JAMA Network Open

Consensus Statement | Health Policy

The Key Features of a Genetic Nondiscrimination Policy
A Delphi Consensus Statement

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Abstract

IMPORTANCE Governments worldwide have become increasingly cognizant of the spread of genetic discrimination (negative treatment or harm on the basis of actual or presumed genetic characteristics). Despite efforts by a number of governments to establish regulations addressing this phenomenon, public concern about genetic discrimination persists.

OBJECTIVE To identify key elements of an optimal genetic nondiscrimination policy and inform policymakers as they seek to allay genetic nondiscrimination and related public anxieties.

EVIDENCE REVIEW Sixty multidisciplinary experts from 20 jurisdictions worldwide were consulted to understand their views on effective genetic nondiscrimination policies. Following standard requirements of the Delphi method, 3 rounds of surveys over the course of 1.5 years were conducted. Round 1 focused on assessing participants' understanding of the intricacies of existing genetic nondiscrimination policies, while rounds 2 and 3 invited participants to reflect on specific means of implementing a more effective regime. A total of 60 respondents participated in the first round, 53 participated in round 2, and 43 participated in round 3.

FINDINGS While responses varied across disciplines, there was consensus that binding regulations that reach across various sectors are most useful in preventing genetic discrimination. Overall, experts agreed that human rights–based approaches are well suited to preventing genetic discrimination. Experts also agreed that explicit prohibition of genetic discrimination within nondiscrimination policies can highlight the importance of genetic nondiscrimination as a fundamental right and ensure robust protection at a national level. While most participants believed the international harmonization of genetic nondiscrimination laws would facilitate data sharing worldwide, they also recognized that regulations must reflect the sociocultural differences that exist among regions.

CONCLUSIONS AND RELEVANCE As the reach of genetic discrimination continues to evolve alongside developments in genomics, strategic policy responses that are harmonious at the international and state levels will be critical to address this phenomenon. In seeking to establish comprehensive frameworks, policymakers will need to be mindful of regional and local circumstances that influence the need for and efficacy of unique genetic nondiscrimination approaches across diverse contexts.

JAMA Network Open. 2024;7(9):e2435355. doi:10.1001/jamanetworkopen.2024.35355

+ Supplemental content

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Introduction

While developments in genomics have improved our understanding of disease and are having a transformative impact on health care, the application of genetic technologies also raises several ethical and legal concerns. One persistent concern is that of genetic discrimination (GD).[1] Broadly put, GD occurs when an individual or group is negatively treated, unfairly profiled, or harmed relative to the rest of the population on the basis of actual or presumed genetic characteristics.[2] Beyond its human rights implications, GD may also disincentivize individuals from accessing clinical genetic services, and may deter people from undergoing genetic testing or participating in research out of concern for how their information may be used.[3,4]

While genetic information is mostly used for health care, extensive evidence has reported that genetic information can be used and misused by third parties across various circumstances.[5] For instance, without legal prohibitions, insurance companies may have an interest in using sensitive genetic information contained in medical files to establish higher insurance premiums for individuals at greater risk of developing a disease.[6,7] Genetic profiling can also exacerbate existing discriminatory practices in contexts such as access to health care, employment, and immigration.[8] These concerns make it crucial for governments to consider the impact GD may have on access to health and other social goods and services.

Worldwide, jurisdictions have obligations to ensure that all individuals can access the benefits of scientific progress and its applications.[9,10] States also have human rights obligations to ensure that health care is affordable and accessible in a fair and just manner.[11] Nevertheless, health care costs remain high, and expensive insurance premiums, in particular, prevent people from accessing essential health services—especially in countries without universal health care programs.[12] In such cases, individuals may have to weigh the benefits of sharing their genetic data to better inform their health care against the risks of having to disclose their sensitive genetic information. To alleviate these concerns, several jurisdictions have taken steps to regulate private insurers and ensure that insurance underwriting does not explicitly or implicitly perpetuate GD.[13,14]

