Secret Code: The Need for Enhanced Privacy Protections in the United States and Canada to Prevent Employment Discrimination Based on Genetic and Health Information

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Secret Code: The Need for Enhanced Privacy Protections in the United States and Canada to Prevent Employment Discrimination Based on Genetic and Health Information

Abstract
The collection of genetic and health information by employers for reasons that are unrelated to the health and safety of workers is an undue infringement of the right to privacy, and consequently should be firmly prohibited by statute. Comprehensive genetic and health information privacy requires the protection of at least three critical elements of the right to privacy-namely choice, secrecy, and confidentiality. While choice and secrecy protect the individual's right to privacy at the collection stage, confidentiality safeguards this right at the point of disclosure. Laws that focus on the inappropriate use of genetic and health information without addressing the act of collecting such information, as is the case with American laws prohibiting genetic discrimination by employers and others, fail adequately to preserve privacy and prevent discrimination. Existing laws that do address the collection of personal information, such as Canada's Personal Information Protection and Electronic Documents Act (PIPEDA), the general and statutory laws of Quebec, and recent Manitoba legislation are insufficiently explicit with respect to the legality of genetic and health information collection by employers.
SECRET CODE: THE NEED FOR ENHANCED PRIVACY PROTECTIONS IN THE UNITED STATES AND CANADA TO PREVENT EMPLOYMENT DISCRIMINATION BASED ON GENETIC AND HEALTH INFORMATION®

BY PATRIK S. FLORENCIO* AND ERIK D. RAMANATHAN**

The collection of genetic and health information by employers for reasons that are unrelated to the health and safety of workers is an undue infringement of the right to privacy, and consequently should be firmly prohibited by statute. Comprehensive genetic and health information privacy requires the protection of at least three critical elements of the right to privacy—namely choice, secrecy, and confidentiality. While choice and secrecy protect the individual's right to privacy at the collection stage, confidentiality safeguards this right at the point of disclosure. Laws that focus on the inappropriate use of genetic and health information without addressing the act of collecting such information, as is the case with American laws prohibiting genetic discrimination by employers and others, fail adequately to preserve privacy and prevent discrimination. Existing laws that do address the collection of personal information, such as Canada's Personal Information Protection and Electronic Documents Act (PIPEDA), the general and statutory laws of Quebec, and recent Manitoba legislation are insufficiently explicit with respect to the legality of genetic and health information collection by employers.

La collecte de renseignements personnels sur la santé et la génétique par les employeurs pour des raisons qui ne sont pas reliées à la santé ou la sécurité des travailleurs contrevient au droit à la vie privée et devraient donc être interdite par voie législative. Trois éléments doivent être protégés pour assurer la protection des renseignements personnels sur la santé et la génétique, le choix, la discrétion et la confidentialité. Malgré que le choix et la discrétion protègent le droit de l'individu au moment de la collecte des informations, la confidentialité assure cette protection au moment du divulgation. Les lois qui interdisent l'usage inapproprié des renseignements sur la santé ou la génétique ont échoué dans leurs objectifs de protéger le droit à la vie privée et de prévenir la discrimination car elles ne s'appliquent pas à la collecte même de cette information. La loi canadienne concernant la discrimination génétique par les employeurs et d'autres gens est un exemple de ce genre d'échec. La législation se rapportant à la collecte de renseignements personnels, tels que la Loi sur la protection des renseignements personnels et les documents électroniques, les lois provinciales québécoises et la nouvelle législation manitobaine ne sont pas suffisamment claires quant à la légalité de la collecte de renseignements sur la santé et la génétique par les employeurs.


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I. INTRODUCTION .................................................. 78

II. THE RIGHT TO PRIVACY ............................................. 80

III. THE CONFLICT BETWEEN THE RIGHT TO PRIVACY AND THE COMMERCIAL INTEREST IN GENETIC INFORMATION ................................. 82

IV. THE THREE PILLARS OF GENETIC AND HEALTH INFORMATION PRIVACY: CHOICE, SECRECY, AND CONFIDENTIALITY ................................. 88

V. A CRITICAL ASSESSMENT OF THE CURRENT LEGAL FRAMEWORK IN CANADA AND THE UNITED STATES .............................................. 92
   A. Common and Equitable Laws ........................................ 93
      1. Choice .......................................................... 93
      2. Secrecy .......................................................... 94
      3. Confidentiality .................................................. 97
   B. Constitutional Law .................................................. 100
      1. Choice .......................................................... 101
      2. Secrecy .......................................................... 103
   C. Federal Legislation .................................................. 105
      1. Personal Information Protection and Electronic Documents Act .......... 106
      2. The Americans with Disabilities Act ................................ 107
      3. The Health Insurance Portability and Accountability Act ................. 110
   D. State/Provincial Legislation ........................................ 111
      1. Canada .......................................................... 111
      2. The United States ................................................ 112

VI. CONCLUSION ........................................................ 116

I. INTRODUCTION

Imagine a vast computerized infrastructure of biomedical informatics—as available in Calgary and Phoenix as it is in Atlanta, Bethesda, and Ottawa—collecting and dispersing epidemiological data at every medical centre on the continent. The value of this public health surveillance data would be rivalled only by its enormous value to biomedical research scientists and clinicians, who could test on a grand scale new theories on the role of genetics, serology, and symptomatology in the etiology, prevention, and treatment of disease. This reality is achievable in the near future. Large pieces of the infrastructure already exist, but the uniformity and coordination of collection and dissemination implied in this account do not. And while scientific advancement has always
churned forward without rigorous coordination, protection of the privacy of those who provide the genetic and health information from which these advancements are derived may suffer gravely when gaps appear in the protection afforded by piecemeal efforts. This is particularly true when health information becomes available to employers and insurers, who may use the information in ways that maximize profitability at the expense of individual and societal interests in protecting privacy and preventing discrimination.

While a person usually decides to undergo genetic testing for personal health-related reasons, the information that is derived from genetic testing can be utilized for purposes unrelated to the prevention or alleviation of disease and suffering. Legal policy commentators have begun to question the role of the law in regulating private uses of genetic and health information. Employers are seeking private genetic and health information when making hiring or firing decisions and there is a strong incentive for employers to make the disclosure of this private information a precondition to the attainment of employment. Likewise, both employers and insurance companies desire private genetic and health information in order to distinguish healthy individuals from individuals who are more likely to develop health-related problems in the future. Once again, there is a strong incentive for employers and insurance companies to make the disclosure of this information mandatory since it would enable them to minimize their costs. Thus, there appears to be a conflict between the privacy interests of the individual and the commercial interests of employers and insurers. This article will explore this tension between the individual's right to privacy and the commercial benefit of genetic and health information by focusing on the employment situation.

The thesis advanced by this article is that comprehensive health information privacy requires the protection of at least three critical elements of the right to privacy—namely choice, secrecy, and confidentiality. While choice and secrecy protect the individual's right to privacy at the collection stage, confidentiality safeguards this right at the point of disclosure. Laws that focus on the inappropriate use of genetic and health information without addressing the original collection of such information, as is the case with American laws prohibiting genetic discrimination by employers and others, fail adequately to preserve privacy and prevent discrimination. Existing laws that do address the collection of personal information, such as Canada's Personal Information Protection and Electronic Documents Act (PIPEDA), the general and statutory laws of Quebec, and recent Manitoba legislation discussed below, are insufficiently explicit with respect to the legality of genetic and health information collection by employers. We take the position that the collection of such
information by employers for reasons that are unrelated to the health and safety of workers is neither appropriate nor legitimate, and should consequently be firmly prohibited by a statutory right to privacy. At least in the employment context, the interests of individuals in decision making and information privacy as well as in being free from discrimination should override the commercial interests of employers in acquiring detailed information regarding the genetic and actual or perceived medical constitutions of those they employ.

Part II offers a brief survey of theories and definitions of the right to privacy. In Part III, the conflict between the right to privacy and genetic and health information is identified and explored. In Part IV, the three fundamental aspects of the right to privacy—choice, secrecy, and confidentiality—are identified and a general framework for comprehensive legislation is presented. In Part V, the existing legal framework of both the United States and Canada is presented, analyzed, and criticized.

II. THE RIGHT TO PRIVACY

A variety of theories, definitions, and justifications for privacy and a legal right to privacy have been offered during the past century. We begin by presenting a brief survey of theories and definitions that attempt to explain the nature of the concept of privacy, and will then turn to justifications that have been provided for the legal enforcement of privacy as a right. Early theorists proposed that the right to privacy was "like the right not to be assaulted or beaten, the right not to be imprisoned, the right not to be maliciously prosecuted, [and] the right not to be defamed." In short, the right to privacy was perceived as an aspect of the right to be let alone, a right that is so basic that it must emanate directly from the "person" or "human dignity." Accordingly, this general right was entitled the principle of "inviolate personality." The modern version of this theory

1 S.D. Warren & L.D. Brandeis, "The Right to Privacy" (1890) 4 Harv. L. Rev. 193 at 205 [hereinafter "The Right to Privacy"].

2 See, for example, ibid. at 205: ("The principle which protects personal writings and all other personal productions, not against theft and physical appropriation, but against publication in any form, is in reality not the principle of private property, but that of inviolate personality"; R. Pound, "Interests of Personality: Part I" (1915) 28 Harv. L. Rev. 343; R. Pound, "Interests of Personality: Part II" (1915) 28 Harv. L. Rev. 445; and E.J. Bloustein, "Privacy as an Aspect of Human Dignity: An Answer to Dean Prosser" (1964) 39 N.Y.U.L. Rev. 962 at 971 (interpreting "inviolate personality" to mean "the individual's independence, dignity and integrity"). It is interesting to note that civil law theorists in the jurisdiction of Quebec have also grounded the privacy interest within the broad principle of "juridical personality." See Civil Code of Québec: A Critical Edition/Code civil du Québec: Édition critique, J.-M.
of privacy is called the principle of "personhood" and has garnered several contemporary supporters.\(^3\)

The principle of inviolate personality or personhood has been criticized by a number of common law scholars as being too imprecise and all-encompassing to be of any practical assistance.\(^4\) Not surprisingly, most common law scholars have attempted to find the justification of the right to privacy elsewhere, for instance, the principle of autonomy.\(^5\) Contrary to the theory of inviolate personality or personhood, the right to privacy is not simply the right to restrict the publication of personal information about oneself. Rather, while the right to privacy may be used to deter the publication of personal information, privacy is essentially "control over when and by whom the various parts of us can be sensed by others."\(^6\) In other words, privacy is grounded in the principle of autonomy or self-determination.

