



# Report on Public Perceptions

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2015 PERCEPTIONS & INSIGHTS STUDY

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# Foreword

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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.

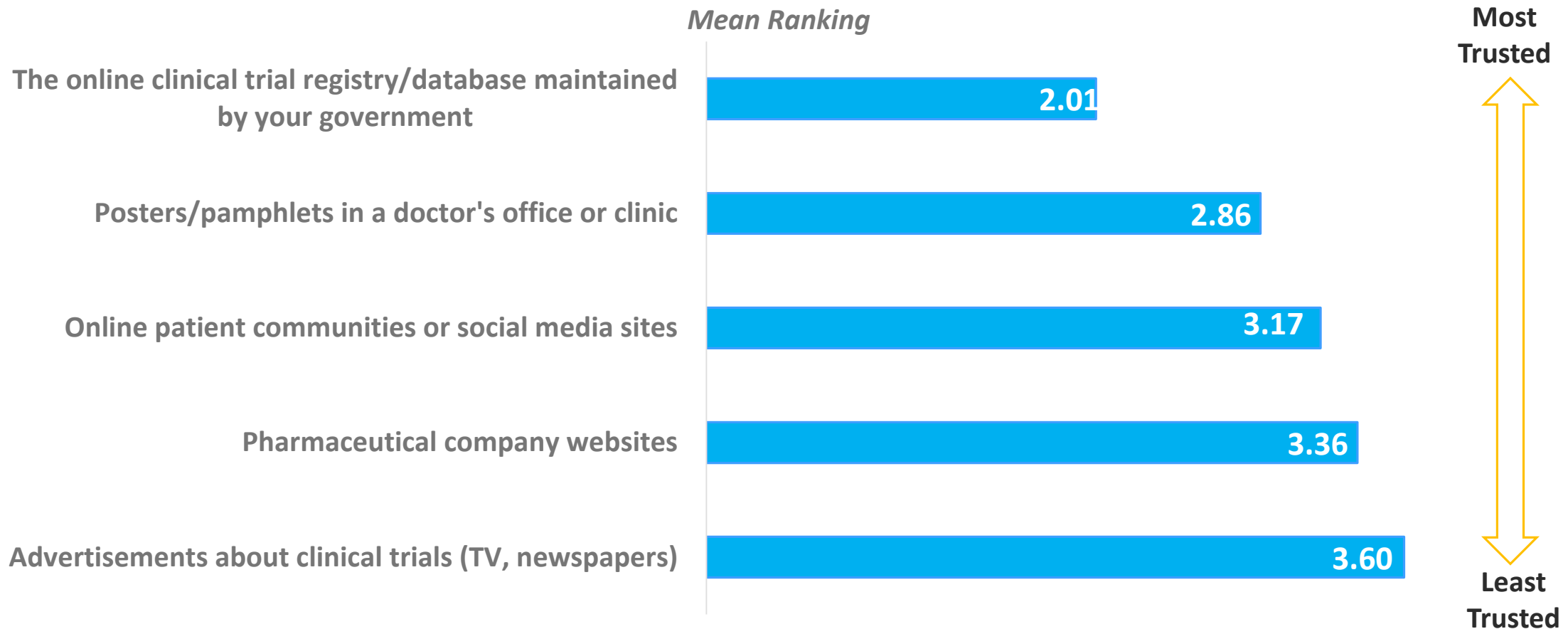
In this report CISCRP explores public perceptions of clinical research. The overall results and subgroup differences - by geographic region, race & ethnicity, income and education level, age and severity of disease - are presented. Throughout the report, we note significant comparisons and key takeaways.

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# Level of Trust in Clinical Research Study Information Sources



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

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

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

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

	OVERALL	AGE					SEVERITY OF DISEASE				
		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
<b>Online clinical trial registry</b>	2.01	2.12	2.12	2.03	1.94	1.89	2.07	2.12	1.98	2.02	2.00
<b>Posters/pamphlets in dr office</b>	2.86	3.03	3.01	2.93	2.74	2.65	2.75	2.88	2.75	2.69	2.51
<b>Online patient communities</b>	3.17	3.21	3.05	3.13	3.19	3.24	3.30	3.36	3.27	3.42	3.26
<b>Pharma company websites</b>	3.36	3.16	3.27	3.26	3.45	3.59	3.49	3.38	3.51	3.47	3.57
<b>Ads about clinical trials</b>	3.60	3.48	3.55	3.64	3.68	3.63	3.38	3.26	3.49	3.40	3.65

