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Looking Beyond GINA: Policy Approaches to Address Genetic Discrimination

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Abstract

Concerns about genetic discrimination (GD) often surface when discussing research and innovation in genetics. Over recent decades, countries around the world have attempted to address GD using various policy measures. In this article, we survey these approaches and provide a critical commentary on their advantages and disadvantages. Our examination begins with regions featuring extensive policy-making activities (North America and Europe), followed by regions with moderate policy-making activities (Australia, Asia, and South America) and regions with minimal policy-making activities (the Middle East and Africa). Our analysis then turns to emerging issues regarding genetic testing and GD, including the expansion of multiomics sciences and direct-to-consumer genetic tests outside the health context. We additionally survey the shortcomings of current normative approaches addressing GD. Finally, we conclude by highlighting the evolving nature of GD and the need for more innovative policy-making in this area.

1. INTRODUCTION

The topic of genetic discrimination (GD) has become unavoidable when discussing research and innovation in genetics (3) because it creates significant concerns for many patients who are considering taking part in genetic research or obtaining genetic services. Although awareness of GD has increased in recent years, the issue is not new. The first reported contemporary cases of GD were discussed decades ago among scholars such as Reilly (61) and Kenen & Schmidt (40), whose work concerned discrimination in life insurance and employment against carriers of sickle-cell trait. Progress in human genetics in the 1980s and 1990s, such as the identification of several rare single-gene disorders, was accompanied by more pronounced concerns about the discriminatory uses of genetic information among scholars and vulnerable populations (8). These concerns, shared across western Europe and North America, eventually led to the inclusion of articles prohibiting GD in two foundational human rights texts in 1997: the European Convention on Human Rights and Biomedicine (12) and the United Nations Educational, Scientific, and Cultural Organization (UNESCO) Universal Declaration on the Human Genome and Human Rights (72).

The turn of the twenty-first century brought the completion of the Human Genome Project, which represented a major achievement in genomics. Nevertheless, public anxiety regarding the inappropriate collection, storage, and use of genetic information, fostered by a few highly mediatized cases of GD, accompanied this scientific landmark (45). Numerous international organizations, including UNESCO (73), the Human Genome Organisation (29), and the United Nations Economic and Social Council (18), have since adopted recommendations addressing GD, but these are solely elective in nature. Progress in genetics has since impacted activities beyond biomedicine, such as law enforcement, education, commercial transactions, and immigration (21, 25, 47, 57). Additionally, private companies providing DNA testing and ancestry services directly to consumers have emerged worldwide as informational and recreational services (59, 60). These companies, along with large-scale research consortia, contributed to pushing genomic research and the flows of genetic data beyond national boundaries (56). Thus, while GD has been investigated mainly in insurance (34, 36) and employment (27, 64), it may occur in a variety of other contexts.

In this article, we outline public policy approaches from across the globe that are used to prevent and redress GD. We classify existing approaches in terms of (*a*) countries that have adopted broad human rights–based statutory proscriptions of GD, (*b*) countries that have adopted specific legal prohibitions to prevent GD in particular domains, (*c*) countries that have adopted a moratorium with government oversight to prevent GD in specific domains, and (*d*) countries that rely on existing traditional legal protection to prevent GD, such as privacy law, the right to equality (equal treatment)/nondiscrimination, insurance law, and disability law. The typology of policy approaches to prevent GD presented in this article is based on a live world map published by the Genetic Discrimination Observatory (24), an international network of researchers dedicated to providing information and tools to address GD.

Our examination begins with regions featuring extensive policy-making activities regarding GD (North America and Europe), followed by regions with moderate policy-making activities (Australia, Asia, and South America) and regions with minimal policy-making activities (the Middle East and Africa). Throughout this article, we highlight novel methods of addressing GD as well as some benefits and pitfalls of certain approaches. Our analysis then turns to emerging issues regarding genetic testing and GD, which include genomics and the use of next-generation sequencing technologies, the expansion of multiomics sciences and direct-to-consumer genetic tests outside the health context, and the shortcomings of current normative approaches addressing GD. Finally, we conclude our discussion by highlighting the evolving nature of GD, which is important because genetics and related sciences and technologies are developing at a fast pace. Therefore, to successfully and effectively address GD, preventive approaches—both normative

and other types—will need to account for these developments by featuring more flexible policies. Importantly, throughout this article, our use of the term GD includes both traditional genetic and newer genomic technologies and approaches unless otherwise noted.

2. KEY CONCEPTS

Discrimination has been defined differently in diverse contexts, which partially explains the different perceptions, expectations, and thresholds concerning GD. Most individuals understand discrimination to be "unjust or prejudicial treatment of different categories of people or things," as defined in the *Oxford English Dictionary* (**https://www.lexico.com/en/definition/discrimination**). In law, however, only discrimination on the basis of explicitly proscribed grounds (such as race, religion, sex, national origin, age, sexual orientation, disability, or genetic characteristics) is considered illicit. These illicit grounds reflect the cultural unacceptability of types of discrimination that do not meet a given society's core values (such as autonomy, beneficence, solidarity, justice, and economic efficiency). A third definition of discrimination emerges from the field of commercial insurance, where discrimination simply means differentiating among various groups of individuals, which is acceptable provided it is legal and has a "rational" scientific or actuarial basis.