Existing genetic nondiscrimination (GND) policies, however, have become outdated and lack the breadth to address the new contexts in which GD is arising. While instances of GD have primarily manifested in insurance, the normalization of genetic testing and data use in nonhealth settings has introduced new avenues for GD. Reports highlight the emergence of GD in employment, education, access to property, sports, adoption, and crime prevention.[15-19] While some scholars dispute the idea of giving genetic information a distinct or stronger level of protection than other types of biological information (genetic exceptionalism), in practice, many jurisdictions have adopted policies to protect against the misuse of genetic information.[3,20] From the implementation of moratoriums by the insurance industry (eg, UK, Australia) to broad human rights–based statutory prohibitions (eg, France), GND policies have taken many forms.[21] Some countries, such as the US, Spain, and Canada, have adopted legislation to prevent GD, while others have only issued nonbinding standards to regulate the insurance industry.[22]

This policy Delphi study catalogs the viewpoints of experts to identify areas of consensus and disagreement on optimal GND approaches. Past studies have identified the range of policy approaches that governments have implemented, but to our knowledge, no study has considered their content and usefulness.[21,23] As such, there is a need to evaluate the gaps in existing policies and identify more-promising strategies for policymaking.

Methods

Study Design

The policy Delphi is a powerful foresight tool that can be used to identify areas of consensus and disagreement among experts on emerging issues in a field.[24] Over the years, it has proven to be a useful method for generating ideas, uncovering solutions, and improving understandings of

problems across a myriad of settings.[25,26] Using the strengths of the policy Delphi, we surveyed 60 experts from 20 jurisdictions (**Figure 1**) to understand their views on GND approaches. Ethical approval was obtained from the research ethics board at the Faculty of Medicine, at McGill University. All prospective respondents were provided with background information to ensure informed consent. Participants were assured of their right to withdraw from the study at any point and that their confidentiality would be respected at all times. To preserve the anonymity of participants' responses, raw data were only viewable by the investigators. On completing the survey, participants were given the option to collaborate as coauthors. They were also informed that their responses would be dissociated from any identifiers and that their names and affiliations would only be disclosed at the time of publication. While participants interested in joining as coauthors were not invited to develop the questionnaire or analyze the resulting data, they were provided the opportunity to review the manuscript before submission. All phases of the study were conducted in accordance with the American Association for Public Opinion Research (AAPOR) reporting guideline.

Participant Recruitment

Recognizing that the study required the expertise of legal and social science scholars, we enlisted members of the Genetic Discrimination Observatory and Global Alliance for Genomics and Health Regulatory & Ethics Workstream[27] to nominate 3 to 5 relevant stakeholders from their respective jurisdictions. We used our international collaborators to strategically recruit expert participants from as many different jurisdictions as possible to promote inclusion and diversity within the study. Participants were screened based on their position in their field, the relevance of their experience on topics related to GD, their availability to participate in all 3 rounds of the study, and their ability to communicate in English. A total of 74 participants were identified through this approach and invited to participate by email.

Data Collection and Analysis

Initially, 74 experts from 20 jurisdictions were surveyed over the course of 1.5 years (June 2021 to November 2022). As Delphi studies often encompass multiple iterative rounds, 3 rounds of surveys

Figure 1. Sociodemographic Characteristics of Study Participants

To which of these groups does your current field of work best relate to?		
Total No. of participant responses: 60		
Field of expertise	No. of participants	%
Legal scholar	21	33.3
Researcher in genetics	14	23.3
Social science and bioethics scholar	12	20
Genetic counselor	4	6.7
Researcher in public health	4	6.7
Community advocacy leader	3	5.0
Insurance expert	1	1.7
Neurologist	1	1.7

How long have you worked in the field mentioned?		
No. of years	No. of participants	%
Worked in the field for 10+ y	44	73.3
Worked in the field for 5-9 y	13	21.7
Worked in the field for 1-4 y	3	5.0

How familiar are you with the topic of genetic discrimination?		
Level of familiarity	No. of participants	%
Very familiar	31	51.7
Familiar	24	40
Slightly familiar	5	8.3

