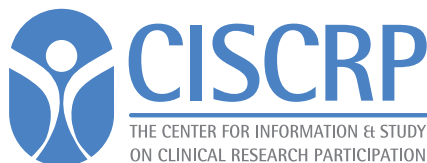


# 2017 Perceptions & Insights Study

Public and Patient Perceptions of  
Clinical Research



## Report on **General Perceptions and Knowledge on Clinical Research**

There are many factors that can shape the public's and patients' views on clinical research. These can include various demographic variables, the local healthcare environment, overall health status, exposure to educational initiatives, and the experience of actual participation in a clinical trial. To what extent do these variables impact perceptions of clinical research? How have attitudes changed over the years? Patients and the public from around the world provide answers to these important questions and more in this latest survey.

In this report, CISCRP takes an in-depth look at general perceptions and knowledge of clinical research and reveals opportunities for stakeholders to develop targeted educational initiatives to meet the unique needs of various populations, and to positively influence perceptions going forward.

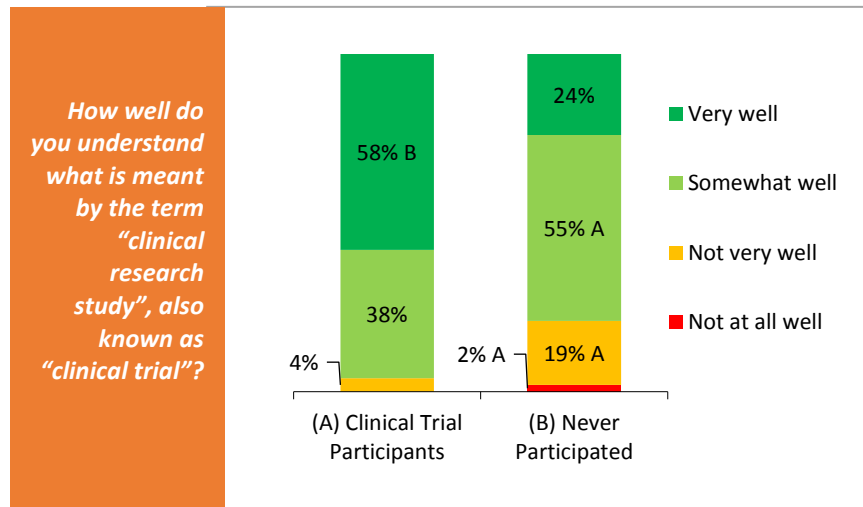
The Center for Information and Study on Clinical Research Participation (CISCRP), founded in 2003, is a non-profit organization dedicated to educating the public and patients about the important role that clinical research plays in advancing public health. As part of its mission, CISCRP provides a variety 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.

## General clinical research perceptions remain unchanged

In general, overall attitudes towards clinical research remain the same as that measured 2 years ago. Most people still view clinical research as safe and their perceptions of the greatest benefits (altruistic reasons and improving one's condition) and risks (side effects and risk to overall health) align with findings from prior studies.

As in years past, people from North America believe they understand the term 'clinical research' more than other regions. Clinical study participants are also significantly more informed than those who have never participated.

Younger people are generally less knowledgeable about clinical research – not knowing where clinical trials are conducted, not knowing what agency oversees the safety of clinical research and unaware of the general duration to develop a drug.



Base: (A) Clinical trial participants who reported having heard the term (n=2,099), (B) Never participated who reported having heard the term (n=8,744) Sample Size = 10,843; Letters indicate statistical significance at the 95% CL

