CISCRP
THE CENTER FOR INFORMATION & STUDY
ON CLINICAL RESEARCH PARTICIPATION

Report on Public Literacy

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 public’s clinical research literacy. 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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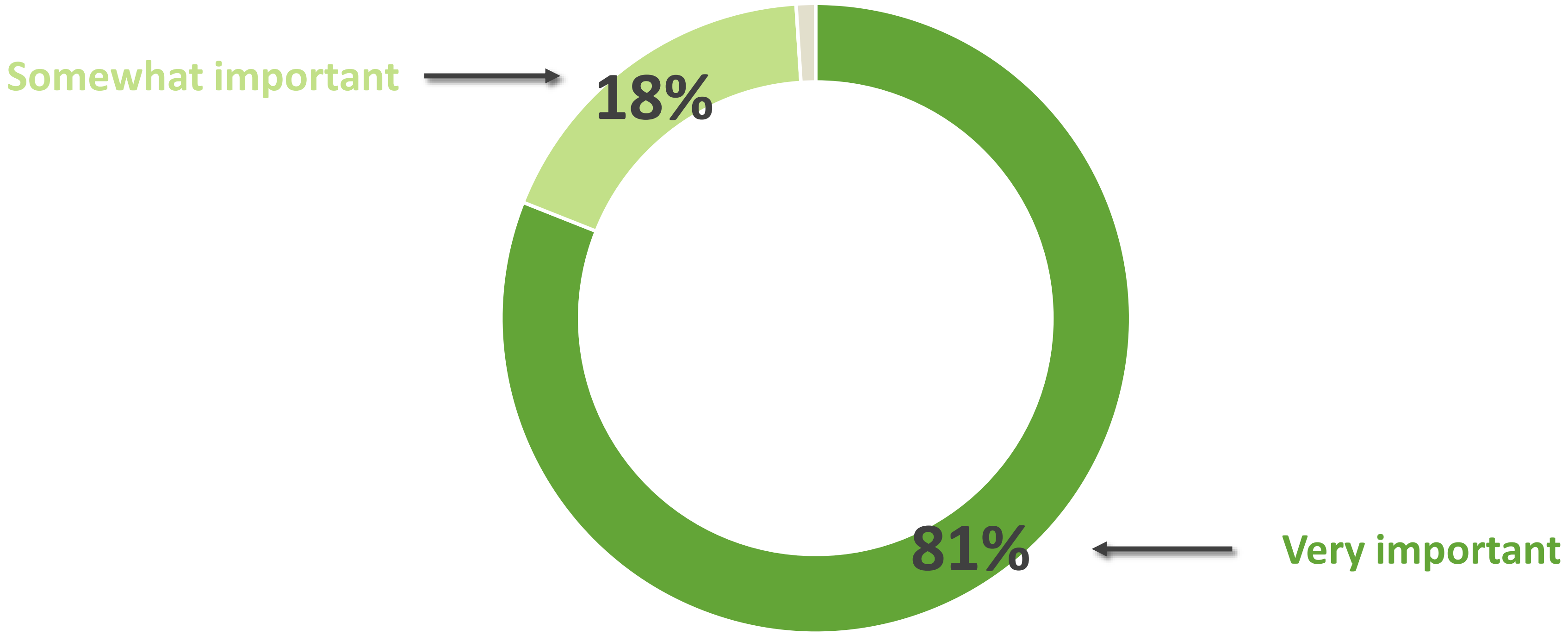
Importance of Clinical Research to Discovery and Development of New Medicines



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**
Very important	81%	82%	80%	73%	84%	82%	79%	74%	82%	78%
Somewhat important	18%	17%	18%	24%	14%	17%	18%	23%	17%	19%
Not very/not at all important	1%	1%	2%	3%	1%	1%	2%	4%	1%	2%

		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**
Very important	81%	65%	77%	82%	84%	79%	81%	82%	85%
Somewhat important	18%	30%	21%	17%	15%	19%	18%	17%	15%
Not very/not at all important	1%	5%	2%	1%	1%	2%	1%	1%	0%

*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				
	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**
Very important	81%	73%	76%	81%	85%	87%	92%	81%	87%	89%	96%
Somewhat important	18%	24%	22%	18%	14%	13%	7%	18%	11%	9%	4%
Not very/not at all important	1%	3%	2%	1%	1%	0%	1%	1%	1%	1%	0%