In what jurisdiction do you reside?		
Total No. of participant responses: 60		
Jurisdiction	No. of participants	%
Canada	12	20
Australia	6	10
United States	5	8.3
Denmark	4	6.7
South Africa	4	6.7
United Kingdom	4	6.7
Belgium	3	5.0
Singapore	3	5.0
Spain	3	5.0
Germany	2	3.3
Mexico	2	3.3
South Korea	2	3.3
Sweden	2	3.3
Ukraine	2	3.3
China	1	1.7
Iceland	1	1.7
India	1	1.7
Ireland	1	1.7
Norway	1	1.7
Taiwan	1	1.7

were issued, each building on the findings of the previous round. Participants were asked a series of multiple-choice, ranking, and short-answer questions to gauge their perspectives on GND policies.

Round 1 focused on collecting demographic information and assessing participants' understanding of the intricacies of existing GND policies. Rounds 2 and 3 invited participants to reflect on specific means of implementing such a policy. Although 74 participants initially submitted responses, 14 individuals did not complete the first round and were thus excluded. Ultimately, the responses of 60 individuals were included in round 1, 53 were included in round 2, and 43 were included in round 3. A retention rate of 88.3% (53 of 60) was maintained in round 2 and 71.7% (43 of 60) in round 3, which is considered excellent for usual Delphi thresholds.[28]

Responses were provided on a Likert scale and analyzed using deductive and inductive reasoning. Two of us (G.D. and K.C.) collected the data and thematic data analysis was performed in tandem by 3 of us (D.U., E.K., and N.P.), with discrepancies mediated by consensus. At the time of study design, consensus was operationalized as 75% agreement among participants. Given that participants were not required to answer all questions to complete a survey round, the number of respondents per question varied, and this consensus statement reports both percentages and denominators.

Results

Overall, participants believed that the regulation of GD through human rights law was the most suitable means of addressing GD. As the results show, this included the addition of genetics as a ground of illicit discrimination in a state's nondiscrimination framework. While participants generally deemed the use of genetic information to inform health care decisions nondiscriminatory, most believed that specific restrictions on third parties' access to genetic information, particularly by insurers, were necessary to prevent GD.

Participant Characteristics

Participants were first asked to identify their area of expertise or field of research. During thematic analysis, they were separated into 8 mutually exclusive categories (Figure 1).

Toward the Harmonization of GND Policies

Participants were then asked to indicate whether the harmonization of existing nondiscrimination regulations was necessary to protect against GD. Overall, 74.1% (43 of 58) of the participants suggested that nondiscrimination laws or policies should be substantially similar around the world. While reasoning varied, most respondents believed that harmonization would standardize human rights protections (52.4% [22 of 42]) and foster data sharing between nations (21.4% [9 of 42]). Few respondents (26.2% [11 of 42]) indicated that harmonization would not be achievable. When asked to explain their reasoning, nearly two-thirds of these participants (63.6% [7 of 11]) stated that GD legislation should be context sensitive and respectful of the social and legal differences that exist among regions.

In round 2, participants were asked to propose strategies for jurisdictions seeking to harmonize global GD legislation. Although most participants (75.0% [27 of 36]) believed that harmonization was possible, they could not agree on how to implement shared standards. The most popular suggestion for harmonization (27.8% [10 of 36]) was that jurisdictions should first identify common foundational principles on which to build specific legislation. By contrast, few individuals cautioned that harmonization was not possible, as legal differences among countries need to be respected. Eight participants did not answer the question.

Finding an Optimal Policy Approach

Participants were also presented with a range of national frameworks and asked to identify the most suitable approach for addressing GD. As participants were experts in the field, definitions were not

provided in the survey. An explanation on our rationale for the different approaches is included in the eTable in the Supplement (**Figure 2**).

Most participants indicated that an overarching nondiscrimination law with explicit protections for genetic data was suitable or very suitable to address GD (86.7% [52 of 60]). A combined 78.3% (47 of 60) of participants also considered ethical guidelines based on international human rights declarations to be suitable or very suitable. While sector-specific laws were considered highly suitable (78.3% [47 of 60]), the moratorium was regarded as a much less suitable option (38.3% [23 of 60]).