Each of these three concepts of discrimination—basic, legal, and actuarial—provides a different framework of analysis that may lead to different conclusions as to what constitutes discrimination and whether it is acceptable. The many meanings of GD have fueled misunderstandings among stakeholders, leading to the polarization of the GD debate (67).

The seemingly unique ethical, legal, and social issues associated with genetics have led some scholars to favor responses to GD grounded in genetic exceptionalism, which asserts that genetic information is unique and deserves special consideration (26). However, other scholars and policymakers insist that genetic information is, in fact, not "uniquely powerful and uniquely personal" and that "we are not obliged to accord it special status or unique privacy protection" (51, p. 14). According to this viewpoint, laws based on genetic exceptionalism may, paradoxically, reinforce stigmas associated with genetic disorders by ignoring the underlying social issues leading to GD (63).

Furthermore, laws often provide restrictive definitions of what constitutes genetics, such as unexpressed genotype, thus further limiting what constitutes illicit discrimination to specific types of genetic information or test results. A novel question regards whether the scope and applicability of current genetic regulations also apply to more recently developed genomic tests. Broadly formulated provisions against discrimination based on genetic characteristics, such as those found in France [Code de la santé publique (1953), Code pénal (1992), and Code civil (1999)], would probably also encompass genomic discrimination (e.g., based on whole-genome sequencing). Some regulations, such as those in Canada [Genetic Non-Discrimination Act, Fed. Bill S-201 (2017)], Germany [Bundesrat Gesetz uber genetische Untersuchnugen bei Menschen (Gendiagnostikgesetz – GenDG) (2009)], and the United States [Genetic Information Nondiscrimination Act, 42 U.S.C. § 2000ff (2008)], explicitly proscribe discrimination based on the DNA composition of an individual's genome. For this reason, these laws should be interpreted as providing protection against discrimination based on both genetic variation at particular loci as well as variation detectable by genomic sequencing. The UK Code on Genetic Testing and Insurance, an example of a more flexible policy, takes the explicit position that "under this Code, a genetic test refers to a test which looks for a particular gene variant. This is regardless of whether the test was carried out as part of a single-gene test, a panel, or up to the level of whole genome sequencing" (4, p. 10). DNA-based definitions of legal protections, however, are unlikely to apply to epigenetics or other sources of variation (66).

Throughout our worldwide search for laws, policies, and other normative strategies to prevent GD, we encountered a substantial number of distinct approaches. While there is significant variability among these countries, four broad categories predominate:

1. Countries that have adopted a broad human rights–based statutory prohibition of GD (e.g., France).
2. Countries that have adopted specific legal prohibitions to prevent GD in particular domains (e.g., the United States). Such laws may prohibit requiring an individual to undergo genetic testing, prohibit access to already existing genetic information about an individual, or prohibit the use or processing of genetic information by a designated entity.
3. Countries that have adopted a moratorium with government oversight to prevent GD in specific domains (e.g., the United Kingdom and Australia).
4. Countries that rely on existing traditional legal protection to prevent GD, such as privacy law, current bases for nondiscrimination, insurance law, and disability law (e.g., Japan).

The analysis below is not intended to be comprehensive; rather, it distills some of the chief findings of our research. A more comprehensive list of existing GD laws and policies is available at the Genetic Discrimination Observatory website (24).

3. REGIONS FEATURING EXTENSIVE POLICY-MAKING ACTIVITIES

3.1. The United States

The first federal law offering substantial legal protection against GD was the Americans with Disabilities Act (ADA) of 1990 (42 U.S.C. §§ 12101–213). Although it is not explicitly geared toward preventing GD, those who currently have a physical or mental impairment that constitutes a substantial limitation of a major life activity, have a record of such an impairment, or are regarded as having such an impairment are covered by the ADA. Those who meet this definition are protected against discrimination in many areas of public life, including employment, government services, and public accommodations (2). In 1996, the US Congress enacted the Health Insurance Portability and Accountability Act (HIPAA) of 1996 (42 U.S.C. § 300gg), one provision of which prohibits the use of genetic information to establish a preexisting condition in the absence of a diagnosis in employer-sponsored group health plans. In 2008, the Genetic Information Nondiscrimination Act (GINA) (42 U.S.C. § 2000ff) was enacted, prohibiting discrimination based on "genetic information" in employment and health insurance. GINA defines genetic information as information about "(i) such individual's genetic tests, (ii) the genetic tests of family members of such individual, and (iii) the manifestation of a disease or disorder in family members of such individual" [42 U.S.C. § 2000ff(4)(A)]. Under GINA, a "genetic test" refers to "an analysis of human DNA, RNA, chromosomes, proteins, or metabolites that detects genotypes, mutations, or chromosomal changes" [42 U.S.C. § 2000ff(7)(A)], a definition drafted by the National Institutes of Health in the 1990s for proposed legislation that eventually became GINA. Although it was a major step forward, subsequent scientific developments illustrated gaps in coverage. For example, the definition's focus on "genotypes, mutations, or chromosomal changes" appears to exclude epigenetic information, which involves changes in gene expression and inherited genetic alterations without changes in the genome sequence (66). In addition, by covering only "human DNA," it would appear to exclude microbiomic data that analyze microorganisms found in humans.

