



PERCEPTIONS AND INSIGHTS STUDY 2021

GENERAL PERCEPTIONS

INTRODUCTION

Consistent with prior years, clinical research continues to be viewed as important and generally safe by most. However, perceptions of research have changed over the last two years, in part due to the COVID-19 pandemic.

In this report, CISCRP provides a summary of the results of the latest global survey of general public and patient perceptions about clinical research. The findings can help inform the development of targeted outreach and educational strategies.

HIGHLIGHTS



While overall awareness has increased, self-reported understanding of clinical research has decreased compared to 2019 – particularly among diverse communities and those who have never participated in clinical research.



A substantial proportion distrust pharmaceutical companies when compared to trust in other organizations – similar to 2019 findings.



Nearly all respondents recognize the importance of including diverse participants in clinical research studies.



Technology and other convenience-enhancing initiatives continue to positively impact overall experiences – smart phone apps, text messaging, and video conferencing are viewed as most helpful.



KEY COMPARISONS (2019 V. 2021)

While perceptions of safety and the importance of clinical research remain generally stable from 2019 to 2021, self-reported understanding has decreased somewhat.

- Despite higher levels of awareness, a quarter of respondents are not confident in their ability to find a clinical research study that is right for them. This is consistent with responses in past years.

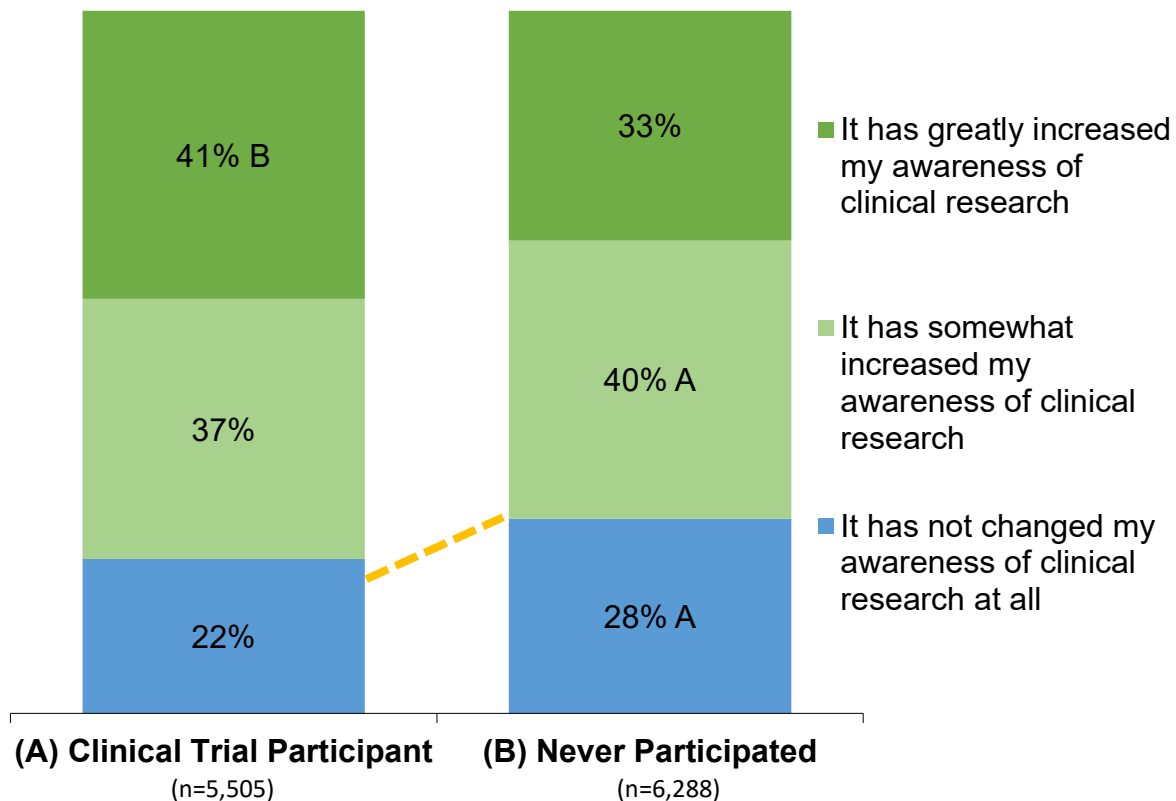
GENERAL PERCEPTIONS, AWARENESS, AND UNDERSTANDING		<div>2019</div> Never Participated (n=8,797)	<div>2021</div> Never Participated (n=6,288)	
How well do you understand what is meant by the term "clinical research study", also known as a "clinical trial"?	Very Well Somewhat Well	40% 50%	31% 54%	Black (35%) and White (31%) respondents were more likely to report they understand clinical research 'Very Well' compared to those identifying as Asian respondents (23%).
In your opinion, how safe are clinical research studies?	Very Safe Somewhat Safe	20% 69%	18% 69%	<u>Top mentions for why clinical research studies are unsafe:</u> There may be side effects (72%); I saw or heard negative news (41%); I don't trust pharmaceutical companies (39%); The safety and quality are not monitored closely enough (37%).
How important do you feel it is for your doctor to be aware of clinical research studies being conducted in your community?	Very Important Somewhat Important	65% 29%	59% 33%	
In general, when discussing treatment or medication options with your doctor, how often do you consider clinical research studies as another option?	Very often Somewhat Often	8% 22%	7% 20%	
During the past six months, do you remember seeing or hearing about a clinical research study that was looking for volunteers?	Yes No	50% 50%	57% 43%	Hispanic subgroups remember seeing more clinical research studies looking for volunteers (80%) compared to Non-Hispanic subgroups (69%).



South American respondents were more likely to report that they understand clinical research 'Very Well', compared to other regions. Additionally, South American and European respondents viewed clinical research studies as the safest.

IMPACT OF THE PANDEMIC

How has the COVID-19 pandemic changed your awareness of clinical research studies, if at all?



Sample Size = 11,793; Base: All respondents
Letters indicate statistical significance at 95%

Most respondents feel the pandemic has made them more aware of clinical research studies – this increased awareness is even greater among communities historically underrepresented in research.

- Hispanic respondents (46%) were more likely to report 'Greatly Increased Awareness' compared to non-Hispanic respondents (33%). Black respondents (43%) were also more likely to report 'Greatly Increased Awareness' compared to White (35%) and Asian (35%) respondents.



South American respondents were most likely to report 'Greatly Increased Awareness' (55%) compared to all other regions.



HEALTHCARE EXPERIENCES

In addition to increasing awareness of clinical research, the pandemic impacted healthcare experiences. More than half of respondents (56%) shared their healthcare had been impacted 'Somewhat' or 'A Lot' by COVID-19.

- Hispanic subgroups were more likely to indicate 'A Lot' (29%) and 'Somewhat' (51%) than non-Hispanic subgroups (15%, 31%).

In what ways has your healthcare been impacted because of the COVID-19 pandemic? (top 3 mentions)



How I prepare for and attend my doctor's appointments has changed (44%)



My doctor has switched to virtual visits (32%)

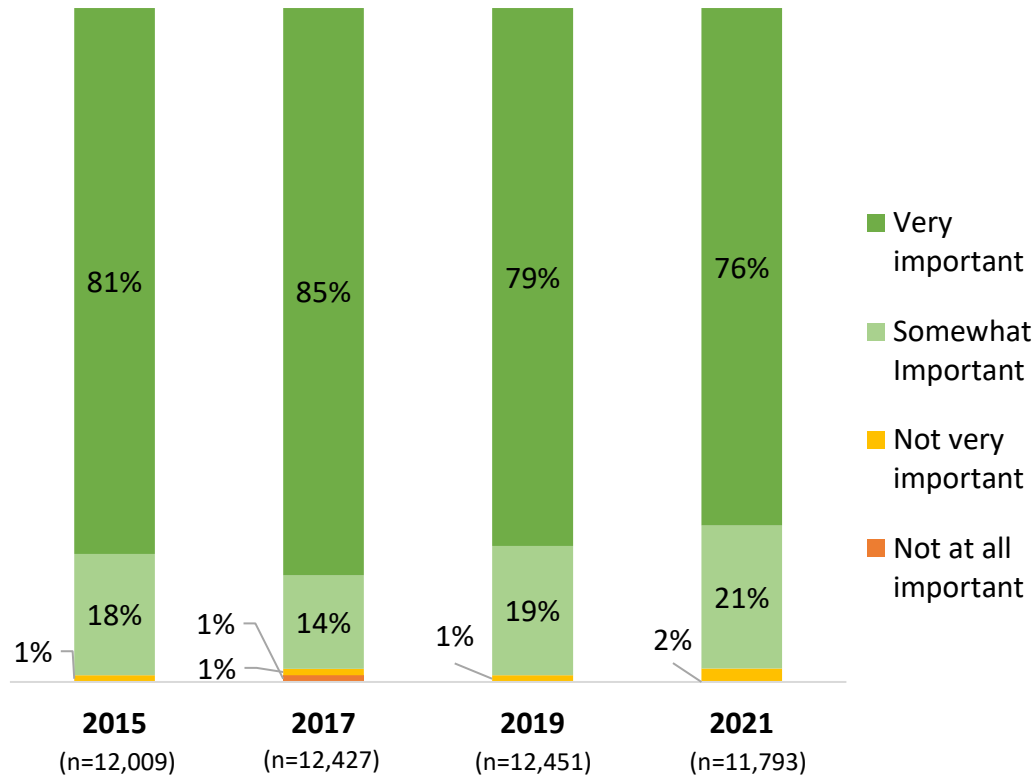
White respondents more likely to report that their doctor has switched to virtual visits (35%) than Black, Asian, and other race subgroups (27%, 26%, and 28%, respectively).



Felt uncomfortable going to doctor's appointments/getting medical care (36%)

IMPORTANCE AND SAFETY

How important do you think clinical research studies are to the discovery and development of new medicines?



Base: All respondents

Since 2015, public opinion has stayed relatively consistent with most believing that clinical research is 'Very Important' to the discovery and development of new medicines.

- White and non-Hispanic respondents were more likely to perceive clinical research as 'Very Important' (81% and 84%, respectively) as compared to other racial and ethnic subgroups.
- Older respondents were more likely to perceive clinical research as 'Very Important' (91% among those 55 to 64 years of age and 93% among those 65 and older) compared to just 57% among 18- to 34-year-old respondents.

Most respondents feel clinical research studies are relatively safe but concerns around potential side effects, health risks, and stopping beneficial treatments are the greatest perceived risks.



Greatest Benefits (Top 3 Mentioned)

- ✓ May help advance science and treatment of my disease/condition (50%)
- ✓ May help save or improve the lives of other patients with my disease/condition (50%)
- ✓ May help improve my disease/condition (35%)



Greatest Risks (Top 3 Mentioned)

- ✓ Possibility of side effects (67%)
- ✓ Possible risk to my overall health (59%)
- ✓ Possibility of stopping treatments that may be providing some benefit to me already (30%)



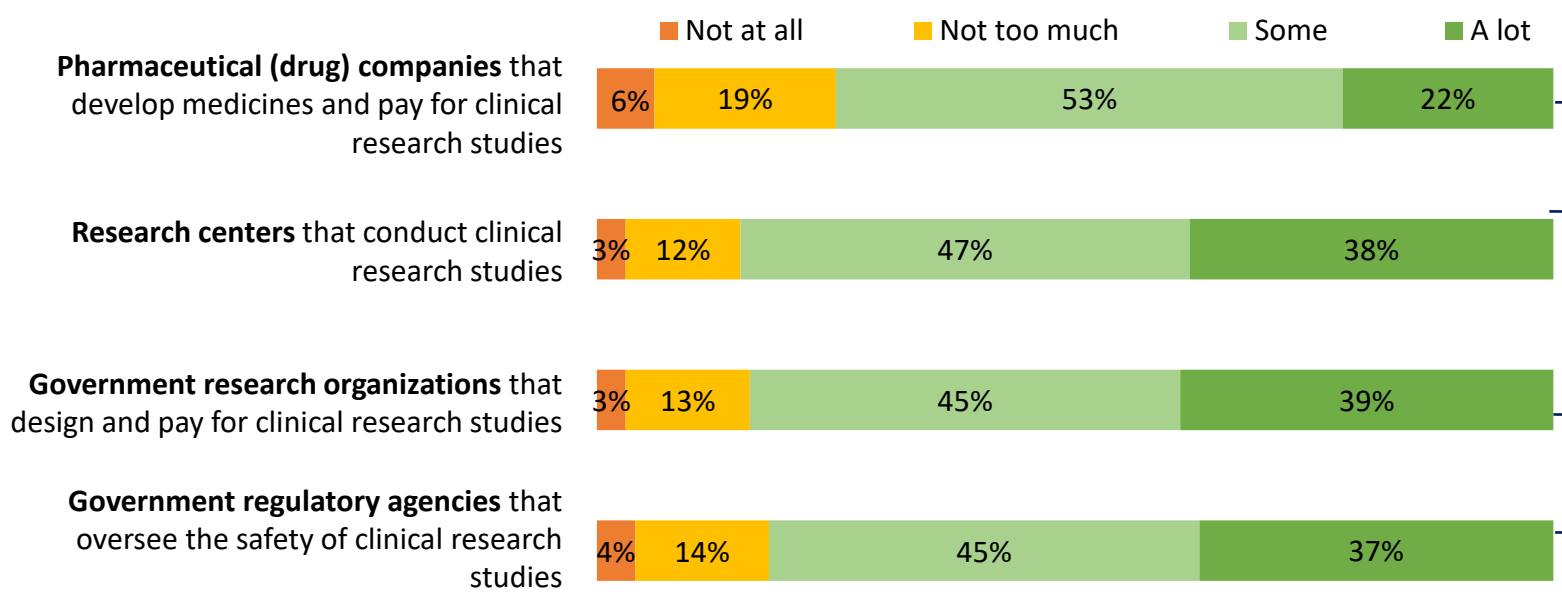
Notably, European respondents (85%) were significantly more likely to report clinical studies are 'Very Important' compared to all other regions.

While the public’s trust in research centers/clinics, government research organizations, and regulatory agencies increased since 2019, trust in pharmaceutical companies remains low.

- Results show that White respondents placed greater trust in government research organizations and research centers than any other race subgroup did.



How much do you trust each of the following organizations, if at all?



Sample Size = 11,793; Base: All respondents

✓ General trustworthiness increased for those reporting ‘A Lot’ from 2019 for research centers/clinics (31%), government research organizations (29%), and regulatory agencies (27%).

- Male respondents were more likely to trust pharma ‘A Lot’ (23%) compared to females (21%).
- White respondents were also more likely to trust research centers ‘A Lot’ (41%) compared to other races.
- Respondents with higher levels of education were generally more trusting of government organizations and authorities.
- Older respondents (55 or older) were more likely to trust government regulatory agencies ‘A Lot’ (39-44%) than younger subgroups (18-54) (33-37%).