Participants were then asked to elaborate on their reasoning during rounds 2 and 3. Most participants (75.0% [45 of 60]) suggested that adding an explicit ground for GD in a nondiscrimination law was optimal, as it would highlight the importance of addressing GD as a matter of human rights. As one participant described, "In this way, protection of genetic information can be deemed to be a fundamental right."

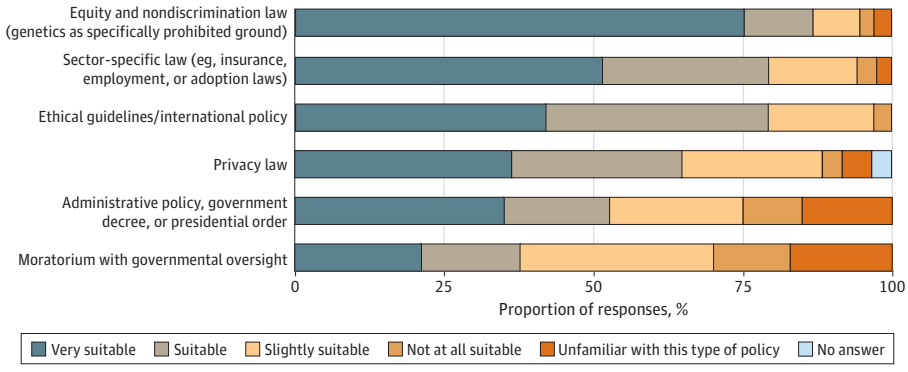
Participants also considered international human rights law to be critical in preventing the spread of GD. As participants reasoned, recognition of GND in international treaties would facilitate the inclusion of genetics as an illicit ground of discrimination as a human right nationally. Following ratification, governments could pass nondiscrimination legislation to give effect to their treaty obligations. As one respondent explained, "If GD was better codified under international law, it would facilitate greater understanding of GND as a human right." While the Oviedo Convention is a binding treaty established to protect human rights in the biomedical field, it only applies to member states of the Council of Europe.

Even when stratified by profession, there was an agreement that international human rights declarations are a highly suitable approach to address GD. Most legal, social sciences, and genetics scholars believed that ethical guidelines and human rights declarations were suitable or highly suitable (eFigure 1 in the Supplement).

On the other hand, a moratorium with government oversight was not highly recommended, with most participants across professions considering it to be only a slightly suitable approach (eFigure 2 in the Supplement). In contrast, an administrative policy (governmental decree or presidential order) and genetic privacy law were both considered a suitable (53.3% [32 of 60]) or very suitable (61.9% [26 of 42]) approach by most participants (eFigure 3 and eFigure 4 in the Supplement).

Most participants (78.3% [47 of 60]) indicated that sector-specific laws were an effective means of preventing GD. While this finding is consistent with current approaches, there is emerging evidence that this approach may only have a limited impact,[29] as GD has been shown to take many forms, and industry-specific policies may struggle to maintain relevance as GD evolves. As participants highlighted, binding legislation is crucial to address GD. Most participants (84.6% [33 of

Figure 2. Suitability of Different Policy Approaches



Sixty responses are displayed in the graph; percentages are rounded up.[2]

39]) justified this reasoning on the grounds that industry self-regulation would be one of the least suitable approaches to hold industries accountable.

