CISCRP

THE CENTER FOR INFORMATION & STUDY
ON CLINICAL RESEARCH PARTICIPATION

Report on the Decision to Participate

2015 PERCEPTIONS & INSIGHTS STUDY

Foreword

The clinical research enterprise is undergoing profound change as it embraces a patient-centric approach to planning and executing clinical research activity. The Center for Information and Study on Clinical Research Participation (CISCRP), a nonprofit organization founded in 2003, is dedicated to supporting the enterprise as it navigates this transition and successfully engages patients and their community of health care support as partners in the clinical research process.

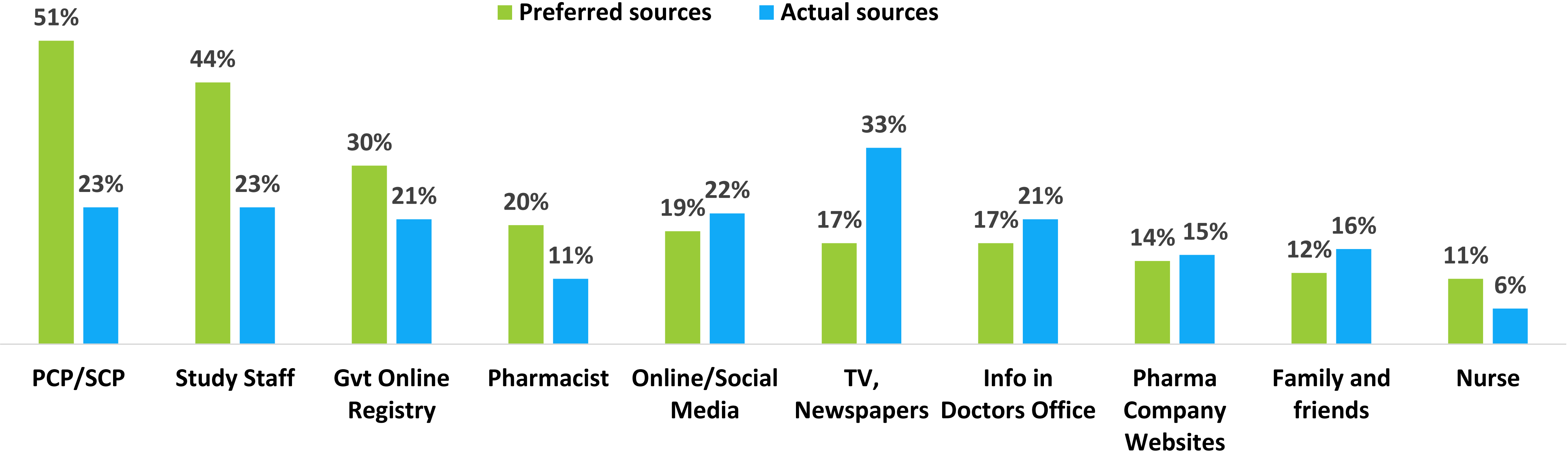
CISCRP's 2015 Perceptions & Insights Study provides valuable and substantive insights into actionable ways that clinical research stakeholders can better understand and more effectively engage with the public and study volunteers.

More than 12,000 people worldwide completed the 2015 Perceptions & Insights survey making this study the largest global assessment of clinical research attitudes, perceptions, behaviors and experiences among the public and patients ever conducted.

In this report CISCRP explores the patient's decision to participate in clinical research. The overall results and subgroup differences - by geographic region, race & ethnicity, income and education level, age and severity of disease - are presented. Throughout the report, we note significant comparisons and key takeaways.

Table of Contents

Preferred and Actual Sources for Information about Clinical Research Studies



Source: 2015 CISCRP Perceptions & Insights Study – All Respondents (n=12,009)

		REGION				***RACE***			***ETHNICITY***	
PREFERRED SOURCES	**OVERALL**	**North America**	**South America**	**Europe**	**Asia Pacific**	**White**	**Black/African American**	**Asian**	**Non-Hispanic**	**Hispanic**
TV/newspapers	17%	15%	28%	15%	21%	16%	23%	24%	16%	23%
PCP/SCP	51%	57%	37%	41%	51%	53%	47%	37%	54%	40%
Research study staff	44%	45%	45%	37%	47%	44%	46%	40%	44%	44%
Online/social media	19%	16%	30%	20%	19%	18%	20%	27%	17%	27%
Info in dr office	17%	17%	17%	14%	17%	16%	21%	19%	17%	16%
Gvt online registry	30%	30%	31%	27%	35%	29%	36%	31%	30%	31%
Family/friends	12%	10%	21%	14%	12%	11%	13%	21%	11%	19%
Pharma company websites	14%	10%	31%	15%	14%	12%	18%	25%	12%	25%
Pharmacist	20%	19%	20%	19%	21%	20%	19%	22%	19%	21%

*A 3% difference is statistically significant at a 95% confidence interval

Source: 2015 CISCRP Perceptions & Insights Study – All Respondents (n=12,009)

		EDUCATION				*INCOME*			
PREFERRED SOURCES	**OVERALL**	**None/primary education only**	**Some/ completed high school**	**Some/ completed college**	**Some/ completed post-graduate**	**Less than $25,000**	**$25,000 to $49,999**	**$50,000 to $99,999**	**$100,000 or more**
TV/newspapers	17%	18%	16%	17%	18%	19%	16%	17%	16%
PCP/SCP	51%	28%	46%	54%	52%	46%	51%	55%	57%
Research study staff	44%	20%	38%	45%	47%	43%	43%	44%	45%
Online/social media	19%	20%	17%	20%	17%	21%	18%	16%	17%
Info in dr office	17%	14%	15%	17%	17%	18%	16%	15%	15%
Gvt online registry	30%	19%	27%	31%	33%	32%	29%	29%	28%
Family/friends	12%	20%	12%	12%	12%	13%	13%	11%	9%
Pharma company websites	14%	17%	13%	14%	15%	18%	13%	12%	12%
Pharmacist	20%	16%	20%	20%	19%	21%	21%	18%	17%

*A 3% difference is statistically significant at a 95% confidence interval

Source: 2015 CISCRP Perceptions & Insights Study – All Respondents (n=12,009)

		AGE					SEVERITY OF DISEASE				
PREFERRED SOURCES	**OVERALL**	**18 to 34 years old**	**35 to 44 years old**	**45 to 54 years old**	**55 to 64 years old**	**65 and older**	**Very mild**	**Mild**	**Moderate**	**Severe**	**Very severe**
TV/newspapers	17%	19%	18%	17%	17%	16%	23%	23%	23%	22%	29%
PCP/SCP	51%	38%	46%	49%	57%	61%	51%	44%	53%	57%	55%
Research study staff	44%	36%	39%	41%	47%	51%	50%	48%	52%	56%	52%
Online/social media	19%	23%	21%	21%	17%	14%	20%	17%	19%	18%	24%
Info in dr office	17%	17%	15%	17%	17%	17%	25%	18%	20%	21%	27%
Gvt online registry	30%	29%	28%	32%	32%	29%	33%	32%	35%	39%	43%
Family/friends	12%	20%	16%	11%	9%	7%	15%	14%	11%	9%	16%
Pharma company websites	14%	20%	16%	15%	11%	8%	16%	14%	13%	14%	15%
Pharmacist	20%	21%	18%	20%	20%	19%	21%	19%	20%	20%	22%

*A 3% difference is statistically significant at a 95% confidence interval

Source: 2015 CISCRP Perceptions & Insights Study – All Respondents (n=12,009)

		REGION				*RACE*			*ETHNICITY*	
ACTUAL SOURCES	**OVERALL**	**North America**	**South America**	**Europe**	**Asia Pacific**	**White**	**Black/African American**	**Asian**	**Non-Hispanic**	**Hispanic**
TV/newspapers	33%	37%	30%	24%	36%	33%	40%	35%	34%	31%
PCP/SCP	23%	24%	24%	20%	26%	23%	22%	29%	23%	24%
Research study staff	23%	25%	23%	20%	23%	23%	24%	27%	23%	22%
Online/social media	22%	21%	24%	21%	23%	22%	21%	27%	22%	25%
Info in dr office	21%	22%	21%	15%	20%	20%	24%	23%	20%	21%
Gvt online registry	21%	23%	19%	16%	20%	20%	28%	29%	21%	20%
Family/friends	16%	13%	29%	18%	17%	15%	15%	26%	14%	24%
Pharma company websites	15%	12%	31%	17%	17%	14%	15%	25%	18%	12%
Pharmacist	11%	7%	19%	14%	15%	10%	9%	17%	9%	17%