Unlike the ADA, GINA does not prohibit discrimination against individuals already affected by a genetic condition. As such, a GINA violation would occur if an insurer refused to issue a health insurance policy to an asymptomatic individual with a genetically increased risk of cancer, but if

the individual subsequently became symptomatic, GINA would no longer apply. This seemingly illogical result reflects the political reality of 2008, when GINA was enacted: There was inadequate political support for requiring health insurance companies to accept applicants with preexisting health conditions. After the 2008 election, when control of both the presidency and Congress changed parties, it was politically feasible to enact the Patient Protection and Affordable Care Act (ACA) (42 U.S.C. § 18001–122), which prohibits discrimination in health insurance for any health-related reason, thereby extending protection to individuals with preexisting health conditions.

State insurance laws prohibiting GD based on certain genetic conditions in specific types of insurance (e.g., health insurance) date to the 1970s. The need for many of these laws was obviated by either GINA or the ACA, both of which provide more comprehensive protection in health insurance. Some laws, such as those addressing life insurance, provide additional protection beyond federal laws.

Therefore, although all states have at least one statute or regulation prohibiting some form of GD in one or more health insurance contexts, some of these laws are very limited in scope. For example, Mississippi prohibits GD in the context of Medicare supplement policies and certificates but not in other health insurance contexts [Miss. Code Ann. 19 R. Pt. 3, R. 10.24(A),(C),(G)]. Similarly, Pennsylvania prohibits GD in this context as well as in group health plans [31 Pa. Cons. Stat. § 89.791(c),(d)]. In addition to these limited laws, many states prohibit GD in the context of group health insurance through provisions that mirror stipulations found in HIPAA [Alaska Stat. § 21.54.100(a),(b); Ark. Code § 28-86-306(a); 40 Pa. Cons. Stat. § 1302.1–7; Wis. Stat. § 632.748(1)(a)(6)]. Many states also prohibit GD beyond group health insurance. These prohibitions are varied in terms of their scope, style and language, and reliance on federal law [Alaska Stat. § 21.36.480(a); Cal. Ins. Code § 10965.3(g)(1)(F); Fla. Stat. § 627.4301(2)(a),(b); Haw. Rev. Stat. § 431:10A-404.5(a)(1),(2); La. Rev. Stat. § 22:1964(23); 24-A Me. Rev. Stat. § 2159-C(2)(A); O.C.G.A. 33-54-4 (2010)].

More than 25% of states have at least one statute or regulation addressing GD in the context of disability insurance, although these laws vary in scope. For example, Colorado prohibits entities that provide group disability insurance from seeking, using, or keeping information from genetic tests for nontherapeutic or underwriting purposes [Colo. Rev. Stat. § 10-3-1104.7(2),(3)]. Idaho prohibits discrimination based on genetic test results or private genetic information in the issuance of coverage or in the determination of premium amounts for any disability insurance policy [Idaho Code § 41-1313(3)].

More than 20% of US states have at least one statute or regulation addressing one or more forms of GD in the context of life insurance, although such laws vary widely in terms of their scope, terminology, and definitions. Arizona, for example, prohibits insurers from refusing to consider an application for life insurance on the basis of a genetic condition, defined as a "specific chromosomal or single-gene genetic condition" [Ariz. Rev. Stat. § 20-448(D),(M)(5)], and specifies that the rejection of an application for life insurance or the determination of premium amounts on the basis of a genetic condition constitutes unfair discrimination [Ariz. Rev. Stat. § 20-448(E)]. California prohibits insurance companies from refusing to issue a life insurance policy and from charging higher premiums "solely by reason of the fact that the person to be insured carries a gene which may, under some circumstances, be associated with disability in that person's offspring, but which causes no adverse effects on the carrier" [Cal. Ins. Code § 10143(a)]. Some states that generally prohibit GD in the context of life insurance allow it if actuarially justified. For example, Arizona's prohibition applies "unless the applicant's medical condition and history and either claims experience or actuarial projections establish that substantial differences in claims are likely to result from the genetic condition, developmental delay or developmental disability" [Ariz. Rev. Stat. § 20-448(E)].

Approximately 10% of U.S. states have at least one statute or regulation that provides some form of protection against GD in the context of long-term care insurance, although these laws vary in terms of their prohibitions and underlying definitions. Colorado, for example, prohibits entities that provide long-term care insurance and that receive information from genetic testing from seeking, using, or keeping the information for any nontherapeutic or underwriting purpose [Colo. Rev. Stat. § 10-3-1104.7(2),(3)]. Additionally, Maine prohibits insurers from engaging in "unfair discrimination" against an individual using genetic information or the results of a genetic test in the issuance, withholding, extension, or renewal of an insurance policy for long-term care (24-A Me. Rev. Stat. § 2159-C).