Types of Genetic Information That Should Be Protected

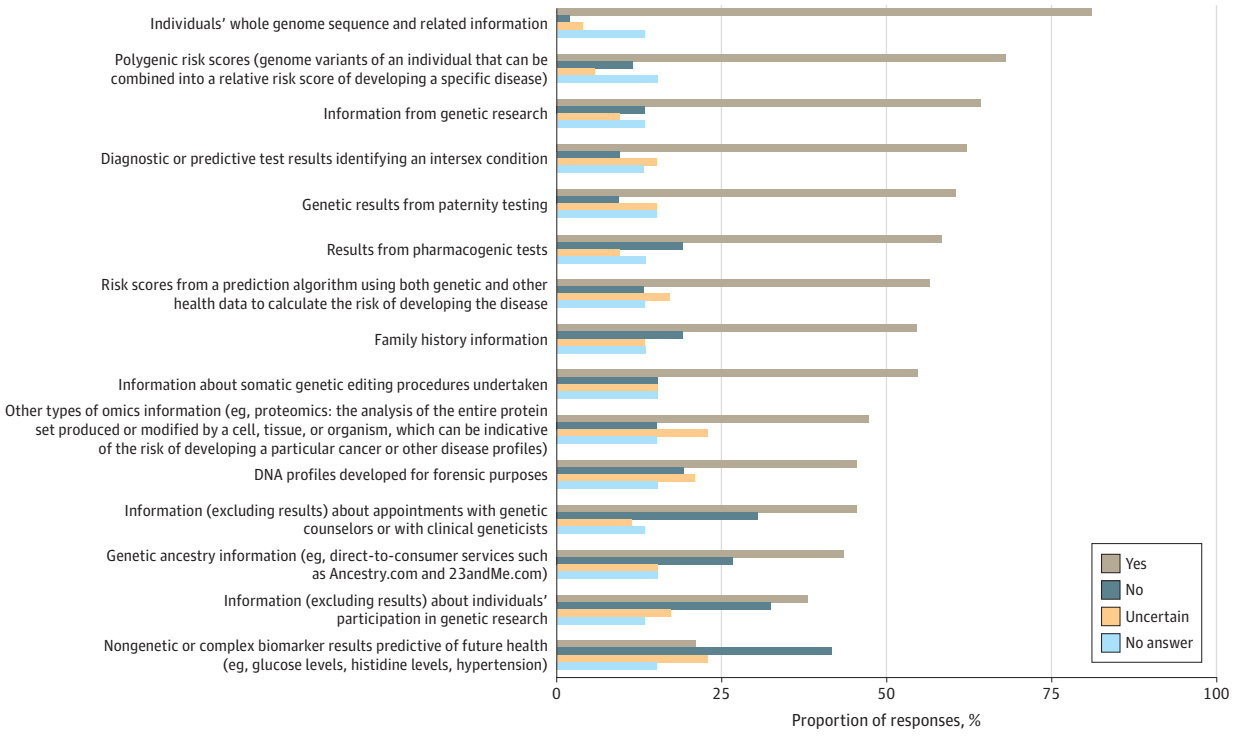
Participants were then asked to decide which types of information should be explicitly protected in a GND policy. **Figure 3** shows the categories that had the greatest support, which include whole genome sequencing and related information (>60%). The categories with the least support included nongenetic or complex biomarkers as predictors of future health (<50%) (Figure 3).

Exemptions of Genetic Information From Policy Protection

While mandatory disclosure of genetic information can infringe on individual rights, under certain circumstances, exemptions to protection from GD may be warranted. Participants were asked to identify where such exemptions might be justified. In round 1, a total of 34.1% (14 of 41) of the participants indicated there should be no circumstances in which genetic data disclosure could be tolerated, with 29.3% (12 of 41) indicating that they were not certain whether exemptions were necessary. By contrast, when asked where disclosure could be tolerated in rounds 2 and 3, participants believed exemptions could be made in the context of health care, with 65.2% (30 of 46) agreement in round 2 and 94.4% (34 of 36) in round 3. A total of 16.7% (6 of 36) of the participants opined that sharing genetic information is necessary to facilitate proper care and protect the health of relatives.

Participants also indicated that exemptions to GD protections could be made for scientific research (71.7% [33 of 46]) and to facilitate criminal investigations (47.8% [22 of 46]). Within the context of scientific research, most (73.1% [19 of 26]) participants believed that use of genetic data would further scientific knowledge for the greater good. To quote one participant, "genetic

Figure 3. Types of Predictive Health Information That Should Be Covered by Genetics Nondiscrimination Policies



Fifty-three responses are displayed in the graph.

information in this context may be useful, as it advances scientific understanding and benefits society as a whole."

Few participants (10.7% [3 of 28]) believed they could tolerate exemptions to solve serious crimes. Despite growing evidence that law enforcement authorities can, in some contexts, use a person's genetic information without their consent, participants still found the maintenance of public safety to be important. As one participant explained, "maintenance of law and order is an important state objective." And in the words of another, "where the risk to the public is high, utilizing genetic information is warranted."