*A 3% difference is statistically significant at a 95% confidence interval

Source: 2015 CISCRP Perceptions & Insights Study – All Respondents (n=12,009)

		EDUCATION				*INCOME*			
ACTUAL SOURCES	**OVERALL**	**None/primary education only**	**Some/ completed high school**	**Some/ completed college**	**Some/ completed post-graduate**	**Less than $25,000**	**$25,000 to $49,999**	**$50,000 to $99,999**	**$100,000 or more**
TV/newspapers	33%	22%	27%	36%	35%	32%	34%	34%	37%
PCP/SCP	23%	19%	20%	24%	29%	21%	23%	26%	27%
Research study staff	23%	17%	17%	23%	31%	22%	22%	26%	26%
Online/social media	22%	23%	18%	23%	24%	23%	22%	22%	19%
Info in dr office	21%	17%	18%	22%	22%	21%	20%	21%	20%
Gvt online registry	21%	18%	18%	22%	22%	23%	20%	21%	21%
Family/friends	16%	21%	15%	16%	17%	18%	15%	15%	14%
Pharma company websites	15%	18%	12%	15%	17%	17%	14%	15%	14%
Pharmacist	11%	25%	11%	10%	11%	12%	11%	10%	9%

*A 3% difference is statistically significant at a 95% confidence interval

Source: 2015 CISCRP Perceptions & Insights Study – All Respondents (n=12,009)

		AGE					*SEVERITY OF DISEASE*				
ACTUAL SOURCES	**OVERALL**	**18 to 34 years old**	**35 to 44 years old**	**45 to 54 years old**	**55 to 64 years old**	**65 and older**	**Very mild**	**Mild**	**Moderate**	**Severe**	**Very severe**
TV/newspapers	33%	29%	31%	32%	36%	38%	39%	36%	43%	43%	45%
PCP/SCP	23%	20%	21%	23%	25%	26%	32%	27%	30%	31%	40%
Research study staff	23%	18%	21%	22%	25%	27%	43%	39%	43%	46%	45%
Online/social media	22%	25%	22%	23%	22%	19%	22%	24%	25%	26%	24%
Info in dr office	21%	21%	21%	20%	20%	21%	29%	25%	25%	28%	22%
Gvt online registry	21%	19%	20%	23%	22%	19%	26%	26%	32%	35%	37%
Family/friends	16%	26%	18%	15%	11%	11%	19%	17%	14%	13%	13%
Pharma company websites	15%	21%	17%	16%	12%	11%	17%	16%	14%	14%	13%
Pharmacist	11%	14%	13%	11%	9%	9%	12%	12%	10%	9%	8%

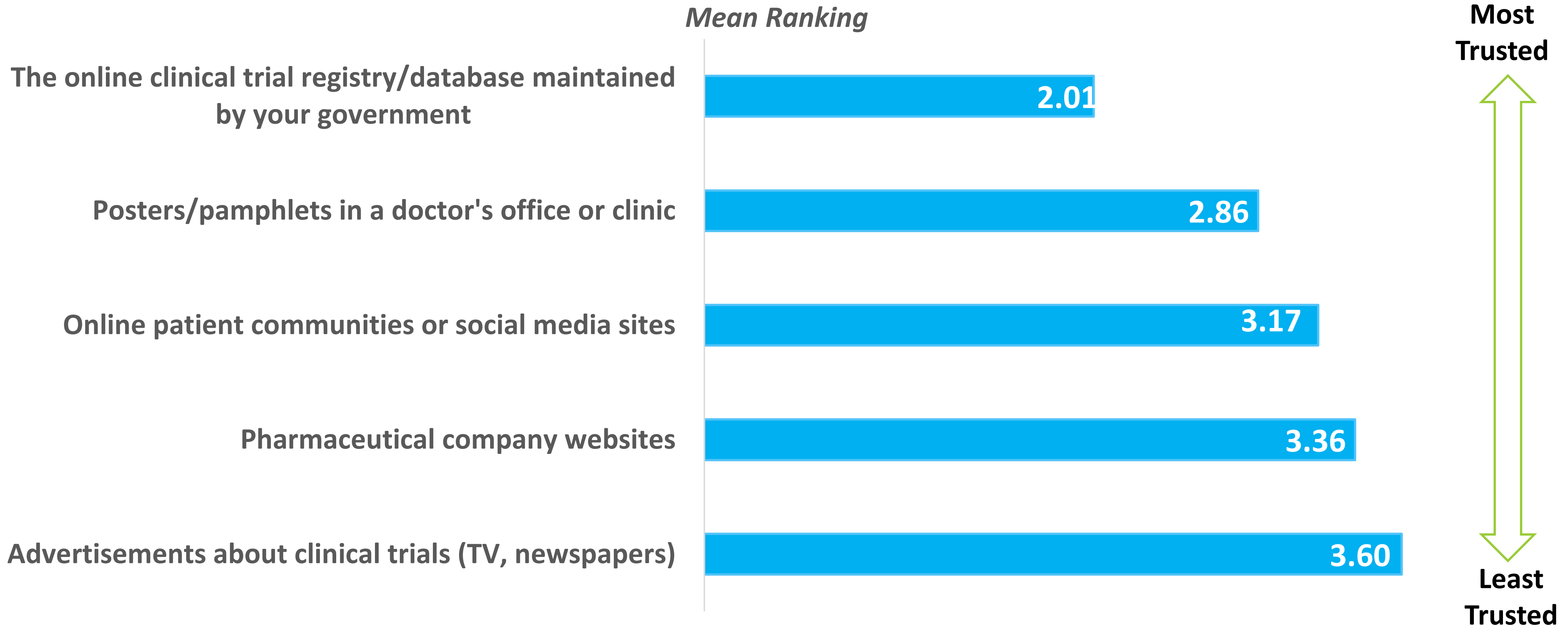
*A 3% difference is statistically significant at a 95% confidence interval

Source: 2015 CISCRP Perceptions & Insights Study – All Respondents (n=12,009)

Takeaways

- While most respondents would prefer to receive clinical research information from their primary care physician (51%) or research study staff (44%), much lower proportions actually receive information from those two sources (23%). Current information sources vary widely – with about a third of respondents mentioning ads about clinical trials (on TV, newspapers, etc..) as a current information source. A similar pattern prevailed in 2013.
- A significantly higher proportion of respondents from South America currently receive clinical research information from family and friends (29%), as well as pharmaceutical company websites (31%), compared to other regions.
- Higher percentages of Black/African American (28%) respondents, as well as Asian respondents (29%), identify the online government registry as a current source of clinical research information compared to North America (20%). Hispanics report family/friends as a current information source more so than non-Hispanics.
- More younger respondents report online/social media and family/friends as current sources of information compared to older respondents.

Level of Trust in Clinical Research Study Information Sources



Source: 2015 CISCRP Perceptions & Insights Study – All Respondents (n=12,009)

		REGION				*RACE*			*ETHNICITY*	
	OVERALL (mean)	**North America**	**South America**	**Europe**	**Asia Pacific**	**White**	**Black/African American**	**Asian**	**Non-Hispanic**	**Hispanic**
Online clinical trial registry	2.01	1.96	2.30	2.02	1.84	1.97	2.15	2.22	1.96	2.19
Posters/pamphlets in dr office	2.86	2.69	3.52	3.01	2.88	2.82	2.91	3.07	2.77	3.31
Online patient communities	3.17	3.22	2.96	3.07	3.28	3.17	3.32	3.15	3.19	3.06
Pharma company websites	3.36	3.41	3.09	3.32	3.55	3.39	3.19	3.18	3.40	3.16
Ads about clinical trials	3.60	3.71	3.13	3.59	3.44	3.65	3.42	3.38	3.67	3.28

Source: 2015 CISCRP Perceptions & Insights Study – All Respondents (n=12,009)

		EDUCATION				*INCOME*			
	OVERALL (mean)	**None/primary education only**	**Some/ completed high school**	**Some/ completed college**	**Some/ completed post-graduate**	**Less than $25,000**	**$25,000 to $49,999**	**$50,000 to $99,999**	**$100,000 or more**
Online clinical trial registry	2.01	2.49	2.15	1.98	1.85	2.07	2.02	1.97	1.86
Posters/pamphlets in dr office	2.86	2.97	2.89	2.83	2.87	2.97	2.85	2.77	2.83
Online patient communities	3.17	3.41	3.17	3.17	3.20	3.20	3.17	3.20	3.11
Pharma company websites	3.36	3.28	3.25	3.37	3.49	3.24	3.35	3.42	3.54
Ads about clinical trials	3.60	2.85	3.54	3.65	3.60	3.53	3.61	3.63	3.66