More than two-thirds of states have laws prohibiting GD in employment, although these laws vary widely in terms of their scope and approach. For example, California recognizes the opportunity to seek, obtain, and hold employment without discrimination based on genetic information as a civil right [Cal. Ins. Code § 12921(a)]. Idaho prohibits employers, in connection with a hiring, promotion, or retention decision, from (*a*) accessing or otherwise taking into consideration private genetic information about an individual, (*b*) requesting or requiring an individual to consent to a release for the purpose of accessing private genetic information, (*c*) requesting or requiring an individual or blood relative to undergo a genetic test, and (*d*) inquiring into the fact that an individual or blood relative has taken or refused to take a genetic test [Idaho Code § 39–8303(1)]. Some states have enacted GD laws covering certain categories of workers. For example, a New York law prohibits discrimination based on "predisposing genetic characteristics" in the narrow context of hiring, retaining, and discharging interns, defined as persons who perform uncompensated work for an employer for training purposes [N.Y. Exec. L. § 296-C(2)]. Nevada similarly prohibits discrimination based on genetic information in the context of "apprenticeships," defined as future job and citizenship training [Nev. Rev. Stat. § 610.020(1)–(3)].

Only a handful of states have laws prohibiting GD in housing, lending, land use, and other contexts. California is the only state to prohibit GD in the context of housing, lending relating to housing, and land use practices [Cal. Gov. Code § 12955(a)–(d),(f), § 12955(e), § 12955(l); Cal. Ins. Code § 12921]. This would, for example, make it unlawful to refuse to rent or sell a condominium in a retirement community because an individual had a genetic predisposition to develop early-onset Alzheimer's disease.

In sum, the patchwork of state laws addressing GD in various contexts spans the domains of life insurance, long-term care insurance, disability insurance, health insurance, employment, and housing, to name a few. Unfortunately, there is a wide variation in coverage among states, and many of the laws lack adequate coverage, protections, or remedies.

There have been very few cases brought under any of these state laws, which parallels the very low volume of cases brought under GINA. This may be attributable to a lack of familiarity with the genetic nondiscrimination laws, the relatively little predictive genetic health information in most health records, or the lack of discriminatory treatment. Significantly, GINA and comparable state laws were enacted not to redress ongoing or expected GD, but rather to "allay [the public's] concerns about the potential for discrimination, thereby allowing individuals to take advantage of genetic testing, technologies, research, and new therapies" [122 Stat. 881 § 2(5)] (62).

3.2. Canada

Canada was relatively late in following the European and US trend of enacting anti-GD legislation. Policy-making initiatives failed to take root because incentives to legislate against GD were mitigated by Canada's universal health care system as well as the limited evidence documenting GD in the country (37). However, stakeholders' opinions and the political sentiment began to shift

following the adoption of GINA in the United States and advocacy from the Huntington Society of Canada (31). Finally, in 2017, the Genetic Non-Discrimination Act (GNDA) received royal assent after lengthy consultations and parliamentary debates, providing an approach that draws from GINA and European laws. The GNDA proscribes imposing genetic testing, or obtaining access to or requiring disclosure of, information obtained from genetic tests as it relates to the provision of goods and services (art. 7). Violating this prohibition constitutes a criminal offense and can result in fines of up to C$1 million (approximately US$750,000) and/or imprisonment of up to 12 months.

Importantly, however, the GNDA provides an exception for medical personnel and researchers and allows certain activities, such as use or disclosure of genetic test results, where written consent of the individual concerned is provided (art. 5 and 6). Furthermore, the GNDA amends the Canadian Human Rights Act [R.S.C. 1985, c. H-6, § 2–3(3)] and the Canadian Labor Code (R.S.C. 1985, c. L-2, div. XV 3) with specific mentions of genetic characteristics as a prohibited ground for discrimination. In December 2018, the province of Quebec challenged the law before the provincial Court of Appeal, questioning its constitutionality. The court unanimously concluded that the GNDA is indeed unconstitutional because the subject matter of the law is not under federal jurisdiction (58). The decision was subsequently appealed to the Supreme Court of Canada, where the fate of the GNDA will soon be decided.

Apart from the GNDA, the Canadian Life and Health Insurance Association, representing 99% of Canadian life and health insurers (11), adopted a voluntary Industry Code on Genetic Testing in 2015. Among other things, this code stipulated that insurers (*a*) cannot require predictive genetic test results from insureds and applicants when the life insurance coverage is under a specified ceiling amount (C$250,000, or approximately US$190,000) and (*b*) cannot require genetic test results when applicants underwent testing in the context of a medical research project and the results were not shared with them or their physician (10).

3.3. Mexico

Subscribing to the human rights approach to GD, Mexico amended its Federal Law to Prevent and Eliminate Discrimination (FLPED) as well as its General Healthcare Law to prohibit discrimination based on genetic characteristics [art. 1 (III)] (37). Although the FLPED is the only national GD legislation in the country, the Mexican state of Chihuahua features a regulation concerning the state-run genetic database, which underscores that "[u]nder no circumstances may the System constitute a basis or source of discrimination or stigmatization, violation of the dignity, privacy, or honor of any person" [Ley Reguladora de la Base de Datos Genéticos para el Estado de Chihuahua, Decreto 583/09 IV P.E. (2009), art. 3].

3.4. Europe

Regional human rights instruments, such as the Charter of Fundamental Rights of the European Union (2000) and the Convention on Human Rights and Biomedicine (1997), laid the groundwork for members of the European Union (EU) to develop national legislation regarding GD, most of which is inspired by the human rights approach (37). More recently, the Council of Europe adopted Recommendation CM/Rec(2016)8, which provides specific provisions on the use of genetic information by insurers. Specifically, principle 4 indicates that insurers "should not require genetic tests for insurance purposes" and that existing predictive genetic data may be processed for insurance purposes only where specifically authorized by law (13). Additionally, existing genetic data from family members of insureds may not be processed for insurance purposes (13).

