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WHAT IS SO UNFAIR ABOUT USING GENETIC INFORMATION? THE PROBLEM OF GENETIC DISCRIMINATION

Introduction

New discoveries in human genetic technology have a significant impact on society and open up new perspectives in medicine. Genetic information provides the ability to diagnose or predict genetic conditions for the risks of illness and may bring about significant benefits to health care in the future. However, the use of genetic information poses daunting questions and great challenges to public health care and our legal systems. One of the most demanding issues of the integration of new genetic technologies into medicine is the challenge of equality. The second biggest issue is the problem of the protection of patients' autonomy and privacy in the age of genomic medicine, especially when genetic information can be used and misused for miscellaneous purposes. Both of the above mentioned concerns are based on a common social fear – the fear of genetic discrimination that has stimulated legislators of many countries to pass special laws guaranteeing genetic privacy or preventing people from genetic discrimination in such fields as the insurance system and employment.

In the present essay I shall discuss some of the issues concerned with the problem of genetic discrimination. I shall present what genetic discrimination means and how it can manifest itself. I shall also discuss the main controversies that arise when the law preventing genetic discrimination is at stake.

Genetic information, testing and screening

One of the most fundamental problems concerning any laws restricting the use of genetic information is the lack of clear definitions of the terms involved. The International Declaration on Human Genetic Data adopted by UNESCO (United Nations Educational, Scientific and Cultural Organization) on October 16, 2003 gives the following definition of genetic information:

> Information about heritable characteristics of individuals obtained by analysis of nucleic acids or by other scientific analysis.

To put it differently, it is information about specific variations in genes and chromosomes learned by genetic testing and other means. Such a broad definition concerns all kinds of information about our genes, including information about our health, as well as information about our identity, which can be also based on our family history and genealogy. Miscellaneous national, international or transnational legal acts define the term differently with regard to special context in which genetic information is used. Thus, one may distinguish definition of genetic information that are based on: (1) the mean of obtaining the information (resulted from genetic testing or screening of an individual; from family history; from test results of the relatives; from other information about an individual etc.); (2) the content of the information (information about our identity, information about our health condition etc.); (3) the purpose of the use of the information (for identification; for the body of evidence in a trial; for reproductive decisions; for treatment; for other social and life decisions etc.); (4) the predictive ability and predictive degree (which concerns especially genetic testing and screening for illness risk) etc.[1]

In this essay which concerns the problem of genetic discrimination, I shall focus on genetic information about individual's health status, especially the predictive aspect obtained from individual's genetic tests, the genetic test of family members or family health history of such individual.

The same problem of the ambiguity of terms occurs when we turn to the definition of genetic testing. A broad definition for genetic testing includes any test that yields genetic data, unambiguously revealing underlying DNA information, irrespective of its technological aspect. A narrower definition that can be used in the context of the paper says that "genetic testing refers to medical procedures that determine the presence or absence of a genetic disease, condition or marker in individual patients (Gostin). Genetic tests involve an examination of chromosomes, DNA, molecules, or gene products (such as proteins) to find evidence of certain mutated sequences."[2]

Genetic testing should be distinguished from genetic screening.[3] Testing is performed on individuals (especially who are at a higher risk of carrying a specific genetic mutation). Screening, by contrast, is performed on a wider group of people, a defined population (including those individuals who are at lower than average risk for carrying a specific genetic mutation). One can distinguish two especially important and well known kinds of genetic screening: newborn genetic screening, which enables newborns to be screened for a wide variety of genetic conditions (such as phenylketonuria, mucoviscidosis and hypothyroidism) and population screening performed at the population level, especially when the particular population is at higher risk than average to suffer a genetic disease (e.g. Ashkenazi Jews are especially threatened by the disease, having a 1 in 30 chance

[1] See A. Krajewska, *Informacja genetyczna a zakres autonomii jednostki w europejskiej przestrzeni prawnej* (*Genetic Information and the Scope of Individual Autonomy in the European Legal Space*), Wrocław 2008, pp. 46–58.

[2] J.G. Hodge, Jr., *Genetic Testing and Screening* [in:] S.G. Post (ed.), *Encyclopedia of Bioethics*, vol. 2, MacMillan Reference Books, 2003, p. 1016.

