THE PATIENT PERSPECTIVE ON CLINICAL TRIALS

A COLLABORATIVE SURVEY REPORT BROUGHT TO YOU BY:

SCORR MARKETING

antidote

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OVERVIEW

INTRODUCTION

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 that 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 such as diabetes, kidney disease, cancer and multiple sclerosis to name a few. These are people whose health understandably takes on a big role in their lives. Because these patients have more motivation to participate in research than the general population, these are the people whom the clinical research industry cannot afford not to reach. After all, if clinical researchers fail to embrace people with conditions that require them to daily monitor their own health, then how can they possibly hope to reach healthy volunteers?

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

- A little more than one-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.[i] But, given that this is a survey of people afflicted with a particular health condition, why is it that three-quarters have never participated and one-third have never given 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.[ii] This finding should have the clinical research industry asking itself a slew of questions, starting with why. Are physicians not getting the information they need about research opportunities? 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 both general findings from the survey as well as more detailed information — results broken down by demographics plus additional questions and responses. Some key conclusions are outlined on page 182. 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.

RESPONDENT PROFILE

There were 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:

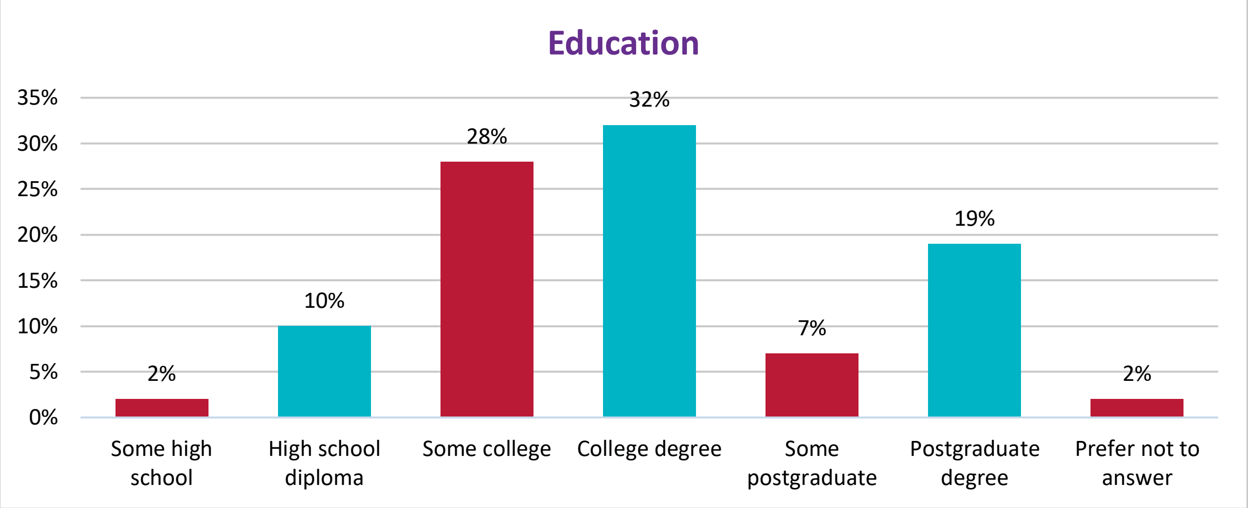
- American Kidney Fund
- Allergy & Asthma Network
- Healthline
- JDRF
- Lung Cancer Alliance
- Lupus Research Alliance
- Melanoma Research Alliance
- Multiple Sclerosis Association of America

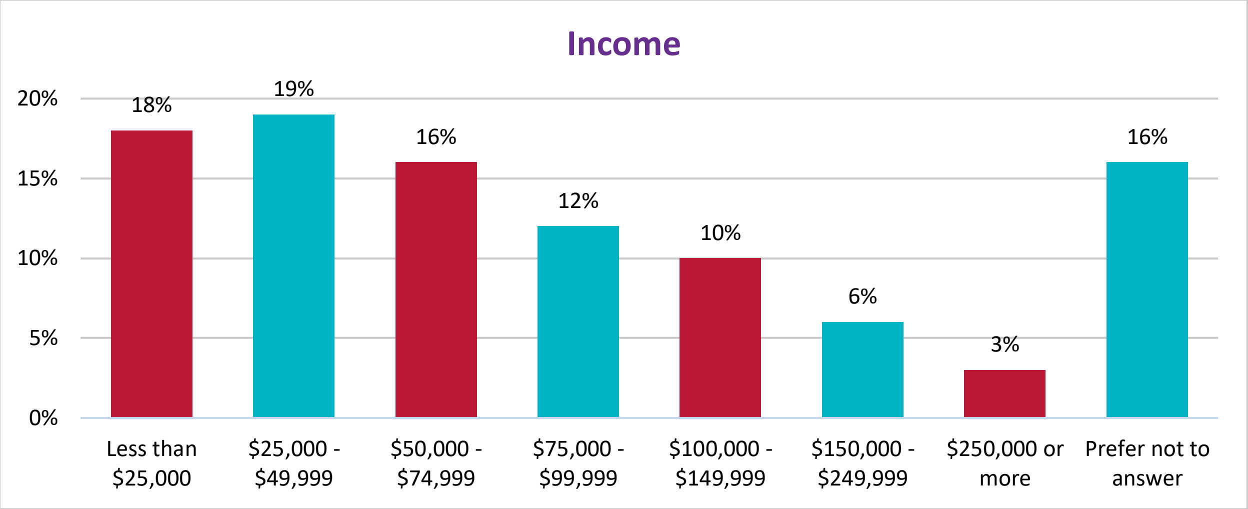
Respondents were mostly female, white patients. The high number of women respondents is consistent with the research on how gender influences online behaviors related to health information,[iii] and it is also supportive of the notion that mothers largely fill the role of "chief medical officer" for their families.[iv]

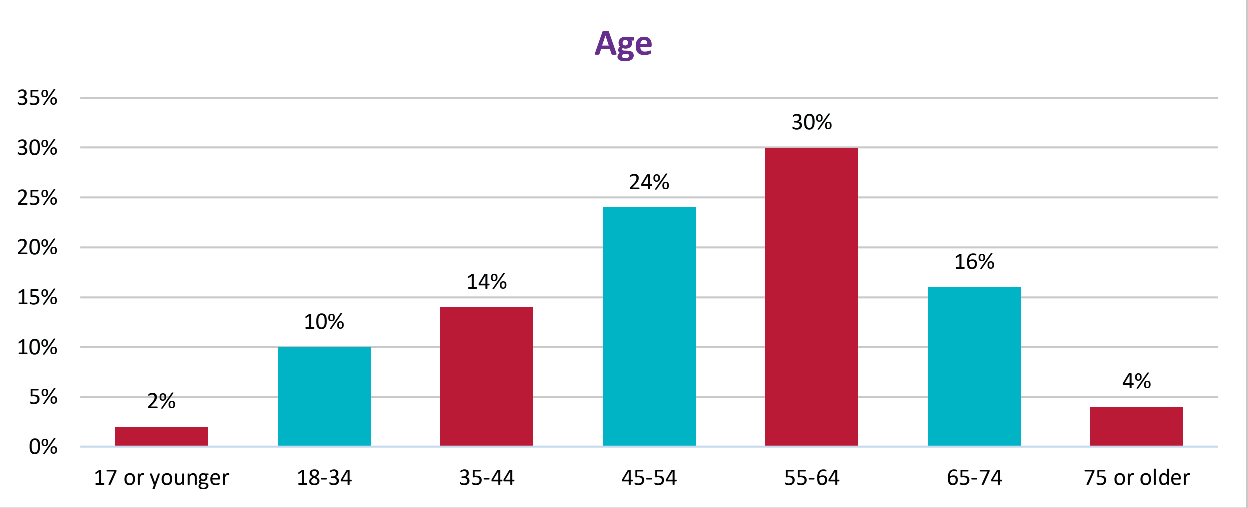
About one-quarter of respondents reported they have participated in clinical trials.

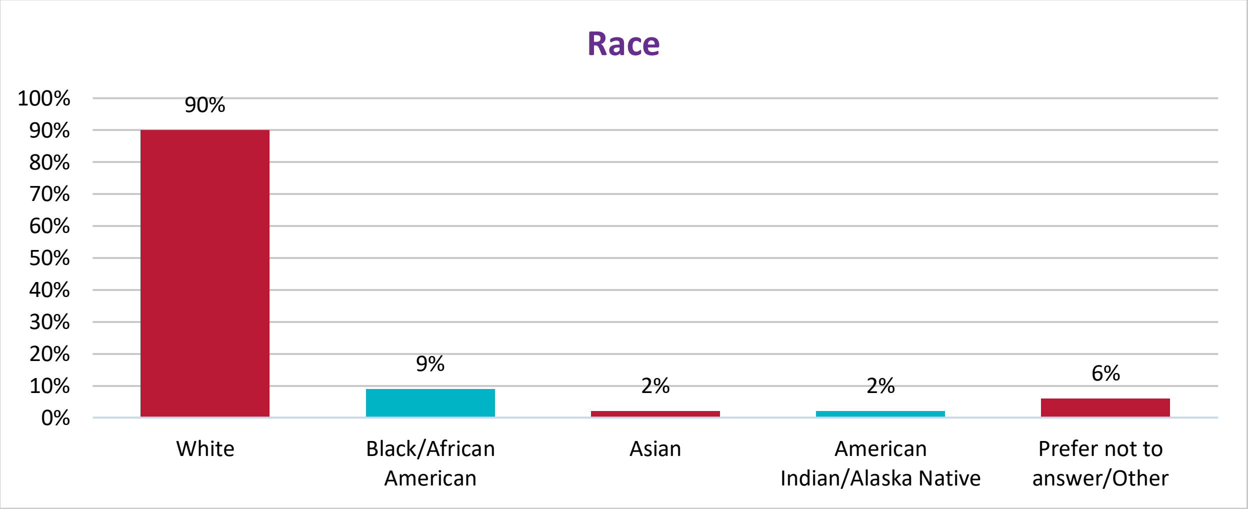
RESPONDENT DEMOGRAPHICS

Therapeutic Condition	Count	Percentage
Lung Cancer	243	6%
Melanoma	459	12%
Type 1 Diabetes	491	12%
Lupus	382	10%
Multiple Sclerosis	1,083	27%
Kidney Disease	509	13%
Gastrointestinal Disease	219	5%
Allergies/Asthma	601	15%

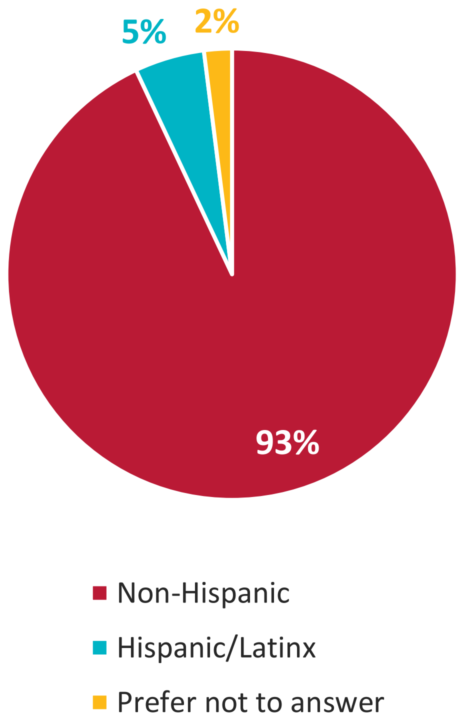



Income
20%
15%
10%
5%
0%
18%
19%
16%
12%
10%
6%
3%
16%
Less than $25,000
$25,000 - $49,999
$50,000 - $74,999
$75,000 - $99,999
$100,000 - $149,999
$150,000 - $249,999
$250,000 or more
Prefer not to answer

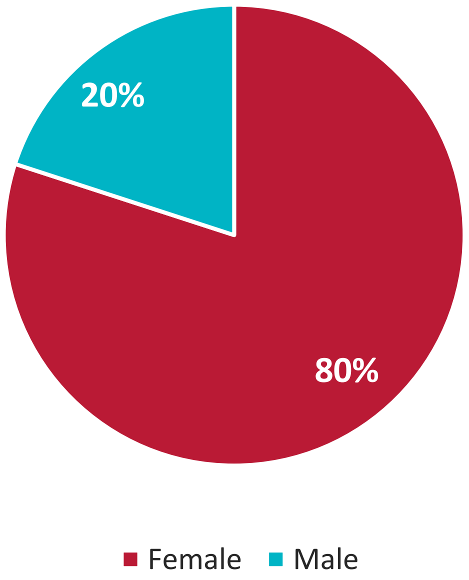

Age
35%
30%
25%
20%
15%
10%
5%
0%
2%
10%
14%
24%
30%
16%
4%
17 or younger
18-34
35-44
45-54
55-64
65-74
75 or older


Race
100%
90%
80%
70%
60%
50%
40%
30%
20%
10%
0%
90%
9%
2%
2%
6%
White
Black/African American
Asian
American Indian/Alaska Native
Prefer not to answer/Other

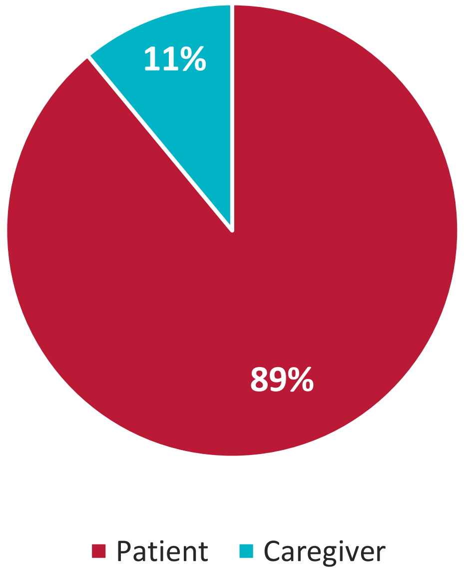
Ethnicity



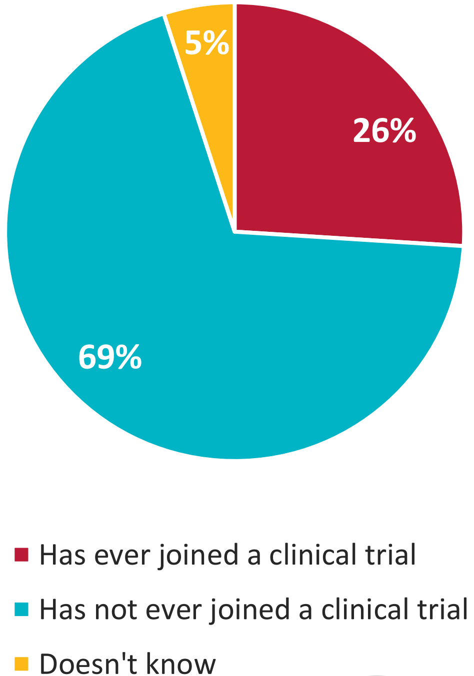
Gender



Patient or Caregiver



Clinical Trial Participation



SUMMARY

Patient Knowledge

Patients with greater clinical trial knowledge are much more likely to have joined a clinical trial. Our survey results show that those respondents who demonstrate a very high level of clinical trial knowledge are more than twice as likely to have joined a clinical trial than are those who exhibit a lower level of clinical trial knowledge.

- 33% of respondents who have demonstrated a strong knowledge of clinical trials have taken part in a trial
- 16% of respondents who have indicated they have little knowledge of clinical trials have participated in one.

This should not necessarily be interpreted to mean that patients are more likely to join a trial if they are knowledgeable about them. It is possible the causal relationship is the opposite. It may be that patients became knowledgeable about clinical research because they participated in a trial.

We also must consider that the people who choose to participate in research may also be people who are more inclined in general to educate themselves about clinical research. Additionally, it would make sense to conclude that patients with more clinical trial knowledge may feel more empowered, which in turn increases the probability they would join a clinical trial.

Throughout much of this report, we look at the specific motivators that prompt patients to join a clinical trial and provide information about how patients prefer to learn about clinical trials.

Patient Participation

Our survey points to several conclusions about who is most likely to participate in clinical research. Demographic groups that have a higher incidence of clinical trial participation include those with more resources such as higher levels of formal education or higher annual household incomes. Our survey results also indicate that older patients have a higher participation rate, and, as indicated earlier, the patients in this survey who have chronic conditions participate in research in higher rates than healthy patients. The patients surveyed who have cancer also were more likely to have joined a clinical trial than other patients.

MORE FORMAL EDUCATION / HIGHER INCOME / HIGHER AGE
MORE CLINICAL TRIAL KNOWLEDGE / PATIENTS WITH CHRONIC DISEASES

= GREATER LIKELIHOOD OF CLINICAL TRIAL PARTICIPATION

Patient Communications

Information deemed most helpful by respondents was information about their disease or condition, and they most wanted to receive this information from their doctor's office. Thus, it is clear that the best way to distribute clinical-trial-relevant information to possible participants is to provide information about the patient's condition through the patient's doctor: what the disease is, what it does and how joining a clinical trial can help.

However, many patient recruitment campaigns already provide information about the patient's condition (though not necessarily through the doctor's office, more on this later) and this in and of itself as a recruitment strategy is often insufficient. Also, not every recruitment strategy works for everyone. For these reasons, it will often be necessary to have secondary recruitment efforts that either complement primary strategies or more precisely target groups that are traditionally more difficult to recruit. These secondary recruitment efforts can be defined as incentives that either provide tangible benefits or overcome barriers to participation.

Specific Participation Stimuli

We asked survey participants to rate the importance of 16 potential motivators to take part in a trial. Each motivator can be placed in one of the following categories: safety concerns, health benefits, logistical concerns, institutional support and financial benefits. The percentage of the survey population rating the type of consideration as very important and the average ordinal ranking (where a lower number indicates a higher ranking) is as follows:

	Avg. % "Very Important"	Avg. Ordinal Ranking
Safety concerns (3)	63%	4
Institutional support (2)	58%	6
Health benefits (3)	54%	8
Logistical concerns (5)	45%	9
Financial benefits (3)	25%	14

What this indicates is that, above all else, patients care most that the clinical trial does no harm. Almost three-quarters (73%) of respondents said that it was very important that "the clinical trial won't interfere with my current treatment or make my current condition worse."

Though safety concerns are generally valued more highly than other types of motivators, each category of motivators was deemed as very important by some segment of the respondent population. Explaining the safeguards in place to protect patient safety is a necessary precursor to a patient opening up to the idea of joining a clinical trial, but to successfully convince the patient to join a trial might require other motivators.

Recruitment Tactics

So how can sponsors and CROs more effectively recruit patients?

First, they will need to do a better job of educating, engaging and working with health care professionals. Even though survey participants prefer receiving information about clinical trials from their doctor or from a medical center, fewer than one-third (32%) of survey participants said their doctor had ever shared information with them about clinical trials.

Second, sponsors and CROs can better distribute clinical trial information and do so to a wider audience. This includes condition-specific medical information, how a clinical trial can benefit the participant and how clinical trials might lead to finding a cure.

Third, secondary strategies to target certain groups should be considered when primary strategies are insufficient or if there is a need to reach out to underrepresented clinical trial populations, such as women, persons of color and the very young or old. These populations, which tend to have fewer resources, such as income or clinical knowledge, might be more receptive to motivators that address logistical concerns or financial benefits. To reach these groups, recruitment campaigns should include messaging or incentives better suited for these audiences.

Fourth, sponsors and CROs can facilitate communication so that it extends beyond the patient to the patient's support network. Forty percent of respondents said that the opinions of their family and friends are essential or matter quite a bit when they consider taking part in research. The influence of a patient's support network is felt even more strongly among those with less knowledge of clinical trials.