Furthermore, the newly promulgated General Data Protection Regulation (GDPR) regulates uses of genetic data, thereby indirectly touching upon GD. The GDPR prohibits the processing of genetic data (as well as other types of data) in the absence of the explicit consent of the individual concerned (i.e., silence or inactivity does not constitute consent) or reasons relating to public interest, the public nature of the data, and so on [GDPR, (EU) 2016/679, art. 9]. Additionally, the conditions for free consent in the GDPR consider whether the performance of a contract or service is conditional on consent to the processing of personal data that is unnecessary for the performance of the contract [art. 7(4)]. As such, a compelled disclosure of genetic data in the context of insurance or employment, for example, would likely be unacceptable under this regulation.

Belgium was the first European country to specifically prohibit access by insurers to genetic information via its insurance law [Loi sur le contrat d'assurance terrestre (1992)] that targeted the insurance industry while excluding reinsurance and insurance covering merchandise transportation [art. 2(1)]. This law prohibited insurance companies from requiring insureds to disclose genetic information (art. 5). Among the G7 European countries, Germany [Bundesrat Gesetz uber genetische Untersuchnugen bei Menschen (Gendiagnostikgesetz – GenDG) (2009)], France [Code de la santé publique (1953), Code pénal (1992), and Code civil (1999)], and Italy [Decreto legislativo 30 giugno 2003, no. 196, Codice in materia di protezione dei dati personali (2003)] all have GD-specific laws. However, unlike Germany and France, Italy chose to address GD through its Personal Data Protection Code. Article 90(1) of this code mandates that the processing of genetic data is authorized only under circumstances designated by the Italian Data Protection Authority, an independent administrative authority, after consultation with the minister of health (General Authorisation 8/2014 for the Processing of Genetic Data). Additionally, genetic data processed for the purposes of prevention, for the diagnosis and/or treatment of the data subject, or for scientific research purposes may be used only "for the said purposes or in order to allow the data subject to make a free, informed decision, or else for the purpose of providing evidence in civil and/or criminal proceedings pursuant to the law" (General Authorisation 8/2014 for the Processing of Genetic Data). Per the 2018 updates to the Personal Data Protection Code, the Data Protection Authority should publish measures establishing when genetic data can be processed at least every two years. These measures consider the guidelines, recommendations, and best practices published by the European Data Protection Board as well as scientific and technological developments in the field relevant to the measures [Decreto legislativo 30 giugno 2003, no. 196, Codice in materia di protezione dei dati personali (2003)]. The Italian approach is innovative in that it introduces some administrative flexibility in the law, allowing for adjustments based on relevant developments in terms of GD and genetic technologies.

In 2001, the United Kingdom also instituted an alternative and forward-looking approach: preventing GD through a concordat and moratorium. (A moratorium is an agreement between a professional association and the government or is otherwise unilaterally organized by an association.) This method has been praised for being more flexible than legislative prohibitions and therefore better equipped to evolve with novel technologies and their associated risks (37). In October 2018, the UK government and the Association of British Insurers (ABI) agreed to replace the former concordat with the Code on Genetic Testing and Insurance, to which all members of the ABI are bound. Similar to the moratorium, the new code is a "code of practice" (4, p. 1). Importantly, the government and the ABI agreed that the code should remain open ended, so that it can be amended along with advancements in genetic testing and changes in the insurance market. Otherwise, the code does not fundamentally differ from the concordat in practice, given that it contains substantially similar modalities. For instance, both include a commitment of insurers to not require or pressure an applicant to undertake a predictive or diagnostic genetic test in order

to obtain insurance (4, p. 7). In the case of predictive tests, insurers agree not to require disclosure of results when a test was undertaken after insurance coverage began, when a blood relative underwent testing, or when a genetic test was performed in the context of scientific research (4, p. 7). However, the results of a designated predictive genetic test may be requested for policies that exceed the financial limits established in the code for specifically approved conditions; currently, the list of approved tests includes only a predictive test for Huntington's disease in cases of life insurance coverage totaling more than £500,000 per individual (4, p. 7). Importantly, the code, like the preceding concordat, considers a diagnostic genetic test to be equivalent to any other diagnostic medical test, such as a blood test, and an applicant may therefore be required to disclose such information when a test was taken prior to applying for insurance coverage (4).

The Netherlands' approach is a further example of dealing with GD using a method other than genetic exceptionalism. The Dutch Medical Examinations Act (Staatsblad 1997-08-21, no. 365, p. 1) regulates insurers' access to medical information concerning serious, untreatable disorders depending on the level of coverage being sought by the insured (life insurance below a ceiling amount set at approximately US$177,000 in 2012) (37). The act provides sweeping protection for medical information, including genetic test results for policies under this monetary sum. The degree of protection offered by the act against GD in the context of employment, if any, remains subject to debate (15).

Although the European continent has adopted a plethora of legal instruments to prevent and redress GD in insurance and employment, European laws generally provide broad powers for government collection and use of genetic information for law enforcement and immigration control (37). For example, numerous countries ratified the 2005 Prüm Convention on the Stepping Up of Cross-Border Cooperation, Particularly in Combating Terrorism, Cross-Border Crime and Illegal Migration, which permits the cross-border exchange and comparison of forensic DNA data between EU member states (20).