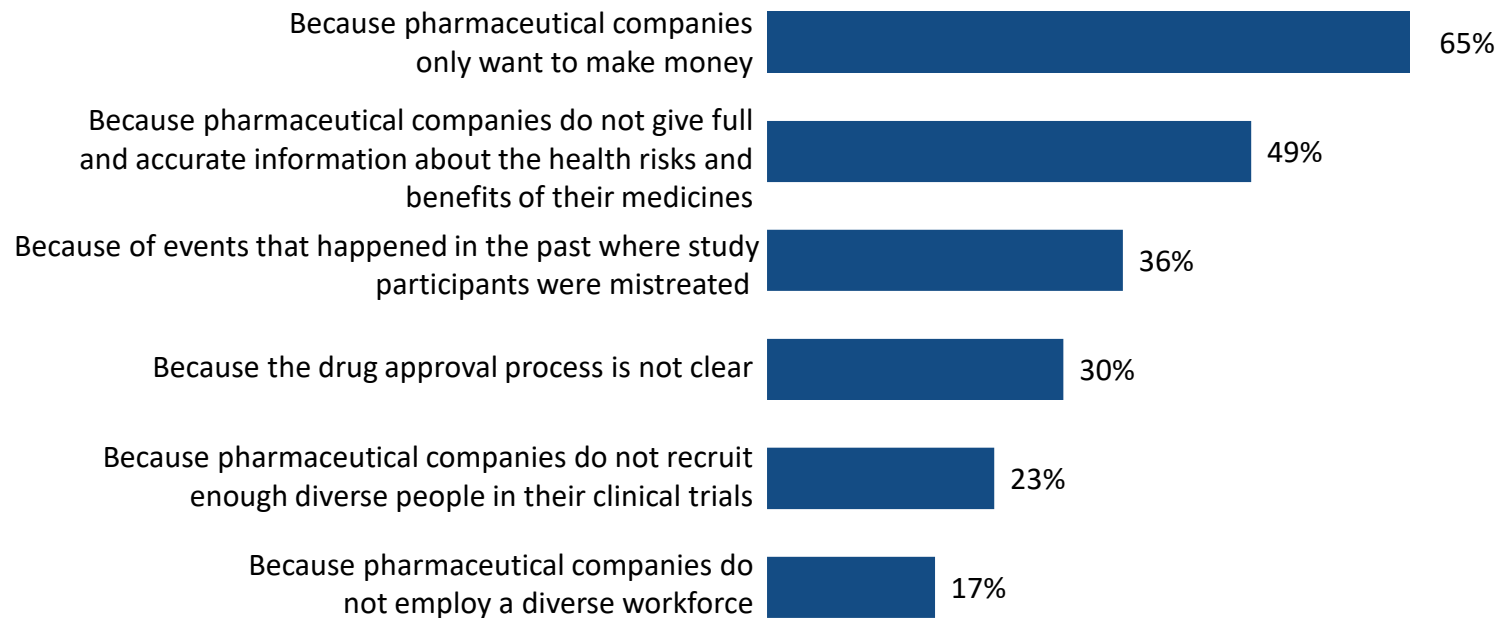
South American respondents (32%) were significantly more likely to cite trusting pharmaceutical companies ‘A Lot’ compared to all other regions (19-22%). African respondents (25%) were less likely to report trusting government research organizations than those in any other region (34-42%).

INCREASING TRUST IN PHARMACEUTICAL COMPANIES

Financial motivations, withholding information about health risks, and past mistreatment of clinical research participants are cited as the top reasons respondents do not trust pharmaceutical companies.

- Black respondents were more concerned than any other race about past events where participants were mistreated (47%).
- White respondents were distrustful due to pharma's focus on money (72%) more than other racial groups (47-51%). Female respondents were also more concerned (71%) than males (63%) about this focus on money.

Why do you not trust pharmaceutical companies?



Sample Size = 2,946

Base: Those that indicated 'not at all' or 'not much' trust in pharmaceutical companies

Trust in pharmaceutical companies can be improved by sharing information, increasing education, and having inclusive practices.



What, if anything, might increase your trust in pharmaceutical companies? (top mentions)

- ✓ By the company sharing more information about health risks/benefits of their medicines (63%)
- ✓ By the company sharing more information about the clinical research that has been done on their medicines (60%)
- ✓ By the company sharing more information about the drug approval process for their medicines (54%)
- ✓ By knowing that the company included a diverse set of participants in their clinical trials (49%)



North American and European respondents were more distrustful due to pharma's focus on money compared to respondents from Asia-Pacific and Africa. Trust among European respondents would be increased more than most other regions by sharing more information about past clinical research (62%) and drug approval processes (57%).



PERCEPTIONS AND INSIGHTS STUDY 2021

ENGAGEMENT PREFERENCES

INTRODUCTION

Supportive services and flexible study visit options continue to play a critical role in improving access to clinical research studies particularly among underrepresented communities.

In this report, CISC RP highlights engagement preferences for participation in clinical research studies. These findings identify important elements of participation, as well as provide a comprehensive view of receptivity to various decentralized clinical research models. The findings can help inform the design and optimize the implementation of these clinical research studies.

HIGHLIGHTS

💡 Options continue to be key as engagement preferences vary widely - no single clinical research model more appealing than another among respondents.

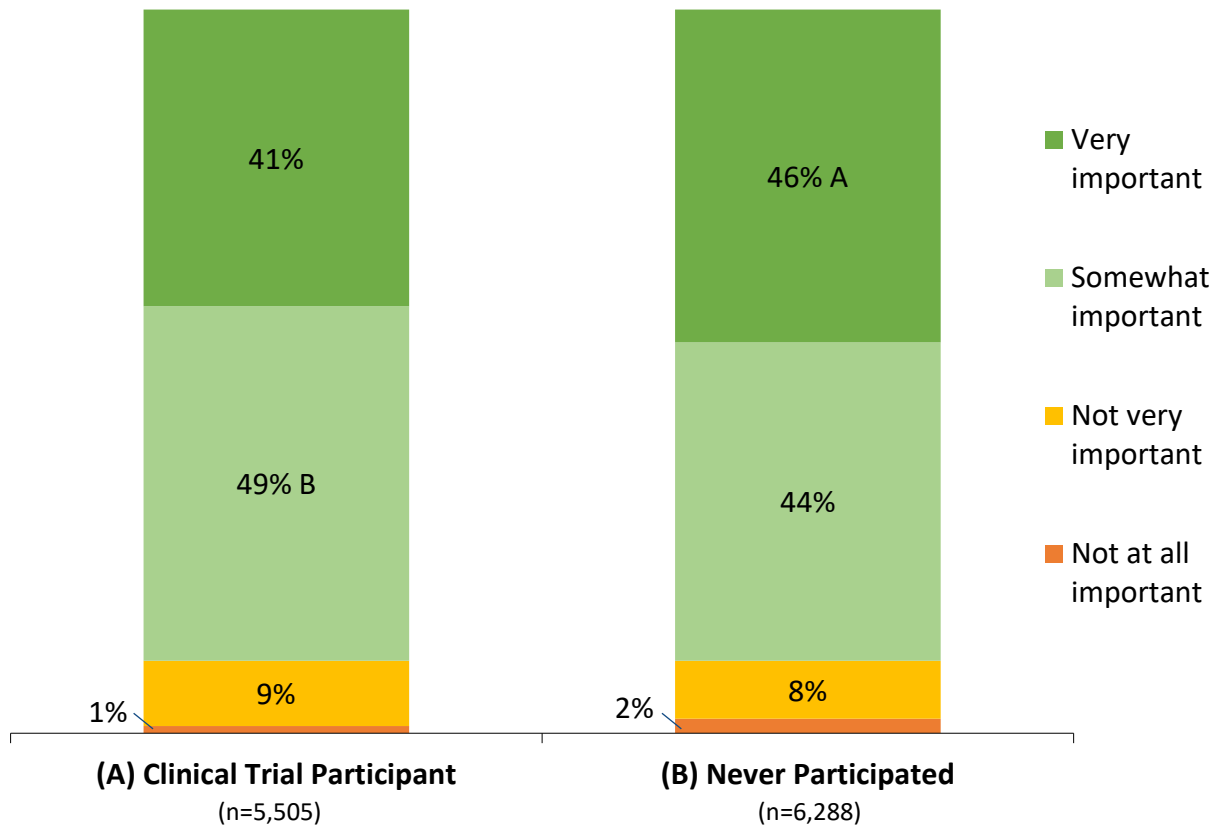
💡 As seen in 2019 findings, access to educational information about condition and study is most important.

💡 Consistent with previous findings, there is continued high interest in receiving a summary of study results, as well as individual results - with e-mail and regular mail as the most preferred methods of delivery.



PROVIDING OPTIONS FOR STUDY VISITS

When thinking about the different ways you could participate in a clinical research study (i.e., study visits at the clinic, virtual visits from home, etc.), how important is it to you to be presented with options for where to have your study visits?



Letters indicate statistical significance at 95%

Sample Size = 11,793; Base: All respondents

The majority of respondents stress the importance of being provided options for completing study visits, such as virtual and home visits.

- Hispanic respondents (41%) were less likely to report being presented options as 'Very Important' compared to non-Hispanic respondents (45%).
- No significant differences were found among White (45%), Black (46%), or Asian (42%) respondents when indicating 'Very Important'.

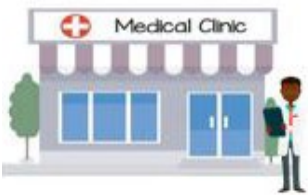
Female respondents were more likely to cite being provided options as 'Very Important' (48%) compared to male respondents (42%).

As a general trend, younger respondents were less likely to report that being provided options was 'Very Important' (18-34, 37%), compared to older respondents (55-64, 51%; 65+, 47%).



North (45%) and South (59%) American respondents were more likely to report 'Very Important' than all other regions.

How willing would you be to participate in each of the following types of clinical research studies?



Having **all** study visits at the study clinic and seeing the study doctor and staff in-person at the clinic **only**



Having **some** study visits at home and **some** visits at the study clinic, and seeing the study doctor sometimes via video conference from home or in-person at the clinic



Having a nurse come to your home for **all** of your study visits and speaking to the study doctors via video conference from home



Collecting **all** of your health data on your own at home using technology and only talking to the study team via video conference from home



Consistent with findings from 2019, individual preferences for engaging in clinical research vary. Importantly, there is a general strong willingness to participate in a range of models.

- Non-Hispanic respondents were significantly more likely to report ‘Very Willing’ for all types of clinical research study models compared to Hispanic respondents.

As a general trend, those with higher self-reported levels of education were more likely to cite ‘Very Willing’ for having some study visits at home and some at the study clinic.

Black respondents were more likely to report ‘Very Willing’ to collect all data at home (38%) compared to Asian respondents (30%), and All Other Races (29%).



- ✓ A slight increase was displayed in those ‘Very Willing’ to have a nurse come to the home for all visits (36%) compared to 2019 (30%).

RESEARCH STUDY FEATURES

When deciding to participate, those who have never participated in a clinical research study value being provided information on both their general health and the clinical research study, as well as the opportunity to complete a satisfaction survey.

- Hispanic and Black subgroups were more likely to cite the following as ‘Very Important’ compared to non-Hispanic and White subgroups: mobile app availability, information specific to caregivers, having documents in electronic format, and some or all study visits conducted at home/office.

If you were to participate in a clinical research study, how important are the following to your participation? <small>% indicating ‘Very Important’</small>	Never Participated <small>(n=6,288)</small>
Being provided with supporting information on managing my health condition in general	52%
Being provided with supporting information on the clinical research study	50%
Being provided the opportunity to complete a satisfaction survey on your clinical research study experience to provide feedback	44%
Supportive services	41%
Availability of mobile applications	33%
Availability of clinical research study information designed specifically for caregivers	36%
Being able to review and sign study documents in an electronic format	31%
Clinical study medicine delivered to my home	33%
Some or all study visits conducted at my home or my office	23%

Females were more likely to report 'Very Important' for being provided supporting information on managing the health condition (57%) and on the clinical research study (57%), compared to males (47%, 42%).

Those with a household income of less than \$25,000 were more likely to rank supportive services as ‘Very Important’ (58%) than any other income group.



✓ Information on managing the health condition, supporting information on the study, and the opportunity to complete a satisfaction survey were consistent from 2019 top mentions.

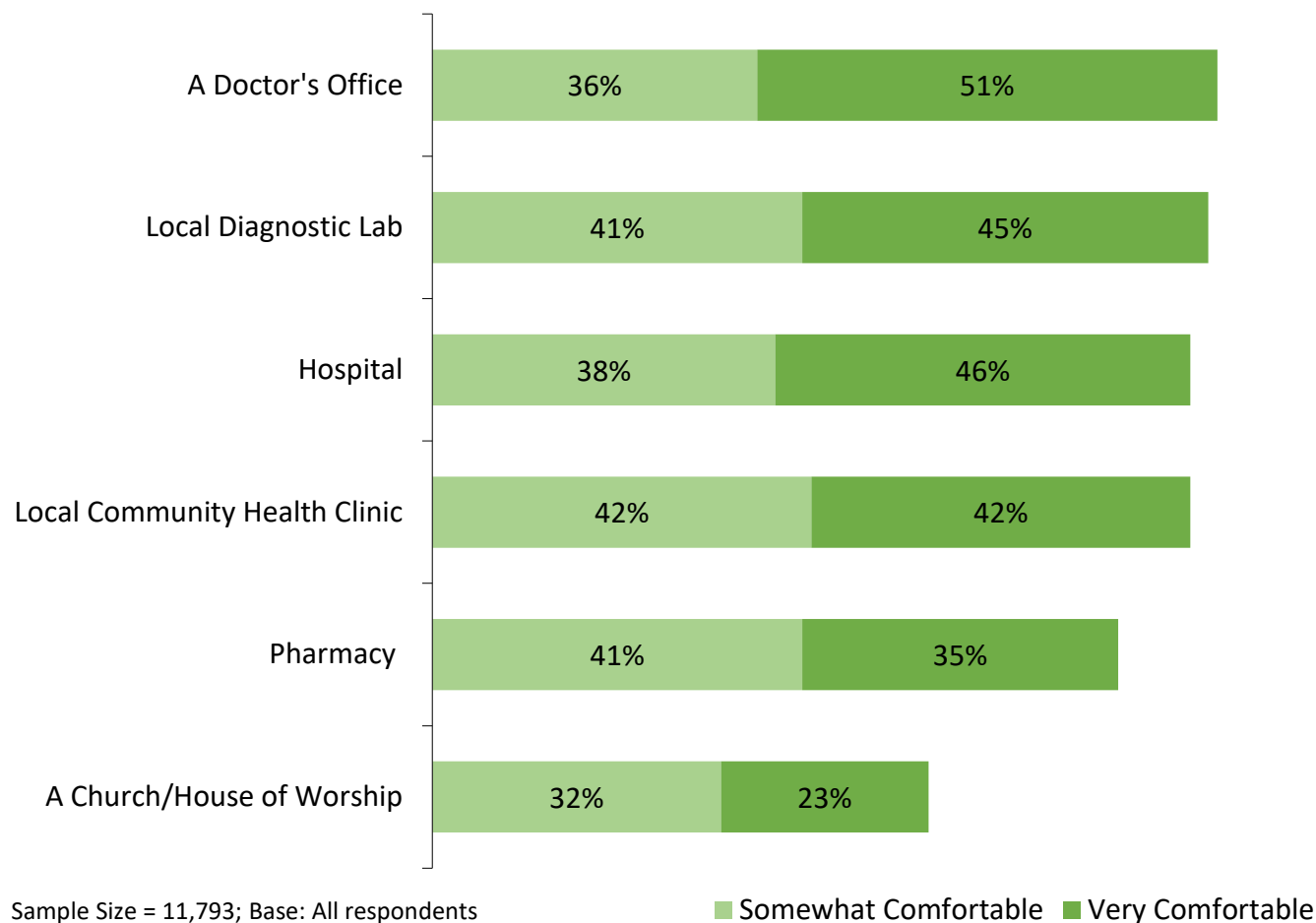
n= 11,793; Base: All respondents



As a general trend, those from South America were significantly more likely to report ‘Very Important’ for all features compared to all other regions.