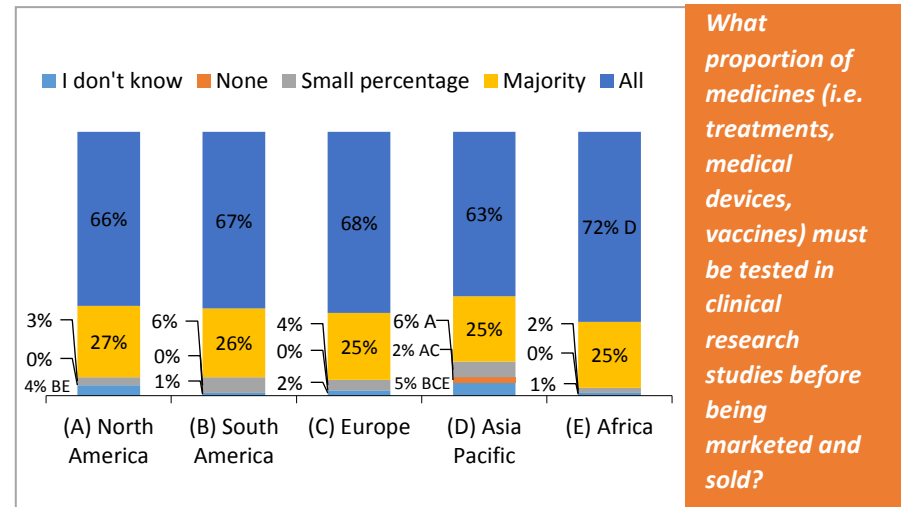
	AGE				
How well understood	18-34	35-44	45-54	55-64	65+
Not at all well	3%	3%	2%	1%	2%
Not very well	17%	14%	16%	15%	17%
Somewhat well	48%	54%	51%	52%	53%
Very well	32%	30%	31%	32%	28%

Sample Size = 10,843, Base: Those who indicated having heard the term  
 □ Indicates statistical significance at the 95% CL

## Taking a closer look at the "well-informed"

While the majority (82%) of people around the world self-reported feeling well-informed about clinical research, results indicate that the level of knowledge is superficial.

Among those people who report being informed, only 66% think that all medicines must be tested in a clinical study prior to marketing, about half do not know where clinical trials are conducted, the majority are unable to name an agency that oversees the safety of clinical research, and almost half think it takes 5 years or less to develop a drug.



Base: (A) North America (n=4,722), (B) South America (n=513), (C) Europe (n=2,278), (D) Asia Pacific (n=1,011), (E) Africa (n=396), Letters indicate statistical significance at the 95% CL

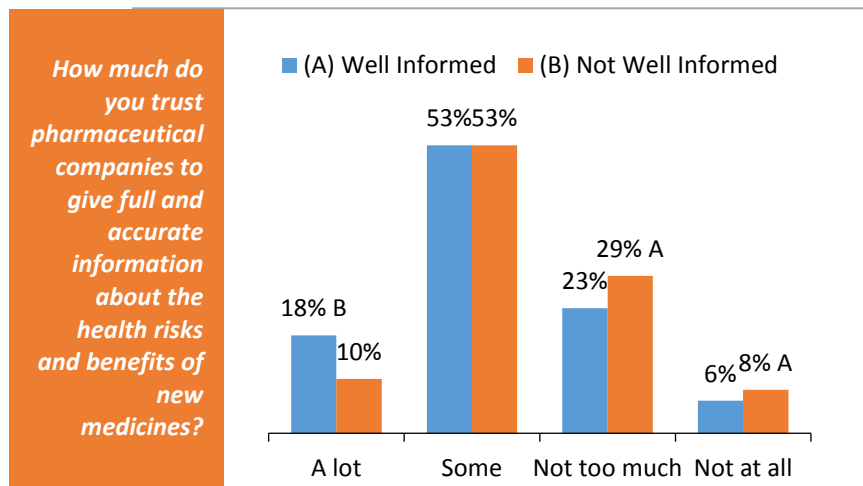
BASE:	% who answered
Those who self-reported being "well-informed" about clinical research	
What proportion of medications are tested?	66% ("all")
Do you know where clinical research is conducted?	51% ("no")
Can you name an agency that oversees safety?	62% ("no")
How long does it generally take to develop a new drug?	43% ("5 years or less")

Sample Size = 8,920 Base: Those who reported understanding the term well  
 □ Indicates statistical significance at the 95% CL

## Lack of knowledge negatively impacts clinical research perceptions

People who are more informed about clinical research generally express more positive views towards the enterprise and want to be aware of clinical studies being conducted in their own communities.

