

How Old Are You, Actuarily?

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HEALTH LAW: PEER-REVIEWED ARTICLE

Abstract

Advances in epigenetic age estimation are now applied in actuarial science to make risk assessment more precise. But such health insurance underwriting practices pose ethical and legal questions about discrimination, privacy, and equity in biological data use. Legal adaptations, such as Canada's Genetic Non-Discrimination Act (GNDA) of 2017, aim to protect persons against genetic discrimination but do not evolve as quickly as epigenetic technology. This article examines the GNDA's regulatory limitations and highlights the need for more adaptable legislative strategies.

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The Canadian Context

As health technologies advance, governments will face mounting pressures to regulate insurers' use of novel assessment tools, including epigenetic technologies. Insurers have embraced epigenetic age estimators^{1,2} that predict health outcomes (ie, mortality and multimorbidity) based on measures of methylation related to aging. While these technologies offer insurers enhanced risk assessment capabilities, they simultaneously intensify fundamental concerns about privacy and discrimination,³ echoing issues related to the use of traditional genetic data, such as single nucleotide polymorphisms.⁴

These concerns are particularly pronounced in Canada, where, despite its universal health care system, private insurers increasingly fill critical gaps in meeting citizens' health needs. 5.6.7 While the public system covers basic health services, rising costs and population growth have created a dependence on the private sector for timely access to essential services and emerging treatments. 6 As private insurers gain greater influence over health care access and thus quality of life, the ethical implications of their utilizing genetic and epigenetic information in risk assessment are becoming increasingly significant.

To address concerns about use of genetic information by providers of goods and services, Canada passed the Genetic Non-Discrimination Act (GNDA) in 2017.8 While the GNDA is groundbreaking in its protection against genetic discrimination, this paper

argues that it contains critical definitional and structural limitations that render it inadequate for regulating emerging epigenetic and future health technologies. By analyzing the act's scope and consent-based framework, we demonstrate that the GNDA's shortcomings could perpetuate inequities as insurers adopt new forms of health data in their underwriting practices. Given Canada's influential position in developing global health policies, examining these regulatory gaps offers valuable insights for creating more adaptive legislation that can evolve alongside rapid scientific advancement.

The Genetic Non-Discrimination Act

The ethical and legal concerns about the use of genetic data did not arise with epigenetic age estimators. When genetic technologies first entered the market, there were anxieties that insurers and other private actors could exploit genetic data for discriminatory purposes. 10,11 Although it is widely accepted that discriminatory practices are foundational to the insurance business—with US state laws variably allowing discrimination based on age, gender, and credit score, for example 12—genetic information was recognized as fundamentally different, partly given its sensitive nature.3 It was argued that private insurers should not be able to deny or alter coverage terms on the basis of predictive genetic information, as this practice would constitute genetic discrimination. 13,14 In response to these concerns, Canada passed the GNDA in 2017, thereby granting special protections to genetic data in the hopes of mitigating these privacy and discrimination risks.9 The act regulates access to and use of genetic test results in contractual settings.9 It defines a genetic test as one that "analyzes DNA, RNA or chromosomes for purposes such as the prediction of disease or vertical transmission risks, or monitoring diagnosis or prognosis."9 Under the GNDA, no person can require individuals to undergo or disclose the results of such tests, and any actors, including insurers, must obtain a client's explicit written consent before collecting or processing genetic data.9 Through this consent-based framework, the GNDA attempts to address ethical concerns about providers' use of genetic data while still permitting its use when individuals voluntarily agree to disclose it.

Despite this protection, concerns persist about the act's ability to adequately regulate emerging health technologies that might also pose ethical risks. This uncertainty is particularly evident when examining whether epigenetic technologies fall within the act's scope. Epigenetic age estimators—which use DNA methylation patterns to gauge an individual's biological age, an indicator of aging at the cellular level—stand out as one of the most prominent recent innovations in aging biology. ¹⁵ Current data suggest that the difference between a person's chronological and biological age, known as age acceleration, can serve as a health outcome predictor comparable to mental health indicators or health behaviors. ¹⁶

At first glance, integrating epigenetic age estimation into underwriting might seem less problematic than using genetic information. Measures of age acceleration might appear to be simply an "objective" and streamlined method for capturing data on a characteristic that is similar to characteristics insurers already use in actuarial calculations. These characteristics include smoking habits, exercise patterns, and other self-reported lifestyle behaviors. When employed in underwriting, accelerated age could be used to predict a person's quality of life or lifespan.² Yet this apparent simplicity masks deeper concerns, as, much like genetic information, epigenetic data—in addition to being predictive—can be inherited and influenced by factors outside of an individual's

control.¹⁷ Despite the important similarities of epigenetic data to genetic data, it remains unclear whether the GNDA should or does apply to epigenetics.