4. REGIONS WITH MODERATE POLICY-MAKING ACTIVITIES

4.1. Australia

Australia developed a sophisticated approach to address GD following substantial research initiatives on the topic (55). The Australian Parliament enacted legislation prohibiting discrimination based on a "genetic predisposition to a disability" in the Disability Discrimination Act 1992 (DDA) (no. 135, § 4). Importantly, the DDA exempts insurance companies from this rule where the discrimination is based on reliable actuarial or statistical data and the discrimination is "reasonable having regard to the matter of the data and other relevant factors" [§ 46(1)(f)]. As such, the definition of disability in the DDA is vast, extending to imputed disabilities and disabilities that existed in the past or may exist in the future, as is the case for genetic predispositions, in addition to existing disabilities (6). It has therefore been said that the Australian approach implies that a genetic predisposition to disease is a form of disability (7). On June 21, 2019, Australia's life insurance industry adopted a voluntary moratorium prohibiting the use of genetic test results for individually assessed life insurance applications for policies of AU$500,000 or less (22, 55).

4.2. Asia

South Korea is the only East Asian country to enact legislation specifically addressing GD (37). Rooted in both the international human rights and domain-specific models, the Korean Bioethics and Biosafety Act [Act 9100 (2005)] specifically prohibits discrimination based on an individual's

"genetic characteristics" in employment and promotion, education, and insurance. By contrast, Taiwan addresses GD indirectly, through its Personal Information Protection Act (2012). This act protects personal information, which includes genetic information (art. 6) collected, used, or processed by governmental as well as nongovernmental agencies (art. 4), such as insurance companies. However, it sets a wide range of classical privacy exceptions where such information may be used. For example, genetic information may be collected, processed, or used "in accordance with law" where necessary for a government agency to perform legal duties, for statistical or "other academic research," where the concerned party has provided consent, and for medical purposes or crime prevention (art. 6).

India features nonbinding ethical guidelines applicable to biomedical, social, and behavioral science research involving human participants or their biological material or data (33). In the ethical guidelines, the only direct reference to GD comes in its discussion on privacy and confidentiality, highlighting that certain information, such as genetic information, is particularly sensitive and should be protected (33, § 2.3.4). A more direct source of protection against GD is through case law. In February 2018, the High Court of Delhi ruled that insurance contracts cannot contain exclusion clauses related to genetic disorders on the basis that health insurance is an essential component of the right to health and the right to health care guaranteed by articles 14 and 21 of the Indian Constitution, respectively (49). The court noted that "[t]he individual's Right to avail health insurance is an inalienable part of the Right to Healthcare. Health insurance with the exclusion of 'genetic disorders' hits at the basic right of an individual to avail of insurance for prevention, diagnosis, management and cure of diseases. . .[and] would be per se discriminatory and violative of the citizen's 'Right to Health'" (49, para. D.4). However, the Supreme Court of India recently limited the scope of this decision to employees of the public sector (50). As such, despite lacking GD-specific legislation, India's legal system presents some protections against GD in health insurance in the public sector.

4.3. South America

There has been little legislative action addressing GD in South America. Among the various objectives of Chile's Law 20.120 [Sobre la Investigacion Cientifica en el Ser Humano, Su Genoma, y Prohibe la Clonacion Humana (2006)] is protecting human genetic diversity and identity in the context of biomedical, scientific, and clinical research (art. 1). The law approaches GD in the research and clinical settings as opposed to targeting certain discriminatory uses of genetic information in employment, insurance, or other areas of concern. Interestingly, the legislation prohibits not only "arbitrary discrimination based on the genetic heritage of individuals" but also "all eugenic practices" (art. 3 and 4). Genetic counseling is excluded from this broad prohibition (art. 3 and 4).

Argentina has a GD-specific law, Law 25.467 [Ciencia, Tecnologia e Innovacion (2001)], that addresses discrimination based on genetic data (art. 3). This law is the only national legislation specifically referring to GD. Notably, however, Argentina features two provincial GD laws, one covering Buenos Aires (Law 712, B.O. 17/1/2002) and one covering Córdoba (Law 8953, B.O. 7/5/2002). The former protects against discriminatory uses of genetic information but clearly indicates that genetic information does not include "other health information," such as physical examinations and blood tests (art. 3). This narrow definition of genetic data seemingly restricts the protection of the Buenos Aires law to information obtained from genetic testing or analysis (e.g., art. 8). The Córdoba law has only one reference to GD, prohibiting the use and circulation of genetic studies when they lack legitimate public interest and can result in discrimination (art. 2).

Unlike Argentina, Ecuador addresses GD through its more general health law [Law 67, Ley Orgánica de Salud (2006)]. Article 211 prohibits discrimination on the basis of "genetic heritage" and requires confidentiality with respect to an individual's genetic information.

