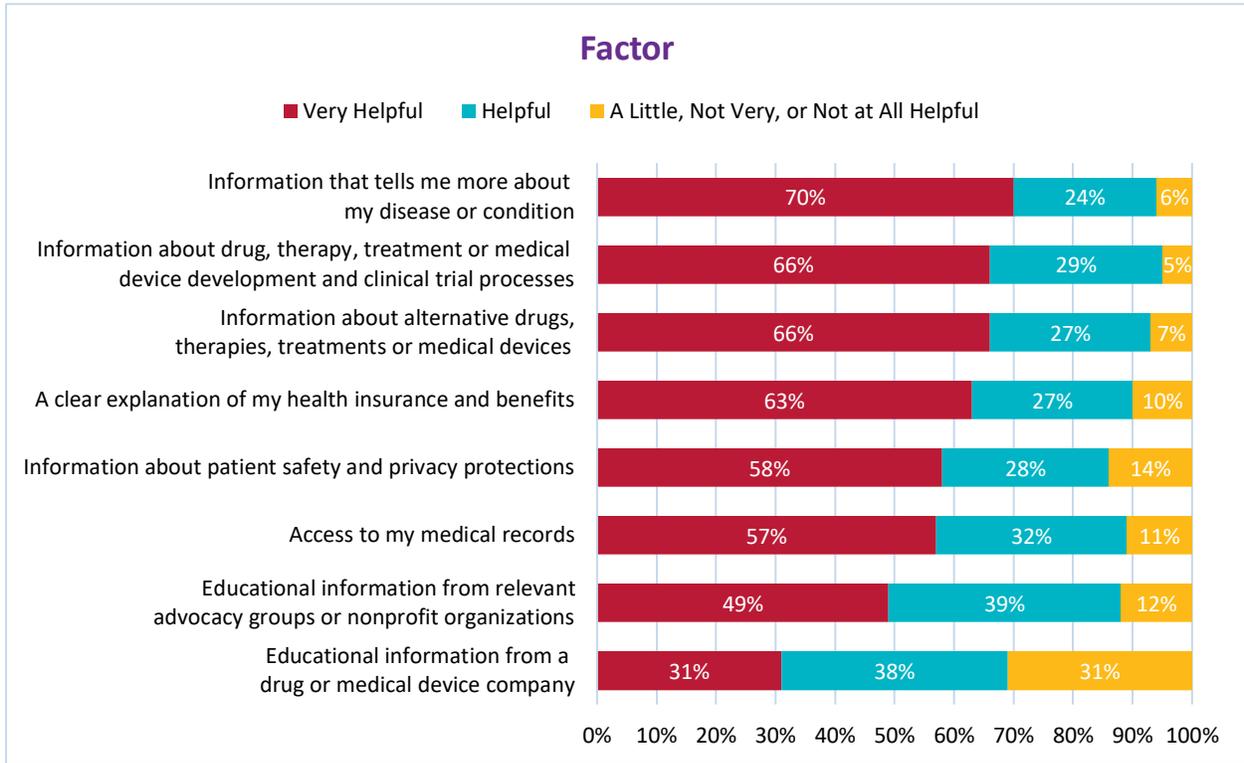
When considering clinical trial participation, how confident patients feel about making well-informed health decisions can influence how they think about trial participation. In the survey sample, 94% of respondents felt confident they could make well-informed health decisions. However, information and educational resources would help these patients feel even more confident, especially information about:

- Their disease or condition
- Drug, therapy, treatment or medical device development and clinical trial processes
- Information about alternative drugs, therapies, treatments or medical devices
- Health insurance and benefits

How confident do you feel to make well-informed health decisions?



Which of these would help make you feel more confident in your health decisions?



PATIENT PREFERENCES FOR LEARNING ABOUT CLINICAL TRIALS

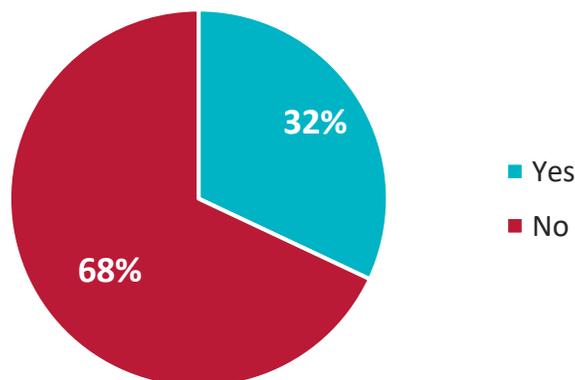
As indicated earlier, having more information about clinical trials could motivate patients to participate in clinical trials and would also build their confidence in their health decisions. So, who should provide this information?

