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# Genetic Discrimination in Access to Life Insurance: Does Ukrainian Legislation Offer Sufficient Protection against the Adverse Consequences of the Genetic Revolution to Insurance Applicants?

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**Abstract:** This paper presents an inter-disciplinary study of the risk for, and protections against, genetic discrimination in access to life insurance in Ukraine. It aims (i) to review questions related to genetic information, health status, and family history currently included in Ukrainian life insurance application forms; (ii) to analyze the Ukrainian legislation related to equity and nondiscrimination and to determine whether it provides adequate protection against genetic discrimination (GD). Research findings of our insurance application forms review show that Ukrainian life insurance companies ask broad questions about health and family history that may be perceived by applicants as requiring the disclosure of their genetic information. Our legal analysis shows that today there are no genetic specific law protecting Ukrainians people against GD in insurance. However, Ukrainian human rights legislation provides some protection against multiple grounds of discrimination and given the ratification by Ukraine of the European Convention on Human Rights it is possible that these grounds could be interpreted by tribunals as also including genetic characteristics. As a next step, Ukrainian researchers should develop a survey to obtain much needed data on the incidence and impact of GD in Ukraine. Following this it will be possible for policymakers to better assess whether there is a need for an explicit non-GD law in this country. Such a law would have the benefit of explicitly aligning Ukraine's legal framework with that of many of its European partners.

**Keywords:** genetic discrimination; genetic information; life insurance; legislation; human rights; Ukraine; Europe



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## 1. Introduction

The rapid development of genomics and growing use of genetic tests in clinical practice and research have stimulated an interest to use test results for insurance underwriting (Newson et al. 2018). The use of genetics in this area remains focused on tests available for a few monogenic conditions where the information is more meaningful for insurers (for example, Huntington's disease, hereditary breast and colon cancer) (Joly et al. 2013b). However, genomics has progressed beyond this paradigm with the completion of the international Human Genome Project in 2003 (Genetic Screening Ethical Issues 1993). According to the latest research, the market now offers about 75,000 genetic testing products (Reinsurance Group of America 2021), although only a few are sufficiently scientifically reliable and clinically relevant to be used by insurance companies (Health Plan Landscape for Genetic Testing 2018). Furthermore, there are more than five thousand genes identified that characterize genetic diseases, and their numbers are increasing (Geetter 2002). Whole-genome sequencing technologies now makes the assessment of the risk of a large

number of common diseases foreseeable. This explains the growing interest in the use of genetic information by the insurance industry (Nicholls et al. 2014) to predict future health outcomes and determine the access and rates of insurance products accordingly (Joly and Marrocco 2020).

GD is interpreted to include prejudicial actions by insurers against policyholders based on knowledge of an existing genetic condition, or the genetic condition of one of their family members (Lapham et al. 1996). This situation makes it necessary to investigate the major social and ethical implications of using personal genetic information for risk assessment in insurance. This is all the more relevant given that documented reports of incidents of GD have emerged from several European and North American countries (Joly et al. 2013b). A summary review of previous research on genetics and insurance shows that researchers have considered the specific nature of genetic data (Boyer-Kassem et al. 2017; Rechfeld 2016), the principles and functioning of life insurance (Barlow-Stewart et al. 2018), genomic stratification and risk classification (Joly et al. 2013b), applicable regulations (Klein 2017), GD (Joly et al. 2013b), the notion of “adverse selection” (Thomas 2018), as well as the psychosocial impact of GD (Godard et al. 2003). This review also indicates that using genetic information in insurance sometimes involves conflicting ethical and economic rationales about who should/should not have access to such information (insurance companies, family members, employers, etc.) and for what purpose (Shannyn 2017). For example, a major concern here is how to avoid GD in insurance underwriting without unduly compromising the viability of this industry sector. According to Nabholz (2011), in countries that have decided to restrict access to genetic information, policymakers have faced the following problems and difficulties: distinguishing between private and social insurance, absence of clear definitions of “genetic test”, and “genetic information”, and the need to distinguish between diagnostic and predictive genetic tests. There is documented evidence of refusal to provide insurance coverage or to increase the insurance premiums based on genetic information regarding some monogenic, fatal, conditions. This situation, of course, is cause for public concern (Joly et al. 2013a) and can have a negative psychosocial impact on vulnerable members of the society (Bombard et al. 2008). Furthermore, Joly et al. (2020) have argued that considering the broad impact of scientific advances in genetics “GD remains one of the most pervasive concerns identified by the public, patients, scientists, clinicians, and research participants worldwide”. As a consequence of GD by insurance companies, some people refuse to participate in genetic research conducted by other scientific organizations (Joly et al. 2013a) and avoid medically recommended genetic testing (Lemmens 2004) out of fear that the data may be used by insurers which could lead to GD (Joly et al. 2013a; Lemmens 2004). Moreover, GD in insurance could discourage individuals and prevent them from seeking treatment or making reproductive choices that could, in the long run, improve their health and reduce healthcare costs. Potential policyholders or research participants have refused to participate in genetic studies because they fear that their genetic test results might not remain confidential (American Medical Association Council on Science and Public Health 2013; Hall and Rich 2000).