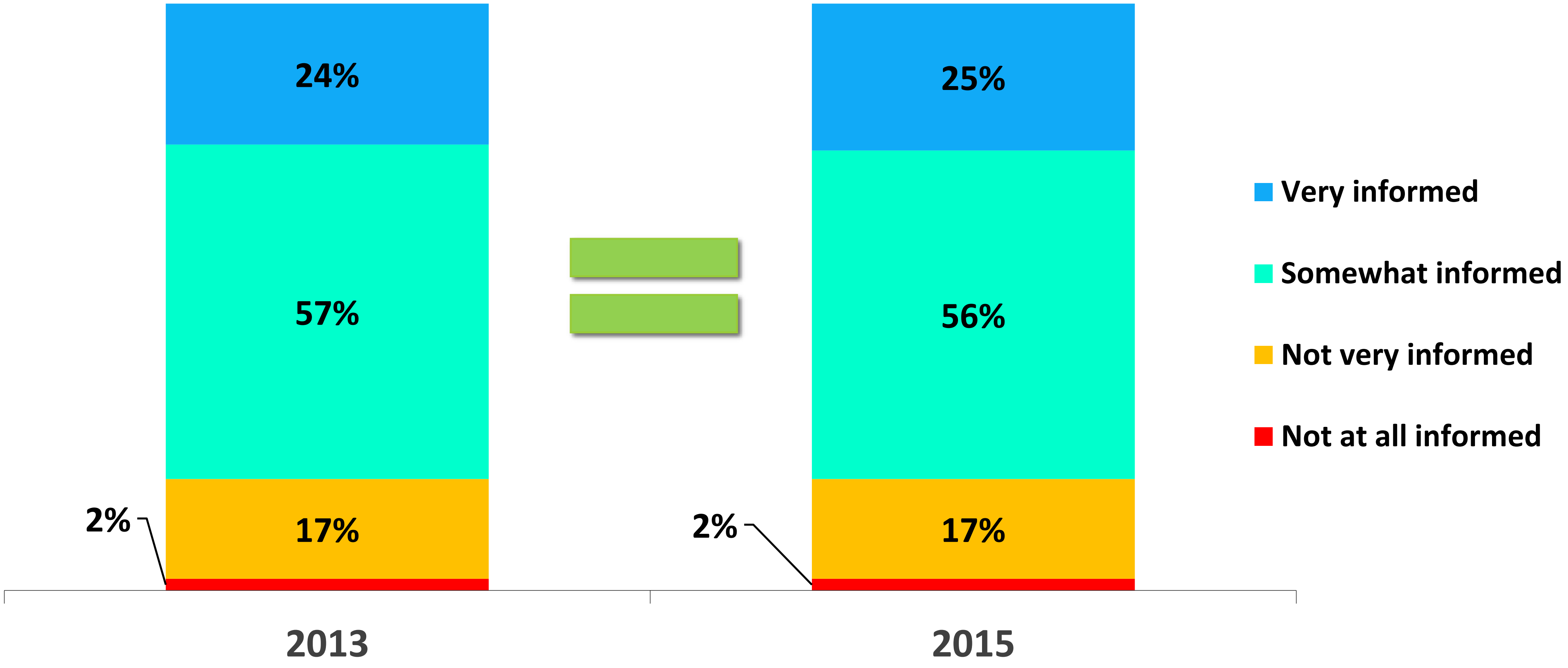
*A 3% difference is statistically significant at a 95% confidence interval

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

Takeaways

- Most (81%) respondents agree that clinical research studies are ‘very important’ to the discovery and development of new medicines.
- A significantly lower proportion of respondents from Europe (73%) agree that clinical research studies were ‘very important’ compared to other regions.
- A higher proportion of White respondents (82%) agree that clinical research studies were ‘very important’ compared to Black/African American (79%) and Asian respondents (74%). Non-Hispanics (82%) also report a higher level of agreement than Hispanics (78%).
- Older respondents report a higher level of agreement on the importance compared to younger respondents. Additionally, higher percentages of respondents with higher education and in higher income brackets find clinical research studies ‘very important’.
- A higher proportion of respondents with very severe conditions (96%) agree that clinical research studies are ‘very important’ compared to those with milder conditions.