Source: 2015 CISCRP Perceptions & Insights Study – All Respondents (n=12,009)

		AGE					*SEVERITY OF DISEASE*				
	OVERALL (mean)	**18 to 34 years old**	**35 to 44 years old**	**45 to 54 years old**	**55 to 64 years old**	**65 and older**	**Very mild**	**Mild**	**Moderate**	**Severe**	**Very severe**
Online clinical trial registry	2.01	2.12	2.12	2.03	1.94	1.89	2.07	2.12	1.98	2.02	2.00
Posters/pamphlets in dr office	2.86	3.03	3.01	2.93	2.74	2.65	2.75	2.88	2.75	2.69	2.51
Online patient communities	3.17	3.21	3.05	3.13	3.19	3.24	3.30	3.36	3.27	3.42	3.26
Pharma company websites	3.36	3.16	3.27	3.26	3.45	3.59	3.49	3.38	3.51	3.47	3.57
Ads about clinical trials	3.60	3.48	3.55	3.64	3.68	3.63	3.38	3.26	3.49	3.40	3.65

Source: 2015 CISCRP Perceptions & Insights Study – All Respondents (n=12,009)

Takeaways

- Respondents report placing the most trust in the clinical research information provided on the online clinical trial registry maintained by their government. This is followed by posters or pamphlets found in a doctor's office or clinic. Respondents indicate that they least trust the clinical research information relayed through advertisements about clinical trials on television or in newspapers.
- Respondents from South America report placing more trust in online patient communities/social media sites and pharmaceutical company websites compared to other regions. In contrast to other regions, these respondents least trust the information found in doctor's offices or clinics.
- Hispanics rank the clinical research information found in doctor's offices or clinics as the least trusted source of clinical research information.
- Less educated respondents indicate placing more trust in clinical research information relayed through advertisements seen on television or in newspapers.

Most Important Information Prior to Decision to Participate

	% who rated 'very important'
Potential risks and benefits	75%
Purpose of the clinical research study	69%
Physical location of the research center (distance from home or work)	55%
If my confidentiality would be protected	56%
Number of study visits and types of medical procedures required	53%
If I would receive a summary of the study results after my participation ended	52%
Length of participation in the clinical research study (time commitment)	49%
Potential costs and reimbursements	49%
If I would have access to the study drug after my participation ended	42%
Hearing about the experiences of previous research participants	40%

Source: 2015 CISCRP Perceptions & Insights Study – All Respondents (n=12,009)

		REGION				*RACE*			*ETHNICITY*	
% rated 'very important'	OVERALL	North America	South America	Europe	Asia Pacific	White	Black/African American	Asian	Non-Hispanic	Hispanic
Risks/benefits	75%	81%	68%	66%	70%	76%	81%	66%	77%	69%
Study purpose	69%	74%	64%	54%	70%	69%	78%	58%	70%	64%
Site location	55%	63%	42%	41%	48%	55%	61%	46%	57%	48%
Confidentiality	56%	62%	57%	45%	50%	55%	71%	55%	56%	58%
# of study visits	53%	60%	47%	39%	47%	52%	67%	50%	54%	49%
Receive study summary	52%	54%	57%	41%	56%	51%	64%	51%	52%	56%
Time commitment	49%	54%	43%	38%	44%	47%	63%	49%	49%	45%
Costs	49%	57%	45%	39%	39%	48%	62%	44%	50%	50%
Access to study drug	42%	46%	43%	30%	39%	41%	48%	37%	42%	43%
Hearing experience of others	40%	41%	45%	36%	39%	38%	52%	45%	39%	45%

*A 3% difference is statistically significant at a 95% confidence interval

Source: 2015 CISCRP Perceptions & Insights Study – All Respondents (n=12,009)

% rated 'very important'	OVERALL	*EDUCATION* None/primary education only	Some/ completed high school	Some/ completed college	Some/ completed post-graduate	*INCOME* Less than $25,000	$25,000 to $49,999	$50,000 to $99,999	$100,000 or more
Risks/benefits	75%	46%	72%	77%	76%	74%	74%	77%	80%
Study purpose	69%	45%	65%	71%	67%	68%	68%	69%	71%
Site location	55%	43%	56%	56%	50%	56%	55%	56%	55%
Confidentiality	56%	41%	55%	58%	54%	57%	55%	54%	57%
# of study visits	53%	37%	53%	54%	51%	52%	52%	54%	55%
Receive study summary	52%	37%	53%	53%	48%	54%	51%	49%	49%
Time commitment	49%	33%	48%	49%	47%	48%	48%	48%	51%
Costs	49%	35%	50%	50%	43%	55%	50%	47%	44%
Access to study drug	42%	33%	41%	43%	40%	43%	40%	40%	44%
Hearing experience of others	40%	35%	43%	40%	36%	44%	38%	38%	38%

*A 3% difference is statistically significant at a 95% confidence interval

Source: 2015 CISCRP Perceptions & Insights Study – All Respondents (n=12,009)

		AGE					*SEVERITY OF DISEASE*				
% rated ‘very important’	**OVERALL**	**18 to 34 years old**	**35 to 44 years old**	**45 to 54 years old**	**55 to 64 years old**	**65 and older**	**Very mild**	**Mild**	**Moderate**	**Severe**	**Very severe**
Risks/benefits	75%	68%	74%	77%	80%	76%	71%	63%	68%	74%	78%
Study purpose	69%	58%	63%	70%	74%	75%	70%	58%	65%	77%	75%
Site location	55%	44%	52%	59%	60%	56%	51%	44%	49%	55%	55%
Confidentiality	56%	52%	58%	60%	60%	51%	55%	52%	50%	58%	66%
# of study visits	53%	48%	52%	57%	57%	50%	51%	42%	43%	50%	54%
Receive study summary	52%	47%	50%	53%	54%	56%	49%	41%	44%	49%	56%
Time commitment	49%	45%	49%	51%	51%	45%	47%	40%	38%	43%	52%
Costs	49%	51%	53%	54%	50%	39%	43%	37%	37%	39%	46%
Access to study drug	42%	35%	41%	45%	45%	41%	41%	30%	35%	44%	52%
Hearing experience of others	40%	43%	45%	41%	38%	35%	36%	24%	28%	29%	35%

*A 3% difference is statistically significant at a 95% confidence interval

Source: 2015 CISCRP Perceptions & Insights Study – All Respondents (n=12,009)

Takeaways

- The majority of respondents agree that knowing the potential risks and benefits (mentioned by 75%), as well as the purpose of the clinical research study (mentioned by 69%), are the most valuable pieces of information to know prior to making a participation decision. Also important is the physical location of the medical center and whether his/her confidentiality would be protected.
- A higher proportion (63%) of respondents from North America is significantly more interested in the physical location of the medical center compared to other regions. Respondents from this region were also more concerned with the number of study visits and types of procedures required.
- Knowing whether he/she would have access to the study drug after participation is particularly important to those respondents with severe conditions (52%).

Top Factors Likely to Influence Participation Decision

Percent who indicated 'somewhat/very likely' to influence participation decision:	**2015 (n=12,009)**	**2013 (n=5,701)**
If I thought the drug/treatment would help me	86%	91%
If I thought a study drug might cure me	84%	88%
If my doctor recommended it	83%	84%
If I knew there were no risks involved	82%	85%
If I had a terminal illness (incurable or fatal)	80%	82%
If I knew the risks associated with the treatment	80%	82%
If I thought the drug/treatment would help someone else in the future	80%	84%
If the time commitment was reasonable	80%	80%

		REGION				RACE			ETHNICITY	
% rated 'somewhat /very likely'	OVERALL	North America	South America	Europe	Asia Pacific	White	Black/African American	Asian	Non-Hispanic	Hispanic
Thought treatment would help me	86%	90%	78%	78%	86%	88%	85%	77%	89%	78%
Thought treatment would cure me	84%	89%	78%	74%	82%	85%	84%	73%	86%	78%
Doctor recommended	83%	87%	74%	73%	85%	85%	81%	72%	85%	75%
No risks	82%	85%	77%	74%	80%	82%	83%	75%	83%	78%
Terminal illness	80%	83%	76%	73%	79%	82%	76%	68%	82%	74%
Knew risks	80%	85%	69%	69%	78%	81%	79%	65%	82%	72%
Help others	80%	84%	75%	69%	84%	81%	80%	71%	82%	76%
Time commitment	80%	85%	65%	66%	80%	81%	82%	67%	82%	68%

*A 3% difference is statistically significant at a 95% confidence interval

Source: 2015 CISCRP Perceptions & Insights Study – All Respondents (n=12,009)