GD can happen very explicitly, in a letter disclosing to an insurance applicant that he has been refused based on results of a genetic test, or more implicitly. In the latter case, his application could be processed very slowly, his phone calls and emails ignored, etc., in the hope to see him abandon the application process (Joly et al. 2013b). Definitions of GD describe it as “... unfair treatment of individuals or groups of people based on genetic conditions, genetic predispositions, genetic risk factors related to health and disease traits, or ancestry” (Personal Genetics Education Project 2021); or “Prejudicial action ... based on observation, family history, genetic testing, or other means of gathering genetic information” (Joly et al. 2013b; Lapham et al. 1996); or “... unfair decisions about someone who is currently healthy based on genetic information (results of genetic testing or family history information)” (Geller et al. 1996; Joly et al. 2013b). Conversely, legal definitions of GD mostly exclude family history and pre-existing genetic conditions from the scope of application of the law. For example, the National Institute of Health, National Human

Genome Research Institute, Genetic Information Nondiscrimination Act (GINA) of 2008 defines that genetic information of any individual includes his or her “... genetic tests, the genetic tests of family members of such individual, and the manifestation of a disease or disorder in family members ...”<sup>1</sup> but it excludes from the application of the law “medical information that is not genetic information about a manifested disease, disorder, or pathological condition of an employee or member, including a manifested disease, disorder, or pathological condition that has or may have a genetic basis” (National Institute of Health 2021; The Genetic Information Nondiscrimination Act (GINA) 2008).

Since the 1990s, countries have used different policies to combat GD (UNESCO 1997). According to a geographical overview of approaches adopted around the world developed by the Genetic Discrimination Observatory (GDO) (The Genetic Discrimination Observatory 2021a), we can distinguish eight broad groups of countries depending on the type of genetic nondiscrimination policy they use. For example, there are countries “with specific laws to prevent GD” or countries “... that have adopted a moratorium or administrative regulations on the use of genetic tests” and countries “... that have not adopted specific laws, regulations, and policies to prevent GD but for which non-binding documents exist” (The Genetic Discrimination Observatory 2021a). To date, Ukraine has not adopted any explicit law or public policy to specifically prevent GD. However, Ukraine has adopted general legislation that protects its people against any form of discrimination based on race, color of skin, political, religion, and other beliefs, sex, ethnic and social origin, nationality, marital status, place of residence, property status, linguistic or other characteristics (European Commission for Democracy through Law 2006; UPR Info 2021; Verkhovna Rada of Ukraine 1996a, 2012c). In addition, many Ukrainian human rights’ laws include the generic illicit ground of discrimination: “other characteristics”. Based on international legislation ratified by Ukraine and on the practice of the European Court of Human Rights, these laws (Ukrainian and international) could be interpreted as providing some protection against GD in Ukraine (European Court of Human Rights 2009; Tyrer 2011). In addition, regarding the Ukrainian insurance sector, there are possibilities to reduce the risks of genetic discrimination via applying the statements of Recommendation CM/Rec(2016)8 of the Committee of Ministers to the member States on the processing of personal health-related data for insurance purposes, including data resulting from genetic tests, that protects insurance applicants against insurance companies’ requirements to provide genetic test for underwriting. However, there is an opportunity to apply existing predictive genetic tests results for insurance purposes (Council of Europe 2016a). Given the high profile of GD and the degree of legal uncertainty still prevailing, it appears very timely to explore the challenge of GD in access to life insurance in Ukraine.

## 2. Materials and Methods

We begin by presenting and analyzing key elements of the Ukrainian insurance market regulations that include the following laws: Law of Ukraine “On insurance” (1996) (The World Trade Organization 2021; Verkhovna Rada of Ukraine 1996c) and Law of Ukraine “On the National Bank of Ukraine” (1999) (Verkhovna Rada of Ukraine 1999). Then, we carry out a comprehensive review of the human rights legislation applicable in Ukraine. Our legal analysis was completed by considering European human rights legislation that is applicable in Ukraine and the landmark *G.N. and Others v. Italy* case involving GD.

To document the current practice of Ukrainian life insurers we examined life insurance application forms used by industry members. For this part of our research, we have adapted the methodology proposed by Feze and Joly (2014). Altogether, 11 life insurance application forms were collected by searching Ukrainian life insurance companies’ websites

<sup>1</sup> GINA does not apply to life insurance, focusing mostly on health insurance and employment. (National Institute of Health 2021; The Genetic Information Nondiscrimination Act (GINA) 2008). However, several U.S. states have chosen to move beyond GINA to protect people against GD in life insurance as well, for example: California, Idaho, Montana, Wyoming, Florida, Massachusetts (Rothstein and Brothers 2020; The Genetic Discrimination Observatory 2021b).

or by contacting company representatives via email to seek a copy of their insurance questionnaire.