People who are less informed about clinical research are less likely to trust pharmaceutical companies, less likely to think clinical research is important to the discovery of new medicines, are less interested in being aware of studies conducted in their communities, and are less likely to think that clinical trials are safe.



Base: Well informed (n=8,921), Not well informed (n=1,922), Sample Size = 10,843, Letters indicate statistical significance at the 95% CL

PERCEPTIONS OF CLINICAL RESEARCH		
	Well Informed	Not Well Informed
Research is 'very important' to drug development	89%	78%
Perceive clinical research as safe	92%	84%
Feel it is 'very important' to be aware of studies in community	46%	35%

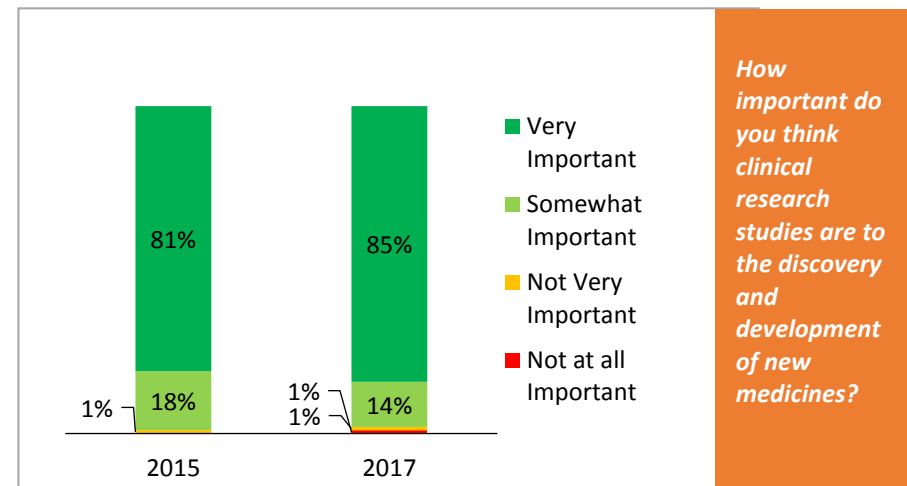
□ Indicates statistical significance at the 95% CL

## Most people agree that clinical research is very important to the discovery of new medicines

Similar to findings in 2015, the majority (85%) of the public exhibits good understanding of the value of clinical research.

Older people and females place higher value on the importance of clinical research than their counterparts.

People from Europe and Asia find clinical research less important than other regions.



Sample Size (2015) = 12,009, Sample Size (2017) = 12,427, Base: All respondents

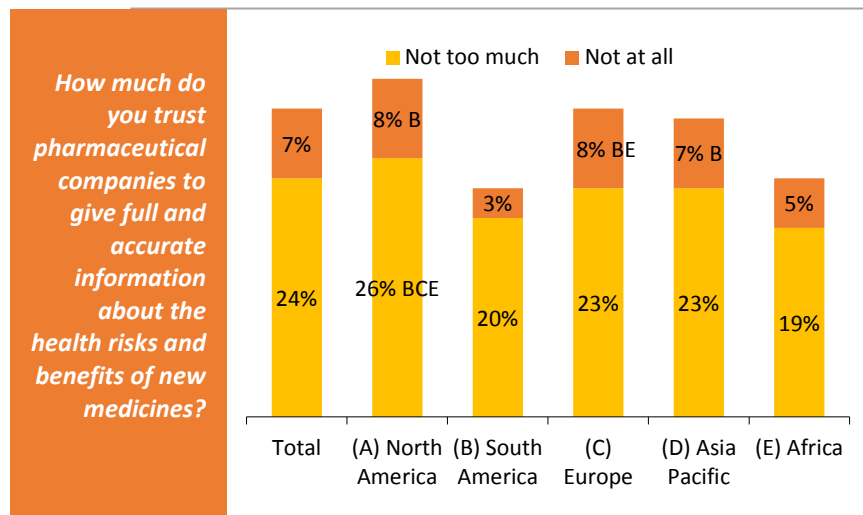
REGION					
	North America	South America	Europe	Asia Pacific	Africa
Not at all/not very important	0%	2%	4%	3%	0%
Somewhat important	11%	12%	18%	15%	8%
Very important	88%	86%	78%	82%	91%

