

There are Many Reasons Why People Are Reluctant to Participate in Clinical Trials

Only a small minority of the public is very confident that patients get high quality care, are not treated like guinea pigs, receive honest and accurate information and do not suffer more than they would from standard care.

A new Harris Interactive survey reveals why many people are nervous about participating in clinical trials. Only about a third of all adults nationwide are very confident that patients in clinical trials get very good medical care. Only about a quarter are very confident that new treatments are tested on humans only after there is valid scientific evidence that the treatments are likely to be effective and safe. Many more people are only “somewhat confident” on these and other aspects of how patients are treated in clinical trials. These results suggest that a major educational campaign is necessary if, as several reports suggest, the need for clinical trial participants is likely to grow rapidly as more, and bigger, trials are planned in the future.

These are the results of a nationwide survey conducted online with a sample of 2,031 adults aged 18 and over between February 21 and 27, 2002. Harris Interactive conducted this survey using the same methodology it used to accurately predict the 2000 election results.

The value and importance of clinical trials

The need for clinical trials is overwhelmingly endorsed by the public. Fully 83% of all adults believe it is “essential” (43%) or “very important” (40%) that “all new prescription drugs or other new treatments should be tested on human beings in clinical trials before they are approved for general use.” Only one percent think that this is not important and only 14% think it is only somewhat important. The belief that clinical trials are essential rises as education increases. Those who believe clinical trials are essential increases from 39%, among those with no college education, to 53% of those with some postgraduate education.

TABLE 1

How Important That All New Drugs be Tested on Humans in Clinical Trials

“How important is it that all new prescription drugs or other new treatments to be tested on human beings in clinical trials before they are approved for general use?”

Base: All adults

	Total %	EDUCATION			
		High School or Less %	Some College %	College Grad %	Post Grad %
Essential	43	39	42	49	53
Very important	40	43	40	37	31
Somewhat important	14	14	17	12	15
Not important	1	1	*	1	1
Don't know	2	3	2	1	1
Essential/Very important	83	82	81	86	84

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Issues for patients who participate in clinical trials

While belief in the importance and value of clinical trials is very strong, the belief that it is good for patients is much weaker. For example, fully 61% are “very confident” that patients in clinical trial contribute to medical knowledge which will help other people in the future, but only 13% to 32% are very confident that patients in clinical trials receive the following benefits:

- Good medical care: 32%
- Treated as patients not as guinea pigs: 24%
- Told honestly and clearly some of the risks of participating: 25%
- Not recruited just so that the doctors and hospitals involved can make more money: 20%
- Do not suffer more pain or side effects than they would from standard treatments: 13%.

In all cases, however, majorities are “somewhat” or “very” confident that patients are well treated in respect to these criteria.

On these issues there are some important differences by race and ethnicity with African Americans and Hispanics having a somewhat lower levels of confidence on some criteria.

TABLE 2

Confidence in How Patients Are Treated in Clinical Trials

“How confident are you that patients in clinical trials . . . ?”

Base: All adults

THAT PATIENTS:	Very Confident %	Somewhat Confident %	Not Confident %	Don't Know %
Contribute to medical knowledge which will help other people in the future	61	31	3	6
Get very good medical care	32	50	6	11
Are treated as patients, not as guinea pigs	24	52	13	11
Are told honestly and clearly of the risks in participating	25	46	18	11
Are not recruited just so that the doctors and hospitals involved can make more money	20	44	20	16
Do not suffer more pain or side effects than they would from standard treatment	13	47	19	21

TABLE 2 (cont.)

Confidence in How Patients Are Treated in Clinical Trials

“How confident are you that patients in clinical trials . . . ?”

Base: All adults

THAT PATIENTS:	EDUCATION				RACE/ETHNICITY		
	High School or less %	Some College %	College Grad %	Post Grad %	White %	Black %	Hispanic %
Contribute to medical knowledge which will help other people in the future	57	63	63	66	62	51	68
Get very good medical care	32	32	30	38	34	24	27
Are treated as patients, not as guinea pigs	22	27	29	22	26	20	24
Are told honestly and clearly of the risks in participating	23	23	29	23	26	15	16
Are not recruited just so that the doctors and hospitals involved can make more money	19	18	23	22	21	14	18
Do not suffer more pain or side effects than they would from standard treatment	16	10	12	10	13	13	11

Safety and efficacy; the big picture

The difficulty of persuading large numbers of people to participate in clinical trials is underlined by another finding. Only one person in four (24%) is very confident that “new treatments are tested in clinical trials only after there is good scientific evidence that the treatments are likely to be effective and safe.” On this question, the replies of African-Americans are substantially more skeptical than Hispanics, who are in turn more skeptical than whites. For example, only nine percent (9%) of African Americans say they are “very confident” that this is true, compared to 26% of both whites and Hispanics. However, many more Hispanics responded that they are “not confident” or that they “don’t know” than African Americans or whites.

TABLE 3

Confidence That New Treatments Are Tested in Clinical Trials Only After There is Good Evidence That They Are Likely to be Safe and Effective

“How confident are you that new treatments are tested in clinical trials only after there is good scientific evidence that the treatments are likely to be effective and safe?”

Base: All adults

THAT PATIENTS:	Total %	EDUCATION				RACE/ETHNICITY		
		High School or less %	Some College %	College Grad %	Post Grad %	White %	Black %	Hispanic %
Very confident	24	25	18	27	28	26	9	26
Somewhat confident	60	59	62	61	59	59	72	39
Not confident	8	7	10	7	9	7	6	12
Don’t know	8	9	10	5	4	7	13	23
Very/Somewhat confident	84	84	81	88	87	86	81	65

These findings are consistent with another Harris Interactive survey of 1,015 adults conducted by telephone in June 2000 which found that:

- 79% of adults thought that research participants were taking a gamble with their health;
- 75% thought that research participants are sometimes treated as guinea pigs;
- 41% doubted whether participants get the best possible treatment; and
- 26% believed that patients were often pressured to participate in clinical trials.

So what?

One obvious conclusion from these data is that very substantial numbers of people fall into the “somewhat confident” category. In other words, they are not sufficiently sure to be “very confident,” nor are they sufficiently hostile toward the issue to say that they are “not confident.” In this sense the glass is half full and half empty.

The good news is that relatively few people tend to be downright hostile toward participating in clinical trials. However, the great majority does not have a great deal of confidence in how patients are treated. In order to increase the public’s willingness to participate, it would obviously be very beneficial if more people could be moved, by a public education campaign for example, from the “somewhat” to the “very confident” column.

One piece of good news in these data is that very substantial majorities are very confident about the contribution to medical knowledge of clinical trials and believe that they are very important or essential. That, fortunately, is not a barrier to participation. The challenge for clinical research is to persuade more people that they will not suffer as a result of participating and that they will be treated as patients and not as guinea pigs. They should understand that they are not likely to suffer more pain or side effects from the experimental treatments than they would from standard treatments.

Given the essential requirement for informing patients about all the potential risks of participation, this is no small challenge.

About Harris InteractiveSM

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