WILLINGNESS TO TRAVEL FOR IN-PERSON VISITS

If you were to participate in a clinical research study, how comfortable (if at all) would you feel going to each of these locations for your study visits?



The majority of respondents are generally comfortable traveling at this time for in-person visits, with preference for doctor's offices and local diagnostic labs. Notably, individuals from diverse communities are less willing to attend in-person clinic visits regardless of location type.

- Hispanic respondents were significantly less likely to cite 'Very Comfortable' for all study visit locations compared to non-Hispanic respondents.
- Comparatively, White respondents were significantly more likely to report 'Very Comfortable' for all locations.

Black respondents were more likely to report 'Very Comfortable' at a doctor's office and hospital (41%, 42%) compared to Asian respondents (34%, 34%) and those indicating All Other Races (32%, 32%).

Respondents with a self-reported medical condition were significantly more likely to report being 'Very Willing' to travel for in-person visits (48%), compared to those without a self-reported medical condition (34%).



Europeans were more likely to cite 'Very Comfortable' at local community health clinics (57%) and a doctor's office (57%) compared to all other regions.

RETENTION FACTORS

Please rank the following starting with the items that would be most likely to keep you enrolled in a clinical research study until the end (i.e., not drop out) and ending with the item that would be least likely to keep you enrolled.	Overall Rank	Total Score*
Feeling/seeing benefit from the study drug	1	79,516
Being informed of the clinical research progress on a regular basis	2	75,617
Having study visits with flexible times	3	73,924
Reimbursing any out-of-pocket expenses	4	69,077
The ability to have my study visits at home (i.e., remote study visits) rather than traveling to a study clinic	5	68,782
Knowing I would receive a larger amount of compensation (money) at the end of the study	6	64,221
Receiving small amounts of compensation (money) after every study visit	7	62,449
Having my study visits not last longer than one hour	8	62,229
Having transportation provided to me to/from the study clinic	9	60,271
Having childcare available	10	32,652

*Total score calculated through assigning a weighted value to each rank.
Total score is sum of weighted values across all respondents.

Sample Size = 11,793; Base: All respondents

Top retention drivers include feeling/seeing benefit from the study drug, being informed of study progress, and having flexible visit times.

- No statistical differences were found by age, gender, race, or ethnicity for the top four retention factors.

Hispanic respondents were significantly more likely to rank having study visits at home higher (4.93) than non-Hispanic respondents (5.26).

Compared to males, female respondents were slightly more likely to rank receiving a larger amount of compensation at the end of the study lower (5.63 for females and 5.49 for males).

On average, Black (5.57) and Asian (5.48) respondents ranked transportation to the clinic higher than White respondents (6.03).



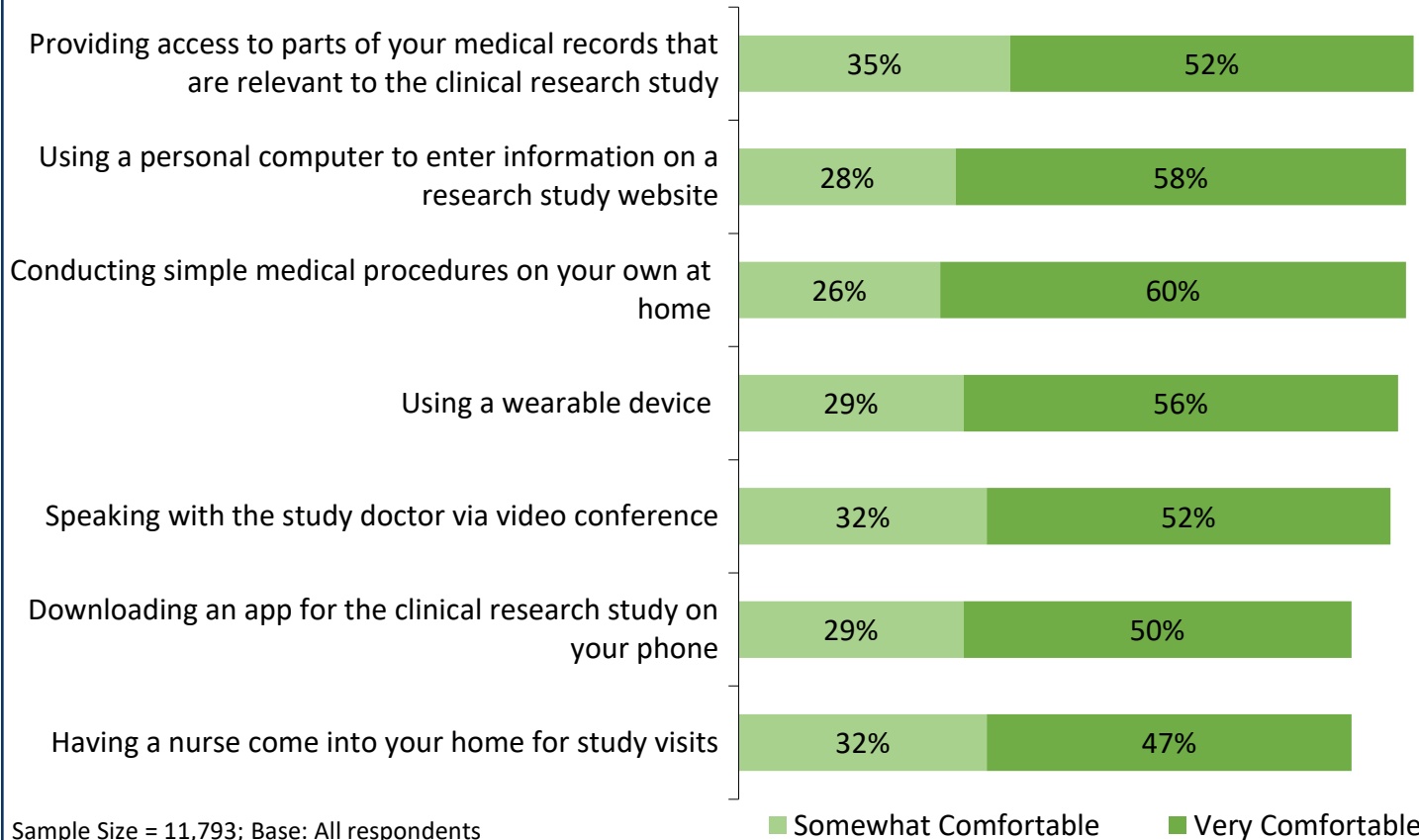
Individuals from South America ranked receiving compensation at the end of the study (6.29) significantly lower than all other regions.

AT-HOME AND TECHNOLOGY PREFERENCES

The majority of respondents report being comfortable providing access to their medical records and completing elements of the clinical research study at home, such as using a personal computer to enter information and conducting simple medical procedures.

- Notably, results showed that White and non-Hispanic respondents were more comfortable providing access to parts of their medical records (55%, 55%) than Black (46%) and Asian respondents (39%), as well as Hispanic respondents (44%).

If you were to participate in a clinical research study, how comfortable would you be with each of the following:



For those not comfortable with using technology, privacy concerns are raised, highlighting the need for additional safety reassurances.

- Black respondents were more likely to be concerned about their privacy and confidentiality (64%) than White (53%) and Asian (49%) respondents.



Reasons not comfortable:
(top mentions)

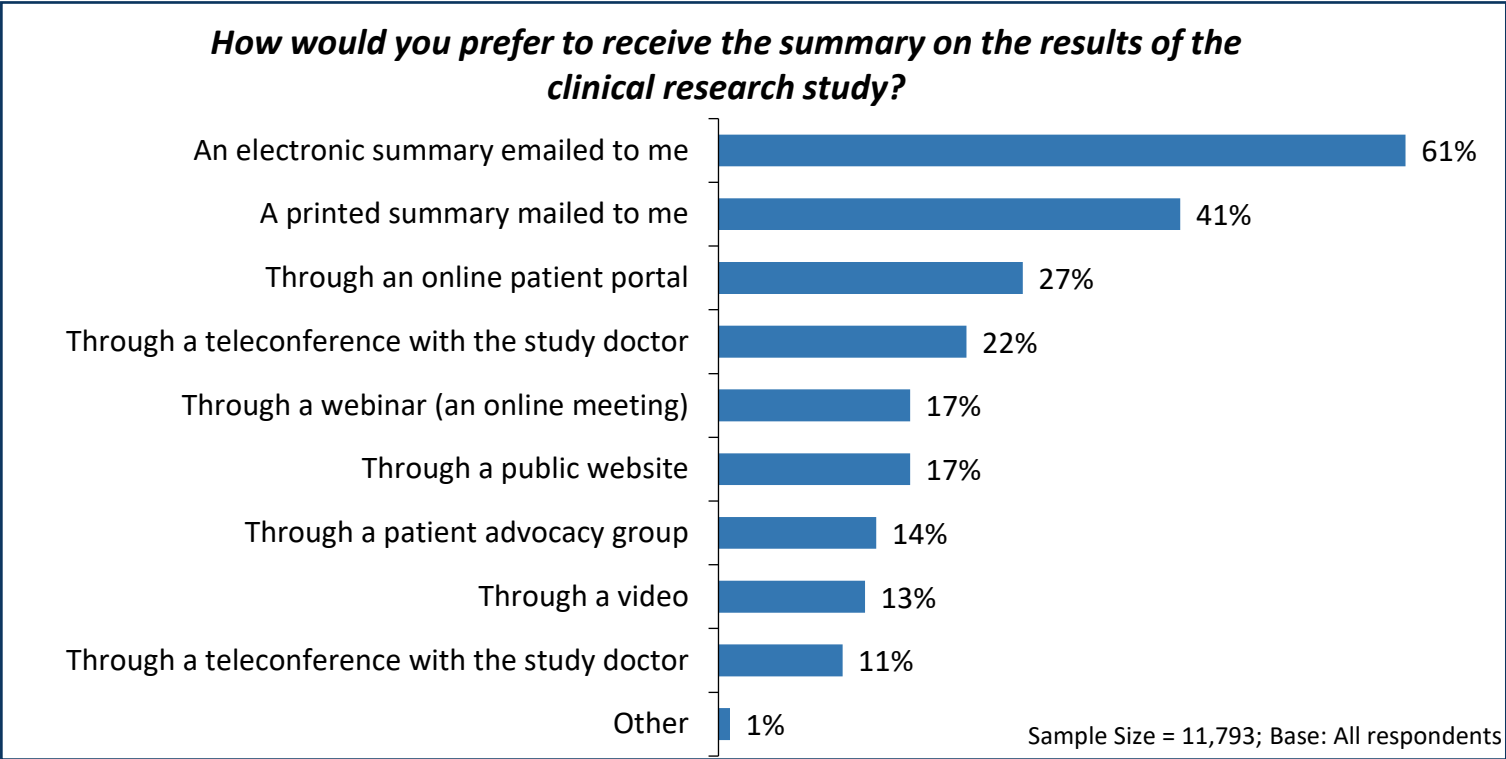
- ✓ I am concerned my privacy/confidentiality would not be protected (53%)
- ✓ I do not feel comfortable using this/these type(s) of technology (43%)
- ✓ I am concerned the use of technology may cost me money (e.g., data/internet usage) (32%)

Sample Size = 3,256
Base: Those indicating 'Not very' or 'Not at all' comfortable with video conference, app, or wearable device

STUDY RESULTS PREFERENCES






Overall preference is to receive a summary of the results via email followed by regular mail. Individuals are most interested in receiving their individual study results and overall study results after completing their participation in a clinical research study.

- As a general trend, older and middle-aged populations preferred printed and electronic summaries, whereas younger populations preferred a webinar, video, teleconference, or public website to share summary results.



What information would you be most interested in receiving after completing your participation in a clinical research study?

Top Mentions:

-  My individual study results (i.e., procedures and test results) (67%)
-  A summary of the study results (65%)
-  Whether I received the study drug or placebo (sugar pill/inactive substance) (58%)
-  Drug approval status by the regulatory agency in your country (45%)
-  The brand name for the study drug (43%)

2019

✓ 91% report it was 'Somewhat/Very Important' to receive a summary on the results in 2021, compared to 85% in 2019.



Respondents from Europe showed greater preference for an electronic summary (67%) than those from North America (60%), Asia-Pacific (55%), or Africa (46%).

