2017 Perceptions & Insights Study

Public and Patient Perceptions of Clinical Research

CISCRP

THE CENTER FOR INFORMATION & STUDY
ON CLINICAL RESEARCH PARTICIPATION

Report on

The Participation Decision-Making Process

Deciding whether or not to participate in a clinical research study can be an overwhelming and difficult decision for most people. Many factors can influence that decision. How do people want to become aware of clinical research studies? What information and resources are most important as they consider participation? What kind of an impact can a trusted healthcare pro-fessional have on their attitudes towards clinical research? Patients and the public from around the world provide answers to these important questions and more in this latest survey.

In this report, CISCRP explores the participation decision-making process and reveals opportunities for stakeholders to support prospective study volunteers as they navigate this journey.

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.

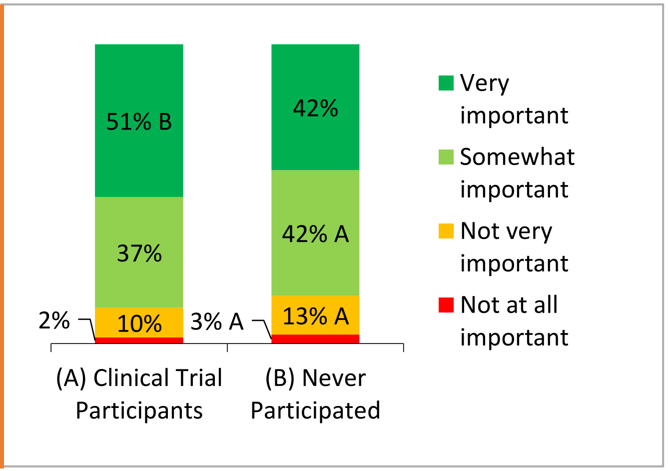
Most feel it is important to be aware of clinical research studies conducted in their community

In general, the majority (84%) of the public feels it is important to be aware of studies being conducted in their own communities. Notably, an even larger proportion (95%) indicates it is also important for their regular doctor to be aware of studies.

Perceived importance rises with age as a significantly higher proportion of older people report it is 'very important' for their doctor to be aware.

Some regions outside of North America, such as Europe and the Asia Pacific regions, believe that doctor involvement is less important.

How important do you feel it is for you to be aware of clinical research studies being conducted in your community?



Base: (A) Clinical trial participants (n=2,194), (B) Never participated (n=10,233), Sample Size = 12,427; Letters indicate statistical significance at the 95% CL

AGE (base: never participated in a study)
(% mentioning important for doctor to be aware)

	18 - 34	35 - 44	45 - 54	55 - 64	65 +
Very important	64%	58%	63%	69%	72%
Somewhat important	30%	33%	30%	26%	23%
Not at all/not very important	7%	9%	7%	5%	5%

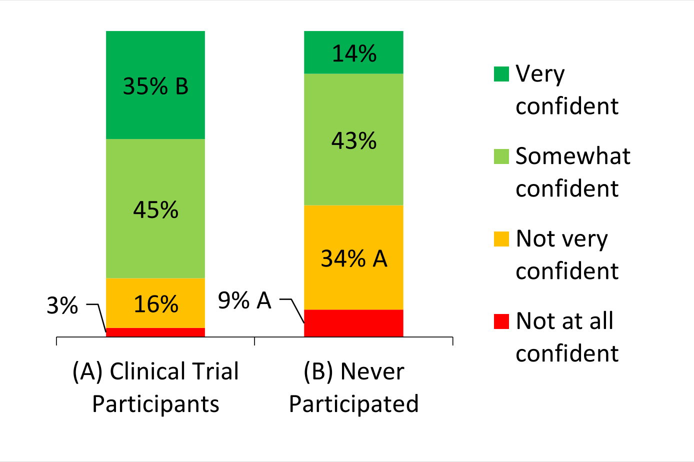
☐ *Indicates statistical significance at the 95% CL*

And yet many express low confidence in finding a clinical research study

Overall, almost 40% of the public are not very confident they would find a clinical study that is right for them.