[3] More on various kinds of genetic testing and screening in: M.J. Mehlman, J.R. Botkin, *Access to the Genome: The Challenge to Equality*, Washington 1998, pp. 20–38.

of carrying the gene for Tay-Sachs, African Americans have a 1 in 11 chance of being gene carriers for sickle cell disease, and thalassemias is prevalent among Southeast Asians).

Among genetic testing (or screening) for inherited conditions for illness one can distinguish: diagnostic genetic testing (they confirm diagnosis for a symptomatic individual); predictive genetic testing (that are aimed at determination of future illness risk in asymptomatic patients) and pharmacogentic testing which seeks to promote a favourable response and to prevent an adverse response to a drug or other treatment based on a genetic predisposition.

Predictive genetic testing for inherited genetic disease risks is one of the most promising branches of genomic medicine. It is intended to identify patients' conditions of risk for future illnesses. Genetic testing can identify conditions that enable specific treatments or preventive measures to be taken, as well as conditions for which there is no treatment or preventive measure available. In the latter cases, genetic testing provide information that can be used by patients to make important life decisions and significant reproductive choices.

Depending on the purpose of the application of predictive genetic testing, one can distinguish: (1) predictive genetic testing to assess reproductive risks; (2) predictive genetic testing to assess future disease risks in healthy adults.

Reproductive genetic testing or screening includes: (1a) preconception testing (carrier testing of adults) to identify if a patient is a carrier of a recessive disease gene that can be passed on to successive generations; (1b) prenatal testing (of foetal cells) to identify all potential future abnormalities of a child; (1c) preimplantation testing (of embryos) to identify conditions of an embryo formed by in-vitro fertilization.

Predictive genetic testing to assess future disease risks in healthy adults are late-onset conditions tests that can vary in their predictive ability. With regard to the predictive degree one can distinguish among: (2a) pre-symptomatic genetic testing that determine the eventual development of symptoms with almost 100 percent certainty when the gene mutation is present (e.g. Huntington disease); and (2b) pre-dispositional genetic testing (susceptibility testing) that the eventual development of symptoms is likely but not certain when the gene mutation is present (e.g. breast and ovarian cancer, testing is based on prognostic markers such as BRCA1 and BRCA2).

Use of genetic information

In the vast literature about genetic testing and screening there is a frequently given distinction between (1) medical and (2) non-medical purposes of the use of genetic information. Among the medical purposes of using genetic information, one usually names: (1a) preventing the onset of diseases; (1b) assuring that early detection and treatment (treatment can be also based on the so-called pharmacogenetic tests); (1c) making genetic-based reproductive decisions; (1d) making life plan decisions (about special diet, about conduct, lifestyle etc.). As far as the use of genetic information for non-medical purposes is concerned, one

usually names: (2a) using genetic information by insurance companies in group health plans (as a basis for denying coverage if a person does not currently have a disease); (2b) using genetic information by employers in group health plans (as a basis for refusing to offer health coverage as part of the benefits); (2c) using results of genetic tests to give or refuse employment; (2d) using results of genetic tests in education system; (2e) using results of genetic tests in adoption procedures etc. Given such a distinction there are many who claim that discrimination may manifest itself only as far as the non-medical purposes of the use of genetic information are concerned. In my further considerations I shall challenge this statement by undermining the distinction.

It is not clear what we mean by medical purposes.[4] Firstly, there are some who define medical purposes as those concerned with a diagnosis or prediction of a specific illness, yet not concerned with specifying any general characteristics such as susceptibility for obesity or alcoholism. One can pose the question about the definition of an illness and discuss which characteristics can be understood as conditions for illnesses. The answer is not easy as far as the definition of illness depends on what a society specifies as the dysfunction of an organism according to some measures of the "normal" function of a human organism. The further question is how can we specify the role of the internal (genetic) and external (social connected with our behaviour) factors in the onset of a disease.

Secondly, one can also argue that medical purposes should be understood as those that *aim at the treatment* of a certain disease when the gene mutation is present. However, it would significantly restrict the scope of the use of genetic information in health care since our predictive ability in medicine is not on a par with effective medical care to enable the prevention of a potential disease. There are many late-onset illnesses that can be predicted by genetic testing yet cannot be healed. The information about the condition for future illness risk can help in preventing or postponing the onset of the disease by undertaking an appropriate diet, physical exercises or lifestyle. What is more, such information can help in preparing people mentally for an illness. Finally, such information can affect the reproductive decisions of an individual and prevent them from passing on the disease to her descendants. As far as reproductive decisions are concerned, there are deep controversies that pose a myriad of questions, especially when decisions based on genetic information are aimed at the selection of embryos or at abortion.