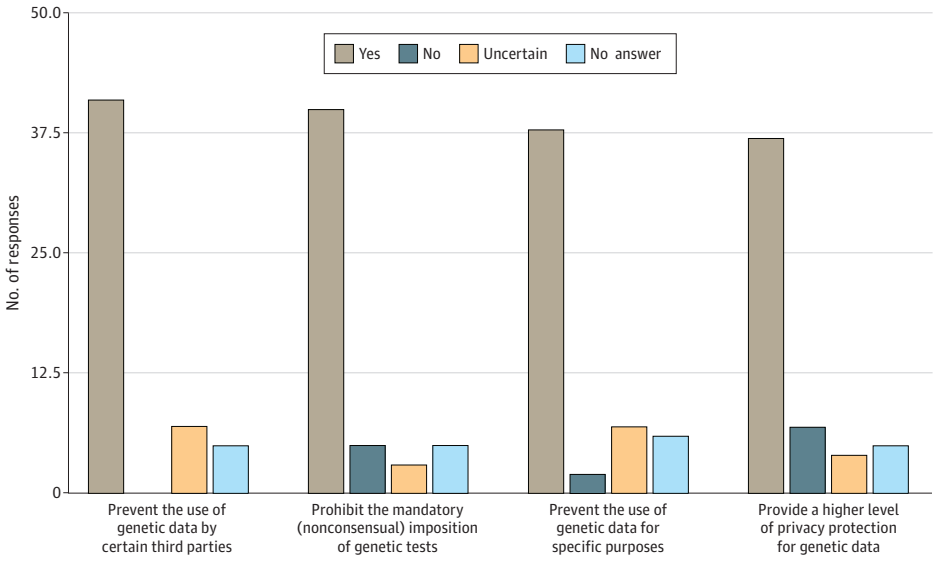
Objectives of a GND Policy

As evidenced from the evolution of responses, effective GND regulations need to target specific situations through actionable policies. Participants were thus asked to consider the concrete ways a GND policy should operate. In round 1, most participants indicated that a GND policy should prevent third parties from imposing genetic testing to determine eligibility for goods and services (86.2% [50 of 58]) and use test results to mediate access to those services (82.8% [48 of 58]). In rounds 2 and 3, participants followed up by identifying the additional objectives of GND. Most (77.4% [41 of 53]) believed that a GND policy should prevent the improper use of genetic data by third parties, such as insurance companies. In addition, 75.5% (40 of 53) indicated that a GND policy should ensure respect for autonomy by prohibiting mandatory imposition of genetic tests and by providing a higher level of privacy protection for genetic data (69.8% [37 of 53]) (**Figure 4**).

Discussion

Our findings suggest the importance of addressing GD through human and civil rights. While the harmonization of existing nondiscrimination laws across jurisdictions may help standardize human rights norms, it is also important to respect the sociolegal differences that exist among countries. The foundation of the international legal order is the supreme political authority of individual governments to self-govern.[30] While this right to sovereignty may conflict with international harmonization, it still provides flexibility for governments to give targeted effect to different international legal principles. As one participant noted, "there may be other, faster means of achieving this goal, but if GD was better codified under human rights treaties, it would be a 'major

Figure 4. Principal Objectives of a Genetics Nondiscrimination Policy



milestone.'" Indeed, evidence suggests that international human rights law can facilitate law reform at the national level.[31,32] It could similarly shape the regulation of genetic information as a matter of human rights.

As our study indicates, however, international law is only one of many routes to address GD. From human rights legislation to sector-specific laws, jurisdictions worldwide have a range of policy options available to prevent the spread of GD. While a number of countries have enacted sector-specific laws to regulate the insurance industry, this approach has drawbacks as it risks becoming rapidly outdated.[29] As our findings suggest, choosing an appropriate policy approach is complex, and laws must still be broad enough to capture the various contexts in which GD is likely to occur. Overwhelmingly, the participants indicated that explicit protection from GD in an equity or nondiscrimination law was necessary, as it would clarify that genetics is an illicit basis for discrimination. Such measures are essential, as they may promote the adoption of additional protections around GD. Following genetic-specific legislation, countries may amend existing policies to ensure more-comprehensive frameworks around the use of genetic information.