In particular, those who have never participated are significantly less confident than those who had participated in a clinical study in the past (i.e. 35% of clinical trial participants felt 'very confident' compared to just 14% among clinical trial naïve respondents).

People from Europe and the Asia Pacific regions were also much less confident when compared to other regions.



How confident are you that you could find a clinical research study that is right for you?

Base: (A) Clinical trial participants (n=2,194), (B) Never participated (n=10,233), Sample Size = 12,427; Letters indicate statistical significance at the 95% CL

REGION (base: never participated in a study)

	North America	South America	Europe	Asia Pacific	Africa
Very confident	15%	25%	12%	9%	23%
Somewhat confident	47%	43%	41%	34%	47%
Not at all/not very confident	39%	31%	47%	56%	30%

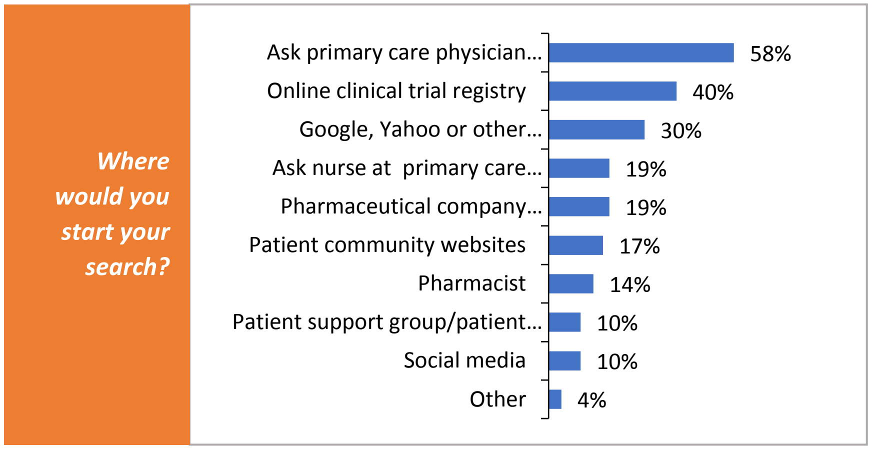
☐ *Indicates statistical significance at the 95% CL*

Where would people start their search for a clinical research study?

The majority (58%) would begin their search by asking their doctor. Online clinical trial registries (40%) and general search engines (30%) are also popular starting options.

Interestingly, prior clinical trial participants are significantly more likely to begin their search through an online registry (50%) (in addition to discussing with their doctor) than those who have not participated (38%).

Younger members of the public are more likely to resort to online options such as search engines, pharmaceutical company websites and social media. Older people are more likely to rely on their doctor.



Where would you start your search?

Sample Size = 7,631, Base: Those indicating confident would find study

AGE					
Where would you start search?	**18 - 34**	**35 - 44**	**45 - 54**	**55 - 64**	**65 +**
Online clinical registry	37%	38%	41%	43%	40%
Search engine	44%	37%	35%	28%	20%
Pharma website	26%	21%	20%	18%	14%
Patient community website	20%	20%	19%	16%	12%
Social media	20%	15%	11%	7%	6%
Ask doctor	48%	50%	54%	61%	67%