KEY OBSERVATIONS

Patient Knowledge

Twenty-one percent of respondents say they are very familiar with clinical trials. The higher the annual household income of a respondent, the more likely the respondent is very familiar with clinical trials.

- 99% of respondents correctly identified this statement as true: “Clinical trials help determine the safety and effectiveness of a new drug, therapy, treatment or medical device.”
- Almost one-third (32%) of those surveyed incorrectly indicated that they believe that children cannot participate in clinical trials.
- 41% of survey participants correctly assessed all eight statements while 11% were correct on five or fewer of the statements. The higher the level of formal education, the more likely the respondent correctly appraised all eight statements.

Clinical Trial Participation

- 26% of respondents have at one time joined a clinical trial. Lung cancer patients (38%) were twice as likely to have participated in a trial than patients with gastrointestinal disease (19%).
- “I wanted to help future patients who come after me” was identified by about one-third (34%) of respondents as the major reason why they joined a trial.
- The less formal education, the more likely a respondent identified wanting to improve their quality of life as the major reason for taking part in a trial. Nearly two-thirds (62%) of respondents whose highest level of formal education was some high school said this, while just 30% of those with a postgraduate degree did.
- More than one-half (52%) of respondents had heard about clinical trials through advertisements.

Patient Motivators

To allow us to delve deeply into what motivates patients to participate, we asked three multipart questions.

In the first question, survey participants were asked to evaluate the importance of 16 possible reasons to join a clinical trial. Each reason was categorized as primarily a safety concern, health benefit, institutional support, logistical concern or financial benefit. In the aggregate, safety concerns were the most important, and logistical concerns and financial benefits were less so.

The second question asked respondents what researchers can do to motivate people “like you” to participate. Respondents could select as many options as they wished from a list of eight motivators.

In the third question seeking to learn more about motivation, we provided respondents with a list of five clinical trial goals (e.g., a trial to “address my condition” or a trial “to lessen a side effect”) and asked them to indicate how likely they would be to participate.

Here are key results from these questions related to motivation:

- 73% said it was very important that the research doesn’t interfere with current treatment or make their conditions worse. This was the chief safety concern expressed.
- About two-thirds (67%) of respondents identified this statement as the top health benefit: “The trial provides me with a drug, therapy, treatment or medical device that potentially could extend or improve the quality of my life.”
- Having someone available to answer questions throughout the trial was deemed the most important support consideration by 66% of respondents.
- Respondents felt it very important that they could complete the entire trial. More than one-half (59%) of respondents deemed this as very important and the top logistical concern.
- Receiving health care for free or at a reduced cost was the financial benefit valued the most. One-third (33%) of respondents considered this very important.
- More than three-fourths (77%) of those surveyed believe researchers could motivate people to participate in clinical trials by making it easier to learn about clinical trials.
- While less than one-half (46%) of respondents said being compensated to participate would be a motivator, those who are younger or who have lower household incomes were much more inclined to think this. When we asked this question slightly differently, 37% of respondents said that being paid to participate was important or very important to them when considering taking part in a clinical trial. And again, higher proportions of younger respondents and those with lower incomes said being paid was important.
- The type of trial matters. Almost two-thirds (65%) of survey participants indicated they were very likely to participate in a clinical trial “to find a cure for my condition.” Fewer (43%) said they were very likely to join to “address my condition.”

Making Personal Health Decisions

- More than one-half (57%) of those surveyed feel very confident in their ability to make well-informed health decisions. Survey participants who have demonstrated more clinical trial knowledge express more confidence in their health-related decision-making.
- When asked about what types or sources of information would be helpful in making them feel more confident, more than two-thirds (70%) identified "information that tells me more about my condition" as very helpful. Information about condition is valued most by older respondents.
- Less than one-third (31%) of respondents find "educational information from a drug or medical device company" as very helpful. This is especially true as the respondent's level of formal education increases.
- 40% of respondents state that the opinions of their family and friends is either essential or matters quite a bit in influencing their decision to take part in a trial. Those with less formal education rely more on family and friends than those with more formal education.

Patient Preferences

- Patients want to hear about clinical trials from medical professionals. Almost three-fourths (73%) of respondents prefer to receive information about clinical trials from their doctor's office. This preference for receiving information from their doctor is true for patients across each of the eight therapeutic conditions in this study.
- However, only one-third (32%) of those surveyed indicated that their doctors have shared information about clinical trials with them. Patients with more formal education or higher incomes are more likely to have received clinical trial information from their doctor.
- Patients with lung cancer (58%), melanoma (45%) and Type I diabetes (32%) are more likely to have gotten information from their physicians about a trial than patients with the other conditions studied. These are the patients more likely to be familiar with clinical trials and more likely to have participated in clinical trials.
- Receiving clinical trial status information more frequently is preferable to less frequently and getting this information at each scheduled office visit is even better.
- Respondents were most interested in helping with clinical research by answering online surveys. 83% said they would be willing to do this.

Patients as Partners

- Patients are most likely to feel like partners in the clinical trial research process when they get to talk with medical professionals such as the physicians involved with the research or with clinical trial coordinators and nurses. Older patients have a stronger preference for talking with not only medical professionals, but also other patients like them or the hospital or company responsible for the project.
- The types of communication that respondents would most like to receive are information about their personal clinical trial results and information about the overall clinical trial results.
- Well over one-half (61%) of those surveyed use message boards and health-based online communities to learn more about their condition and the experiences of other patients. Women (62%) are slightly more likely than men (56%) to use message boards and online health-based communities.

Patient Perspectives by Condition

Lung Cancer

- The most important benefit identified (84%) is health-related: "The trial provides me with a drug, therapy, treatment or medical device that potentially could extend or improve the quality of my life."
- 75% are very likely to join a trial "for a new drug, therapy, treatment or device to find a cure for my condition."
- 46% say the opinions of family and friends are essential or matter quite a bit in their decision to participate in a clinical trial.

Melanoma

- The most important benefit identified (74%) is health-related: "The trial provides me with a drug, therapy, treatment or medical device that potentially could extend or improve the quality of my life."
- 68% are very likely to join a trial "for a new drug, therapy, treatment or device to find a cure for my condition."
- 50% say the opinions of family and friends are essential or matter quite a bit in their decision to participate in a clinical trial.

Type 1 Diabetes

- The most important benefit identified (75%) is safety-related: “The clinical trial won’t interfere with my current treatment or make my condition worse.”
- 69% are very likely to join a trial “for a new drug, therapy, treatment or device to find a cure for my condition.”
- 68% say the opinions of family and friends are essential or matter quite a bit in their decision to participate in a clinical trial.

Lupus

- The most important benefit identified (79%) is safety-related: “The clinical trial won’t interfere with my current treatment or make my condition worse.”
- 66% are very likely to join a trial “for a new drug, therapy, treatment or device to find a cure for my condition.”
- 36% say the opinions of family and friends are essential or matter quite a bit in their decision to participate in a clinical trial.

Multiple Sclerosis

- The most important benefit identified (75%) is safety-related: “The clinical trial won’t interfere with my current treatment or make my condition worse.”
- 60% are very likely to join a trial “for a new drug, therapy, treatment or device to find a cure for my condition.”
- 43% say the opinions of family and friends are essential or matter quite a bit in their decision to participate in a clinical trial.

Kidney Disease

- The most important benefit identified (80%) is safety-related: “The clinical trial won’t interfere with my current treatment or make my condition worse.”
- 67% are very likely to join a trial “for a new drug, therapy, treatment or device to find a cure for my condition.”
- 47% say the opinions of family and friends are essential or matter quite a bit in their decision to participate in a clinical trial.

Gastrointestinal Disease

- The most important benefit identified (68%) is logistical-related: "I feel I can complete the entire trial."
- 68% are very likely to join a trial "for a new drug, therapy, treatment or device to find a cure for my condition."
- 28% say the opinions of family and friends are essential or matter quite a bit in their decision to participate in a clinical trial.

Allergies/Asthma

- The most important benefit identified (68%) is safety-related: "The clinical trial won't interfere with my current treatment or make my condition worse."
- 62% are very likely to join a trial "for a new drug, therapy, treatment or device to find a cure for my condition."
- 29% say the opinions of their family and friends are essential or matter quite a bit in their decision to participate in a clinical trial.
- 27% say it's very important that they are paid to participate in a clinical trial.

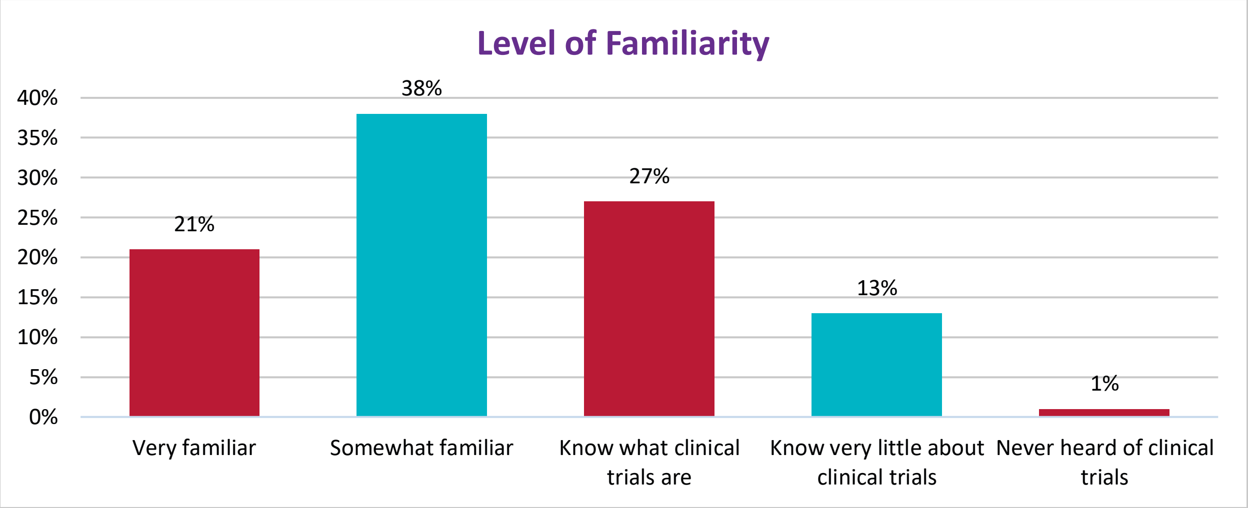
STUDY DATA

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.[v]) Respondents self-selected their level of familiarity with clinical trials, and eight true/false questions about clinical research basics were asked to evaluate 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?



- **Overall** – Most respondents are familiar with clinicals trials or at least know what they are.
- **Condition** – 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.

Percentage of Respondents Who Are Very Familiar With Clinical Trials (by condition)

Lung Cancer	Melanoma	Type 1 Diabetes	Lupus	Multiple Sclerosis	Kidney Disease	GI Disease	Allergy-Asthma
32%	29%	21%	22%	17%	18%	14%	25%

- **Education** – Respondents with more education are more apt to be familiar with clinical trials than are less educated respondents. For example, respondents with a postgraduate degree (32%) are more than twice as likely than those whose highest level of education is a high school diploma (13%) to say they are very familiar with clinical trials.
- **Income** – Patients with higher annual household incomes are more likely to be very familiar with clinical trials than are survey participants with lower incomes.

Percentage of Respondents Who Are Very Familiar With Clinical Trials (by income)						
<$25K	$25,000-49,999	$50,000-74,999	$75,000-99,999	$100,000-149,999	$150,000-249,999	$250K+
15%	18%	21%	23%	22%	30%	45%

- **Race** – There are no significant differences in familiarity with clinical trials across different racial groups. However, patients who consider themselves Hispanic/Latinx are much more likely to never have heard of clinical trials (7%) than are those who do not consider themselves Hispanic/Latinx (1%).
- **Gender** – Males (24%) are slightly more likely to be very familiar with clinical trials than are females (21%).
- **Patient vs. Caregiver** – While patients are more likely to be very familiar with clinical trials, caregivers are more likely to be either very or somewhat familiar with clinical trials.

Familiarity With Clinical Trials: Patients vs. Caregivers		
	Patients	Caregivers
Very familiar	22%	19%
Somewhat familiar	37%	45%

- **Clinical Trial Knowledge** – Unsurprisingly, respondents who were able to answer more of the true/false questions correctly were also more likely to be very familiar with clinical trials. Those who answered all eight of the questions correctly (28%) are more than twice as likely than those who correctly answered five or fewer of the questions (12%) to say they are very familiar with clinical trials.

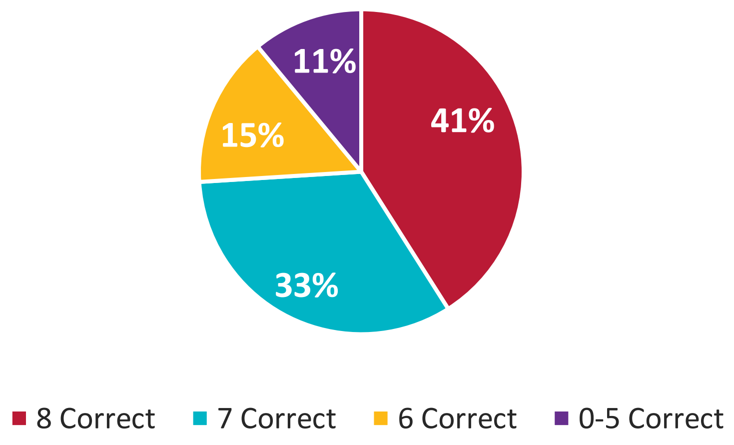
- **Clinical Trial Participation** – As expected, survey participants who have participated in clinical trials are much more familiar with clinical trials than survey participants who have not.

Familiarity With Clinical Trials: Respondents Who Have Been in Clinical Trials vs. Those Who Have Not		
	Trial Participant	Not a Trial Participant
Very familiar	52%	11%
Somewhat familiar	38%	39%
Know what clinical trials are	9%	33%

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



- **Overall**
  - Almost everyone correctly identified these two statements as true:
    - "Clinical trials help determine the safety and effectiveness of a new drug, therapy, treatment or medical device."
    - "I can ask as many questions as I like about a clinical trial before deciding to participate."
  - Two-thirds of patients incorrectly indicated that children cannot participate in clinical trials.
  - A plurality of respondents (41%) correctly identified all eight true/false statements. Another one-third correctly appraised seven of the eight statements.
- **Condition** – Even though more patients with lung cancer or melanoma consider themselves familiar with clinical trials than any of the other patient categories studied, they weren't the two groups of patients that best understood key principles. More than one-half of the respondents with Type 1 diabetes (54%) or allergies/asthma (53%) correctly assessed the validity of all eight statements.

Percentage of Respondents by the Number of Correct Answers (by condition)

Number Correct	Lung Cancer	Melanoma	Type 1 Diabetes	Lupus	Multiple Sclerosis	Kidney Disease	GI Disease	Allergy-Asthma
8	37%	35%	54%	43%	35%	36%	39%	53%
7	35%	35%	27%	30%	35%	36%	32%	30%
6	21%	17%	11%	14%	17%	17%	17%	10%
0-5	7%	13%	8%	13%	13%	11%	12%	7%

- **Education** – Respondents with more formal education demonstrate more clinical trial knowledge than those with less formal education.

Percentage of Respondents by the Number of Correct Answers (by education level)

Some HS	HS Diploma	Some College	College Degree	Some Postgraduate	Postgraduate Degree
32%	29%	34%	44%	46%	52%

- **Income** – Wealthier respondents were more likely to answer all eight questions correctly than those with lower incomes. The proportion that correctly answered all eight questions ranged from a high of 51% (those earning $250,000 or more) to a low of 31% (those earning less than $25,000).
- **Age** – Younger survey participants were more likely to answer all eight questions correctly.

Percentage of Respondents Who Answered All Eight Questions Correctly (by age)					
18-34	35-44	45-54	55-64	65-74	75+
49%	48%	40%	39%	36%	33%

- **Race** – White respondents (42%) were more likely to correctly assess the validity of each of the eight statements than were African-American (36%) or Hispanic/Latinx (also 36%) respondents.
- **Gender** – Females (74%) were slightly more likely to correctly answer seven or eight of the questions than were males (71%).

Percentage of Respondents by the Number of Correct Answers (by gender)		
Number Correct	Male	Female
8	40%	41%
7	31%	33%
6	16%	15%
0-5	13%	11%

- **Patient vs. Caregiver**
  - Caregivers were less likely to say that children cannot participate in clinical trials. Just 18% of caregivers answered this question incorrectly (compared to 33% of patients).
  - A higher proportion of caregivers (52%) were able to correctly identify the truthfulness of all eight statements than were patients (40%). Parents/guardians (57%) are the caregiver subgroup most knowledgeable.

- **Clinical Trial Participation** – It comes as no surprise that those who have previously participated in clinical trials know more about them.

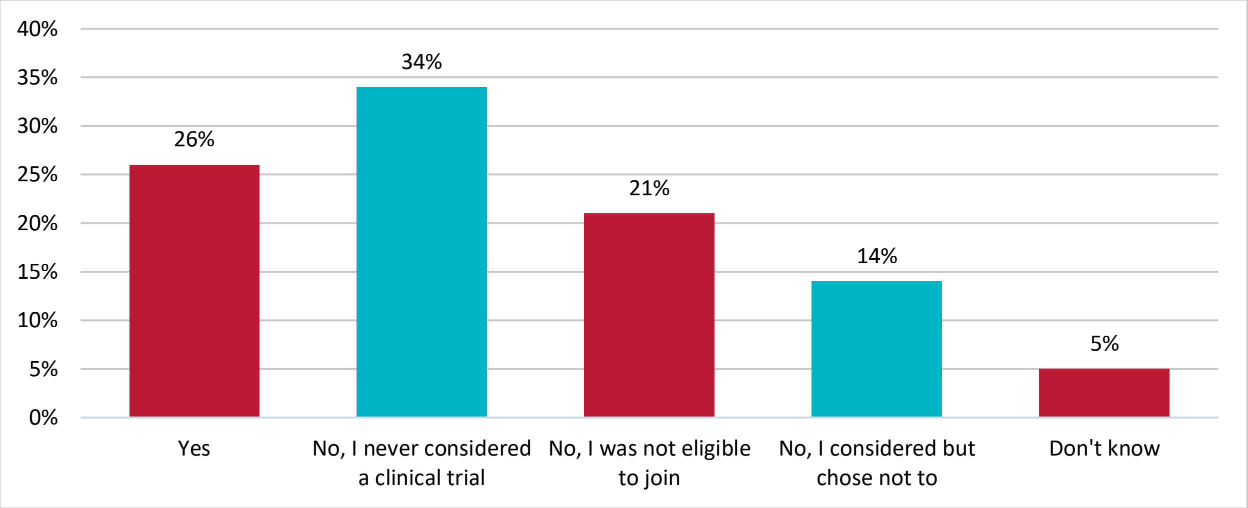
Percentage of Respondents by the Number of Correct Answers (by trial participation)		
Number Correct	Trial Participant	Not a Trial Participant
8	52%	38%
7	30%	34%
6	12%	16%
0-5	6%	12%

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?



- **Overall** – About one-fourth (26%) of the survey sample has at one time joined a clinical trial. More than one-third (34%) has never considered participating.

- **Condition** – Survey participants with lung cancer (38%) are the most likely of all patients surveyed to have joined a clinical trial. Patients with gastrointestinal disease (19%) are the least likely.

