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## Participation in Clinical Trials Lower in Europe and India than in the United States

*Harris Interactive studies public perceptions of clinical trials in six European countries and India*

5 | Volume  
7 | Issue  
June 27

2005

This issue of the Harris Interactive *Healthcare News* is the second of two reports this year on adult participation in clinical trials. The first three landmark surveys conducted in 2001, 2003 and 2004 focused on the public and participating subjects in the United States. For the first time, this year's study extends out to the international community to determine views and attitudes of clinical trials in France, Germany, Spain, Italy, United Kingdom, Poland and India. These findings can now be compared to the views and attitudes of the U.S. adult population found in Harris Interactive's 2005 U.S. study available in a separate issue of *Healthcare News* (Volume 5, Issue 6, June 27, 2005, [http://www.harrisinteractive.com/news/newsletters\\_healthcare.asp](http://www.harrisinteractive.com/news/newsletters_healthcare.asp)).

The international survey is based on online interviews conducted by Harris Interactive in collaboration with Fast4wD Ogilvy, Eli Lilly and Company, and CISCRP between April 26 and May 16, 2005 among 2,935 adults aged 18 and older from the following countries: France, Germany, Spain, Italy, United Kingdom, Poland, and India. Additionally, key metrics and comparisons from the U.S. survey conducted parallel to this survey are included in this report.

### Opportunity and Participation in Clinical Trials

Adults surveyed in six European countries and in India report low levels of participation in clinical research studies (6%). Very few (8%) say they have ever had the opportunity to participate in a clinical research study. These numbers are slightly lower than what was reported in the United States, as 10 percent of U.S. adults surveyed say they have ever participated in clinical trials, and 15 percent say they have ever had the opportunity to participate. Of the European and Asian countries surveyed, India boasts the highest level of opportunity to participate (14%) with eight percent of Indian respondents saying they have ever participated in a clinical research study.

**TABLE 1**  
**Participation/Opportunity to Participate in Clinical Research Study**

Base: All Adults

	U.S. n=2,261	Total Non- U.S. n=2,935	France n=509	Germany n=599	Spain n=622	Italy n=574	U.K. n=369	Poland n=134	India n=128
	%	%	%	%	%	%	%	%	%
Ever had the opportunity to participate in clinical research study	15	8	9	9	5	5	13	10	14
Ever participated in a clinical research study	10	6	6	6	4	4	9	9	8

### Reasons for Participation and Likelihood of Future Participation

The top reasons cited for participation in clinical trials are similar in the United States and in the non-U.S. countries surveyed. Nearly half (46%) of respondents in Europe and India who have ever participated in a clinical trial reported that they participated in order to advance medicine and science. A somewhat smaller percentage (37%) say they participated to obtain better treatment for their condition, while 35 percent say they participated to help others with the condition. Approximately one-third of participants in both the United States (36%) and Europe/India (33%) report that earning extra money was a reason for their participation.

**TABLE 2**  
**Reasons for Participation**

“Please indicate which of the following, if any, are reasons you decided to participate in a clinical research study. Please select all that apply.”

Base: Have ever participated in clinical research study

	Total Non-U.S. n=154	U.S. n=261
	%	%
To advance medicine/science	46	51
To obtain better treatment for my condition	37	46
To help others with the condition	35	39
My doctor recommended the study.	34	31
To earn extra money	33	36
The information I read, saw, or had heard about the study influenced me.	28	25
I was curious about the specifics of the study.	27	26
To obtain education about treatment/improving my health	25	30
There were no other treatment options available.	18	4
Friend recommended the study	16	5
I have a life-threatening illness.	15	5
To obtain free medication (if applicable)	13	19
If I knew someone else who had the condition being studied	11	7
Family recommended the study	8	8
Other	7	6
There were no reasons in particular.	3	1

Note: Multiple-response question.

For those in Europe and India who have ever participated in a clinical research study, the likelihood that they would participate in another clinical research study is 80 percent compared to 84 percent in the United States. Among those who say they have not participated in clinical trials or who say they have not had the opportunity to participate, 43 percent of European and Indian respondents overall say they would consider taking part in one, which is lower than the U.S. results (63%).

**TABLE 3**

**Consider Participating in Clinical Research Study**

“Would you consider participating in (another) clinical research study?”