However, the autonomy-based theory of privacy has been criticized. Although, to be sure, the right to privacy safeguards respect for autonomy, the right to privacy is not itself synonymous with the principle of autonomy and is in fact better understood as a "state of inaccessibility."\(^7\) The right to privacy promotes respect for autonomy by imparting to the individual a legal means of preserving and protecting his or her state of inaccessibility. This protected sphere is an environment in which individuals can think and act voluntarily, unencumbered by the coercive influence of the outside world. Persons are in a state of inaccessibility when they, their mental state, or information about them "is beyond the range of other's five senses and

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Brisson & N. Kasriner, eds. (Cowansville, Quï.: Les Éditions Yvons Blais, 2000), art. 1 & 3 [hereinafter Civil Code].


\(^6\) R.B. Parker, "A Definition of Privacy" (1973–74) 27 Rutgers L. Rev. 275 at 281. See also, A.F. Westin, Privacy and Freedom (New York: Atheneum, 1967) at 7 [hereinafter Privacy] (defining privacy as "the claim of individuals, groups, or institutions to determine for themselves when, how, and to what extent information about them is communicated to others").

any devices that can enhance, reveal, trace, or record human conduct, thought, belief or emotion. The advantage of the inaccessibility definition is that it offers useful distinctions from which to conceptualize the different types of privacy losses that individuals may suffer. For instance, individuals may experience a loss of privacy when their physical state, disposition, or informational inaccessibility is disturbed by an unauthorized intruder.

A number of justifications have been put forth for the enforcement of privacy as a legal right. For Westin, a certain degree of privacy protection is essential in order to ensure liberty and democracy because the right to privacy restrains the ability of the state to pry into the lives of its citizens. The right to privacy has also been justified on the basis that it safeguards what is described as being a number of basic rights, such as the right not to be looked at, not to be listened to, not to be caused distress, not to be harmed, hurt, or tortured, and so on. Other justifications for the right to privacy have included the prevention of prejudice and stigmatization in society, the maintenance of "degrees of intimacy" in friendship and love, the argument that privacy is a basic human need, and the protection of autonomy.

III. THE CONFLICT BETWEEN THE RIGHT TO PRIVACY AND THE COMMERCIAL INTEREST IN GENETIC INFORMATION

It is debatable whether genetic information is sufficiently distinct from other medical information as to justify its special treatment by the law, such as through the enactment of specific genetic privacy and anti-
discrimination legislation. Those in favour of special legal protection for genetic information have argued that genetic information, unlike other medical information, is predictive not only of the individual's medical future, but also that of his or her first-degree relatives. These commentators compare the genome to a "future diary." Despite what might have been viewed by the donor as a disclosure of genetic material for a specific purpose, holders of a sample of an individual's DNA will be able to learn more and more about that individual and his or her family as medical research continues to unlock the genetic codes that comprise the human genome. In addition, genetic information is distinguished from other medical information because it offers uncertain predictions that an individual may wish to ignore or suppress from the attention of insurers or employers. This incentive exists because the predictive and therapeutic value of genetic information is more likely than real-time diagnostic medical information to be outweighed by long-term anxiety of the individual or her family, or by the threat of stigmatization or discrimination at the hands of third parties.

Others have argued against the enactment of special legal protection for genetic information, referring to this viewpoint as "genetic exceptionalism." Mr. Justice Ginsburg has, for instance, expressed the view that unique legal solutions will lead to reductionism and genetic determinism, and that the common law is capable of addressing the new

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challenges posed by genetic information. The more popular view, however, is that the enactment of legislation is necessary, but that this legislation should protect the privacy of all predictive medical information, whether or not genetic in nature, with equal vigour.

These commentators have noted numerous theoretical and practical difficulties associated with treating genetic data differently from other sources of health data. First, stricter genetic-specific privacy standards may significantly restrain the dissemination of genomic data in relation to other forms of data, thereby curtailing legitimate uses of the information such as for scientific advancement and drug development. Second, genomic data may not be more sensitive than, and may therefore not be deserving of any greater protection than other forms of sensitive health information such as a diagnosis of HIV infection, sexually transmitted disease, or mental illness. Third, given that the transmission of electronic health data, whether for medical consultation, research, or public health, is seldom limited to one type of information, requiring hospitals, research institutions, health departments, insurers, and others to maintain separate records systems or separate security standards for genomic data would be costly and impracticable. Since these commentators view the difference between genetic information and other medical information to be one of degree, not of kind, they propose uniform national privacy protection for all health information.

Regardless of whether genetic information is regarded as sui generis or part of the broader category of health information, it raises specific concerns relating to privacy and discrimination. Genetic technology may be used to predict, and eventually effectively to treat, cure, or prevent genetic illnesses. However, genetic technology can also be used for illicit or questionable purposes. There is preliminary evidence which suggests that advances in genetic technology will be used to increase employment and

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insurance discrimination.\textsuperscript{20} Health, life, and long-term care insurance discrimination might consist of exaggerated premiums or the outright denial of insurance, while genetically motivated employment discrimination might include unfavourable treatment in hiring, promotion, compensation, and assignment of duties, or might even result in the termination of employees. The risk of discrimination is likely to be higher in jurisdictions where the costs of health care are largely borne by employers and private insurers,\textsuperscript{21} than it is in jurisdictions that have a publicly funded and universal health care system.\textsuperscript{22} This is so because the financial incentive on employers and private insurers to attempt to reduce their employee health care costs by weeding out individuals who are predisposed to developing serious or costly illnesses later in life is absent in the case of universal medical systems whose mandate is to provide care to all those in need regardless of their ability to pay.


\textsuperscript{22} Such as in Canada. See C.D. Naylor, Canadian Health Care and the State: A Century of Evolution (Montreal: McGill-Queen's University Press, 1992). Yet, even in Canada, a jurisdiction proclaiming to provide its citizens with a comprehensive and universal health care plan, approximately 30 per cent of the costs of care are privately paid. See C. Fuller, Caring for Profit: How Corporations are Taking Over Canada's Health Care System (Vancouver: New Star Books, 1993) at 98.
Since 5 per cent of health care claimants reportedly consume 50 per cent of the health care resources in any given jurisdiction, and 10 per cent of claimants reportedly consume 70 per cent of resources, the financial incentive to identify and exclude costly individuals is significant. This incentive has existed for insurers ever since the community rating system of calculating premiums, which holds that all members of a given community pay comparable rates, was replaced by the experience rating system, which holds that the cost of insurance is based on expected claims. It is clear, then, that insurers are in the business of identifying those individuals who are likely to be above average consumers of health care.

Genetic information is an enticing basis upon which to make these predictions when it comes to genetic illnesses. In jurisdictions where employers use health benefit packages as a means of attracting qualified workers, these employers are also likely to be interested in using genetic information, most notably as a method of determining whether a current or prospective employee is predisposed to becoming ill in the future. By avoiding high-risk individuals, employers can expect to reduce their insurance premiums and minimize productivity losses due to illness. Not surprisingly, many insurance companies and employers feel that genetic technology provides them with the best available means of reducing costs and, in so doing, increasing profit.

However, utilizing genetic or health information for these commercial ends is likely detrimental to the social welfare. First of all, insofar as insurance companies are entitled to charge high-risk individuals larger premiums than persons situated in the low-risk category, the practice of cross-subsidization that renders health insurance affordable to everyone, including high-risk individuals, will cease. In so doing, high-risk individuals would be required to pay obscene insurance premiums or simply resolve to live without insurance. Moreover, where the cost of a treatment for a genetic disorder are significant, insurance companies may simply deny coverage to high-risk individuals rather than run the risk of having to pay for the necessary treatment in the future. As a result, the percentage of the

population without medical insurance would likely grow. Finally, individuals who are predisposed to costly genetic illnesses may also have trouble finding and maintaining employment. Employers who are wary of lost work days and elevated insurance premiums may fail to hire prospective employees and may discharge current employees who are identified as being predisposed to costly illnesses, or they may disproportionately shift their insurance costs onto their genetically predisposed employees thereby making health care less accessible for that class of employees. The meagre marginal benefit that is obtained by insurers and employers utilizing genetic and health information would result in a devastating loss to persons with undesirable genetic predispositions. For this reason, the practice of identifying and excluding high-risk individuals must be construed as a form of discrimination.

This conflict between the individual's right to privacy and the commercial interest in genetic and health information is exacerbated by the proliferation of information technology. Public health and medical research are improved when genetic and health information is stored in electronic form on large networks, because the information becomes easily accessible to researchers and public health officials. However, given that these very detailed medical records will be accessible when they are stored in electronic form, it is all the more clear that there is a need for legislation that will ensure that the right to privacy is respected.

25 There are reportedly forty-four million individuals, or 16 per cent of the population, without health insurance in the United States. See "Critical Condition" Newsweek 58 (8 November 1999), online: WL (NEWSWEEK) [hereinafter "Critical Condition"].

26 Employers are increasingly engaging in cost shifting tactics such as capping their "total benefit contribution and thus requiring the employee to trade off health insurance against pension and other fringe benefits; requiring employees to bear some of the cost of premiums; covering employees but not their family members; offering only health plans that stringently cap some services such as prescription drugs and nonemergency outpatient psychiatric benefits; and increasing the amounts of deductibles or copayments for indemnity and PPO plans." See R. Kuttner, "The American Health Care System: Employer-Sponsored Health Coverage" (1999) 340:3 New Eng. J. Med 243 at 249.