Percentage of Respondents Who Have Joined a Clinical Trial (by condition)								
Answer	Lung Cancer	Melanoma	Type 1 Diabetes	Lupus	Multiple Sclerosis	Kidney Disease	GI Disease	Allergy-Asthma
Yes	38%	29%	27%	23%	25%	22%	19%	29%
No, I never considered a clinical trial.	26%	37%	28%	36%	34%	39%	39%	33%
No, I was not eligible to join.	17%	21%	30%	19%	22%	20%	22%	17%
No, I considered a trial but chose not to.	13%	9%	12%	18%	14%	14%	15%	17%
Don’t know	5%	3%	3%	4%	5%	5%	5%	3%

- **Education** – One-third of patients with some postgraduate education have joined a clinical trial. On the other hand, just one-fifth (20%) of those whose highest education was graduating from high school did so.
- **Income** – Clinical trial participation correlates positively with annual household income.

Percentage of Respondents Who Have Joined a Clinical Trial (by income)						
<$25K	$25,000-49,999	$50,000-74,999	$75,000-99,999	$100,000-149,999	$150,000-249,999	$250K+
20%	25%	27%	27%	27%	36%	32%

- **Age** – Older respondents have more likely participated in clinical research. Younger patients are more likely to have never considered joining a clinical trial. For each age group, there were more people who never considered participating than had.
- **Race** – Clinical trial participation was higher among white survey participants (27%) than African-American (23%) or Hispanic/Latinx (22%).

- **Gender** – Male respondents were more likely to have joined a clinical trial than were female respondents.

Percentage of Respondents Who Have Joined a Clinical Trial (by gender)		
Answer	Male	Female
Yes	30%	25%
No, I never considered a clinical trial.	31%	35%
No, I was not eligible to join.	20%	22%
No, I considered a trial but chose not to.	14%	14%
Don't know	5%	4%

- **Patient vs. Caregiver** – Even though caregivers are more likely to know more about clinical trials than patients, just 20% indicate that the people in their care have joined a clinical trial — a lower number than the 27% of patients who, while answering on their own behalf, said they had joined a trial.
- **Clinical Trial Knowledge** – Predictably, those who are more knowledgeable about research (33%: correctly answered eight questions) are twice as likely to have joined a clinical trial than those who are more uncertain (16%: answered between 0 and 5 correctly).

Percentage of Respondents Who Have Joined a Clinical Trial by Demonstrated Clinical Trial Knowledge		
Answer	0-5 Correct	All 8 Correct
Yes	16%	33%
No, I never considered a clinical trial.	50%	28%
No, I was not eligible to join.	16%	22%
No, I considered a trial but chose not to.	11%	14%
Don't know	7%	3%

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%

- **Overall** – The two statements most identified as the major reason for joining a clinical trial were "I wanted to help future patients who come after me" and "I wanted to improve my quality of life." Relatively few people named following their doctor's recommendation as a primary motivation.

- **Condition** – Melanoma (56%) and lung cancer (54%) patients who joined clinical trials were primarily concerned with extending their own lives. Those with lupus (48%) or kidney disease (44%) were especially interested in helping future patients.

Percentage of Respondents Who Said "This Was the Major Reason" for Joining a Clinical Trial (by condition)

Reason	Lung Cancer	Melanoma	Type 1 Diabetes	Lupus	Multiple Sclerosis	Kidney Disease	GI Disease	Allergy-Asthma
I wanted to help future patients who come after me.	26%	32%	32%	48%	33%	44%	33%	29%
I wanted to improve my quality of life.	29%	38%	23%	38%	31%	36%	26%	38%
I wanted to receive the best care possible.	37%	52%	20%	28%	27%	33%	21%	26%
I wanted to receive the most up-to-date therapies without the high expense.	20%	31%	23%	21%	24%	26%	21%	27%
I joined to extend my life.	54%	56%	9%	16%	9%	14%	7%	10%
I was following my doctor's recommendation.	28%	29%	8%	11%	10%	11%	10%	6%

- **Education** – Those with less formal education were more likely to join a clinical trial to improve their quality of life than were those with more formal education.

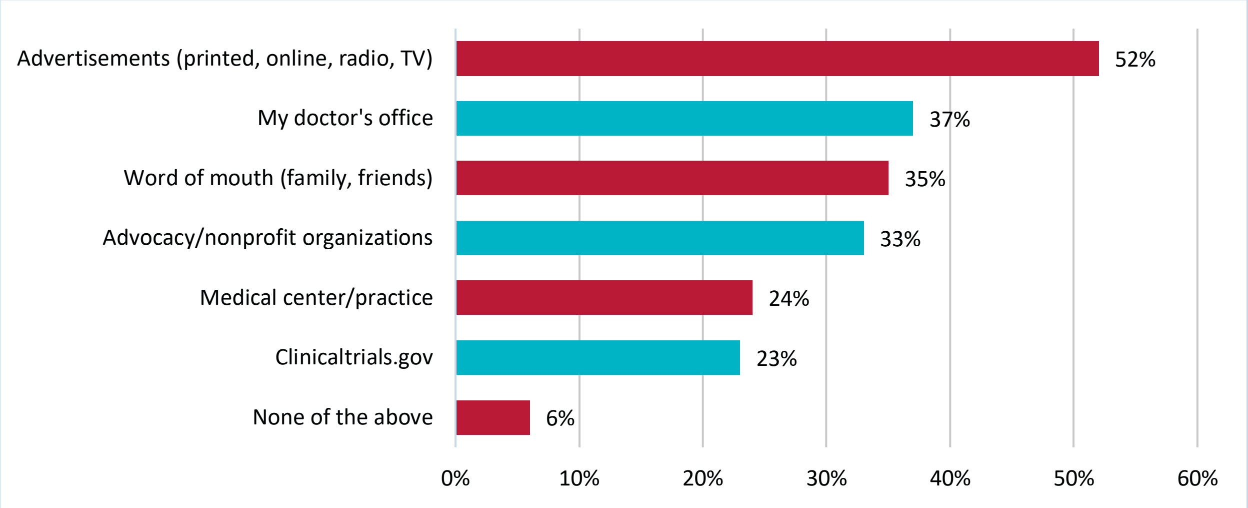
Percentage of Respondents Who Said "I Wanted to Improve My Quality of Life" as the Major Reason for Joining a Clinical Trial (by education level)					
Some HS	HS Diploma	Some College	College Degree	Some Postgraduate	Postgraduate Degree
62%	41%	36%	33%	21%	30%

- **Income** – Higher income respondents were more likely to join a clinical trial to extend their lives than survey participants with more modest means.
- **Age** – Older respondents are more inclined to identify "I wanted to receive the best care possible" or "I wanted to improve my quality of life" as major reasons for joining a clinical trial.
- **Race** – Persons of color were more likely than white respondents to say they joined a clinical trial to either help future patients or to improve their quality of life.

Percentage of Respondents Who Said "This Was the Major Reason" for Joining a Clinical Trial (by race/ethnicity)			
The Major Reason	White	Hispanic/Latinx	African-American
I wanted to help future patients who come after me.	33%	36%	40%
I wanted to improve my quality of life.	33%	40%	39%

- **Gender** – The reason most often identified by women respondents (35%) as the major reason for joining a clinical trial is to help future patients. Men most often named wanting to receive the best care possible (33%).
- **Patient vs. Caregiver** – Patient respondents (33%) are somewhat more likely to say they want to improve quality of life than are the caregivers who responded on behalf of their patients (28%).
- **Clinical Trial Knowledge** – Those who correctly identified all eight true/false statements (34%) most often named the need to help future patients as the major reason to join a clinical trial. Meanwhile, a plurality (43%) of those who correctly assessed up to five statements said they joined to extend their own lives.

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



- **Overall** – More than one-half of all respondents have heard about clinical trials through advertisements. About one-third have heard of them either through their doctor's office, word of mouth or an advocacy group. About one-fourth have heard about clinical trials through a medical center or the clinicaltrials.gov website.
- **Condition** – For those with lung cancer (59%) or melanoma (51%), the primary way of getting information about clinical trials is through their doctor's office. For those with Type 1 diabetes, the primary source of information is advocacy groups (50%). For everyone else, the primary means is through ads.

How Respondents Have Heard About Clinical Trials (by condition)

	Lung Cancer	Melanoma	Type 1 Diabetes	Lupus	Multiple Sclerosis	Kidney Disease	GI Disease	Allergy-Asthma
Ads	36%	42%	43%	53%	52%	60%	66%	61%
Advocacy groups	42%	29%	50%	44%	32%	28%	19%	19%
Clinicaltrials.gov	40%	23%	30%	27%	22%	13%	24%	20%
Word of mouth	37%	37%	40%	33%	34%	32%	36%	35%
Medical center/practice	35%	31%	25%	21%	22%	24%	17%	22%
My doctor's office	59%	51%	37%	32%	41%	27%	19%	25%

- **Education** – While respondents irrespective of education level hear about clinical trials through advertising, those with more education have a more diverse set of information sources.

How Respondents Have Heard About Clinical Trials (by education level)			
Source	HS Diploma	College Degree	Postgraduate Degree
Advertisements (printed, online, radio, TV)	53%	52%	47%
Advocacy/nonprofit organizations	16%	35%	47%
Clinicaltrials.gov	10%	25%	35%
Word of mouth (family, friends)	28%	37%	36%
Medical center/practice	13%	25%	32%
My doctor's office	32%	38%	41%

- **Income** – Advertisements play a substantial role in getting the word out to all respondents regardless of income, but information source diversity becomes greater with greater affluence. For example, those who earn $250,000 or more per year are more likely to hear about clinical trials from their doctor's office (55%), advocacy groups (54%) and word of mouth (45%) than from ads (42%).
- **Age** – Older respondents are slightly less reliant on getting information through word of mouth than are younger respondents. For example, 46% of those aged 18-34 receive information through word of mouth while just 30% of those aged 65-74 do.
- **Race** – While African-American survey participants (56%) are more likely than whites (51%) to hear about clinical trials through ads, white respondents (36%) are somewhat more likely than are African-Americans (30%) to hear about them through word of mouth.
- **Gender** – Women are slightly more likely to hear about clinical trials through ads than are men, while men are more likely to hear about them from their doctor's office than are women.

How Respondents Have Heard About Clinical Trials (by gender)		
Source	Male	Female
Advertisements (printed, online, radio, TV)	47%	53%
My doctor's office	41%	35%

- **Patient vs. Caregiver** – In addition to hearing about clinical trials through advertisements (48%), caregivers are also likely to hear about them through word of mouth (42%) and advocacy organizations (40%).

How Caregivers Have Heard About Clinical Trials	
Source	Percent
Advertisements (printed, online, radio, TV)	48%
Word of mouth (family, friends)	42%
Advocacy/nonprofit organizations	40%
My doctor's office	34%
Medical center/practice	23%
Clinicaltrials.gov	22%

- **Clinical Trial Knowledge** – Those respondents who exhibited greater clinical trial knowledge are more likely to hear about clinical trials from each information source than are those who exhibited less clinical trial knowledge.
- **Clinical Trial Participation** – Respondents who have participated in clinical trials are almost twice as likely to have heard about them from their doctor's office than those who have not joined a clinical trial.

How Respondents Have Heard About Clinical Trials (by trial participation)		
	Trial Participation	Not a Trial Participant
Advertisements (printed, online, radio, TV)	43%	56%
Advocacy/nonprofit organizations	36%	32%
Word of mouth (family, friends)	32%	37%
My doctor's office	56%	29%

PATIENT MOTIVATORS TO PARTICIPATE IN CLINICAL TRIALS

While the answers to many questions in this survey provide information about the motivations of patients to participate in clinical research, the responses to three multipart questions are particularly insightful.

The first question asked patients to assign a level of importance to various motivations related to potential health benefits, safety concerns, financial benefits, support and logistical concerns. 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 concern motivators. This is information we gained from our second question that asked respondents what would motivate people "like you" to participate. One of the results indicates that making it easier to learn about clinical trials and making information readily available about research findings are important factors.

A third question asked patients what kind of trials they would be more likely to join. Patients preferred 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.

In addition, the survey also asked how much the opinions of friends and family count when a patient considers participating in a clinical trial. Forty percent reported that their family's and friends' 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%

Safety Concerns

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%
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%

- **Overall** – Respondents believe that safety is of the utmost importance in determining to join a study. When we compare our "very important" responses across all 16 considerations, the three safety-related reasons were named most often, fifth-most often and sixth-most often.
- **Condition** – Of the eight condition categories, kidney disease patients assign the highest importance to the idea that the clinical trial should do no harm.

"Very Important"	Lung Cancer	Melanoma	Type 1 Diabetes	Lupus	Multiple Sclerosis	Kidney Disease	GI Disease	Allergy-Asthma
The clinical trial won't interfere with my current treatment or make my current condition worse.	67%	70%	75%	79%	75%	80%	67%	68%

- **Education** – No matter their level of education, respondents are concerned that the drug, therapy, treatment or medical device being tested has been shown to be safe.

"Very Important"	Some HS	HS Diploma	Some College	College Degree	Some Postgraduate	Postgraduate Degree
I believe the drug, therapy, treatment or medical device being studied has been shown to be safe and effective in previous trials.	68%	63%	59%	59%	49%	55%

- **Income** – Respondents with less income are more likely to view financial considerations as "very important" than are respondents with higher income.

"Very Important"	<$25K	$25,000-49,999	$50,000-74,999	$75,000-99,999	$100,000-149,999	$150,000-249,999	$250K+
I believe the drug, therapy, treatment or medical device being studied has been shown to be safe and effective in previous trials.	61%	59%	59%	54%	56%	55%	53%

- **Age** – While all respondents don't want the trial to interfere with their current treatment or make their condition worse, this is especially important to older respondents.

"Very Important"	18-34	35-44	45-54	55-64	65-74	75+
The clinical trial won't interfere with my current treatment or make my current condition worse.	68%	72%	73%	74%	73%	76%

- **Race** – African-American and Hispanic/Latinx survey participants are more concerned with safety considerations than are white respondents.

"Very Important"	White	Hispanic/ Latinx	African-American
The clinical trial won't interfere with my current treatment or make my current condition worse.	72%	74%	83%
I believe the drug, therapy, treatment or medical device being studied has been shown to be safe and effective in previous trials.	57%	72%	69%

- **Gender** – Women place greater emphasis on safety factors.

"Very Important"	Male	Female
The clinical trial won't interfere with my current treatment or make my current condition worse.	66%	75%
I believe the drug, therapy, treatment or medical device being studied has been shown to be safe and effective in previous trials.	50%	61%
I am willing to undergo the medical procedures or tests involved in the study.	55%	59%

- **Patient vs. Caregiver** – Caregivers are more likely than patients to care deeply about the safety and effectiveness of the treatment being studied.

"Very Important"	Patient	Caregiver
I believe the drug, therapy, treatment or medical device being studied has been shown to be safe and effective in previous trials.	58%	63%

- **Clinical Trial Knowledge** – Survey participants who are less knowledgeable about clinical trials place more value on previous demonstrations of safety.

"Very Important"	0-5 Correct	All 8 Correct
I believe the drug, therapy, treatment or medical device being studied has been shown to be safe and effective in previous trials.	68%	56%

- **Clinical Trial Participation** – Those who have been a part of clinical trials are slightly less concerned about safety than those who haven't participated.

"Very Important"	Trial Participant	Not a Trial Participant
The clinical trial won't interfere with my current treatment or make my current condition worse.	68%	76%
I believe the drug, therapy, treatment or medical device being studied has been shown to be safe and effective in previous trials.	54%	60%

Health Benefits

Reason	Very Important	Important	A Little, Not Very or Not at All Important
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%
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%

- **Overall** – Of all the 16 categories, the health benefit regarding extending or improving life was considered to be “very important” second-most often.

- **Condition** – Oncology patients are especially likely to place a greater importance on quality of life or access to a drug or device and less likely to care about being given equipment for tracking or access to a website.

"Very Important"	Lung Cancer	Melanoma	Type 1 Diabetes	Lupus	Multiple Sclerosis	Kidney Disease	GI Disease	Allergy-Asthma
The trial provides me with a drug, therapy, treatment or medical device that potentially could extend or improve the quality of my life.	84%	74%	63%	67%	66%	72%	63%	61%
I can get access to a drug, therapy, treatment or medical device not otherwise available to me.	64%	59%	44%	46%	44%	53%	47%	39%
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.	32%	41%	41%	49%	49%	53%	46%	48%

- **Education** – The less formal education a respondent has, the more likely that respondent will consider it very important that the trial could improve quality of life.

"Very Important"	Some HS	HS Diploma	Some College	College Degree	Some Postgraduate	Postgraduate Degree
The trial provides me with a drug, therapy, treatment or medical device that potentially could extend or improve the quality of my life.	71%	71%	69%	67%	60%	65%

- **Income** – Survey participants with lower annual household incomes value tracking equipment or website access more highly.

"Very Important"	<$25K	$25,000-49,999	$50,000-74,999	$75,000-99,999	$100,000-149,999	$150,000-249,999	$250K+
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.	53%	49%	48%	40%	43%	34%	40%

- **Age** – It matters more to older patients to have access to a drug, therapy, treatment or medical device previously unavailable to them than it does to younger patients.

"Very Important"	<=17	18-34	35-44	45-54	55-64	65-74	75+
I can get access to a drug, therapy, treatment or medical device not otherwise available to me.	39%	43%	44%	48%	49%	50%	53%

- **Race** – African-American and Hispanic/Latinx respondents are more likely to value health benefits derived from clinical trial participation than are white respondents.

"Very Important"	White	Hispanic/ Latinx	African-American
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.	44%	55%	58%
The trial provides me with a drug, therapy, treatment or medical device that potentially could extend or improve the quality of my life.	67%	70%	73%

- **Gender** – Women are more inclined to consider each of the health-related factors as very important.

"Very Important"	Male	Female
The trial provides me with a drug, therapy, treatment or medical device that potentially could extend or improve the quality of my life.	62%	69%
I can get access to a drug, therapy, treatment or medical device not otherwise available to me.	45%	48%
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.	36%	48%

- **Clinical Trial Knowledge** – Patients with less demonstrated clinical trial knowledge find each health benefit more important than those with more clinical trial knowledge.

"Very Important"	0-5 Correct	All 8 Correct
The trial provides me with a drug, therapy, treatment or medical device that potentially could extend or improve the quality of my life.	72%	64%
I can get access to a drug, therapy, treatment or medical device not otherwise available to me.	57%	44%
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.	52%	41%

- **Clinical Trial Participation** – Potential health benefits are less of a concern among patients who have already joined a trial.

"Very Important"	Trial Participant	Not a Trial Participant
The trial provides me with a drug, therapy, treatment or medical device that potentially could extend or improve the quality of my life.	59%	70%
I can get access to a drug, therapy, treatment or medical device not otherwise available to me.	45%	49%
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.	34%	50%

Institutional Support

Reason	Very Important	Important	A Little, Not Very or Not at All Important
Someone is available to help me with my questions throughout.	66%	25%	9%
My doctor supports my decision to participate.	50%	32%	18%

- **Overall** – Having someone available to answer questions is considered “very important” third-most often by all respondents when evaluating all 16 considerations.
- **Condition** – Lung cancer and melanoma patients are most likely to deem it “very important” that their doctor supports their decision to join a clinical trial.

“Very Important”	Lung Cancer	Melanoma	Type 1 Diabetes	Lupus	Multiple Sclerosis	Kidney Disease	GI Disease	Allergy-Asthma
My doctor supports my decision to participate.	60%	61%	36%	53%	54%	57%	38%	37%

- **Education** – Patients with less formal education have a slightly greater preference for needing someone to answer their questions than those with more formal education.