General Knowledge of Clinical Research



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

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

Statistically significant at 95%: none

		REGION				RACE			ETHNICITY	
	OVERALL	North America	South America	Europe	Asia Pacific	White	Black/African American	Asian	Non-Hispanic	Hispanic
Very informed	25%	30%	26%	16%	22%	24%	38%	29%	25%	28%
Somewhat informed	56%	57%	54%	54%	57%	57%	48%	52%	56%	53%
Not very/not at all informed	19%	14%	20%	31%	21%	19%	14%	19%	18%	18%

		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
Very informed	25%	30%	19%	25%	36%	25%	23%	27%	33%
Somewhat informed	56%	43%	54%	58%	51%	53%	58%	58%	55%
Not very/not at all informed	19%	27%	28%	17%	13%	22%	18%	14%	13%

*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***				
	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**
Very informed	25%	21%	25%	27%	27%	25%	52%	38%	42%	46%	53%
Somewhat informed	56%	56%	54%	55%	57%	57%	43%	56%	52%	48%	40%
Not very/not at all informed	19%	23%	20%	18%	16%	18%	5%	7%	5%	5%	6%

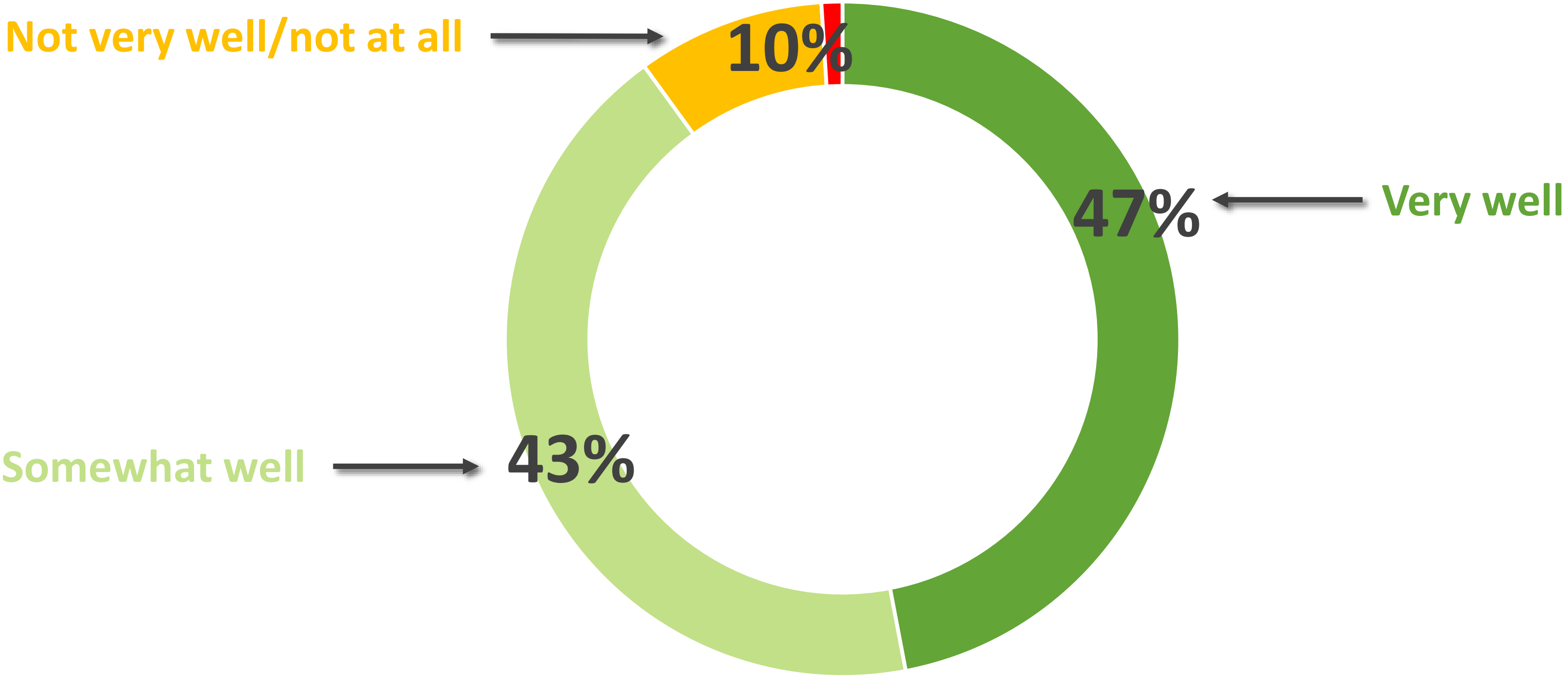
*A 3% difference is statistically significant at a 95% confidence interval