27 See L.O. Gostin et al., "Privacy and Security of Health Information in the Emerging Health Care System" (1995) 5 Health Matrix 1 at 4-5 ("[T]he ease of collection, storage, and transmission of data over electronic networks also creates significant risks to privacy. Health records contain a vast amount of personal information: demographic information such as age, sex, race, and occupation; financial information such as employment status, income, disabilities, and participation in federal or state programs; medical information such as diagnosis, treatment, and disease histories including mental illness, drug or alcohol dependency, aids, or sexually transmitted diseases (STDs); and sexual information such as family, sexual relationships, and lifestyle choices."). See also A.F. Westin, Computers, Health Records, and Citizen Rights (Washington, D.C.: United States Department of Commerce, National Bureau of Standards, 1976) at 92-99; National Research Council, Committee on Maintaining Privacy and Security in Health Care Applications of the National Information
IV. THE THREE PILLARS OF GENETIC AND HEALTH INFORMATION PRIVACY: CHOICE, SECRECY, AND CONFIDENTIALITY

To accomplish the objective of comprehensive genetic and health information privacy, we suggest that each jurisdiction enact a statutory right to privacy that addresses at least three important aspects: choice, secrecy, and confidentiality.28 The objective that is being pursued here is the modest purpose of providing a statutory framework to base the protection of genetic and health information privacy.

Comprehensive genetic and health information privacy requires legislation that address choice, secrecy, and confidentiality. Choice or decisionmaking privacy derives from the principles of autonomy and self-determination and is essentially the right to be unencumbered by an external authority, such as an employer or insurer, when making personal choices for oneself, such as submitting to a genetic test.29 While the common law right to self-determination could be used to prevent employers and insurance companies from forcing individuals to submit to genetic testing, it could not be used to prevent them from making genetic

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28 According to the Canadian Medical Association (CMA), there are five elements to the right to privacy: (1) physical, bodily and psychological integrity and privacy; (2) privacy of personal information; (3) freedom from surveillance; (4) privacy of personal communications; (5) privacy of personal space. See Canadian Medical Association, “Health Information Privacy Code” (1998) 159 C.M.A.J. 997, c. C, s. 1(1). The exact nature of these elements is somewhat unclear and there would appear to be some overlap between them. Also, while the CMA has identified decisions affecting bodily integrity as being worthy of privacy protection (element one), its definition of the right to privacy is similar to Westin’s in that it does not address this element but is instead limited to the protection of personal information. See CMA, ibid., c. B (the right to privacy “includes a patient’s right to determine with whom he or she will share information and to know of and exercise control over use, disclosure and access concerning any information collected about him or her; it entails the right of consent. Nonconsensual collection, use, disclosure or access violates the right to privacy, even if it is justified.”).

29 In short, it would be an “interest in independence in making certain kinds of important decisions.”: Whalen v. Roe, 429 U.S. 589 at 599–600 (1977), per Justice Stevens [hereinafter Whalen].
testing a precondition to obtaining or maintaining employment or insurance status. As a result, persons who exercise their right to autonomy and refused to undergo testing could find themselves unemployed or uninsured. Given this unsatisfactory state of affairs, it is clear that simply safeguarding the right to medical autonomy will not yield comprehensive protection.

One means of addressing this situation would be to protect the initial choice and allow discrimination laws to deal with the consequences of that choice. Qualified individuals who refuse to submit to genetic testing and are subsequently denied employment or insurance could sue on the basis of discrimination. However, while discrimination laws offer comprehensive protection in theory, in practice there are problems associated with this solution. First, it may be difficult to convince a court that a denial of benefits on the basis of a refusal to undergo medical testing constitutes discrimination. Second, it would be difficult to prove that the denial of benefits had to do with the testing refusal rather than with some other consideration, such as the quality of the claimant's employment application. Third, while discrimination laws provide a disincentive, they are incapable of preventing discrimination. A statutory right to decision-making privacy would avoid these limitations by outright preventing employers, insurance companies, and others from requesting, whether formally as part of an application form or informally during an interview, that individuals submit to genetic testing.

A complete right to decision-making privacy would fully shield the individual from those external agents seeking to influence the medical decision-making process for their own benefit. Some commentators have argued that while individuals are entitled to complete decision-making privacy with employers, they are not so entitled with insurance companies since a genetic disorder is a valid consideration when determining appropriate insurance premiums. Some consumers, politicians, and geneticists feel that because most genetic tests will merely indicate a predisposition for developing a disease or illness that may not occur at some future time, insurers should be prohibited from using such information in the decision-making process. This reflects a misunderstanding of the risk selection process and the basic premise of insurance. The process of underwriting is based upon the existence of uncertainty. In fact, if there were no uncertainty as to the outcome, then we would not be talking about insurance at all, since by definition, insurance is protection against an uncertain event.

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all individuals are theoretically granted unqualified access to comprehensive medical care. In jurisdictions such as the United States, where the health care system is privately funded, a statutory right to decision-making privacy could be used to prevent insurance companies from excluding genetically predisposed yet asymptomatic individuals from insurance benefits. This would ensure that the current practice of cross-subsidization would survive and that insurance would be affordable by all.

The right to secrecy or information privacy would ensure an individual's right to privacy after he or she has resolved to undergo genetic testing by allowing the individual to keep the results private. By explicitly making it unlawful for employers or insurance companies to either request or require, whether formally or informally, the disclosure of health information that is not directly related to workplace safety, a statutory right to information privacy would cure the shortcomings of the right to privacy existing in the general laws of the United States and Quebec and would greatly enhance the almost nonexistent protection that is available in common law Canada. Moreover, by linking secrecy violations to progressively scaled monetary penalties, the statutory right to secrecy would have significant deterrent value.

Both the right of decision-making privacy and the right to secrecy need to be qualified. An exception to the rights of decision-making and information privacy should be provided where workers are routinely exposed to toxins, chemicals, or other potentially harmful agents. Given the elevated risk of disease that is associated with placing someone who is genetically vulnerable to a particular occupational illness in direct contact with a workplace toxin that is known to induce that illness, employers would be entitled to test potential employees for genetic predispositions for occupational illnesses. In these cases, employers should remain subject to the confidentiality requirements.

32 See Whalen, supra note 29 at 599, where Justice Stevens notes the "individual interest in avoiding disclosure of personal matters .... "
The third aspect of privacy—confidentiality—would govern the secondary disclosure of personal information by those who become privy to it. It would be the right to impose on others the obligation of keeping secret personal information that they know about you. In the doctor-patient relationship, the common law right to confidentiality prevents physicians from disclosing information received from the patient to anyone not directly involved in the patient's care and treatment. This entitlement has ancient roots, being an important element of the Hippocratic Oath. The statutory right to confidentiality would go beyond its common law counterpart. Chronologically, confidentiality would lie at the tail end of privacy, arising only after the individual would have freely chosen to undergo genetic testing, and have voluntarily conveyed the testing results to a "trustee" of the information. It is upon these trustees, the persons admitted into the inner circle of the individual's confidence, that the duty of confidentiality would be imposed. The duty would not be premised on the existence of a doctor-patient relationship and would not therefore be limited in application to primary care physicians. By attaching to the information itself rather than to the therapeutic relationship in which personal information is often revealed, the statutory duty would apply to everyone that becomes privy to the confidential information. Absent the free and informed consent of the individual to whom the information pertains, trustees would be prohibited from disclosing the personal information. More specifically, each new disclosure of confidential information, whether full or partial, would require prior authorization. This would enable individuals to choose whether or not they want to admit a new trustee into their inner circle of confidence and, if so, the nature and quantum of the specific information that is revealed to that new trustee.

35 The modern version of the Hippocratic Oath reads: "Whatever in connection with my professional practice or not in connection with it I may see or hear in the lives of my patients which ought not to be spoken abroad, I will not divulge, reckoning that all such should be kept secret." See The Hippocratic Oath, online: Tripod <http://members.tripod.com/~jsturo/hippocr.htm> (date accessed: 2 October 2001).
36 Some scholars have begun to identify the elements of consent that would need to be present in order for it to be truly informed. See "Genetic Privacy," supra note 19 at 327:

To render consent meaningful, the process must incorporate clear content areas: how privacy and security will be maintained; the person's right of ownership of, and control over, the data; specific instructions on means of access, review, and correction of records; the length of time that the information will be stored and the circumstances when it would be expunged; authorized third-party access to the data; and future secondary uses. If secondary uses of those data go beyond the scope of the original consent additional consent must be sought.
Compliance with the statutory duty of confidentiality would require that genetic and health information be stored in anonymous form and that electronic security tools be a standard feature of institutional record storage systems. In addition, given that the telecommunications age has practically erased jurisdictional boundaries, what is required are laws that are uniform or at least consistent across jurisdictions.

A basic exception to a statutory right to confidentiality would exist in the case of disclosures of personal information that occur between health care professionals and are necessary for the patient's care. Yet, in even these cases, the primary care provider to whom the personal information is first revealed should not pass on more information than is reasonably required to perform the task at hand. The exact quantum of information that is disclosed between health care providers is a matter of professional discretion, but should be analyzed by means of an objective test should the issue be litigated. Moreover, other exceptions to the statutory right to confidentiality would be necessary in order to promote other important yet competing interests. Further consideration is required on how to balance the right to privacy with other competing interests, such as the advancement of medical research and improved public health surveillance. A major factor that will need to be taken into consideration is whether the information is linked to a personal identifier, in which case prior authorization should be required, or whether the information is being transmitted in an unlinked format. In this case, prior authorization would seem less vital given that the risk of privacy intrusion is greatly mitigated. Violations of any of these aspects of privacy could be associated with progressively scaled monetary penalties, which would ensure the right to privacy by establishing significant disincentives.