### 3. Results and Discussion

#### 3.1. *The Life Insurance Industry in Ukraine: Context and Legal Framework*

Today, the Ukrainian life insurance industry is growing both in terms of the amount of earned premiums, +3717.5 million UAH or +410.1%, from 2010 to 2019, and by the number of policyholders, +2,242,844 insured (a 77.6% increase), for the same period. However, looking at these data in isolation can be misleading. Indeed, the number of life insurance companies in business has sharply declined from 67 insurers in 2010 to 2020 in the third quarter of 2020 ([National Bank of Ukraine 2020a, 2020b](#); [National Commission for State Regulation of Financial Services Markets 2018, 2020](#)). Notably, the top three highest insurance premium earners now make up 57.6% of the market share premiums and, the top 10 accounts for 96.7% ([National Commission for State Regulation of Financial Services Markets 2020](#)). These data show that Ukraine now has a very concentrated life insurance market providing for a generally low level of competition. For consumers, this means that a person whose application has been rejected or charged above standard rate has fewer opportunities to seek a lower insurance coverage from another company.

##### 3.1.1. The Law of Ukraine “On insurance” (1996)

The main legislative text that regulates the insurance market (life and non-life) is the Law of Ukraine “On insurance” (1996). This document describes in detail the role of life insurance (article 6); insurance payments and insurance tariffs (article 10); insurance application and entry into force of the insurance policy (article 18); duties of an insurer and an insured (articles 20, 21); rejection of insurance claims or insurance indemnification (article 26); licensing of insurance activity (article 38) and so on ([The World Trade Organization 2021](#); [Verkhovna Rada of Ukraine 1996c](#)). Thus, according to the Law of Ukraine “On insurance” (1996), Life insurance is defined as follows:

“Life insurance—Is a kind of personal insurance, which provides for the obligation of the insurer to make an insurance payment in accordance with the insurance agreement in the case of death of the insured person, and also, if the insurance agreement provides so, in the event that the insured person reaches the age specified in the agreement or is alive at the end of the agreement. Terms of an agreement of life insurance may require the insurer to make an insurance payment in the case of an accident that happened to the insured person, or in the case of sickness of the insured person. If in the case of the insurance event the agreement provides for regular annuity insurance payments (annuity pension insurance), the agreement must provide for insurance against the risk of death of the insured person during the period between the beginning of the insurance agreement and the first annuity insurance payment. In other cases, taking into account the risk of death of the insured person is obligatory during the entire period of the life insurance agreement.”<sup>2</sup> ([The World Trade Organization 2021](#); [Verkhovna Rada of Ukraine 1996c](#))

Subparagraph 2 of article 21 of the Law of Ukraine “On Insurance” (1996) stipulates that an insured “when entering an agreement on insurance, provides information to the insurer on all circumstances known to him which are essential for the evaluation of insurance risks, and subsequently, inform him of any changes in the insurance risk,”<sup>3</sup> ([The World Trade Organization 2021](#); [Verkhovna Rada of Ukraine 1996c](#)). Moreover, the insurance company may deny insurance benefits if the insured knowingly gave false information about the subject of the contract. For example, this information may be related to the health or medical history of the insured, or even his immediate family ([The](#)

<sup>2</sup> Translation from Ukrainian by [The World Trade Organization \(2021\)](#) and with authors’ edits.

<sup>3</sup> Ibid.

[World Trade Organization 2021](#); [Verkhovna Rada of Ukraine 1996c](#)). This stipulation could be interpreted as imposing a duty to an applicant to disclose clinically relevant genetic information about himself to an insurer and thus opens the door to genetic discrimination.

### 3.1.2. The Law of Ukraine “On the National Bank of Ukraine” (1999)

To date, in Ukraine, the insurance market is regulated (beginning from 1 July 2020) by the National Bank of Ukraine (NBU) following the Law of Ukraine “On the National Bank of Ukraine” (1999) ([Verkhovna Rada of Ukraine 1999](#)). The sphere of financial market management by NBU also includes credit unions, financial companies, and credit bureaus ([Verkhovna Rada of Ukraine 1999](#)). Other financial market entities, such as private pension funds, mortgage issuers, construction, and real estate financing funds, as well as trust companies, are within the scope of regulation and the responsibility of the National Commission on Securities and Stock Market—a state collegiate body subordinated to the President of Ukraine and accountable to the Verkhovna Rada of Ukraine ([Verkhovna Rada of Ukraine 2019](#)).