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

# Takeaways

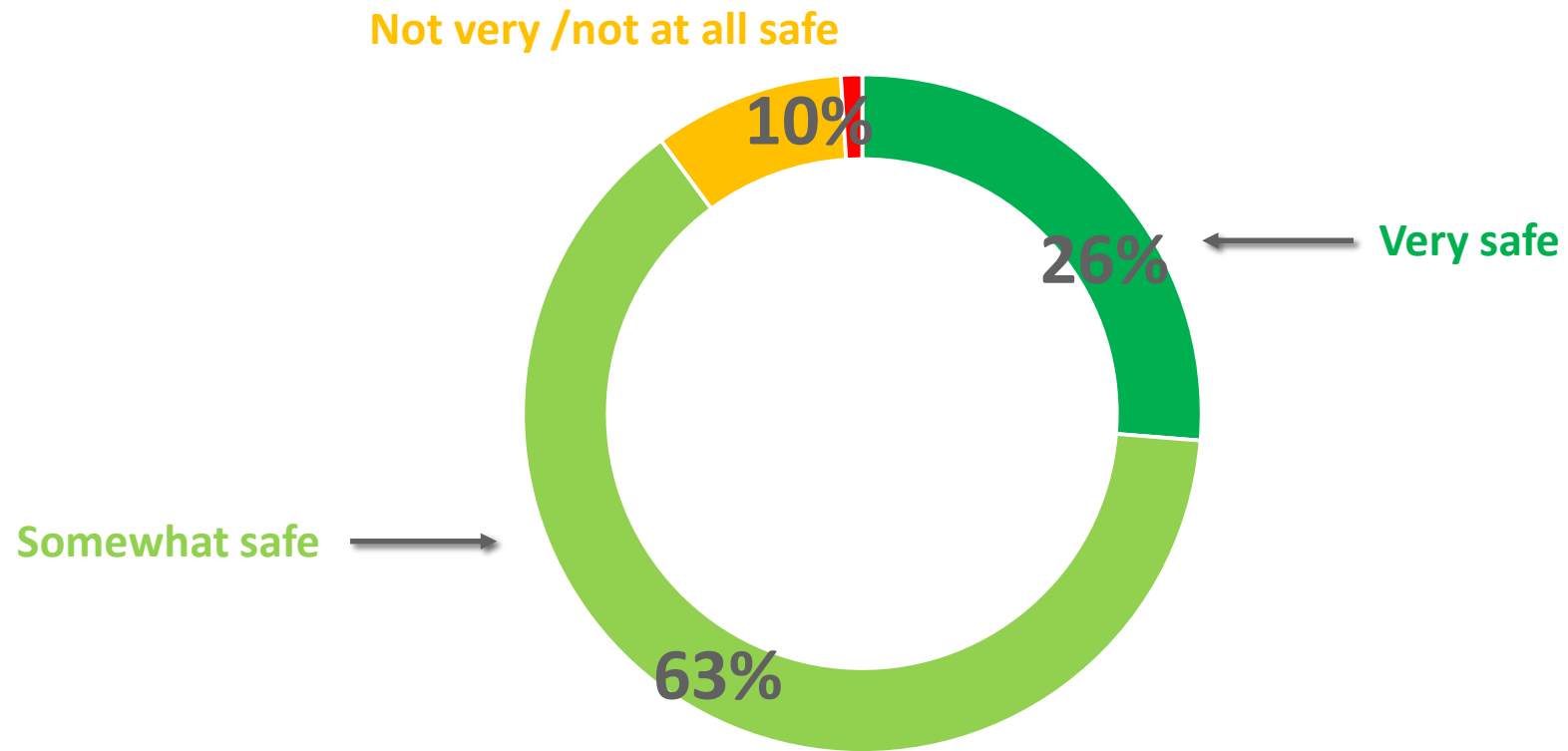
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- Respondents report placing the most trust in the clinical research information provided on the online clinical trial registry maintained by their government. This is followed by posters or pamphlets found in a doctor's office or clinic. Respondents 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.