Base: All Adults

	Adults who say they have not participated in a clinical research study or who say they have not ever had the opportunity to participate		Adults who say they have participated in a clinical research study (ever)	
	U.S. n=2,000	Non-U.S. n=2,781	U.S. n=261	Non-U.S. n=154
	%	%	%	%
Yes	63	43	84	80
No	8	15	2	7
Not Sure	29	42	14	13

**Factors Very Likely to Influence Participation**

With the exception of India, substantial majorities of adults (67% to 80%) in the European and Asian countries surveyed who would consider participating in a clinical research study say they would be very likely to participate if they had a terminal illness. Two-fifths (40%) of those respondents in India indicated that having a terminal illness would very likely influence their decision to participate, perhaps reflecting the negative perception of this topic in this culture.

Other notable differences in responses among U.S., European, and Indian respondents who would consider participating in a clinical research study include the following:

- Between 64 and 70 percent of those in Germany, Spain, Italy, United Kingdom, and Poland would be very likely to participate if they thought the drug would cure them, compared to 53 percent in France and 51 percent in India.
- Overall, more than one-quarter (28%) of adults in Europe and Asia say they would be very likely to participate if they knew they would receive an active drug and not a placebo. However, a closer look at the data shows that only 18 percent of adults in Poland would be very likely to be influenced to participate in a clinical research study given this option.
- A lower percentage of adults in Italy (31%) and Poland (33%) compared to the other non-U.S. countries (from 39% to 47%) and the United States (46%) report being very likely to participate if they received money for their participation.
- One-third of adults in India (33%) and the United Kingdom (34%) say they would be very likely to participate if they knew the risks associated with the treatment compared to 42 percent of Europeans and Asians surveyed overall.

**TABLE 4**

**Factors Very Likely to Influence Decision to Participate**

“On a scale from 1-5, with 1 being “Not likely” and 5 being “Very likely”, please rate the factors below on their likeliness to influence your decision to participate in a clinical research study.”

Percent saying “5” (“very likely”)

Base: Would consider participating in a clinical research study

	U.S. n=1,525	Total Non- U.S. n=1,335	France n=215	Germany n=266	Spain n=238	Italy n=227	U.K. n=229	Poland n=71*	India n=89*
	%	%	%	%	%	%	%	%	%
If I had a terminal illness	72	72	67	77	78	76	69	80	40
If I thought the drug might cure me	67	64	53	69	70	68	64	70	51
If I knew that I would receive an active drug and not a sugar pill (placebo)	33	28	24	31	27	31	28	18	26
If I received money for participating	46	40	47	43	39	31	42	33	43
If I knew the risks associated with the treatment	45	42	48	42	41	50	34	40	33
If I knew there were no risks involved	61	63	56	64	67	65	59	74	58
If my doctor recommended it	47	45	43	51	46	37	46	36	55
If the treatment were free of charge to me (if applicable)	53	46	39	58	44	40	50	42	39
If I thought the drug/treatment would help me	61	60	54	68	59	58	55	68	64
If it were convenient for me to participate	43	48	49	50	53	53	38	33	52
If I had a condition other than a terminal illness	29	31	38	36	24	27	33	18	29
If there were no other medical options available to me	66	59	46	61	76	49	62	75	42
If there were minimal side effects associated with the treatment	43	42	47	33	49	42	40	55	38
If the location were convenient for me	43	44	50	49	41	40	40	34	44
If I thought the drug/treatment would help someone else in the future	45	46	54	42	47	46	41	39	51
If I already take a drug/treatment made by the pharmaceutical company sponsoring the study	28	23	24	31	21	11	26	16	25
If I knew someone else who had the condition being studied.	30	31	41	24	40	25	28	26	36

\*Very small base.

## Informed Consent Process

Among the participants who agreed to be a part of the clinical research study, a majority of them from both the United States and Europe and India understood that participation in the clinical research study was voluntary (84% and 81%, respectively). However, compared to their U.S. counterparts, a smaller percentage of European and Indian participants report that they were aware of the risks involved, understood their right to withdraw at anytime and were clear on the purpose of the study. Approximately two-thirds of clinical trial participants in Europe and India strongly agree that they fully understood what was required of them (68% vs. 78% of U.S. participants) and that they could stop participating at anytime (65% vs. 75% of U.S. participants). More than half (53%) of participants in Europe and India strongly agree that they were made aware of the risks involved, compared to two-thirds (65%) of U.S. participants. Furthermore, while 85 percent of U.S. participants strongly agree that the purpose of the study was clear, only 64 percent of European and Indian participants felt similarly.