V. A CRITICAL ASSESSMENT OF THE CURRENT LEGAL FRAMEWORK IN CANADA AND THE UNITED STATES

The available privacy protections in both the United States and Canada are fragmented and inconsistent, and include major gaps in coverage. Neither jurisdiction has comprehensive national laws regulating how private genetic and health information are protected, secured, or verified. This section will identify the laws intended to safeguard the right to privacy in the context of genetic and health information in the United

States and Canada, and then analyze and criticize their effectiveness in light of the framework for protecting genetic and health information privacy we have proposed.

A. Common and Equitable Laws

The common and equitable laws of the United States, common law Canada, and Quebec offer inadequate protection for the choice, secrecy, and confidentiality elements of the right to privacy.

1. Choice

Medical decision-making privacy, or privacy of choice, is protected on the basis of autonomy. This is the same philosophical foundation upon which the requirements of informed consent are premised. The doctrine of informed consent requires that prior to the performance of a medical procedure a patient's physician must accurately describe and characterize the proposed treatment and disclose any risks associated with the treatment that the patient would reasonably deem significant. Only then can a patient consent to a medical procedure of his or her own free will. Thus, the doctrine of informed consent ensures that it is ultimately the patient and no one else who decides whether to accept or reject treatment, no matter how foolish the decision may appear to be. While medical decision-making

38 For early sources making reference to this right, see Union Pacific Railroad v. Botsford, 141 U.S. 250 at 251 (1891), Cray J. ("No right is held more sacred, or is more carefully guarded by the common law, than the right of every individual to the possession and control of his own person, free from the restraint or interference of others, unless by clear and unquestionable authority of law."); and Schoendorff v. Society of New York Hospital, 211 N.Y. 125 (1914), per Justice Cardozo: "Every human being of adult years and sound mind has a right to determine what shall be done with his own body." See generally T.L. Beauchamp, "Informed Consent" in R.M. Veatch, ed., Medical Ethics (Boston: Jones & Bartlett, 1989) at 173.


41 In common law Canada, see Fleming v. Reid (1991), 4 O.R. (3d) 74 (C.A.) ("The fact that serious risks or consequences may result from a refusal of medical treatment does not vitiate the right of medical self-determination. The doctrine of informed consent ensures the freedom of individuals;
autonomy would require employers and insurance companies to seek consent before subjecting an individual to genetic testing, it would not stop them from making such testing a precondition to procuring or maintaining employment or insurance. Thus, unlike the statutory right to decision-making privacy that is being proposed in this article, the common law right to autonomy does not adequately protect individuals from undue influence in making personal medical decisions in the absence of subsequent adverse social consequences such as the loss of employment or insurance benefits.

2. Secrecy

The right to secrecy is the right to prevent the unlawful collection of personal information by third parties. This right is poorly protected by the common law. In the United States, the common law right to privacy might be used to prevent third parties from collecting personal information about an individual. For instance, employers and insurers that attempt to unlawfully collect genetic and health information through mandatory disclosure policies might be liable for damages on the grounds that this constitutes an intrusion into the seclusion of employees and policyholders. However, the common law right to privacy has not typically been applied to the unlawful collection of genetic or health information. In common law Canada, on the other hand, the right to secrecy receives even less

42 The common law right to privacy has long been recognized in the United States. See, for example: *De May v. Roberts*, 46 Mich. 160 (1881) [hereinafter *De May*] (holding that the common law right to privacy grants to women the right to exclude strangers from the delivery room during childbirth); *Pavesich v. New England Life Insurance*, 122 Ga. 190 (1905) (holding that the common law right to privacy protects against appropriations of name or likeness). But see *Roberson v. Rochester Folding Box*, 171 N.Y. 538 (1902) (rejecting the view that there is a general common law right to privacy). In 1960, William Prosser reviewed American privacy jurisprudence and concluded that the common law recognizes a right to privacy in at least four instances: (1) intrusion upon the plaintiff's seclusion or solitude, or into his private affairs; (2) public disclosure of embarrassing private facts about the plaintiff; (3) publicity which places the plaintiff in a false light in the public eye; and, (4) appropriation, for the defendant's advantage, of the plaintiff's name or likeness. See W.L. Prosser, "Privacy" (1960) 48 Cal. L. Rev. 383 at 389.

43 See, for example, *Berthiaume's Estate v. Pratt*, 365 A.2d 792 (Me. 1976) (unauthorized use of photograph of dying patient for documentation in medical record held to be intrusion into seclusion).
protection than in the United States, since it is not yet clear whether a common law right to privacy has been acknowledged by the courts.\footnote{44}

In the civil law jurisdiction of Quebec, privacy is considered to be a "personality right"—a concept that is foreign to common law jurisdictions where invasion of privacy is categorized as falling within the realm of tort law—and is expressly enumerated in its \textit{jus commune}.\footnote{45} This right to privacy offers greater privacy protection than that which is available in either the United States or common law Canada. In addition to granting to individuals a private law right of action against those who make an unauthorized use of their name, image, likeness, and so forth,\footnote{46} the Quebec right to privacy makes it illegal for anyone to establish "a file on another person" unless there exists a "serious and legitimate" reason for doing so.\footnote{47} Moreover, only information that is "relevant" to the stated objective of the file may be collected.\footnote{48}

Employers have serious and legitimate reasons for establishing and maintaining files on current and prospective employees. For instance, information needs to be collected so that employers can weigh the qualifications of job candidates and assess the work performance of existing employees. Since employers are required by law to provide their employees with a safe working environment, they also have a legitimate interest in collecting genetic and health information regarding predispositions to workplace illnesses. Conversely, the collection of genetic and health


\footnote{45}See \textit{Civil Code, supra} note 2, arts. 3, 35.

\footnote{46}See \textit{ibid.}, arts. 35, 36. Six particular acts are identified by the \textit{Civil Code} as constituting an invasion of privacy: (1) entering or taking anything in a person's dwelling; (2) intentionally intercepting or using a person's private communications; (3) appropriating or using a person's image or voice while he or she is in private premises; (4) keeping a person's private life under observation by any means; (5) using a person's name, image, likeness, or voice for a purpose other than the legitimate information of the public; and, (6) using a person's correspondence, manuscripts, or other personal documents. See \textit{ibid.}, art. 36.

\footnote{47}See \textit{ibid.}, art. 37.

\footnote{48} \textit{Ibid.}
information for purposes that are unrelated to workplace health and safety would constitute an unlawful invasion of privacy. Where employers require the disclosure of irrelevant genetic or health information as a precondition to attaining or retaining employment, there is a clear infringement on the right to privacy. However, what happens when employers merely request irrelevant health information? While the Quebec legislation seems to offer a comprehensive solution to the problem, there are some ambiguities with the prohibition that could be exploited by employers and insurance companies. For instance, where an individual is denied employment following his or her refusal to acquiesce to the employer’s request for irrelevant genetic and health information, there is an infringement of the right to privacy but not necessarily an unlawful act according to the Quebec legislation. If indeed compliance with a request for irrelevant genetic and health information constitutes a waiver, then the individual would not be entitled to any reparations under the right to privacy provisions.

At the same time, an individual who is discharged or fails to obtain employment after having disclosed irrelevant health information pursuant to either a mandatory or discretionary disclosure policy instituted by the employer could elect to sue the employer on the ground of discrimination. However, proof of causation would be an impediment to recovery since the individual has the burden of proof and would have to establish that the rejection was based on illegitimate considerations. By explicitly making it unlawful for employers to either request or require, whether formally or informally, the disclosure of health data that is not directly related to workplace safety, a statutory right to information privacy would cure the shortcomings of the right to privacy existing in the general laws of the United States and Quebec, and would greatly enhance the almost nonexistent protection that is available in common law Canada. Moreover, by linking privacy violations to progressively scaled monetary penalties, the statutory right to privacy would have significant deterrent value.

49 See Syndicat des Employées v. Caisse Populaire St-Stanislas de Montréal, [1999] R.J.D.T. 350 (holding that while employers can require of their workers that they provide a medical certificate should they need to miss work on the basis of illness, they cannot mandate that the precise nature of the illness be disclosed in the certificate since this would constitute a violation of the right to privacy).
3. Confidentiality

Both American and Canadian courts have used common law sources, such as contract, civil liability, and fiduciary law to protect and preserve the confidentiality of health information. These sources protect the privacy of information that is disclosed during the doctor-patient encounter by placing the obligations of trust and loyalty on primary care physicians who are entrusted to maintain the confidentiality of the personal information. The general rule is that health care professionals may disclose medical information only if the patient has expressly or impliedly consented to the disclosure or if the law requires or permits disclosure.\(^5\) Physicians who breach their duty of confidentiality by making an unauthorized disclosure could be pursued on a number of legal grounds. First, given that the doctor-patient relationship is recognized in law as having a contractual basis,\(^5\) the unauthorized disclosure of medical information by health care professionals could give rise to an action for breach of contract.\(^5\) Second, patients could also elect to sue in civil liability should the disclosure result in foreseeable injury.\(^5\) Third, given the fiduciary nature of the doctor-patient relationship, patients could also sue on equitable grounds. As fiduciaries, health care professionals have the obligation to hold information received from or about the patient in confidence. Breach of

\(^{50}\) See, for example, *Hay v. University of Alberta Hospital* (1990), 69 D.L.R. (4th) 755 (Alb. Q.B.) at 757-58:

The physician-patient relationship is clothed with confidentiality, a right which may be waived by the patient. Confidentiality is an important attribute of the physician-patient relationship, essential in promoting open communication between physician and patient. The patient may expressly waive this right or, by his actions, be found to have impliedly waived it. Alternatively, an overriding public interest or a statutory direction may justify a physician disclosing information about the patient. In the absence of such circumstances, the right remains and a physician who divulges confidential information could face an action for breach of confidentiality.


that confidence is actionable and could give rise to an equitable remedy. Fourth, the right to privacy that is available in the United States and in Quebec could be used to pursue a physician who unlawfully publishes genetic or health information regarding a patient in identifiable form, for instance in a medical journal or newspaper. Fifth, the obligation of confidentiality can additionally be found in the codes of ethics, and more recently in the health information privacy codes that are promulgated by professional medical associations. Health care providers that breach the confidentiality requirement of these codes could face disciplinary proceedings and be subject to penalties, such as the suspension or removal of licensure.