□ Indicates statistical significance at the 95% CL

## But many people mistrust pharma companies to some extent

People from North America express the highest level of mistrust compared to other regions. Additionally, the level of trust decreases with age, with older people placing less trust in pharmaceutical companies than their younger counterparts.

The Asian population is the least likely to indicate that they trust pharmaceutical companies “a lot”.



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

AGE					
How much trust pharma	18-34	35-44	45-54	55-64	65+
Not too much/not at all	24%	31%	31%	33%	35%
Some	53%	52%	55%	51%	51%
A lot	22%	17%	14%	16%	14%

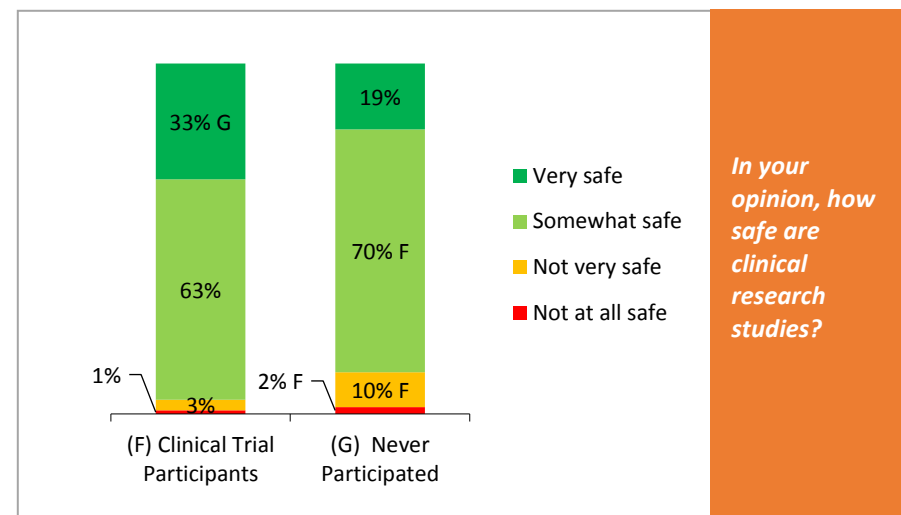
RACE			
How much trust pharma	White	Black/African American	Asian
Not too much/not at all	32%	28%	26%
Some	51%	51%	65%
A lot	16%	21%	9%

□ Indicates statistical significance at the 95% CL

## Most still view clinical research studies as safe however

Overall, perceptions on the safety of clinical research remain unchanged – with the majority of the public (90%) viewing studies as ‘somewhat/very safe’. Clinical study participants are much more likely to perceive studies as ‘very safe’ compared to those who have never participated. People from Europe and the Asia Pacific regions, as well as younger populations, are less likely to find clinical studies to be safe.

Concerns about side effects, lack of trust in pharmaceutical companies, and symptoms becoming worse if placed on a placebo were some of the top mentioned reasons for viewing research as unsafe.



Base: (F) Clinical trial participants (n=2,194), (G) Non-participants (n=10,233), Sample Size = 12,427; Letters indicate statistical significance at the 95% CL

TOP REASONS PEOPLE FEEL CLINICAL RESEARCH IS NOT SAFE	
There may be side effects	65%
I don't trust pharmaceutical companies	37%
Symptoms may worsen with placebo	29%
The safety of clinical studies are not monitored closely enough	25%
I don't know enough about clinical studies	21%

