Genetic Testing: What You Need To Know

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What Is Insurance?

- A sharing or pooling of risk
- Individuals should have equal likelihood of collecting
- The real impact of destroying the principle of insurance rests on the individuals who have it or wish to purchase it, not on the insurance company

Forms of Insurance

- Life Insurance
- Annuities
- Disability Income
- Long-Term Care
- Health Insurance (medical expense reimbursement coverage)
- Why the focus on (major medical) health insurance? Society's view of major medical

Underwriting Insurance

- Process of classifying individuals into appropriate pools
- Individual vs. group
- Antiselection
- Examples:
  - burning house
  - bank loan
- In individual health insurance, the question is "Are you sick now?" We know that you will get sick tomorrow. "But are you sick now?"

Underwriting Insurance

- Why “Are you sick now” focus?
- Average policy duration of major medical policy is about 3 years
- How is disability different?
  - Longer term than major medical
  - Heavily occupation driven; not generally genetic dependent (but some issues are present here)
  - Genetic antiselection is greater than major medical but probably less than in long term care
  - Society’s view - less essential

Underwriting Insurance

- How is long-term care different?
  - Again, longer term than major medical
  - Occupation is taken out of picture
  - Heredity plays a significant role in an individual's longevity and may indicate possible outcome as he/she ages
  - Potential for antiselection is increased tremendously
  - Society's view - Changing

Current Practices/Laws

- Each state has privacy regulations and fair trade practice laws
- Insurers have an excellent track record of handling personal information
- Federal privacy requirements already in place
- HIPAA
  - Prevents group coverage from using genetic information in issuing, pricing, and renewing
  - Provides for guaranteed renewability of individual major medical coverage in general

Current Areas of Concern

- Definitions very broad
- Unintended consequences
- Destruction of the ability to underwrite, even using the current tools
- Access vs. affordability
- Concern that the result will be even higher costs and more uninsured

Definitions

- S. 318 - Daschle, plus 24 other Senators (H.R. 602, Rep. Slaughter)
- S. 382 - Snowe, Frist, Jeffords, Collins, DeWine, Enzi
- Amendment 849 (Section 122) to S. 1052 (PBOR) - Ensign Genetic Testing Amendment

Definitions - S. 318 - Daschle

- Genetic Test - The term ‘genetic test’ means the analysis of human DNA, RNA, chromosomes, proteins, and metabolites that detect genotypes, mutations, or chromosomal changes
- Protected Genetic Information -
  - The term ‘protected genetic information’ means -
    - (i) information about an individual’s genetic tests;
    - (ii) information about genetic tests of family members of the individual; or
    - (iii) information about the occurrence of a disease or disorder in family members.

Definitions - S. 318 - Daschle

- Protected Genetic Information (Continued) -
  - LIMITATIONS ... The term ‘protected genetic information’ shall not include -
    - (i) information about the sex or age of the individual;
    - (ii) information about chemical, blood, or urine analyses of the individual, unless these analyses are genetic tests; or
    - (iii) information about physical exams of the individual, and other information that indicates the current health status of the individual.

Definitions - S. 382 - Snowe

- Genetic Test - The term ‘genetic test’ means the analysis of human DNA, RNA, chromosomes, proteins, and certain metabolites including analysis of genotypes, mutations, phenotypes, or karyotypes for the purpose of predicting risk of disease in asymptomatic or undiagnosed individuals. Such term does not include physical tests, such as the chemical, blood, or urine analyses of the individual including cholesterol tests, and physical exams of the individual, in order to detect symptoms, clinical signs, or a diagnosis of disease.

Definitions - S. 382 - Snowe

- Predictive Genetic Information -
  - (A) IN GENERAL - The term ‘predictive genetic information’ means, in the absence of symptoms, clinical signs, or a diagnosis of the condition related to such information -
    - (i) information about an individual’s genetic tests;
    - (ii) information about genetic tests of family members of the individual; or
    - (iii) information about the occurrence of a disease or disorder in family members.

Definitions - S. 382 - Snowe

- Predictive Genetic Information (Continued) -
  - (B) EXCEPTIONS - The term ‘predictive genetic information’ shall not include-
    - (i) information about the sex or age of the individual;
    - (ii) information derived from physical tests, such as the chemical, blood, or urine analyses of the individual including cholesterol tests; and
    - (iii) information about physical exams of the individual.

Definitions - Ensign Amendment

- 'Genetic Test' defined essentially the same way as it is in Snowe (S. 382)
- 'Predictive Genetic' Information is defined essentially the same as 'Protected Genetic Information' is defined in Daschle (S. 318)

Future Issues

- Unintended consequences as a result of future scientific discoveries/changes
- Extension to other forms of insurance in which the one-sided knowledge of genetic information is more important
- Will any law prevent the concerns and the fears that are being reported today?
- What can we do to solve that problem?
- Dividing line

Future Issues

- Testimony from July 2001
  - "Legislation must cover all genetic information, including family history that predicts future health risks in healthy individuals."
- Where is the dividing line?
- Is someone with a given genetic flaw healthy?
- This will become a very difficult issue to decide.

Legislation

- Issues to consider in developing legislation regarding major medical insurance include:
  - Consistency between processes and standards for protecting the confidentiality of genetic information and the privacy requirements of all patient medical information
  - Scope of genetic test definition
  - “Safe harbor” provisions to define what is not a genetic test
  - Prohibitions against genetic testing requirements for health insurance applicants
  - Limitations on the use of genetic information

Life Insurance vs. Health Insurance

- Health insurance pays cost of care *if* insured is sick.
- Life insurance pays full face amount *when* insured dies.