A majority of patients named health care professionals as the people who should provide this information. Seventy-three percent indicated a preference for their doctor’s office and 52% for a medical center or practice. This is troubling, considering less than one-third of the respondents indicated that a doctor had ever shared information about clinical trials with them.

From which of the following would you most like to receive more information about clinical trials? (Check all that apply.)

Source	Percent
My doctor’s office	73%
Medical center/practice	52%
People who have participated in a clinical trial	49%
Clinicaltrials.gov	47%
Advocacy/nonprofit organizations	42%
Health and wellness information websites (Healthline, WebMD, etc.)	42%
Drug company	22%
Advertisements (printed, online, radio, TV)	21%
Word of mouth (family, friends)	18%

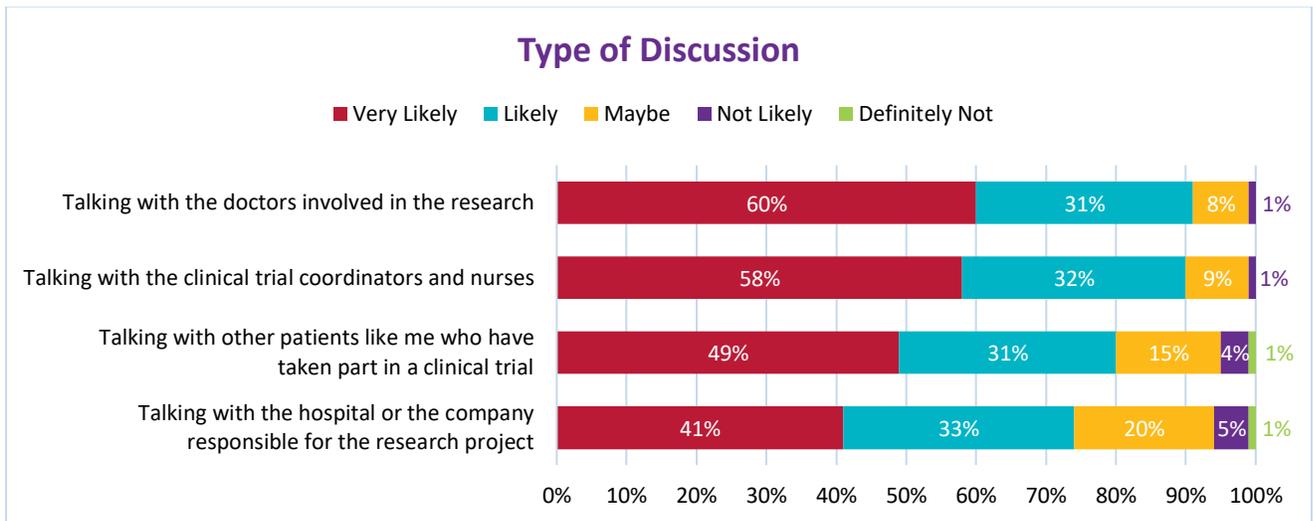
Has your doctor ever shared information with you about clinical trials?



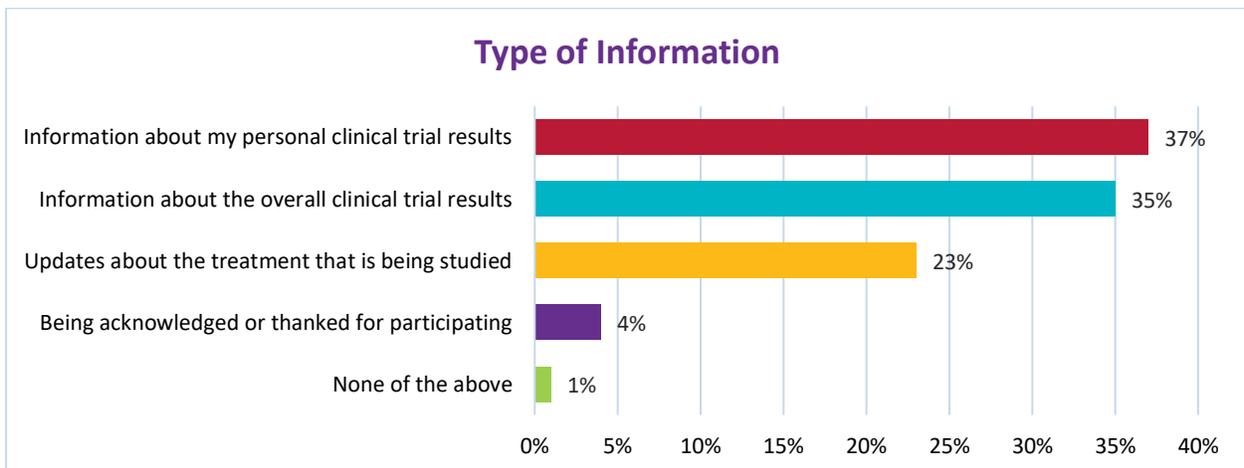
PATIENTS AS PARTNERS

To make the new collaborative ecosystem of clinical research work, clinical research will have to embrace patients as partners. To make this happen, medical professionals appear to be the key. Ninety percent of these patients said that talking with doctors, clinical trial coordinators and nurses involved in the research would either “very likely” or “likely” help them feel more like a partner in the research.