“Very Important”	Some HS	HS Diploma	Some College	College Degree	Some Postgraduate	Postgraduate Degree
Someone is available to help me with my questions throughout.	68%	68%	67%	68%	63%	63%

- **Income** – Though a majority of respondents across all household income categories want institutional support, this is more true among those with lower incomes.

"Very Important"	<$25K	$25,000-49,999	$50,000-74,999	$75,000-99,999	$100,000-149,999	$150,000-249,999	$250K+
Someone is available to help me with my questions throughout.	68%	67%	69%	63%	66%	60%	59%
My doctor supports my decision to participate.	51%	52%	51%	45%	47%	46%	46%

- **Age** – For the most part, there is not much difference in prioritization of institutional support considerations across age groups. The outliers are that older patients are slightly more likely to consider it "very important" that their doctor supports their decision to join a clinical trial.

"Very Important"	<=17	18-34	35-44	45-54	55-64	65-74	75+
My doctor supports my decision to participate.	48%	47%	47%	50%	50%	54%	53%

- **Race** – Both African-American and Hispanic/Latinx survey participants are slightly more likely to label having someone available to answer questions or getting their doctor's support as "very important" than are white respondents.

"Very Important"	White	Hispanic/ Latinx	African-American
Someone is available to help me with my questions throughout.	66%	70%	69%
My doctor supports my decision to participate.	50%	51%	52%

- **Gender** – Women are more likely to value the importance of having a person available to answer their questions.

"Very Important"	Male	Female
Someone is available to help me with my questions throughout.	59%	68%

- **Clinical Trial Knowledge** – Respondents with more clinical trial knowledge rely less on their doctor's support when deciding whether or not to participate in a clinical trial.

"Very Important"	0-5 Correct	All 8 Correct
My doctor supports my decision to participate.	60%	43%

- **Clinical Trial Participation** – Patients who have participated in a clinical trial are less worried about the possible absence of institutional support.

"Very Important"	Trial Participant	Not a Trial Participant
Someone is available to help me with my questions throughout.	58%	69%

Logistical Concerns

Reason	Very Important	Important	A Little, Not Very or Not at All Important
I feel I can complete the entire trial.	59%	36%	5%
I can get to the location of the trial easily.	57%	34%	9%
I believe I can attend all the appointments at the trial site for the study.	49%	39%	12%
I won’t have to take time away from my job,my school or my other obligations in order to participate.	39%	30%	31%
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%

- **Overall** – Of all five logistical concerns, being able to complete the trial was named as “very important” by the most respondents. It came in as the fourth-most often named concern among all 16 considerations.

- **Condition** – Kidney disease, multiple sclerosis and allergy/asthma patients place a higher priority on logistical factors than do patients with other conditions.

"Very Important"	Lung Cancer	Melanoma	Type 1 Diabetes	Lupus	Multiple Sclerosis	Kidney Disease	GI Disease	Allergy-Asthma
I feel I can complete the entire trial.	45%	56%	59%	59%	60%	60%	68%	61%
I can get to the location of the trial easily.	54%	48%	54%	59%	59%	60%	56%	61%
I believe I can attend all the appointments at the trial site for the study.	51%	47%	44%	47%	48%	54%	49%	51%
I won't have to take time away from my job, my school or my other obligations in order to participate.	25%	33%	41%	44%	34%	42%	41%	49%
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.	18%	17%	15%	21%	25%	28%	20%	15%

- **Education** – Logistical considerations matter more to patients with less formal education.

“Very Important”	Some HS	HS Diploma	Some College	College Degree	Some Postgraduate	Postgraduate Degree
I feel I can complete the entire trial.	65%	64%	61%	59%	55%	54%
I can get to the location of the trial easily.	69%	62%	58%	55%	53%	55%
I believe I can attend all the appointments at the trial site for the study.	62%	54%	50%	48%	40%	47%
I won’t have to take time away from my job, my school or my other obligations in order to participate.	52%	43%	38%	39%	33%	36%
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.	39%	33%	24%	19%	17%	11%

- **Income** – Logistical considerations matter more to patients with lower incomes.

"Very Important"	<$25K	$25,000-49,999	$50,000-74,999	$75,000-99,999	$100,000-149,999	$150,000-249,999	$250K+
I feel I can complete the entire trial.	64%	60%	63%	55%	59%	57%	58%
I can get to the location of the trial easily.	65%	58%	58%	53%	57%	52%	43%
I believe I can attend all the appointments at the trial site for the study.	56%	49%	50%	46%	43%	45%	44%
I won't have to take time away from my job, my school or my other obligations in order to participate.	39%	38%	40%	39%	40%	33%	32%
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.	32%	23%	20%	16%	14%	10%	12%

- **Age** – Overall, only a minority of respondents say it is very important that a trial doesn't force them to take time away from their obligations and, similarly, only a minority consider it very important to have clinical researchers make home visits. However, the distribution of responses to these two statements is considerably different. Younger respondents care more about making sure a clinical trial won't keep them from doing other things, while older respondents place a higher value on in-home visits.

"Very Important"	<=17	18-34	35-44	45-54	55-64	65-74	75+
I won't have to take time away from my job, my school or my other obligations in order to participate.	56%	47%	45%	41%	35%	31%	32%
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.	11%	19%	20%	21%	21%	21%	27%

- **Race** – Logistical concerns are of greater importance to African-American and Hispanic/Latinx survey participants than to white survey participants.

"Very Important"	White	Hispanic/ Latinx	African-American
I feel I can complete the entire trial.	59%	62%	63%
I can get to the location of the trial easily.	56%	65%	66%
I believe I can attend all the appointments at the trial site for the study.	48%	56%	53%
I won't have to take time away from my job, my school or my other obligations in order to participate.	37%	42%	47%
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.	18%	36%	33%

- **Gender** – Logistical reasons are more important to women than to men.

"Very Important"	Male	Female
I can get to the location of the trial easily.	47%	60%
I won't have to take time away from my job, my school or my other obligations in order to participate.	32%	40%

- **Patient vs. Caregiver** – Patients are more likely than caregivers to care about being able to attend all the appointments for a study and less likely to be concerned about the time away from work and other obligations

"Very Important"	Patient	Caregiver
I believe I can attend all the appointments at the trial site for the study.	49%	45%
I won't have to take time away from my job, my school or my other obligations in order to participate.	38%	44%

- **Clinical Trial Knowledge** – Those with more demonstrated clinical trial knowledge are slightly more likely to consider the ability to complete the trial or make all the appointments as "very important". Those with less demonstrated clinical trial knowledge are more concerned with getting to the site, not missing time for work or other obligations, or, if need be, having a doctor or nurse come to the house.

"Very Important"	0-5 Correct	All 8 Correct
I feel I can complete the entire trial.	56%	59%
I can get to the location of the trial easily.	60%	55%
I believe I can attend all the appointments at the trial site for the study.	44%	48%
I won't have to take time away from my job, my school or my other obligations in order to participate.	43%	38%
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.	35%	15%

- **Clinical Trial Participation** – By and large, logistical concerns are a more important set of considerations to patients who have yet to join a clinical trial than to those who previously have.

"Very Important"	Trial Participant	Not a Trial Participant
I can get to the location of the trial easily.	53%	59%
I won't have to take time away from my job, my school or my other obligations in order to participate.	32%	41%
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.	11%	24%

Financial Benefits

Reason	Very Important	Important	A Little, Not Very or Not at All Important
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%
I am paid to participate.	15%	22%	63%

- **Overall** – Financial benefits, while very important to some, are generally viewed as less important than other considerations. The three financial statements make up three of the four factors that were named by the fewest respondents as being "very important."
- **Condition** – Oncology and Type 1 diabetes patients are the least inclined to be concerned with financial considerations.

"Very Important"	Lung Cancer	Melanoma	Type 1 Diabetes	Lupus	Multiple Sclerosis	Kidney Disease	GI Disease	Allergy-Asthma
I can receive health care for free or at a reduced cost.	24%	29%	24%	34%	34%	40%	35%	38%
I am reimbursed for time and travel.	14%	17%	21%	27%	25%	37%	24%	36%
I am paid to participate.	5%	6%	11%	11%	14%	22%	18%	27%

- **Education** – Receiving health care for free or at reduced cost is more important for patients with less formal education.

"Very Important"	Some HS	HS Diploma	Some College	College Degree	Some Postgraduate	Postgraduate Degree
I can receive health care for free or at a reduced cost.	49%	40%	36%	34%	26%	24%

- **Income** – Understandably, those with lower annual household incomes place a greater value on financial considerations.

"Very Important"	<$25K	$25,000-49,999	$50,000-74,999	$75,000-99,999	$100,000-149,999	$150,000-249,999	$250K+
I can receive health care for free or at a reduced cost.	48%	37%	32%	28%	24%	20%	17%
I am reimbursed for time and travel.	38%	30%	25%	22%	19%	16%	13%
I am paid to participate.	26%	17%	14%	11%	8%	6%	4%

- **Age** – While financial considerations are a low priority across all age groups, they are especially low among the youngest and oldest age groups where respondents are less likely to be working.

"Very Important"	<=17	18-34	35-44	45-54	55-64	65-74	75+
I can receive health care for free or at a reduced cost.	19%	34%	36%	37%	35%	26%	21%
I am reimbursed for time and travel.	19%	34%	31%	30%	24%	20%	15%
I am paid to participate.	9%	24%	18%	17%	14%	10%	8%

- **Race** – Financial benefits matter more to African-American and Hispanic/Latinx respondents than to white respondents.

"Very Important"	White	Hispanic/Latinx	African-American
I can receive health care for free or at a reduced cost.	30%	48%	50%
I am reimbursed for time and travel.	23%	41%	46%
I am paid to participate.	12%	26%	33%

- **Gender** – Women are more likely than men to weigh financial ramifications when deciding whether to participate in a clinical trial.

"Very Important"	Male	Female
I can receive health care for free or at a reduced cost.	25%	35%
I am reimbursed for time and travel.	20%	28%
I am paid to participate.	13%	16%

- **Clinical Trial Knowledge** – Respondents who know more about clinical trials are less likely to say that potential financial benefits are very important.

"Very Important"	0-5 Correct	All 8 Correct
I can receive health care for free or at a reduced cost.	45%	30%
I am reimbursed for time and travel.	32%	25%
I am paid to participate.	22%	15%

- **Clinical Trial Participation** – Patients who have not been in clinical trials place a slightly greater emphasis on financial considerations than those who have.

"Very Important"	Trial Participant	Not a Trial Participant
I can receive health care for free or at a reduced cost.	28%	34%
I am reimbursed for time and travel.	24%	27%
I am paid to participate.	15%	15%

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%

- **Overall** – A solid majority of those surveyed (83%) said they would be willing to answer online surveys to help clinical researchers.

- **Condition** – While a majority of respondents from each therapeutic condition showed a willingness to help with clinical research in surveys or focus groups, those with Type 1 diabetes or gastrointestinal disease were the most enthusiastic while those with melanoma or lung cancer were the most reluctant.

Answer	Lung Cancer	Melanoma	Type 1 Diabetes	Lupus	Multiple Sclerosis	Kidney Disease	GI Disease	Allergy-Asthma
Answering online surveys	80%	78%	88%	81%	85%	80%	83%	82%
Participating in individual in-person surveys	58%	56%	69%	60%	65%	61%	72%	69%
Being part of focus groups	57%	51%	66%	64%	62%	62%	64%	66%
I would be interested in helping researchers in any of these ways.	31%	29%	41%	42%	38%	35%	40%	36%
I would not be interested in helping researchers in other ways.	14%	12%	5%	12%	10%	10%	9%	11%

- **Education** – Those with more formal education are more interested in helping with clinical research development by answering surveys or joining focus groups.

"Very Important"	**Some HS**	**HS Diploma**	**Some College**	**College Degree**	**Some Postgraduate**	**Postgraduate Degree**
Answering online surveys	70%	74%	81%	85%	85%	88%
Participating in individual in-person surveys	53%	52%	63%	66%	69%	70%
Being part of focus groups	42%	42%	61%	64%	67%	70%

- **Income** – Wealthier respondents are slightly more willing to help clinical researchers by participating in individual in-person surveys or being a part of focus groups.
- **Age** – Younger respondents showed a greater willingness to participate in clinical research via an online survey, in-person survey or focus group than did older respondents.
- **Gender** – Women expressed more interest in helping clinical research by taking online surveys or being a part of focus groups than did men.

Answer	Male	Female
Answering online surveys	78%	84%
Participating in individual in-person surveys	64%	64%
Being part of focus groups	59%	63%
I would be interested in helping researchers in any of these ways.	37%	37%
I would not be interested in helping researchers in other ways.	11%	10%

- **Patient vs. Caregiver** – Patient respondents indicated a greater willingness to help clinical researchers than did caregivers.
- **Clinical Trial Knowledge** – Respondents with more knowledge of clinical trials expressed a greater desire to help with clinical research via surveys and focus groups than those with less knowledge of clinical trial research.
- **Clinical Trial Participation** – Those who have already participated in a clinical trial are slightly more likely to be interested in helping with surveys and focus groups.

Answer	Trial Participant	Not a Trial Participant
Answering online surveys	86%	82%
Participating in individual in-person surveys	70%	62%
Being part of focus groups	67%	60%
I would be interested in helping researchers in any of these ways.	39%	35%
I would not be interested in helping researchers in other ways.	10%	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%

- **Overall** – Respondents feel that researchers could do more to motivate people to participate in clinical trials by making it easier for them to learn about the trials. Patients also indicated they want the clinical trial findings more readily available. Providing transportation, explaining what happens when people do not participate or providing payment are viewed as less essential. In a related finding described later in this report, 73% of patients prefer to learn about trials from their doctor's office but only 32% of their doctors have that conversation.
- **Condition** – Allergy/asthma patients are more than twice as likely to believe payment for participation would be a motivator than are melanoma or lung cancer patients.

"Pay Me to Participate" as a Motivator							
Lung Cancer	Melanoma	Type 1 Diabetes	Lupus	Multiple Sclerosis	Kidney Disease	GI Disease	Allergy-Asthma
25%	28%	47%	47%	46%	48%	48%	61%

- **Income** – While few respondents believe providing transportation to the trial site is a necessary motivator, those with lower incomes are more likely to feel that it is.

"Provide Transportation to the Clinical Trial Site" as a Motivator						
Less than $25K	$25,000-49,999	$50,000-74,999	$75,000-99,999	$100,000-149,999	$150,000-249,999	$250K+
52%	42%	33%	29%	28%	18%	19%

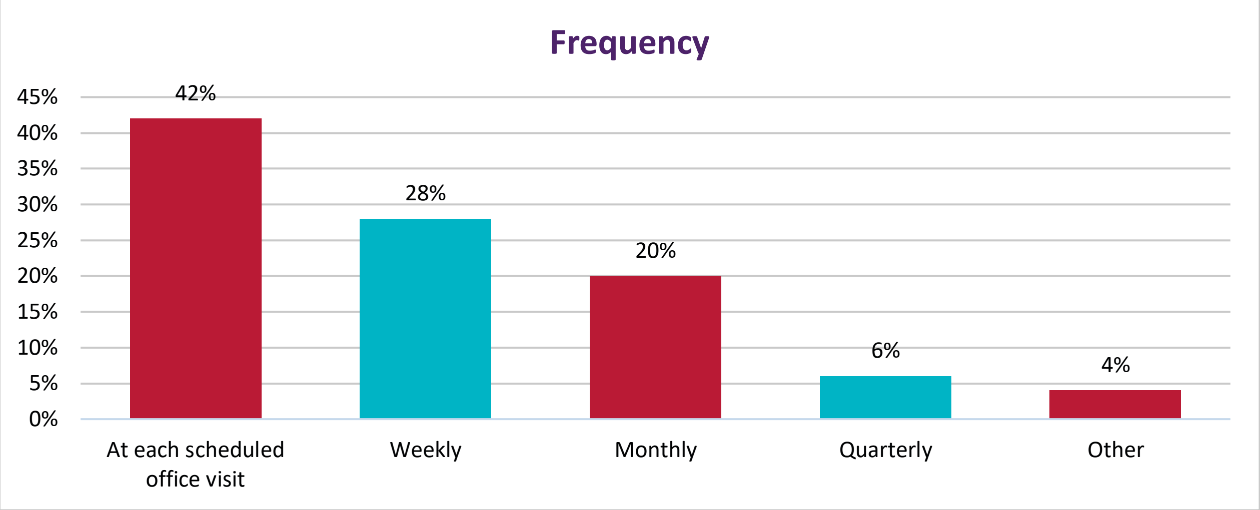
- **Age** – Younger respondents believe payment for clinical trial participation is a greater motivator than do older respondents.

"Pay Me to Participate" as a Motivator					
18-34	35-44	45-54	55-64	65-74	75 or older
65%	53%	49%	42%	33%	26%

- **Clinical Trial Participation** – Those who have not participated in clinical trials are more likely to be motivated by having clearer information about the costs incurred when joining a trial.

"Provide Clearer Information About Costs" as a Motivator	
Trial Participants	Not a Trial Participant
59%	68%

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



- **Overall** – A plurality of those surveyed prefer to receive clinical trial status information at each scheduled office visit. More than one-fourth (28%) prefer receiving information on a weekly basis.
- **Condition** – A plurality of survey participants across conditions prefer to receive clinical trial information at each scheduled office visit. This is especially true of patients with lung cancer.

Answer	Lung Cancer	Melanoma	Type 1 Diabetes	Lupus	Multiple Sclerosis	Kidney Disease	GI Disease	Allergy-Asthma
At each scheduled office visit	48%	44%	40%	38%	40%	46%	47%	41%

- **Income** – For the most part, respondents with lower incomes are more likely to want to receive clinical trial information at each scheduled office visit than are patients with higher incomes. The exception is patients with the highest incomes, who also want information presented at each office visit.

Answer	<$25K	$25,000-49,999	$50,000-74,999	$75,000-99,999	$100,000-149,999	$150,000-249,999	$250K+
At each scheduled office visit	46%	45%	42%	39%	37%	32%	50%
Weekly	27%	27%	28%	29%	31%	32%	18%
Monthly	19%	19%	19%	21%	23%	24%	14%
Quarterly	4%	5%	6%	7%	7%	8%	9%

- **Clinical Trial Participation** – Survey participants who have not yet participated in clinical trials are more likely to feel the need to receive clinical trial information more frequently.

Answer	Trial Participant	Not a Trial Participant
At each scheduled office visit	42%	42%
Weekly	18%	32%
Monthly	22%	19%
Quarterly	12%	4%

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%

- **Overall** – Respondents are most likely to participate in a clinical trial aiming to find a cure and least likely to participate when the goal of the research is to lessen a side effect.
- **Condition** – Respondents with gastrointestinal disease or lung cancer are much more inclined to participate in a clinical trial that addresses their condition than are respondents with multiple sclerosis or lupus.

% Very Likely							
Lung Cancer	Melanoma	Type 1 Diabetes	Lupus	Multiple Sclerosis	Kidney Disease	GI Disease	Allergy-Asthma
55%	46%	47%	42%	35%	46%	56%	43%

- **Age** – Older respondents are more likely to participate in a trial for a new drug, therapy, treatment or device to address their condition than are younger respondents.

% Very Likely						
<=17	18-34	35-44	45-54	55-64	65-74	75+
35%	42%	43%	44%	44%	41%	52%

- **Gender** – Women are more likely than men to join a trial that does not involve a drug, therapy, treatment or medical device but seeks to understand how the health of people living with a condition changes over time.