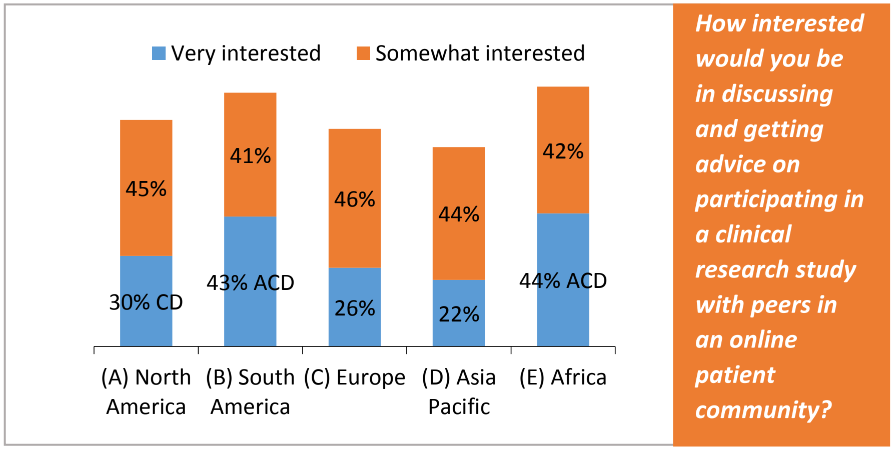
☐ *Indicates statistical significance at the 95% CL*

Connecting with peers in an online community for advice on clinical study participation is also of interest

Many (74%) express interest in discussing and soliciting advice on clinical trial participation from an online peer community. This is particularly appealing to younger people.

People from North America, South America and Africa also express a strong interest in online communities.

An online peer community strongly appeals to Black/African Americans and Hispanics as well.



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

Sample Size = 12,427, Base: All respondents; Letters indicate statistical significance at the 95% CL

RACE			
	White	**Black/African American**	**Asian**
Very interested	28%	45%	24%
Somewhat interested	46%	38%	43%

ETHNICITY		
	Non-Hispanic	**Hispanic**
Very interested	28%	41%
Somewhat interested	46%	41%

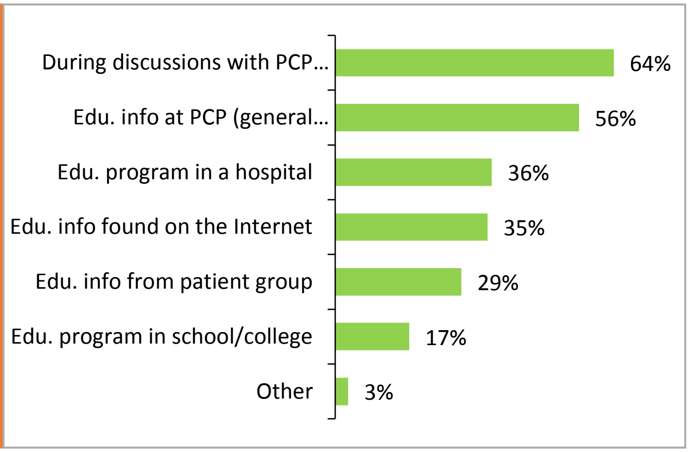
☐ *Indicates statistical significance at the 95% CL*

The doctor is still the preferred way to learn about clinical research

Well over half of the public (64%) reports that people should best learn about clinical research through discussions with their doctor, once again highlighting the importance of this trusted resource. Furthermore, most (68%) report that they would discuss their potential participation with their doctor – similar to findings from prior studies.

Educational programs at schools or hospitals particularly appeal to younger populations. Older populations placed heavier emphasis on discussions with their doctor or through educational information at their doctor's office.

How should people best learn about the clinical research process and where to go to find clinical trials?



Sample Size = 12,427, Base: All respondents

AGE *(% mentioning)*					
How should people best learn?	**18 - 34**	**35 - 44**	**45 - 54**	**55 - 64**	**65 +**
Discussions with doctor	51%	55%	61%	68%	71%
Information at doctor's office	49%	50%	54%	59%	59%
Educational program at hospital	43%	40%	36%	36%	32%
Educational program at school	32%	20%	16%	14%	11%