## 3.2. European and Ukrainian Human Rights Legislation to Prevent Genetic Discrimination

### 3.2.1. European Law

- The Convention on Human Rights and Biomedicine

According to the geographical overview of approaches adopted around the World provided by the Genetic Discrimination Observatory Ukraine currently has “not adopted specific laws, regulations, and policies to prevent GD” ([The Genetic Discrimination Observatory 2021a](#)). On 22 March 2002, Ukraine signed the Convention on Human Rights and Biomedicine ([Oviedo Convention 1997](#)) but has not yet ratified it ([Council of Europe 2021](#)). This means that while there may be an intention from Ukraine to implement the content of the Oviedo Convention, there is no legal obligation to enforce it yet. The Convention on Biomedicine is important at the European level here because it contains an explicit provision against GD included in article 11. More specifically article 11 of the Oviedo Convention states that “Any form of discrimination against a person on grounds of his or her genetic heritage is prohibited” ([Oviedo Convention 1997](#)). Furthermore, article 12 states, that predictive genetic tests “... may be performed only for health purposes or for scientific research linked to health purposes ...” ([Oviedo Convention 1997](#)). Thus, this provision of the Oviedo Convention also could be a non-GD tool in life insurance in Ukraine after its ratification, but still does not clearly address the issue of using existing genetic tests results for insurance purposes.

- Recommendation CM/Rec(2016)8 of the Committee of Ministers to the member States on the processing of personal health-related data for insurance purposes, including data resulting from genetic tests

This international legislation can be implemented as a tool to reducing the risks of GD for Ukraine as a member of Council of Europe as well as a members of the Committee of Ministers, because its regulates “... the processing of personal health-related data for insurance purposes, including data resulting from genetic tests” ([Council of Europe 2016a](#)). Similarly, with the provisions of article 12 of the Convention on Biomedicine, this recommendation (principle 4) also states that “... predictive genetic tests must not be carried out for insurance purposes” ([Council of Europe 2016a](#)). It means insurers are not entitled to subject the conclusion or modification of an insurance policy to the holding of a predictive genetic test ([Council of Europe 2016b](#)). Furthermore, regarding the existing genetic tests results paragraph 16 in principle 4 states that it “... should not be processed for insurance purposes unless specifically authorised by law” ([Council of Europe 2016a](#)). While the above mentioned Recommendation does not provide a directly transposable non-GD policy for Ukraine, its provisions can play an influential role in the shaping of human rights protection against genetic discrimination in Ukraine.

- The European Convention on Human Rights and its interpretation by the European Court of Human Rights

While it has yet to ratify the Convention on Biomedicine, Ukraine has both signed and ratified the European Convention on Human Rights which does protect people against “... discrimination on any ground such as sex, race, colour, language, religion, political or other opinions, national or social origin, association with a national minority, property, birth or other status” (article 14) (Council of Europe 1950; Verkhovna Rada of Ukraine 1997a). According to article 9 of the Constitution of Ukraine, valid international agreements, that have been approved by the Verkhovna Rada of Ukraine, are part of national legislation (European Commission for Democracy through Law 2006; Verkhovna Rada of Ukraine 1996a). Thus, the European Convention on Human Rights has the force of law in Ukraine. While article 14 of the European Convention on Human Rights does not provide explicit protection against discrimination based on health status, genetic status or characteristics among the specifically prohibited grounds, it does include the expressions “any ground” and “or other status” (Council of Europe 1950). In the landmark Case of G.N. and Others v. Italy, the European Court of Human Rights stated that a difference in treatment based on a genetic disease should be considered “other status” within the meaning of article 14 of the European Convention on Human Rights (European Court of Human Rights 2009; Tyrer 2011). This important case shows that the expression “other status” in non-discrimination laws and policies could be interpreted to provide protection against other grounds of discrimination not specifically prohibited including, perhaps, GD. While the Decision of the Court was limited to “genetic diseases” the justification provided by the Court seem to indicate that this finding could be extended to include “genetic characteristics” (European Court of Human Rights 2009; Tyrer 2011).

In theory, the European Court of Human Rights cannot establish formal legal precedents through its judgements. In practice, however, its judgments are a highly influential source of law and are cited by international and national courts in order to provide strategic legitimation for their judgements (Lupu and Voeten 2010). For instance, according to article 2 of the Law of Ukraine “On the Fulfillment of Decisions and Application of Practice of the European Court of Human Rights” and article 46 of the European Convention on Human Rights (Verkhovna Rada of Ukraine 2006), the judgments of the European Court of Human Rights are obligatory. Additionally, according to part 4 of article 382 of the Criminal Code of Ukraine (intentional non-compliance by an official with a decision of the European Court of Human Rights is considered a criminal act (Verkhovna Rada of Ukraine 2001d). Article 17 of the Law of Ukraine “On the Fulfillment of Decisions and Application of Practice of the European Court of Human Rights” also stipulates that Ukrainian courts of law should apply the precedents established by case-judgments of the European Court of Human Rights as a source of law in their proceedings (Verkhovna Rada of Ukraine 2006). This basic provision is expanded upon by other acts of the national Ukrainian legislation in part 2 of article 6 of the Code of Administrative Proceedings of Ukraine (Verkhovna Rada of Ukraine 2005) which states that “The Court applies the principle of the rule of law, taking into account the practice of case-judgments of the European Court of Human Rights”<sup>4</sup> (Verkhovna Rada of Ukraine 2005). The Criminal Procedural Code of Ukraine also includes similar provisions (Verkhovna Rada of Ukraine 2012d). Thus, Ukrainian courts of law ought to refer to the judgment of the European Court of Human Rights in Case of G.N. and Others v. Italy (European Court of Human Rights 2009; Tyrer 2011) in discrimination cases involving discrimination based on genetic characteristics or genetic diseases.