Regardless of the policy approach adopted, it is important that GND laws regulate the use of genetic information by third parties. Seventy-five percent of participants believed that regulating third parties, including insurance companies, was crucial to ensure protection against GD. In circumstances where GD is not regulated, companies may use a person's genetic information to determine insurance premiums or limit coverage for people with genetic predispositions. Increasingly, research reports that people's concern of having their genetic information used against them by third parties, such as insurers or employers, remains a fundamental barrier to genetic testing.[4] If not adequately addressed, it may keep individuals from accessing essential social services, with potentially severe consequences on quality of life.

Participants recognized, however, that certain exemptions may be necessary to promote scientific research and ensure public safety. The maintenance of public safety is an important governmental objective, and if used carefully, DNA can facilitate criminal investigations. Nonetheless, our findings suggest that this is a complex issue, and participants were split as to its necessity. Forensic use of DNA information may implicate rights to privacy, nondiscrimination, and equality and can also undermine public trust in government.[33] Even then, context is important and the sociolegal differences that exist among regions cannot be overlooked. In the US, for example, there have been instances when investigators have relied on private databases to identify criminals, bringing families of suspects into investigations.[34] However, use of genetic data from research biobanks for secondary purposes, such as criminal investigations, is strictly prohibited in Taiwan to preserve public trust in scientific research.[35] The European Court of Human Rights has also found that the use of private DNA databases to identify genetic relationships between individuals violates their right to privacy.[36]

By assessing the viewpoints of a range of experts, this study provides the groundwork for future research on GD and highlights the need for sophisticated regulations. While not determinative, it identifies the steps policymakers can take to protect against GD. Our study also shows how complex the question of GD is, even for experts. In part, this is because an understanding of policy challenges associated with GD requires some interdisciplinary knowledge, including genetics, philosophy, law, and economics. As a result, participants' knowledge on the distinct points covered by the survey varied substantially. The more technical a policy approach was shown to be, the more diverse were participant responses, with many indicating that they were not aware of what certain policies were (moratorium and administrative policy).

Limitations

As this project began during the COVID-19 pandemic, there was a considerable time lapse between rounds 1 and 2, which could have accounted for the small loss of participants between the rounds. Even then, the total number of respondents (43) in round 3 and the overall retention rate (71.7%) compare favorably with other policy Delphi studies.[27]

While the study included participants from more than 20 different jurisdictions, Canadian experts were overrepresented. The different fields of expertise in the study were not all equally represented. This limitation made it difficult to generalize the results across different regions and all areas of expertise. Nevertheless, given the geographic diversity of the coauthors and the quality of participants' expertise, our findings may be of great interest to genomics policymakers across countries and disciplines.[21]

Working definitions of technical legal and scientific terms were also not provided in the survey. Given the diverse background of all the participants, this absence may have impacted their understanding. Yet this was a voluntary trade-off since respondents self-identified as being experts and the introduction of completely neutral information on a topic as polarizing as GD would have been nearly impossible. The inclusion of definitions could have led to bias, which was an important concern for us.

Conclusions

Our policy Delphi consensus statement considers the core elements of an optimal GND policy and aggregates the opinions of experts regarding the steps jurisdictions can take to adopt such legislation. We used the strengths of the Delphi method to reveal areas of consensus and dissensus among a variety of GD experts with decades of experience in the field. Providing participants with the opportunity to act as coauthors while ensuring protection for their right to privacy further provided a path to a more participative approach.

As evidenced by the findings, human rights law can ensure protection against GD. Scientific and cultural differences between countries, however, cannot be overlooked. Further research will thus be necessary to validate and complement the rich data identified throughout this study.

A possible next step would be for the Global Alliance for Genomics and Health and the international Genetic Discrimination Observatory to formulate model GND legislation that could assist policymakers looking to implement anti-GD statutes. As instances of GD continue to proliferate alongside new developments in technology, it will become increasingly important for jurisdictions to adopt flexible laws and policies that keep up with the pace of science and evolving ethical and social norms.

