Health Care News

2 Volume
14 Issue
July 1
2002

If Genetic Tests Were Available for Diseases Which Could be Treated or Prevented, Many People Would Pay to Have Them

But what about privacy? And the cost of treatment?

A new Harris Interactive survey finds that a large number of people would be interested in paying for genetic tests with their own money, if there were effective treatments, or ways of greatly reducing the risk, for the relevant diseases.

While many people are not very familiar with the concept of genetic testing, a majority claims to be at least somewhat familiar. And more than four out of five adults believe (when it is explained to them) that genetic testing is a good thing.

These are some of the results of *The Harris Poll®*, a survey conducted by telephone by Harris Interactive among a national cross section of 1,013 adults aged 18 and over, between May 15 and 21, 2002.

This poll found that people's interest in having a genetic test varies substantially, depending on whether or not there is a treatment or a way of substantially reducing the risks of getting the genetically inherited disease. However, fully half of all adults say they would be interested in having a test for a very serious disease *even if there was no known treatment or a way to prevent it.*

Of those who are interested in having a genetic test for a serious disease for which there is an effective treatment, many people say they would be willing to spend substantial amounts to get it. The median price is just a little over $300, and 34% of all those interested in having these tests say they would be willing to pay more than $400 for genetic tests.

This survey also finds that the public has strong opinions about who should, and who should not, have access to their genetic test results.

Familiarity With Genetic Testing

Seventy percent of the public says they are at least somewhat familiar with the words "genetic testing," but this includes only 18% who are "very familiar."

TABLE 1

"How familiar are you with the words "genetic testing" and what they mean?"

Base: All adults

	Total %
Very familiar	18
Somewhat familiar	52
Not very familiar	15
Not at all familiar	14
Not sure/refused	1

Health Care News

2 Volume
14 Issue
2002
July 1

Is genetic testing a good or bad idea?

An overwhelming eight-to-one majority believes that genetic testing – when it is explained to them – is a good thing.

TABLE 2

"'Genetic testing' involves testing someone's genes or DNA to see if they have inherited a high risk of getting one or more diseases. This is likely to become much more common in the future. In general do you think it is a good or a bad thing that we will be able to use genetic testing to find out what diseases individual people are likely to get?"

Base: All adults

	TOTAL %	FAMILIARITY		
		Very %	Somewhat %	Not Very/ Not At All %
Good thing	81	81	83	81
Bad thing	11	13	12	10
Not sure/refused	8	7	5	9

Likelihood of Requesting Inexpensive Genetic Tests

Fully 69% of all adults say they would be somewhat likely to ask for a comprehensive genetic test that would indicate the likelihood that they might get several major diseases if it were not at all expensive. And 39% say they would be very likely to do so. The more familiar people are with genetic testing, the more likely they are to say they would have it.

TABLE 3

"If you could have a comprehensive genetic test which would tell you about the likelihood that you might get several major diseases, and it was not at all expensive, how likely do you think you would be to have it – very likely, somewhat likely, or not very likely?"

Base: All adults

	TOTAL %	FAMILIARITY		
		Very %	Somewhat %	Not Very/ Not At All %
Very likely	39	56	39	29
Somewhat likely	30	22	30	36
Not very likely	29	21	30	31
Not sure/refused	2	2	1	3

Likelihood of Requesting Free Genetic Tests For Conditions Which Can/Cannot Be Treated

When offered a free genetic test for a disease for *which **there is a treatment** or other ways to greatly reduce risks*, 81% of all adults say they would be likely to have it, and 56% say they would be very likely to do so.

However, 49% say they would be likely to ask for such a test *if **there is no known treatment** or any other ways to reduce the risk of that disease*. Only 26% say that they would be very likely to do so. It is perhaps surprising that these numbers are so large and that so many people want to know about the likelihood of getting a disease, even when they can do nothing to prevent or treat it.

TABLE 4

"Please consider two possible situations and say how likely you would be to ask for a free genetic test for each one. Would you be very likely, somewhat likely or not very likely to have it?

(a) A test which would tell you if you are at high risk of getting a very serious disease and, if so, *there are treatments or other ways to greatly reduce your risk* of getting it.

(b) A test which would tell you if you were at high risk of getting a very serious disease, but where *there is no known treatment or other ways to reduce that risk*."

Base: All adults

	(a) Treatment exists %	(b) No known treatment %
Very likely	56	26
Somewhat likely	25	23
Not very likely	17	49
Not sure/refused	3	2

How much would people pay for tests?

When the 81% of all adults who said they would be somewhat likely to ask for a genetic test for a serious disease for which an effective treatment exists were asked how much they would pay, the median response was just over $300 (e.g. $314). However, a quarter of them (28%) said they didn't know how much they would be willing to pay, and 34% said they would be willing to pay more than $400. Among people with household incomes of $50,000 or more the median rises to over $450.