### 3.2.2. National Law

- The Law of Ukraine “On the Ukrainian Parliament Commissioner for Human Rights” and the duties of the Ukrainian Parliament Commissioner for Human Rights

<sup>4</sup> Translation from Ukrainian by authors.

After analyzing the applicable European law and of the Law of Ukraine “On the Ukrainian Parliament Commissioner for Human Rights”, we suggest that the Commissioner may have an implicit duty to protect people against GD in Ukraine. In Ukraine, the governmental organization related to human rights protection that provides information to help people facing discrimination is the Ukrainian Parliament Commissioner for Human Rights (hereafter Commissioner). According to subparagraph 6 of article 3 of the Law of Ukraine “On the Ukrainian Parliament Commissioner for Human Rights” the purpose of the parliamentary control by the Commissioner is the “... prevention of any forms of discrimination in relation to the fulfillment of person’s rights and freedoms;”<sup>5</sup> ([International Labour Organization 2021](#); [Verkhovna Rada of Ukraine 1997b](#)). In addition, article 16 of the Law states that based on the information about human rights and freedom violations the Commissioner conducts legal proceedings and inspections according to appeals of (1) citizens of Ukraine; (2) foreigners; (3) stateless persons or their representatives; (4) People’s Deputies of Ukraine or, (5) on its own initiative ([International Labour Organization 2021](#); [Verkhovna Rada of Ukraine 1997b](#)). While considering these appeals, the Commissioner has the following options:

- “1. initiate proceedings on violation of human and citizens’ rights and freedoms;
2. explain what measures the person who has filed an appeal with the Commissioner should undertake;
3. submit an appeal, as appropriate, to the body which is competent to consider the case, and control the consideration of this appeal;
4. decline consideration of an appeal”.<sup>6</sup> ([International Labour Organization 2021](#); [Verkhovna Rada of Ukraine 1997b](#))

In the context of filling the gaps in Ukrainian non-GD policy it is also useful to consider the provisions of article 13 of the above-mentioned Law, that states:

“the Commissioner has right to: ... (3) appeal to the Constitutional Court of Ukraine with regard to: conformity of the laws of Ukraine ... ; the official interpretation of the Constitution of Ukraine and the laws of Ukraine; (3-1) make in due course proposals for improvement of legislation of Ukraine in the sphere of protection of human and citizen’s rights and freedoms;”.<sup>7</sup> ([International Labour Organization 2021](#); [Verkhovna Rada of Ukraine 1997b](#))

This right of the Commissioner could be used to ask a question to the Constitutional Court of Ukraine regarding the official interpretation of the broad discrimination grounds such as “other characteristics”, “other status”, “other grounds”, or “other circumstances” in article 24 of the Constitution of Ukraine and in other Ukrainian human rights laws. The Commissioner could also, following proper investigation on the matter, make a recommendation to clarify Ukrainian human rights and non-discrimination legislation to explicitly include “genetic characteristics” as a prohibited ground of discrimination.

Indeed, while Ukraine has no specific laws that protect people against GD, there are several human rights laws that include sections prohibiting discrimination based on illicit grounds. The more relevant of these laws include: Constitution of Ukraine ([Verkhovna Rada of Ukraine 1996a](#)); Law of Ukraine “On the Principles of Prevention and Counteracting Discrimination in Ukraine” (2012) ([Verkhovna Rada of Ukraine 2012c](#)) and the Law of Ukraine “On Protection of Personal Data” (2010) ([Verkhovna Rada of Ukraine 2010](#)).

- The Constitution of Ukraine (1996)

The basis of Ukrainian legislation for the protection of human rights and freedoms, including against discrimination, is article 24 of the Constitution of Ukraine which establishes that “citizens have equal constitutional rights and freedoms and are equal before

<sup>5</sup> Translation from Ukrainian by [International Labour Organization \(2021\)](#) and with authors’ edits.

<sup>6</sup> Ibid.