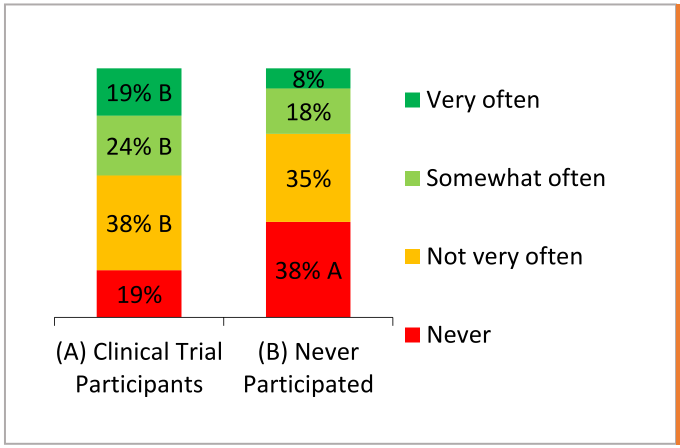
☐ *Indicates statistical significance at the 95% CL*

Yet many people rarely consider clinical studies as an option in discussions with their doctor

Close to 70% of the public has never or rarely considered clinical studies as an option when discussing treatment or medication options with their doctor. People who never participated in a clinical trial were significantly less likely to consider this as an option compared to study participants.

People from Europe and the Asia Pacific regions were significantly less likely to consider studies as an option compared to other regions. Older people were also much less likely to consider this as an option.

Significantly higher proportions of white, non-Hispanic populations reported 'never' considering clinical research as an option.



How often do you consider clinical research studies as another treatment option?

Sample Size = 7,988 Base: Those with condition; Letters indicate statistical significance at the 95% CL

REGION (base: never participated in study)					
Consider clinical research as option	**North America**	**South America**	**Europe**	**Asia Pacific**	**Africa**
Never	38%	13%	44%	42%	22%
Not very often	37%	28%	32%	32%	43%

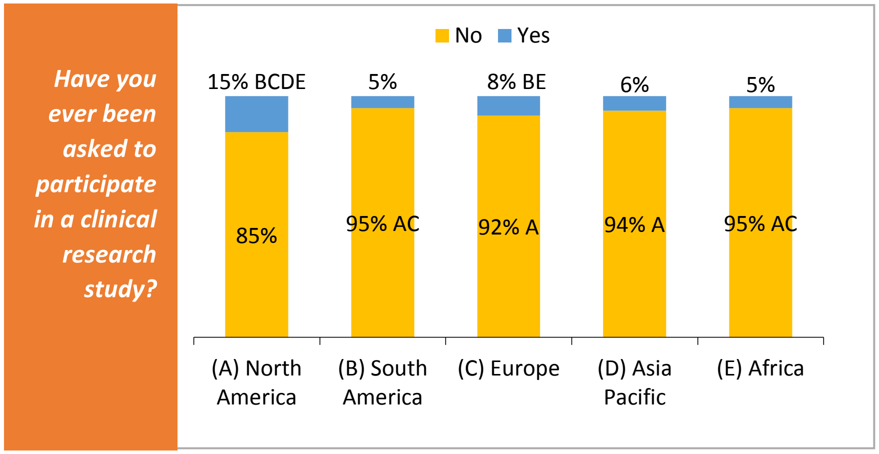
RACE (base: never participated in a study)			
Consider clinical research as option	**White**	**Black/African American**	**Asian**
Never	40%	27%	28%
Not very often	35%	30%	37%

☐ *Indicates statistical significance at the 95% CL*

The majority have never been asked to participate in a clinical trial

Despite a high comfort level identifying studies together with their doctor, few (10% among those who have never participated) have actually been asked to participate in a study in general and even less have been asked by their doctor specifically.

More people from North America report being asked to participate in a clinical study. Older members of the public are also much more likely to have ever been asked.


