

# Existing Structures for Privacy and Nondiscrimination Protections:

## Beyond the Genetic Information Nondiscrimination Act



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Workshop

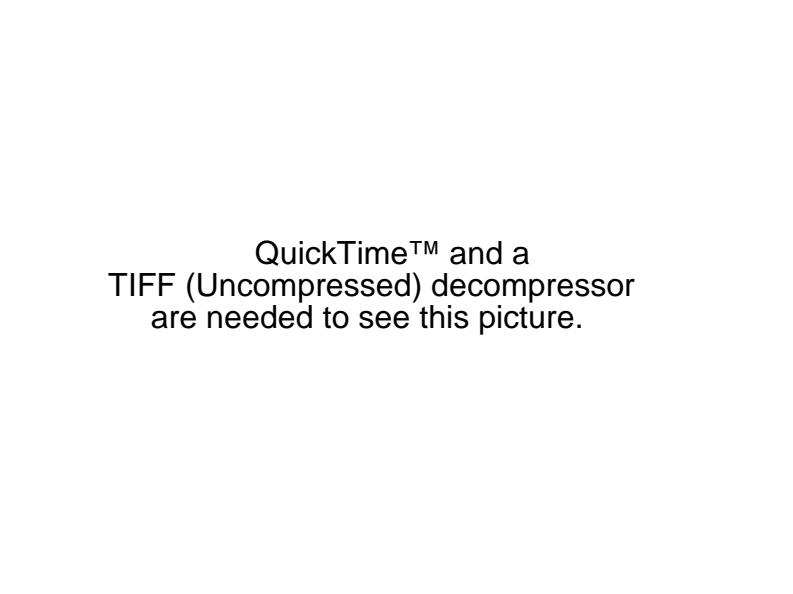
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# The Genetic Information Nondiscrimination Act (GINA) and Beyond

- Purpose and scope of GINA.
- Other privacy and nondiscrimination protections that exist (or don't, but could).
- What does this have to do with DTC genetic testing, anyway?

# Why Focus on Genetics?

- Privacy
- Fairness
- Impact



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are needed to see this picture.

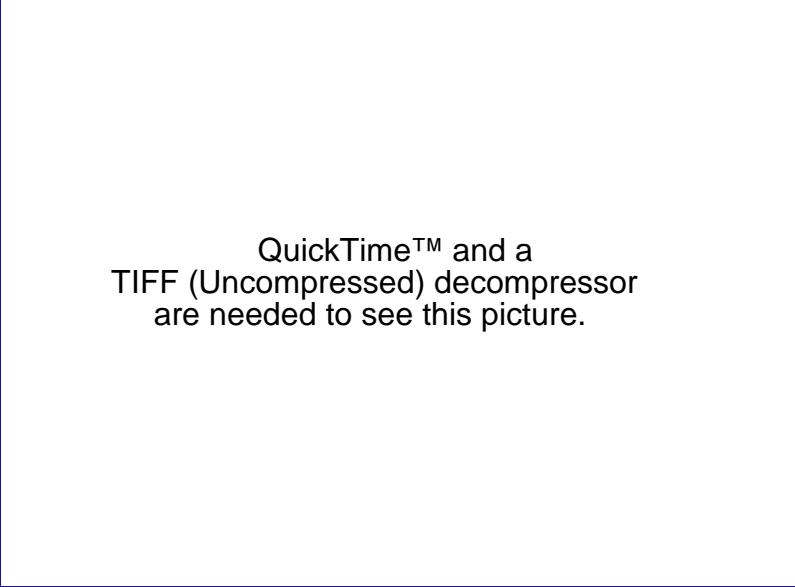
# Why Focus on Genetics?

- Privacy: This information is invisible and inherently private. I should control it.