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

Takeaways

- The majority of respondents claim to be ‘somewhat/very informed’ on clinical research (81%), similar to findings in 2013.
- A significantly higher proportion of respondents from Europe (31%) report not being informed on clinical research particularly in comparison to respondents from North America (14%).
- Black/African American respondents claim to be much more informed on clinical research (38% report being ‘very informed’) when compared to White (24%) and Asian respondents (29%).
- Significantly higher percentages of less educated respondents and those in lower income brackets report not being informed. Younger respondents also report being less informed on clinical research compared to older respondents.

Understanding of Clinical Research



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**
Very well	47%	52%	44%	41%	37%	47%	60%	42%	48%	51%
Somewhat well	43%	41%	40%	45%	50%	44%	32%	45%	43%	38%
Not very/not at all well	10%	7%	16%	13%	13%	9%	9%	13%	9%	11%

		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**
Very well	47%	41%	38%	49%	59%	44%	46%	51%	56%
Somewhat well	43%	37%	47%	43%	35%	43%	44%	42%	37%
Not very/not at all well	10%	23%	15%	9%	7%	12%	9%	8%	7%

*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*				
	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**
Very well	47%	44%	49%	48%	49%	46%	70%	61%	65%	71%	73%
Somewhat well	43%	42%	42%	43%	43%	44%	27%	37%	32%	24%	23%
Not very/not at all well	10%	14%	9%	9%	8%	10%	2%	2%	2%	4%	4%

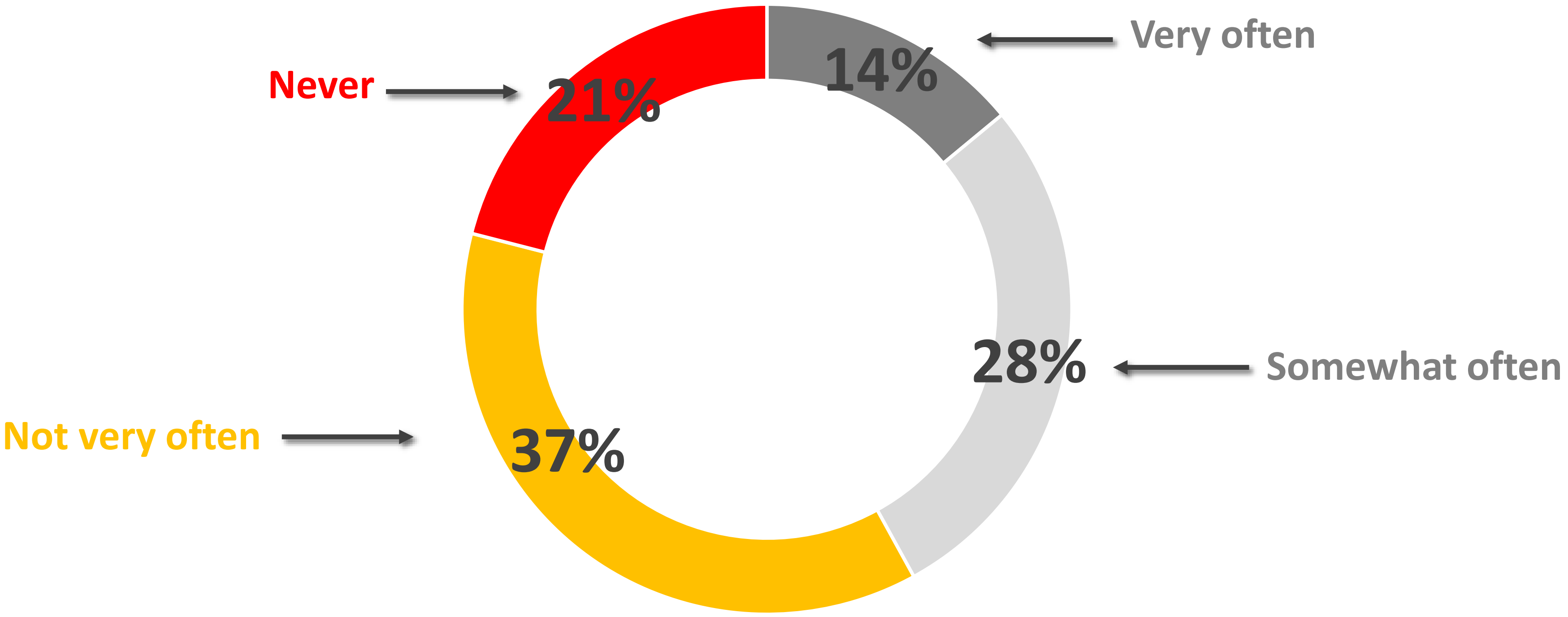
*A 3% difference is statistically significant at a 95% confidence interval