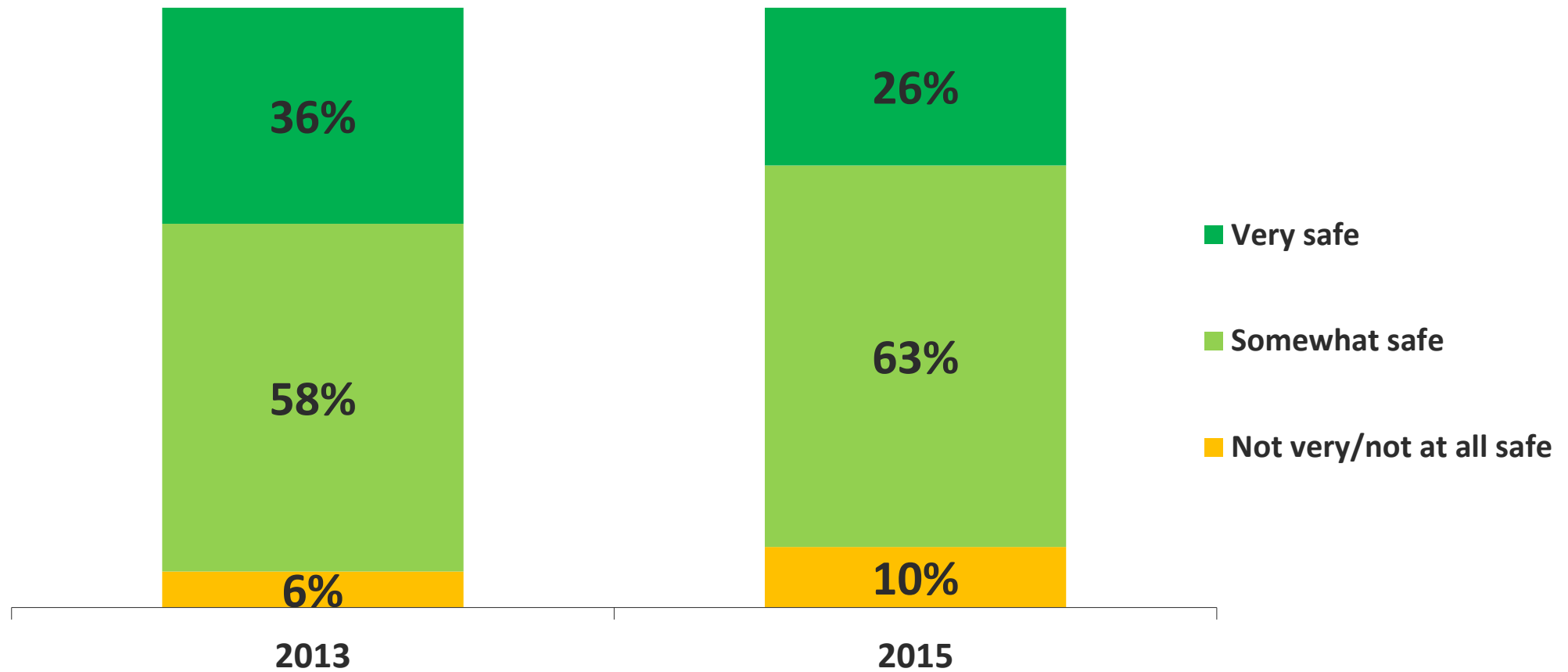


# Safety of Clinical Research

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# Safety of Clinical Research



Source: 2013 CISCRP Perceptions & Insights Study (n=5,701)

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

		<i>REGION</i>				<i>RACE</i>			<i>ETHNICITY</i>	
<b>OVERALL</b>		<b>North America</b>	<b>South America</b>	<b>Europe</b>	<b>Asia Pacific</b>	<b>White</b>	<b>Black/African American</b>	<b>Asian</b>	<b>Non-Hispanic</b>	<b>Hispanic</b>
<b>Very safe</b>	26%	25%	38%	20%	32%	26%	27%	32%	25%	32%
<b>Somewhat safe</b>	63%	65%	51%	64%	61%	64%	61%	54%	65%	56%
<b>Not very/not at all safe</b>	10%	9%	11%	16%	8%	10%	12%	14%	10%	12%

		<i>EDUCATION</i>				<i>INCOME</i>			
<b>OVERALL</b>		<b>None/primary education only</b>	<b>Some/ completed high school</b>	<b>Some/ completed college</b>	<b>Some/ completed post-graduate</b>	<b>Less than \$25,000</b>	<b>\$25,000 to \$49,999</b>	<b>\$50,000 to \$99,999</b>	<b>\$100,000 or more</b>
<b>Very safe</b>	26%	34%	24%	26%	28%	27%	26%	27%	28%
<b>Somewhat safe</b>	63%	48%	64%	63%	62%	61%	64%	65%	65%
<b>Not very/not at all safe</b>	10%	18%	12%	10%	10%	13%	10%	8%	7%

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

		<b>AGE</b>					<b>SEVERITY OF DISEASE</b>				
	<b>OVERALL</b>	<b>18 to 34 years old</b>	<b>35 to 44 years old</b>	<b>45 to 54 years old</b>	<b>55 to 64 years old</b>	<b>65 and older</b>	<b>Very mild</b>	<b>Mild</b>	<b>Moderate</b>	<b>Severe</b>	<b>Very severe</b>
<b>Very safe</b>	26%	23%	24%	25%	28%	30%	48%	40%	40%	43%	43%
<b>Somewhat safe</b>	63%	61%	62%	64%	64%	64%	48%	57%	56%	54%	54%
<b>Not very/not at all safe</b>	10%	16%	15%	10%	8%	7%	3%	3%	4%	3%	3%

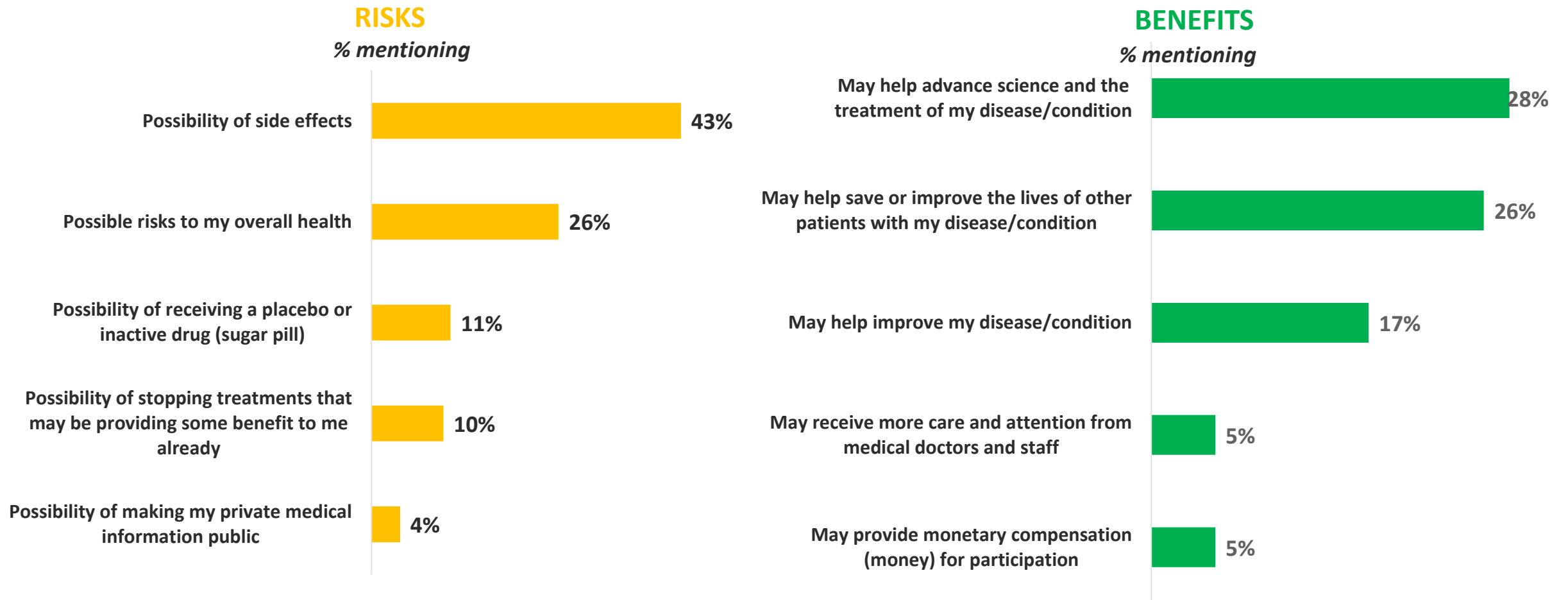
\*A 3% difference is statistically significant at a 95% confidence interval