		EDUCATION				*INCOME*			
% rated ‘somewhat /very likely’	**OVERALL**	**None/primary education only**	**Some/ completed high school**	**Some/ completed college**	**Some/ completed post-graduate**	**Less than $25,000**	**$25,000 to $49,999**	**$50,000 to $99,999**	**$100,000 or more**
Thought treatment would help me	86%	58%	83%	88%	87%	83%	87%	90%	92%
Thought treatment would cure me	84%	52%	81%	86%	84%	80%	84%	87%	90%
Doctor recommended	83%	54%	80%	85%	83%	78%	83%	87%	89%
No risks	82%	53%	78%	83%	83%	78%	81%	85%	88%
Terminal illness	80%	47%	75%	82%	83%	75%	81%	84%	88%
Knew risks	80%	47%	75%	81%	83%	75%	80%	85%	88%
Help others	80%	50%	77%	82%	79%	77%	81%	82%	84%
Time commitment	80%	50%	75%	81%	79%	74%	80%	84%	86%

*A 3% difference is statistically significant at a 95% confidence interval

Source: 2015 CISCRP Perceptions & Insights Study – All Respondents (n=12,009)

		AGE					*SEVERITY OF DISEASE*				
% rated ‘somewhat /very likely’	**OVERALL**	**18 to 34 years old**	**35 to 44 years old**	**45 to 54 years old**	**55 to 64 years old**	**65 and older**	**Very mild**	**Mild**	**Moderate**	**Severe**	**Very severe**
Thought treatment would help me	86%	75%	82%	87%	92%	93%	90%	81%	90%	95%	99%
Thought treatment would cure me	84%	73%	80%	85%	89%	89%	85%	81%	87%	92%	94%
Doctor recommended	83%	70%	78%	83%	88%	92%	88%	79%	87%	91%	91%
No risks	82%	74%	79%	83%	85%	85%	85%	76%	81%	84%	84%
Terminal illness	80%	71%	78%	82%	83%	83%	82%	75%	79%	84%	87%
Knew risks	80%	67%	76%	81%	86%	86%	84%	77%	85%	87%	87%
Help others	80%	69%	76%	81%	85%	87%	87%	81%	87%	92%	92%
Time commitment	80%	67%	73%	81%	86%	87%	86%	80%	87%	88%	90%

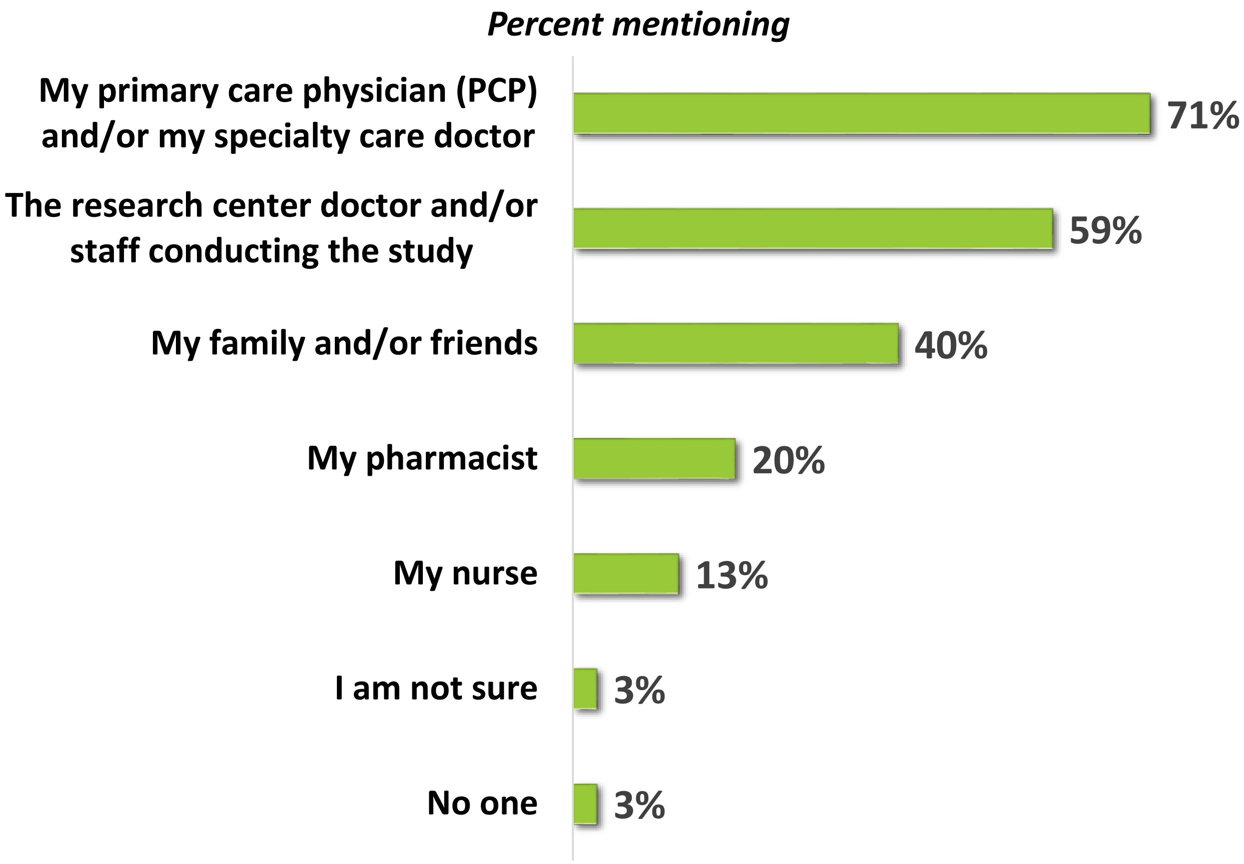
*A 3% difference is statistically significant at a 95% confidence interval

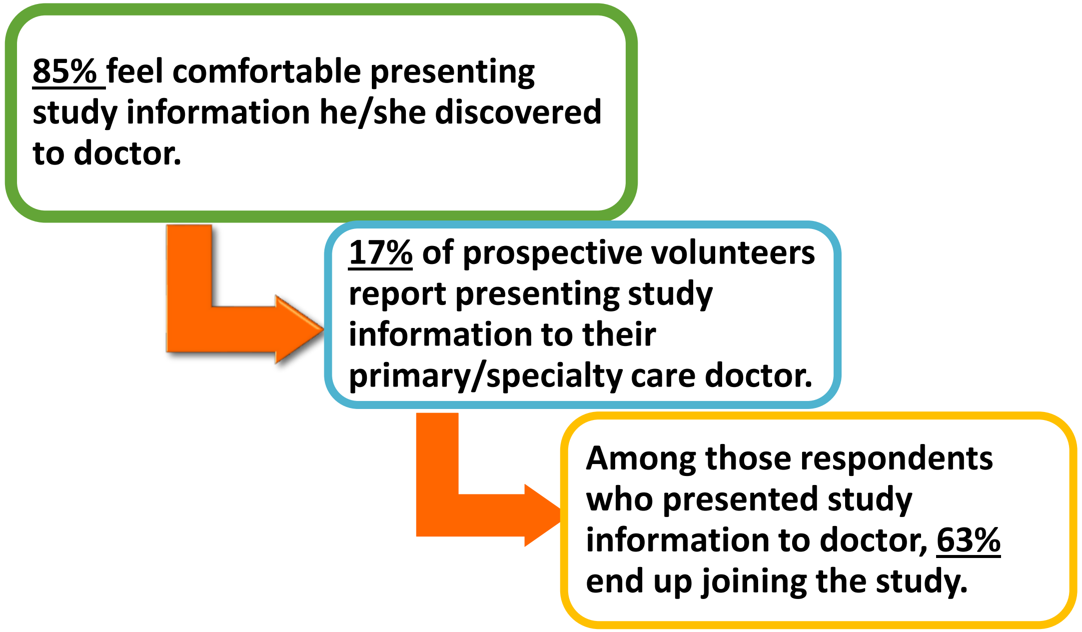
Source: 2015 CISCRP Perceptions & Insights Study – All Respondents (n=12,009)

Takeaways

- Similar to results in 2013, the top factors that are most likely to influence participation decisions are if a study/drug or treatment would help him/her (86%), if a study drug or treatment would cure him/her (84%), a doctor recommendation (83%), and if there were no risks involved (82%).
- A significantly higher proportion of respondents with a severe condition report being more likely to be influenced by the following factors particularly in comparison to those respondents with a mild condition - if they thought the study drug or treatment might help or cure them, if the doctor recommended participation, if they thought the study drug or treatment might help others, and if they had a terminal illness.

Which of the Following People Would you Talk to Before Participating?





