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## Only a Quarter (25%) Of U.S. Adults Would Consider Allowing a Child of Theirs to Participate In a Clinical Research Study

*Willingness to have a child participate is influenced by adults' perceptions of risks, benefits, physician involvement and compensation.*

The need for clinical research involving children is largely endorsed by U.S. adults with two-thirds (67%) believing pediatric research studies are needed to advance the treatment of diseases that affect children. However, only a quarter (25%) of adults would consider allowing a child of theirs to participate in a clinical research study, while 30 percent would not consider it, and 45 percent are unsure.

**TABLE 1**

### Are Pediatric Research Trials Necessary?

"Do you believe that clinical research studies involving children are necessary to advance the treatment of diseases that affect children?"

Base: All Adults (n=5,822)

	%
Yes	67
No	4
Not Sure	29

**TABLE 2**

### Allow Own Child To Participate In A Clinical Research Study Or Not?

"Would you consider allowing a child of yours to participate in a clinical research study?"

Base: All Adults

	Total (n=5,822)	Adults with no children (n=2,602)	Adults with one child (n=794)	Adults with two or more children (n=2,426)
	%	%	%	%
Yes	25	24	23	27
No	30	28	39	30
Not Sure	45	48	38	44

NOTE: Numbers may not add up to 100 percent due to rounding.

These are some of the results of a Harris Interactive survey conducted online in the U.S. between May 6 and 17, 2004 among a nationwide cross section of 5,822 adults, of whom 3,220 have one or more children.

## Interest and Lack of Opportunity to Participate

The majority of U.S. adults who have one or more children (92%) report their children have not had the opportunity to participate in a clinical research study. Of those whose children had an opportunity, 59 percent of the parents (or guardians) allowed their child to participate. Similarly, only a small portion of adults (19%) report having had the opportunity to participate in a clinical trial. Of those, 61 percent actually participated.

**TABLE 3**

### Child Participation In Clinical Research Studies

“Has your child ever had the opportunity to participate in a clinical research study?”

Base: Adults who have children (n=3,220)

	%
Yes	4
No	92
Not Sure	4

**TABLE 4**

### Child Participation In Clinical Research Studies

“Did your child participate in the clinical research study?”

Base: Adults whose child has had the opportunity to participate (n=157)

	%
Yes	59
No	41

**TABLE 5**

### Adult Participation In Clinical Research Studies

“Have you ever had the opportunity to participate in a clinical research study?”

Base: All adults (n=5,822)

	%
Yes	19
No	81

**TABLE 6**

### Adult Participation In Clinical Research Studies

“Have you ever participated in a clinical research study?”

Base: Adults who have had the opportunity to participate (n=1,239)

	%
Yes	61
No	39

## Many Factors Influence the Decision to Allow Participation in a Clinical Research Study

Factors that influence decisions to allow participation include: the health and well being of their child, whether or not their child has a terminal illness, physician influence, remuneration, opportunity, and previous participation. Adults' perceptions of these factors play an important role in determining whether or not they will allow a child of theirs to participate in a clinical research study.

Three in four (75%) U.S. adults would be more likely to consider their child's participation if they thought the drug or treatment would cure their child. The severity of the condition is equally influential with 73 percent of adults reporting that they would be more likely to consider allowing their child to participate if their child had a terminal illness. More specifically, if their child had cancer, 56 percent of adults (excluding parents whose children have these conditions) would be "very likely" to allow their child to participate in a clinical research study compared to diabetes, 37 percent, or chronic headaches, 28 percent.

Only a quarter (26%) of adults are likely to consider their child's participation if the child is healthy, e.g., there was no perceived direct health benefit. The majority of adults (69%) would be more likely to consider allowing their child to participate in a clinical research study if it would benefit their child or someone else's child.

**TABLE 7**

**Factors Which Increase Likelihood Of Participation**

“Assuming a child of yours were eligible, would you be more likely to consider allowing your child to participate in a clinical research study if...?”