ARTICLE INFORMATION

Accepted for Publication: July 17, 2024.

Published: September 26, 2024. doi:10.1001/jamanetworkopen.2024.35355

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Administrative, technical, or material support: Dalpé, Cheung, Kondrup, Blizinsky, Bombard, Chung, Ho, Nair, Ryan.

Supervision: Ramiro Aviles, Chung, Doerr, Dupras, Minssen, Nicolás, Ryan, Van Hoyweghen, Zawati, Joly.

Conflict of Interest Disclosures: Ms Bentzen reported receiving grants from the Research Council of Norway and the European Union during the conduct of the study. Dr Bombard reported having equity founder ownership in Genetics Adviser outside the submitted work; in addition, Dr Bombard holds a patent for Genetics Adviser. Prof Gunnarsdóttir reported being a PhD candidate whose project was supported by the Collaborative Research Program for Biomedical Innovation Law, which is a scientifically independent collaborative research program supported by a Novo Nordic Foundation grant. Dr Jamuar reported being a member of the Ministry of Health, Singapore, Genetic Testing Advisory Committee, which also looks into this issue of genetic discrimination, with no financial compensation. Dr Minssen reported receiving grants from Novo Nordisk Foundation during the conduct of the study; grants from European Union; and personal fees from X-officio Advokat AB in a small Swedish Law Form specializing in large research infrastructures and projects outside the submitted work. Dr Nicol reported receiving grants from the Australian Research Council during the conduct of the study. Dr Stedman reported receiving personal fees from Canada's Drug Agency; nonfinancial support from CIHR-Institute of Genetics Member, Canadian Organization for Rare Disorders, and York University outside the submitted work; is chair of the Canadian Autoinflammatory Network; executive of the Canadian Rare Disease Network; and former board member of the Canadian Organization for Rare Disorders. No other disclosures were reported.

Funding/Support: This study was supported by a Novo Nordisk Foundation Grant for a scientifically independent Collaborative Research Programme in Biomedical Innovation Law (Grant agreement number NNF17SA0027784) (Prof Gunnarsdottir); by National Medical Research Council Clinician Scientist Award (NMRC/CSAINVJun21-0003) (Dr Jamuar); and by a Novo Nordisk Foundation Grant for a scientifically independent Collaborative Research Programme in Biomedical Innovation Law (grant agreement NNF17SA0027784), and by a Novo Nordisk Foundation Grant for a scientifically independent International Collaborative Bioscience Innovation & Law Programme (Inter-CeBIL programme—grant NNF23SA0087056) (Prof Minssen).

Role of the Funder/Sponsor: The funding organizations had no role in the design and conduct of the study; collection, management, analysis, and interpretation of the data; preparation, review, or approval of the manuscript; and decision to submit the manuscript for publication.

Disclaimer: Views and opinions expressed in this article are those of the authors and do not necessarily reflect those of the European Union or the Health and Digital Executive Agency. Neither the European Union nor the granting authority can be held responsible for them.

Additional Contributions: We thank Kacey San Diego, BA (Centre of Genomics and Policy, McGill University), for her assistance in creating the figures for this study. We also thank Shu Hui Chen, PhD (Office of Data Science and Strategy, National Institutes of Health), for her feedback, and Derek So, MSc (Centre of Genomics and Policy, McGill University), and Brandon Willmore, JD, for their editorial assistance.

Additional Information: Dr Joly is the principal investigator and the scientific director of the Genetic Discrimination Observatory (GDO) and the co-lead of the Global Alliance for Genomics and Health (GA4GH) Regulatory & Ethics Workstream (REWS). All authors are experts in matters related to genetic discrimination, with all but Mr Sillon being members of the GDO and/or GA4GH REWS.

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SUPPLEMENT.

eTable. Explanation of Policy Approaches
eFigure 1. Suitability of Ethical Guidelines and Human Rights Declarations
eFigure 2. Suitability of Moratorium
eFigure 3. Suitability of Administrative Policy
eFigure 4. Suitability of Genetic Privacy