**TABLE 5**  
**Informed Consent Process Views**

“The following statements describe how well the process was explained to you when you agreed to be part of the clinical research study. Please indicate how strongly you agree or disagree with these statements by using the scale below.”  
Percent saying “strongly agree”

Base: Have ever participated in clinical research study

	U.S. n=261	Total Non-U.S. n=154
	%	%
I understood that participation was voluntary.	84	81
I understood that I was agreeing to participate in a clinical research study.	83	77
I fully understood what was required of me (number of visits, how long the study lasted, etc.).	78	68
I knew I could stop participating in the study at any time.	75	65
I felt comfortable asking additional questions regarding the study.	75	67
I was assured confidentiality of any and/or all other personal information that I provided, with the exception of those allowed by federal law. (Note: Governmental replaced for federal in global study)	73	63
I felt secure that my confidentiality was protected throughout the study.	69	69
I was made aware of the benefits involved in participating in the clinical research study.	68	65
I was made aware of the risks involved in participating in the clinical research study.	65	53
I understood that I could choose other treatment options, including no treatment at all.	63	55
The informed consent document was easy to read and understand.	61	58

**TABLE 6**  
**Overview of Informed Consent Process**

Base: Have ever participated in clinical research study

	U.S. n=261	Total Non-U.S. n=154
	%	%
– Purpose of the study was clear after reading the informed consent.	85	64
– Purpose of the study was only somewhat clear after reading the informed consent.	12	26
Majorities agreed questions were answered regarding the informed consent by the study team.	80	56
Read the informed consent by themselves	48	59
– Percentage who said the study coordinator conducted the informed consent process	54	23
– Percentage who said the physician conducted the informed consent process	25	58

## Risks and Benefits of Participating in Clinical Trials

Adults surveyed in the United States and in Europe and Asia have similar perceptions of the risks and benefits of participating in a clinical research study. Participants perceived possible side effects to be the greatest risk of participating in a clinical research study in both the United States (47%) as well as in Europe and India (45%).

A significantly higher percentage of adults in Germany (52%) and Spain (46%) perceive health risks as the greatest risk of participating in a clinical research study. The greatest perceived benefits of clinical research studies for both groups is helping to advance science and find a cure for diseases/conditions (36% of U.S. respondents vs. 42% of European and Asian respondents). Overall, a significantly smaller percentage of adults surveyed in Europe and Asia compared to the United States believe that the greatest benefit of participation in clinical research studies is that it may help the participant's condition (9% vs. 17% in the United States).

**TABLE 7**  
**Greatest Perceived Risk of Participating in Clinical Research Study**

"Which of the following do you consider to be the greatest risk of participating in a clinical research study? Please select only one response."

Base: All Adults

	U.S. n=2,261	Total Non-U.S. n=2,935	France n=509	Germany n=599	Spain n=622	Italy n=574	U.K. n=369	Poland n=134	India n=128
	%	%	%	%	%	%	%	%	%
Possible side effects	47	45	47	39	42	49	52	50	43
Health risks	32	39	34	52	46	29	30	37	32
Unproven therapy	9	8	9	3	7	15	9	6	12
Receiving a placebo (sugar pill)	5	2	2	1	1	1	4	2	0
Privacy concerns	2	1	2	2	0	1	1	3	5
Other	1	1	1	1	1	1	0	1	1
None, I do not believe there are any risks	4	4	5	2	3	4	4	0	7

**Table 8**  
**Greatest Perceived Benefits of Participating in Clinical Research Study**

“Which of the following do you consider to be the greatest benefits of a clinical research study? Please select only one response.”