Base: All Adults (n=5,822)

		Yes	No	Not Sure
<b>CHILD HEALTH AND WELL BEING</b>				
You thought the drug would cure your child	%	75	10	15
Your child had a terminal illness	%	73	11	17
There were no risks involved	%	72	12	16
Your child’s current treatment options were no longer effective	%	70	12	18
It would benefit your child or someone else’s child	%	69	11	20
You would receive your child’s test results during the study	%	64	16	20
The benefits outweighed the risks	%	64	13	23
You knew all the risks associated with the treatment	%	62	15	23
You were able to talk to the parents of other children in the study	%	57	19	24
There were minimal side effects associated with the treatment	%	56	19	25
Your child would see a doctor more often	%	48	25	27
Your child would get an active drug and not a sugar pill (placebo)	%	47	20	33
The drug/treatment had not been tested in children but had previously been tested in adults and animals	%	34	28	39
Your child did not have a terminal illness	%	27	36	38
Your child were healthy	%	26	44	30
<b>PHYSICIAN SUPPORT</b>				
Your child’s pediatrician/specialist recommended it	%	68	12	21
Your child’s physician recommended that he/she participate in the study	%	66	13	21
Your child’s physician would be informed and kept up to date about your child’s participation in the trial	%	65	16	19
Your child’s physician/specialist were conducting the study	%	56	18	26
Your child’s physician/specialist were <b>not</b> conducting the study	%	21	34	45
<b>COMPENSATION</b>				
The drug/treatment were free	%	58	19	24
Your family received compensation	%	37	29	33

NOTE: Multiple response question.

**TABLE 8**

**Interest In Participation Is Different For Different Diseases**

“How likely would you be to allow your child to participate in a clinical research study if he/she were diagnosed with...?”

Base: All adults excluding those adults who have children with these conditions. (n=4,171)

		Likely (NET)	Very Likely	Somewhat Likely	Neither Likely Nor Unlikely	Unlikely (NET)	Somewhat Unlikely	Very Unlikely
Cancer	%	79	56	23	13	8	2	6
Diabetes	%	69	37	32	19	12	4	8
Chronic headaches	%	62	28	34	24	14	6	8
Depression	%	56	24	32	25	19	8	11
Allergies/ Asthma	%	61	24	36	24	16	7	9
ADHD	%	53	23	30	26	20	9	12

**Perceived Risks and Benefits Are Also Central to the Decision-Making Process for Pediatric Participation**

Nearly three-fourths (72%) of all adults would be more likely to consider allowing their child to participate if there were no risks involved or if the child’s current treatment options were no longer effective (70%). Eighty percent would be likely to allow their child to participate if they had a zero percent chance of receiving a placebo. This percentage decreases to 74 percent when a 15 percent chance of receiving a placebo is introduced.

**TABLE 9**

**Interest Increases As Likelihood Of Getting A Placebo Declines**

“How likely would you be to let your child participate in a clinical research study if he/she had a ...chance of receiving a placebo (sugar pill)? Note: A placebo is an inactive substance given in place of treatment.”

Base: Would consider having a child participate in a clinical research study (n=1,687)

Chance of Receiving a Sugar Pill:		Likely (NET)	Very Likely	Somewhat Likely	Neither Likely Nor Unlikely	Unlikely (NET)	Somewhat Unlikely	Very Unlikely
0%	%	80	52	29	17	3	3	*
15%	%	74	32	41	17	9	6	3
30%	%	64	28	36	17	18	14	4
50%	%	62	29	33	20	18	12	7

\*Less than 0.5%

## Physician Support and Compensation

The physician, or principal investigator conducting the study, plays a crucial role in child participation. Issues such as the parental familiarity with the physician and the way the physician is compensated can have both a positive and negative impact on the parent's perception of the clinical research study. (See table 7)

By more than 2-to-1, adults would consider allowing their child to participate if their child's physician/specialist was conducting the study as opposed to an unknown physician/specialist (56% compared to 21%). Even more important than having their child's physician conducting the study is their child's physician's recommendation: 66 percent of adults would be more likely to consider allowing their child to participate if their physician/specialist recommended it. (See table 7)