2019

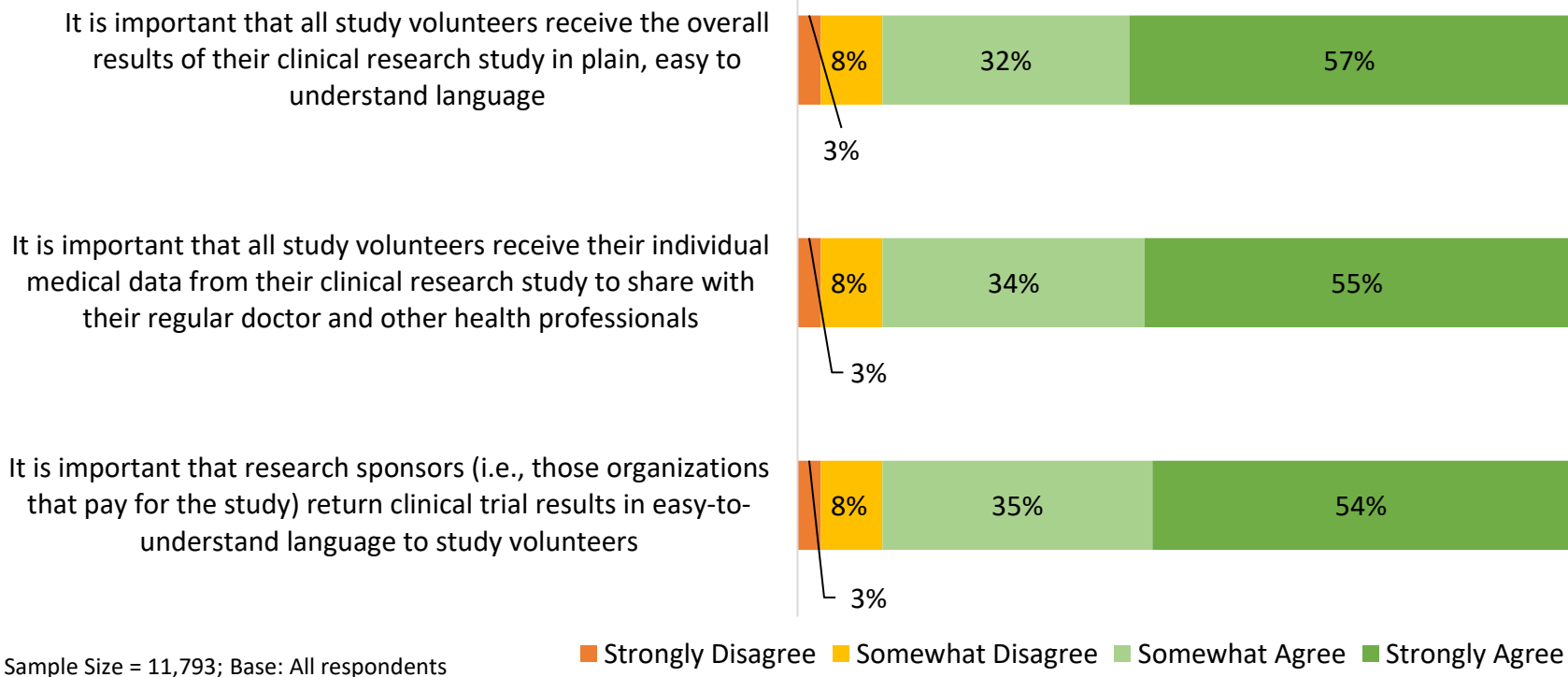
✓ Consistent with 2019 findings, top mentions were: a summary (68%), individual results (64%), and study drug vs. placebo (52%).

TRANSPARENCY AND PLAIN LANGUAGE

Overall, there is a strong desire for transparency and the use of plain language when sharing the results of the clinical research study with study participants.

- As a general trend, non-Hispanic respondents were more likely to report 'Strongly Agree' compared to Hispanic respondents for all indicators.
- White respondents were also more likely to report 'Strongly Agree' compared to Black and Asian respondents for all indicators.

Please indicate your level of agreement with each of the following statements.



Male respondents were less likely to 'Strongly Agree' (52%) that it is important to receive overall results in plain, easy-to-understand language compared to females (65%).

Respondents with a self-reported medical condition were more likely to 'Strongly Agree' that it is important to share medical data with their health care providers (71%) than those without a self-reported medical condition (40%).

As a general trend, older respondents were more likely to cite 'Strongly Agree' for returning results in easy-to-understand language: 18-34 years (33%), 35-44 years (46%), 45-54 years (61%), 55-64 years (69%), 65+ years (72%).



Respondents from South America (67%) were more likely to report they 'Strongly Agree' with research sponsors returning results in easy-to-understand language compared to those from North America (55%), Europe (55%), Asia-Pacific (35%), and Africa (35%).



PERCEPTIONS AND INSIGHTS STUDY 2021

DECIDING TO PARTICIPATE


INTRODUCTION


While the COVID-19 pandemic appeared to increase willingness to participate among prior study participants, general willingness to participate among the general public has slightly decreased since 2019.

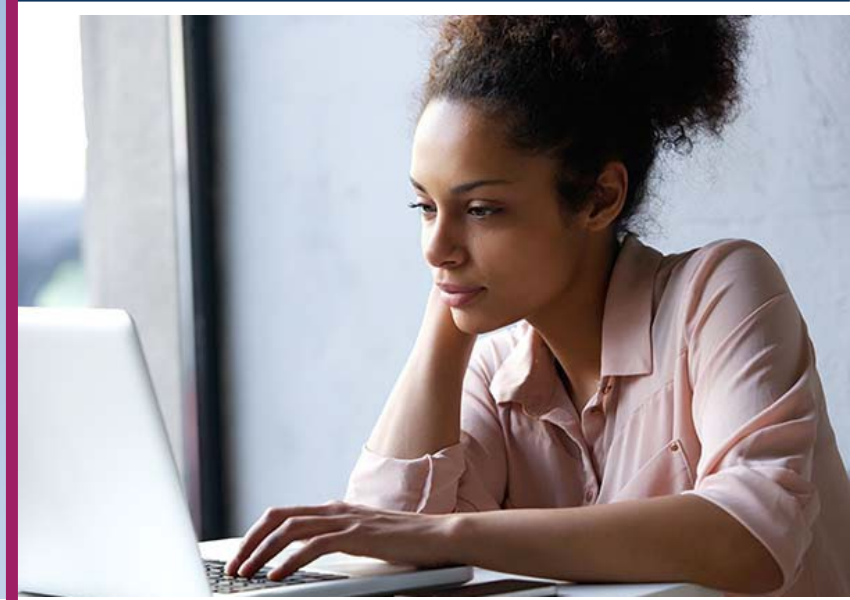
In this report, CISCRP explores the decision-making process for those considering clinical research participation – specifically, sources of information about participation opportunities, drivers vs. barriers to enrollment, information needed, and other factors considered from the patient perspective. Learnings from this report can help guide communication and recruitment strategies.

HIGHLIGHTS

 A greater proportion of respondents reported being asked to join a study compared to the 2019 survey – email, telephone, and social media were cited as primary means of recruitment.

 Information about risks and benefits, study purpose, types of medical procedures required, confidentiality protection, as well as various logistical aspects continue to be critical to informed decision making.

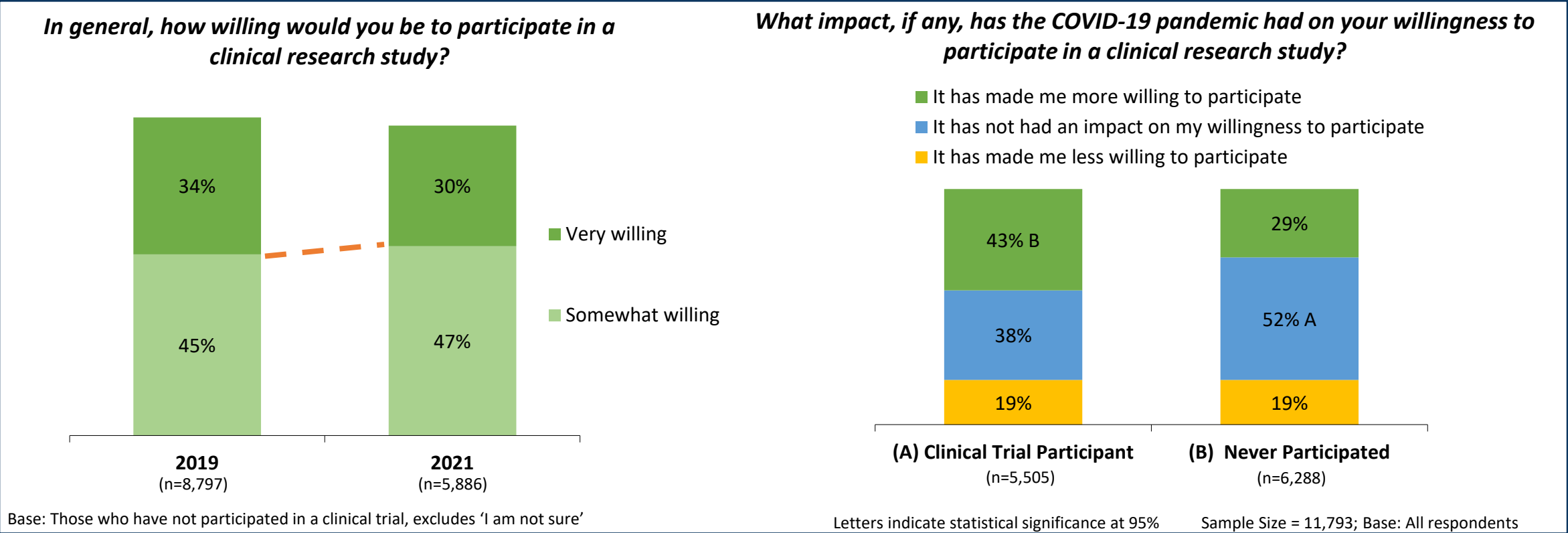
 Notably, knowing the study staff and clinical trial participants were diverse was cited as critically important to deciding whether to participate among Black and/or Hispanic respondents.




WILLINGNESS TO PARTICIPATE

Since 2019, general willingness to participate in clinical research has decreased slightly, with a notable impact on willingness to participate as a result of the COVID-19 pandemic.

- Those who have participated in clinical research were more likely to report that the COVID-19 pandemic has made them more willing to take part in a clinical research study, whereas those who have not participated were more likely to report that the pandemic has not affected their willingness to participate.



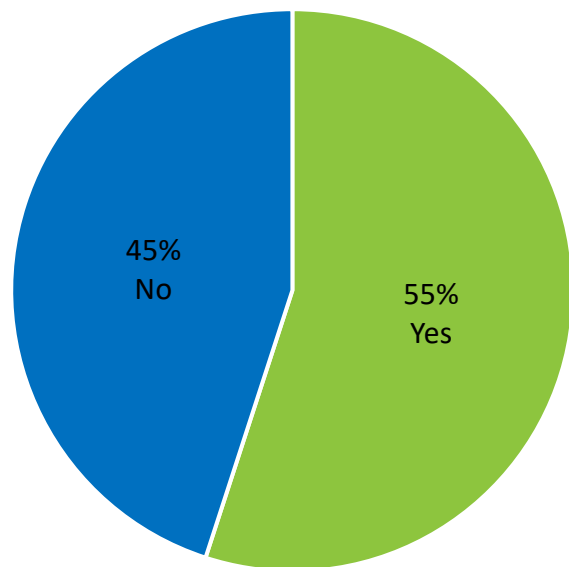
Non-Hispanic respondents were more likely to be 'Very Willing' to participate in a clinical research study (44%) than Hispanic respondents (35%).



Those from South America were more likely to report that the pandemic 'Greatly Increased' their willingness to participate than any other region, with respondents from Africa and Asia-Pacific more likely to report the pandemic decreasing their willingness to participate than other regions.

Have you ever been asked to participate in a clinical research study?

% Responding



Sample Size = 11,793; Base: All respondents

Over half of respondents reported that they had been asked to participate in a clinical research study in 2021 (55%), an increase from 2019 when less than half (45%) of respondents had been asked to participate.

- In 2021, Hispanic respondents were more likely to have been asked to participate in a clinical research study (65%) than non-Hispanic respondents (52%), and Black respondents were more likely to be asked to participate (65%) than White respondents (52%).

The most common ways study volunteers were asked to participate were through direct contact or targeted social media, with social media rising as a leading method compared to 2019.

Top Mentions:



Through an email I received from a research study center or patient recruitment company (30%)



Through a telephone call from a research study center or patient recruitment company (17%)



Through social media (e.g., Facebook, Twitter, Instagram) (16%)



Through my doctor (14%)



Those from North and South America were less likely to report being asked to participate in a clinical research study (52% and 41%) than those from Europe (62%), Asia-Pacific (62%), and Africa (63%).

INFORMATION NEEDED

Prior to deciding to participate in a clinical research study, the majority of respondents indicated it was most important to know about the potential risks and benefits of the study, the purpose, and information about the study drug.

- For “high importance” information, non-Hispanic subgroups were more likely to select ‘Very Important’ than Hispanic subgroups.

HIGH IMPORTANCE

Before making a decision to participate in a clinical research study, how important is it to you to know each of the following types of information? % indicating ‘Very Important’	Never Participated (n=6,288)
Potential risks and benefits	77%
Purpose of the clinical research study	71%
Information about the study drug being researched	68%
Types of medical procedures required	67%
How my confidentiality would be protected	62%
Results and information from earlier phase studies on the study drug	56%
If I would receive a summary of the study results after my participation ended	55%
Potential costs and reimbursements	54%
Length of participation in the clinical research study	51%
Physical location of the research study center	50%

White respondents were more likely to report that it was ‘Very Important’ to know each of the top four types of “high importance” information than any other racial group.

As a general trend, older respondents were more likely to report that knowing the purpose of the study was ‘Very Important’ (45-54 76%; 55-64, 82%; 65+, 83%) compared to younger respondents (18-34, 51%; 35-44, 65%).

Black (66%) and White (62%) respondents were more likely to report that knowing their confidentiality would be protected was ‘Very Important’, compared to Asian respondents (55%).

n= 11,793; Base: All respondents



Respondents without clinical research experience from Europe, Asia-Pacific, and Africa were less likely to think knowing results and information from earlier phase studies on the study drug was ‘Very Important’ (48%, 44%, 46%) than those from North (59%) and South America (62%).

INFORMATION NEEDED (continued)

LOWER IMPORTANCE

Before making a decision to participate in a clinical research study, how important is it to you to know each of the following types of information? % indicating 'Very important'	Never Participated (n=6,288)
Information about the company sponsoring the study	48%
If I would have access to the study drug after my participation ended	46%
Hearing about the experiences of previous research participants	45%
Duration of each study visit	44%
Number of study visits	43%
Flexible visit scheduling	42%
Knowing a group of patients and caregivers with your condition had provided feedback on the study design before beginning to enroll study volunteers	41%
If time off from work is compensated	40%
Knowing that other clinical trial participants are representative of diverse communities	35%
Knowing that the staff conducting the study are representative of diverse communities	28%

Having information about the company sponsoring the study drug, having access to the study drug after participation, and hearing the experiences of previous research participants are viewed as 'Very Important' to know prior to joining a study.

- However, Black respondents were more likely to cite knowing participants and staff represent diverse communities, knowing feedback has been provided on the trial from patients, and hearing previous participants' experiences as 'Very important'.