The physician's duty of confidentiality is not absolute. Occasionally, the law imposes on the physician the duty to warn ascertainable third parties who may be at risk. In these cases, the physician is permitted to

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55 See De May, supra note 42. Warren & Brandeis were referring to this aspect of privacy when they said that "[t]he design of the law must be to protect those persons with whose affairs the community has no legitimate concern, from being dragged into an undesirable and undesired publicity and to protect all persons, whatsoever their person or station, from having matters which they may properly prefer to keep private, made public against their will." See "The Right to Privacy," supra note 1 at 214–15.

56 See Civil Code, supra 2, art. 37 (holding that no person may, "without the consent of the person concerned or authorization by law, communicate such information to third persons or use it for purposes that are inconsistent with the purposes for which the file was established.").

57 In Canada, see Canadian Medical Association, Code of Ethics of the Canadian Medical Association (1996), s. 22, online: Canadian Medical Association <http://www.cma.ca/inside/policybase/1996/10-15.htm> (date accessed: 24 September 2001) ("Respect the patient's right to confidentiality except when this right conflicts with your responsibility to the law, or when the maintenance of confidentiality would result in a significant risk of substantial harm to others or to the patient if the patient is incompetent."). In the United States, see American Medical Association, Code of Medical Ethics, online: American Medical Association <http://www.ama-assn.org/apps/pf_online/pf_online?n=browse&doc=policyfiles/CEJA/E-5.05-HTM&s_t=&s_p=&nth=1&prev_pol=policyfiles/CEJA/E-4.07.HTM&next_pol=policyfiles/CEJA/E-5.01.HTM&> (date accessed: 1 October 2001) ("The physician should not reveal confidential communications or information without the express consent of the patient, unless required to do so by law.").

58 CMA, supra note 28, ss. 1.3(j), 2.1(d). The "duty of confidentiality" is defined in the code as "the duty of physicians and other health professionals in a fiduciary relationship with patients to ensure that health information is kept secret and not disclosed or made accessible to others unless authorized by patient consent." See CMA, ibid., c. B.
disclose the relevant information and will not be held liable to the individual for breach of medical confidentiality.\textsuperscript{59}

The common law does not adequately protect an individual's right of confidence. First of all, these safeguards apply only to information that is revealed to primary care physicians, notwithstanding that many persons have access to a patient's genetic and health information.\textsuperscript{59} In addition, it is unclear whether the duty of confidence is imposed on physicians who work for employers and insurance companies and who examine or test persons on behalf of these entities.\textsuperscript{61} But most significantly, by attaching protection to the doctor-patient relationship rather than to the information

\textsuperscript{59} For instance, where a patient informs his or her physician that they intend to harm an identifiable third party, the physician is required to breach the duty of confidence. Should the third party suffer injury as a result of the physician's failure to discharge his or her duty to warn, the law could impose civil liability upon that physician. In Canada, see Smith v. Jones, [1999] 1 S.C.R. 455. In the United States, see Tarasoff v. Regents of the University of California, 551 P 2d 334 (Cal. 1976); and Lipari v. Sears, Roebuck & Co., 497 F. Supp. 185 (D.C. Neb. 1980). Another instance in which physicians may have a duty to warn is when they know that their patient is predisposed to developing a genetic illness that is likely to run in the patient's family. While it is not yet clear in law whether the duty to warn will trump the duty of confidentiality in these cases, what does seem to be reasonably clear is that physicians would be wise to breach their patient's confidence unless the particular genetic illness at issue is both serious and preventable. See W.F. Flanagan, "Genetic Data and Medical Confidentiality" (1995) 3 Health LJ. 269 at 237 ("unless the information pertains to a serious genetic disorder that is unlikely to be detected by other means, and can be used to seek some helpful treatment, or avoid harmful environmental stimuli, a physician is ill-advised to disclose this information without patient consent, as the physician's breach of confidentiality may not be excused by a court of law"). At least one American court has already addressed this issue. See Safery v. Pach, 677 A.2d 1183 (1996).

\textsuperscript{60} J.G. Hodge, Jr., "National Health Information Privacy and New Federalism" (2000) 14 Notre Dame J.L. Ethics & Pub. Pol'y 791 at 798-99:

While it [i.e., confidentiality] protects health data as part of the physician-patient relationship, modern data collection is based only in small part on this relationship. Health records, moreover, contain a substantial amount of information gathered from numerous primary and secondary sources: laboratories, pharmacies, schools, public health officials, researchers, insurers, and other individuals and institutions. Patient health records are not merely kept in the office of private physicians or health plans, but also by government agencies, regional health database organizations, and information brokers. Databases maintained in each of these settings are collected and transmitted electronically, reconfigured, and linked. The duty of confidentiality which arises at the point of clinical care simply does not extend to all these parties for all these purposes. Focusing legal protection of health information privacy on the therapeutic relationships between physicians and patients within a national health information infrastructure is thus highly inadequate.

itself, the confidentiality safeguards do not extend to those individuals or organizations that obtain personal information from primary care givers. This may be less of a problem in Quebec given that confidentiality is protected pursuant to the right to privacy which itself applies to "[e]very person who establishes a file on another person." Once the primary care physician has made an authorized or unauthorized disclosure, the common and equitable law no longer provides a remedy against further disclosures of the information.

B. Constitutional Law

Neither the American Constitution nor the Canadian Constitution expressly affirms a right to privacy. Nevertheless, the supreme courts of both jurisdictions have found privacy to be deserving of a certain degree of constitutional protection and have proceeded to discover or read in privacy safeguards. At the same time, these safeguards are not absolute and must be balanced against various other interests. A number of American states have amended their constitutions so as to afford additional privacy protection. Although Canadian provinces do not possess their own constitutions, Quebec has enacted the Charter of Human Rights and

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62 See "Genetic Privacy," supra note 19 at 326.
63 See Civil Code, supra note 2, art. 37.
64 In Canada, see Canadian Charter of Rights and Freedoms, Part I of the Constitution Act, 1982, being Schedule B to the Canada Act 1982 (U.K.), 1982, c. 11 [hereinafter Canadian Charter]. In the United states, see the Amendments to the United States Constitution [hereinafter U.S. Const. amend.].
67 "Health Information Privacy," supra note 37 at 498.
Freedoms that explicitly acknowledges the right to privacy. This provincial legislation is a quasi-constitutional document since Quebec laws that are inconsistent with the Quebec Charter's provisions may be overturned.

In both the United States and Canada, the constitutional right to privacy is primarily protected by the prohibition against unreasonable searches and seizures. This right has been used to uphold an accused's right to decision-making privacy and information privacy. However, the existence and extent of a constitutional right to privacy independent and more fundamental than the guarantee against unreasonable searches and seizures remains a matter of conjecture. The Supreme Court of Canada has expressed sympathy for the proposition that section 7 of the Canadian Charter includes a right to privacy. In the United States, "zones of privacy protection" have been found to be located within the first and third amendments, the liberty interest of the fourteenth amendment, the fifth amendment's right against self-incrimination, the ninth amendment's reservation of rights to the people, as well as within the "penumbra" of the Bill of Rights.

1. Choice

A constitutional right to decision-making privacy would arguably safeguard the right of individuals to be unencumbered by the state when considering whether to undergo any form of medical or bodily intervention, whether it be conventional health care treatment, an abortion, genetic testing, the termination of life-sustaining treatment, or euthanasia. In Canada, medical decision making has been grounded in the rights to liberty and security of the person, and has been justified on the basis of respect for

68 R.S.Q. 1985, c. C-12, s. 5 (stating that "every person has a right to the respect of his private life.").
69 In Canada, see Canadian Charter, supra note 64, s. 8. See Southam, supra note 65 at 169 (where the court stated that the purpose of section 8 of the Canadian Charter "is ... to protect individuals from unjustified state intrusions upon their privacy"). In the United States, see U.S. Const. amend IV.
70 In Canada, see, for example, R. v. Stillman, [1997] 1 S.C.R. 607.
autonomy and self-determination. Given that decision-making privacy is a necessary precondition to autonomy, it too must be protected pursuant to section 7 of the Canadian Charter. For a decision to be truly autonomous, the decision maker must be free from external coercion and oppression, which would otherwise threaten the voluntariness of the decision. The right to decision-making privacy safeguards the sanctity of autonomous action by shielding the individual from those, including the state, who would use their power to unduly influence the decision-making process. While the Supreme Court of Canada has not yet explicitly recognized the existence of a right to decision-making privacy under section 7 of the Canadian Charter, it has used liberty and security of the person as a means of preventing the loss of privacy that can result from government infringements upon personal autonomy and state imposed psychological trauma. In the United States, the existence of a constitutional right to privacy has been acknowledged and has been used to protect the integrity of personal decisions, such as whether to use contraceptives or have an abortion.

2. Secrecy

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73 See R. v. Rodriguez, [1993] 3 S.C.R. 519 at 588 per Justice Sopinka, writing for the majority: "[t]here is no question, then, that personal autonomy, at least with respect to the right to make choices concerning one's own body, control over one's physical and psychological integrity, and basic human dignity are encompassed within security of the person, at least to the extent of freedom from criminal prohibitions which interfere with these." This finding was echoed by the minority in Rodriguez when Justice McLachlin, as she was then, noted that "[s]ecurity of the person has an element of personal autonomy, protecting the dignity and privacy of individuals with respect to decisions concerning their own body. It is part of the persona and dignity of the human being that he or she have the autonomy to decide what is best for his or her body." See ibid., at 618. See also, Morgentaler, supra note 71 at 171 where Justice Wilson stated that "I would conclude, therefore, that the right to liberty contained in s. 7 guarantees to every individual a degree of personal autonomy over important decisions intimately affecting their private lives."