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

Takeaways

- Similar to findings in 2013, the majority of respondents (90%) claim to understand the clinical research term ‘somewhat/very well’.
- A significantly higher proportion of respondents from North America report understanding the term ‘very well’ (52%) compared to other regions; similar to findings in 2013 where a higher proportion of North American respondents claimed to understand the term very well also.
- A higher percentage of Black/African American respondents (60%) report understanding the term ‘very well’ compared to White (47%) and Asian (42%) respondents.
- Higher proportions of respondents with more education and in higher income brackets also report understanding the clinical research ‘very well’.
- Similar to findings in 2013, a significantly higher proportion of younger respondents report not understanding the term very well.
- A higher percentage of respondents with more severe conditions report understanding the clinical research term ‘very well’ compared to those with less severe conditions.

Consider Research as Option When Discussing with your Doctor



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**
Very often	14%	13%	25%	12%	15%	13%	18%	21%	13%	21%
Somewhat often	28%	27%	39%	30%	28%	27%	32%	37%	27%	38%
Not very often/never	58%	60%	36%	58%	58%	60%	49%	42%	60%	41%

		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**
Very often	14%	28%	13%	14%	16%	15%	14%	13%	16%
Somewhat often	28%	30%	28%	28%	31%	29%	30%	28%	26%
Not very often/never	58%	41%	59%	58%	53%	56%	56%	59%	59%

*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*				
	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**
Very often	14%	16%	15%	15%	13%	12%	32%	21%	25%	29%	27%
Somewhat often	28%	36%	33%	28%	25%	22%	30%	39%	37%	34%	41%
Not very often/never	58%	48%	51%	57%	62%	65%	38%	40%	38%	37%	32%