# Takeaways

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- Similar to prior surveys, the majority of respondents perceive clinical studies to be safe (89%). While this proportion is somewhat lower than the proportion in the 2013 study (94%), the variation could be explained by the increased sample size and more geographically diverse sample in the 2015 study.
- Notably, respondents outside of North America are less likely to perceive clinical studies as safe – particularly in Europe where 16% of respondents report clinical studies to be ‘not very/not at all safe’ compared to 9% of respondents who think the same in North America.
- A higher percentage of Asian respondents (32%) indicate clinical research studies are ‘very safe’ in comparison to White (26%) and Black/African American (27%) respondents. A significantly higher proportion of Hispanics (32%) report clinical research studies as ‘very safe’ compared to non-Hispanics (25%).
- Higher proportions of less educated respondents and those in lower income brackets report clinical research studies as ‘not very/not at all safe’.
- Similar to findings in 2013, a significantly higher percentage of younger respondents perceive clinical research studies to be less safe than older respondents.

# Top Perceived Risks and Benefits



<b>RISKS</b>	<b>OVERALL</b>	<b>REGION</b>				<b>RACE</b>			<b>ETHNICITY</b>	
		<b>North America</b>	<b>South America</b>	<b>Europe</b>	<b>Asia Pacific</b>	<b>White</b>	<b>Black/African American</b>	<b>Asian</b>	<b>Non-Hispanic</b>	<b>Hispanic</b>
<b>Side effects</b>	43%	42%	46%	45%	42%	43%	45%	41%	43%	45%
<b>Risks to overall health</b>	26%	27%	23%	28%	22%	26%	27%	24%	26%	24%
<b>Receiving placebo</b>	11%	13%	7%	8%	12%	11%	8%	8%	11%	8%
<b>Stopping treatments</b>	10%	10%	9%	9%	12%	11%	8%	9%	11%	8%
<b>Disclosure of private medical information</b>	4%	3%	10%	5%	5%	3%	6%	10%	3%	8%

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

		<b>EDUCATION</b>				<b>INCOME</b>			
<b>RISKS</b>	<b>OVERALL</b>	<b>None/primary education only</b>	<b>Some/ completed high school</b>	<b>Some/ completed college</b>	<b>Some/ completed post-graduate</b>	<b>Less than \$25,000</b>	<b>\$25,000 to \$49,999</b>	<b>\$50,000 to \$99,999</b>	<b>\$100,000 or more</b>
<b>Side effects</b>	43%	28%	44%	44%	40%	44%	45%	42%	40%
<b>Risks to overall health</b>	26%	26%	26%	26%	25%	26%	25%	25%	27%
<b>Receiving placebo</b>	11%	13%	9%	11%	13%	9%	10%	14%	14%
<b>Stopping treatments</b>	10%	20%	10%	10%	12%	9%	11%	10%	12%
<b>Disclosure of private medical information</b>	4%	8%	5%	3%	4%	5%	4%	3%	3%

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



<b>RISKS</b>	<b>OVERALL</b>	<b>AGE</b>					<b>SEVERITY OF DISEASE</b>				
		<b>18 to 34 years old</b>	<b>35 to 44 years old</b>	<b>45 to 54 years old</b>	<b>55 to 64 years old</b>	<b>65 and older</b>	<b>Very mild</b>	<b>Mild</b>	<b>Moderate</b>	<b>Severe</b>	<b>Very severe</b>
<b>Side effects</b>	43%	43%	46%	45%	44%	39%	42%	39%	41%	36%	30%
<b>Risks to overall health</b>	26%	31%	28%	27%	22%	21%	20%	19%	20%	17%	21%
<b>Receiving placebo</b>	11%	7%	7%	9%	12%	17%	14%	15%	15%	22%	18%
<b>Stopping treatments</b>	10%	7%	9%	10%	12%	13%	12%	13%	13%	14%	17%
<b>Disclosure of private medical information</b>	4%	8%	6%	3%	3%	1%	6%	6%	5%	3%	4%

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<b>BENEFITS</b>	<b>OVERALL</b>	<b>REGION</b>				<b>RACE</b>			<b>ETHNICITY</b>	
		<b>North America</b>	<b>South America</b>	<b>Europe</b>	<b>Asia Pacific</b>	<b>White</b>	<b>Black/African American</b>	<b>Asian</b>	<b>Non-Hispanic</b>	<b>Hispanic</b>
<b>Help advance science</b>	28%	29%	25%	25%	29%	29%	23%	20%	29%	26%
<b>Help others</b>	26%	26%	27%	25%	28%	26%	28%	23%	26%	25%
<b>Help improve own condition</b>	17%	19%	10%	16%	14%	18%	13%	13%	18%	12%
<b>More care and attention from medical staff</b>	5%	5%	8%	6%	5%	5%	5%	7%	5%	7%
<b>Monetary compensation</b>	5%	5%	5%	6%	3%	5%	7%	7%	5%	6%