74 Ibid.

75 See Mills, supra note 71 at 920, per Justice Lamer, who held that security of the person protects against state imposed psychological trauma that can take the form of "stigmatization of the accused, loss of privacy, stress and anxiety resulting from a multitude of factors, including possible disruption of family, social life and work, legal costs, uncertainty as to outcome and sanction." [emphasis added].

76 See, for example, Griswold, supra note 72 (striking down statutory prohibitions on the use of contraceptives by married couples); and Eisenstadt v. Baird, 405 U.S. 438 (1972) (striking down statutory prohibitions on the use of contraceptives by unmarried couples).

2. Secrecy

A constitutional right to information privacy is slowly being developed in both Canada and the United States. The Supreme Court of Canada has recognized the importance of protecting the privacy of personal information in third-party records, such as medical or psychotherapy records, against their compelled production during legal proceedings. The Court has also mentioned that it intends to safeguard a "biographical core of personal information" by granting to the individual control over the dissemination of this information at the point of disclosure. Medical information, including genetic data, would certainly be counted within the biographical core. The right to information privacy, for instance, prohibits the state from appropriating serum or tissue samples that are stored at medical facilities—and that were collected from individuals for medical purposes—in order to extract genetic or other health data from them.

Since the constitutional right to information privacy has typically been considered in cases dealing with criminal proceedings, the extent to which this right restricts the government from gathering personal information regarding its citizens in other instances, such as for public health reasons, is not yet clear. In the United States, the constitutional right to privacy does not prevent the collection, storage, and dissemination of health information in government data banks so long as the state has implemented adequate

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78 See O'Connor, supra note 71 at 434, per Justice Sopinka: "a constitutional right to privacy extends to information contained in many forms of third party records." See also, ibid. at 437, per Justice L'Heureux-Dubé: "s. 7 requires a reasonable system of 'pre-authorization' to justify court-sanctioned intrusions into the private records of witnesses in legal proceedings." See also, R. v. Ozolin, [1993] 4 S.C.R. 595.

79 See R. v. Plant, [1993] 3 S.C.R. 281 at 293:

[The Charter should seek to protect a biographical core of personal information which individuals in a free and democratic society would wish to maintain and control from dissemination to the state. This would include information which tends to reveal intimate details of the lifestyle and personal choices of the individual.

80 See Duarte, supra note 66 at 46, per Justice La Forest, where the right to information privacy is defined as "the right of the individual to determine for himself when, how, and to what extent he will release personal information about himself." See also O'Connor, supra note 71 at 456-87, per Justice L'Heureux-Dubé: "The essence of privacy, however, is that once invaded, it can seldom be regained. For this reason, it is all the more important for reasonable expectations of privacy to be protected at the point of disclosure."

standards and procedures for protecting the privacy of the information. Provided that the state articulates a legitimate societal purpose and employs reasonable security measures, American courts have not interfered with the traditional governmental activities of information collection. Nevertheless, when the government is acting in the capacity of an employer and has in its possession the tissues and cells of current and prospective employees, the right to privacy will protect against the genetic testing of these tissues and cells by the government for purposes going beyond those which were originally consented to.

The protection afforded by any decision-making or information privacy rights within the Canadian and American constitutions apply only to transgressions perpetrated by the state, and do not apply to private sector relationships, such as those existing between individuals and medical professionals, employers, and insurers. As a result, constitutional law is at best an incomplete instrument for disciplining the collection practices of a health system which, particularly in the United States, is largely privately run.

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82 See Whalen, supra note 29 at 605, per Justice Stevens, where the court acknowledged "the threat to privacy implicit in the accumulation of vast amounts of personal information in computerized data banks or other massive government files," but nevertheless held that the supervision of public health and other important government activities "require the orderly preservation of great quantities of information, much of which is personal in character and potentially embarrassing or harmful if disclosed."

83 See, for example, Nixon v. Administrator of General Services, 433 U.S. 425 (1977); United States v. Westinghouse Electric, 638 F.2d 570 (3d Cir. 1980); and Barry v. City of New York, 712 F.2d 1554 (2d Cir. 1983).

84 See Norman-Bloodsaw v. Lawrence Berkeley Laboratory, 135 F.3d 1260 (9th Cir. 1998) [hereinafter Norman-Bloodsaw]. In this case, a government employer made general health examinations a precondition to obtaining employment. Having collected blood and urine samples from job applicants, the employer then proceeded to conduct unauthorized analyses of the samples for syphilis, the sickle cell trait, and pregnancy. The court upheld the right to decision-making privacy on the basis of the fourth amendment, but noted that the Due Process Clause of the Fifth or Fourteenth Amendments was also implicated: "the most basic violation possible involves the performance of unauthorized tests—that is, the non-consensual retrieval of previously unrevealed medical information that may be unknown even to plaintiffs. These tests may also be viewed as searches in violation of Fourth Amendment rights that require Fourth Amendment scrutiny." See ibid. at 1269. The court also differentiated between consent that is provided for a general medical examination and consent that is necessary for the performance of more intrusive medical analyses: "[t]hat one has consented to a general medical examination does not abolish one's privacy right not to be tested for intimate, personal matters involving one's health—nor does consenting to giving blood or urine samples, or filling out a questionnaire." See ibid. at 1270.

Finally, the question of confidentiality, or the right of individuals to impose on the state the obligation of keeping confidential the information it collects about them, has only been indirectly addressed, such as through the requirement that governments implement reasonable information security safeguards. Because governments are the foremost collectors of personal information, it is important that the confidentiality of the information that they collect is diligently preserved. A flow of personal information from government data banks to the private market, or to any unauthorized user, would greatly undermine the legitimacy of the state as an accumulator of information, thereby impairing the valid purposes for which the data was originally collected.

C. Federal Legislation

Both the United States and Canada have passed general privacy laws that govern the collection, use, and disclosure of personal information by federal institutions. Unfortunately, they apply only to the actions of the federal government. Recently, however, the need for legislation that protects the right to privacy has been acknowledged and governments in both jurisdictions have started to take action. The Canadian Parliament recently enacted the Personal Information Protection and Electronic Documents Act (PIPEDA), which governs the collection, use, and disclosure of personal information by private organizations. Despite numerous attempts, the United States Congress has not yet succeeded in enacting private sector health information privacy laws. Yet a certain degree of

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87 Personal Information Protection and Electronic Documents Act, S.C. 2000, c. 5 [hereinafter PIPEDA].
89 Nevertheless, the Department of Health and Human Services (HHS) very recently enacted privacy regulations to safeguard the privacy of individually identifiable health information. See 45 CFR § 160-164, online: WL (CFR). These regulations most likely apply to genetic information. See the definition of “health information” at 45 C.F.R. § 160.103, online: WL (CFR). These entities covered by the regulations—that is, health plans, health care clearinghouses, and health care providers who
private sector privacy protection is nevertheless available through statutes such as the *Americans With Disabilities Act* (ADA),90 the *Civil Rights Act of 1964*,91 and the *Health Insurance Portability and Accountability Act* (HIPAA).92

1. Personal Information Protection and Electronic Documents Act

The PIPEDA was expressly designed to govern the collection, use, and dissemination of personal information, including health data, by federally regulated organizations.93 The application of the Act with respect to “personal health information,” which would encompass genetic information,94 does not come into force until January 2002.95 The Act also provides for a lag period of three years, after which time it purports to apply to provincially regulated industries.96 The privacy protections that are imparted by the PIPEDA are substantively similar to those that are made available by the general law of Quebec.97 Like the general law of Quebec, the PIPEDA makes use of an objective test by restricting the purposes for which personal information may be collected to those that a “reasonable person” would consider “appropriate” under the circumstances.98 This is another way of saying that organizations must have a “serious” and “legitimate” reason for gathering each piece of information that they request. The PIPEDA also provides that the gathering purposes must be identified by the organization “at or before the time the information is transmitted in electronic form, see *Code of Federal Regulations*, Public Welfare, Definitions, 45 C.F.R. § 160.102, online: WL (CFR)—are required to be in compliance with the regulations by 14 April 2003. See 45 C.F.R. § 164.534, online: WL (CFR).


93 See PIPEDA, *supra* note 87, ss. 3, 4.

94 *Ibid.*, s. 2 (defining personal health information as including “information derived from the testing or examination of a body part or bodily substance of the individual”).

95 *Ibid.*, ss. 30(1.1), 30(2.1).

96 *Ibid.*, ss. 30 (1), 30(2).

97 See *supra* notes 94, 95, and accompanying text.

98 See PIPEDA, *supra* note 87, ss. 3, 5(3).
collected,"99 and that the gathering must be limited "to that which is necessary for the purposes identified by the organization."103

The PIPEDA also protects privacy by requiring that organizations obtain the informed consent of individuals prior to the collection and subsequent disclosure of personal information.101 For the consent to be informed, organizations must disclose to individuals the intended purposes for which the information is to be used or disclosed.102 Unlike the common and equitable laws discussed above, the PIPEDA does not provide for a private right of action following an alleged breach of its provisions. Instead, individuals who feel that their rights under the Act have been violated must file a complaint with the Privacy Commissioner who will investigate the matter.103 Although the PIPEDA is a step in the right direction, it inadequately protects information privacy and fails to address the issue of decisionmaking privacy.