85% feel comfortable presenting study information he/she discovered to doctor.

17% of prospective volunteers report presenting study information to their primary/specialty care doctor.

Among those respondents who presented study information to doctor, 63% end up joining the study.

Source: 2015 CISCRP Perceptions & Insights Study – All Respondents (n=12,009)

		REGION				RACE			ETHNICITY	
	OVERALL	North America	South America	Europe	Asia Pacific	White	Black/African American	Asian	Non-Hispanic	Hispanic
PCP/SCP	71%	77%	53%	60%	73%	73%	67%	58%	74%	59%
Research staff	59%	62%	47%	52%	63%	60%	57%	53%	62%	48%
Family/friends	40%	38%	53%	42%	44%	39%	39%	50%	39%	47%
Pharmacist	20%	20%	18%	19%	22%	20%	19%	25%	20%	19%
Nurse	13%	13%	14%	16%	11%	13%	17%	15%	13%	14%

		EDUCATION				INCOME			
	OVERALL	None/primary education only	Some/ completed high school	Some/ completed college	Some/ completed post-graduate	Less than $25,000	$25,000 to $49,999	$50,000 to $99,999	$100,000 or more
PCP/SCP	71%	38%	66%	73%	72%	66%	70%	77%	77%
Research staff	59%	37%	53%	62%	61%	57%	59%	61%	62%
Family/friends	40%	38%	39%	40%	40%	41%	40%	40%	39%
Pharmacist	20%	24%	19%	21%	21%	20%	21%	20%	19%
Nurse	13%	24%	13%	13%	13%	14%	13%	13%	13%

Source: 2015 CISCRP Perceptions & Insights Study – All Respondents (n=12,009)

		AGE					***SEVERITY OF DISEASE***				
	OVERALL	**18 to 34 years old**	**35 to 44 years old**	**45 to 54 years old**	**55 to 64 years old**	**65 and older**	**Very mild**	**Mild**	**Moderate**	**Severe**	**Very severe**
PCP/SCP	71%	56%	65%	71%	78%	82%	66%	60%	66%	73%	75%
Research staff	59%	48%	54%	58%	65%	67%	63%	59%	66%	72%	74%
Family/friends	40%	52%	47%	40%	35%	31%	35%	31%	33%	34%	28%
Pharmacist	20%	24%	19%	19%	21%	19%	21%	19%	16%	16%	21%
Nurse	13%	20%	14%	12%	11%	9%	18%	15%	13%	14%	20%

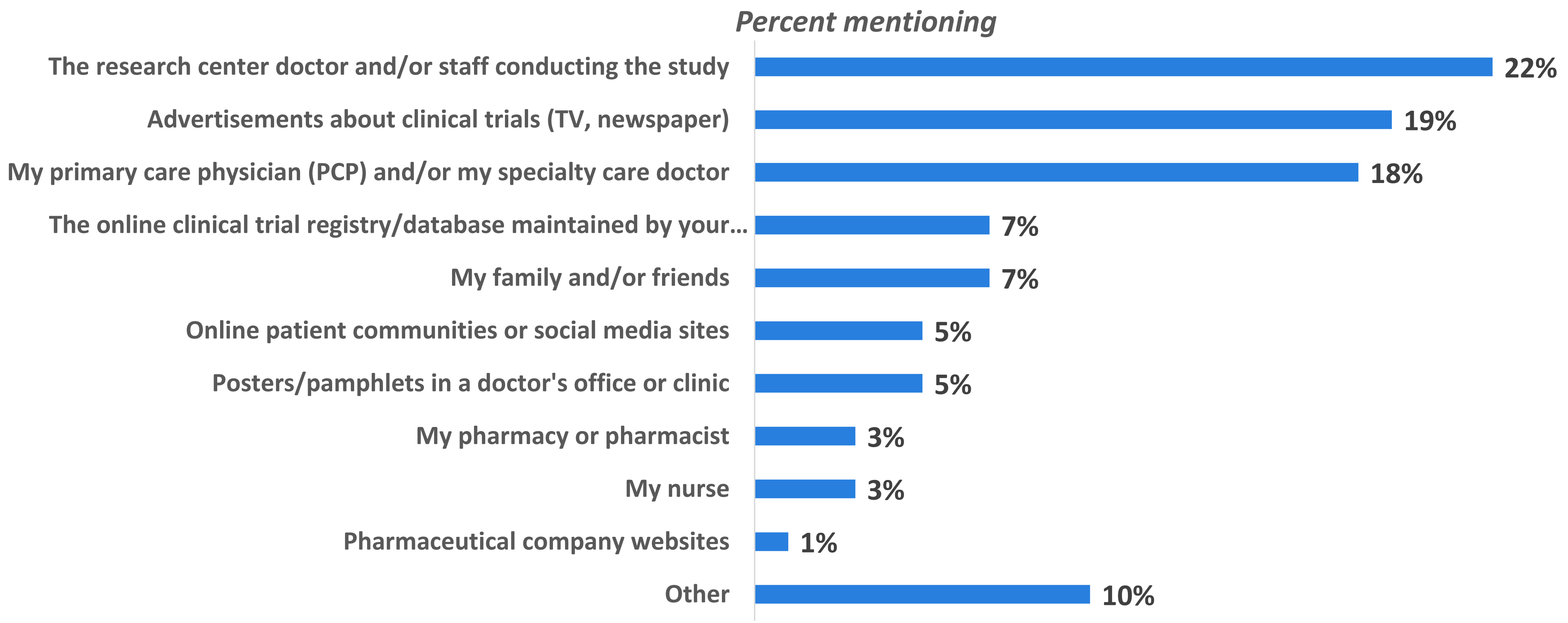
*A 3% difference is statistically significant at a 95% confidence interval

Source: 2015 CISCRP Perceptions & Insights Study – All Respondents (n=12,009)

Takeaways

- Research studies are rarely considered as an option at doctor visits - well over half of the respondents (58%) mention ‘never/not very often’ considering research as an option in discussions with their doctor. Interestingly, while most (85%) are generally comfortable presenting any clinical research information they find to their doctor, only 17% have actually presented clinical research information to their doctor. Among those respondents who presented information, the majority (63%) ended up joining the study.
- Similar to findings in the 2013 study, the majority of respondents would discuss their participation decision with their primary care physician and/or specialty care doctor, as well as research study staff.
- A higher percentage (53%) of respondents from South America report discussing their participation decision with their family and friends compared to other regions.
- A higher proportion of Hispanics (47%) also indicate discussing their participation decision with family and friends compared to non-Hispanics (39%). Younger respondents are also more likely to indicate the same.

How First Learned About Clinical Research Study



Source: 2015 CISCRP Perceptions & Insights Study – Clinical Trial Participants (n=3,152)

		REGION				RACE			ETHNICITY	
	OVERALL	North America	South America	Europe	Asia Pacific	White	Black/African American	Asian	Non-Hispanic	Hispanic
Research staff	22%	25%	15%	17%	19%	23%	25%	16%	23%	19%
TV/newspaper	19%	21%	4%	16%	22%	20%	19%	15%	20%	11%
PCP/SCP	18%	17%	23%	20%	18%	19%	11%	13%	17%	17%
Online gvt registry	7%	8%	3%	5%	6%	7%	10%	12%	7%	5%
Family/friends	7%	5%	19%	9%	6%	6%	9%	10%	6%	14%
Online/social media	5%	5%	4%	5%	6%	5%	6%	7%	5%	6%
Info in dr office	5%	5%	4%	6%	3%	4%	7%	5%	5%	6%
Pharmacist	3%	1%	13%	6%	4%	2%	1%	9%	2%	9%
Nurse	3%	2%	10%	7%	3%	3%	4%	5%	3%	8%
Pharma company websites	1%	1%	5%	3%	1%	1%	1%	2%	1%	3%

*A 3% difference is statistically significant at a 95% confidence interval

Source: 2015 CISCRP Perceptions & Insights Study – Clinical Trial Participants (n=3,152)

		EDUCATION				*INCOME*			
	OVERALL	**None/primary education only**	**Some/ completed high school**	**Some/ completed college**	**Some/ completed post-graduate**	**Less than $25,000**	**$25,000 to $49,999**	**$50,000 to $99,999**	**$100,000 or more**
Research staff	22%	5%	17%	23%	28%	20%	23%	23%	25%
TV/newspaper	19%	11%	18%	21%	15%	19%	20%	19%	18%
PCP/SCP	18%	25%	17%	17%	19%	15%	17%	18%	18%
Online gvt registry	7%	9%	7%	7%	6%	7%	6%	8%	6%
Family/friends	7%	21%	8%	6%	6%	10%	5%	6%	6%
Online/social media	5%	2%	7%	5%	4%	6%	5%	6%	5%
Info in dr office	5%	0%	5%	5%	5%	5%	5%	4%	5%
Pharmacist	3%	19%	3%	2%	3%	4%	3%	2%	2%
Nurse	3%	7%	6%	2%	3%	5%	3%	3%	3%
Pharma company websites	1%	0%	2%	1%	1%	1%	2%	1%	1%