<sup>7</sup> Ibid.

the law”<sup>8</sup> ([European Commission for Democracy through Law 2006](#); [Verkhovna Rada of Ukraine 1996a](#)). Furthermore, this article notes that “There shall be no privileges or restrictions based on race, color of skin, political, religious, and other beliefs, sex, ethnic and social origin, property status, place of residence, linguistic, or other characteristics”<sup>9</sup> ([European Commission for Democracy through Law 2006](#); [Verkhovna Rada of Ukraine 1996a](#)). Thus, the Constitution of Ukraine provides protection against discrimination of citizens on various grounds. In this case, “genetics” is not explicitly included among the listed characteristics in article 24.2, but the expression “other characteristics” clarify that the enumerated grounds are not exhaustive.

It is also helpful to analyze how Ukrainian courts of law have interpreted “other characteristics” in the meaning of the anti-discrimination part of article 24 of the Constitution of Ukraine. To date, in Ukraine, there are only two judgments by the Constitutional Court of Ukraine—the Court responsible to provide the official interpretation of the Constitution of Ukraine ([Verkhovna Rada of Ukraine 2017](#))—that are related to the non-discrimination grounds of article 24.2 of the Constitution and to the expression “other characteristics”. In both cases, the plaintiffs argued that “age”, as a ground of discrimination, should be placed among “other characteristics” in the meaning of article 24.2 ([Constitutional Court of Ukraine 2004](#); [Constitutional Court of Ukraine 2007](#)). However, these two judgments by the Constitutional Court lack specificity and are difficult to reconcile with one another. Thus, they neither strengthen nor weaken our claim.<sup>10</sup>

- The Law of Ukraine “On the Principles of Prevention and Counteracting Discrimination in Ukraine” (2012)

The Law of Ukraine “On the Principles of Prevention and Counteracting Discrimination in Ukraine” (2012) describes discrimination and illicit grounds in greater details, according to subparagraph 2 of article 1:

“discrimination—is a situation in which the individual and/or group of persons because of their race, skin color, political, religious or other beliefs, sex, age, disability, ethnic or social origin, nationality, and marital status, place of residence, linguistic or other characteristics that existed, exist and can be real or perceived, suffered, incurred or may incur limitations in any form, established by this Law except the cases when such limitation has a legal, objectively reasonable goal, ways to achieve what are appropriate and objective”<sup>11</sup>. ([UPR Info 2021](#); [Verkhovna Rada of Ukraine 2012c](#))

The broad formulation used that include “perceived” characteristics could be interpreted as prohibiting genetic discrimination based on the results of predictive genetic testing ([European Court of Human Rights 2009](#); [Tyrrer 2011](#)). The scope of the Law (according to article 4) extends to such areas of public relations as “... health care; education; the social protection; housing relations; access to goods and services; to other areas of public relations”<sup>12</sup> ([UPR Info 2021](#); [Verkhovna Rada of Ukraine 2012c](#)). This indicates that it also applies to life insurance contracts.

There are several other laws in Ukraine that complement the protection against discrimination in different areas and also could provide some protection against GD based on a similar reasoning. What these laws have in common is that the list of discriminatory grounds they enumerate is not exhaustive, as established by the use of expressions such as:

<sup>8</sup> Translation from Ukrainian by [European Commission for Democracy through Law \(2006\)](#) and with authors’ edits.

<sup>9</sup> Ibid.

<sup>10</sup> According to case 1, “age” is the discrimination ground in the hiring decision based on the provision of anti-discrimination part of article 24.2 of the Constitution of Ukraine, but this judgment didn’t state directly that “age” should be placed among “other characteristics” in the meaning of the mentioned article. In contrast, case 2 directly defined that “other characteristics” doesn’t include “age” as a discrimination ground ([Constitutional Court of Ukraine 2004, 2007](#)).

<sup>11</sup> Translation from Ukrainian by [UPR Info \(2021\)](#) and with authors’ edits.

<sup>12</sup> Ibid.



“ . . . and/or other features (characteristics, grounds, signs) or, all forms of discrimination”. The most relevant of these legislations are the Law of Ukraine “Fundamentals of the Legislation of Ukraine on Health Care” (Verkhovna Rada of Ukraine 1992); Law of Ukraine “On Higher Education” (Verkhovna Rada of Ukraine 2014); the Law of Ukraine “On Complete General Secondary Education” (Verkhovna Rada of Ukraine 2020), the Law of Ukraine “On Employment of Population” (Verkhovna Rada of Ukraine 2012b); the Labor Code of Ukraine (Verkhovna Rada of the Ukrainian SSR 1971); the Law of Ukraine “On Collective Agreements and Contracts” (Verkhovna Rada of Ukraine 1993); the Law of Ukraine “On Advertising” (Verkhovna Rada of Ukraine 1996b); the Law of Ukraine “On Social Work with Children and Youth” (Verkhovna Rada of Ukraine 2001c).