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

Sample Size = 10,233, Base: Never participated in a study; Letters indicate statistical significance at the 95% CL

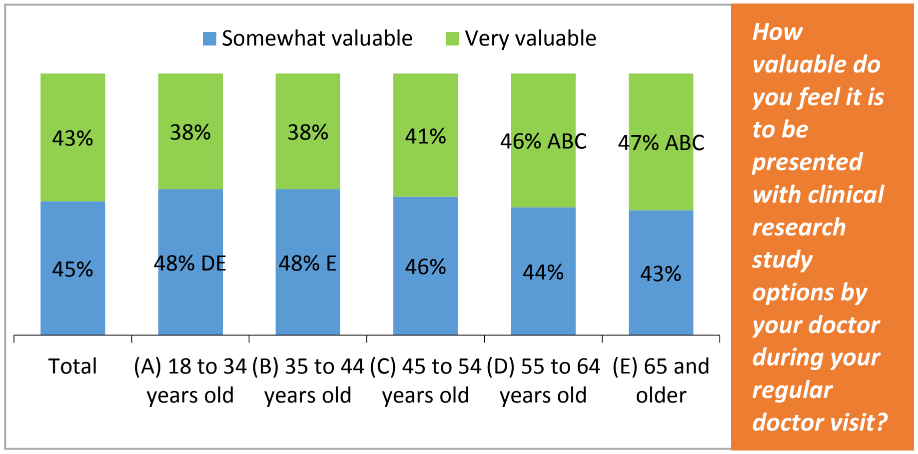
RACE (base: never participated in a study)			
Have ever been asked to participate?	**White**	**Black/African American**	**Asian**
Yes	10%	16%	8%
No	90%	84%	92%

☐ *Indicates statistical significance at the 95% CL*

Yet most want their regular doctor to present clinical research options during visit

Close to 90% of the public believes it is valuable for their regular doctor to present clinical research study options during their visit. And almost all (90%) feel comfortable discussing clinical research study options they discovered with their doctor. Older people find this much more valuable than younger people.

People from Europe and the Asia Pacific regions feel being presented with options by their doctor is less valuable and are generally less comfortable discussing clinical research options with their doctor.


How valuable do you feel it is to be presented with clinical research study options by your doctor during your regular doctor visit?

Sample Size = 12,427, Base: All respondents; Letters indicate statistical significance at the 95% CL

REGION					
	North America	**South America**	**Europe**	**Asia Pacific**	**Africa**
Very valuable	50%	50%	34%	36%	46%
Somewhat valuable	42%	42%	50%	47%	43%
Not at all/not very valuable	8%	9%	16%	17%	11%

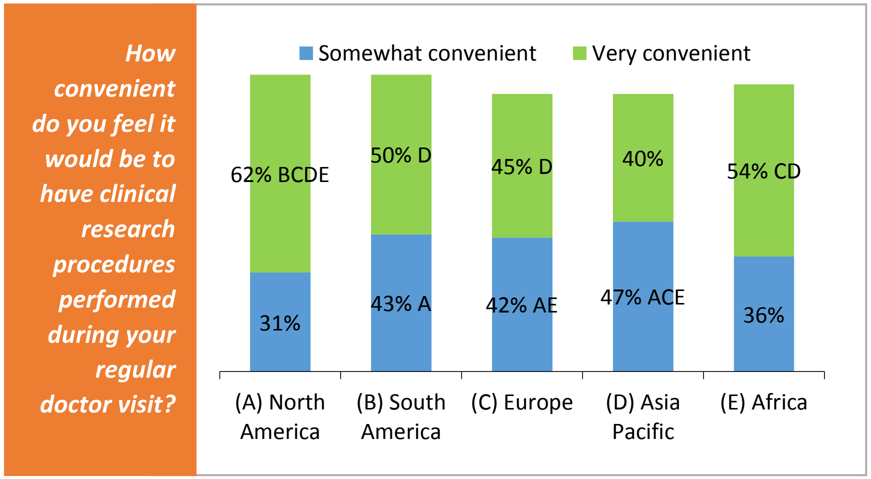
☐ *Indicates statistical significance at the 95% CL*

The convenience of having study procedures performed during regular doctor visits is an important consideration

Most (91%) of the public agrees that having clinical study procedures conducted during a regular doctor visit versus visiting a separate clinic is more convenient.