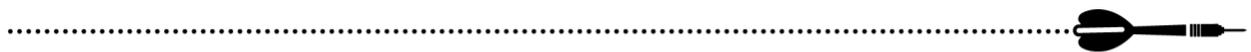
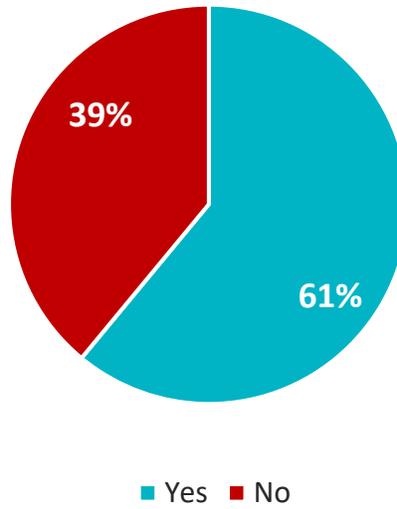
What would make you feel like a partner in a clinical trial?



What would most make you feel like a partner in the research process? (Check one.)



Do you use message boards and health-based online communities to learn more about your condition and the experiences of other patients?



KEY CONCLUSIONS

- Patients are willing to participate in clinical trials to help others and improve their quality of life. However, patients prefer certain types of studies over others, and transparent communication about the study's safety implications is essential so they can make an informed decision.
- Nearly two-thirds of patients use message boards and health-based online communities to learn more about their disease.
- Family members or friends are often important influences when a patient is considering clinical trial participation.
- Knowledge and information about their disease and clinical research are key motivators behind the decision to join a clinical trial and are equally important to patients during the trial.
- The importance of physicians and other health care practitioners cannot be overstated. Patients want to hear about clinical trials primarily from medical professionals. And, talking with the doctors or clinical researchers involved in a trial would make these patients feel more like a partner in the research.
- More than two-thirds of respondents said they have never had a conversation about clinical research with their doctors.

COMPARISON TO 2017 CISCRP SURVEY

The Center for Information and Study on Clinical Research Participation (CISCRP) conducted a survey in 2017 of 2,194 former clinical research participants from around the world. While that study focused on those who had already participated in research and the SCORR/Antidote study focused on patients with health conditions, a comparison of the two studies yields some interesting conclusions.

Respondent Profile Comparison

Age			
CISCRP		SCORR/Antidote	
		17 or younger	2%
18-34	9%	18-34	10%
35-44	8%	35-44	14%
45-54	15%	45-54	24%
55-64	29%	55-64	30%
65 or older	39%	65-74	16%
		75 or older	4%

Race			
CISCRP		SCORR/Antidote	
White	84%	White	90%
Black/African-American	7%	Black/African-American	9%
Asian	5%	Asian	2%
American Indian	2%	American Indian/Alaska Native	2%
Prefer not to answer/Other	5%	Prefer not to answer/Other	6%

Ethnicity			
CISCRP		SCORR/Antidote	
Non-Hispanic	90%	Non-Hispanic	93%
Hispanic/Latinx	6%	Hispanic/Latinx	5%
Prefer not to answer	4%	Prefer not to answer	2%

Gender			
CISCRP		SCORR/Antidote	
Female	57%	Female	80%
Male	42%	Male	20%

How people hear about clinical trials

CISCRP’s 2017 Perceptions & Insights Study asked study participants how they first learned about clinical research opportunities. The SCORR/Antidote study asked a similar question. Besides the difference in the participants — former research participants worldwide answered the CISCRP survey while the SCORR/Antidote survey asked Americans with health conditions, some who had been in trials and some who had not — this survey question also differed in the permitted response. The CISCRP question required one answer while the SCORR/Antidote survey question allowed more than one answer to be selected.

While these are different questions asked to different populations in different ways, the results in both point to the importance of medical professions. The information presented below provides an opportunity to compare answers to these similar questions about how patients hear about clinical trials.