5. REGIONS WITH MINIMAL POLICY-MAKING ACTIVITIES

5.1. The Middle East

Biopolitics is omnipresent in Israeli legislation (48), as exemplified in its immigration legislation, the Law of Return (5710-1950). Biopolitics, a term popularized by Foucault, refers to the emergence of particular political knowledge coupled with new disciplines, including biology and genomics (44). Laws based on biopolitics allow governments to analyze processes of life and thereby govern populations through correction, exclusion, normalization, therapeutics, and so on, by virtue of biological characteristics (44). The Law of Return allows Jews from the Diaspora, as determined by ancestry, to become Israeli citizens. Genetics-centric biopolitics is most evident in recent media attention regarding cases where citizenship applicants as well as couples seeking legal marriage in the country were requested to undergo DNA testing to determine their "Jewishness" (46, 75).

Interestingly, given the presence of such genetics-centric policies, Israel is currently the only Middle Eastern country to enact anti-GD legislation, albeit narrowly framed. Similar to Canada's GNDA, the Genetic Information Law (5761-2000) specifically targets GD in employment and insurance. For example, article 30(b) prohibits insurers from requesting genetic information or genetic testing, and even prohibits them from inquiring whether an insured has undergone genetic testing in the past. However, article 32 allows for broad uses of genetic information by security and law enforcement for purposes related to crime investigation, intelligence, and identifying missing persons, among others.

5.2. Africa

Policy Requirements, Procedures and Guidelines for the Conduct and Review of Human Genetic Research in Malawi (53) is the only legally enforceable GD-specific measure on the African continent. Although it is only a policy measure, its application is legally enforceable via the Science and Technology Act of 2003 (37, 53). This policy operates in the context of human genetic research and therefore would not apply to GD outside this specific context. It applies to researchers and stakeholders involved in human genetic research in the country and represents "minimum standards" (53, p. 2). This measure is illustrative of a genetic exceptionalism approach, highlighting that genetic information, "more than any other health information," is particularly susceptible to risks of harmful social consequences when used in employment, insurance, and immigration, and that it may lead to the stigmatization and discrimination of individuals, families, tribes, and societies (53, p. 10). As such, it mandates researchers to demonstrate how the confidentiality of data will be maintained so as to prevent "the adoption of discriminatory and exclusionary practices" (53, p. 10).

Two other African countries, Tunisia (Loi organique 2004-63 du 27 juillet 2004, portant sur la protection des données à caractère personnel) and Morocco [Dahir n° 1-09-15 of 22 safar 1430 (February 18th 2009) promulgating law n° 09-08 on the protection of individuals with regard to processing personal data], address GD through privacy laws rather than GD-specific laws. For example, in both of these countries, the general privacy legislation includes genetic information in the category of sensitive personal information. Tunisia's privacy law makes an exception to the general rule that requires the authorization of the individual concerned prior to the use of sensitive data in the case of genetic information used by medical professionals in the course of medical treatment, prevention, and diagnosis (art. 12).

In South Africa, the insurance industry instituted a nonbinding Standard on Genetic Testing in 2009 (5). The standard requires that insurers take the value of specialist surveillance, medical intervention, and successful treatment into consideration when assessing an individual's risk profile (41, p. 22).

6. EMERGING ISSUES

In the past, discussions on GD have referred mostly to adverse differential treatment by insurance companies or employers based on genetic test results for serious monogenic conditions (17, 25, 65). In this section, we suggest that there is a need to expand ethical and public policy reflections on GD beyond this narrow sphere of social interactions. First, we argue that it is problematic to focus on discrimination by private companies or employers in a context where public agencies (28, 52) also demonstrate an interest in using genetic information. Second, we argue that recent developments in gene editing and gene therapy may lead to new kinds of GD (based on intervention rather than test results) that are not considered by existing nondiscrimination policies, such as GINA (32). Third, we argue that the rise of nongenetic predictive biological data, such as epigenetic, microbiomic, metabolomic, and proteomic data, requires broader, more flexible policy frameworks to prevent unfair discrimination.

With the rapidly growing number of individuals undergoing genetic profile sequencing and the increasing amount of genetic data stored in databases in the United States and abroad, forensic genetics' potential has increased significantly. Recently, in the United States, law enforcement authorities have increasingly used the repositories of private companies offering direct-to-consumer online services for such purposes (69, pp. 202–3). For instance, comparing genetic data from biological samples found at a crime scene with identifiable genetic data contained in these private repositories can allow investigators to identify unknown criminals or one of their close relatives (57). Another emerging forensic technique that is currently advancing is genetic phenotyping—the use of genetic information to determine physical characteristics (e.g., a facial portrait) of an unknown individual (39, 47). While using genetic technology to improve the efficacy of police investigations appears beneficial overall, a concerning number of problematic uses have been documented. These uses include arbitrary collection of genetic information, ill-informed or coerced consent, compelled disclosure by data access officers, and misinterpretation of genetic data (14, 23, 68). Not all of these scenarios constitute GD, but if we consider the overrepresentation of vulnerable population groups in criminal databases (9), the unfettered use of DNA for criminal investigation will likely be conducive to it. It will also, in many cases, constitute an unacceptable encroachment on individuals' privacy rights.