2. The Americans With Disabilities Act

While the ADA was not designed to regulate the collection of personal information by private organizations, it can nevertheless be used to guard against the adverse consequences that may be associated with such collection, namely discrimination. Title VII of the ADA prevents discrimination on the basis of certain enumerated grounds including race, religion, nationality, colour, and sex.104 This title could be invoked in cases where an individual possesses a genetic predisposition to an illness that is exclusively or disproportionately found in people of a certain race, religion, or other enumerated category.105 Title I of the ADA prevents discrimination

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99 See Schedule 1 of PIPEDA, ibid., s. 4.2.
100 Ibid., s. 4.4.
101 Ibid., s. 4.3.1.
102 Ibid., ss. 4.2.5., 4.3.2.
103 See PIPEDA, supra note 87, s. 11.
104 See ADA, supra note 90, § 2000e-2(a).
105 For instance, differential treatment following selective testing of African Americans for the sickle cell anemia trait, or of Ashkenazi Jews for the Tay-Sachs trait, would constitute discrimination under Title VII of the ADA. This fact scenario occurred in Nemer-Bloch v. Law, supra note 84, where the employer selectively tested its African-American applicants for the sickle cell trait and its women applicants for pregnancy. While this practice was held to violate the Title VII of the Civil Rights Act of 1964, the court did not specifically address whether it might also constitute a violation of Title VII of the ADA. All claims based on the ADA were dismissed by the Ninth Circuit on the grounds that the employer had not taken any job-related action against the plaintiffs on the basis of the testing and that
Most relevant to the issue of genetic discrimination is the fact that employers are prohibited under Title I from discriminating on the basis of information acquired through "medical examinations and inquiries." While this term is not expressly defined in the ADA, commentators have agreed that it encompasses genetic testing and inquiries.

A claimant alleging genetic discrimination would have the burden of proving that he or she has a disability, was otherwise qualified for the employment or benefit, and was excluded from the employment or benefit on the basis of disability. The difficulty in proving causation—namely, that the lost employment opportunity was based on an illegitimate considerations, such as an immaterial disability, rather than on merit, experience, or some other valid factor—is a major impediment to the vindication of legal rights. Since the second element is a question of fact to be decided on a case-by-case basis, the crucial question of law that needs to be decided is in relation to the first element of the test—namely, whether genetic predispositions to future illnesses can be considered to be disabilities under the ADA. The ADA provides three different means of proving disability: (1) existence of a physical or mental impairment that substantially limits one or more major life activity; (2) existence of a record of physical or mental impairment; and, (3) being regarded as having a physical or mental impairment. Of these three definitions, a genetic predisposition is most likely to be accepted as a disability according to the

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106 See ADA, supra note 90 at § 12112(a).
107 Ibid., § 12112(d)(1).
108 See, for example, M.B. Kaufmann, "Genetic Discrimination in the Workplace: An Overview of Existing Protections" (1999) 30 Loy. U. Chi. L.J. 393 at 405 [hereinafter "Genetic Discrimination"] ("while there is no precise meaning of a medical test it cannot seriously be argued that a genetic test is not a medical test under the ADA.").
109 See ADA, supra note 90 at § 12112(a).
110 Ibid., § 12102(2).
language in the third test. The “being regarded as having a disability” test would require the claimant to show that the denial of employment, promotion, or any other benefit was based on the employer’s perception that the claimant’s genetic predisposition constituted an impairment. The Equal Employment Opportunity Commission has opined that discrimination on the basis of a genetic predisposition falls within the ambit of the “being regarded as having a disability” test. Moreover, inasmuch as individuals with asymptomatic HIV have been found to be deserving of protection under the ADA, then it is conceivable that asymptomatic individuals who are predisposed to genetic illnesses are also deserving of protection.

We agree with the commentators who are concerned that the ADA is insufficiently protective against genetic discrimination. First, the ADA only covers employers with fifteen or more employees. Second, the ADA does not expressly stipulate that genetic predispositions are covered by the Act. Third, while the ADA prohibits employers from requiring that individuals undergo genetic testing during the “pre-offer” stage, it does

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111 What is most limiting with the first and second definitions of disability is that while a genetic predisposition may substantially limit a major life function in the future, they do not do so in the present. Nor is there, by definition, a current record of symptomatic impairment. Of course, as with any other symptomatic disease, these definitions would be available to individuals whose genetic predispositions has already become phenotypic.

112 See “Genetic Discrimination,” supra note 103 at 413:

Unlike the other disability categories, this section is based on the employer’s perceptions, not the existence of a true disability or even the individual’s own perception of himself or herself as disabled. Individuals with asymptomatic genetic disorders, therefore, would most likely be covered by this section because employers would be discriminating based on the presence of a genetic anomaly, not on the employee’s inability to perform.

113 See Equal Employment Opportunity Commission, EEOC Compliance Manual § 902.8(a) (1995), online: WL (EEOCCM), stating that the ADA:

applies to individuals who are subjected to discrimination on the basis of genetic information relating to illness, disease, or other disorders. Covered entities that discriminate against individuals on the basis of such genetic information are regarding the individuals as having impairments that substantially limit a major life activity. These individuals, therefore, are covered by the third part of the definition of “disability”.


115 See ADA, supra note 90 at § 12111(5)(A).

116 Ibid., § 12112(d)(2)(A).
not prohibit employers from requiring individuals to undergo genetic testing following a conditional offer of employment, whether or not the test is job-related or consistent with business necessity.117

3. The Health Insurance Portability and Accountability Act

Like the ADA, the HIPAA is more concerned with inappropriate uses of personal information than with the initial collection of such information. The HIPAA prohibits "group health insurers" from basing initial or continued insurance eligibility on health status-related factors, including genetic information.118 Moreover, while the Act does permit group health insurers from limiting or excluding benefits in the case of "preexisting conditions,"119 it explicitly prohibits these insurers from treating genetic predispositions as preexisting conditions in the absence of accompanying illness.120 Taken together, these provisions prevent group health insurers from denying, cancelling, or refusing to renew health insurance on the basis of unexpressed genetic predispositions. Consequently, individuals are meant to be able to change jobs without the fear that their health insurance coverage will be terminated in the process.121

Unfortunately, the HIPAA does not offer comprehensive protection. First, the HIPAA does not explicitly prohibit genetic discrimination outside the group health insurance context. Consequently, it does not provide protection to those who are self-employed or to those whose jobs do not provide health benefits. Second, because the HIPAA is concerned with discrimination, which is an adverse consequence of information collection, rather than with the regulation of the collection itself, proof of causation

117  Ibid., § 12112(d)(3).
118  See HIPAA, supra note 92 at § 300gg-1(a)(1)(F). Genetic information is defined under HIPAA as information "about genes, gene products or inherited characteristics that may derive from an individual or a family member. This includes information regarding carrier status and information derived from laboratory tests that identify mutations in specific genes or chromosomes, physical medical examinations, family histories, and direct analysis of genes or chromosomes." See Rules and Regulations for Group Health Plan Requirements, 29 C.F.R. 2590.701-2.
119  See HIPAA, ibid., § 42 U.S.C.A § 300gg(b)(1)(A) (defining the term "preexisting condition exclusion" as "a limitation or exclusion of benefits relating to a condition based on the fact that the condition was present before the date of enrollment for such coverage, whether or not any medical advice, diagnosis, care, or treatment was recommended or received before such date.").
120  Ibid., § 300gg(b)(1)(B).
is once again a significant hindrance to the vindication of rights. Both the HIPAA and the ADA would have offered far greater protection had they simply prevented insurers and employers from collecting irrelevant health information in the first place. Finally, since the HIPAA applies solely to the insurance industry, it does not provide protection against employment discrimination beyond that which is afforded by the ADA.

D. State/Provincial Legislation

1. Canada

Although most, if not all, Canadian provinces have enacted legislation to safeguard the privacy of personal information held by public bodies,\footnote{See, for example, Freedom of Information and Protection of Privacy Act, R.S.O. 1990, c. F.31; Freedom of Information and Protection of Privacy Act, R.S.B.C. 1996, c. 165; Freedom of Information and Protection of Privacy Act, S.A. 1994, c. F-18.5; and An Act Respecting Access to Documents Held By Public Bodies and the Protection of Personal Information, R.S.Q. 1993, c. A-2.1.} the actual protection afforded by these statutes is circumscribed by a number of factors. Many of the statutes are ineffective because their application is restricted to the public sector, the prohibitions are subjected to a wide array of exceptions, and the language is overtly general or makes no specific reference to genetic health information.

At least two Canadian provinces, Quebec and Manitoba, have nevertheless enacted legislation that is designed to govern the collection of personal information in the private sector,\footnote{See An Act Respecting the Protection of Personal Information in the Private Sector, R.S.Q. 1993, c. P-39.1 [hereinafter Personal Information in the Private Sector]; and Personal Health Information Act, S.M. 1997, c. 51 [hereinafter Health Information Act].} and similar legislation has been proposed in other provinces.\footnote{See, for example, G. Sharpe, “Regulating Health Information: The Ontario Approach” (2000) 20 Health L. Can.69.} The Quebec legislation provides specific rules with respect to the collection, use, and dissemination of personal information and is meant to complement the right to privacy that is made available by the general law of Quebec.\footnote{Ibid., ss. 4, 5, 9.} Two advantages of this legislation over the general law are that the legislation expressly makes it unlawful for employers to refuse to hire applicants who refuse to disclose irrelevant personal information,\footnote{Personal Information in the Private Sector, supra note 123, s. 1.} and that the legislation associates the breach of its provisions with elevated penalties and therefore has significant


\footnote{123 See An Act Respecting the Protection of Personal Information in the Private Sector, R.S.Q. 1993, c. P-39.1 [hereinafter Personal Information in the Private Sector]; and Personal Health Information Act, S.M. 1997, c. 51 [hereinafter Health Information Act].}

\footnote{124 See, for example, G. Sharpe, “Regulating Health Information: The Ontario Approach” (2000) 20 Health L. Can.69.}

\footnote{125 Personal Information in the Private Sector, supra note 123, s. 1.}

\footnote{126 Ibid., ss. 4, 5, 9.}
The Quebec legislation is nevertheless beset by the same shortcomings as those that we discussed above in relation to the general law of Quebec.\(^2\) The Manitoba legislation operates in much the same way as both the PIPEDA and the general and statutory laws of Quebec. It prohibits the collection of personal information about an individual unless the information is collected for a “lawful” purpose.\(^2\) This is presumably similar to saying that the collection of personal information will be authorized only for “appropriate,” “legitimate,” and “serious” purposes. Moreover, similarly to the laws of Quebec and the PIPEDA, the Manitoba legislation limits the collection of information to that which is “reasonably necessary” to accomplishing the lawful objective.\(^3\) An advantage of the Manitoba legislation is that it was expressly designed to regulate the collection, use, and disclosure of personal health information, including genetic information.\(^3\) A significant disadvantage, however, is that instead of attaching protection to the health information itself, the provisions of the legislation apply only to “trustees,” a term which has been narrowly defined as encompassing health professionals, health facilities, public bodies, and health service agencies that collect or maintain personal health information.\(^3\) The Manitoba legislation would therefore not restrict the collection of personal health information by employers and insurers.