Middle-aged respondents (45-64) were more likely to think that flexible visit scheduling and number of study visits were 'Very Important' than any other age subgroup.

n= 11,793; Base: All respondents

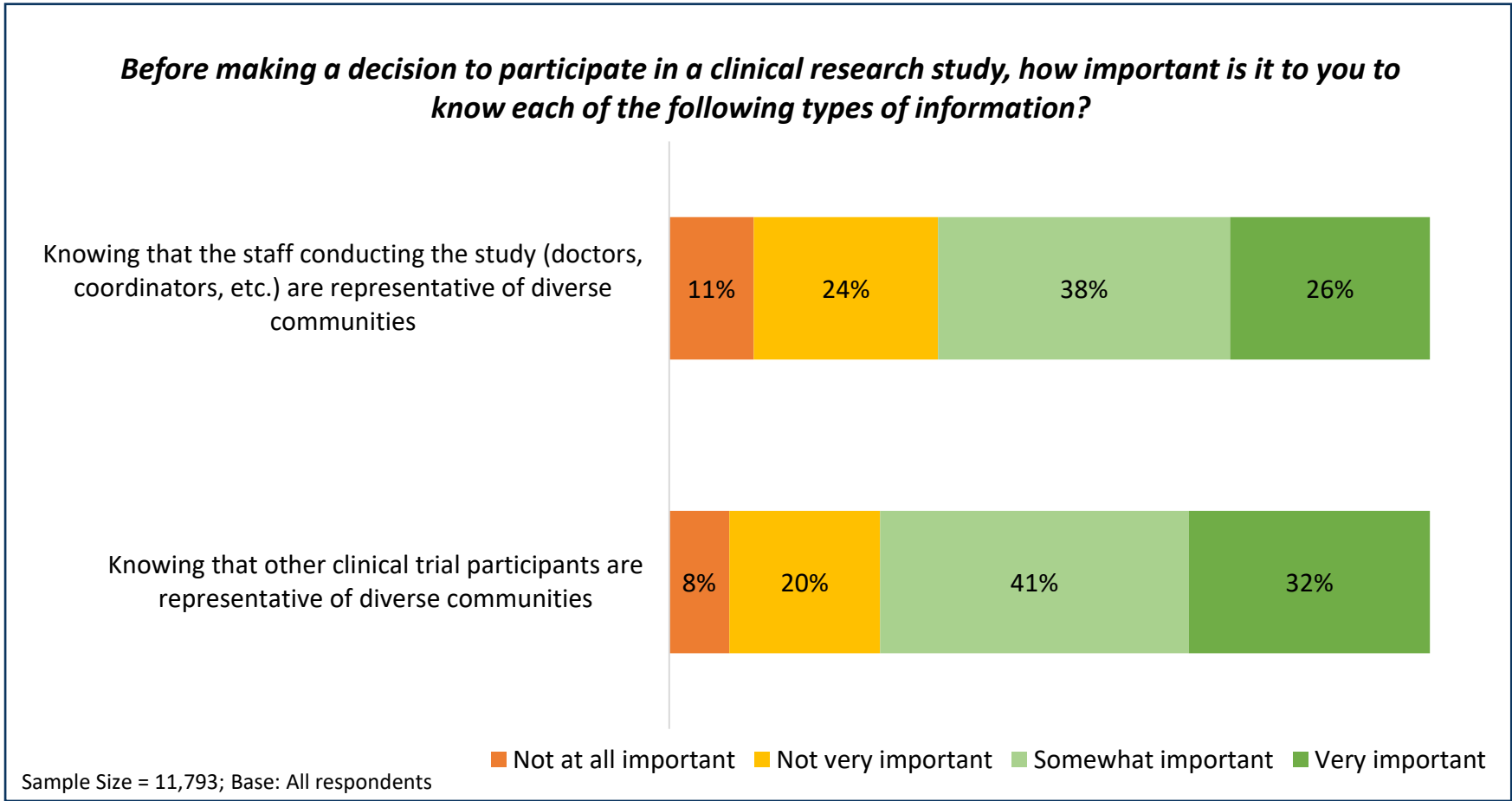


Those from North and South America without clinical research experience were more likely to think that knowing information about the company sponsoring the study was 'Very Important' (52% and 57%) than those from Europe (37%), Asia-Pacific (36%), and Africa (39%).

IMPORTANCE OF DIVERSITY

Overall, most respondents indicated that knowing the study staff and study participants are representative of diverse communities was important, highlighting the importance of diversity and inclusion within clinical research.

- Black respondents were more likely to report that having both diverse staff and diverse participants was ‘Very Important’ (39%, 44%) than White (25%, 31%) and Asian respondents (27%, 31%).
- Hispanic subgroups were more likely to report that having diverse staff and participants was ‘Very Important’ (29%) than non-Hispanic subgroups (25%).



Female respondents were more likely to report that having study staff (28%) and participants (36%) representative of diverse communities was ‘Very Important’, compared to male respondents (25%, 29%).

Older respondents (45 and older) were more likely to report that knowing study staff (14-17%) and participants (8-10%) represented diverse communities was ‘Not At All Important’ than younger respondents (18-44) (5-7%, 5-6%).



Those from North America were more likely to think that knowing participants are representative of diverse communities was ‘Very Important’ (35%) than those from Europe (23%), Asia-Pacific (26%), and Africa (27%).



PERCEPTIONS AND INSIGHTS STUDY 2021

PARTICIPATION EXPERIENCE

INTRODUCTION

The 2021 Perceptions & Insights Study collected information on the experiences of over 5,500 clinical research participants - more than any prior study - shedding light on the most burdensome aspects of participation and ways to best overcome these challenges.

In this report, CISCRP provides a summary of participation experiences at critical time points - before, during and after - as well as the impact of the COVID-19 pandemic on participation. Learnings can help guide best practices for future clinical research studies.

HIGHLIGHTS

💡 Compared to 2019, the proportion who learned about clinical study from their doctor declined while social media rose.

💡 During participation, more reported disruption to daily routines compared to previous years, citing length of visits, travel, and diagnostic tests as top burdens.

💡 Increased use of technology and other convenience-enhancing initiatives - smart phone apps, text messaging, and video conferencing with study doctors were cited as most helpful.

💡 Overall, more frequent communication was reported, both during and after participation.

💡 Among those enrolled during the pandemic, top reported changes were virtual visits and the use of telemedicine – with a strong desire to continue both post-pandemic.

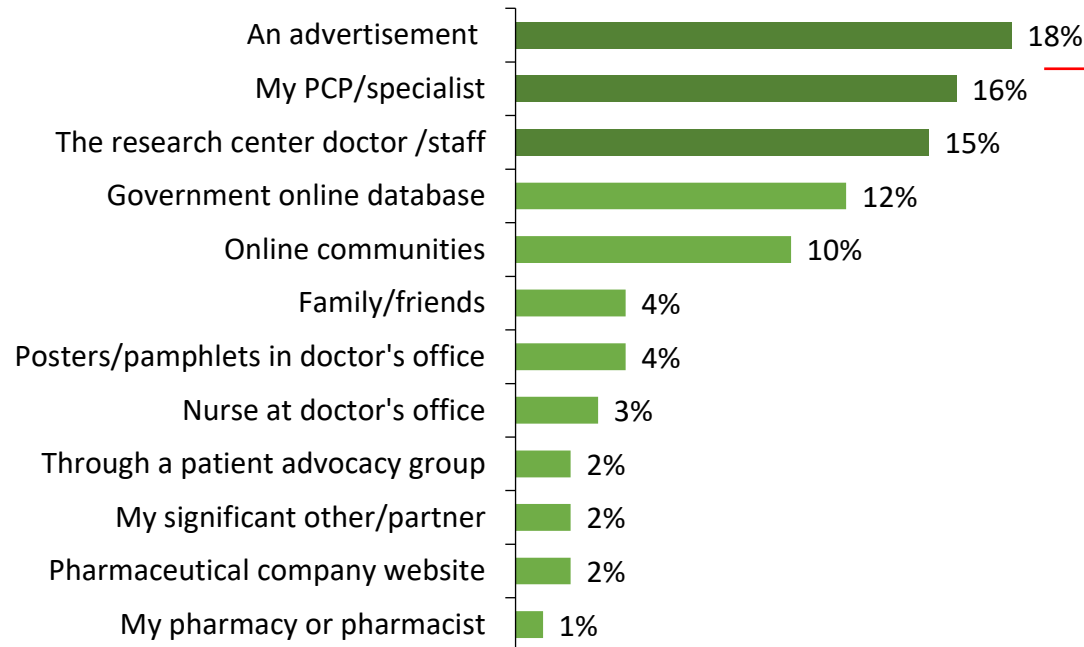


LEARNING ABOUT CLINICAL RESEARCH STUDIES

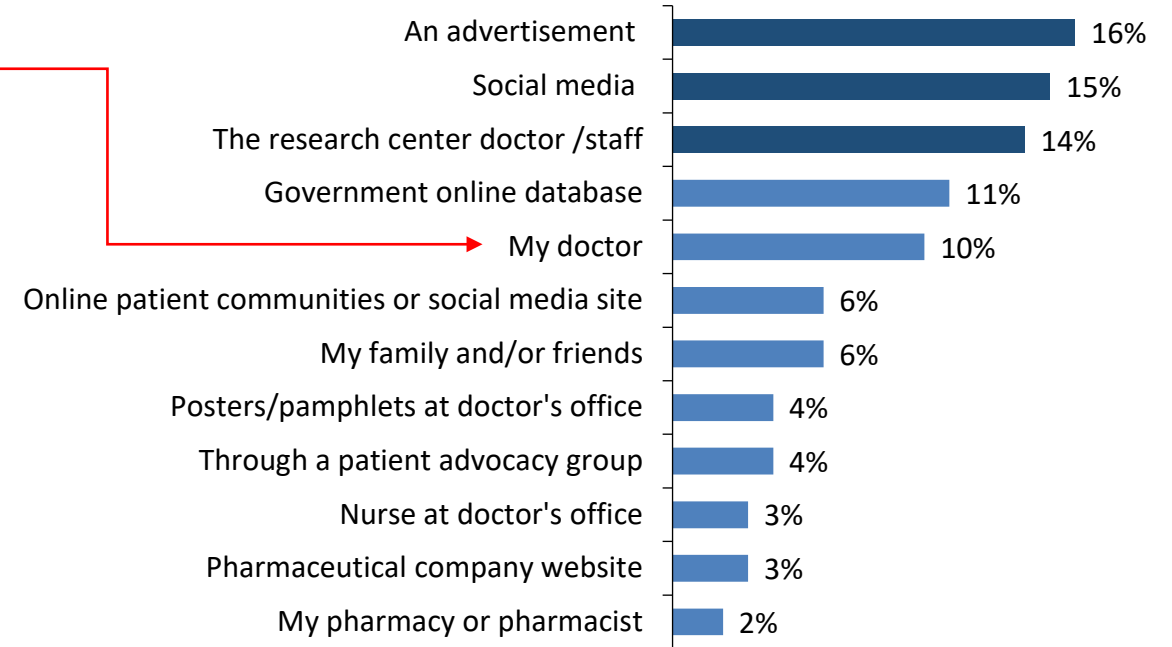
Advertisements (e.g., on the TV, radio, newspaper, public transportation) remain the primary source where clinical research participants learned of the study opportunity, followed closely by social media and the research center staff.

- Notably, a rise in engagement via social media (15%) is present, whereas a decline was displayed in learning from their doctor (16% in 2019 to 10% in 2021).

Where did you learn about the clinical research study?



Sample Size = 3,654; Base: Those who have participated in clinical research, 2019



Sample Size = 5,505; Base: Those who have participated in clinical research, 2021



South American respondents were more likely to hear about a clinical research study through social media (24%) than respondents in Europe (12%).

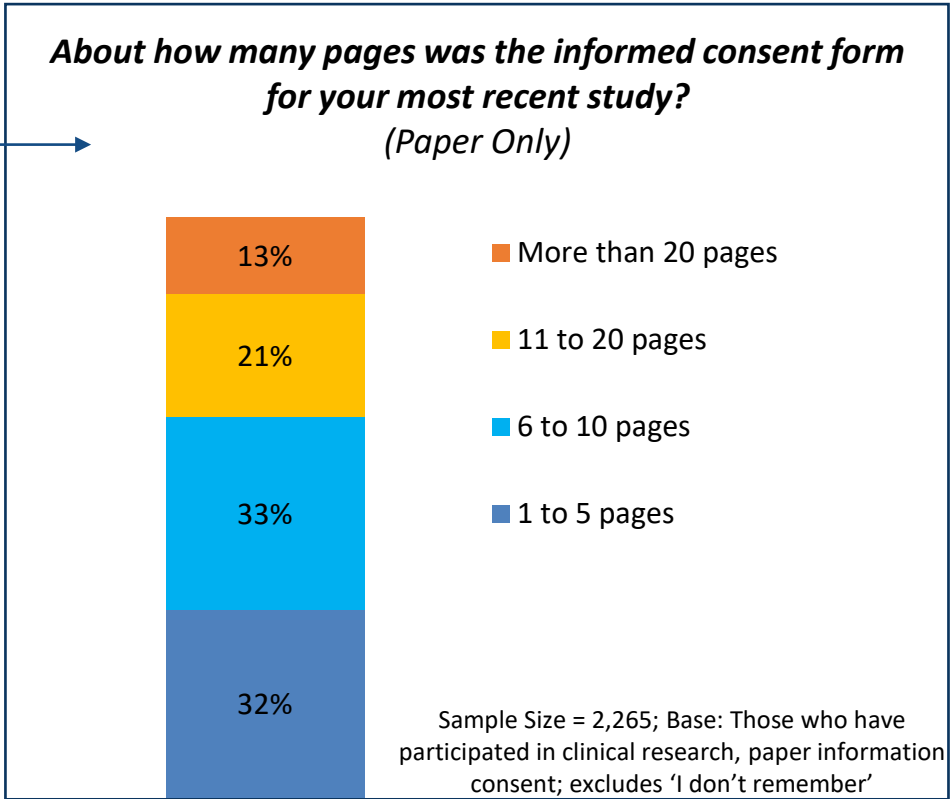
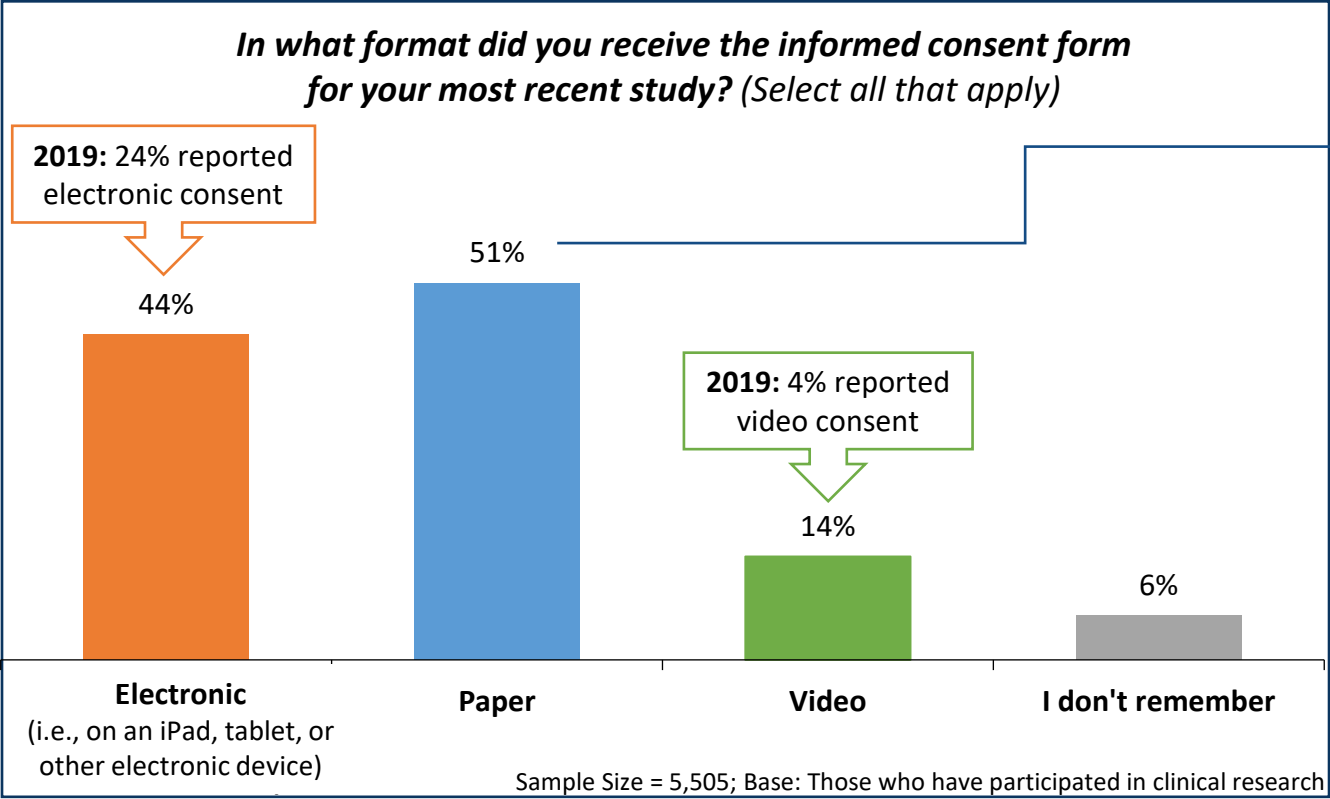
As a general trend, White respondents were more likely to learn of a clinical research study from their doctor (12%) than Black (6%), Asian (6%), or any other races (6%).