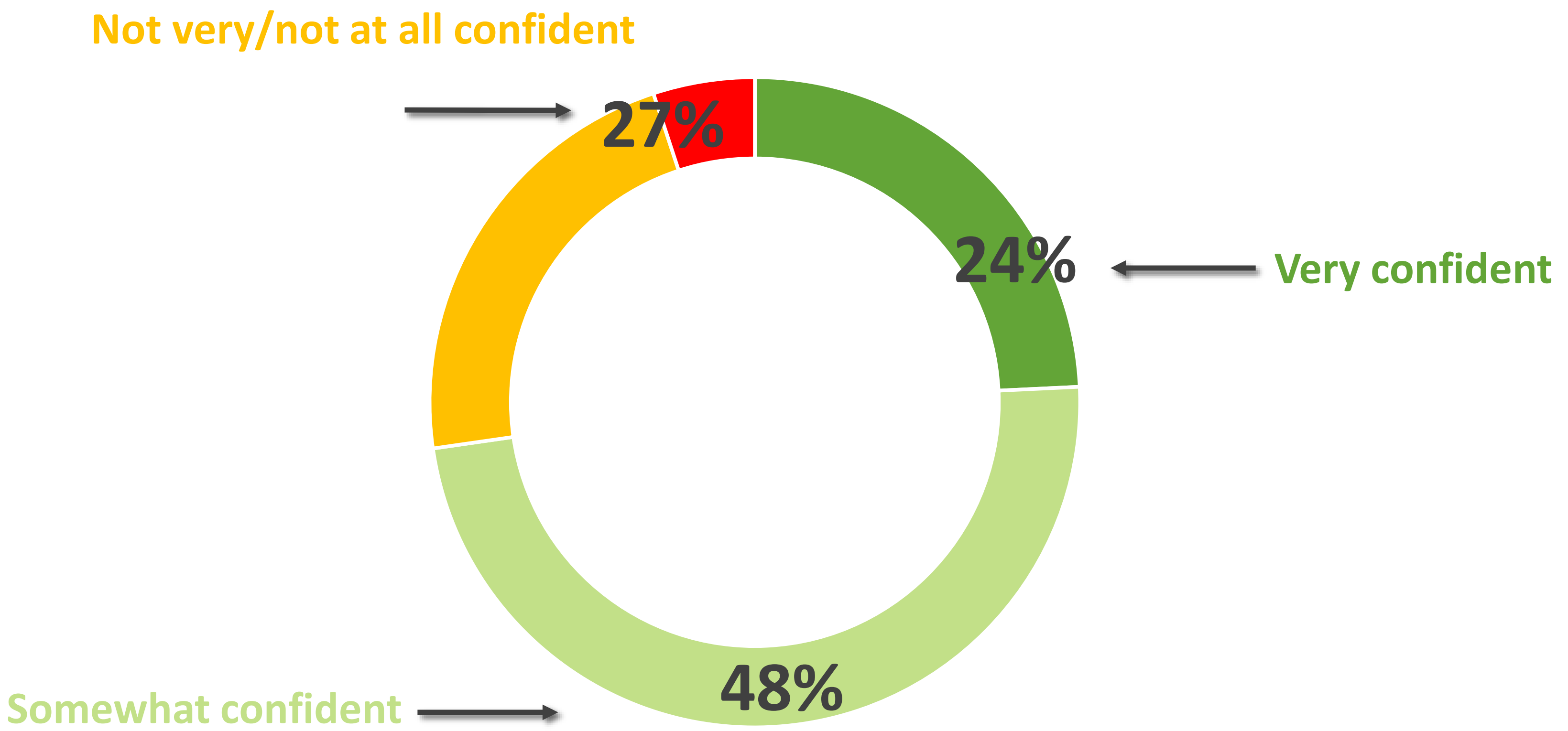
*A 3% difference is statistically significant at a 95% confidence interval

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

Takeaways

- Well over half of the respondents (58%) rarely, if ever, consider discussing clinical research options with their doctor.
- Respondents from South America report considering discussing clinical research as an option with their doctor significantly more often compared to other regions (64% report considering 'very/somewhat often').
- A significantly higher percentage of White respondents (60%) report rarely considering research in discussions with their doctor compared to Black/African American (49%) and Asian respondents (42%). Non-Hispanics are less likely to consider research in discussions with their doctor compared to Hispanics.
- Less educated respondents report considering clinical research as an option more often than higher educated respondents. Younger respondents claim to consider research more often than older respondents.

General Confidence in Finding Appropriate Clinical Research 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**
Very confident	24%	25%	35%	18%	23%	23%	36%	29%	23%	33%
Somewhat confident	48%	48%	46%	48%	49%	49%	43%	46%	48%	47%
Not very/not at all confident	27%	27%	19%	35%	28%	28%	21%	24%	28%	20%

		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**
Very confident	24%	36%	22%	24%	28%	24%	25%	25%	27%
Somewhat confident	48%	38%	48%	49%	46%	47%	49%	49%	49%
Not very/not at all confident	27%	25%	31%	27%	26%	29%	26%	26%	23%

*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*				
	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**
Very confident	24%	23%	26%	27%	24%	21%	51%	37%	41%	44%	46%
Somewhat confident	48%	48%	48%	47%	48%	49%	37%	52%	49%	41%	34%
Not very/not at all confident	27%	29%	26%	25%	28%	29%	12%	11%	10%	15%	20%