2. The United States

Many American states have enacted laws that explicitly prohibit employment and insurance discrimination on the basis of genetic predispositions. While these laws were enacted to compensate for the arguably weak measures that are made available by federal legislation, they are nevertheless subject to the critique of genetic exceptionalism discussed above, since they apply specifically to genetic information rather than to

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\(^{127}\) *Ibid.*, s. 91 (while the penalty associated with a first offence ranges between $1000 and $10,000, the penalty associated with a second offence ranges between $10,000 and $20,000).

\(^{128}\) See discussion in Part V.A, *Common and Equitable Laws*, infra.

\(^{129}\) *Health Information Act, supra* note 123, s.13(1).

\(^{130}\) *Ibid.*, s. 13(2).

\(^{131}\) *Ibid.*, s. 1(1) (defining “personal health information” as including “recorded information about an identifiable individual that relates to the individual’s health, or health care history, including genetic information about the individual”).

health information generally. In many instances, the actual scope of the privacy protection granted in any given state depends largely on how broadly that state has defined 'genetic information.' For instance, while some states have defined genetic information as encompassing information which may be derived from chromosomal, DNA, or RNA analysis, other states have adopted a broader definition that would include information that can be gathered through routine laboratory tests indicating the presence or absence of gene products as well as family history data.

A further constraint on state law protections against health insurance discrimination is the Employee Retirement Income Security Act (ERISA). The ERISA pre-empts state laws that attempt to regulate self-insured employee health plans. Thus, employees deriving their health insurance from self-insured employers—employers that finance their own health plans—would not be covered by prohibitions of insurance discrimination based on genetic predispositions. Various permutations of state legislation are currently available. These are not mutually exclusive and, in any given state, one or more of the forms of legislation may be available. Three main types of laws will be noted: (1) legislation prohibiting discrimination in relation to particular genetic traits; (2) legislation prohibiting discrimination on the basis of the results of genetic testing; and (3) legislation prohibiting discrimination in relation to genetic information.

Beginning with laws prohibiting discrimination in relation to particular genetic traits, the first state to take legislative action against genetic discrimination was North Carolina, which in 1975 prohibited employers from discriminating on the basis of the sickle cell or hemoglobin C anemia traits. Other jurisdictions soon followed by enacting their own trait-specific legislation. New York law, for instance, expressly prohibits employers from discriminating on the basis of the sickle cell, Tay-Sachs, or Cooley's anemia traits. Similarly, New Jersey law prohibits employment discrimination on the basis of the sickle cell, hemoglobin C, thalassemia, Tay-Sachs, or cystic fibrosis traits. Trait-specific laws offer highly circumscribed legal protection. Although they outlaw discriminatory

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134 Ibid., § 1144 (1994).
135 "Genetic Information and the Workplace," supra note 20 at 1755.
136 New York Civil Rights Law, § 4A, online: WL (NY CIV RTS). Differential treatment on the basis of these traits is only permissible where it "can be clearly shown that a person's unique genetic disorder would prevent such person from performing the particular job." Ibid., § 43-a.
137 New Jersey Civil Rights Law, § 10:5-5(c), 10:5-12, online: WL (NJST) [hereinafter New Jersey].
practices in relation to certain specified genetic traits, they are usually silent with respect to the collection side of the equation, and could not therefore be used to prevent employers from collecting the trait-specific information in the first place. Even worse, these laws offer no protection whatsoever, whether at the collection or the use stage, when it comes to genetic traits that are not expressly identified in the legislation.

The second category of laws prohibits discrimination on the basis of information that is obtained from genetic testing. Texas law, for instance, prohibits employers from discharging or refusing to hire an individual on the procedural ground that the individual refuses to submit to genetic testing.138 What is more, substantive discrimination is prohibited in circumstances where the individual decides to acquiesce to his or her employer’s request for the disclosure of genetic information.139 The term genetic information is defined by the Texas Labor Code as information derived from the results of a genetic test,140 which is in turn defined as “a laboratory test of an individual's DNA, RNA, proteins, or chromosomes to identify by analysis of the DNA, RNA, proteins, or chromosomes the genetic mutations or alterations in the DNA, RNA, proteins, or chromosomes that are associated with a predisposition for a clinically recognized disease or disorder.”141 This definition would not encompass other predictive information such as family history data. In addition to the anti-discrimination provisions, the legislation protects the confidentiality of the collected information by imposing on employers the obligation of obtaining informed and written consent of individuals prior to disclosing their personal information.142 While this source-specific legislation is more inclusive than trait-specific legislation, it would not prohibit employers from discriminating on the basis of genetic information obtained from sources other than such testing.143 Moreover, although the legislation protects the confidentiality of genetic information that has been collected by employers and prohibits illegitimate uses of such information by them, it does not address the primary issue of whether such collection is justified in the first place.

138 § 21.402(a)(2), online: WL (TX LABOR).
139 Ibid., § 21.402(a)(1).
140 Ibid., § 21.401(2).
141 Ibid., § 21.401(3).
142 Ibid., § 21.403(a)(b).
143 "Genetic Information and the Workplace," supra note 20.
The final category of state legislation prohibits discrimination in relation to genetic information. New Jersey law, for example, makes it unlawful for employers to refuse to hire, to require to retire, or to discharge an individual on the basis of the individual's genetic information—which information cannot be obtained without the individual's prior informed consent—or on the basis of the individual's refusal to submit to genetic testing. Employers are additionally prohibited from discriminating on the basis of an individual's genetic information in the compensation, terms, privileges, and conditions of employment. As in the case of the HIPAA, genetic information is broadly defined in the legislation as information "about genes, gene products or inherited characteristics that may derive from an individual or family member." Thus, unlike the source-specific laws that focus on genetic testing alone, the New Jersey legislation could arguably be interpreted as preventing discrimination on the basis of family history data and other predictive information. New York law also prohibits employment discrimination on the basis of genetic information regardless of the source from which that information was derived. Like the source-specific laws, however, this final category of legislation, the most comprehensive genetic discrimination legislation that is available in the United States, is silent with respect to the initial collection of such information by employers and insurers.

An individual who is discharged or not hired after having disclosed irrelevant health information pursuant to an employer's mandatory or discretionary disclosure policy could elect to sue the employer on the ground of discrimination. Causation requirements would nevertheless be an impediment to recovery since the individual would need to show that the lost employment opportunity was based on an illegitimate consideration such as genetic discrimination, rather than on merit, experience, or some other valid cause. Similarly, an individual who is discharged or not hired after having refused to disclose irrelevant health information would have the burden of proving that it was the refusal to disclose, rather than a relevant factor, that caused the lost employment opportunity.

144 New Jersey, supra note 137, § 10:5-45.
145 Ibid., § 10:5-12.
146 Ibid., § 10:5-12.
147 Ibid., § 10:5-5(a).
VII. CONCLUSION

We cannot and should not attempt to stop the rapidly expanding use of genetic and other health information to benefit the health of our society. However, a democratic and just society ought to minimize the extent to which scientific advancement infringes upon the right to privacy and permits discrimination against individuals by employers, insurance companies, or others who may profit from the violation of those rights.

In light of the significant shortcomings of the existing common law, statutory, and constitutional protections in the United States and Canada, we propose the enactment of comprehensive privacy legislation that adequately addresses each of the three pillars of the modern conception of privacy rights: choice, secrecy, and confidentiality. Swift action is imperative because the largest gap in privacy coverage relates not to re-disclosure of our genetic and health information years down the road, but rather to collection of that information today. Moreover, unless the public perceives that the privacy of genetic and health information are adequately protected, the disincentive for patients to be completely forthcoming with physicians could result in bad medical decisions.\(^\text{149}\) For these reasons, safeguarding the right to privacy as it relates to genetic and health information is a justifiable normative objective.

\(^{149}\) Individuals who believe that they can trust their health care professional to maintain the confidentiality of the information that is imparted in the context of the doctor-patient relationship are more likely to submit to medical tests, divulge sensitive information, or seek treatment. See, for instance, R. Bayer & K. E. Toomey, "HIV Prevention and the Two Faces of Partner Notification" (1992) 82 Am. J. Pub. Health 1158. Conversely, individuals who doubt the confidence of the doctor-patient relationship may avoid medical tests, fail to disclose pertinent medical information or simply avoid medical care altogether. For instance, the CMA explicitly recognizes the adverse health consequences that can result from a lack of trust on the part of patients in relation to health care providers. See CMA, supra note 28 (section 2.2(d) states "were it not for the reputation of health professionals for trustworthiness and the expectation that information disclosed to them will be held in confidence, patients would be less willing to confide health information fully and truthfully in the therapeutic context"); and section 2.2(e) states "to the extent that provisions for health information inhibit patients from confiding health information fully and truthfully, their care will be adversely affected"). See also J. Dawson, "Compelled Production of Medical Records" (1998) 43 McGill L.J. 25 at 47, which notes the difficulties associated with judicially mandated disclosures of health information:

Therapy may be abandoned if confidential material is released, adversely affecting the patient’s health. Clinicians who are aware of the possibilities of forced disclosure may feel obliged to warn patients at the outset, compromising communication between them. Note-taking may be affected, even to the extent that a therapist refuses to keep official records. If a professional is subpoenaed to testify, the expert may be forced to choose between the health needs of the patient and imprisonment for contempt.