*A 3% difference is statistically significant at a 95% confidence interval

Source: 2015 CISCRP Perceptions & Insights Study – Clinical Trial Participants (n=3,152)

		AGE					*SEVERITY OF DISEASE*				
	OVERALL	**18 to 34 years old**	**35 to 44 years old**	**45 to 54 years old**	**55 to 64 years old**	**65 and older**	**Very mild**	**Mild**	**Moderate**	**Severe**	**Very severe**
Research staff	22%	15%	20%	22%	23%	26%	22%	22%	22%	25%	23%
TV/newspaper	19%	11%	15%	18%	20%	24%	18%	19%	22%	17%	16%
PCP/SCP	18%	15%	14%	18%	18%	19%	17%	16%	18%	20%	20%
Online gvt registry	7%	7%	6%	9%	8%	5%	6%	5%	8%	9%	10%
Family/friends	7%	16%	11%	8%	5%	3%	9%	9%	6%	4%	6%
Online/social media	5%	6%	5%	5%	6%	5%	6%	5%	5%	6%	6%
Info in dr office	5%	5%	8%	5%	5%	3%	5%	6%	4%	5%	4%
Pharmacist	3%	10%	8%	2%	1%	0%	3%	5%	3%	1%	2%
Nurse	3%	9%	5%	3%	2%	1%	5%	3%	3%	2%	1%
Pharma company websites	1%	3%	2%	2%	0%	0%	1%	1%	1%	1%	3%

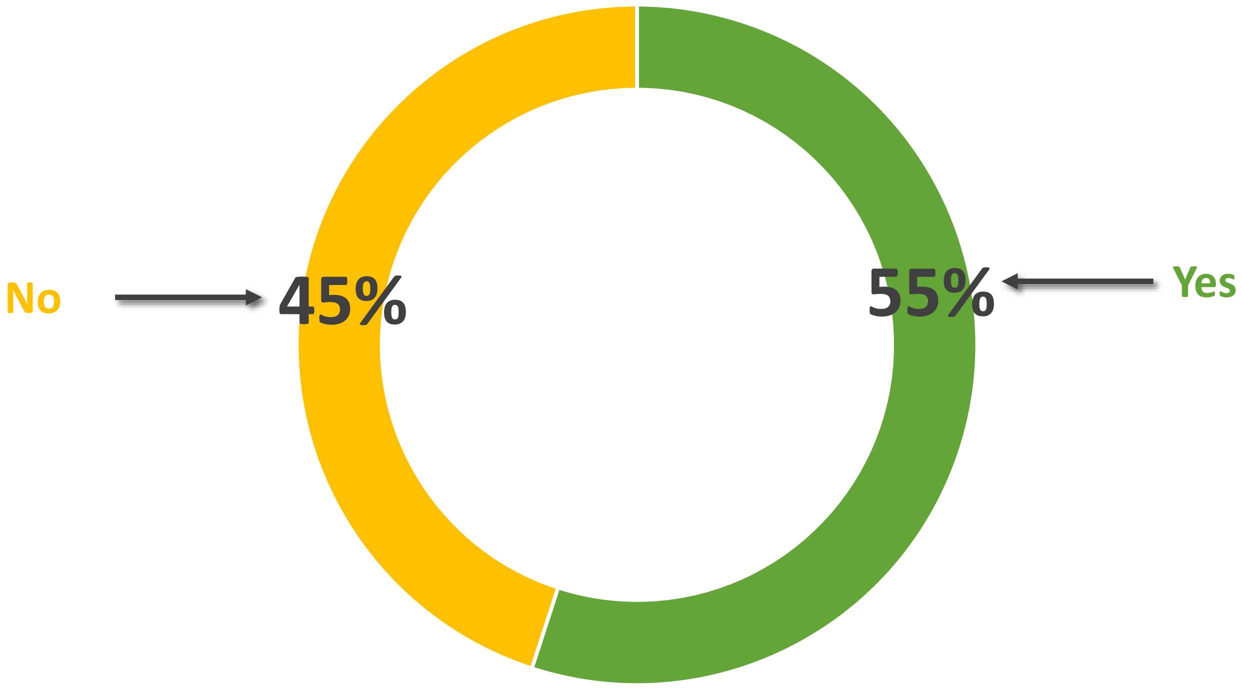
*A 3% difference is statistically significant at a 95% confidence interval

Source: 2015 CISCRP Perceptions & Insights Study – Clinical Trial Participants (n=3,152)

Takeaways

- Similar to findings in the 2013 study, respondents who participated in a clinical research study most frequently mentioned first learning of the study through the clinical research staff (22%), advertisements (19%), and/or through their doctor/specialist (18%).
- A significantly higher proportion of respondents from South America report first learning about the study through family and friends (19%) or their pharmacist (13%) compared to other regions. A significantly lower percentage of respondents from South America first learn about the study through TV or newspaper ads compared to other regions.
- More Hispanics report first learning about the study from family/friends (14%) or their pharmacist (9%) compared to non-Hispanics (6% and 2% respectively).
- Less educated respondents report first learning about the study from family/friends or their pharmacist. A similar pattern is evident among younger respondents as well.

Qualified to Participate in a Clinical Research Study



Source: 2015 CISCRP Perceptions & Insights Study – Respondents Who Tried to Join Study (n=5,098)

		REGION				*RACE*			*ETHNICITY*	
	OVERALL	**North America**	**South America**	**Europe**	**Asia Pacific**	**White**	**Black/African American**	**Asian**	**Non-Hispanic**	**Hispanic**
Yes	55%	55%	85%	56%	54%	54%	57%	59%	54%	64%
No	45%	45%	15%	44%	46%	46%	43%	41%	46%	36%

		EDUCATION				*INCOME*			
	OVERALL	**None/primary education only**	**Some/ completed high school**	**Some/ completed college**	**Some/ completed post-graduate**	**Less than $25,000**	**$25,000 to $49,999**	**$50,000 to $99,999**	**$100,000 or more**
Yes	55%	78%	53%	54%	62%	50%	56%	59%	61%
No	45%	22%	47%	46%	38%	50%	44%	41%	39%

*A 3% difference is statistically significant at a 95% confidence interval

Source: 2015 CISCRP Perceptions & Insights Study – Respondents Who Tried to Join Study (n=5,098)

		AGE					***SEVERITY OF DISEASE***				
	OVERALL	**18 to 34 years old**	**35 to 44 years old**	**45 to 54 years old**	**55 to 64 years old**	**65 and older**	**Very mild**	**Mild**	**Moderate**	**Severe**	**Very severe**
Yes	55%	60%	57%	49%	53%	60%	86%	85%	82%	85%	77%
No	45%	40%	43%	51%	47%	40%	14%	15%	18%	15%	23%

*A 3% difference is statistically significant at a 95% confidence interval

Source: 2015 CISCRP Perceptions & Insights Study – Respondents Who Tried to Join Study (n=5,098)

Takeaways

- Among those who tried to join a study, a little over half (55%) ended up qualifying for the study.
- A significantly higher percentage (85%) of respondents from South America report qualifying for the study compared to other regions.
- More Hispanics (64%) report qualifying for a study compared to non-Hispanics (54%).
- More respondents in higher income brackets report qualifying for a study compared to those respondents in lower income brackets.