People from North America are most in favor of having clinical study procedures performed during their regular doctor visit compared to other regions.

White and Black/African American populations are also more likely to find this convenient.


How convenient do you feel it would be to have clinical research procedures performed during your regular doctor visit?

Sample Size = 12,427, Base: All respondents; Letters indicate statistical significance at the 95% CL

RACE			
How convenient is it to have clinical research procedures performed during regular doctor visit?	**White**	**Black/African American**	**Asian**
Very convenient	55%	57%	30%
Somewhat convenient	37%	33%	52%
Not at all/not very convenient	8%	10%	18%

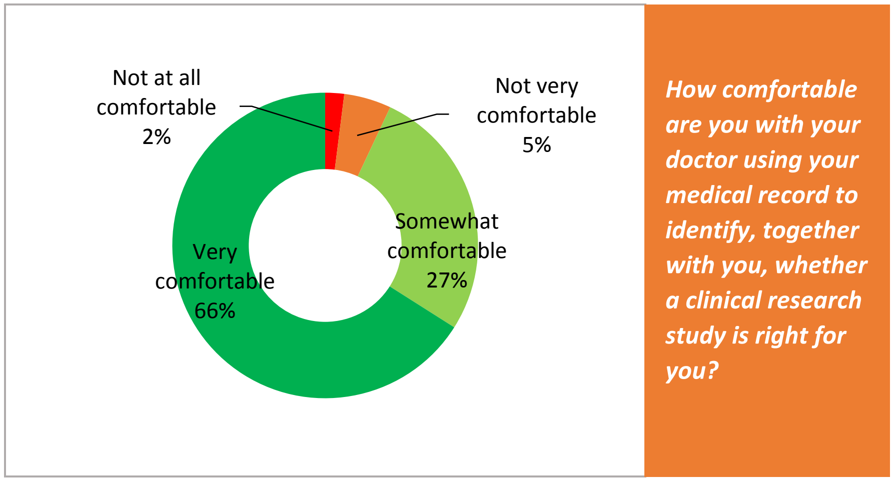
☐ *Indicates statistical significance at the 95% CL*

Most feel comfortable using their medical health record to identify a clinical study with doctor

The majority (93%) of the public reports feeling comfortable using their medical health record to identify an appropriate clinical study with their doctor. Under half (43%) are familiar with electronic health records (EHR) and express being just as comfortable using these to identify a study.

A larger proportion of the public from North America feels more comfortable in comparison to other regions.

Females, and older people, reported being more comfortable than their counterparts.


How comfortable are you with your doctor using your medical record to identify, together with you, whether a clinical research study is right for you?

Sample Size = 12,427, Base: All respondents

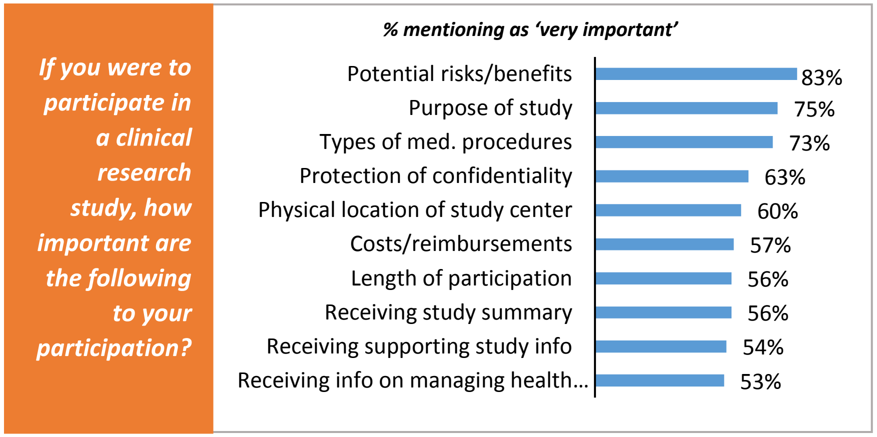
REGION					
How comfortable are you with your doctor using your medical record to identify, with you whether a study right for you?	**North America**	**South America**	**Europe**	**Asia Pacific**	**Africa**
Very comfortable	76%	61%	58%	55%	66%
Somewhat comfortable	21%	31%	32%	32%	30%
Not at all/not very comfortable	4%	7%	11%	12%	5%

☐ *Indicates statistical significance at the 95% CL*

What information do people want to know before making a decision to participate?