% Very Likely	Male	Female
A trial for a new drug, therapy, treatment or device to find a cure for my condition	67%	65%
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	44%	56%
A trial for a new drug, therapy, treatment or device to find a better alternative to an existing treatment	46%	45%
A trial for a new drug, therapy, treatment or device to address my condition	47%	43%
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	38%	37%

- **Patient vs. Caregiver** – Patients (55%) are more likely than caregivers (44%) to join a clinical trial that seeks to understand how the health of people changes over time.
- **Clinical Trial Knowledge** – Respondents who correctly assessed the validity of all eight true/false statements (56%) are more likely than those who correctly appraised only five or fewer of the statements (49%) to take part in a clinical trial that does not involve a drug, therapy, treatment or medical device but seeks to understand how the health of people living with a condition changes over time.

- **Clinical Trial Participation** – Respondents who have already participated in clinical trials are more likely to join these trials than those who have no clinical research experience. The largest differential (11 percentage points) is for a trial for a new drug, therapy, treatment or device to address the patient's condition.

% Very Likely	Trial Participant	Not a Trial Participant
A trial for a new drug, therapy, treatment or device to find a cure for my condition	70%	64%
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	59%	52%
A trial for a new drug, therapy, treatment or device to find a better alternative to an existing treatment	51%	43%
A trial for a new drug, therapy, treatment or device to address my condition	51%	40%
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	43%	35%

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%

- **Overall** – A majority of respondents (60%) say the opinion of family and friends matters little or not at all in their decision to participate in a clinical trial.
- **Condition** – Respondents with melanoma, kidney disease and 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. For those with gastrointestinal disease or allergies/asthma, the input of their families and friends matters the least.

Answer	Lung Cancer	Melanoma	Type 1 Diabetes	Lupus	Multiple Sclerosis	Kidney Disease	GI Disease	Allergy-Asthma
Their opinions are essential	12%	14%	10%	13%	16%	20%	6%	8%
Quite a bit	34%	36%	25%	23%	27%	27%	22%	21%

- **Education** – Patients with less formal education place a greater reliance on the input of family and friends than do respondents with more formal education.

Answer	Some HS	HS Diploma	Some College	College Degree	Some Postgraduate	Postgraduate Degree
Their opinions are essential	18%	21%	14%	13%	10%	11%
Not at all	16%	10%	11%	10%	11%	9%

- **Income** – While respondents in households with less income are more likely to say their family's and friends' opinions are essential, those in higher income households are more likely to say their opinions matter quite a bit.
- **Age** – Respondents in the youngest and oldest categories say their family and friends are more likely to influence their decision to join a clinical trial.

Answer	<=17	18-34	35-44	45-54	55-64	65-74	75+
Their opinions are essential	18%	14%	13%	14%	12%	14%	17%
Quite a bit	35%	26%	26%	24%	26%	31%	29%

- **Race** – Hispanic/Latinx respondents (22%) are more likely to say the opinions of their family and friends are essential than do their African-American (19%) or white (12%) counterparts.
- **Gender** – Men are more likely to place a higher value on the opinions of their family and friends than women in making their clinical trial participation decision.
- **Patient vs. Caregiver** – Caregivers are often family or friends of the patient, so it is not surprising that they place a greater importance on the influence of family and friends.

Answer	Patient	Caregiver
Their opinions are essential	13%	17%
Quite a bit	26%	29%

- **Clinical Trial Knowledge** – The more clinical knowledge exhibited by a respondent, the greater the independence in making a decision to participate in a clinical trial free from the influence of family and friends.

- **Clinical Trial Participation** – Patients who have already participated in clinical trials rely on the input of their family and friends less heavily.

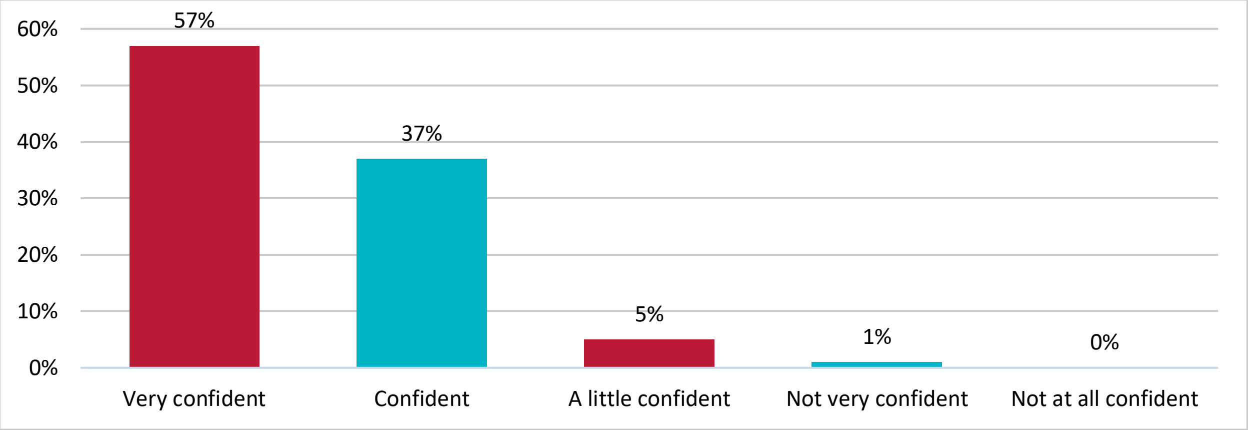
Answer	Trial Participant	Not a Trial Participant
Their opinions are essential	10%	14%
Quite a bit	20%	29%
A little	34%	31%
Not very much	21%	17%
Not at all	15%	9%

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 our 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
- Alternative drugs, therapies, treatments or medical devices
- Health insurance and benefits

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



- **Overall** – The overwhelming majority of those who participated in the survey feel either "very confident" or "confident" about their ability to make well-informed health decisions.
- **Condition** – Kidney disease patients exhibit the most confidence in making well-informed health decisions, while lung cancer and Type 1 diabetes patients express the least.

% Very Confident							
Lung Cancer	Melanoma	Type 1 Diabetes	Lupus	Multiple Sclerosis	Kidney Disease	GI Disease	Allergy-Asthma
51%	55%	51%	58%	55%	63%	56%	60%

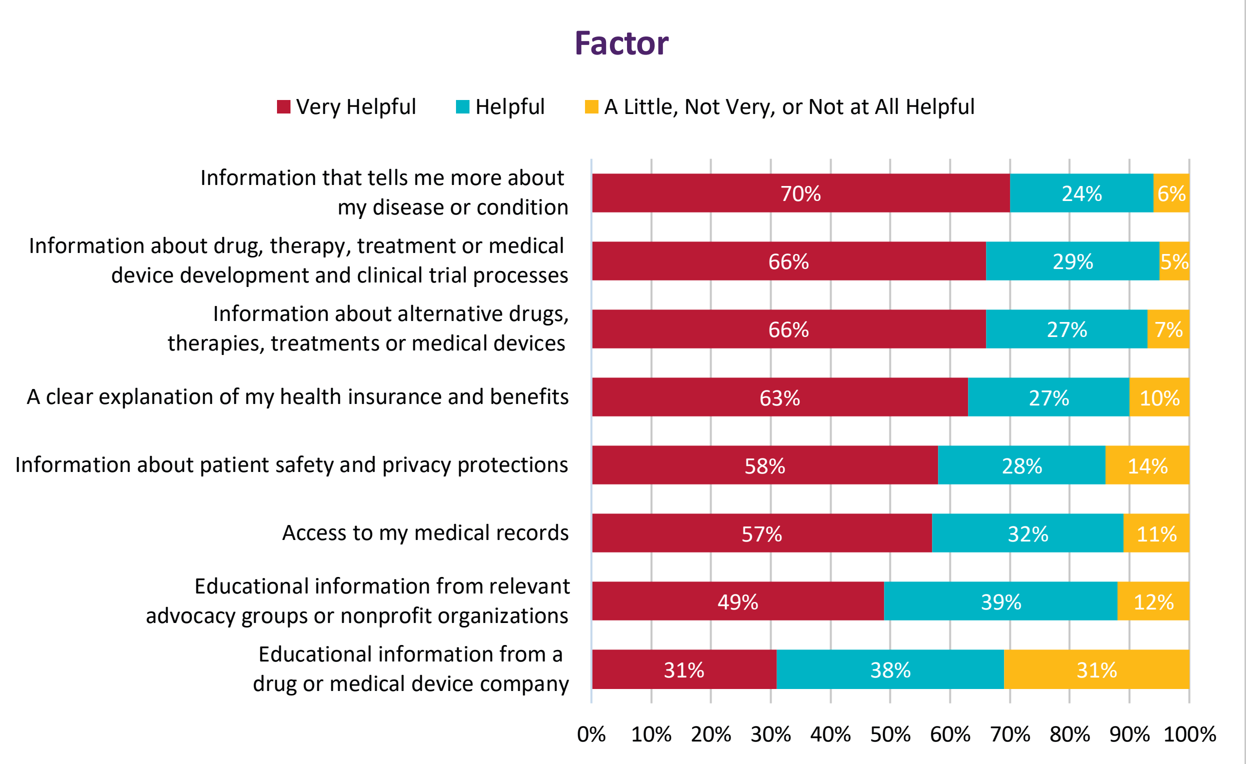
- **Education** – Those with more formal education express greater confidence about their own abilities to make well-informed health decisions than do those with less formal education.
- **Age** – Younger respondents are slightly less confident than are respondents who are aged 35 or older.
- **Patient vs. Caregiver** – Patient respondents are more confident than caregivers.
- **Clinical Trial Knowledge** – Patients who exhibited less clinical trial knowledge expressed less confidence in their ability to make well-informed health decisions.

Confidence in Making Well-Informed Health Decisions	0-5 Correct	All 8 Correct
Very confident	47%	60%
Confident	41%	36%
A little confident	9%	4%
Not very confident	3%	0%
Not at all confident	1%	0%

- **Clinical Trial Participation** – Patients who have taken part in a clinical trial are marginally more confident about making well-informed health decisions than are those who have not.

% Very Confident	
Trial Participant	Not a Trial Participant
59%	56%

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



- **Overall** – On one hand, respondents note the importance of information that tells them more about their condition or about drug or device development and clinical trials. On the other hand, they are less likely to value this information if it comes from a drug or device company or, to a lesser extent, from an advocacy group.
- **Condition** – Respondents with gastrointestinal or kidney disease are more likely to feel it is very important to get information about their condition in order to feel more confident in their health decisions.

% Very Important							
Lung Cancer	Melanoma	Type 1 Diabetes	Lupus	Multiple Sclerosis	Kidney Disease	GI Disease	Allergy-Asthma
72%	75%	53%	76%	65%	79%	84%	71%

- **Education** – Receiving educational information from a drug or device company is not valued highly and becomes even less so among respondents with more education.

% Very Important					
Some HS	HS Diploma	Some College	College Degree	Some Postgrad	Postgrad Degree
40%	44%	35%	30%	29%	20%

- **Income** – For the most part, respondents who have lower incomes place a higher priority on receiving educational information from a drug or device company or information about patient safety and privacy protections.
- **Age** – Older respondents are more likely to consider it very important to receive more information about their disease or condition in order to gain confidence in their health decisions.

% Very Important						
<=17	18-34	35-44	45-54	55-64	65-74	75+
58%	61%	67%	69%	72%	74%	77%

- **Race** – African-American and Hispanic/Latinx respondents are more likely to welcome receiving information of any type and from any source than are white respondents.

Factor	White	Hispanic/ Latinx	African-American
Information that tells me more about my disease or condition	69%	74%	77%
Information about drug, therapy, treatment or medical device development and clinical trial processes	65%	67%	70%
Information about alternative drugs, therapies, treatments or medical devices	66%	71%	71%
A clear explanation of my health insurance and benefits	62%	65%	68%
Information about patient safety and privacy protections	56%	66%	69%
Access to my medical records	56%	61%	65%
Educational information from relevant advocacy groups or nonprofit organizations	48%	59%	59%
Educational information from a drug or medical device company	29%	45%	45%

- **Gender** – Women (60%) are much more inclined to place a premium on gaining access to their medical records than are men (48%).
- **Clinical Trial Knowledge** – Patients with more clinical trial knowledge are less likely to believe it very important to receive educational information from a drug or medical device company.
- **Clinical Trial Participation** – Respondents with prior clinical trial experience, perhaps already more confident about the ability to make health decisions, are less likely to require any type of information to make them feel more confident.

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. 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%

- **Overall** – Respondents appear to most prefer receiving more information about clinical trials from authoritative sources such as their doctor or from a medical center. They are less likely to want the information from word of mouth, the drug company itself or ads.

- **Condition** – While all respondents would like to receive more information about clinical trials from their doctor's office, the second- and third-most preferred sources vary.

	Lung Cancer	Melanoma	Type 1 Diabetes	Lupus	Multiple Sclerosis	Kidney Disease	GI Disease	Allergy-Asthma
#1 Answer	Doctor	Doctor	Doctor	Doctor	Doctor	Doctor	Doctor	Doctor
#2 Answer	Clinical trial participants	Clinical trial participants	Advocacy group	Advocacy group	Med center	Med center	Health/ wellness websites	Med center
#3 Answer	Med center	Med center	Med center	Clinicaltrials .gov	Clinicaltrials .gov	Clinical trial participants	Clinicaltrials .gov	Health/ wellness websites

- **Education** – Respondents with more education are most likely to prefer getting information from advocacy organizations and least likely to want the information from ads.

Source	**HS Diploma**	**College Degree**	**Postgraduate Degree**
Advocacy/nonprofit organization	27%	44%	52%
Advertisements	25%	21%	16%

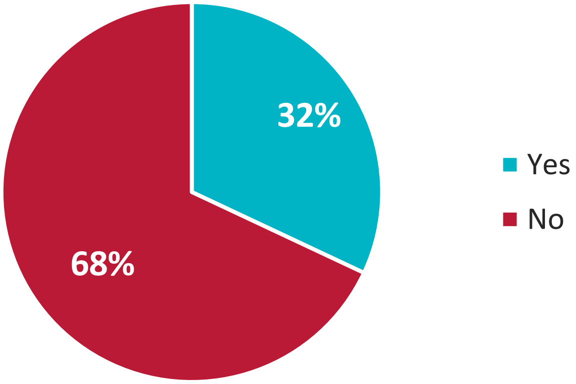
- **Income** – Respondents with lower annual household incomes are more likely to most prefer receiving more clinical trial information from health and wellness websites than are respondents with higher incomes.
- **Age** – Older respondents are more likely to most prefer receiving more clinical trial information from health and wellness websites.
- **Patient vs. Caregiver** – There are no significant differences between patient respondents and caregiver respondents in where they would most like to receive more clinical trial information.

- **Clinical Trial Knowledge** – Patients with more clinical trial knowledge are much more likely to prefer getting information from advocacy organizations than are those who demonstrate less clinical trial knowledge.

Source	0-5 Correct	All 8 Correct
Medical center/practice	45%	55%
Clinicaltrials.gov	36%	51%
Health and wellness information websites (Healthline, WebMD, etc.)	37%	42%
Advocacy/nonprofit organizations	29%	50%

- **Clinical Trial Participation** – For both those who have joined clinical trials and those that have not, the doctor's office and medical centers are the top two preferred sources of clinical trial information.

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



- **Overall** – About one-third (32%) of survey participants have had their doctor share clinical trial information with them.
- **Condition** – While lung cancer patients are likely to have had their doctor share clinical trial information with them, patients with gastrointestinal disease, kidney disease or allergies/asthma are least likely to have discussed clinical research with their doctors.

% Yes							
Lung Cancer	**Melanoma**	**Type 1 Diabetes**	**Lupus**	**Multiple Sclerosis**	**Kidney Disease**	**GI Disease**	**Allergy-Asthma**
58%	45%	32%	26%	38%	22%	15%	20%

- **Education** – Doctors seem more likely to share clinical trial information with more educated patients.

% Yes					
Some HS	HS Diploma	Some College	College Degree	Some Postgrad	Postgrad Degree
19%	25%	27%	32%	40%	42%

- **Income** – Respondents with higher incomes have doctors who are more likely to share clinical trial information with them.

% Yes						
<$25K	$25,000-49,999	$50,000-74,999	$75,000-99,999	$100,000-149,999	$150,000-249,999	$250K+
23%	31%	28%	35%	38%	43%	44%

- **Race** – 24% of Hispanic/Latinx respondents, 31% of African-American patients and 32% of white respondents report receiving clinical trial information from their doctors.
- **Gender** – Men are more likely to receive clinical trial information from their doctors than are women.

% Yes	
Male	Female
36%	31%

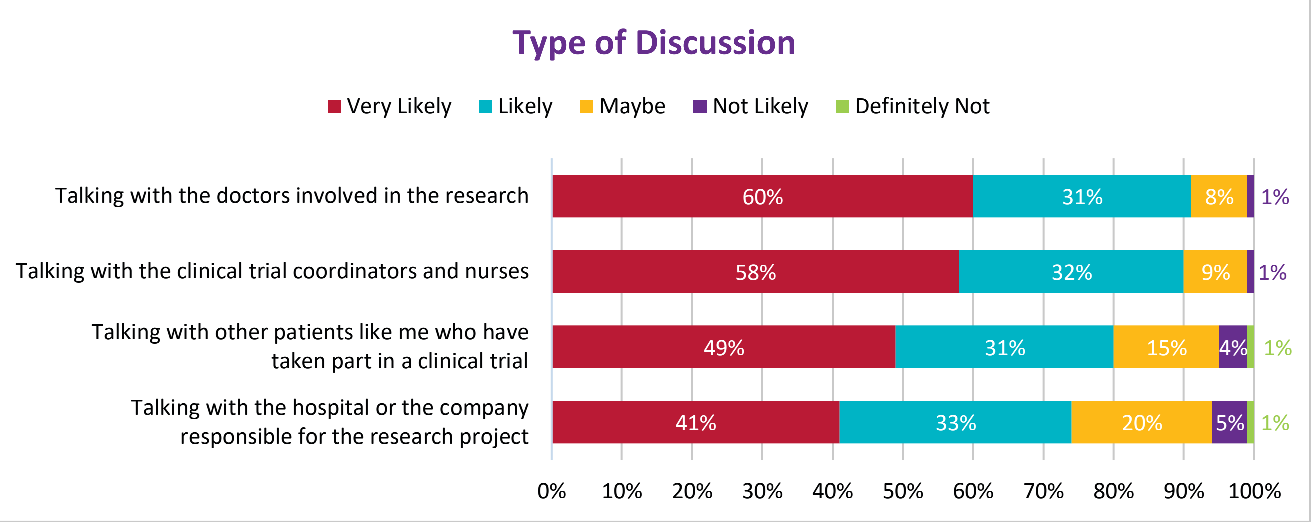
- **Clinical Trial Knowledge** – There is a positive correlation between knowledge of clinical trials and having a doctor share clinical trial information.
- **Clinical Trial Participation** – Respondents with previous clinical trial experience are almost three times as likely to report that their doctor has shared information with them about clinical trials than are respondents who have not participated in a clinical trial.

% Yes	
Trial Participant	Not a Trial Participant
62%	21%

PATIENTS AS PARTNERS

The industry has implemented many initiatives in recent years to make clinical research more patient-centric with the expectation that doing so will improve participation rates. A key element of patient-centricity may relate to the industry's ability to truly embrace patients as partners. And, this effort revolves around medical professionals. Ninety percent of the patients in this survey 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?



- **Overall** – Respondents are more likely to feel like a partner in the clinical trial process if they are able to discuss it with clinical researchers (e.g., doctors, coordinators, nurses) and less so if they are only given the opportunity to talk with other patients or the hospital or company responsible for the project.

- **Condition** – Lung cancer patients are especially inclined to want to speak with doctors involved in clinical research and, to a lesser extent, other patients who have taken part in a clinical trial. Respondents with allergies or asthma or Type 1 diabetes do not feel as much of a need to talk with doctors or other patients.