Ineligible Volunteers

	TOTAL
Percent ineligible because they live too far away to participate	14%
Percent who don’t know why they are ineligible	22%
Percent ineligible who decide not to continue looking for another trial	36%

Source: 2015 CISCRP Perceptions & Insights Study – Respondents Who Did Not Qualify (n=2,281)

		REGION				*RACE*			*ETHNICITY*	
	OVERALL	**North America**	**South America**	**Europe**	**Asia Pacific**	**White**	**Black/African American**	**Asian**	**Non-Hispanic**	**Hispanic**
Live too far away	14%	12%	22%	15%	15%	13%	14%	18%	13%	16%
Don't know why	22%	25%	16%	20%	16%	22%	19%	19%	22%	22%
Stopped looking	36%	37%	38%	35%	31%	35%	33%	37%	35%	38%

		EDUCATION				*INCOME*			
	OVERALL	**None/primary education only**	**Some/ completed high school**	**Some/ completed college**	**Some/ completed post-graduate**	**Less than $25,000**	**$25,000 to $49,999**	**$50,000 to $99,999**	**$100,000 or more**
Live too far away	14%	14%	15%	14%	10%	14%	14%	14%	13%
Don't know why	22%	21%	25%	23%	18%	21%	21%	22%	27%
Stopped looking	36%	35%	40%	37%	28%	35%	35%	36%	40%

Source: 2015 CISCRP Perceptions & Insights Study – Respondents Who Did Not Qualify (n=2,281)

		AGE					*SEVERITY OF DISEASE*				
	OVERALL	**18 to 34 years old**	**35 to 44 years old**	**45 to 54 years old**	**55 to 64 years old**	**65 and older**	**Very mild**	**Mild**	**Moderate**	**Severe**	**Very severe**
Live too far away	14%	19%	17%	12%	13%	12%	7%	11%	11%	8%	14%
Don't know why	22%	22%	23%	24%	23%	20%	18%	22%	20%	10%	28%
Stopped looking	36%	41%	40%	36%	36%	32%	25%	33%	31%	18%	42%

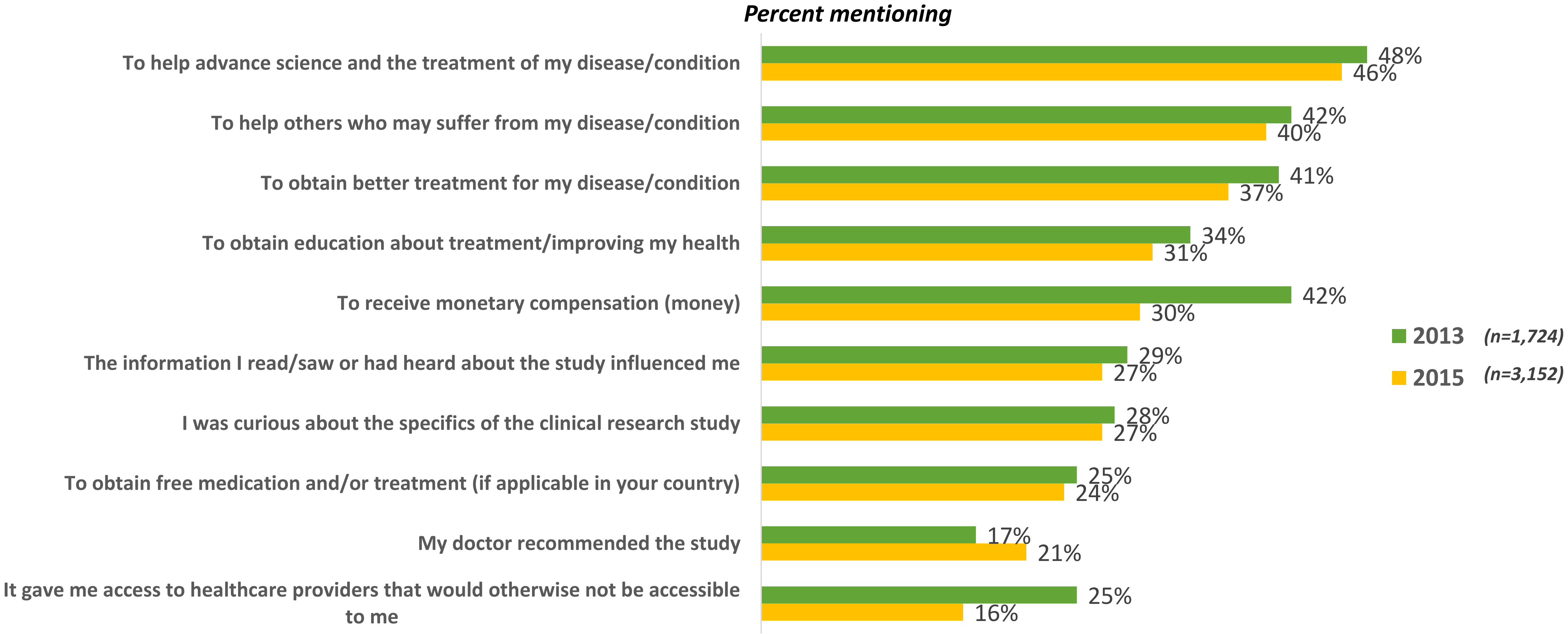
*A 3% difference is statistically significant at a 95% confidence interval

Source: 2015 CISCRP Perceptions & Insights Study – Respondents Who Did Not Qualify (n=2,281)

Takeaways

- About 22% of respondents were not told why they did not qualify for a study, this compares to 35% in 2013. Another 14% of respondents lived too far away to participate in the study. When queried on next steps after finding out he/she did not qualify, 36% stopped looking for a clinical research study to participate in.
- A significantly higher percentage of younger respondents report stopping their search for a clinical study.

Top Participation Drivers



Source: 2015 CISCRP Perceptions & Insights Study – Clinical Trial Participants

		REGION				RACE			ETHNICITY	
	OVERALL	North America	South America	Europe	Asia Pacific	White	Black/African American	Asian	Non-Hispanic	Hispanic
Help advance science	46%	49%	27%	37%	53%	49%	35%	29%	49%	30%
Help others	40%	43%	20%	31%	44%	43%	32%	27%	43%	26%
Obtain better treatment	37%	41%	27%	22%	34%	37%	36%	31%	38%	26%
Education	31%	32%	23%	21%	36%	31%	36%	28%	32%	25%
Monetary compensation	30%	40%	19%	15%	8%	29%	44%	19%	31%	27%
Information I saw/read	27%	28%	18%	19%	32%	27%	30%	26%	28%	22%
Curiosity	27%	27%	16%	21%	32%	26%	31%	26%	27%	23%
Free medication	24%	31%	16%	9%	13%	24%	32%	21%	25%	19%
Doctor reco	21%	20%	32%	21%	24%	21%	13%	27%	21%	26%
Access to drs	16%	17%	14%	11%	16%	16%	17%	19%	17%	11%

*A 4% difference is statistically significant at a 95% confidence interval

Source: 2015 CISCRP Perceptions & Insights Study – Clinical Trial Participants (n=3,152)

		EDUCATION				INCOME			
	OVERALL	None/primary education only	Some/ completed high school	Some/ completed college	Some/ completed post-graduate	Less than $25,000	$25,000 to $49,999	$50,000 to $99,999	$100,000 or more
Help advance science	46%	19%	39%	49%	47%	43%	48%	47%	48%
Help others	40%	19%	38%	41%	42%	40%	38%	43%	42%
Obtain better treatment	37%	21%	34%	385	33%	40%	34%	38%	33%
Education	31%	16%	29%	33%	27%	34%	29%	29%	30%
Monetary compensation	30%	12%	28%	31%	28%	34%	31%	31%	24%
Information I saw/read	27%	25%	24%	27%	29%	26%	27%	28%	28%
Curiosity	27%	11%	27%	26%	31%	24%	26%	28%	29%
Free medication	24%	9%	20%	26%	23%	23%	26%	24%	21%
Doctor reco	21%	16%	22%	21%	24%	20%	21%	21%	22%
Access to drs	16%	12%	15%	17%	13%	18%	16%	16%	12%

Source: 2015 CISCRP Perceptions & Insights Study – Clinical Trial Participants (n=3,152)

		AGE					SEVERITY OF DISEASE				
	OVERALL	**18 to 34 years old**	**35 to 44 years old**	**45 to 54 years old**	**55 to 64 years old**	**65 and older**	**Very mild**	**Mild**	**Moderate**	**Severe**	**Very severe**
Help advance science	46%	20%	29%	44%	53%	58%	42%	42%	49%	58%	54%
Help others	40%	18%	23%	43%	46%	49%	35%	35%	45%	49%	54%
Obtain better treatment	37%	20%	29%	37%	42%	40%	26%	32%	44%	53%	48%
Education	31%	20%	20%	31%	35%	34%	26%	30%	33%	40%	40%
Monetary compensation	30%	24%	30%	36%	34%	24%	31%	27%	29%	26%	30%
Information I saw/read	27%	17%	16%	25%	32%	31%	27%	23%	28%	30%	33%
Curiosity	27%	20%	22%	27%	30%	27%	29%	26%	26%	25%	27%
Free medication	24%	15%	23%	28%	29%	20%	20%	22%	26%	29%	34%
Doctor reco	21%	22%	21%	21%	21%	21%	23%	16%	21%	26%	30%
Access to drs	16%	13%	14%	16%	19%	15%	13%	14%	19%	18%	28%

