



Linking Health Information Seeking, Genetic Testing and Public Awareness of the Genetic Information Nondiscrimination Act (GINA) in the U.S.

Jung A Lee, M.A. and Mia Liza A. Lustria, Ph.D.
Florida State University, Tallahassee, Florida

Background

- ✓ Along with developments in medical information technology and medical knowledge, public databases increasingly include personal and confidential health information, such as genetic information.
- ✓ The Human Genome Project has helped in the understanding of diseases, such as diabetes and cancer.
- ✓ However, the ability to predict a person's predisposition for certain diseases has led to abuses (i.e., discrimination in health insurers and employers based on the genetic information).
- ✓ As a possible solution to these problems, the Genetic Information Nondiscrimination Act (GINA) was enacted in 2008 and will be enforced in November 2009.

Hypothesis

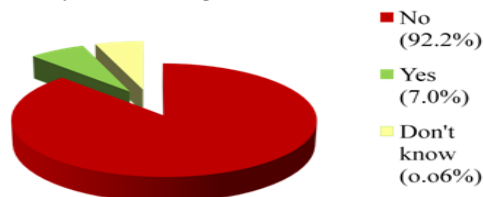
- ✓ Active health information seeking is related to higher awareness about genetic information.
- ✓ Active health information seeking is related to higher use of genetic testing.

Method

- ✓ National Cancer Institute's Health Information National Trends Survey (2009, $N=7,672$)
- ✓ Survey Questions
 - ✓ Health information use
 - ✓ Awareness about genetic information
 - ✓ Participation in genetic testing_MO
- ✓ Regression analyses

Results

- ✓ Have you ever had a genetic test?



- ✓ Have you ever heard or read about these genetic tests?



- ✓ A significant positive relationship between health information seeking and genetic testing ($p < 0.05$).

Conclusion

- ✓ The results indicate limited public awareness about genetic testing and policies regarding genetic information.
- ✓ Individuals who actively seek health information are more likely to undergo genetic testing than those who do not.
- ✓ This supports the view that health information seeking can lead to positive health behavior changes.

Implication

- ✓ This finding also indicates the need for more health education and promotion efforts in order to increase public awareness of the benefits of genetic testing.
- ✓ At the same time, these interventions must also emphasize issues related to ownership of genetic information and how to prevent disclosure of personal genetic information, including policies designed to protect sensitive information (i.e., genetic testing and HIV/AIDS).

HINTS Data Users Conference, September 24-25, 2009
Silver Spring, MD
National Cancer Institute
U.S. National Institutes of Health