"Very Likely"	Lung Cancer	Melanoma	Type 1 Diabetes	Lupus	Multiple Sclerosis	Kidney Disease	GI Disease	Allergy-Asthma
Talking with doctors involved in the research	73%	62%	54%	64%	60%	65%	62%	51%
Talking with other patients like me who have taken part in a clinical trial	58%	52%	40%	52%	47%	58%	51%	40%

- **Education** – Respondents with less formal education care more about talking with other patients who have taken part in a clinical trial or with the hospital or company responsible for the research than do those with more formal education.
- **Income** – Respondents with lower annual household incomes value being able to discuss the clinical trial process with clinical research participants and clinical trial coordinators and nurses more than those with higher income.

"Very Likely"	<$25K	$25,000-49,999	$50,000-74,999	$75,000-99,999	$100,000-149,999	$150,000-249,999	$250K+
Talking with the clinical trial coordinators and nurses	64%	59%	59%	53%	57%	57%	44%
Talking with other patients like me who have taken part in a clinical trial	56%	50%	50%	44%	44%	46%	40%

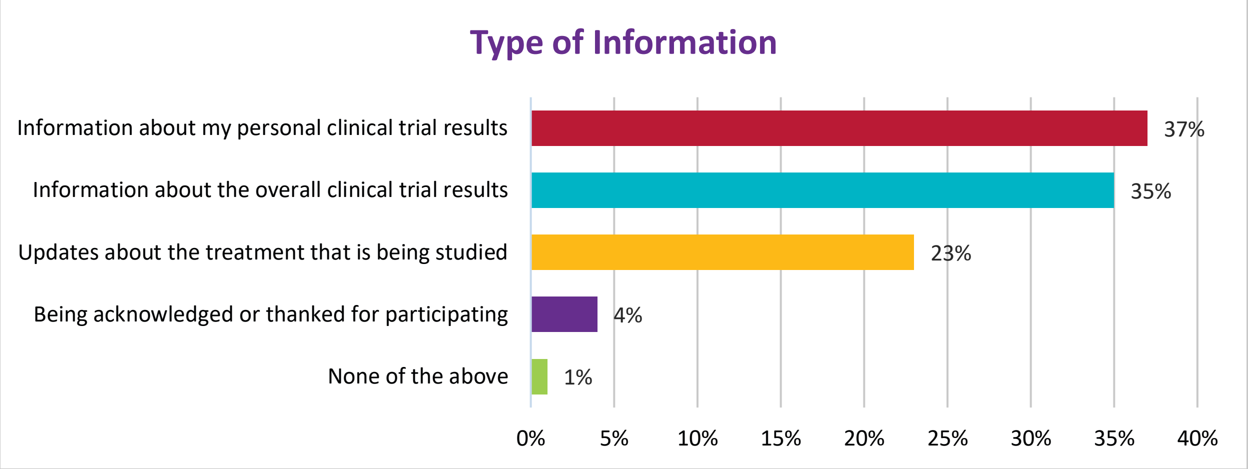
- **Age** – Older respondents place greater value on being able to discuss the clinical trial process with just about anyone compared to their younger counterparts.

"Very Likely"	<=17	18-34	35-44	45-54	55-64	65-74	75+
Talking with doctors involved in the research	52%	59%	56%	60%	61%	60%	69%
Talking with the clinical trial coordinators and nurses	39%	52%	51%	60%	60%	62%	66%
Talking with other patients like me who have taken part in a clinical trial	37%	46%	44%	50%	50%	50%	48%
Talking with the hospital or the company responsible for the research project	32%	38%	36%	41%	42%	46%	49%

- **Race** – It matters more to Hispanic/Latinx and African-American survey participants to be able to discuss with other patients who have participated in a clinical trial or with the hospital or company responsible for the research than it matters to respondents who are white.
- **Patient vs. Caregiver** – Patients (59%) value the chance to speak with clinical trial coordinators more than caregivers (52%).
- **Clinical Trial Knowledge** – Patients with less demonstrated clinical knowledge express more of a desire to speak to other patients who have previously participated in a clinical trial than do people who have demonstrated greater familiarity with clinical trials.
- **Clinical Trial Participation** – Respondents who have not yet participated in clinical trials are more likely to value the opportunity to speak to other patients like them who have taken part in a clinical trial or to the hospital or company overseeing the research.

Answer	Trial Participant	Not a Trial Participant
Talking with other patients like me who have taken part in a clinical trial	40%	51%
Talking with the hospital or the company responsible for the research project	34%	44%

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



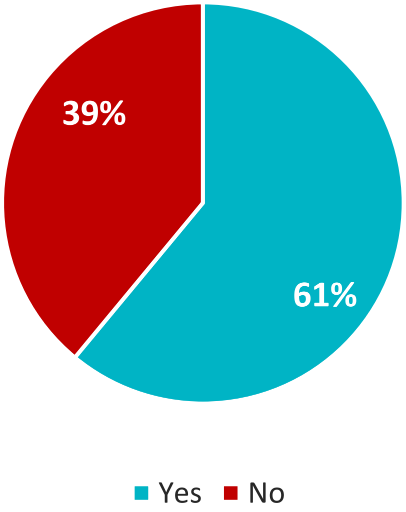
- **Overall** – There are about as many respondents who prefer to have information about their personal clinical trial results as there are who prioritize information about the overall clinical trial results.
- **Age** – There's a slight preference for having information about personal clinical trial results among older respondents and an equally slight preference for information about overall clinical trial results among younger respondents.

Answer	<=17	18-34	35-44	45-54	55-64	65-74	75+
Overall clinical trial results	39%	40%	40%	33%	33%	33%	32%
Personal clinical trial results	30%	31%	33%	37%	38%	40%	34%

- **Clinical Trial Participation** – Respondents who have participated in clinical trials are a little more likely to prefer receiving information about the overall clinical trial results than their personal clinical trial results. The opposite is true for those who have never taken part in a trial.

Answer	Trial Participant	Not a Trial Participant
Information about the overall clinical trial results	38%	34%
Information about my personal clinical trial results	33%	38%

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



- **Overall** – About three in five respondents use message boards and health-based online communities to learn more about their condition and the experiences of other patients.
- **Condition** – About two-thirds of melanoma, gastrointestinal disease, lung cancer, lupus and Type 1 diabetes patients use message boards and health-based online communities to learn more about their condition and the experiences of other patients. Just one-half of allergy/asthma respondents do.

Lung Cancer	Melanoma	Type 1 Diabetes	Lupus	Multiple Sclerosis	Kidney Disease	GI Disease	Allergy-Asthma
66%	68%	64%	66%	59%	60%	67%	50%

- **Education** – There is a positive correlation between education level and use of message boards and online communities.

% Yes					
Some HS	HS Diploma	Some College	College Degree	Some Postgrad	Postgrad Degree
57%	53%	63%	61%	59%	63%

- **Age** – Younger respondents are more disposed to use message boards and online communities to learn more about their conditions and the experiences of others.

% Yes						
<=17	18-34	35-44	45-54	55-64	65-74	75+
65%	62%	66%	64%	60%	55%	52%

- **Gender** – Women are slightly more likely to use message boards or online communities than are men.

% Yes	
Male	Female
56%	62%

- **Clinical Trial Knowledge** – There is a positive correlation between demonstration of clinical trial knowledge and proclivity toward using message boards or online communities.

MOTIVATORS BY DISEASE

LUNG CANCER

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

	Overall	Lung Cancer		
Reason	**Very Important**	**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%	67%	25%	8%
The trial provides me with a drug, therapy, treatment or medical device that potentially could extend or improve the quality of my life.	67%	84%	15%	1%
Someone is available to help me with my questions throughout.	66%	67%	25%	8%
I feel I can complete the entire trial.	59%	45%	45%	10%
I believe the drug, therapy, treatment or medical device being studied has been shown to be safe and effective in previous trials.	59%	51%	36%	13%
I am willing to undergo the medical procedures or tests involved in the study.	58%	59%	35%	6%
I can get to the location of the trial easily.	57%	54%	34%	12%
My doctor supports my decision to participate.	50%	60%	30%	10%
I believe I can attend all the appointments at the trial site for the study.	49%	51%	39%	10%
I can get access to a drug, therapy, treatment or medical device not otherwise available to me.	48%	64%	31%	5%
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%	32%	33%	35%

I won't have to take time away from my job, my school or my other obligations in order to participate.	39%	25%	33%	42%
I can receive health care for free or at a reduced cost.	33%	24%	35%	41%
I am reimbursed for time and travel.	26%	14%	30%	56%
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%	18%	17%	65%
I am paid to participate.	15%	5%	14%	81%

Safety Concerns

	Overall	Lung Cancer		
Reason	**Very Important**	**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%	67%	25%	8%
I believe the drug, therapy, treatment or medical device being studied has been shown to be safe and effective in previous trials.	59%	51%	36%	13%
I am willing to undergo the medical procedures or tests involved in the study.	58%	59%	35%	6%

- While lung cancer patients consider safety to be very important or important, they are slightly less concerned than the survey population as a whole.

Health Benefits

	Overall	Lung Cancer		
Reason	**Very Important**	**Very Important**	**Important**	**A Little, Not Very or Not at All Important**
The trial provides me with a drug, therapy, treatment or medical device that potentially could extend or improve the quality of my life.	67%	84%	15%	1%
I can get access to a drug, therapy, treatment or medical device not otherwise available to me.	48%	64%	31%	5%
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%	32%	33%	35%

- Lung cancer patients are especially concerned about two immediate health benefits — more so than any other patient group included in this report. Obtaining a treatment that has the potential to extend or improve their quality of life is critical to these patients. They also value having access to a treatment that would otherwise not be available to them.

Institutional Support

	Overall	Lung Cancer		
Reason	**Very Important**	**Very Important**	**Important**	**A Little, Not Very or Not at All Important**
Someone is available to help me with my questions throughout.	66%	67%	25%	8%
My doctor supports my decision to participate.	50%	60%	30%	10%

- Patients with lung cancer want support from their doctor and to have someone there to answer any questions throughout the clinical trial process.

Logistical Concerns

	Overall	Lung Cancer		
Reason	Very Important	Very Important	Important	A Little, Not Very or Not at All Important
I feel I can complete the entire trial.	59%	45%	45%	10%
I can get to the location of the trial easily.	57%	54%	34%	12%
I believe I can attend all the appointments at the trial site for the study.	49%	51%	39%	10%
I won't have to take time away from my job, my school or my other obligations in order to participate.	39%	25%	33%	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%	18%	17%	65%

- Lung cancer patients, though somewhat concerned with logistical considerations, are generally less concerned with them than are patients with other conditions.

Financial Benefits

	Overall	Lung Cancer		
Reason	Very Important	Very Important	Important	A Little, Not Very or Not at All Important
I can receive health care for free or at a reduced cost.	33%	24%	35%	41%
I am reimbursed for time and travel.	26%	14%	30%	56%
I am paid to participate.	15%	5%	14%	81%

- Financial benefits are of limited importance to lung cancer patients.

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 (Overall)	Percent (Lung Cancer)
Answering online surveys	83%	80%
Participating in individual in-person surveys	64%	58%
Being part of focus groups	62%	57%
I would be interested in helping researchers in any of these ways.	37%	31%
I would not be interested in helping researchers in other ways.	10%	14%

- The rankings for ways that patients can help with clinical research are the same for lung cancer patients as they are for the survey population overall. However, those with lung cancer are slightly less likely to want to participate overall.

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

Incentive	Percent (Overall)	Percent (Lung Cancer)
Make it easier for me to learn about clinical trials.	77%	78%
Make information about findings from clinical trials more readily available.	70%	74%
Provide clearer information about the costs that I will incur (time, financial, etc.).	66%	66%
Talk to me earlier about taking part in a clinical trial (not when I have only a few days to decide).	56%	56%
Ask me what I want from a new drug, therapy, treatment or medical device.	53%	47%
Explain why it is important for me and people like me to take part in a trial.	47%	50%
Pay me to participate.	46%	25%
Explain how it impacts me and my treatment options if people like me don't take part in clinical trials.	43%	41%
Provide transportation to the clinical trial site.	36%	41%

- The motivators for patients with lung cancer mirror those for patients with other conditions, except for the most explicitly financial one. Lung cancer patients are about half as likely to feel that payment for participation is a sufficient motivator.

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

Frequency	Percent (Overall)	Percent (Lung Cancer)
At each scheduled office visit	42%	48%
Weekly	28%	26%
Monthly	20%	18%
Quarterly	6%	5%
Other	4%	3%

- Almost one half of lung cancer patients (48%) prefer receiving information about how their trial is going at each scheduled office visit.

How likely are you to participate in clinical trials?

	Overall	Lung Cancer				
Trial Type	**Very Likely**	**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%	75%	17%	8%	0%	0%
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%	44%	25%	26%	4%	1%
A trial for a new drug, therapy, treatment or device to find a better alternative to an existing treatment	45%	51%	31%	15%	2%	1%
A trial for a new drug, therapy, treatment or device to address my condition	44%	55%	29%	13%	2%	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%	42%	32%	22%	2%	2%

- Respondents with lung cancer would be most likely to participate in a trial seeking to find a cure.

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

Answer	Percent (Overall)	Percent (Lung Cancer)
Their opinions are essential	13%	12%
Quite a bit	27%	34%
A little	32%	30%
Not very much	18%	18%
Not at all	10%	6%

- Lung cancer patients, though slightly less inclined to say the opinions of family and friends are essential, are more likely to say their opinions matter quite a bit.

MELANOMA

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

	Overall	**Melanoma**		
Reason	**Very Important**	**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%	70%	25%	5%
The trial provides me with a drug, therapy, treatment or medical device that potentially could extend or improve the quality of my life.	67%	74%	22%	4%
Someone is available to help me with my questions throughout.	66%	73%	22%	5%
I feel I can complete the entire trial.	59%	56%	37%	7%
I believe the drug, therapy, treatment or medical device being studied has been shown to be safe and effective in previous trials.	59%	55%	35%	10%
I am willing to undergo the medical procedures or tests involved in the study.	58%	59%	36%	5%
I can get to the location of the trial easily.	57%	48%	41%	11%
My doctor supports my decision to participate.	50%	61%	27%	12%
I believe I can attend all the appointments at the trial site for the study.	49%	47%	41%	12%
I can get access to a drug, therapy, treatment or medical device not otherwise available to me.	48%	59%	31%	10%
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%	41%	34%	25%
I won't have to take time away from my job, my school or my other obligations in order to participate.	39%	33%	30%	37%

I can receive health care for free or at a reduced cost.	33%	29%	31%	40%
I am reimbursed for time and travel.	26%	17%	25%	58%
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%	17%	20%	63%
I am paid to participate.	15%	6%	13%	81%

Safety Concerns

	Overall	Melanoma		
Reason	**Very Important**	**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%	70%	25%	5%
I believe the drug, therapy, treatment or medical device being studied has been shown to be safe and effective in previous trials.	59%	55%	35%	10%
I am willing to undergo the medical procedures or tests involved in the study.	58%	59%	36%	5%

- Patients with melanoma hold safety concerns as very important or important.

Health Benefits

	Overall	Melanoma		
Reason	**Very Important**	**Very Important**	**Important**	**A Little, Not Very or Not at All Important**
The trial provides me with a drug, therapy, treatment or medical device that potentially could extend or improve the quality of my life.	67%	74%	22%	4%
I can get access to a drug, therapy, treatment or medical device not otherwise available to me.	48%	59%	31%	10%
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%	41%	34%	25%

- A trial's immediate health benefits are much more important to melanoma patients than receiving equipment that track symptoms.

Institutional Support

	Overall	Melanoma		
Reason	**Very Important**	**Very Important**	**Important**	**A Little, Not Very or Not at All Important**
Someone is available to help me with my questions throughout.	66%	73%	22%	5%
My doctor supports my decision to participate.	50%	61%	27%	12%

- Patients with melanoma value having someone available to answer their questions and also appreciate having their doctor's support.

Logistical Concerns

	Overall	Melanoma		
Reason	**Very Important**	**Very Important**	**Important**	**A Little, Not Very or Not at All Important**
I feel I can complete the entire trial.	59%	56%	37%	7%
I can get to the location of the trial easily.	57%	48%	41%	11%
I believe I can attend all the appointments at the trial site for the study.	49%	47%	41%	12%
I won't have to take time away from my job, my school or my other obligations in order to participate.	39%	33%	30%	37%
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%	17%	20%	63%

- Logistical concerns were considered less important than other factors for the survey population as a whole and even less so for melanoma patients.

Financial Benefits

	Overall	Melanoma		
Reason	**Very Important**	**Very Important**	**Important**	**A Little, Not Very or Not at All Important**
I can receive health care for free or at a reduced cost.	33%	29%	31%	40%
I am reimbursed for time and travel.	26%	17%	25%	58%
I am paid to participate.	15%	6%	13%	81%

- Financial benefits, though important to some, are seen by most patients with melanoma as less important than other factors.

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 (Overall)	Percent (Melanoma)
Answering online surveys	83%	78%
Participating in individual in-person surveys	64%	56%
Being part of focus groups	62%	51%
I would be interested in helping researchers in any of these ways.	37%	29%
I would not be interested in helping researchers in other ways.	10%	12%

- Though a majority of melanoma patients express a willingness to help clinical research via online surveys, in-person surveys or being a part of focus groups, their willingness to do so is more tempered than that of patients with other conditions.

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

Incentive	Percent (Overall)	Percent (Melanoma)
Make it easier for me to learn about clinical trials.	77%	75%
Make information about findings from clinical trials more readily available.	70%	70%
Provide clearer information about the costs that I will incur (time, financial, etc.).	66%	57%
Talk to me earlier about taking part in a clinical trial (not when I have only a few days to decide).	56%	56%
Ask me what I want from a new drug, therapy, treatment or medical device.	53%	39%
Explain why it is important for me and people like me to take part in a trial.	47%	49%
Pay me to participate.	46%	28%
Explain how it impacts me and my treatment options if people like me don't take part in clinical trials.	43%	45%
Provide transportation to the clinical trial site.	36%	31%

- Melanoma patients say they would be more motivated to participate if it were easier to learn about clinical trials and if findings were more readily available.

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

Frequency	Percent (Overall)	Percent (Melanoma)
At each scheduled office visit	42%	44%
Weekly	28%	24%
Monthly	20%	24%
Quarterly	6%	5%
Other	4%	3%

- Respondents with melanoma prefer receiving clinical trial information more frequently.

How likely are you to participate in clinical trials?

	Overall	Melanoma				
Trial Type	**Very Likely**	**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%	68%	23%	8%	1%	0%
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%	50%	26%	19%	5%	0%
A trial for a new drug, therapy, treatment or device to find a better alternative to an existing treatment	45%	45%	35%	19%	1%	0%
A trial for a new drug, therapy, treatment or device to address my condition	44%	46%	32%	20%	2%	0%
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%	40%	33%	22%	5%	0%

- Melanoma patients are more inclined to join a trial when the trial is seeking to find a cure. They are less inclined when the purpose of the trial is to find a better treatment alternative or to reduce a side effect of an existing treatment.

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

Answer	Percent (Overall)	Percent (Melanoma)
Their opinions are essential	13%	14%
Quite a bit	27%	36%
A little	32%	28%
Not very much	18%	15%
Not at all	10%	7%

- One half of melanoma patients state that the opinions of family and friends are either essential or matter quite a bit.