TABLE 5

"If you had to pay yourself to get such a test for a very serious disease for which there are treatments or other ways to greatly reduce your risk, about how much do you think you would be willing to pay for this test?"

Base: Somewhat or very likely to ask for test (81% of all adults) for which a treatment exists

		HOUSEHOLD INCOME			
	Total %	Less than $25,000 %	$25,000 - $49,999 %	$50,000 - $74,999 %	$75,000 or more %
Nothing	5	8	5	5	*
$1 - $25	4	6	1	2	5
$26 - $100	16	18	20	14	11
$101 - $400	14	15	13	16	15
More than $400	34	23	32	41	49
Not sure/refused	28	29	29	21	19
MEDIAN	**$314**	**$184**	**$222**	**$459**	**$483**

Who should have access to results?

Almost everyone (90%) says that they think their regular doctor should have access to the results of their genetic tests. Most people (69%) think that any doctor who is helping them to prevent such a disease should have access to them.

However only minorities think that their employers (17%), life insurance companies (25%) or health insurance companies (39%) should have access to their genetic test results.

TABLE 6

"If you were given a genetic test which showed how likely you were to get one or more serious diseases, which of the following do you think should be allowed to see this information?"

Base: All adults

	Total %
Your regular doctor	90
Any doctor who is helping you to prevent a disease for which the test shows you are at risk	69
Your health insurance company which is paying the cost of this treatment or care	39
A life insurance company from which you want to obtain life insurance	25
Your employer who is paying for part of your health insurance	17
Not sure/refused	5

So what? A Word of Caution on These Results

Some of the worst mistakes made in marketing research have come from people believing too literally the detailed answers given by the public as to what they might do at some point in the future. It is almost always true that far fewer people actually buy a product than say they would do so. We can be sure that fewer people would actually take genetic tests if they were available over the next few years than is indicated by this survey, and that fewer people would pay as much as they say they would.

Nevertheless, the results of this survey are very dramatic and establish that there is surely a real market for genetic testing if the costs of these tests are not prohibitive. So, the demand for these tests will depend heavily on the extent to which the genetically inherited diseases can be treated or prevented.

Third Party Payment And The Privacy Issue

While many people will be willing to pay for genetic testing if they have to, there will surely be a call for third party payment. If insurers will pay for blood chemistry tests, why should they not also pay for genetic tests?

However, if insurers pay, willingly or reluctantly, for part of the cost of genetic testing, they will want to have access to the results. If testing identifies a risk factor which can be treated or reduced, the insurer will want proof that the treatment is justified by the test results. And, more ominously for the public, the insurer will want to know whether the patient is genetically predisposed to get various diseases which would require expensive medical care. And this information could be used to refuse coverage (or charge higher premiums) for those with "bad genes."

For some consumers, this loss of privacy may be an acceptable price to pay for coverage of the costs of genetic testing. For others who value their privacy, it will certainly not be. Those patients, therefore, are likely to pay for the costs of their own tests in order to prevent them from being seen and used by insurers or employers. The privacy issue will increase the consumer-paid market for genetic testing – just as it has for mental health care.

The Cost of Therapy: Who Pays?

These questions, and our conclusions, only address the demand for genetic testing. However, when the tests are positive (and they show that patients need care), the cost of the intervention may be much higher than the cost of the tests – far more than many patients can afford. So a

key issue will be whether or not, under what circumstances and when, some plans will start to pay for this type of medical care.

Methodology

The Harris Poll® was conducted by telephone within the United States between May 15th and 21st, 2002 among a nationwide cross-section of 1,013 adults. Figures for age, sex, race, education, number of adults and number of voice/telephone lines in the household were weighted where necessary to align them with their actual proportions in the population.

In theory, with a probability sample of this size, one can say with 95 percent certainty that the results have a statistical precision of plus or minus 3 percentage points of what they would be if the entire adult population had been polled with complete accuracy. 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, interviewer bias, weighting by demographic control data and screening (e.g., for likely voters). It is impossible to quantify the errors that may result from these factors.

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

About Harris Interactive®

Harris Interactive (www.harrisinteractive.com) is a worldwide market research and consulting firm best known for *The Harris Poll*® and its pioneering use of the Internet to conduct scientifically accurate market research. We combine the power of unique methodologies and technology with international expertise in predictive, custom and strategic research. Headquartered in Rochester, NY, with offices across the United States, in the United Kingdom, Japan and a global network of local market and opinion research firms, the Company conducts international research with fluency in multiple languages. EOE M/F/D/V

To become a member of the Harris Poll Online℠ and be invited to participate in future online surveys, visit www.harrispollonline.com.

For more information, please contact us at:

877.919.4765
or visit our website at
www.harrisinteractive.com

Media inquiries, contact:
Nancy Wong 585.214.7316

J16507A Q505, Q510, Q515, Q520-521, Q525, Q530