In addition, other sector specific laws containing non-discrimination provisions have a narrower formulation, each including what appears to be a comprehensive list of prohibited grounds. These laws are unlikely to be interpreted by a Court of law as providing protection against GD. They include: the Law of Ukraine “On Political Parties in Ukraine” (Verkhovna Rada of Ukraine 2001a); the Law of Ukraine “On Civil Associations” (Verkhovna Rada of Ukraine 2012a); the Law of Ukraine “On Civil Service” (Verkhovna Rada of Ukraine 2015); the Law of Ukraine “On Service in Bodies of Local Self-Government” (Verkhovna Rada of Ukraine 2001b); the Law of Ukrainian SSR “On Consumer Rights Protection” (Verkhovna Rada of the Ukrainian SSR 1991).

- The Law of Ukraine “On Protection of Personal Data” (2010)

More specifically subparagraph 1 of article 7 states:

“The processing of personal data shall be prohibited if such data are about racial or ethnic origin, political views, religious or other convictions, membership in political parties and trade unions, criminal record as well as if data relate to health or sexual life, biometric or genetic information . . . ”<sup>13</sup>. (Ukrainian Parliament Commissioner for Human Rights 2021; Verkhovna Rada of Ukraine 2010)

However, based on subparagraph 2 of article 7 this prohibition “ . . . shall not apply if the processing of personal data: (1) is conducted in case the personal data subject gives a univocal consent to the processing of such data;”<sup>14</sup> (Ukrainian Parliament Commissioner for Human Rights 2021; Verkhovna Rada of Ukraine 2010). This ‘consent exception’ substantially limits the protection of the law, since as we will discuss, most insurance application forms in Ukraine require the consent of the applicant to the processing of their health data for verification purposes.

Thus, based on our review of Ukraine’s national legislation, this country has not adopted any laws, regulations, and policies that explicitly prevent GD. However, keeping in mind Ukraine’s ratification of the European Convention on Human Rights and the practice of the European Court of Human Rights (Case of G.N. and Others v. Italy (European Court of Human Rights 2009; Tyrer 2011)), we believe that a legal basis for such protection does exist in Ukraine.

### 3.3. Exploration of Life Insurance Application Forms: Are Ukrainian Insurers Seeking Genetic Information?

Exploring life insurance application forms and medical declarations (questionnaires) can provide precious information about the life insurance industry’s current practices regarding genetic information. Notably, previous research on this topic in the context of the Canadian life insurance industry argues that in Canada “ . . . insurers do not explicitly or specifically request information on genetic test results in their primary questionnaires. Nevertheless, these questionnaires contain broadly-formulated questions, which can provide life insurers with access to a wealth of medical (including genetic) and non-medical infor-

<sup>13</sup> Translation from Ukrainian by Ukrainian Parliament Commissioner for Human Rights (2021) and with authors’ edits.

<sup>14</sup> Ibid.

mation on the applicants and on some of his/her family members” (Feze and Joly 2014). For our research of the Ukrainian life insurance market, we used a similar methodology to that of Feze and Joly’s (2014). We reviewed 11 life insurance application forms and medical declarations that were available on Ukrainian insurance companies’ website or that were sent to us by insurers via email following a request from our group (see Table 1 below).

**Table 1.** Personal and medical information related to health family history required from future policyholders in life insurance applications<sup>15</sup>.

NO.	Life Insurance Company	Medical and GD Risk Relevant Questions
1	Private JSC “UAIC ASKA-LIFE”	Have your parents, siblings, living or dead before the age of 60, suffered from diabetes, cancer, stroke, hypertension, heart disease or kidney disease, mental illness, tumors, tuberculosis or other inherited diseases?
2	Private JSC IC “PZU Ukraine Life Insurance”	Have any of your parents, sisters or brothers under the age of 60 ever been diagnosed with type 1 or type 2 diabetes, cancer (breast, ovarian, rectal/colon cancer, melanoma, etc.), cardiovascular and nervous system diseases (heart disease, stroke, transient ischemic attacks, heart attacks), kidney disease, muscular dystrophies, etc. The insurer may establish the presence of increased risk which may be due, for example, family history; medical indicators (height, weight, pressure, etc.); other grounds?
3	Private JSC “IC “KD Life”	Have any of your parents or siblings ever had high blood pressure, diabetes, heart disease, mental illness, tumors, tuberculosis, birth defects or other inherited diseases?
4	Private JSC “Insurance company KNIAZHA LIFE VIENNA INSURANCE GROUP”	Have any of your parents or siblings ever been suffered from the following diseases: diabetes, stroke, heart attack, heart disease, kidney disease, cancer, tuberculosis, mental illness?
5	Private JSC “Insurance company “UNIQA Life”	No directly relevant question
6	LTD “IC Greenwood Life Insurance”	No directly relevant question
7	Private JSC “Insurance company “TAS”	No directly relevant question
8	Private JSC “MetLife”	Have any of your parents or siblings ever suffered from high blood pressure, diabetes, heart or kidney disease, mental illness, tuberculosis, hereditary diseases, tumors, or attempted suicide? I declare that: None of my close relatives (father, mother, brother, sister, son, daughter) - ever had any inherited diseases, congenital malformations, cancer, mental disorders, heart disease, kidney, liver, pancreas, respiratory system.
9	Private JSC “GRAWE UKRAINE Life insurance”	Have you ever had any form of hereditary or congenital disease? Have your natural parents or siblings ever suffered from diabetes, cardiovascular disease, kidney disease, multiple sclerosis, stroke, tumors, mental illness or hereditary diseases?
10	Private JSC “IC “FORTE LIFE”	Have any of your parents or siblings ever suffered from hypertension, heart disease, strokes, diabetes, hereditary diseases?
11	ALC “IC” ARX Life”	No directly relevant question

