

An Analysis of the Adequacy of Current Law in Protecting against Genetic Discrimination in Health Insurance and Employment

*A Report Commissioned by the
Secretary's Advisory Committee on Genetics, Health, and Society
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Relevant Congressional Findings (Section 2 of S. 306/H.R. 1227)

- **Federal law addressing genetic discrimination in health insurance and employment is incomplete in both the scope and depth of its protections**
- **State law varies widely in approach, application, and level of protection**
- **The public and medical community find existing State and Federal law confusing and inadequate**
- **A national, uniform standard is needed to fully protect the public from discrimination and to allay their concerns about the potential for discrimination**

Scope of Analysis

- **Federal statutes governing health insurance**
- **Federal protections for the privacy of medical information**
- **State genetic non-discrimination and privacy law**
- **Federal employment nondiscrimination statutes**
- **Constitutional protections**
- **Protections for Federal employees**

Current Laws Protecting against Genetic Discrimination in Health Insurance

Health Insurance in the U.S.

- **Most Americans with health coverage have employment-based coverage**
- **Employee benefits provided through employers are generally governed by the Employee Retirement Income Security Act (ERISA)**

Health Insurance Portability and Accountability Act (HIPAA) Group Market

- **Amends ERISA and other statutes to prohibit group health plans and issuers from:**
 - **Imposing a preexisting condition exclusion on the basis of genetic information (unless there is an actual diagnosis of a condition)**
 - **Establishing eligibility requirements for any individual based on genetic information**
- **Prohibits health insurance issuers in the group market from refusing to renew a policy based on genetic information about an enrollee or potential enrollee**

HIPAA

Small Group Market

- **Prohibits health insurance issuers in the small group market from denying a policy to a small employer on the basis of the genetic information of any enrollee or potential enrollee**

HIPAA

Individual Market

- **Guarantees certain individuals who have lost group coverage the opportunity to purchase individual coverage without an exclusion based on genetic information**
- **Prohibits an issuer from refusing to renew an individual policy based on genetic information**

Gaps in HIPAA

A group health plan or issuer is not prohibited from:

- Requesting, purchasing or otherwise obtaining genetic information about an individual
- Requiring an individual to take a genetic test as a condition of coverage
- Charging all members of a group higher premiums on the basis of genetic information

Gaps in HIPAA

The preexisting condition exclusion and nondiscrimination provisions do not apply to:

- Very small plans**
- Retiree-only coverage**
- Self-insured non-federal governmental plans that elect to take advantage of a statutory exception**

Gaps in HIPAA

- **Nondiscrimination provisions do not apply to individual health insurance policies**
- **An issuer is not prohibited from adjusting an individual's premium for an individual policy on the basis of genetic information (despite the guaranteed renewability requirement)**

Social Security Act (SSA)

- Contains provisions that prohibit discrimination in the pricing or issuance of Medigap policies on the basis of health status or medical condition, but
 - Does not specifically state that “health status” or “medical condition” includes genetic information

Title III of the Americans with Disabilities Act

- Prohibits private businesses from discriminating against any individual on the basis of disability in the “full enjoyment of the goods, services, facilities, privileges, advantages or accommodations of any place of public accommodation,” but
 - Courts of Appeals decisions conclude that it does not apply to health insurance policies

Title III of the Americans with Disabilities Act

- **Pertinent provisions are not to be interpreted to prohibit or restrict an insurer from underwriting, classifying or administering risks that are consistent with State law**
 - **This “safe harbor” provision has been broadly construed by the courts in favor of insurers**

HIPAA Privacy Rule

- **Establishes a minimum national standard for protecting the privacy of individually identifiable health information, including genetic information**
- **Requires patient authorization in order for a covered entity to disclose protected health information to an employer in certain cases**

Gaps in HIPAA Privacy Rule

- **Allows medical (including genetic) information to be used without consent for underwriting (health care operations)**
- **Allows an employer to contract with providers not covered by the regulation, obtain genetic information, and freely use and disclose such information**
- **Does not cover health care providers who do not transmit health information electronically**

State Law

- All but three States have enacted laws restricting the use of genetic information to determine health insurance rates or eligibility in group or individual health insurance plans, or both
- 20 States have enacted privacy laws that are specific to genetic information, but
 - They vary widely and are inconsistent in scope and definition of genetic information
- State level protection against discrimination by health plans and issuers is limited because self-insured employee benefit plans are generally exempt from State regulation under ERISA

Current Laws Protecting against Genetic Discrimination in Employment

State Law

- **32 states have enacted laws restricting the use of genetic information in the workplace and, as of August 2004, 9 states were considering such legislation**
- **Laws are diverse and inconsistent and may impose a substantial burden on companies operating across State lines**

Americans with Disabilities Act (ADA)

- Prohibits discrimination in employment against individuals who:
 - have a physical or mental impairment that substantially limits them in a major life activity;
 - have a record of such impairment; or
 - are regarded as having such an impairment.
- Interpreted by EEOC as prohibiting genetic discrimination
 - Settled its first court action in 2002 challenging an employer's genetic screening of employees
- Applicability to genetic discrimination is untested in court

ADA's Limitations

- **Scope has been narrowed by recent court cases that have limited the definition of disability**
- **Unclear whether a genetic predisposition would be considered a disability**
- **Highly unlikely that a court would find that predispositions are disabilities in all situations**

ADA's Limitations

- **Does not prevent employers from asking for genetic information or requiring that certain individuals take genetic tests**
- **Does not prevent employers from obtaining genetic information after a conditional offer of employment has been made**
- **Allows employers to use genetic information as the basis for refusing to hire an employee if hiring could be costly in terms of attendance, productivity, or insurance**

ADA's Limitations

- **Employers can raise several defenses against allegations of genetic discrimination:**
 - Lack of qualification for the position
 - Employment decisions were based on factors others than those alleged
 - Disabled worker may pose a direct threat to self or others

Title VII of the Civil Rights Act

- **Prohibits employment discrimination on the basis of race, color, religion, sex and national origin**
- **Provides protection against discrimination on the basis of a person's genetic makeup when that discrimination disproportionately affects individuals belonging to one of the protected groups**
 - **For example, a refusal to hire carriers of sickle cell disease or Tay-Sachs could constitute discrimination on the basis of race/ethnicity**

Federal Constitutional Protections

- **US Court of Appeals (Ninth Circuit) asserted that:**
 - **When it comes to genetic information, a person has the highest expectation of privacy**
 - **Fourth Amendment protection against unreasonable searches and seizures applies both to the taking of a blood sample and the subsequent analysis of the sample**

Limitations to Federal Constitutional Protections

- Apply only to governmental action
- Courts will weigh infringement of individual rights under the Constitution against the public health or other interests of the government in taking the action

Protections for Federal Employees

- **Executive Order 13145 prohibits departments and agencies of the of the Federal government from using protected genetic information to discharge, not hire, or otherwise discriminate against any applicant or employee with respect to compensation or the terms, conditions, or privileges of employment**
 - **Limited to Federal employees**

Report's Conclusions

- **Currently, there are no Federal laws that directly and comprehensively address the issues raised by the use of genetic information**
- **There are laws and court decisions that address parts of these issues, but they leave substantial gaps in coverage and offer inconsistent safeguards**
- **Existing avenues for relief are both uncertain and likely to lead to costly litigation**
- **Current law does not adequately protect against genetic discrimination based on genetic predisposition**