



Genetic Information: What do people really want?

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Genetic Information

- Much of what we know about people's attitudes about genetic information comes from testing in clinical settings
 - Newborn screening
 - Prenatal diagnosis
 - Carrier testing
 - Predictive testing for highly penetrant, relatively rare, single-gene mutations
- What about other kinds of genomic information in different settings

We have a dearth of data

- Who wants genomic information
- Are there different types of information that are viewed as more or less important
 - Somatic tumor testing for treatment decisions
 - Pharmacogenomic information
 - Low risk variants for common, complex disease
 - Non-medical traits
 - Ancestry information
- What do people do with the information
- What are the informational/educational needs
- Does the setting testing is offered make a difference

Settings to Access Genetic Information

- Health-care setting
- Direct-to-consumer genetic testing market
- Large cohort research studies

Increasing number of U.S. Large Cohort Studies

- Northwestern University
- Vanderbilt University
- Marshfield Clinic
- Department of Veterans' Affairs
- Children's Hospital of Philadelphia
- Howard University
- Kaiser Permanente, Northern California
- Coriell Personalized Medicine Project/Delaware Valley

Background: Proposed U.S. Prospective Cohort Study

STUDY PARTICIPATION



452.2431

- Informed by the NIH document “Design Considerations....”
- Enroll 500,000 individuals representative of the U.S. population
 - Recruit across the U.S.
 - Enroll individuals and 30% households
 - Collect DNA and other specimens
 - Physical/developmental/psychological exam
 - Lifestyle and behavioral information
 - Environmental exposures
 - Follow for a decade
 - Contact for periodic updates and a second exam

PCP I – 2006-2008

Support for the Study

- Sophisticated understanding of interaction of genes and environment in complex diseases and the benefits of the proposed study design
- 84% of US survey said should be done
- 60% would be willing to participate

“It’s hard to see an end to the benefits that could come from a study of this nature.”

(Male, Portland Middle Class Elderly)

PCP I - Interest in Obtaining Individual Research Results (IRR)

- 75% said they would be less likely to participate if IRR not returned
- 96% wanted to know risk for treatable disease like severe asthma
- 88% for untreatable disease like Alzheimer disease

Kaufman et al., *Genetics in Medicine*, 2008

Follow-Up Public Consultation Project

- To explore in more detail interest in receiving genetic information from participating in large cohort genomic research
- Year 1
 - 8 in-person focus groups
 - 2 online focus groups
- Year 2
 - National survey

Genetic Information

- Types of information
 - Availability of treatment
 - Level of risk
 - Not medically relevant
- Limitations of information
 - Changing risk
 - Unknown meaning

Reasons for wanting genetic information

- Some viewed lack of utility a problem

“You can worry yourself to death about something that you can’t do anything about.” (Male, DC, Mixed, Low SES)

“I would want to know everything but a 1% change doesn’t tell [me] anything enlightening.” (Female, Mixed, Online)

Reasons for want genetic information

- However, many other possible sources of personal utility identified – *“there is always something you can do”*
 - Motivate health changes
 - Feeling of control
 - Gather information, follow and participate in research
 - Prepare oneself
 - Important for the family

I would want to know because it is pertaining to me, myself...

(Male, DC, Mixed, N-SN)

Concerns about Certainty, Changing Info

“I don’t want to know if you’re not 100 percent. If you’re not sure, don’t tell me....[in] five years, call me and let me know what’s up. (Female, PHL, AA, Low SES)

“...there should be a threshold of certainty that should be put in place....on the higher end of the spectrum” (Male, DC, Mixed)

It seems like common sense would tell you that...things are going to change. (Male, DC, Cauc, Low SES)

Privacy

- Privacy does not exist anymore
- Concerns focus on harms from misuse of data
 - Discrimination by insurance or employers
 - Identity theft
- Description of protections under GINA did little to reassure people



The Genetic Case 1: GINA and Family History

A Discussion

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I. 1

In May 2008
Nondiscrimi
ongoing, and

GINA protec
employers
appropriate

This docume
talking about GINA with p

II. An Overview

GINA does not change, and
employers, and the law's
considering genetic testin



Genetic Information

What is genetic information and why is it important?

GINA & Health Insurance

What are GINA's health insurance protections?

GINA & Employment

What are GINA's employment protections?

What is GINA?

The Genetic Information Nondiscrimination Act of 2008 (GINA) is a federal law that protects individuals from genetic discrimination in health insurance and employment. Genetic discrimination is the misuse of genetic information. This resource provides an introduction to GINA and its protections in health insurance and employment. It includes answers to common questions and examples to help you learn. Click on a link to the left to begin!

- ✉ Have questions, comments or suggestions? [Send us a note.](#)
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