TYPE 1 DIABETES

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

	Overall	Type 1 Diabetes		
Reason	Very Important	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%	75%	21%	4%
The trial provides me with a drug, therapy, treatment or medical device that potentially could extend or improve the quality of my life.	67%	63%	28%	9%
Someone is available to help me with my questions throughout.	66%	60%	30%	10%
I feel I can complete the entire trial.	59%	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%	56%	30%	14%
I am willing to undergo the medical procedures or tests involved in the study.	58%	60%	33%	7%
I can get to the location of the trial easily.	57%	54%	38%	8%
My doctor supports my decision to participate.	50%	36%	39%	25%
I believe I can attend all the appointments at the trial site for the study.	49%	44%	43%	13%
I can get access to a drug, therapy, treatment or medical device not otherwise available to me.	48%	44%	35%	21%
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%	41%	37%	22%
I won't have to take time away from my job, my school or my other obligations in order to participate.	39%	41%	32%	27%

I can receive health care for free or at a reduced cost.	33%	24%	34%	42%
I am reimbursed for time and travel.	26%	21%	31%	48%
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%	15%	16%	69%
I am paid to participate.	15%	11%	20%	69%

Safety Concerns

	Overall	Type 1 Diabetes		
Reason	**Very Important**	**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%	75%	21%	4%
I believe the drug, therapy, treatment or medical device being studied has been shown to be safe and effective in previous trials.	59%	56%	30%	14%
I am willing to undergo the medical procedures or tests involved in the study.	58%	60%	33%	7%

- Patients with Type 1 diabetes, like the rest of the respondents, consider safety concerns to be very important. They want to be reassured that taking part in a clinical trial will not make their condition worse.

Health Benefits

	Overall	Type 1 Diabetes		
Reason	**Very Important**	**Very Important**	**Important**	**A Little, Not Very or Not at All Important**
The trial provides me with a drug, therapy, treatment or medical device that potentially could extend or improve the quality of my life.	67%	63%	28%	9%
I can get access to a drug, therapy, treatment or medical device not otherwise available to me.	48%	44%	35%	21%
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%	41%	37%	22%

- First and foremost, patients with Type 1 diabetes want a trial to provide them with treatment that could either extend their life or improve their quality of life.

Institutional Support

	Overall	Type 1 Diabetes		
Reason	Very Important	Very Important	Important	A Little, Not Very or Not at All Important
Someone is available to help me with my questions throughout.	66%	60%	30%	10%
My doctor supports my decision to participate.	50%	36%	39%	25%

- Though Type 1 diabetes patients value institutional support, they value it somewhat less than do patients with other conditions. Just over one-third believe it is very important that their doctor supports their decision to take part in a clinical trial.

Logistical Concerns

	Overall	Type 1 Diabetes		
Reason	**Very Important**	**Very Important**	**Important**	**A Little, Not Very or Not at All Important**
I feel I can complete the entire trial.	59%	59%	36%	5%
I can get to the location of the trial easily.	57%	54%	38%	8%
I believe I can attend all the appointments at the trial site for the study.	49%	44%	43%	13%
I won't have to take time away from my job, my school or my other obligations in order to participate.	39%	41%	32%	27%
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%	15%	16%	69%

- Logistical concerns matter to patients with Type 1 diabetes but are not paramount.

Financial Benefits

	Overall	Type 1 Diabetes		
Reason	**Very Important**	**Very Important**	**Important**	**A Little, Not Very or Not at All Important**
I can receive health care for free or at a reduced cost.	33%	24%	34%	42%
I am reimbursed for time and travel.	26%	21%	31%	48%
I am paid to participate.	15%	11%	20%	69%

- For patients with Type 1 diabetes, financial benefits are generally seen as less important than other types of considerations.

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 (Overall)	Percent (Type 1 Diabetes)
Answering online surveys	83%	88%
Participating in individual in-person surveys	64%	69%
Being part of focus groups	62%	66%
I would be interested in helping researchers in any of these ways.	37%	41%
I would not be interested in helping researchers in other ways.	10%	5%

- Respondents with Type 1 diabetes are especially willing to answer online surveys to help with clinical research.

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

Incentive	Percent (Overall)	Percent (Type 1 Diabetes)
Make it easier for me to learn about clinical trials.	77%	81%
Make information about findings from clinical trials more readily available/	70%	68%
Provide clearer information about the costs that I will incur (time, financial, etc.).	66%	64%
Talk to me earlier about taking part in a clinical trial (not when I have only a few days to decide).	56%	56%
Ask me what I want from a new drug, therapy, treatment or medical device.	53%	53%
Explain why it is important for me and people like me to take part in a trial.	47%	35%
Pay me to participate.	46%	47%
Explain how it impacts me and my treatment options if people like me don’t take part in clinical trials.	43%	43%
Provide transportation to the clinical trial site.	36%	30%

- Patients with Type 1 diabetes, above all else, believe researchers could best motivate them to join a trial by making it easier for them to learn about clinical trials.

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

Frequency	Percent (Overall)	Percent (Type 1 Diabetes)
At each scheduled office visit	42%	40%
Weekly	28%	30%
Monthly	20%	19%
Quarterly	6%	7%
Other	4%	4%

- A plurality (40%) of patients with Type 1 diabetes say they prefer to receive clinical trial status information at each scheduled office visit while almost one-third (33%) prefer receiving information on a weekly basis.

How likely are you to participate in clinical trials?

	Overall	Type 1 Diabetes				
Trial Type	**Very Likely**	**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%	69%	19%	11%	1%	0%
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%	46%	29%	19%	6%	0%
A trial for a new drug, therapy, treatment or device to find a better alternative to an existing treatment	45%	47%	33%	17%	3%	0%
A trial for a new drug, therapy, treatment or device to address my condition	44%	47%	32%	18%	3%	0%
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%	33%	32%	26%	8%	1%

- Patients with Type 1 diabetes are most likely to join a trial that seeks to find a cure.

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

Answer	Percent (Overall)	Percent (Type 1 Diabetes)
Their opinions are essential	13%	10%
Quite a bit	27%	25%
A little	32%	34%
Not very much	18%	21%
Not at all	10%	10%

- Patients with Type 1 diabetes are less swayed by the opinions of family and friends than are patients with other conditions. Just over one-third (35%) of them say that the opinions of those close to them are essential or factor quite a bit in their decision to join a trial.

LUPUS

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

	Overall	Lupus		
Reason	**Very Important**	**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%	79%	17%	4%
The trial provides me with a drug, therapy, treatment or medical device that potentially could extend or improve the quality of my life.	67%	67%	28%	5%
Someone is available to help me with my questions throughout.	66%	67%	26%	7%
I feel I can complete the entire trial.	59%	59%	34%	7%
I believe the drug, therapy, treatment or medical device being studied has been shown to be safe and effective in previous trials.	59%	62%	27%	11%
I am willing to undergo the medical procedures or tests involved in the study.	58%	55%	36%	9%
I can get to the location of the trial easily.	57%	59%	32%	9%
My doctor supports my decision to participate.	50%	53%	32%	15%
I believe I can attend all the appointments at the trial site for the study.	49%	47%	38%	15%
I can get access to a drug, therapy, treatment or medical device not otherwise available to me.	48%	46%	36%	18%
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%	49%	34%	17%
I won't have to take time away from my job, my school or my other obligations in order to participate.	39%	44%	30%	26%

I can receive health care for free or at a reduced cost.	33%	34%	33%	33%
I am reimbursed for time and travel.	26%	27%	35%	38%
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%	24%	55%
I am paid to participate.	15%	11%	26%	63%

Safety Concerns

	Overall	Lupus		
Reason	**Very Important**	**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%	79%	17%	4%
I believe the drug, therapy, treatment or medical device being studied has been shown to be safe and effective in previous trials.	59%	62%	27%	11%
I am willing to undergo the medical procedures or tests involved in the study.	58%	55%	36%	9%

- Lupus patients feel quite strongly that a clinical trial must not interfere with their current treatment or make their condition worse.

Health Benefits

	Overall	Lupus		
Reason	**Very Important**	**Very Important**	**Important**	**A Little, Not Very or Not at All Important**
The trial provides me with a drug, therapy, treatment or medical device that potentially could extend or improve the quality of my life.	67%	67%	28%	5%
I can get access to a drug, therapy, treatment or medical device not otherwise available to me.	48%	46%	36%	18%
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%	49%	34%	17%

- Two-thirds of lupus patients find it very important that a trial they are a part of provide some way to extend their lives or improve their quality of life.

Institutional Support

	Overall	Lupus		
Reason	**Very Important**	**Very Important**	**Important**	**A Little, Not Very or Not at All Important**
Someone is available to help me with my questions throughout.	66%	67%	26%	7%
My doctor supports my decision to participate.	50%	53%	32%	15%

- Patients with lupus, like many of the other patients in this survey, place a high importance on having someone available to answer their questions and having their doctor support their decision to take part in a trial.

Logistical Concerns

	Overall	Lupus		
Reason	**Very Important**	**Very Important**	**Important**	**A Little, Not Very or Not at All Important**
I feel I can complete the entire trial.	59%	59%	34%	7%
I can get to the location of the trial easily.	57%	59%	32%	9%
I believe I can attend all the appointments at the trial site for the study.	49%	47%	38%	15%
I won't have to take time away from my job, my school or my other obligations in order to participate.	39%	44%	30%	26%
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%	24%	55%

- Lupus patients view logistical considerations similarly to the other patients in this survey.

Financial Benefits

	Overall	Lupus		
Reason	Very Important	Very Important	Important	A Little, Not Very or Not at All Important
I can receive health care for free or at a reduced cost.	33%	34%	33%	33%
I am reimbursed for time and travel.	26%	27%	35%	38%
I am paid to participate.	15%	11%	26%	63%

- Respondents with lupus do not prioritize financial benefits when compared to safety concerns or health benefits.

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 (Overall)	Percent (Lupus)
Answering online surveys	83%	81%
Participating in individual in-person surveys	64%	60%
Being part of focus groups	62%	64%
I would be interested in helping researchers in any of these ways.	37%	42%
I would not be interested in helping researchers in other ways.	10%	12%

- Lupus patients, like other patients, are most willing to help with clinical research by answering online surveys.

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

Incentive	Percent (Overall)	Percent (Lupus)
Make it easier for me to learn about clinical trials.	77%	73%
Make information about findings from clinical trials more readily available.	70%	74%
Provide clearer information about the costs that I will incur (time, financial, etc.).	66%	68%
Talk to me earlier about taking part in a clinical trial (not when I have only a few days to decide).	56%	54%
Ask me what I want from a new drug, therapy, treatment or medical device.	53%	60%
Explain why it is important for me and people like me to take part in a trial.	47%	52%
Pay me to participate.	46%	47%
Explain how it impacts me and my treatment options if people like me don't take part in clinical trials.	43%	49%
Provide transportation to the clinical trial site.	36%	33%

- About three-fourths of respondents with lupus feel researchers could better encourage clinical trial participation by making it easier for people to learn about clinical trials and making findings more available or accessible.

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

Frequency	Percent (Overall)	Percent (Lupus)
At each scheduled office visit	42%	38%
Weekly	28%	30%
Monthly	20%	21%
Quarterly	6%	7%
Other	4%	4%

- Lupus patients prefer receiving information about their clinical trial more often.

How likely are you to participate in clinical trials?

	Overall	Lupus				
Trial Type	**Very Likely**	**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%	66%	17%	16%	1%	0%
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%	58%	25%	14%	2%	1%
A trial for a new drug, therapy, treatment or device to find a better alternative to an existing treatment	45%	44%	31%	21%	4%	0%
A trial for a new drug, therapy, treatment or device to address my condition	44%	42%	29%	24%	4%	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%	39%	28%	25%	8%	0%

- Two-thirds of lupus patients say it is very likely they would join a clinical trial if the trial was for a new drug, therapy, treatment or device to find a cure.

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

Answer	Percent (Overall)	Percent (Lupus)
Their opinions are essential	13%	13%
Quite a bit	27%	23%
A little	32%	35%
Not very much	18%	19%
Not at all	10%	10%

- While some patients with lupus highly value the opinions of their family and friends in determining whether to take part in a trial, they are slightly less influenced by them than are patients with other conditions.

MULTIPLE SCLEROSIS

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

	Overall	Multiple Sclerosis		
Reason	**Very Important**	**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%	75%	19%	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%	66%	27%	7%
Someone is available to help me with my questions throughout.	66%	65%	24%	11%
I feel I can complete the entire trial.	59%	60%	35%	5%
I believe the drug, therapy, treatment or medical device being studied has been shown to be safe and effective in previous trials.	59%	61%	27%	12%
I am willing to undergo the medical procedures or tests involved in the study.	58%	58%	34%	8%
I can get to the location of the trial easily.	57%	59%	31%	10%
My doctor supports my decision to participate.	50%	54%	29%	17%
I believe I can attend all the appointments at the trial site for the study.	49%	48%	41%	11%
I can get access to a drug, therapy, treatment or medical device not otherwise available to me.	48%	44%	35%	21%
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%	49%	33%	18%

I won’t have to take time away from my job, my school or my other obligations in order to participate.	39%	34%	30%	36%
I can receive health care for free or at a reduced cost.	33%	34%	29%	37%
I am reimbursed for time and travel.	26%	25%	33%	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%	25%	22%	53%
I am paid to participate.	15%	14%	21%	65%

Safety Concerns

	Overall	Multiple Sclerosis		
Reason	**Very Important**	**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%	75%	19%	6%
I believe the drug, therapy, treatment or medical device being studied has been shown to be safe and effective in previous trials.	59%	61%	27%	12%
I am willing to undergo the medical procedures or tests involved in the study.	58%	58%	34%	8%

- Safety concerns are of high importance to multiple sclerosis patients. Three-fourths of them want to know that a clinical trial would not interfere with their current treatment or make things worse for them.

Health Benefits

	Overall	Multiple Sclerosis		
Reason	**Very Important**	**Very Important**	**Important**	**A Little, Not Very or Not at All Important**
The trial provides me with a drug, therapy, treatment or medical device that potentially could extend or improve the quality of my life.	67%	66%	27%	7%
I can get access to a drug, therapy, treatment or medical device not otherwise available to me.	48%	44%	35%	21%
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%	49%	33%	18%

- Similar to overall results, two-thirds of patients with multiple sclerosis consider it very important that a trial potentially could extend or improve upon their quality of life.

Institutional Support

	Overall	Multiple Sclerosis		
Reason	**Very Important**	**Very Important**	**Important**	**A Little, Not Very or Not at All Important**
Someone is available to help me with my questions throughout.	66%	65%	24%	11%
My doctor supports my decision to participate.	50%	54%	29%	17%

- Almost two-thirds (65%) of patients with multiple sclerosis find it very important that someone is available to help answer their questions throughout the clinical trial process.

Logistical Concerns

	Overall	Multiple Sclerosis		
Reason	Very Important	Very Important	Important	A Little, Not Very or Not at All Important
I feel I can complete the entire trial.	59%	60%	35%	5%
I can get to the location of the trial easily.	57%	59%	31%	10%
I believe I can attend all the appointments at the trial site for the study.	49%	48%	41%	11%
I won’t have to take time away from my job, my school or my other obligations in order to participate.	39%	34%	30%	36%
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%	25%	22%	53%

- About three in five multiple sclerosis patients deem it very important that they can complete the trial (60%) and can easily get to the site (59%).

Financial Benefits

	Overall	Multiple Sclerosis		
Reason	**Very Important**	**Very Important**	**Important**	**A Little, Not Very or Not at All Important**
I can receive health care for free or at a reduced cost.	33%	34%	29%	37%
I am reimbursed for time and travel.	26%	25%	33%	42%
I am paid to participate.	15%	14%	21%	65%

- Financial benefits are not a primary consideration for most patients with multiple sclerosis.

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 (Overall)	Percent (Multiple Sclerosis)
Answering online surveys	83%	85%
Participating in individual in-person surveys	64%	65%
Being part of focus groups	62%	62%
I would be interested in helping researchers in any of these ways.	37%	38%
I would not be interested in helping researchers in other ways.	10%	10%

- Most of the respondents with multiple sclerosis said they would be willing to answer online surveys to help clinical researchers. Solid majorities said they would also participate in individual in-person surveys or in focus groups.

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

Incentive	Percent (Overall)	Percent (Multiple Sclerosis)
Make it easier for me to learn about clinical trials.	77%	76%
Make information about findings from clinical trials more readily available.	70%	71%
Provide clearer information about the costs that I will incur (time, financial, etc.).	66%	67%
Talk to me earlier about taking part in a clinical trial (not when I have only a few days to decide).	56%	59%
Ask me what I want from a new drug, therapy, treatment or medical device.	53%	57%
Explain why it is important for me and people like me to take part in a trial.	47%	48%
Pay me to participate.	46%	46%
Explain how it impacts me and my treatment options if people like me don't take part in clinical trials.	43%	42%
Provide transportation to the clinical trial site.	36%	44%

- Respondents with multiple sclerosis feel most strongly that researchers could do more to encourage clinical trial participation by making it easier for them to learn about trials and by making findings more readily available.

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

Frequency	Percent (Overall)	Percent (Multiple Sclerosis)
At each scheduled office visit	42%	40%
Weekly	28%	26%
Monthly	20%	22%
Quarterly	6%	7%
Other	4%	5%

- A plurality of multiple sclerosis patients want clinical trial status information communicated at each scheduled office visit. About one-fourth of these patients (26%) prefer receiving this information on a weekly basis.

How likely are you to participate in clinical trials?

	Overall	Multiple Sclerosis				
Trial Type	Very Likely	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%	60%	22%	14%	2%	2%
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%	56%	25%	15%	3%	1%
A trial for a new drug, therapy, treatment or device to find a better alternative to an existing treatment	45%	38%	31%	24%	5%	2%
A trial for a new drug, therapy, treatment or device to address my condition	44%	35%	29%	28%	5%	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%	32%	29%	28%	8%	3%

- Multiple sclerosis patients are most likely to join a clinical trial if the goal of the treatment is to find a cure and less likely if the purpose of the trial is to lessen a side effect of a current treatment.

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

Answer	Percent (Overall)	Percent (Multiple Sclerosis)
Their opinions are essential	13%	16%
Quite a bit	27%	27%
A little	32%	32%
Not very much	18%	16%
Not at all	10%	9%

- Patients with multiple sclerosis are slightly more likely than patients with other conditions to rely on the opinions of their family and friends when thinking about taking part in a clinical trial.

KIDNEY DISEASE

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

	Overall	Kidney Disease		
Reason	**Very Important**	**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%	80%	18%	2%
The trial provides me with a drug, therapy, treatment or medical device that potentially could extend or improve the quality of my life.	67%	72%	24%	4%
Someone is available to help me with my questions throughout.	66%	68%	24%	8%
I feel I can complete the entire trial.	59%	60%	36%	4%
I believe the drug, therapy, treatment or medical device being studied has been shown to be safe and effective in previous trials.	59%	66%	28%	6%
I am willing to undergo the medical procedures or tests involved in the study.	58%	58%	36%	6%
I can get to the location of the trial easily.	57%	60%	34%	6%
My doctor supports my decision to participate.	50%	57%	32%	11%
I believe I can attend all the appointments at the trial site for the study.	49%	54%	35%	11%
I can get access to a drug, therapy, treatment or medical device not otherwise available to me.	48%	53%	35%	12%
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%	53%	37%	10%

I won't have to take time away from my job, my school or my other obligations in order to participate.	39%	42%	32%	26%
I can receive health care for free or at a reduced cost.	33%	40%	34%	26%
I am reimbursed for time and travel.	26%	37%	32%	31%
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%	28%	27%	45%
I am paid to participate.	15%	22%	26%	52%

Safety Concerns

	Overall	Kidney Disease		
Reason	**Very Important**	**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%	80%	18%	2%
I believe the drug, therapy, treatment or medical device being studied has been shown to be safe and effective in previous trials.	59%	66%	28%	6%
I am willing to undergo the medical procedures or tests involved in the study.	58%	58%	36%	6%

- Kidney disease patients place a high importance on safety concerns and want to be assured that participation in a trial will do no harm.

