



2019
Perceptions
and Insights
Study



Engagement Preferences

Introduction:

Patients and their loved ones often have different needs and preferences when it comes to clinical trial participation. Each patient's clinical trial journey is unique – with each person balancing varying degrees personal commitments and work responsibilities. While a myriad of new patient engagement initiatives are now being offered as part of clinical research studies, what may work for one person may not work for another. Therefore, the ability to have various options capable of accommodating different lifestyles is critical.

In this report, CISCRP provides a summary of the results of the latest global survey of the general public and patient perceptions about clinical research – including valuable insights on patient engagement preferences among various sub-groups of patient populations. The findings identify the most critical elements of participation as identified by patients and the public, as well as receptivity to new clinical trial models.



The Center for Information and Study on Clinical Research Participation (CISCRP), founded in 2003, is a non-profit organization dedicated to educating the public and patients about the important role that clinical research plays in advancing public health. As part of its mission, CISCRP provides a variety of services designed to assist clinical research stakeholders in (1) understanding public and patient attitudes and experiences and (2) improving volunteer participation experiences and satisfaction. Please consider making a charitable donation to support our mission.

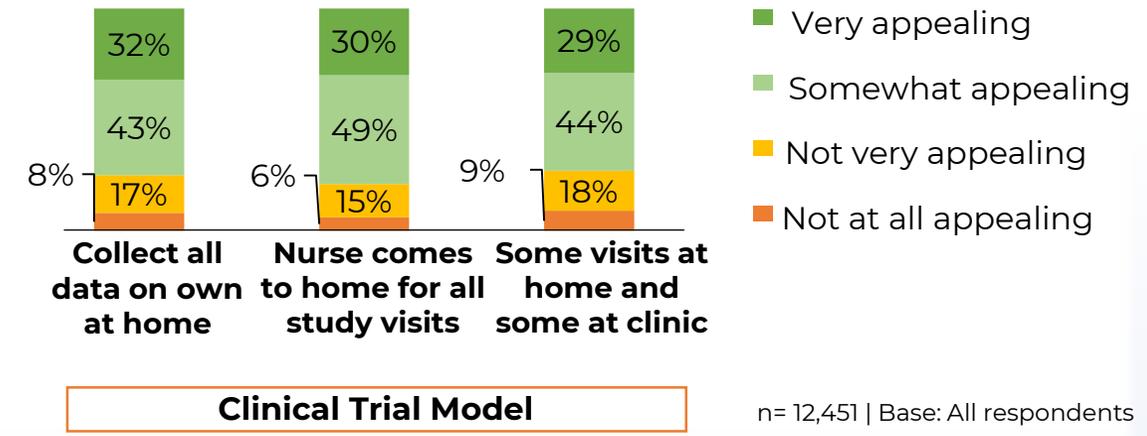
If you were to participate in a clinical research study, how important are the following to your participation?

Values indicate % responding 'Very important'	Never Participated n=8,797
Supporting information on managing my health	52%
Supporting information on the clinical study	50%
Satisfaction survey available after the study	42%
Concierge services (ex. Transportation provided)	36%
Clinical study medicine delivered to my home	34%
Information designed for caregivers about the study	33%
Mobile/electronic applications	32%
Ability to review/sign documents electronically	29%
Study visits conducted at my home or office	24%

As seen in the 2017 study, access to supporting information remains the top priority during participation. The availability of a satisfaction survey and logistical support systems such as transportation assistance and home study drug delivery are also highly valued.

- Both past participants and those who have never participated agree on the items of highest importance.
- Women, those who identify as Black, and those who are Hispanic are more likely to indicate that each of the listed aspects of the participation experience are 'Very important' compared to their counterparts (men, those of all other races, and those who are not Hispanic, respectively).

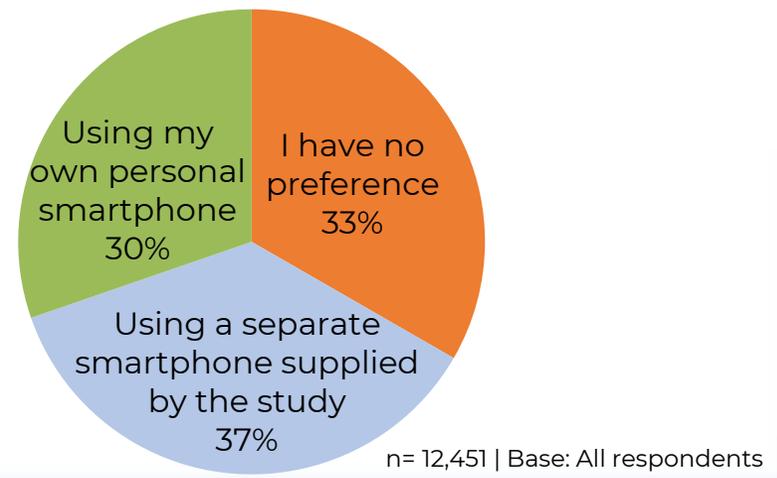
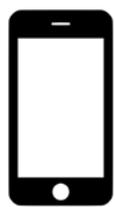
Compared to traveling to a study clinic for all of your study visits, how appealing is each of the following options?