When considering participation in a clinical study, the most important information includes the potential risks and benefits (83%) and the study purpose (75%). More practical aspects closely follow such as the medical procedures required, confidentiality protection, physical site location, potential costs and reimbursements, length of participation, and access to a study summary.

Younger people place more importance on being compensated for time off from work. Older people find access to the study drug after participation ended more important.



Sample Size = 12,427, Base: All respondents

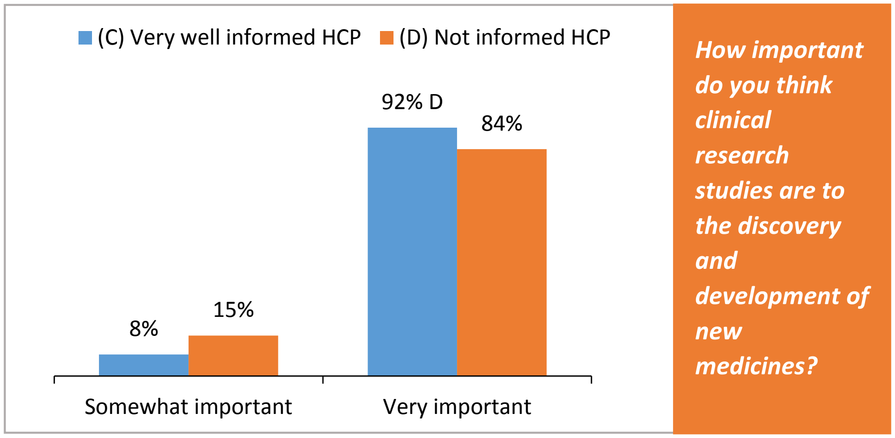
AGE *(% rating 'very important')*					
If you were to participate, how important are the following?	**18 - 34**	**35 - 44**	**45 - 54**	**55 - 64**	**65 +**
Compensation for time off from work	49%	48%	50%	42%	24%
Access to study drug after participation	38%	41%	48%	50%	50%

☐ *Indicates statistical significance at the 95% CL*

A well informed healthcare professional positively impacts perceptions and attitudes towards clinical research

Among those that viewed their healthcare professional as 'very well' informed on a clinical study, a much more positive general perception of clinical research was evident.

Specifically, they were much more likely to feel clinical research was important to the discovery of new medicines. This group was also much more comfortable discussing clinical research options with their regular doctor and indicated a higher overall willingness to participate in a study.



Sample Size = 502, Base: Those who first learned of study through HCP

HCP Knowledge Level		
	Very well informed HCP	**Not informed HCP**
'Very comfortable' discussing research options with HCP	87%	68%
'Very willing' to participate in a study	58%	44%

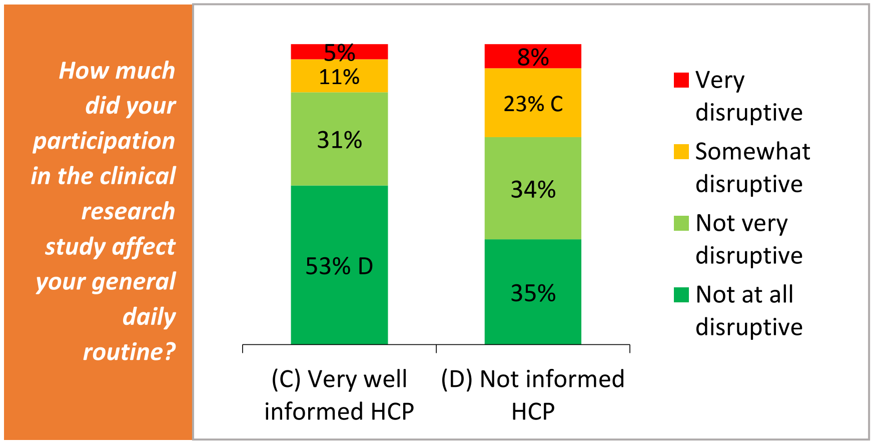
☐ *Indicates statistical significance at the 95% CL*