Non-Hispanic respondents were more likely to learn about the clinical research study from the research center doctor/staff (16%) than Hispanic respondents (11%).

INFORMED CONSENT FORMATS

Compared to 2019, there is an increase in the use of electronic and video informed consent. For those who provided consent on paper, 44% report the document being more than 10 pages – an increase since 2019.

- Individuals identifying as Black and Hispanic were significantly more likely to receive the informed consent form electronically or via video compared to their White and non-Hispanic counterparts.



European respondents were significantly more likely to receive a paper informed consent (72%) compared to all other regions.

Hispanic respondents more commonly received their informed consent electronically (59%) or via video (25%) than non-Hispanic respondents (35%, 7% respectively).

Younger respondents (18-34 years) were more likely to report receiving an informed consent of 6 to 10 pages (46%), compared to all other ages.

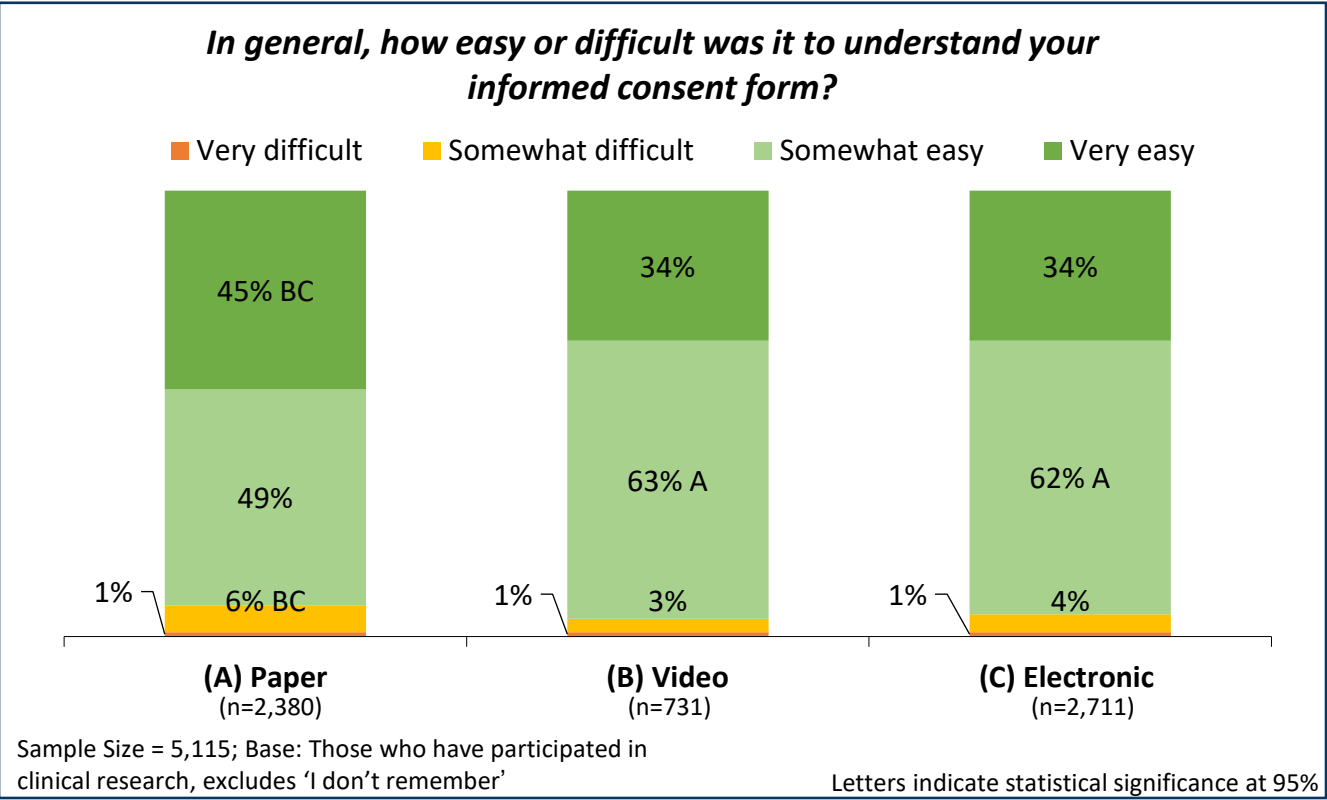
2019

✓ In 2019, 29% of paper consents were more than 10 pages.

UNDERSTANDING THE INFORMED CONSENT FORM

The Informed Consent Form is generally self-reported to be easy to understand, with nearly half of respondents reviewing with the study coordinator and one third with the Principal Investigator (PI).

- Notably, respondents who received electronic consent forms were more likely to report they did not review with anyone, compared to those who completed paper or video consent.



North American respondents were more likely to report it was 'Very Easy' to understand their Informed Consent Form compared to those in Europe (33%) and Asia-Pacific (32%).

Female respondents (42%) were more likely than men (36%) to report it was 'Very Easy' to understand the Informed Consent Form, regardless of format.

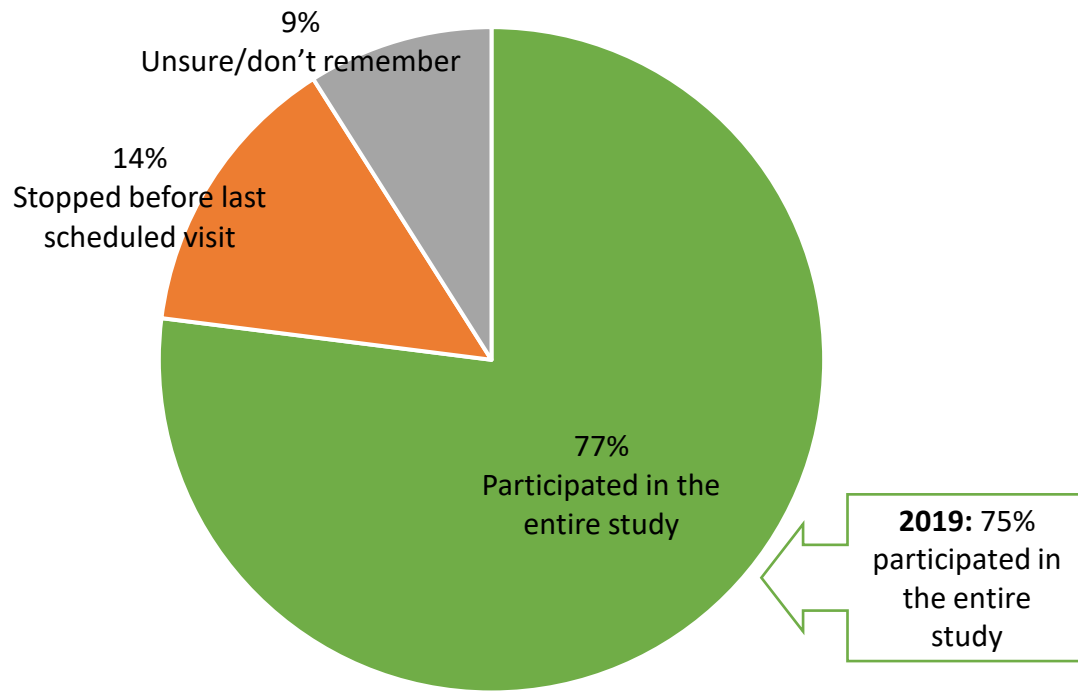
Generally, respondents who reviewed the form with a principal investigator/study doctor were significantly more likely to report 'Very Easy' to understand.



European respondents were more likely to have the principal investigator/study doctor review the Informed Consent Form with them (42%).

STOPPING PARTICIPATION

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



Sample Size = 5,505; Base: Those who have participated in clinical research

Of those with clinical research experience, the majority of respondents cited participating in the entire study – an increase from 2019.

- Notably, White and Black respondents participated in the entire clinical study more frequently (82% and 78%, respectively) than Asian respondents (66%).



Of those who stopped participation, concerns were raised regarding communication, travel, and overall health/safety.

- Hispanic subgroups were more likely to stop due to the location of the study center (23%) than non-Hispanic subgroups (13%).

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

(Top Mentions)



There was poor communication with the study center (18%)



The location of the study center (18%)



The side effects of the study drug (16%)



The procedures during my study visits were too cumbersome (16%)

2019

- ✓ In 2019, 'time commitment was too much' was a top mention (11%).



North and South American respondents were less likely to report being asked to participate in a clinical research study (52% and 41%) than those from Europe (62%), Asia-Pacific (62%), and Africa (63%).

PARTICIPATION BURDENS

Consistent with 2019 findings, travel to the study clinic remains a top burden of participation, with a quarter of respondents traveling over an hour one-way for in-person clinic visits. As a result, preference for virtual visits and reduced travel time are indicated.

- Required tests and assessments (e.g., diagnostic, lab work, questionnaires) also contributed to the experienced burden for study participants.

How burdensome was each of the following? % 'Somewhat' or 'Very' Burdensome	2019 (n=3,654)	2021 (n=5,505)
Traveling to the study clinic	29%	44%
Undergoing diagnostic tests (e.g., x-rays, MRIs)	21%	42%
The length of the study visits	21%	40%
Lab work (e.g., blood tests, urine)	17%	38%
Taking the clinical study medicine	15%	37%
Completing health questionnaires	18%	32%

Sample Size = 5,505; Base: Those who have participated in clinical research



As a general trend, North American respondents were significantly more likely to cite all indicators were more burdensome than respondents from Europe.

- ✓ 15 minutes or less: 10%
- ✓ 15 to 30 minutes: 29%
- ✓ 30 minutes to 1 hour: 38%
- ✓ 1 to 2 hours: 17%
- ✓ 2 to 3 hours: 5%
- ✓ More than 3 hours: 3%

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



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

Providing alternative options to in-person clinic visits or site clinics located closer to home were top recommendations to help reduce disruption and minimize burden.



What could have made your participation in the clinical research study less disruptive? (top mentions)

- ✓ Virtual study visits (38%)
- ✓ Not having to travel as far to get to my study visits (32%)
- ✓ Having a study nurse or doctor come to my home for some of my study visits (31%)
- ✓ Receiving a pre-paid debit card for study-related expenses (27%)
- ✓ Having help/assistance traveling to and from the study (24%)

TECHNOLOGY USE

An increased use of technology is present compared to 2019. Notably, participants report text messaging (49%), video conferences with the study doctor (49%) and smart phone apps (47%) as most helpful to participation.

- Compared to 2019, fewer people reported that no technology was used during their participation (27% in 2019 to 13% in 2021).