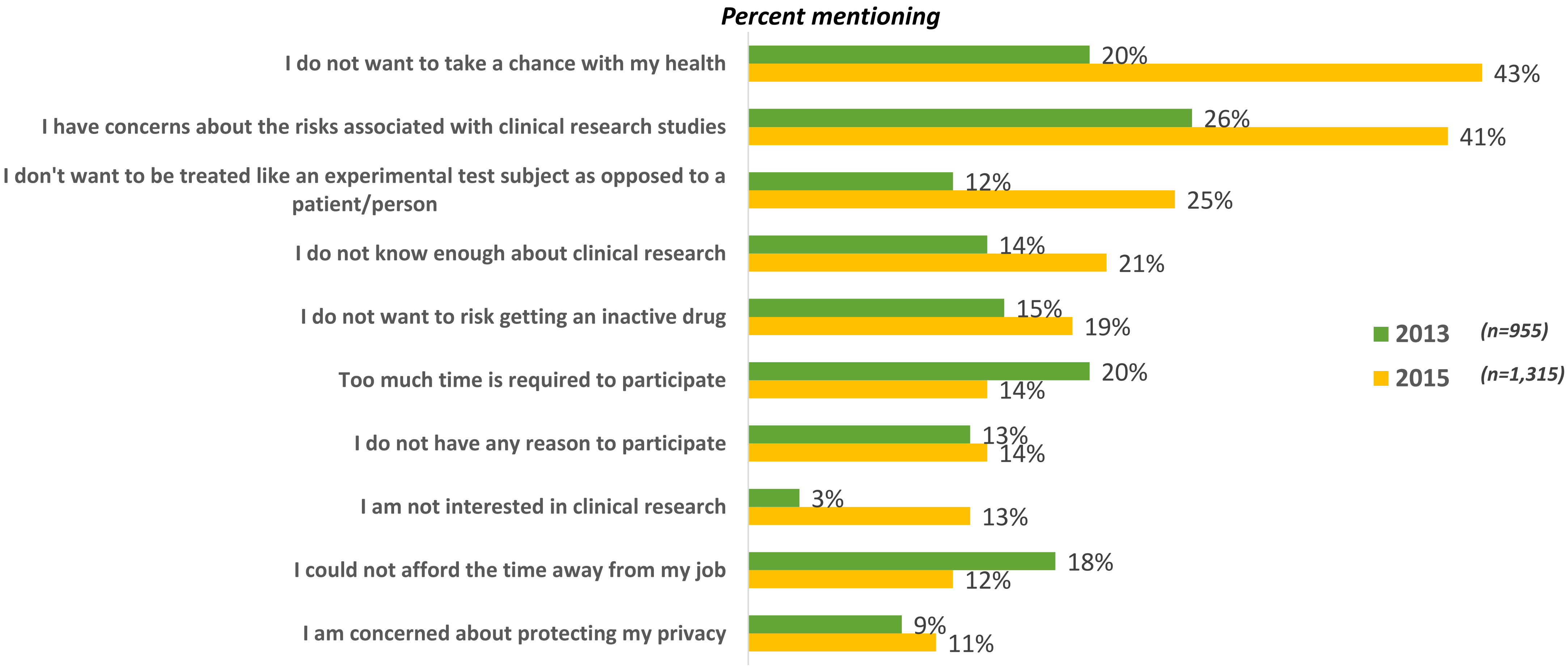
*A 3% difference is statistically significant at a 95% confidence interval

Source: 2015 CISCRP Perceptions & Insights Study – Clinical Trial Participants (n=3,152)

Takeaways

- The main drivers of participation among respondents who participated in a clinical study are comparable to 2013 study results, they include altruistic reasons such as helping to advance science and treatment of condition (46%) and helping others (40%); as well as self-improvement reasons such as obtaining better treatment for his/her condition (37%).
- A significantly higher proportion of respondents from South America are motivated by a doctor recommendation (32%) compared to other regions.
- Black/African American respondents report monetary compensation as a top driver for participation compared to White and Asian respondents. Younger respondents report monetary compensation as a top participation driver as well.
- Less educated respondents report being more influenced by information they saw or heard about the clinical study.
- Altruistic motivations were more evident among older respondents and respondents with severe conditions.

Top Reasons Not Willing to Participate



Source: CISCRP Perceptions & Insights Studies – Respondents Not Willing to Participate

		REGION				***RACE***			***ETHNICITY***	
	OVERALL	**North America**	**South America**	**Europe**	**Asia Pacific**	**White**	**Black/African American**	**Asian**	**Non-Hispanic**	**Hispanic**
Don’t want to take chance with health	43%	50%	20%	39%	49%	43%	47%	45%	46%	31%
Concerns with risks	41%	45%	29%	38%	42%	42%	39%	34%	44%	38%
Don’t want to be treated like subject	25%	28%	25%	21%	30%	24%	27%	32%	26%	27%
Do not know enough about research	21%	20%	23%	21%	22%	21%	26%	18%	21%	25%
Don’t want to risk receiving placebo	19%	20%	23%	18%	19%	19%	17%	20%	19%	24%

*A 3% difference is statistically significant at a 95% confidence interval

Source: CISCRP Perceptions & Insights Studies – Respondents Not Willing to Participate (1,315)

		EDUCATION				INCOME			
	OVERALL	None/primary education only	Some/ completed high school	Some/ completed college	Some/ completed post-graduate	Less than $25,000	$25,000 to $49,999	$50,000 to $99,999	$100,000 or more
Don't want to take chance with health	43%	33%	43%	42%	48%	41%	47%	46%	53%
Concerns with risks	41%	33%	36%	41%	49%	41%	40%	43%	49%
Don't want to be treated like subject	25%	24%	26%	24%	28%	29%	20%	24%	28%
Do not know enough about research	21%	14%	25%	19%	20%	23%	20%	22%	20%
Don't want to risk receiving placebo	19%	19%	19%	19%	20%	22%	19%	19%	12%

*A 3% difference is statistically significant at a 95% confidence interval

Source: CISCRP Perceptions & Insights Studies – Respondents Not Willing to Participate (1,315)

		AGE				
	OVERALL	18 to 34 years old	35 to 44 years old	45 to 54 years old	55 to 64 years old	65 and older
Don’t want to take chance with health	43%	37%	39%	47%	46%	50%
Concerns with risks	41%	34%	37%	41%	47%	49%
Don’t want to be treated like subject	25%	23%	23%	26%	30%	24%
Do not know enough about research	21%	19%	18%	24%	21%	24%
Don’t want to risk receiving placebo	19%	20%	17%	14%	22%	23%

*A 3% difference is statistically significant at a 95% confidence interval

Source: CISCRP Perceptions & Insights Studies – Respondents Not Willing to Participate (1,315)

Takeaways

- Among those respondents who are not willing to participate in a clinical research study, the most frequently mentioned reasons are that they are not willing to take a chance with their health (43%) and that they are concerned about the risks associated with clinical research (41%). This is similar to findings in the 2013 study.
- Respondents from North America and Asia Pacific regions are particularly concerned with not taking a chance with their health. More educated respondents, those in higher income brackets, and older respondents are also more concerned with this factor.
- Other top reasons mentioned for not willing to participate include not wanting to be treated like an experimental test subject (25%), not knowing enough about clinical research (21%), and not wanting to risk receiving the placebo (19%). These reasons suggest that educational opportunities still remain.

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 April and May 2015, 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, PMG Research, and Quintiles to reach and engage respondents.

A total of 12,009 respondents completed the survey. Respondent characteristics are as follows:

Gender: 54% Female | 46% Male

Region: 56% North America | 7% South America | 22% Europe | 11% Asia-Pacific | 5% Africa

Age: 6% 18 - 24 years old | 12% 25 - 34 years old | 15% 35 - 44 years old | 21% 45 - 54 years old | 24% 55 - 64 years old | 17% 65 - 74 years old | 5% 75 or older

Race: 82% White | 7% Black or African American | 3% Asian Indian | 2% American Indian or Alaska Native | 1% Filipino | 1% Chinese

Ethnicity: 83% Non-Hispanic | 2% Mexican | 1% Puerto Rican | 8% other Hispanic origin

Incidence of participation in a clinical trial: 74% have never participated | 26% have participated

A Special Thank You

To All of the Working Group Companies and:

- AbbVie
- Amgen
- Astellas
- AstraZeneca
- Biogen
- Bristol-Myers Squibb
- Eli Lilly
- Genentech
- ICON
- INC Research
- InVentiv
- Janssen
- Parexel
- Pfizer
- PRA
- Sanofi
- Sunovion

Acurian
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Tomorrow's Medicine Today

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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.

- 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.

- 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 20 major pharmaceutical companies to provide non-technical, lay-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.