In the United States, Canada, and many European countries, genetic tests are routinely performed by immigration agencies in the context of family reunification procedures (38). In this case, genetic tests offer highly reliable proof of genetic relationships among family members. However, this practice is also marked with ethical and legal concerns (21, 38). For instance, technical or human errors in performing these tests and interpreting or communicating their results can have devastating consequences for families seeking to reunite. These tests also promote discrimination between biological and adopted children. Other concerns include consent to—or, put differently, the right to refuse—such a test and the protection of immigrants' privacy in the process. In fact, particularly concerning news reports of widespread data collection practices targeting specific population groups have recently surfaced in China (30, 74), Kuwait (71), and the United States (16). While we recognize that such practices are not so much instances of GD as attempts to use genetic technologies to facilitate discrimination among population groups of different ancestral origins, the fact that genetic information enables this type of discrimination should not be ignored (43).

Most genetic nondiscrimination policies apply to discrimination based on genetic test results (35, 36). This has been criticized by some scholars for its limited scope, which often allows for discrimination based on medical information concerning familial history of disease (e.g., stroke) or risks that may be largely inherited (e.g., cholesterol level). In the context of insurance, for instance, some scholars object to the idea that differential treatment based on genetic test results should be prohibited, while the use of familial history of disease is acceptable to them (26, 54, 63, 66). They assert that genetic and familial influences both are beyond individual control and can be predictive of individuals' future health. An opposing position is that life insurers have used actuarial predictions of mortality risks to make decisions on insurability and rates for many years. Guaranteed-issue, community-rated life insurance is available only for small burial policies, and it is difficult to imagine life insurance underwriting in the United States that does not consider health history or personal habits (e.g., smoking). An important consequence of insurers' use of genetic test results is the reluctance of many at-risk individuals to be tested, possibly causing unnecessary illness and death. For this reason, whether life insurers should be allowed to use family history information but not the results of genetic tests is debatable (45).

More prospectively, it is possible that discriminatory practices in the near future could target individuals whose genes have been selected or modified. Gene editing and gene therapy may indeed lead to a novel form of GD: discrimination based on genetic intervention rather than test results (32). Considering the possible unknown adverse effects associated with gene editing, individuals could be stigmatized or discriminated against. This would also likely be the case for those attempting cutting-edge preventive gene therapies. Conversely, should such genetic interventions become common in our societies, it may be those who do not want to be gene altered or cannot afford it who will be at risk of discrimination. These considerations indicate that forward-looking approaches to regulating GD should seriously consider genetic intervention–based discrimination scenarios in order to prevent future unfair treatment of individuals who have had genetic interventions.

Similar to the case with genetic data, epigenetic, microbiomic, metabolomic, and proteomic data may reveal sensitive predictive information about an individual's risk of developing a given disease later in life. Some epigenetic and microbiomic variants can even be inherited from parents. In addition, such biological variants may provide information about someone's past exposures to physicochemical (e.g., air pollution or cosmetics) or psychosocial (e.g., familial stress or psychological trauma) disruptors of epigenetic mechanisms, which may sometimes be shared by members of the same family or social group.

Genotype inference using epigenetic data can reveal genetic information through the analysis of nongenetic biomarkers. In many laws, including GINA, the definition of a genetic test appears to consider this possibility. For example, as stated in GINA, "[t]he term 'genetic test' does not mean an analysis of proteins or metabolites that does not detect genotypes, mutations, or chromosomal changes" (§ 7). When considered in view of new predictive tests, this definition seems to imply that when nongenetic analysis allows for the detection of genotype, the law will consider that test to be a genetic test. Conversely, omic tests that do not allow for the detection of genotypes, mutations, or chromosomal changes but may provide information on inheritable biological variants (e.g., epigenetic variants) are excluded from the scope of GINA and other similarly designed laws. Moreover, by covering only human DNA, current laws appear to exclude metagenomic microbiomic data used to analyze microorganisms found in humans (e.g., the gut microbiome).

Illustrating the need to expand the current scope of GD laws, in 2016, Life Epigenetics (a subsidiary of GWG Holdings, Inc.) secured a license for an epigenetic clock technology that allows for the prediction of a person's life expectancy using DNA methylation assessment. In 2017, the company announced that it had started collecting and analyzing saliva samples provided by policy

owners to determine their true biological age. Similarly, the identification of other nongenetic predictive biomarkers (e.g., amyloid and tau in Alzheimer's disease) may also interest insurance companies in the future (42). The potential use of epigenetic age estimators by forensic scientists and immigration officers at public agencies is also generating ethical and legal concerns (1, 19, 70).

7. CONCLUSION

GD has raised and continues to raise substantial popular concern, has stimulated a plethora of public policies, and has promoted the much-debated concept of genetic exceptionalism. Throughout this article, we have presented the chief categories of public policies developed around the world to counter GD. A key issue identified in our survey of approaches to GD is that their protections are often based on restrictive definitions of genetic tests or genetic information. Furthermore, such policies are generally intended to prevent GD in the context of insurance and employment and are based on the use of positive genetic test results for serious monogenic and highly heritable disorders. However, new scientific developments and the use of genetic information in a growing number of contexts suggest that there is a need to revisit and remodel some of these laws. This need is accentuated by the possibility of new forms of GD, such as intervention-based discrimination. Additionally, current legal approaches to preventing GD often leave important lacunae in terms of epigenetic, microbiomic, metabolomic, and proteomic data used to reveal sensitive predictive information—and unlike the more futuristic concerns, such predictive testing already exists. This suggests that the development of international standards and collaborative initiatives along with more flexible, better-promoted national policies may be the most appropriate strategy to address GD in the coming years.

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