Base: (n=1,244) Those who indicated clinical research studies are not safe

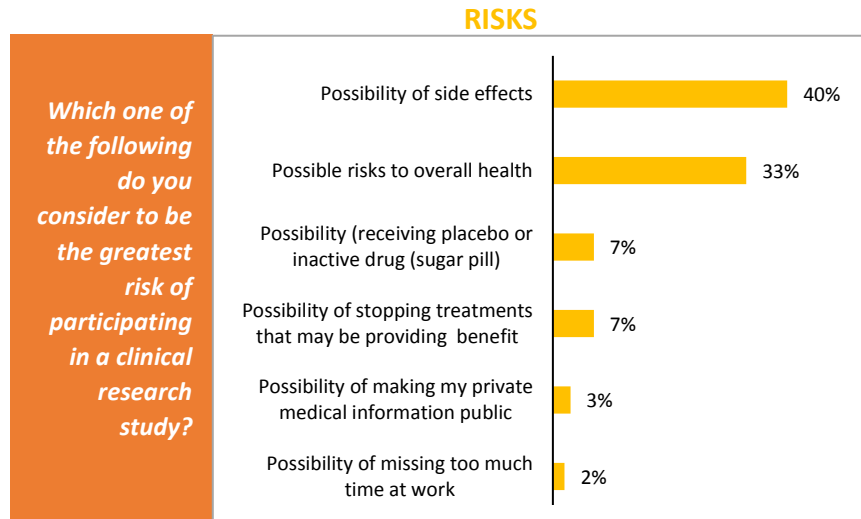
□ Indicates statistical significance at the 95% CL

## Top perceived risks of participation

Similar to previous studies, the possibility of side effects and possible risks to overall health are still viewed as the top risks of participating in a clinical study.

People from the Asia Pacific region exhibit higher concern about the possibility of side effects compared to other regions.

Younger populations are more concerned about the possibility of missing too much work and privacy issues, while older populations express more concern with receiving a placebo and the possibility of discontinuing a treatment that may be of some benefit.



Sample Size = 12,427, Base: All respondents

**AGE**

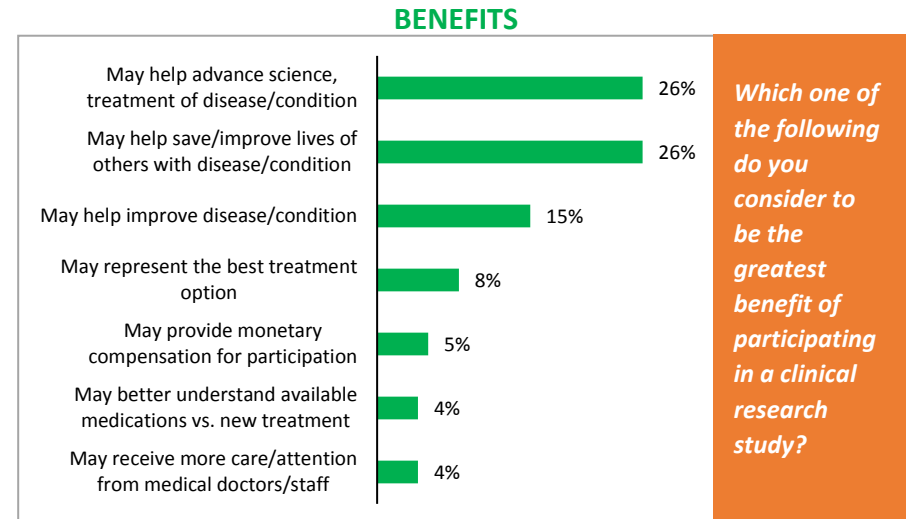
	18-34	35-44	45-54	55-64	65+
<b>Receiving a placebo</b>	4%	5%	6%	7%	10%
<b>Missing too much work</b>	4%	4%	2%	1%	0%
<b>Privacy</b>	4%	4%	3%	2%	1%

□ Indicates statistical significance at the 95% CL

## Top perceived benefits of participation

Also similar to prior studies, people rank altruistic reasons (such as helping others and helping to advance science) as the greatest benefits of participating in a clinical study.