Base: All Adults

	U.S. n=2,261	Total Non- U.S. n=2,935	France n=509	Germany n=599	Spain n=622	Italy n=574	U.K. n=369	Poland n=134	India n=128
	%	%	%	%	%	%	%	%	%
Help advance science and find a cure for diseases/conditions	36	42	53	38	45	36	41	29	40
May help to save lives	24	22	15	24	22	26	22	34	21
May help me with my condition	17	9	6	9	9	10	14	6	9
Allow medical team to find a more effective treatment	11	12	15	13	7	11	15	12	13
Monetary compensation (money) is provided	4	4	7	3	3	3	2	5	4
Allows me to help others with the condition	3	7	1	7	11	9	4	10	4
Provide information on current medications	1	1	1	2	0	2	1	0	3
Free medication is provided (if applicable in your country)	1	1	0	0	0	1	1	1	3
Other	1	1	0	1	1	1	1	2	0
None, I do not believe there are any benefits	2	1	1	2	1	1	1	0	3

## Pros and Cons of Clinical Trials

Although public perceptions of the pros and cons of clinical trials are very similar in the two studies, European and Indian respondents expressed stronger opinions on a few issues. Higher percentages of adults in Germany (60%) compared to the United States (48%) and total European and Asian countries surveyed (47%) strongly or somewhat agree that people who participate in clinical research studies receive the best possible treatment.

Similarly, a higher percentage of adults in Germany (54%), Italy (56%), and Poland (56%) strongly or somewhat agree that participants of clinical research studies will gain access to the best physicians. This observation is higher compared to the U.S. respondents and overall European and Indian respondents (46%). Additionally, a higher proportion of adults in Europe and India typically believe that people's participation is making a contribution to science (92% vs. 86% in the United States) and that they are part of an experiment to test medications/treatments not already available to the general public (84% vs. 79% in the United States).

**TABLE 9**  
**Perceived Pros and Cons of Clinical Trials**

“The following statements describe how some people feel about clinical research studies. Please indicate how strongly you agree or disagree with these statements by using the scale below.

People who participate in clinical research studies...”  
Percent saying “strongly agree” or “somewhat agree”

Base: All Adults

	U.S. n=2,261	Total Non-U.S. n=2,935	France n=509	Germany n=599	Spain n=622	Italy n=574	U.K. n=369	Poland n=134	India n=128
	%	%	%	%	%	%	%	%	%
Have access to the best physicians	46	46	38	54	36	56	36	56	52
Get the best possible treatment	48	47	44	60	43	48	41	38	49
Are like guinea pigs <i>*In global: Are like experimental test subjects as oppose to a patient/person</i>	46	39	49	28	44	36	36	34	62
Are making a contribution to science	86	92	95	94	90	89	92	91	93
Have a chance to get free medicine	65	48	50	58	33	45	47	66	52
Are taking a gamble with their health	48	41	54	42	42	28	38	48	41
Learn more about their condition and health in general	76	73	68	77	78	70	72	76	72
Do not have to pay for their medical care	53	47	41	49	48	57	39	41	56
Spend a lot of time at the doctor's office	34	40	41	53	41	34	22	43	45
Are part of an experiment to test medications/treatments already available to the public	33	34	33	24	47	28	32	35	39
Are part of an experiment to test medications/treatments not already available to the public	79	84	88	87	80	81	81	85	81

Note: Numbers may not add up to 100% due to rounding.

## How People Learn and How They Would Prefer to Learn About Clinical Trials

The percentage of adults who have not been exposed to clinical research studies was virtually the same in both the United States and internationally (40% vs. 39%, respectively). Adults in Poland (84%) and Italy (76%) are more likely than others to have been exposed to information about clinical research studies. Regardless of the country, the participants' main sources of information about clinical research studies are the media and the Internet. While the media appears to be the main source of information among all countries surveyed (38% in European and Asian countries vs. 37% in the United States), the Internet is a more prevalent source of information for those in Europe and India (32% vs. 22% in the United States).

**TABLE 10**  
**Method of Learning About Clinical Trials**

"Please indicate from which source(s), if any, you receive information about clinical research studies."