And positively affects participation experiences

A well informed healthcare professional can also positively influence participation experiences.

Those who viewed their healthcare professional as ‘very well’ informed reported significantly less disruption to their daily routine as a result of participation. This group also found the Informed Consent Form, as well as the accompanying study medicine instructions, to be much easier to understand.

This group was also significantly more likely to participate in another clinical study in the future and recommend participation to others.



Sample Size = 502, Base: Those who first learned of study through HCP

HCP Knowledge Level		
	Very well informed HCP	**Not informed HCP**
Found ICF ‘very easy’ to understand	45%	29%
Found study medicine instructions ‘very easy’ to understand	81%	66%

☐ *Indicates statistical significance at the 95% CL*

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 May and July 2017, 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, CureClick, HealthUnlocked, and Quintiles to reach and engage respondents.

A total of 12,427 respondents completed the survey. Respondent characteristics are as follows:

Gender: 59% Female | 40% Male

Region: 46% North America | 7% South America | 28% Europe | 14% Asia-Pacific | 5% Africa

Age: 13% 18 - 34 years old | 11% 35 - 44 years old | 19% 45 - 54 years old | 27% 55 - 64 years old | 29% 65 or older

Race: 81% White | 6% Black or African American | 5% Asian

Ethnicity: 88% Non-Hispanic | 8% Hispanic

Incidence of participation in a clinical trial: 82% have never participated | 18% have participated

**Throughout this report, ▭ indicates statistical significance at the 95% CL with one or more values in the row.*

About CISCRP

Founded in 2003, the Center for Information and Study on Clinical Research Participation (CISCRP) is an independent, Boston-based, globally focused nonprofit organization. In addition to conducting periodic research on public and patient attitudes and experiences, CISCRP also provides a variety of educational initiatives including:

AWARE for All clinical research education programs designed to introduce individuals to their local research community through sessions, workshops, and free health screenings. Between 2003 and 2015, these live and online programs have reached 450,000 households in cities across the United States and in Europe.

Medical Heroes public service campaigns raise awareness and appreciation for the brave individuals who give the gift of participation in clinical research each year. Our Medical Heroes communications generate over 120 million impressions quarterly.

Educational books, DVDs, and brochures cover a wide range of topics for research participants, in culturally sensitive 6th to 8th grade reading level language, and are translated into two dozen languages. Since 2004, investigative sites, sponsors, and CROs have distributed nearly one million copies.

SearchClinicalTrials.org is a “high touch” service designed to manually search for relevant clinical trials on behalf of patients, family, and friends overwhelmed by the online search process. CISCRP performs searches for nearly 5,000 unique requests annually.

Patient Advisory Board panels are an invaluable approach to engaging study volunteers and enhancing their participation experience. Patient advisory boards also provide unprecedented insight into improving study feasibility, recruitment and retention, and in understanding patient perceptions and receptivity to current approaches, new practices and technology solutions. CISCRP has collaborated with top pharmaceutical companies on patient advisory boards in various therapeutic areas.

Clinical trial results communication program—one of our most active and fastest growing initiatives—involves the translation of technical clinical trial results for study volunteers who participated in those trials. CISCRP is now collaborating regularly with nearly 30 major pharmaceutical companies to provide non-technical, plain-language clinical trial results summaries.

For more information about any of our services, contact CISCRP at 617-725-2750 or visit our web site at www.ciscrp.org.

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