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		<b>EDUCATION</b>				<b>INCOME</b>			
<b>BENEFITS</b>	<b>OVERALL</b>	<b>None/primary education only</b>	<b>Some/ completed high school</b>	<b>Some/ completed college</b>	<b>Some/ completed post-graduate</b>	<b>Less than \$25,000</b>	<b>\$25,000 to \$49,999</b>	<b>\$50,000 to \$99,999</b>	<b>\$100,000 or more</b>
<b>Help advance science</b>	28%	14%	26%	29%	30%	25%	27%	31%	30%
<b>Help others</b>	26%	15%	27%	27%	23%	28%	26%	25%	25%
<b>Help improve own condition</b>	17%	14%	16%	17%	17%	15%	17%	19%	21%
<b>More care and attention from medical staff</b>	5%	12%	6%	5%	6%	5%	6%	5%	6%
<b>Monetary compensation</b>	5%	12%	5%	5%	5%	7%	6%	4%	3%

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

<b>BENEFITS</b>	<b>OVERALL</b>	<b>AGE</b>					<b>SEVERITY OF DISEASE</b>				
		<b>18 to 34 years old</b>	<b>35 to 44 years old</b>	<b>45 to 54 years old</b>	<b>55 to 64 years old</b>	<b>65 and older</b>	<b>Very mild</b>	<b>Mild</b>	<b>Moderate</b>	<b>Severe</b>	<b>Very severe</b>
<b>Help advance science</b>	28%	24%	25%	26%	31%	34%	29%	26%	30%	30%	34%
<b>Help others</b>	26%	25%	24%	28%	26%	26%	25%	24%	27%	30%	23%
<b>Help improve own condition</b>	17%	14%	15%	18%	19%	18%	15%	16%	16%	19%	16%
<b>More care and attention from medical staff</b>	5%	6%	7%	5%	5%	6%	5%	6%	5%	5%	7%
<b>Monetary compensation</b>	5%	8%	7%	5%	3%	3%	5%	6%	5%	3%	7%

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

# Takeaways

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- As seen in past surveys, altruistic reasons – helping to advance science and medical treatments (28%) and helping others (26%) - remain the top perceived benefits of participation.
- Overall, a low percentage (5%) of respondents perceive monetary compensation as a benefit. Higher percentages of less educated respondents, as well as younger respondents, perceive monetary compensation as a benefit however.
- Similar to findings in 2013, the possibility of side effects remains the top perceived risk (43%). A higher percentage (10%) of respondents from South America report the disclosure of private medical information as a risk compared to other regions.
- A significantly higher percentage (20%) of less educated respondents report the possibility of stopping treatments that may be providing some benefit among the top risks.

# Public Perceptions

<i>Percent who indicated 'strongly/somewhat agree' that people who participate in clinical trials:</i>	<b>2015 (n=12,009)</b>	<b>2013 (n=5,701)</b>
Get access to the best doctors	54%	60%
Get access to the best possible treatment	59%	60%
Learn more about their condition and health	79%	78%
Make a contribution to science	84%	83%
Have a chance to receive free medicines and care	68%	70%
Are like experimental test subjects NOT people	38%	38%
Are gambling with their health	35%	29%

<i>% who agree</i>	OVERALL	REGION				RACE			ETHNICITY	
		North America	South America	Europe	Asia Pacific	White	Black/African American	Asian	Non-Hispanic	Hispanic
Access to best doctors	54%	52%	65%	51%	58%	55%	53%	52%	54%	59%
Access to best treatment	59%	56%	70%	53%	63%	59%	60%	55%	58%	64%
Learn more about condition	79%	82%	72%	70%	82%	80%	79%	70%	80%	73%
Contribution to science	84%	86%	75%	75%	85%	85%	80%	72%	85%	76%
Receive free medicine/care	68%	76%	66%	57%	58%	69%	72%	63%	70%	65%
Experimental test subjects	38%	39%	35%	38%	35%	37%	42%	41%	38%	38%
Gambling with health	35%	36%	38%	36%	28%	34%	38%	37%	34%	37%

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

		<b>EDUCATION</b>				<b>INCOME</b>			
<i>% who agree</i>	<b>OVERALL</b>	<b>None/primary education only</b>	<b>Some/ completed high school</b>	<b>Some/ completed college</b>	<b>Some/ completed post-graduate</b>	<b>Less than \$25,000</b>	<b>\$25,000 to \$49,999</b>	<b>\$50,000 to \$99,999</b>	<b>\$100,000 or more</b>
<b>Access to best doctors</b>	54%	47%	55%	55%	54%	54%	55%	54%	54%
<b>Access to best treatment</b>	59%	45%	60%	59%	58%	60%	60%	58%	58%
<b>Learn more about condition</b>	79%	50%	77%	80%	78%	77%	79%	81%	80%
<b>Contribution to science</b>	84%	51%	79%	86%	85%	80%	83%	87%	89%
<b>Receive free medicine/care</b>	68%	36%	62%	71%	71%	66%	69%	74%	73%
<b>Experimental test subjects</b>	38%	24%	38%	38%	37%	39%	39%	37%	39%
<b>Gambling with health</b>	35%	28%	34%	35%	36%	35%	34%	34%	36%