Monetary compensation for participation is not as important as receiving free study drug and/or treatment. More than half (58%) of all adults feel free study drug and treatment are important compared to 37 percent who feel compensation is important. (See table 7)

Another factor influencing people's decisions is their perception of how a physician is compensated for their child's participation. Thirty-five percent of adults feel there is a conflict of interest when told that physicians receive money for each participant enrolled in a clinical research study. When told that the money the physician receives is from a grant to cover costs of conducting the study, fewer (25%) feel there is a conflict of interest.

**TABLE 10**  
**Physician Compensation**

"In most cases the physician conducting the study (or the medical facility) receives money for each person (subject) who participates in the study. Do you feel this represents a conflict of interest (i.e., a conflict between the financial interests of the doctor/medical facility and his/her responsibility to your child)?"

Base: All Adults (n=5,822)

	%
Yes	35
No	32
Not Sure	33

**TABLE 11**  
**Physician Compensation**

"The money the physician receives is a grant to cover the costs of completing the study. Does this change your opinion of whether it is a conflict of interest (i.e., a conflict between the financial interests of the doctor/medical facility and his/her responsibility to your child)?"

Base: All Adults (n=5,822)

	%
Yes	25
No	49
Not Sure	25

NOTE: Numbers may not add up to 100 percent due to rounding.

## Views and Attitudes of U.S. Adults Surveyed

- 41 percent of adults “strongly” or “somewhat” agree that their child will receive better medical care if he/she participates in a clinical research study.
- 51 percent “strongly” or “somewhat” agree that if their child participates in a clinical research study designed to test a new drug, the findings from the study will be published, even if the new drug does not work.
- 46 percent “strongly” or “somewhat” agree if their child participates in a clinical research study, the doctor will always select the treatment that is best for their child.

**TABLE 12**

### If My Child Participates In A Clinical Research Study...

“Please indicate how strongly you agree or disagree with these statements by using the scale below.”

Base: All adults (n=5,822)

		Strongly Agree	Somewhat Agree	Neither Agree Nor Disagree	Somewhat Disagree	Strongly Disagree
My child will receive better medical care if he/she participates in a clinical research study.	%	11	30	45	10	4
If my child participates in a clinical research study, the doctor will always select the treatment that is best for my child.	%	17	29	36	13	4
If my child participates in a clinical research study designed to test a new drug, the findings from the study my child is participating in will be published, even if the new drug does not work.	%	19	32	37	8	4

## Previous Child Participation

Of the small number of parents whose child had participated in a clinical research study, 72 percent would allow their child to participate in another one. This is fairly consistent with adults who have participated in a past research study who say they would consider participating in a future study (82%).

**TABLE 13**

### Future Child Participation In Clinical Research Study

“Would you allow your child to participate in another clinical research study?”

Base: Adults whose child participated in a clinical research study (n=106)

	%
Yes	72
No	1
Not Sure	27

**TABLE 14**

### Future Adult Participation In Clinical Research Study

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

Base: Adults who have participated in a clinical research study (n=730)

	%
Yes	82
No	3
Not Sure	15

**Note:** Findings for the adult population are available in a separate issue of *Health Care News* (Volume 4, Issue 10).

## Methodology

This survey was conducted online within the United States between May 6 and 17, 2004 among a nationwide cross section of 5,822 adults (aged 18 and over), of whom 3,220 have one or more children. Figures were weighted for age, education, gender, race/ethnicity and region where necessary to bring them into line with their actual proportions in the population. This sample was also propensity weighted 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 2 percentage points of what they would be if the entire U.S. adult population had been polled with complete accuracy, and statistical precision is lower and varies for the sub-samples (see tables above). 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 (non-response), question wording and question order, and weighting. It is impossible to quantify the errors that may result from these factors. This online sample was not a probability sample.

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

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