Health Benefits

	Overall	Kidney Disease		
Reason	Very Important	Very Important	Important	A Little, Not Very or Not at All Important
The trial provides me with a drug, therapy, treatment or medical device that potentially could extend or improve the quality of my life.	67%	72%	24%	4%
I can get access to a drug, therapy, treatment or medical device not otherwise available to me.	48%	53%	35%	12%
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%	53%	37%	10%

- A trial that could allow them to live longer or improve their quality of life is especially valued by patients with kidney disease.

Institutional Support

	Overall	Kidney Disease		
Reason	**Very Important**	**Very Important**	**Important**	**A Little, Not Very or Not at All Important**
Someone is available to help me with my questions throughout.	66%	68%	24%	8%
My doctor supports my decision to participate.	50%	57%	32%	11%

- More than two-thirds (68%) of respondents with kidney disease consider it very important that someone be able to help them with their questions. More than one-half (57%) said it is very important that their doctor support their decision to join a clinical trial.

Logistical Concerns

	Overall	**Kidney Disease**		
Reason	**Very Important**	**Very Important**	**Important**	**A Little, Not Very or Not at All Important**
I feel I can complete the entire trial.	59%	60%	36%	4%
I can get to the location of the trial easily.	57%	60%	34%	6%
I believe I can attend all the appointments at the trial site for the study.	49%	54%	35%	11%
I won't have to take time away from my job, my school or my other obligations in order to participate.	39%	42%	32%	26%
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%	28%	27%	45%

- While logistical concerns, such as being able to complete the trial or easily getting to the trial location, are especially important to kidney disease patients, all logistical concerns are valued more highly by this group of patients than by the survey population overall.

Financial Benefits

	Overall	Kidney Disease		
Reason	**Very Important**	**Very Important**	**Important**	**A Little, Not Very or Not at All Important**
I can receive health care for free or at a reduced cost.	33%	40%	34%	26%
I am reimbursed for time and travel.	26%	37%	32%	31%
I am paid to participate.	15%	22%	26%	52%

- Financial benefits, while not of primary importance to most kidney disease patients, are more important to them than they are to patients with other conditions.

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 (Overall)	Percent (Kidney Disease)
Answering online surveys	83%	80%
Participating in individual in-person surveys	64%	61%
Being part of focus groups	62%	62%
I would be interested in helping researchers in any of these ways.	37%	35%
I would not be interested in helping researchers in other ways.	10%	10%

- A majority of kidney disease patients express a willingness to help with clinical research by answering online surveys, participating in individual in-person surveys or being a part of focus groups.

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

Incentive	Percent (Overall)	Percent (Kidney Disease)
Make it easier for me to learn about clinical trials.	77%	74%
Make information about findings from clinical trials more readily available.	70%	67%
Provide clearer information about the costs that I will incur (time, financial, etc.)/	66%	68%
Talk to me earlier about taking part in a clinical trial (not when I have only a few days to decide).	56%	54%
Ask me what I want from a new drug, therapy, treatment or medical device.	53%	54%
Explain why it is important for me and people like me to take part in a trial.	47%	54%
Pay me to participate.	46%	48%
Explain how it impacts me and my treatment options if people like me don't take part in clinical trials.	43%	50%
Provide transportation to the clinical trial site.	36%	39%

- Patients with kidney disease feel that researchers could best motivate people to participate in clinical trials by making it easier for patients to learn about patients, by providing clearer information about costs incurred and by making the findings more readily available.

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

Frequency	Percent (Overall)	Percent (Kidney Disease)
At each scheduled office visit	42%	46%
Weekly	28%	33%
Monthly	20%	14%
Quarterly	6%	4%
Other	4%	3%

- Almost one-half (46%) of respondents with kidney disease want to receive clinical trial status information at each scheduled office visit.

How likely are you to participate in clinical trials?

	Overall	Kidney Disease				
Trial Type	**Very Likely**	**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%	67%	23%	8%	2%	0%
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%	58%	26%	14%	2%	0%
A trial for a new drug, therapy, treatment or device to find a better alternative to an existing treatment	45%	52%	31%	15%	2%	0%
A trial for a new drug, therapy, treatment or device to address my condition	44%	46%	31%	19%	2%	2%
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%	44%	31%	21%	3%	1%

- Two-thirds (67%) of kidney disease patients say they are most likely to participate in a clinical trial with the goal of finding a cure.

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

Answer	Percent (Overall)	Percent (Kidney Disease)
Their opinions are essential	13%	20%
Quite a bit	27%	27%
A little	32%	29%
Not very much	18%	14%
Not at all	10%	10%

- Almost one-half (47%) of these patients with kidney disease say that the opinion of family and friends is essential or matters quite a bit in their decision to participate in a clinical trial.

GASTROINTESTINAL DISEASE

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

	Overall	Gastrointestinal Disease		
Reason	Very Important	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%	67%	24%	9%
The trial provides me with a drug, therapy, treatment or medical device that potentially could extend or improve the quality of my life.	67%	63%	24%	13%
Someone is available to help me with my questions throughout.	66%	63%	25%	12%
I feel I can complete the entire trial.	59%	68%	30%	2%
I believe the drug, therapy, treatment or medical device being studied has been shown to be safe and effective in previous trials.	59%	51%	35%	14%
I am willing to undergo the medical procedures or tests involved in the study.	58%	62%	32%	6%
I can get to the location of the trial easily.	57%	56%	36%	8%
My doctor supports my decision to participate.	50%	38%	33%	29%
I believe I can attend all the appointments at the trial site for the study.	49%	49%	37%	14%
I can get access to a drug, therapy, treatment or medical device not otherwise available to me.	48%	47%	33%	20%
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%	46%	37%	17%
I won't have to take time away from my job, my school or my other obligations in order to participate.	39%	41%	24%	35%
I can receive health care for free or at a reduced cost.	33%	35%	33%	32%
I am reimbursed for time and travel.	26%	24%	36%	40%
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%	20%	16%	64%
I am paid to participate.	15%	18%	17%	65%

Safety Concerns

	Overall	Gastrointestinal Disease		
Reason	**Very Important**	**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%	67%	24%	9%
I believe the drug, therapy, treatment or medical device being studied has been shown to be safe and effective in previous trials.	59%	51%	35%	14%
I am willing to undergo the medical procedures or tests involved in the study.	58%	62%	32%	6%

- Patients with gastrointestinal disease, while still valuing safety concerns, emphasize them slightly less than patients with other conditions.

Health Benefits

	Overall	Gastrointestinal Disease		
Reason	**Very Important**	**Very Important**	**Important**	**A Little, Not Very or Not at All Important**
The trial provides me with a drug, therapy, treatment or medical device that potentially could extend or improve the quality of my life.	67%	63%	24%	13%
I can get access to a drug, therapy, treatment or medical device not otherwise available to me.	48%	47%	33%	20%
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%	46%	37%	17%

- Gastrointestinal patients deem it very important that a trial provides treatment that could improve their quality of life.

Institutional Support

	Overall	Gastrointestinal Disease		
Reason	**Very Important**	**Very Important**	**Important**	**A Little, Not Very or Not at All Important**
Someone is available to help me with my questions throughout.	66%	63%	25%	12%
My doctor supports my decision to participate.	50%	38%	33%	29%

- While a solid majority of patients with gastrointestinal disease said it is very important for someone to help them with their questions during the clinical trial process, it is less important to them that their doctor supports their decision to participate.

Logistical Concerns

	Overall	Gastrointestinal Disease		
Reason	**Very Important**	**Very Important**	**Important**	**A Little, Not Very or Not at All Important**
I feel I can complete the entire trial.	59%	68%	30%	2%
I can get to the location of the trial easily.	57%	56%	36%	8%
I believe I can attend all the appointments at the trial site for the study.	49%	49%	37%	14%
I won't have to take time away from my job, my school or my other obligations in order to participate.	39%	41%	24%	35%
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%	20%	16%	64%

- It is quite important for patients with gastrointestinal disease to feel that they can complete the entire trial (68%).

Financial Benefits

	Overall	Gastrointestinal Disease		
Reason	Very Important	Very Important	Important	A Little, Not Very or Not at All Important
I can receive health care for free or at a reduced cost.	33%	35%	33%	32%
I am reimbursed for time and travel.	26%	24%	36%	40%
I am paid to participate.	15%	18%	17%	65%

- Financial benefits, though very important to a minority of these patients with gastrointestinal disease, are generally less valued by them than are other types of benefits.

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 (Overall)	Percent (GI Disease)
Answering online surveys	83%	83%
Participating in individual in-person surveys	64%	72%
Being part of focus groups	62%	64%
I would be interested in helping researchers in any of these ways.	37%	40%
I would not be interested in helping researchers in other ways.	10%	9%

- Patients with gastrointestinal disease are as likely as patients with other conditions to be interested in helping with clinical research through online surveys, in-person surveys or participation in focus groups.

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

Incentive	Percent (Overall)	Percent (GI Disease)
Make it easier for me to learn about clinical trials.	77%	84%
Make information about findings from clinical trials more readily available.	70%	71%
Provide clearer information about the costs that I will incur (time, financial, etc.).	66%	69%
Talk to me earlier about taking part in a clinical trial (not when I have only a few days to decide).	56%	54%
Ask me what I want from a new drug, therapy, treatment or medical device.	53%	58%
Explain why it is important for me and people like me to take part in a trial.	47%	51%
Pay me to participate.	46%	48%
Explain how it impacts me and my treatment options if people like me don't take part in clinical trials.	43%	47%
Provide transportation to the clinical trial site.	36%	40%

- Respondents with gastrointestinal disease feel that researchers could motivate them to join a trial by making it easier for patients to learn about clinical trials.

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

Frequency	Percent (Overall)	Percent (GI Disease)
At each scheduled office visit	42%	47%
Weekly	28%	26%
Monthly	20%	16%
Quarterly	6%	4%
Other	4%	7%

- Almost one-half (47%) of patients with gastrointestinal disease would prefer to receive clinical trial status information at each scheduled office visit.

How likely are you to participate in clinical trials?

	Overall	Gastrointestinal Disease				
Trial Type	**Very Likely**	**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%	68%	21%	7%	1%	3%
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%	60%	23%	13%	3%	1%
A trial for a new drug, therapy, treatment or device to find a better alternative to an existing treatment	45%	54%	31%	12%	1%	2%
A trial for a new drug, therapy, treatment or device to address my condition	44%	56%	26%	16%	1%	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%	42%	32%	21%	4%	1%

- More than one-half of patients with gastrointestinal disease indicated they are most likely to participate in trials that attempt to find a cure or that seek to understand how health changes over time.

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

Answer	Percent (Overall)	Percent (GI Disease)
Their opinions are essential	13%	6%
Quite a bit	27%	22%
A little	32%	32%
Not very much	18%	25%
Not at all	10%	15%

- While more than one-fourth (28%) of patients with gastrointestinal disease indicate that the opinions of family and friends are either essential or matter quite a bit, most of these patients say these opinions matter little or not at all.

ALLERGIES/ASTHMA

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

	Overall	Allergies/Asthma		
Reason	Very Important	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%	68%	26%	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%	61%	30%	9%
Someone is available to help me with my questions throughout.	66%	67%	26%	7%
I feel I can complete the entire trial.	59%	61%	35%	4%
I believe the drug, therapy, treatment or medical device being studied has been shown to be safe and effective in previous trials.	59%	57%	31%	12%
I am willing to undergo the medical procedures or tests involved in the study.	58%	59%	35%	6%
I can get to the location of the trial easily.	57%	61%	33%	6%
My doctor supports my decision to participate.	50%	37%	37%	26%
I believe I can attend all the appointments at the trial site for the study.	49%	51%	39%	10%
I can get access to a drug, therapy, treatment or medical device not otherwise available to me.	48%	39%	40%	21%
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%	48%	38%	14%

I won’t have to take time away from my job, my school or my other obligations in order to participate.	39%	49%	31%	20%
I can receive health care for free or at a reduced cost.	33%	38%	33%	29%
I am reimbursed for time and travel.	26%	36%	37%	27%
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%	15%	21%	64%
I am paid to participate.	15%	27%	31%	42%

Safety Concerns

	Overall	Allergies/Asthma		
Reason	**Very Important**	**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%	68%	26%	6%
I believe the drug, therapy, treatment or medical device being studied has been shown to be safe and effective in previous trials.	59%	57%	31%	12%
I am willing to undergo the medical procedures or tests involved in the study.	58%	59%	35%	6%

- Patients who suffer from allergies/asthma consider safety concerns very important.

Health Benefits

	Overall	Allergies/Asthma		
Reason	Very Important	Very Important	Important	A Little, Not Very or Not at All Important
The trial provides me with a drug, therapy, treatment or medical device that potentially could extend or improve the quality of my life.	67%	61%	30%	9%
I can get access to a drug, therapy, treatment or medical device not otherwise available to me.	48%	39%	40%	21%
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%	48%	38%	14%

- Health benefits are of high importance to patients with allergies/asthma.

Institutional Support

	Overall	Allergies/Asthma		
Reason	**Very Important**	**Very Important**	**Important**	**A Little, Not Very or Not at All Important**
Someone is available to help me with my questions throughout.	66%	67%	26%	7%
My doctor supports my decision to participate.	50%	37%	37%	26%

- About two-thirds (67%) of allergy/asthma patients feel it is very important for someone to be available to help them with their questions. Over one-third (37%) believe it is very important that their doctor supports their decision to participate.

Logistical Concerns

	Overall	Allergies/Asthma		
Reason	**Very Important**	**Very Important**	**Important**	**A Little, Not Very or Not at All Important**
I feel I can complete the entire trial.	59%	61%	35%	4%
I can get to the location of the trial easily.	57%	61%	33%	6%
I believe I can attend all the appointments at the trial site for the study.	49%	51%	39%	10%
I won't have to take time away from my job, my school or my other obligations in order to participate.	39%	49%	31%	20%
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%	15%	21%	64%

- Logistical hurdles are of greater importance to allergy/asthma patients than to patients with other conditions.

Financial Benefits

	Overall	Allergies/Asthma		
Reason	**Very Important**	**Very Important**	**Important**	**A Little, Not Very or Not at All Important**
I can receive health care for free or at a reduced cost.	33%	38%	33%	29%
I am reimbursed for time and travel.	26%	36%	37%	27%
I am paid to participate.	15%	27%	31%	42%

- Financial benefits, though often of secondary importance to patients with allergies/asthma, are more highly valued by them than by patients with other therapeutic conditions.

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 (Overall)	Percent (Allergies/Asthma)
Answering online surveys	83%	82%
Participating in individual in-person surveys	64%	69%
Being part of focus groups	62%	66%
I would be interested in helping researchers in any of these ways.	37%	36%
I would not be interested in helping researchers in other ways.	10%	11%

- Most allergy/asthma patients express a willingness to help with clinical research by answering online surveys. The majority also indicated they would participate in individual in-person surveys or in focus groups.

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

Incentive	Percent (Overall)	Percent (Allergies/Asthma)
Make it easier for me to learn about clinical trials.	77%	76%
Make information about findings from clinical trials more readily available.	70%	67%
Provide clearer information about the costs that I will incur (time, financial, etc.).	66%	68%
Talk to me earlier about taking part in a clinical trial (not when I have only a few days to decide).	56%	51%
Ask me what I want from a new drug, therapy, treatment or medical device.	53%	48%
Explain why it is important for me and people like me to take part in a trial.	47%	43%
Pay me to participate.	46%	61%
Explain how it impacts me and my treatment options if people like me don't take part in clinical trials.	43%	42%
Provide transportation to the clinical trial site.	36%	28%

- The attitudes of patients with allergies/asthma generally reflect the opinions of people with other conditions when considering possible incentives to clinical participation. However, allergy/asthma patients are much more likely to want to be paid for their participation.

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

Frequency	Percent (Overall)	Percent (Allergies/Asthma)
At each scheduled office visit	42%	41%
Weekly	28%	29%
Monthly	20%	18%
Quarterly	6%	7%
Other	4%	5%

- A plurality (41%) of allergy/asthma patients want clinical trial status information communicated at each scheduled office visit.

How likely are you to participate in clinical trials?

	Overall	Allergies/Asthma				
Trial Type	**Very Likely**	**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%	62%	25%	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%	55%	29%	13%	3%	0%
A trial for a new drug, therapy, treatment or device to find a better alternative to an existing treatment	45%	48%	34%	16%	1%	1%
A trial for a new drug, therapy, treatment or device to address my condition	44%	43%	34%	19%	2%	2%
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%	36%	34%	22%	6%	2%

- Allergy/asthma patients are most apt to join a clinical trial when the purpose of the research is to find a cure.

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

Answer	Percent (Overall)	Percent (Allergies/Asthma)
Their opinions are essential	13%	8%
Quite a bit	27%	21%
A little	32%	33%
Not very much	18%	24%
Not at all	10%	14%

- While some patients with allergies/asthma say the opinions of family and friends are either essential or matter quite a bit, the majority says differently. Overall, the opinions of family and friends are less influential to allergy/asthma patients than to patients with other conditions.

CONCLUSIONS

Considering that improvements in medicines and treatments cannot happen without clinical research, it is startling how few people know much about it, much less have ever really considered participating. This report is meant to shed more light into the reasons behind the low participation by reporting on the motivators of some of the people we would expect to know the most about clinical research — patients with cancer, kidney disease or other conditions. The information they provided about why they joined a clinical trial or about what would motivate them to participate in the future provides valuable insight that can enable deeper engagement with patients and physicians in more significant ways.

This study also reaffirms the influence physicians and other health care practitioners have. The importance of their roles cannot be overstated: Patients want to hear about clinical trials primarily from medical professionals. Furthermore, talking with the doctors or clinical researchers involved in a trial would make these patients feel more like a partner in the research. Unfortunately, more than two-thirds of the patients in this survey said they have not had these discussions with their doctors.

It is clear that reaching physicians and understanding their concerns and reluctance to have these conversations will be a key to improving participation for both patients with medical conditions like the respondents in this survey as well as for the general population.

Some of the report’s noteworthy discoveries:

- 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 influencers 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.
- Patients with different conditions have different priorities when it comes to health benefits, safety concerns, institutional support or financial incentives. For example, having a trial that could extend or improve quality of life was most important to lung cancer and melanoma patients while being able to finish the trial was most important to those with gastrointestinal disease. Other patients placed the most value on safety: that the trial would not interfere with current treatment or make things worse.

In conclusion, the findings in this report are meant to encourage and further the conversations taking place among companies involved in clinical research and between clinical researchers, physicians and patients. A single solution to patient recruitment, participation and engagement isn't realistic. The more we can encourage collaboration among all the stakeholders — especially patients and physicians — the more impact we can make in these areas that are so critical to our work to advance health care.

APPENDIX – COMPARISON TO 2017 CISCRP SURVEY

RESPONDENT PROFILE COMPARISON

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 in ordinal rankings below.

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

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.

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[i] "Public Perception of Clinical Trials," Research America! July 2017, https://www.researchamerica.org/sites/default/files/July2017ClinicalResearchSurveyPressReleaseDeck_0.pdf

[ii] "Public Perception of Clinical Trials," Research America! July 2017, https://www.researchamerica.org/sites/default/files/July2017ClinicalResearchSurveyPressReleaseDeck_0.pdf

[iii] 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

[iv] "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

[v] "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.scorrmarketing.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^{TM}, 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.