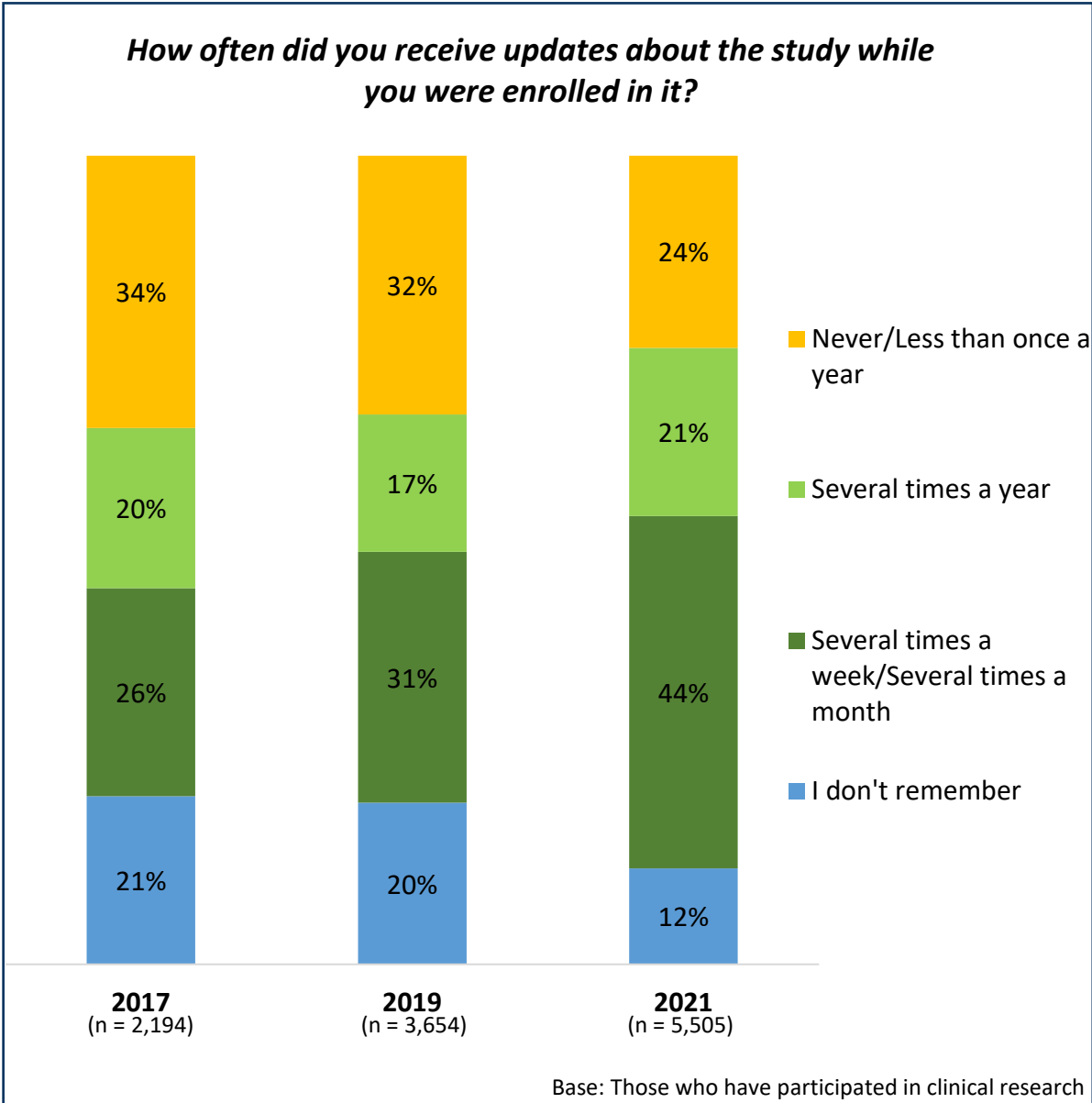
Which of the following were used during your clinical research study?	2019 % Mentioning	2021 % Mentioning	2021 % Indicating 'Very' Helpful
Surveys to collect information on my clinical trial experience	29%	30%	44%
Smartphone apps for study data collection	15%	24%	47%
Text messaging	21%	22%	49%
Informed consent on an electronic tablet	15%	21%	38%
Supportive services	11%	19%	42%
Wearable devices	13%	19%	40%
Some or all of my study visits were conducted at my regular doctor's office rather than the study doctor's office	n/a	18%	42%
Some or all of my study visits were conducted at my home or my office	8%	16%	39%
Social media	5%	16%	35%
Video conference with the study doctor	4%	13%	49%
Childcare or childcare reimbursement	2%	6%	35%
None of the above	27%	13%	-

Respondents residing in suburban areas were more likely to think that text messaging in a clinical research study was 'Very Helpful' (62%) than those in rural (40%) or urban areas (44%).

Respondents with a self-reported medical condition were more likely to think that having some or all of their study visits conducted at their home or office was 'Very Helpful' (57%) than those without a self-reported medical condition (33%).




No significant differences were found by region for engagement via text messaging. Those from North America, however, were more likely to use smartphone apps (28%) and video conference (15%) than those from Europe (14%, 6% respectively).



More respondents reported receiving updates several times a year/month (44%) compared to previous years, which may be attributed to the COVID-19 pandemic.

- Those in a traditional study (22%) were significantly more likely to report ‘Never’ receiving updates compared to those in remote/virtual (5%) and hybrid studies (10%).
- As a general trend, those who were in a clinical study when the COVID-19 pandemic began received updates more frequently than those who were not.




COMPENSATION


Of those who participated in a clinical research study, nearly all received some sort of compensation (85%), whether it was for their time, reimbursement of expenses, or being allowed to keep the technology provided.

- For individuals who reported some of the costs were not covered, transportation (e.g., parking, gas, tolls), accommodation and food were top mentions.


Did you experience any of the following as part of the clinical research study? (top 3 mentions)



I received compensation for my time (50%)



I was allowed to keep the mobile device or other technology that was provided as part of the study after my participation ended (28%)



I was reimbursed for my out-of-pocket expenses through cash or check (26%)

POST-PARTICIPATION COMMUNICATION

A greater number of respondents indicate receiving a report or update on the results once their study finished (43%) compared to previous years (32%, 2019; 30%, 2017).

- Hispanic respondents were more likely to receive updates (57%) than those identifying as non-Hispanic (35%).
- White respondents were less likely to receive updates (39%) than Black (51%) respondents.

A summary of the study results, individual study results and information about upcoming research studies are top mentions among information provided. Participants find information about their individual study results to be most helpful, closely followed by whether they received the study drug or placebo.

- As a general trend, respondents in later phase clinical studies were more likely to receive information on whether they received the study drug or placebo – 47% in Phase IV compared to 22% in Phase I.
- White and non-Hispanic respondents mentioned higher instances of receiving a summary of the study results (50%, 50%) than those identifying as Black (35%), Asian (31%), or Hispanic (34%).

What information did you receive?	% Mentioning	% Indicating 'Very' Helpful
A summary of the study results	43%	45%
My individual study results (i.e., procedures and test results)	42%	51%
Information about upcoming clinical research studies	33%	45%
Whether I received the study drug or placebo	28%	49%
Drug approval status by the regulatory agency in your country	28%	45%
The brand name for the study drug	27%	40%
Information about scientific publications	21%	37%



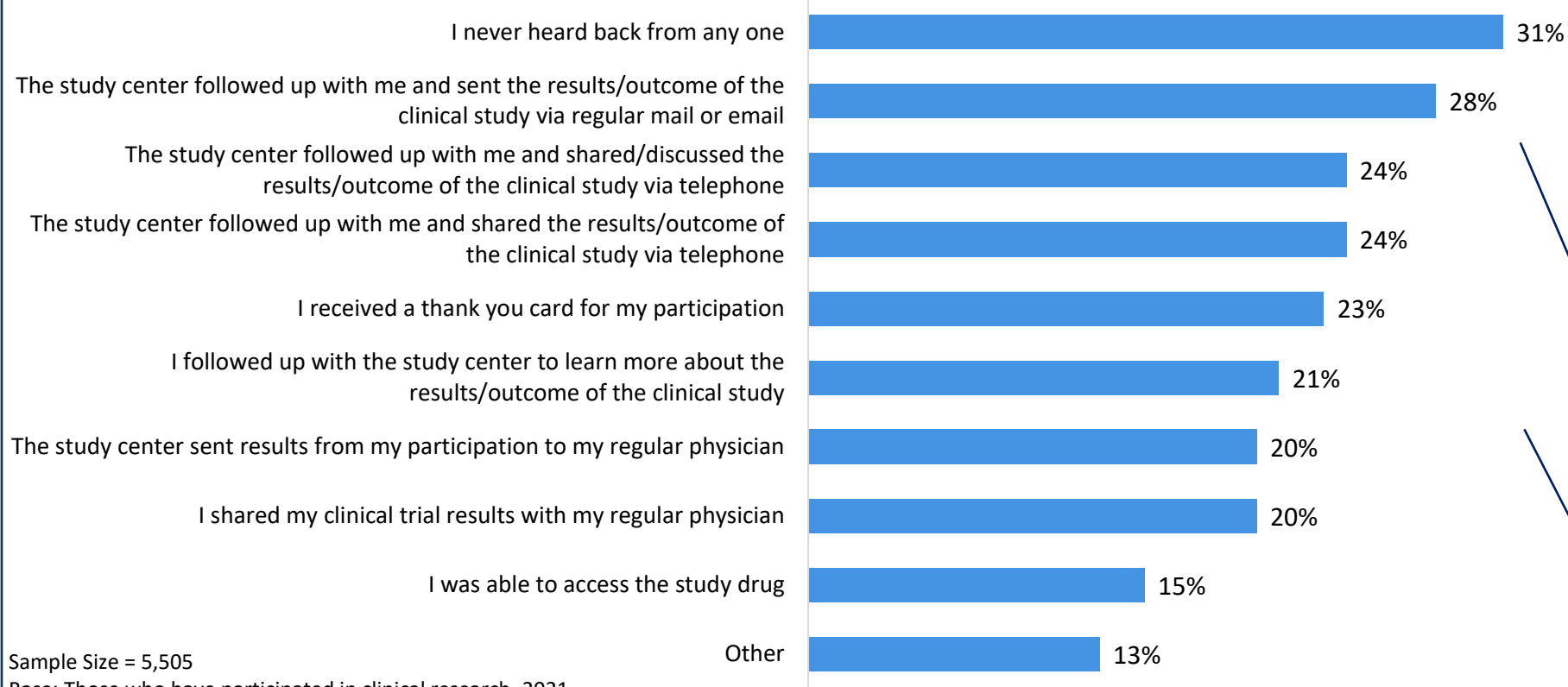
Individuals from Europe were more likely to receive a summary of the study results (50%) than individuals from South America (26%) or Africa (19%).

POST-PARTICIPATION COMMUNICATION (cont'd)

There was a noted increase in communication following participation compared to 2019. However not hearing back from anyone was still a common theme among a large proportion of participants.

- Hispanic respondents were more likely to follow up with the study center to learn more (32%), have the study center follow up with them via regular mail or email (34%), and/or discuss the results via telephone (35%) compared to those identifying as non-Hispanic (14%, 24%, 18%).

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



2019

- ✓ The number of respondents who never heard back decreased from 2019 (39%), as centers following up by telephone (16%) and individuals following up with the study center (13%) increased from 2019.

Female respondents were more likely to report they never heard back from anyone (35%) compared to males (29%).

White respondents were less likely to follow up with the study center to learn more about the clinical study (17%) than Black (27%), Asian (24%), or respondents identifying as All Other Races (31%).

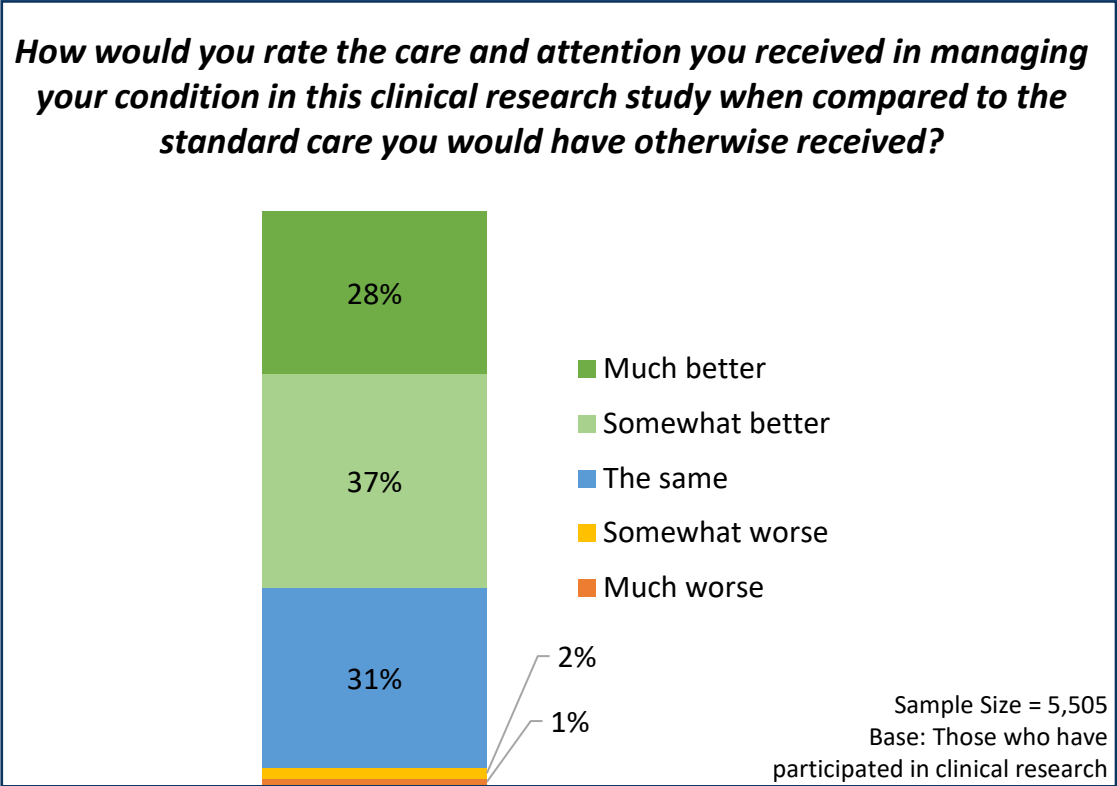
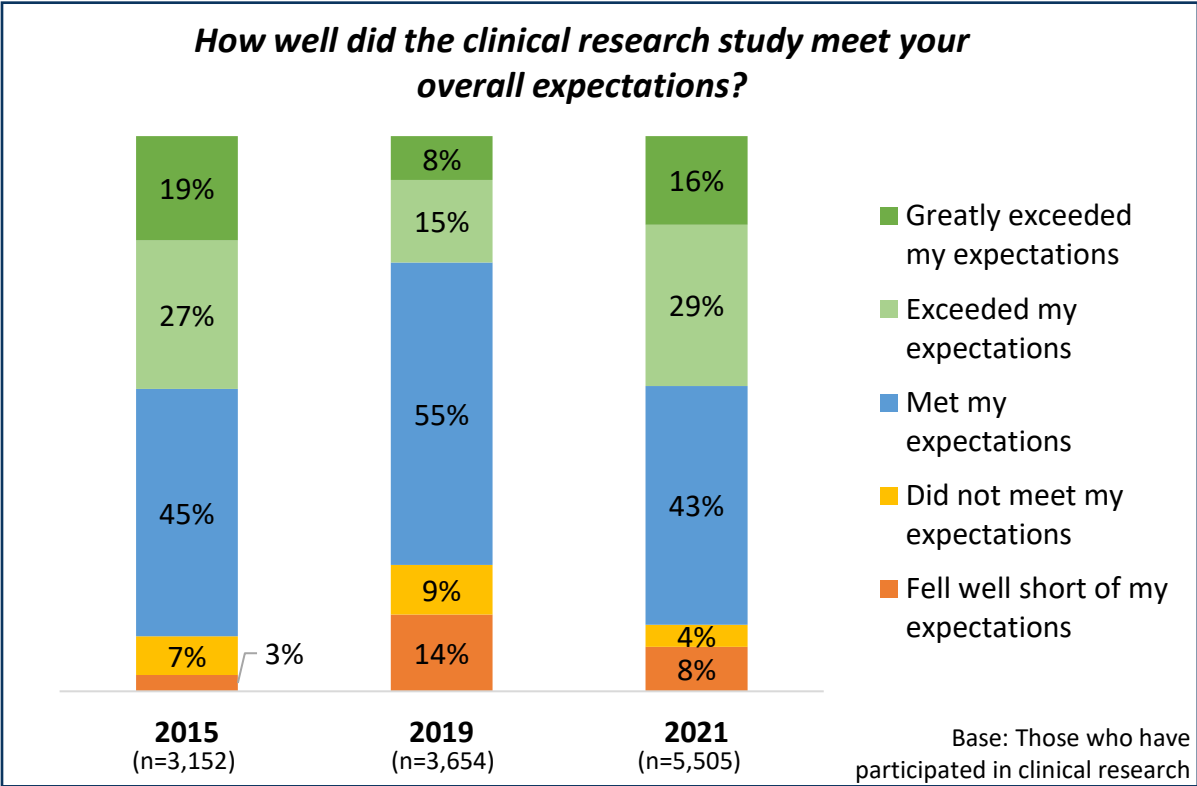


Those from Europe were more likely to never hear back from anyone (41%) than those from North America (30%), Asia-Pacific (24%), and Africa (24%).