CISCRP		SCORR/Antidote	
How did study participants first learn about clinical research opportunities?		Where have you heard about clinical trials?	
PCP office (general practitioner)	25%	My doctor’s office	37%
Research center doctor/staff	18%	Medical center/practice	24%
Advertisement	16%	Advertisements	52%
Online trial registry/database	9%	Clinicaltrials.gov	23%
Online patient communities/advocacy group	8%	Advocacy/nonprofit organizations	33%
Family and/or friends	6%	Word of mouth (family, friends)	35%
Pharma co. website	2%		
Pharmacy/pharmacist	1%		
Other	14%	None of the above	6%

THE INFORMATION PRESENTED ABOVE IS PRESENTED AS ORDINAL RANKINGS BELOW.

	CISCRP	SCORR/Antidote
PCP/doctor's office	1 st	2 nd
Research/medical center	2 nd	5 th
Advertisements	3 rd	1 st
Online trial registry/clinicaltrials.gov	4 th	6 th
Online patient community/advocacy group	5 th	4 th
Family/friends	6 th	3 rd

The differences in rankings here are possibly due to differences in phrasing and sample and are not necessarily in conflict. A former study participant could have initially heard about clinical trials from the doctor's office but also heard about clinical trials through advertisements.

Why people join clinical trials

Comparing the two studies provides an opportunity to look in depth into why participants joined a clinical trial. CISCRP asked study participants what drove them to join a clinical trial. The SCORR/Antidote study had separate questions that, when reviewed collectively, help paint a picture of why they joined.

For the SCORR/Antidote numbers, the percentages represent those respondents who had both been in a trial and also considered the statement to be a major reason for participating.

CISCRP		SCORR/Antidote	
Why people join clinical trials		Why did you join?	
Help advance science, treatment of disease/condition	49%		
Obtain better treatment	44%	"I wanted to improve the quality of my life."	69%
		"I wanted to receive the best care possible."	62%
Help others with same disease/condition	39%	"I want to help future patients who come after me."	75%
Monetary compensation	29%		
Study information read/seen/heard	27%		
Obtained education about treatment/improving health	22%		
Obtain free medication, treatment	20%	"I wanted to receive the most up-to-date therapies without the high expense."	53%
		"I joined to extend my life."	41%
PCP recommended study	18%	"I was following my doctor's recommendation."	32%

When comparing the two surveys, the ordinal rankings are somewhat consistent. Respondents in both surveys said the top reason for their clinical trial participation was altruistic — “to help advance science” or “to help future patients.” Obtaining better treatment or improving quality of life are more influential decision drivers than are financial ones.

¹ “Public Perception of Clinical Trials,” Research America! July 2017,
https://www.researchamerica.org/sites/default/files/July2017ClinicalResearchSurveyPressReleaseDeck_0.pdf

² “Public Perception of Clinical Trials,” Research America! July 2017,
https://www.researchamerica.org/sites/default/files/July2017ClinicalResearchSurveyPressReleaseDeck_0.pdf

³ Rowley, J., Johnson, F. and Sbaffi, L. (2017), Gender as an influencer of online health information-seeking and evaluation behavior. J Assn Inf Sci Tec, 68: 36–47,
<https://pdfs.semanticscholar.org/c04d/8a366a880509f8d341afc604e11985bbc41f.pdf>

⁴ “Women Responsible for Most Health Decisions in the Home,” OHSU News, May 11, 2017,
<https://news.ohsu.edu/2017/05/11/women-responsible-for-most-health-decisions-in-the-home>

⁵ “Public Perception of Clinical Trials,” Research America! July 2017,
https://www.researchamerica.org/sites/default/files/July2017ClinicalResearchSurveyPressReleaseDeck_0.pdf

About SCORR Marketing

SCORR Marketing is the leading full-service marketing and communications firm in the health science industry. We are a global partner for organizations around the world involved in research, development and commercialization of biopharmaceutical and device products and the delivery of health care products and services. At SCORR, we provide integrated programs that help our clients achieve their goals and improve health and well-being worldwide. For more information, visit www.scormarketing.com.

About Antidote

Antidote is a digital health company on a mission to accelerate the breakthroughs of new treatments by bridging the gap between medical research and the people who need it. In a world where 80% of clinical trials are delayed or closed due to lack of participants, Antidote uses cutting-edge technology to match the right patients with the right trials, helping medical researchers make faster progress, and offering new treatment options to patients. Antidote Match™, the company's unique trial matching tool, currently powers clinical trial search for more than 250 patient communities and health portals — bringing clinical trial awareness, matching, and access to more than 15 million patients a month. Antidote was launched as TrialReach and is based in the US and UK. For more information, please visit www.antidote.me.

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