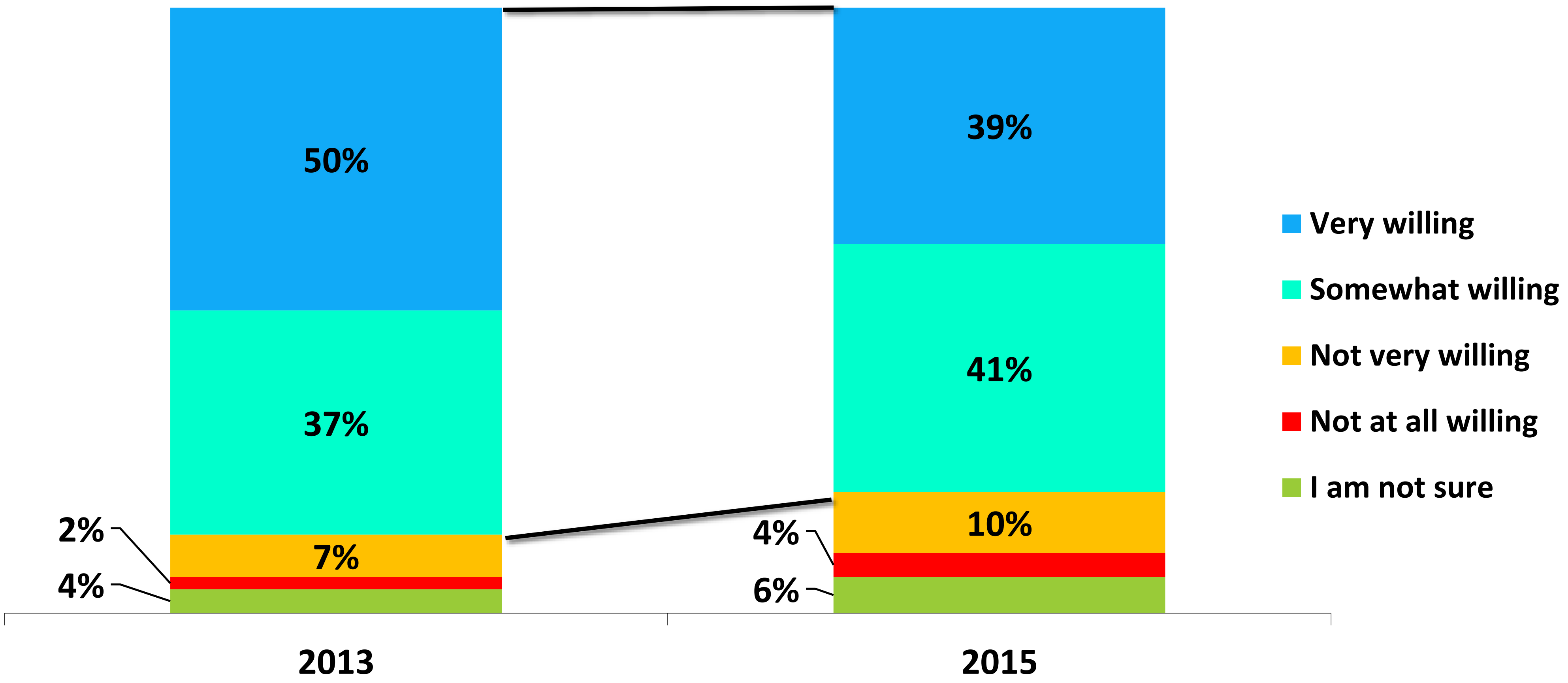
*A 3% difference is statistically significant at a 95% confidence interval

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

Takeaways

- About a third (27%) of respondents report being ‘not very/not at all confident’ that he or she would find an appropriate research study.
- Respondents from South America are significantly more confident they will find an appropriate research study compared to other regions – particularly in comparison to respondents from Europe.
- Black/African American respondents are more confident (36%) that they will find the right research study compared to White respondents (23%). A significantly higher proportion of Hispanics (33%) report being ‘very confident’ compared to non-Hispanics (23%).
- A significantly higher proportion of respondents with very severe conditions are less confident they will find the right research study compared to those respondents with milder conditions.

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)

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

		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**
Very willing	39%	41%	36%	41%	38%	39%	39%	42%	43%
Somewhat willing	41%	30%	40%	41%	43%	37%	43%	43%	42%
Not very/not at all willing	14%	21%	17%	13%	13%	17%	13%	11%	11%
I am not sure	6%	9%	8%	5%	5%	7%	5%	4%	4%

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**
Very willing	39%	24%	32%	42%	47%	46%	69%	55%	64%	72%	75%
Somewhat willing	41%	45%	43%	40%	38%	41%	27%	40%	29%	24%	20%
Not very/not at all willing	14%	23%	17%	12%	10%	9%	3%	5%	5%	4%	3%
I am not sure	6%	7%	8%	6%	5%	4%	1%	1%	1%	0%	1%

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

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

Takeaways

- 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

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

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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.