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



<i>% who agree</i>	OVERALL	AGE					SEVERITY OF DISEASE				
		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
Access to best doctors	54%	51%	52%	54%	55%	59%	57%	50%	57%	52%	63%
Access to best treatment	59%	51%	54%	60%	60%	65%	61%	56%	64%	61%	65%
Learn more about condition	79%	69%	73%	79%	84%	86%	79%	74%	81%	85%	85%
Contribution to science	84%	72%	78%	84%	88%	91%	86%	78%	85%	89%	90%
Receive free medicine/care	68%	64%	69%	71%	73%	65%	70%	69%	65%	67%	72%
Experimental test subjects	38%	38%	39%	37%	38%	37%	37%	31%	32%	30%	30%
Gambling with health	35%	42%	41%	33%	33%	28%	31%	28%	25%	23%	22%

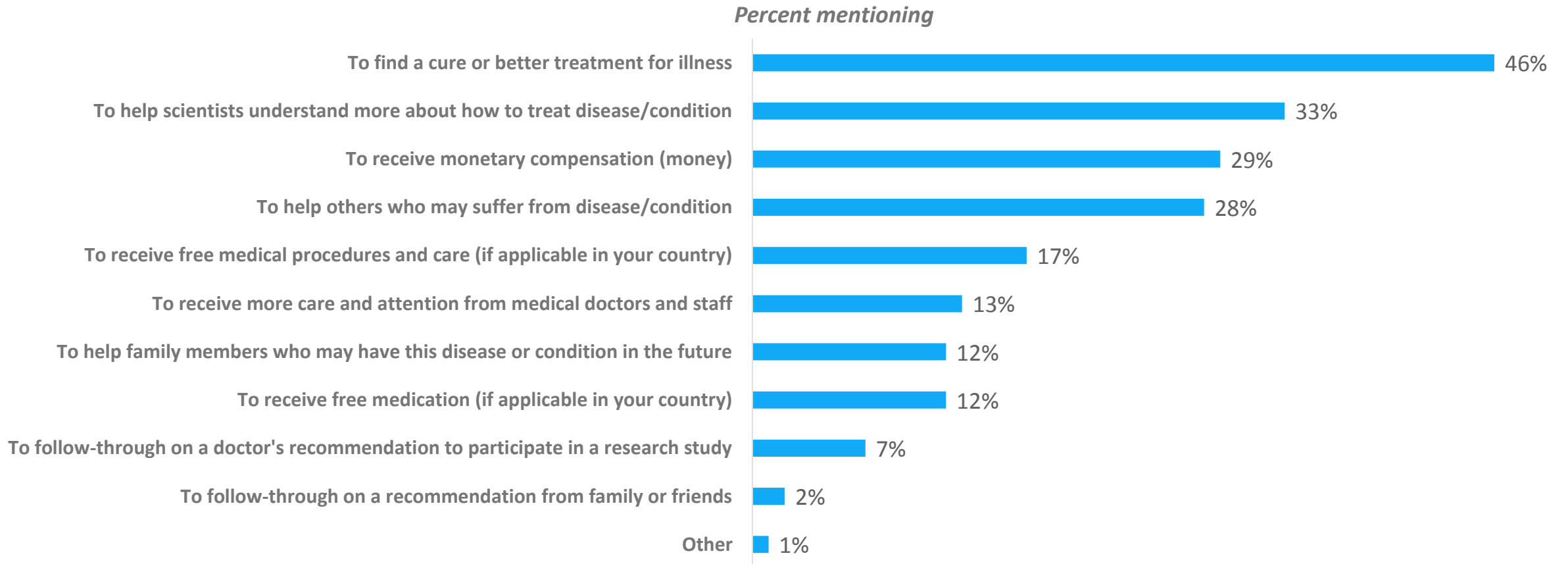
\*A 3% difference is statistically significant at a 95% confidence interval

# Takeaways

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- Consistent with past surveys, the majority (84%) of respondents agree that research participants are making a contribution to science.
- A higher proportion of respondents in 2015 (35%) agree that research participants are gambling with their health compared to 2013 (29%) – however, this proportion is still lower than the percentage seen in the 2005 survey (49%).
- A significantly higher percentage (70%) of respondents from South America agree that research participants have access to the best possible treatment and access to the best doctors (65%) compared to other regions. More respondents (76%) from North America agree that research participants have a chance to receive free medicines and care.
- Higher percentages of younger respondents and those with milder conditions agree that research participants are gambling with their health.

# Perceptions on General Clinical Research Study Participation Drivers



		<i>REGION</i>				<i>RACE</i>			<i>ETHNICITY</i>	
	<b>OVERALL</b>	<b>North America</b>	<b>South America</b>	<b>Europe</b>	<b>Asia Pacific</b>	<b>White</b>	<b>Black/African American</b>	<b>Asian</b>	<b>Non-Hispanic</b>	<b>Hispanic</b>
<b>Find cure/better treatment</b>	46%	46%	41%	43%	50%	47%	41%	39%	47%	40%
<b>Help scientists</b>	33%	30%	30%	34%	43%	33%	30%	31%	34%	29%
<b>Receive compensation</b>	29%	34%	21%	28%	13%	29%	35%	23%	29%	26%
<b>Help others</b>	28%	25%	29%	31%	33%	28%	28%	26%	28%	28%
<b>Receive free care</b>	17%	20%	15%	12%	12%	17%	18%	19%	17%	18%
<b>More attention from staff</b>	13%	12%	18%	14%	13%	12%	12%	15%	12%	17%
<b>Help family</b>	12%	10%	20%	16%	15%	12%	13%	15%	11%	16%
<b>Receive free medication</b>	12%	14%	10%	10%	8%	12%	12%	14%	12%	11%
<b>Doctor recommended</b>	7%	6%	10%	8%	9%	7%	6%	12%	6%	9%