OVERALL SATISFACTION

Overall satisfaction with participation experiences improved from years past, with the majority having their expectations met or exceeded. Satisfaction may be attributed to the care and attention received while enrolled.

- Hispanic respondents were significantly more likely to report participation ‘Exceeded’ or ‘Greatly Exceeded’ their expectations (58%), compared to non-Hispanic respondents (38%), citing the care and attention received was ‘Much’ or ‘Somewhat’ better (84% and 55%, respectively).
- As a general trend, younger respondents were more likely to cite higher levels of satisfaction.



European respondents were more likely to cite participation ‘Met my expectations’ (52%) and the care received was ‘The same’ (40%) than those from North America (42%, 31%), Asia-Pacific (41%, 28%), and Africa (34%, 12%).

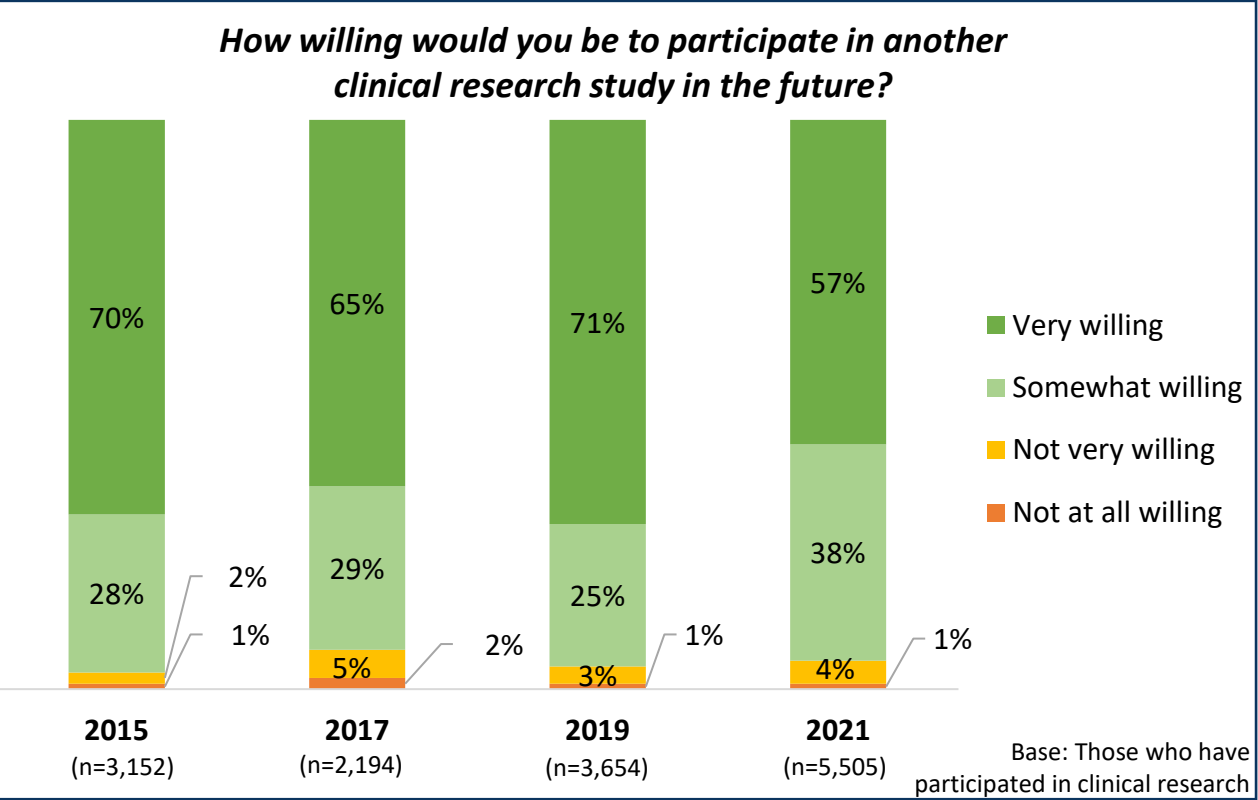
2019

✓ In 2019, 45% reported ‘Much’ or ‘Somewhat’ better care, compared to 65% in 2021.

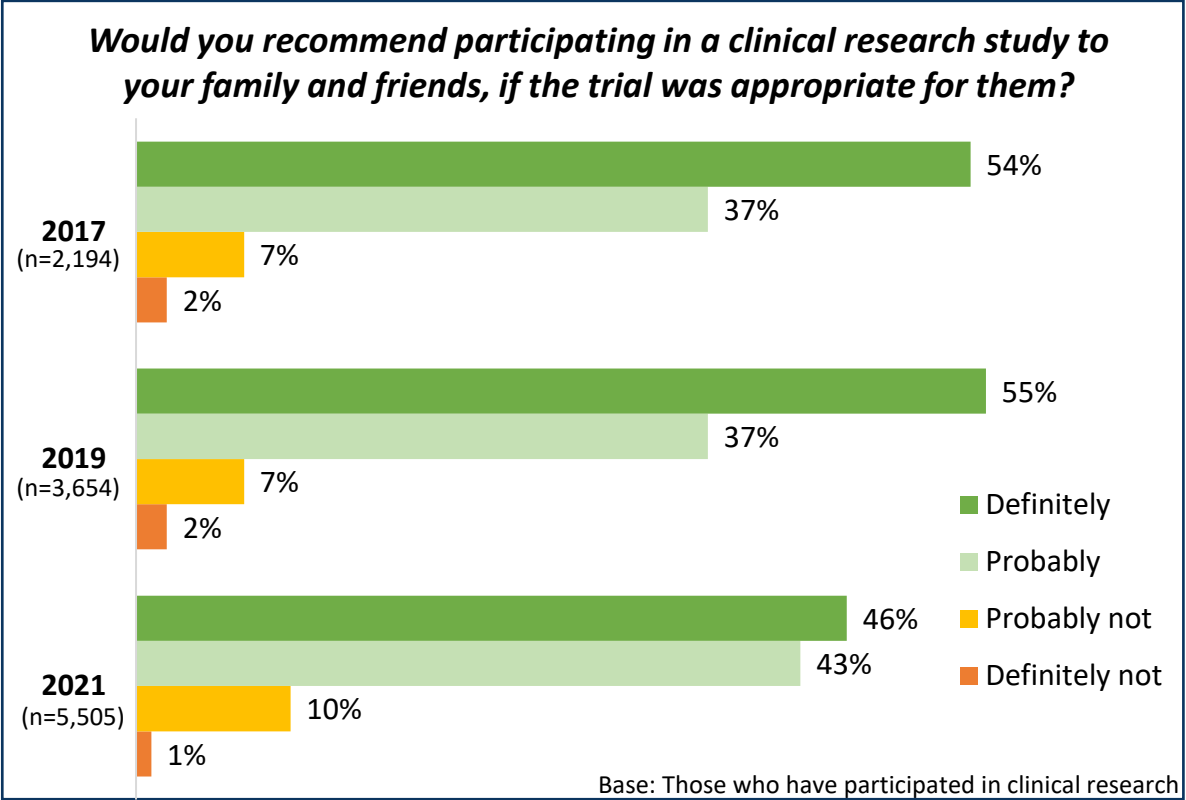
FUTURE PARTICIPATION AND RECOMMENDATIONS

The majority of respondents (95%) are still generally willing to participate again. However, a lower proportion of those are ‘Very Willing’ when compared to prior years.

- No significant difference in willingness to participate in the future was found between those enrolled in a clinical research study during the start of the COVID-19 pandemic and those who were not.
- However, those enrolled in a remote study were less likely to report they would ‘Definitely’ recommend participation (30%) compared to those in a traditional (55%) or hybrid (45%) study.



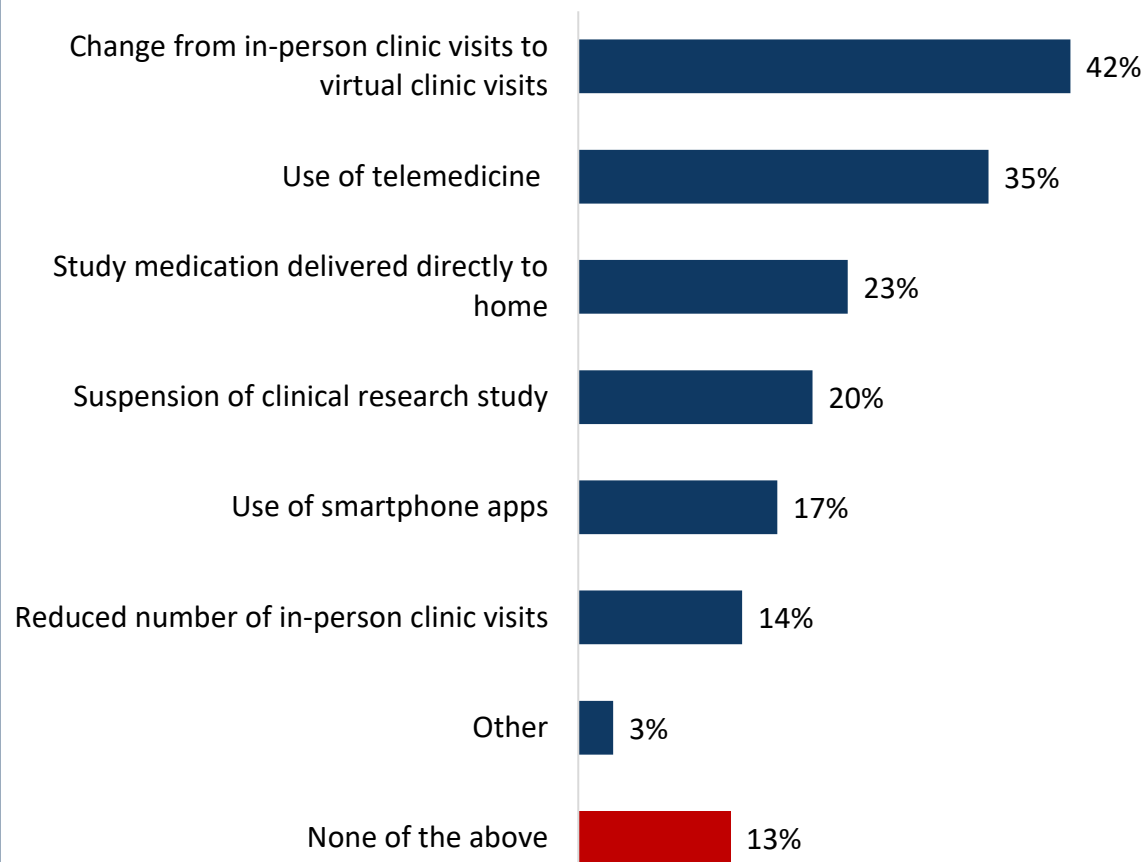
Respondents who participated in a traditional clinical research study were more likely to report ‘Very Willing’ to participate in another study (67%) as compared to hybrid (54%) or remote (39%) clinical research study participants.



White and Black respondents were more likely to ‘Definitely’ recommend participation (51% and 45%, respectively) than Asian respondents and those identifying as All Other Races (32% and 34%, respectively).

IMPACT OF COVID-19 PANDEMIC ON PARTICIPATION

What types of changes, if any, did you experience in your clinical research study because of the COVID-19 pandemic?



Sample Size = 5,505; Base: Those who have participated in clinical research



Respondents in North America were more likely to report changing to use of telemedicine because of the COVID-19 pandemic (42%) than respondents in South America (11%), Europe (17%), and Africa (22%).

Over one third (35%) of respondents reported being enrolled in a clinical research study when the COVID-19 pandemic began in February 2020. Top reported changes as a result were shifts from in-person to virtual visits and the use of telemedicine.

- As a general trend, respondents who participated in a clinical research study with a more severe medical condition were less likely to report switching to the use of telemedicine.

Post-pandemic, half of respondents said they desire the use of telemedicine and virtual clinic visits to continue, either replacing or in addition to in-person clinic visits.

- Hispanic and Black respondents were significantly more likely to show preference for the continuation of virtual clinic visits (61%, 56%) than non-Hispanic (42%) and White (44%) respondents.

What changes, if any, do you think should continue to be a part of clinical research studies even after the pandemic has ended?

(Top Mentions)



Use of telemedicine (54%)



Change from in-person clinic visits to virtual clinic visits (49%)



Study medication delivered directly to home (32%)



Use of smartphone apps and other technologies (31%)



Reduced number of in-person clinic visits (28%)

ABOUT THIS STUDY

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

Between April and July 2021, CISCRP conducted an online international survey. The survey instrument was based in part on questions posed in past surveys. CISCRP received input and support from pharmaceutical, biotechnology, and contract research organizations, and from investigative sites. The survey instrument was reviewed by an ethical review committee. CISCRP collaborated with Clariness, AES, CureClick, Benchmark Research, and IQVIA to reach and engage respondents.

A total of 11,793 respondents completed the survey. Respondent characteristics are as follows:

Gender	51% Female 45% Male 4% All other genders
Region	69% North America 3% South America 19% Europe 6% Asia-Pacific 3% Africa
Age	31% 18 - 34 years old 16% 35 - 44 years old 14% 45 - 54 years old 18% 55 - 64 years old 21% 65 or older
Race	74% White 7% Black or African American 5% Asian
Ethnicity	72% Non-Hispanic 28% Hispanic
Incidence of participation in a clinical trial	53% have never participated 47% have participated

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

ABOUT CISCRP

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



Engage



Insights guiding public and patient engagement in clinical research

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



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

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



Information in plain and easy-to-read language

- Trial Results Summaries
- Educational Brochures
- Health Communication Projects
- Review Panels



Helpful facts and information about clinical research

- Content Licensing
- Media Awareness Campaigns: USA Today, Patient Diversity
- Website Content Development
- New Brochure Development



Educate



Inform