We found that currently in Ukraine there is possibility for life insurers to collect genetic information through these questionnaires. Reviewing them, we noted that none of the companies explicitly required results from genetic tests or imposed such a test on their applicants. However, in addition to requiring future policyholders’ information on their current medical conditions (ex. diabetes, stroke, heart attack, heart disease, kidney disease), several forms (7 out of 11) also required the disclosure of current and past hereditary

<sup>15</sup> All the insurance form in this table were obtained online or directly from insurance companies between November 2020 and January 2021.

diseases. Thus, to complete these questionnaires truthfully, applicants would likely have to disclose any existing genetic diseases they may have, or afflicting one of their family members, or that they have had in the past. This practice of using broad and open question is similar to what was observed by [Feze and Joly \(2014\)](#). Thus, we believe their above-mentioned conclusion would also apply to Ukraine.

Furthermore, broadly formulated questions makes it difficult to comply with the conditions included in principle 1, paragraph 5 of the Recommendation CM/Rec(2016)8, that requires relevance, necessity and proportionality for risk assessment and processing of health-related personal data ([Council of Europe 2016a](#)). In addition, in these circumstances the main question and issue is related to the relevance of the family history as well as other risk factors for the assessment of the risk covered due to necessity for the protection of personal data and family privacy. Similar to the Canadian context, Ukrainian insurers generally required insurance applicants to waive their right to the confidentiality of their health information, which could include genetic data, through specific contractual clauses included in questionnaires. Such clauses exist to allow insurers to confirm the veracity of the applicants' declaration with their physicians or other relevant third parties. While the specific formulation of these clauses varied across questionnaires, all forms included a waiver of confidentiality. Finally, one company reserved itself the right to request future policyholders to undertake an "extended examination". This company, Private JSC "MetLife", is the market leader in Ukraine if we consider the number of persons covered by life insurance (66.47% in 2019) ([Forinsurer 2021](#)). Such exams are to take place only in cases of insurance coverage above 750,000 UAH (27,000 USD) and for insureds over 55 years old. It is unclear what this "extended examination" may entail because there is no clear determination or explanation in the publicly available documents from this insurance company. Taken together, none of the clauses we reviewed specifically target genetic disease, but several were sufficiently broadly formulated or used synonyms for genetics that would allow them to be interpreted as such. Slightly more reassuring, it does not appear that the formulation used would require the applicant to disclose the positive result of a predictive genetic test (i.e., their future risk of developing disease) if he is not yet afflicted by the disease.

#### 4. Conclusions

To date, in Ukraine, no legislation, similar to those found in Canada or western Europe, has been adopted to explicitly address the topic of GD. Ukraine has a fairly large private life insurance market with relatively low level of competition where insurers are used to ask applicants broad questions about family history of disease, and inherited diseases, via their company questionnaires. Thus, it appears that there is currently a risk of genetic discrimination in the context of purchasing private life insurance in Ukraine. But no empirical survey concretely establishing the incidence and impact of GD has been performed in this country.

Our research shows that Ukraine has ratified the European Convention on Human Rights which includes at article. 14 (prohibition of discrimination) the broad category of prohibited grounds of discrimination: "and other status", preceded by the expression "any ground such as". This formulation has led the European Court of Human Rights in the Case of G.N. and Others v. Italy to rule that the difference in treatment based on a genetic disease should be considered "other status" within the meaning of article 14 of the European Convention on Human Rights. Given the ratification of the European Convention on Human Rights by Ukraine, article 14 and its interpretation by the European Court of Human Rights should be directly applicable in this country.

While this last finding is comforting, it appears important to confirm that Ukrainian life insurers are aware of this interpretation of the European Convention on Human Rights and are not asking their applicants about their genetic test results or, more likely, using this information when provided to them as a response to a broadly formulated health question. The only way to document the current national situation would be through launching a

large-scale mixed method study of GD in life insurance in Ukraine. Once this important step is realized, we will be able to further engage the Ukrainian population about genetic discrimination and the role of insurance to assess if the adoption of an explicit law to address GD in Ukraine is warranted.

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