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

		<b>EDUCATION</b>				<b>INCOME</b>			
<b>OVERALL</b>		<b>None/primary education only</b>	<b>Some/ completed high school</b>	<b>Some/ completed college</b>	<b>Some/ completed post-graduate</b>	<b>Less than \$25,000</b>	<b>\$25,000 to \$49,999</b>	<b>\$50,000 to \$99,999</b>	<b>\$100,000 or more</b>
<b>Find cure/better treatment</b>	46%	30%	46%	46%	46%	43%	46%	48%	48%
<b>Help scientists</b>	33%	22%	33%	33%	34%	31%	33%	33%	35%
<b>Receive compensation</b>	29%	22%	27%	30%	28%	32%	29%	28%	24%
<b>Help others</b>	28%	36%	31%	28%	25%	29%	28%	26%	29%
<b>Receive free care</b>	17%	17%	15%	17%	19%	17%	17%	18%	19%
<b>More attention from staff</b>	13%	14%	12%	12%	16%	12%	13%	13%	13%
<b>Help family</b>	12%	15%	15%	12%	11%	14%	12%	11%	11%
<b>Receive free medication</b>	12%	18%	12%	13%	12%	12%	13%	13%	12%
<b>Doctor recommended</b>	7%	12%	7%	7%	7%	7%	6%	8%	6%

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

		<b>AGE</b>					<b>SEVERITY OF DISEASE</b>				
	<b>OVERALL</b>	<b>18 to 34 years old</b>	<b>35 to 44 years old</b>	<b>45 to 54 years old</b>	<b>55 to 64 years old</b>	<b>65 and older</b>	<b>Very mild</b>	<b>Mild</b>	<b>Moderate</b>	<b>Severe</b>	<b>Very severe</b>
<b>Find cure/better treatment</b>	46%	40%	40%	46%	49%	52%	44%	40%	44%	51%	46%
<b>Help scientists</b>	33%	25%	29%	32%	34%	42%	36%	35%	37%	40%	38%
<b>Receive compensation</b>	29%	32%	33%	31%	29%	20%	25%	27%	28%	24%	30%
<b>Help others</b>	28%	28%	25%	28%	28%	32%	29%	27%	31%	32%	38%
<b>Receive free care</b>	17%	18%	18%	17%	19%	13%	18%	17%	16%	14%	13%
<b>More attention from staff</b>	13%	14%	14%	12%	12%	12%	13%	14%	12%	14%	10%
<b>Help family</b>	12%	15%	15%	13%	10%	11%	13%	13%	11%	9%	8%
<b>Receive free medication</b>	12%	13%	14%	13%	13%	9%	11%	14%	11%	9%	10%
<b>Doctor recommended</b>	7%	8%	8%	6%	6%	7%	7%	7%	8%	4%	5%

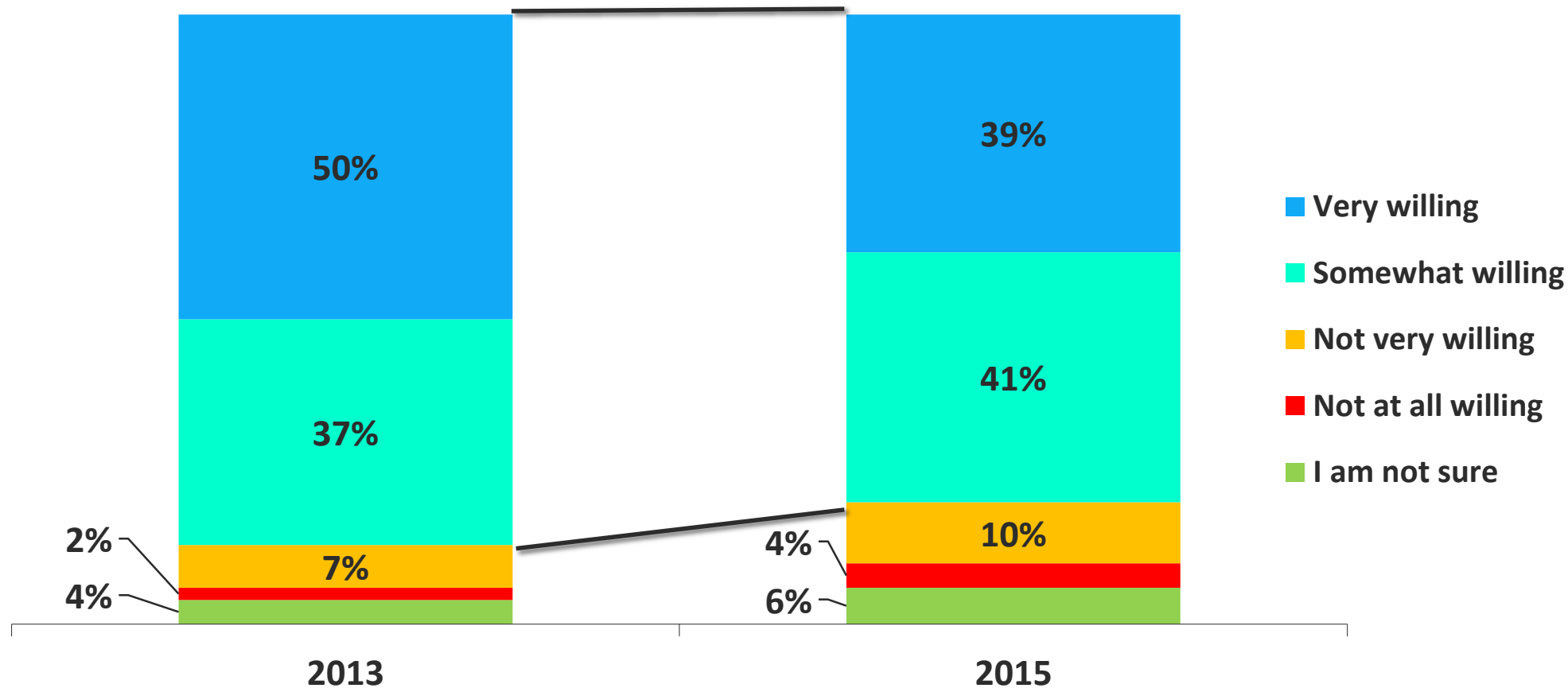
\*A 3% difference is statistically significant at a 95% confidence interval