While alternative clinical trial models are generally regarded as appealing when compared to the traditional model, there is no single preferred option suggesting that no one size fits all as preferences can vary widely by participant.

- Women are more likely to find home visits from a nurse and home data collection to be 'Very appealing,' compared to men.
- 40% of those who identify as Black report that they find home visits from a nurse to be 'Very appealing,' but only 24% of those who identify as Asian mention that they find this option to be 'Very appealing,' indicating the importance of cultural considerations when offering these study visit options.
- Few significant differences exist between the opinions of those who have previously participated in clinical studies and those who have not.

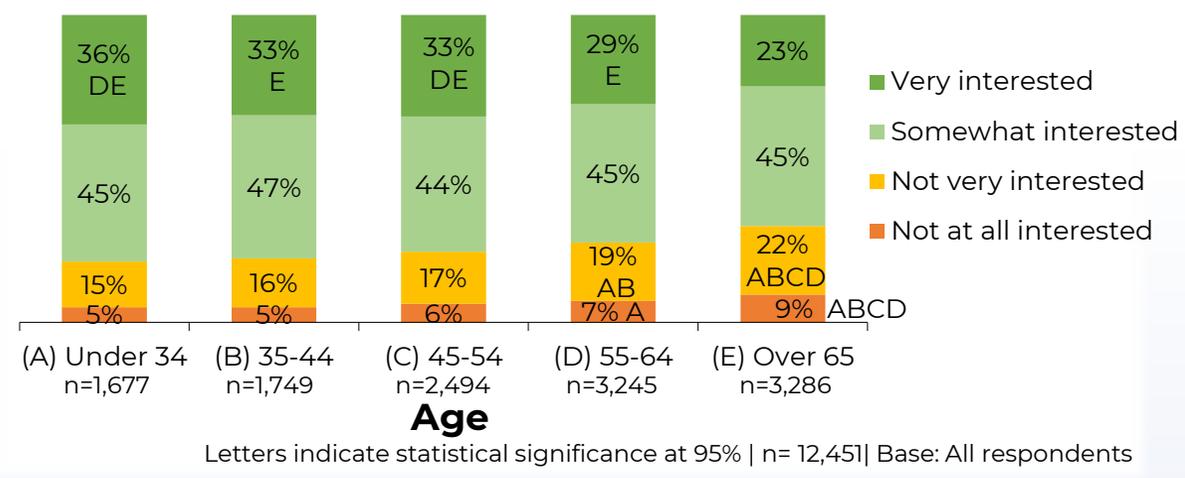
Participation in a clinical research study may require the use of smartphones. Which option do you prefer?



People did not express a clear preference between using their own devices and the provision of an additional smartphone, once again emphasizing the need for flexibility and options.

- Younger people are more apt to prefer using their own smartphones, while older people, especially those over 65, are more apt to prefer using a separate smartphone provided by the study.
- No significant differences exist between the smartphone usage preferences of those who have previously participated and those who have not.
- Those living in North America and Europe tend to prefer using a separate smartphone (34% and 41%, respectively) compared to their own smartphone (28% and 31%).

How interested would you be in discussing and getting advice on participating in a clinical research study with peers in an online patient community?

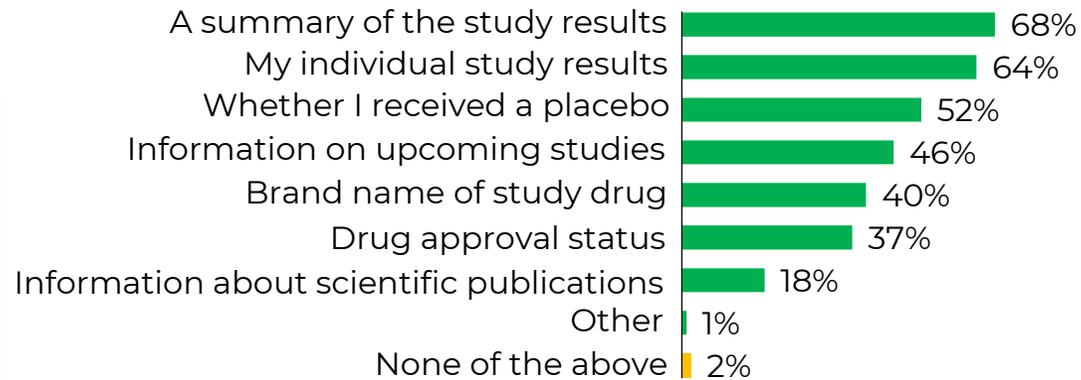


Consistent with results seen in 2017, 75% overall indicate interest in discussing clinical trial participation with their peers in an online patient community.

