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# A Serious Question

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**This proposal, if implemented, could also prevent LTC insurers from using family histories or genetic test results to help keep healthy policyholders functionally independent for as long as possible.**

I am an actuary, so when it comes to laws and regulations, I may not be best qualified to interpret the language. Yet I believe I am well-qualified to question the proposals from Health and Human Services (HHS) beginning in 2009, that have been quietly seeking to restrict the use of family histories and the results of genetic tests in underwriting Long-Term Care Insurance (LTCI) by making LTCI subject to the Genetic Information Nondiscrimination Act of 2008 (GINA).

What ultimate good could such a move serve, for current and future insureds and for the industry?

Underwriters use family histories and, at times, results from genetic tests to underwrite LTCI policies. This is appropriate, for both are effective ways to best determine longer-term future potential risk factors and to price coverage appropriately.

Incorporating LTCI under GINA, however, would take these underwriting tools away, thereby jeopardizing the ability of long-term care carriers to fully, fairly and prudently underwrite coverage.

I am not the only person questioning this move. In its talking points on the issue, The American Council of Life Insurers (ACLI) has stated that lack of access to genetic testing and family history by LTC insurers could generate adverse selection issues for these insurers. Following are two examples from its talking points:

- “A long-term care policy cannot be cancelled, nor can premiums for the policy be increased based on any deterioration in an insured’s health. Premiums may only be increased for a whole class; thus medical underwriting at the inception is critically important.”
- “The majority of long-term care insurance is individually underwritten; as a result, medical underwriting is critically important to long term care insurers’ ability to decisions regarding issuance of coverage and premiums that are fair and financially prudent.”

As the general populace ages and the issue of paying for long-term care looms larger, individuals will most likely use their own family histories, supplemented with the genetic tests they themselves can obtain (as the tests continue to drop in price), to help decide whether to apply for LTCI coverage. This could increase adverse selection risk and make LTCI too difficult to price at a reasonable level for its market if insurers lack these tools.

This proposal, if implemented, could also prevent LTC insurers from using family histories or genetic test results to help keep healthy policyholders functionally independent for as long as possible. In addition, as the issuing insurers would have the information on file, they could be accused of using that information to underwrite existing policyholders applying for enhanced benefits.

The proposal would not, however, prevent policyholders from using their own family histories and genetic tests to exercise their policies’ guaranteed purchase options or to apply for enhanced benefits. The HHS even provides a portal on its website ([www.hhs.gov](http://www.hhs.gov)), “My Family Health Portrait,” so that users can create and save their family health histories.

Perhaps HHS should consider whether this proposal concurs with GINA’s history. Because GINA focused specifically on medical coverage, the ACLI compared LTCI to medical coverage. A fundamental point of comparison is that medical insurance addresses nearly immediate medical expenses, while LTCI addresses the distant (20 to 30 years after purchase) expenses related to care to assist with performing activities of daily living.

GINA initially arose in the 1990s due to concerns over workplace discrimination with regard to medical coverage. The major concern was that genetic tests, which were becoming more common, might be used to deny coverage or substantially raise premiums for those with genetic predispositions for certain diseases or conditions.



The Genetic Information Nondiscrimination in Health Insurance Act of 1995, from which GINA evolved, was introduced in and failed to pass the 104th Congress. The failed bill defined health insurance coverage as follows:

“The term ‘health insurance coverage’ means a contractual arrangement for the provision of a payment for health care, including:

- (A) a group health plan; and
- (B) any other health insurance arrangement, including any arrangement consisting of a hospital or medical expense incurred policy or certificate, hospital or medical service plan contract, or health maintenance organization subscriber contract.”

Clearly the 1995 bill had medical expenses in view when it referred to health insurance.

GINA’s own purpose—to address discrimination with regard to medical coverage and employment—is apparent from the “Findings” section in the actual bill. The Findings cited a judicial case (*Norman-Bloodsaw v. Lawrence Berkeley Laboratory*) where employees complained about genetic tests being conducted in pre-employment medical exams without their knowledge or consent. Not only did the medical examinations in this case not address the ability of the employee to perform his or her job, but they were also discriminatory, as only black appli-

cants were being tested for sickle cell anemia and syphilis, and female applicants were being tested for pregnancy. In addition, the results of the tests were in employee files, available to anyone. This suggests that Berkeley Labs was performing these screenings to mitigate projected expenses of covering medical care for particular race and gender-based conditions.

Subsequent to GINA’s adoption, the Federal Register/Volume 74, Number 193/Wednesday, October 7, 2009/Rules and Regulations provided a set of proposed rules for implementation. Examples in that entry do not suggest anything other than individual medical coverage for reimbursement of medical expenses.

Finally, with a stated vision “to help policymakers, the press, and the public understand and respond to the challenges and opportunities of genetic medicine and its potential to transform global public health,” even the Genetics & Public Policy Center acknowledges in its website’s FAQ section that long-term care insurance is not included under “health insurance coverage” for GINA’s purposes.

When GINA passed in the U.S. House of Representatives in 2008, only one member voted against it. I believe that if insurance policies other than medical care had been in view, many more members might have registered a negative vote.

If HHS succeeds in altering GINA’s original intent by including LTCI under GINA, HHS could very well be generating discrimination that would compromise not just LTCI’s future, but the future of long-term care protection in the United States as well. This would not be good news for a product where such a strong need currently exists, and where the need for it, as the population ages, is only bound to become greater.

We might not have individual votes in Congress, but perhaps we can express our opinion about this plan to HHS. ■