

National poll shows public divided on genetic testing to predict cancer risk

February 5 2014



Genetic testing to predict the likelihood of developing a hereditary cancer could help save millions of lives each year. This year's survey shows significant work is still needed to educate the public about the important role genetic testing plays in both prevention and treatment of cancer. Credit: University of Utah

A national poll from the University of Utah's Huntsman Cancer Institute



shows 34 percent of respondents would not seek genetic testing to predict their likelihood of developing a hereditary cancer – even if the cost of the testing was not an issue.

Concerns about employment and insurability were cited as the primary reason, even though current laws prohibit such discrimination.

The poll also shows only 35 percent of <u>respondents</u> would be extremely or very likely to seek aggressive prophylactic or preventive treatment, such as a mastectomy, if they had a family history of <u>cancer</u> and <u>genetic testing</u> indicated a genetic pre-disposition to cancer.

"I see patients every week who could have taken steps to reduce their risk if they'd known they'd had a predisposition for a certain type of cancer. The best treatment for cancer is prevention, of which genetic testing plays an integral role," said Saundra Buys, M.D., co-director of the Family Cancer Assessment Clinic and medical director of the High Risk Cancer Research at Huntsman Cancer Institute (HCI), and professor of medicine at the University of Utah. "In addition to educating the public about the important role genetic testing plays in both prevention and treatment of cancer, we must also work to eliminate perceived false barriers to testing, such as concerns about insurability and employment."

Nearly 40 percent of those who said they wouldn't seek testing reported being somewhat or extremely concerned that the results would impact opportunities for employment, while 69 percent of that same group reported being somewhat or extremely concerned that the results would have an adverse impact on their ability to get insurance.

Inherited mutations play a major role in the development of approximately 5 percent of all cancers. Genetic mutations associated with more than 50 hereditary cancer syndromes – including those



discovered at the University of Utah for melanoma, colon and breast cancer – have been identified.

Buys says the survey demonstrates that even with increased media attention to genetic testing in recent months more work is needed to educate the public about the type of information genetic testing provides and who should seek it. She says family and personal health history are the most important factors in determining whether a person should consider genetic testing.

She warns, however, that genetic testing is only as good as the genetic counseling that accompanies it. "There are many genetic tests being ordered in physician offices around the country without the benefit of genetic counseling. The results of these tests are complex, and without appropriate counseling, can cause confusion and unneeded anxiety for patients," said Buys.

Other findings from the poll:

Following recommended screenings: 63 percent of respondents reported being extremely or very likely to follow all recommended screenings if they knew there was a history of cancer in their family.

Testing to help identify best course of treatment: 85 percent of respondents stated that if diagnosed with cancer they would be willing to undergo genetic testing if it could help determine the most effective course of treatment.

Sharing of genetic information: Of the 85 percent of respondents who said they would seek testing to determine best course of treatment, 72 percent reported their willingness to provide scientists with their genetic information for research purposes. Of that group, 64 percent reported they would be most comfortable sharing their genetic information with a



medical center associated with a university or dedicated cancer hospital.

Overall rates of genetic testing: Only 8 percent of respondents reported having ever had a genetic test.

The online poll was conducted in October 2013 for the University of Utah's Huntsman Cancer Institute by Harris Interactive who surveyed 1,202 men and women nationwide between the ages of 25-70 with either commercial or government insurance.

Provided by University of Utah Health Sciences

Citation: National poll shows public divided on genetic testing to predict cancer risk (2014, February 5) retrieved 29 February 2024 from https://medicalxpress.com/news/2014-02-national-poll-genetic-cancer.html

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