- There is higher interest in online communities among younger populations. However, a large proportion (68%) of those over 65 also express interest, indicating that the opportunity to connect with peers online would be valued across age groups.
- When grouped by disease severity, past participants show some differences in opinion regarding their interest in online patient communities. For example, 25% of those who participated in clinical trials as healthy volunteers in the past report that they are 'Very interested' in online communities, while this figure jumps to 36% among those who participated in a study in the past and label their disease/condition as 'severe.'

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

% Mentioning



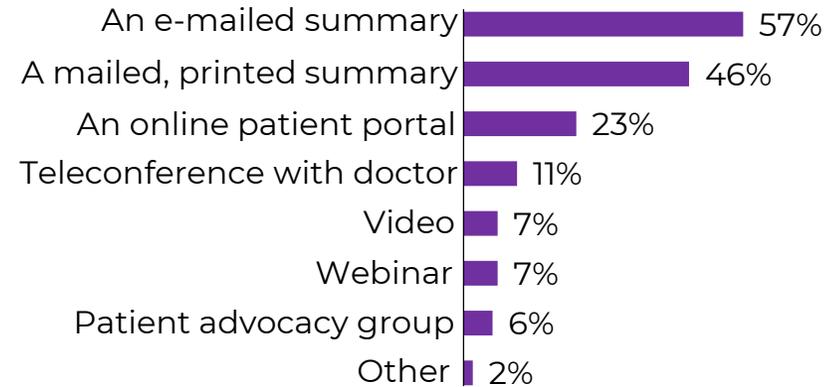
n= 3,654 | Base: Those who have participated in a clinical trial

Overall study results and individual study results are the types of information participants are most interested in receiving after study completion, highlighting the importance of maintaining engagement after participation has ended.

- Compared to other regions, those living in North America were more likely to indicate that they were interested in receiving a summary of the study results (74%), their individual study results (70%), and an explanation of whether or not they had been given a placebo (58%).
- Similarly, those over 65 were more interested in receiving individual (76%) and overall study results (69%), as well as information about whether they received a placebo (59%), compared to younger age groups.

How would you prefer to receive the summary of the results of the clinical research study? Select all that apply.

% Mentioning



n= 3,654 | Base: Those who have participated in a clinical trial

Though paper summaries still rank high among preferable formats, electronic mediums are even more desirable. E-mailed summaries are the most popular choice of format, and one in four express interest in receiving their results via an online patient portal.

- Those over 65 prefer mailed, printed summaries (55%), followed by electronic summaries (54%). Younger age groups show a more varied range of preferences, but their responses highlight an inclination toward electronic formats. Those under 34 are much more likely to desire study results via interactive electronic formats like teleconferences with the study doctor (27%), webinars (22%), or patient advocacy groups (18%) compared to their older counterparts.
- Those who identify as Asian and those who identify as Hispanic are also more likely to desire results via webinars and patient advocacy groups compared to other race and ethnicity groups.

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 participation 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 June and July 2019, 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 Acurian, Clariness, Continuum Clinical, CureClick, and IQVIA to reach and engage respondents.

A total of 12,451 respondents completed the survey. Respondent characteristics are as follows:

Gender	55% Female 44% Male 1% All other genders
Region	55% North America 6% South America 27% Europe 11% Asia-Pacific 1% Africa
Age	13% 18 - 34 years old 14% 35 - 44 years old 20% 45 - 54 years old 26% 55 - 64 years old 26% 65 or older
Race	80% White 6% Black or African American 10% Asian
Ethnicity	85% Non-Hispanic 13% Hispanic
Incidence of participation in a clinical trial	71% have never participated 29% have participated

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.



Insights guiding public and patient engagement in clinical research

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



Information in plain and easy-to-read language

- Trial Results Summaries
- Health Communication Projects
- Editorial Panels



Helpful facts and information about clinical research

- Content Licensing
- Media Awareness Campaign: USA Today; Patient Diversity
- Website Content Development; New Brochure Development
- Volunteer Community: Medical Hero's Alumni; Ambassador Network



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

- AWARE-for-All
- Medical Hero's Appreciation 5K
- Journey to Better Health Traveling Exhibit

Additional Resources

Designed to help professionals best engage patients as partners in the clinical research process. www.ciscrp.org Education Center, Quarterly eNewsletter, Search Clinical Trials, Sponsorship Opportunities, Webinars, Online Store