# Takeaways

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- The top perceived reasons for why people participate in research remain the same as in 2013 – to find a cure or better treatment for illness (46%), to help scientists understand more about how to treat a disease/condition (33%), to receive compensation (29%), and to help others (28%).
- A significantly higher proportion (34%) of respondents from North America perceives compensation as one of the top participation drivers in comparison with respondents from South America (21%) and Asia Pacific (13%) regions in particular.
- Black/African American respondents and younger respondents also mention compensation as a top participation driver.

# General Willingness to Participate in a Clinical Research Study



Source: 2013 CISCRP Perceptions & Insights Study (n=5,701)

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



		<i>REGION</i>				<i>RACE</i>			<i>ETHNICITY</i>	
<b>OVERALL</b>		<b>North America</b>	<b>South America</b>	<b>Europe</b>	<b>Asia Pacific</b>	<b>White</b>	<b>Black/African American</b>	<b>Asian</b>	<b>Non-Hispanic</b>	<b>Hispanic</b>
<b>Very willing</b>	39%	44%	29%	25%	43%	40%	45%	35%	41%	30%
<b>Somewhat willing</b>	41%	40%	45%	44%	41%	41%	34%	41%	41%	44%
<b>Not very/not at all willing</b>	14%	11%	21%	23%	10%	13%	14%	17%	12%	20%
<b>I am not sure</b>	6%	5%	6%	8%	5%	6%	7%	7%	6%	6%

		<i>EDUCATION</i>				<i>INCOME</i>			
<b>OVERALL</b>		<b>None/primary education only</b>	<b>Some/ completed high school</b>	<b>Some/ completed college</b>	<b>Some/ completed post-graduate</b>	<b>Less than \$25,000</b>	<b>\$25,000 to \$49,999</b>	<b>\$50,000 to \$99,999</b>	<b>\$100,000 or more</b>
<b>Very willing</b>	39%	41%	36%	41%	38%	39%	39%	42%	43%
<b>Somewhat willing</b>	41%	30%	40%	41%	43%	37%	43%	43%	43%
<b>Not very/not at all willing</b>	14%	21%	17%	13%	13%	17%	13%	11%	11%
<b>I am not sure</b>	6%	9%	8%	5%	5%	7%	5%	4%	4%

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

		<b>AGE</b>					<b>SEVERITY OF DISEASE</b>				
	<b>OVERALL</b>	<b>18 to 34 years old</b>	<b>35 to 44 years old</b>	<b>45 to 54 years old</b>	<b>55 to 64 years old</b>	<b>65 and older</b>	<b>Very mild</b>	<b>Mild</b>	<b>Moderate</b>	<b>Severe</b>	<b>Very severe</b>
<b>Very Willing</b>	39%	24%	32%	42%	47%	46%	69%	55%	64%	72%	75%
<b>Somewhat Willing</b>	41%	45%	43%	40%	38%	41%	27%	40%	29%	24%	20%
<b>Not very/not at all Willing</b>	14%	23%	17%	12%	10%	9%	3%	5%	5%	4%	3%
<b>I am not sure</b>	6%	7%	8%	6%	5%	4%	1%	1%	1%	0%	1%

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

# Takeaways

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- Consistent with past surveys, the majority of respondents (80%) would be willing to participate in a research study. While this represents a lower proportion than the 2013 study (87%), the variation could be due to the substantially larger and more geographically diverse sample of respondents in 2015. Those that have participated in a clinical trial are generally much more willing to participate than those respondents who have never participated.
- Similar to findings in 2013, respondents from South America and Europe are significantly less willing to participate compared to respondents from North America and Asia Pacific regions.
- A significantly higher proportion of Black/African American respondents (45%) are ‘very willing’ to participate compared to White (40%) and Asian (35%) respondents. A significantly higher percentage of non-Hispanics (41%) are ‘very willing’ to participate compared to Hispanics (30%).
- Younger respondents (18 to 24 years old) are the least willing to participate in a clinical research study – similar to findings in 2013.

# About this Study

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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.

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***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

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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



**CLARINNESS**



# About CISCRP

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