Limitations of the Genetic Non-Discrimination Act

As technologies continue to push the boundaries of what qualifies as genetic information, it is imperative to clarify the scope of the GNDA. While there has yet to be a determination pertaining to the reach of the act, Canada's Supreme Court has indicated that the scope of "genetic characteristics" is not stagnant and should be broadly interpreted.18 This opinion lends credibility to speculation on the part of genetic experts that the act would likely apply to epigenetic data. 18 Although epigenetic clocks do not analyze the amino acid sequence of proteins, they do analyze methylation marks found on DNA and could therefore qualify as a form of "DNA analysis," per the GNDA.15 Moreover, there is abundant evidence to support the "vertical," or generational, transmission of certain epigenetic biomarkers when gametes are exposed to stressors, and genetic tests, per the GNDA, predict "vertical transmission" risks. 19 That said, the strength of this argument is tempered by the fact that epigenetic technologies are not typically used to predict "disease or vertical transmission risks, or [for] monitoring, diagnosis or prognosis."9 While it seems likely that courts would rule in favor of the GNDA's application to epigenetic data, the narrow terminology used to describe genetic tests leaves room for doubt.

Regardless of whether epigenetic data ultimately fall within the GNDA's scope, long-standing criticisms of the legislative approach taken by the Canadian government persist. The first of these critiques revolves around the consent-based nature of the act, which places the onus on individuals to understand their right to withhold genetic data from insurers and the risks entailed should they provide consent. Without knowledge of the GNDA, clients might feel compelled to share the results of a genetic test even if sharing might not be to their benefit.²⁰ Such a framework mistakenly treats consent as a sufficient barrier against genetic discrimination, despite mounting evidence that individuals can underestimate the sensitivity of genetic information and might be unaware that private actors are not entitled to such data.^{7,20}

The risks of genetic discrimination are compounded by the heritability of genetic information. An analysis of a given client's health data can provide an insurer with significant insight into heritable traits that might also impact that client's blood relatives. While the GNDA is clear about the need for explicit written consent "to collect, use or disclose the results of a genetic test of the individual,"9 consent is only required of the person to whom the data belongs. This provision leaves open the possibility that one person's health data could be used to inform decisions about another's coverage. Until there is legal clarification on this potential loophole, the consequences for individuals of the use of genetic test results, including estimates of age acceleration, could be significant. Research suggests that age acceleration is heritable, 21,22 meaning that if a parent voluntarily shares signs of rapid age acceleration with an insurer, they might unknowingly expose their children to risk of higher premiums, as an insurer, using a parent's data, could infer health risks in the children and adjust the children's premiums accordingly without needing additional consent. This scenario illustrates how the GNDA's reliance on individual consent fails to account for the collective nature of genetic information and the potential for discrimination against family members. Given the lack of transparency in health insurance underwriting practices, 23,24,25 it remains difficult to determine whether the use of genetic information to discriminate against

family members occurs in practice, underscoring the broader challenge of regulating health data in the private insurance sector.

The limited protection of individuals against discrimination is further magnified at the population level. A growing body of evidence demonstrates that age acceleration varies significantly with sociodemographic background, 26,27,28 revealing how biological markers can reflect broader social disparities. This variation points to a more troubling concern about the risk of discrimination at the population level, such that the use of health data in underwriting could further entrench and magnify preexisting inequities. Factors that disproportionately impact certain populations—including chronic stress from discrimination, limited access to health care, and involuntary environmental exposures from substandard housing—might become embedded in these epigenetic markers. 26,27,28 As a result, individuals from certain racial, ethnic, or socioeconomic groups might face higher insurance premiums not because of personal choices but because their biology reflects the structural disadvantages they have endured. This dynamic, known as proxy discrimination, 29 strengthens the case for granting special legislative protections to certain forms of health data, particularly when similar protections are not extended to other involuntary characteristics.

Keeping Pace

The challenges identified with both familial and proxy discrimination through biological markers highlight the urgent need for legislation to better account for the continued development of health technologies, including biological age estimators. Current definitional and structural limitations that might exclude certain kinds of health data from GNDA protections represent just one facet of a broader problem: the law's struggle to keep pace with rapidly evolving science. While, arguably, epigenetic information could be protected under the GNDA, other adjacent technologies with similar discriminatory potential might fall squarely outside of the act's scope. For example, emerging types of proteomic analysis, which rely not on DNA, RNA, or chromosomes, but on a set of proteins present in a person's body, can now be used to determine biological age as well.³⁰ As has been observed with epigenetic clocks, results from these new proteomic age estimators also vary with sociodemographic background and, importantly, would not be protected by the GNDA.31 Such examples illustrate how the same equity concerns raised by the use of epigenetic age estimators extend to the potential use of other health technologies in insurance, pointing to a need for forward-thinking definitions that allow legislation to evolve with science.

Addressing definitional and structural gaps, however, represents only half the solution. Additional accountability and oversight mechanisms will be necessary to protect against the discriminatory impact of shifting actuarial practices. Without adequate transparency regarding the ways biological information is processed by insurers, it is impossible to evaluate the direct link between specific actuarial practices and their impact on genetic discrimination. As is the case with all forms of discrimination, laws might have their limitations but still represent a crucial piece in dismantling inequities. With continual monitoring of actuarial practices, laws and policies can be refined to better meet the needs of the people they are intended to serve and protect.

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