Life Insurance vs. Health Insurance

The **leverage** associated with **"anti-selection"** (purchase of insurance only after impairment is known) is much greater for life insurance.

- For $1,000 of annual premium, life insurance benefit may be $1 million, and it is paid in cash.

Life Insurance vs. Health Insurance

Life insurance is normally sold as a **voluntary individual coverage**, rather than as part of an employer or group sponsored plan.

- **Implications**: Life insurance customers want to pay premiums that are **appropriate for their own level of risk.**
- Companies can't be sure of getting an "average" distribution of risks, so they **can't just average in the effects of anti-selection in pricing.**

Perceptions and Realities

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1. **Perception:** An individual who tests positive for a gene linked to a specific disease will contract that disease.

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- **Reality**: With few exceptions, a positive genetic test result indicates only an increased probability of developing such a disease.

Perceptions and Realities

Example: **Genetic breast cancer** (associated with the BRCA1 and BRCA2 mutations) increases the *levelized* mortality risk for a 20-year old female by an amount approximately equal to the increase attributable to:

- high blood pressure,
- smoking, or
- being male.

Perceptions and Realities

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- **Reality**: Voluntary individual life insurance **cannot be cancelled**, and premium increases are either prohibited or tightly restricted.

Perceptions and Realities

3. **Perception**: Insurance companies may require applicants to take genetic tests.

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- **Reality**: While no life insurer is known to currently require DNA-based tests, it is possible that such tests may be required in the future.

Perceptions and Realities

4. **Perception**: Life insurers will require applicants to reveal results of genetic tests already performed.

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- **Reality**: To prevent anti-selection from asymmetric information, insurers may indeed require applicants to reveal such results.

Perceptions and Realities

5. **Perception**: Genetic testing will cause more people to be denied life insurance.

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5. **Perception**: Genetic testing will cause more people to be denied life insurance.

- **Reality**: Genetic tests will not have a uniform effect on availability of insurance. Some people could gain greater access to coverage; others, with specific genetic conditions, could see reduced access to coverage or higher premium costs.

Perceptions and Realities

Example: **Polycystic Kidney Disease (PKD):** Autosomal dominant - 50% chance of inheriting; onset in 20s or 30s.

- **Current underwriting**: Under 30, premium 6-7 times standard, unless clear test (ultrasound—genetic would be better). Over 30, could be standard premium if no symptoms and no biochemical markers (normal urinalysis, etc.).

- **Potential effect of genetic testing**: Determine if prospective insured has gene. If not, standard or preferred rates.

Perceptions and Realities

Example: **Hemochromatosis -** Disease of iron storage in body; can result in deposits of iron in liver, pancreas, and heart muscle.

- **Current underwriting**: Can be controlled by blood removal - if controlled before damage occurs, standard.
- **Potential effect of genetic testing**: Could lead to earlier detection and more standard cases.

Perceptions and Realities

Example: **Hereditary nonpolyposis colon cancer (HNPCC or Lynch syndrome):** Lynch 1- Early onset colon cancer. Standard if colon removed.

- **Lynch 2** - Multiple cancer sites. Not insurable.
- **Potential effect of genetic testing**: Allow those with family history but without the gene to get standard or preferred rates.

Perceptions and Realities

6. **Perception**: Insurers will not keep genetic test results confidential.

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- **Reality**: Even prior to the passage of Gramm-Leach-Bliley, states required insurers to keep all underwriting information confidential.

Perceptions and Realities

7. **Perception**: It is difficult to recruit participants for genetic research studies because of insurance fears.

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- **Reality**: Some people may decline to participate in research projects because they fear loss of insurability.

Perceptions and Realities

- Conceptual solution: An academic has suggested that **genetic testing insurance** could be provided in conjunction with the tests. Those with unfavorable results would receive the right to buy a certain amount of insurance at standard rates.

- This is still only an academic idea. To test the economic viability of the idea, a greater volume of genetic tests would have to be carried out, and statistics on the outcomes of these tests would have to be made available to insurers.

Perceptions and Realities

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- **Reality**: It is generally believed that genetic testing will not greatly change the current life insurance market.

Perceptions and Realities

Analogous situation - preferred underwriting: Preferred underwriting was introduced in the 1990s. The old standard class was subdivided based on evidence of reduced risk (low cholesterol, good driving record, etc.).

- Preferred underwriting resulted in reduced premiums for preferred classes and **no increase** for standard classes.

Ten-Year Level Premium Term

Typical rate per $1,000, male, age 45, nonsmoker, $250K

	Best Preferred Class	*"Standard" Class*
1997	$1.67	$3.08
1992	$2.26 (25%)	$3.10 (1%)
1990	$2.64 (37%)	$3.03 (-2%)

Perceptions and Realities

Actual impact in analogous situation: Preferred underwriting resulted in reduced premiums for preferred classes and **no increase** for standard classes.

Why?

- Without information, actuaries have to be conservative and put in a large "risk premium."
- Thus, improved underwriting has **reduced the overall cost of life insurance to the public.**

Perceptions and Realities

Possible impact if genetic testing is restricted:

- If genetic testing is **narrowly defined** - those who could have inherited an unfavorable trait but didn't might not get standard or preferred rates.

- If genetic testing is **broadly defined** - the significant reduction in rates ushered in by preferred underwriting could be rolled back, resulting in an increase in the overall cost of life insurance to the public.

Contact Information

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