# Why Focus on Genetics?

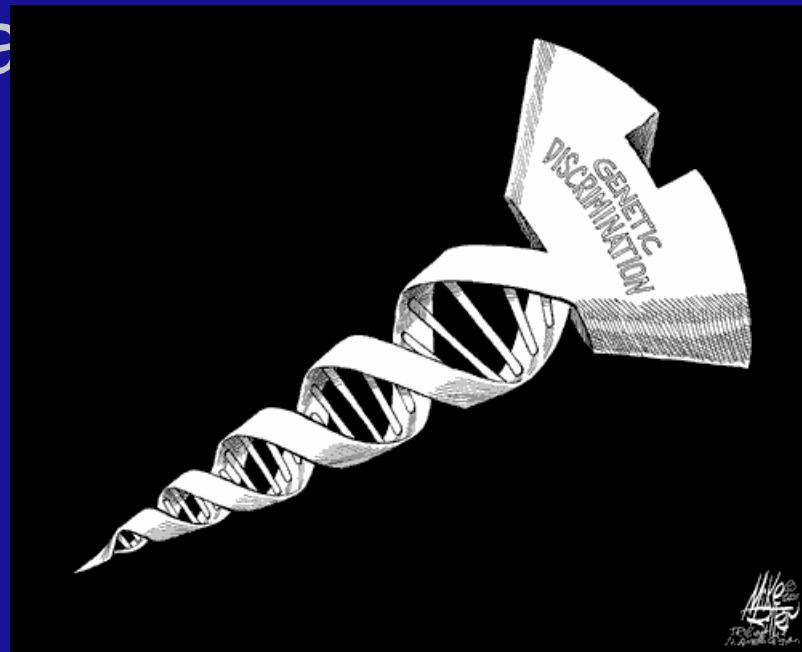
- Fairness: It is unfair to mistreat me and my loved ones because of (variably accurate) predictions based on my genes.



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# Why Focus on Genetics?

- Impact: The fear of discrimination discourages valuable genetic testing, follow-up health care, research. We all lose if people are afraid of discrimination.



# What Does GINA Do?

## Health Insurers

- Prohibits group and individual health insurers from using a person's genetic information in setting eligibility or premium or contribution amounts.
- Prohibits health insurers from requesting or requiring that a person undergo a genetic test.

# What Does GINA Do?

## Employers

- Prohibits employers from using a person's genetic information in decisions such as hiring, firing, job assignments, and promotions.
- Prohibits employers from requesting, requiring, or purchasing genetic information about an individual employee or family member.

# Other Federal Laws

- HIPAA (privacy and nondiscrimination)
- Americans with Disabilities Act (ADA)

# What GINA left alone (but states are considering)

- Life Insurance 16 states
- Disability Insurance 16 states
- Long-Term Care Insurance 10 states

# Questions About GINA (and why any of this matters to DTC)

- ? Follow-up care?
- ? Employer wellness programs' access to genetic information?
- ? Employers and social networks?

# DTC Genetic Testing and Privacy

Does DTC really protect privacy and prevent discrimination?

See also: Hudson, K., G. Javitt, W. Burke, and P. Byers. 2007. ASHG Statement on Direct-to-Consumer Genetic Testing in the United States. *The American Journal of Human Genetics* 81: 635–637.

# DTC Genetic Testing and Privacy

- Does DTC really protect privacy and prevent discrimination?
- DTC marketing often appeals to the desire to control access, for those who prefer to pay out of pocket, out of sight.
- However, privacy may be temporary.

# DTC Genetic Testing and Privacy

BUT-HIPAA's privacy protections do not apply to many DTC testing companies.

For the most part, testing companies are not “covered entities” under the privacy rule.

Consumers need to know and understand the company's privacy policy.

# Is DTC Privacy an Illusion?

Most DTC sites say, “talk to your doctor” about follow-up care.

DTC genetic test results become part of the medical record as soon as an individual discusses it with a physician.

Protected by HIPAA and GINA but...

# Is DTC Privacy an Illusion?

If information goes into the medical record, that record may be requested, in whole or in part, by life, disability insurers or long-term care insurer.

Plus, once an individual knows a test result, obligated to reveal it if asked by these insurers.

# Is DTC Privacy an Illusion?

Bottom line:

If the information matters to your health, it may not stay private from your doctor, medical record, or your life, disability, or LTC insurer.

# Additional Issues

- Who “owns” the information?
- What are companies’ rules for use, sale, disclosure, research?
- Who can change the rules?
- How will state laws on discrimination in insurance markets interact with state laws on DTC testing?

# Many thanks!



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