Younger people are more likely to additionally view monetary compensation and receiving free medicine as benefits when compared to older people. Additionally, helping family members understand an inherited condition is another benefit younger populations identify with.



Sample Size = 12,427, Base: All respondents

**REGION**

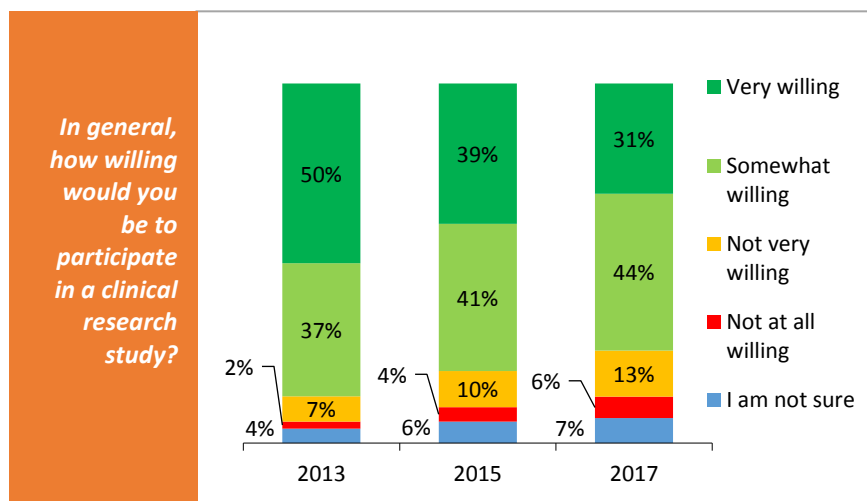
	North America	South America	Europe	Asia Pacific	Africa
<b>Improve condition</b>	18%	10%	15%	12%	9%
<b>Monetary compensation</b>	3%	5%	6%	7%	4%
<b>Free medical procedures/care</b>	3%	6%	2%	4%	3%

□ Indicates statistical significance at the 95% CL

## Most are willing to participate, lower proportion 'very willing' in 2017

The proportion of people 'very willing' (31%) to participate is lower in 2017 compared to prior studies. However, those who have participated in a clinical trial in the past are much more willing to participate in general compared to those who have never participated in a study.

People from South America, Europe, and Asia are less willing to participate in a clinical study than people from other regions, with Asian populations the least willing to participate in a clinical trial. Younger populations indicated a lower willingness to participate as well.



Sample Size (2013) = 5,701, Sample Size (2015) = 12,009, Sample Size (2017) = 12,427, Base: All respondents

REGION					
	North America	South America	Europe	Asia Pacific	Africa
Not at all/not very willing	11%	24%	25%	28%	18%
Somewhat willing	44%	42%	43%	41%	46%
Very willing	39%	30%	23%	22%	31%
I am not sure	6%	4%	9%	9%	5%

Sample Size = 12,427, Base: All respondents

□ Indicates statistical significance at the 95% CL

AGE					
	18-34	35-44	45-54	55-64	65+
Not at all/not very willing	25%	22%	19%	16%	17%
Somewhat willing	42%	42%	42%	43%	46%
Very willing	27%	28%	31%	35%	30%
I am not sure	6%	8%	9%	6%	6%

RACE			
	White	Black/African American	Asian
Not at all/not very willing	16%	14%	38%
Somewhat willing	45%	40%	37%
Very willing	32%	40%	16%
I am not sure	6%	7%	10%

ETHNICITY		
	Non-Hispanic	Hispanic
Not at all/not very willing	18%	21%
Somewhat willing	44%	43%
Very willing	31%	31%
I am not sure	7%	5%

PARTICIPATION IN CLINICAL TRIAL		
	Participated in clinical trial	Never participated
Not at all/not very willing	5%	21%
Somewhat willing	33%	46%
Very willing	59%	25%
I am not sure	2%	8%

Sample Size = 12,427, Base: All respondents

□ 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.

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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](http://www.ciscrp.org).