Base: All Adults

	U.S. n=2,261	Total Non- U.S. n=2,935	France n=509	Germany n=599	Spain n=622	Italy n=574	U.K. n=369	Poland n=134	India n=128
	%	%	%	%	%	%	%	%	%
None; I have not been exposed to clinical research studies.	40	39	34	47	50	24	51	16	30
Media source, (e.g., TV, radio, newspaper, magazine)	38	37	41	29	29	55	26	59	37
Internet	22	32	27	33	22	48	22	47	48
Primary care physician	14	18	15	27	9	29	8	6	15
Other doctor (e.g., specialist)	11	16	11	24	13	19	11	14	18
Friends	11	10	11	9	9	9	8	15	20
Harris Interactive	10	6	5	5	5	3	7	10	26
Family	9	8	8	9	6	8	7	14	17
Other	6	5	6	4	4	5	4	15	9
Nurse	5	4	4	1	4	5	5	3	4
Co-workers	3	5	6	3	6	6	6	1	8
Spiritual advisor/leader	1	0	0	0	0	1	0	0	5
Social worker	0	1	1	1	1	0	1	1	10

Note: Multiple-response question

More than half (53%) of European and Asian adults surveyed would prefer to learn about clinical research study opportunities from their regular physician. Germans (58%) and Italians (63%) are more likely to prefer this source than participants in the other countries surveyed. Three in 10 (30%) respondents in Europe and Asia prefer to receive email notifications of relevant clinical trials based on their profile, with a greater percentage of participants in the United Kingdom (34%) and India (37%) preferring this method of communication.

**TABLE 11**  
**Preferred Method of Learning About Clinical Trials**

“How would you prefer to learn about clinical research study opportunities?”

Base: All Adults

	U.S. n=261	Total Non- U.S. n=2935	France n=509	Germany n=599	Spain n=622	Italy n=574	U.K. n=369	Poland n=134	India n=128
	%	%	%	%	%	%	%	%	%
My regular/usual physician	51	53	55	58	52	63	40	44	40
Email notifications of relevant clinical trials based upon my profile	28	30	29	30	25	31	34	27	37
Traditional media (e.g., newspapers/magazines, TV, radio)	21	27	18	25	30	35	17	33	33
A relevant advocacy organization/patient support group	21	21	18	29	25	15	17	18	20
Internet websites	19	31	26	46	22	35	18	35	41
Mail	19	15	25	12	11	10	17	10	35
Harris Interactive	17	10	12	4	10	4	13	18	47
Family/Friends	16	11	7	14	11	8	12	10	22
I have no preference.	15	13	12	10	15	8	22	21	8
I am not interested in learning about clinical research opportunities.	10	7	5	9	8	5	7	6	9

Note: Multiple-response question.

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## Methodology

### International Study

This survey was conducted online within France, Germany, Spain, Italy, United Kingdom, Poland, and India between April 26 and May 15, 2005 among a nationwide cross section of 2,935 adults (aged 18 and over). European data were weighted for age, education, income and region where necessary to bring them into line with their actual proportions in the population. Data for France, Germany, Spain, Italy, and the United Kingdom were propensity weighted to adjust for respondents' propensity to be online. Indian data were weighted for age and gender where necessary to bring them into line with their actual proportions in the population.

In theory, with probability samples of this size, one could say with 95 percent certainty that the overall results have a sampling error of plus or minus 2 percentage points of what they would be if the entire adult population in those seven countries had been polled with complete accuracy. Sampling error for the various sub-sample results (as shown in the tables above) is higher and varies.

Unfortunately, there are several other possible sources of error in all polls or surveys that are probably more serious than theoretical calculations of sampling error. They include refusals to be interviewed (nonresponse), question wording and question order, and weighting. It is impossible to quantify the errors that may result from these factors. These online samples were not probability samples.

### U.S. Study

This survey was conducted online within the United States between April 19 and 26, 2005 among a nationwide cross section of 2,261 adults (aged 18 and over). Data were weighted for age, education, gender, income, race/ethnicity and region where necessary to bring them into line with their actual proportions in the population. Propensity score weighting was also used to adjust for respondents' propensity to be online.

In theory, with probability samples of this size, one could say with 95 percent certainty that the results have a sampling error of plus or minus 3 percentage points of what they would be if the entire U.S. adult population had been polled with complete accuracy. Sampling error for the sub-samples of those who have participated in a clinical research study (261) and those who would consider participating in a clinical research study (1,525) is higher and varies.

Unfortunately, there are several other possible sources of error in all polls or surveys that are probably more serious than theoretical calculations of sampling error. They include refusals to be interviewed (nonresponse), question wording and question order, and weighting. It is impossible to quantify the errors that may result from these factors. These online samples were not probability samples.

# Healthcare News

5 | Volume  
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**June 27**  
2005

*These statements conform to the principles of disclosure of the National Council on Public Polls.*

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