Thirdly, one can assume that medical purposes are those concerned with a diagnosis or prediction of a specific illness which is a mental or psychical dysfunction of an organism that *should be* treated (even if no treatment is available yet). However, such a definition of medical purposes do not determine what kind of decisions individuals would make on the basis of genetic information about the dysfunction of a human organism. For instance, it is still unclear whether reproductive decisions for eugenic reasons (selection of embryos or selective abortion) could be understood as the use of genetic information for medical purposes even when in such cases it is not the elimination of a dysfunction (the condition for disease) but rather the elimination of the subjects (possible people) with a dys-

[4] See A. Krajewska, *op.cit*., pp. 189–191.

function is at stake. Actually, any genetic testing or screening is, according to the above mentioned definition, performed for medical purposes – for the diagnosis or prediction of an illness. The difference consists in for what such information is used. In other words, such a definition of medical purposes is useless and makes the whole distinction between medical and non-medical purposes questionable.

Since it is very difficult to specify a clear definition of medical purposes, perhaps it would be better to distinguish between genetic information used for *health purposes* from genetic information used for *all other purposes*. By health purposes I mean those concerned with promoting health (improving health condition) and challenging illness of individuals. But such a definition depends on another unclear notion – health. According to a very broad and frequently objected definition given by the World Health Organization (WHO), health is a state of complete physical, mental and social *well-being* and not merely the absence of disease or infirmity.[5] On the basis of such a definition of health, *every* kind of use of genetic information could be understood as the use for health purposes if only it could affect our well-being which is a very vague concept. One can also assume a narrower definition where health is understood as a lack of illness and illness is specified as a mental or psychical dysfunction of an organism that should be treated. Such a definition of an illness consists of a descriptive (dysfunction is specified by frequency of appearance of a feature) and a normative (some kinds of deviation are tolerated and some are seen as dysfunctions that ought to be treated) element. This definition is open for any content that would meet both descriptive and normative conditions and can evolve within societies.

Nevertheless, the distinction between the use of genetic test results for health purposes and for all other purposes is neither disjunctive nor comprehensive. For instance, the use of genetic information which results in refusing employment can be aimed at the protection of the health of the person when the conditions of work would increase the risk of the ouset of a disease. Reproductive genetic testing can be also aimed at either elimination of a dysfunction of an embryo of the elimination of an embryo. Everything depends on the context of the use of genetic information, not on the kind of testing or the information itself.

What is genetic discrimination?

Before I turn to an analysis of genetic discrimination I shall specify what I mean by the term "discrimination." The problem of discrimination is tightly connected with the concept of justice since as discrimination we can understand a special kind of injustice. Every discrimination is injustice but not every injustice must manifest itself in a form of discrimination. To make it more clear,

[5] Preamble to the Constitution of the World Health Organization as adopted by the International Health Conference, New York, 19–22 June, 1946; signed on 22 July 1946 by the representatives of 61 States (Official Records of the World Health Organization, no. 2, p. 100) and entered into force on 7 April 1948.

let me briefly introduce the concept of justice.[6] One should distinguish between the formal and substantive levels of justice. Formal justice requires that equal people are to be treated equally or that like cases are to be treated alike and different cases are to be treated differently. Everything depends on what we mean by equal and not equal, i.e. how we differentiate between people. The rule of equal treatment is empty, there is no content since the criteria of differentiation as well as its aims come from the substantive level of justice which must complement the formal level to make a concept of justice full-fledged. The formal level of justice is aimed at guaranteeing its impartiality and consistency – it requires one to obey the adopted criteria of justice. The substantive level of justice, on the other hand, can be defined as principles of distribution of goods (broadly understood, they include rights and duties, wealth and income, positions and jobs, rewards and punishments etc.) among people according to particular criteria. Nevertheless, such a criteria of the differentiation of people cannot be arbitrary and have to be justified. The underlying differences between individuals that justify the criteria of distribution which results in differences in their treatment must be differences relevant to the aim of distribution. Even when the same people are treated in the same way (the condition of formal justice is satisfied), there can be injustice when we question either the aim of distribution or the criteria of differentiation.

In short, by discrimination one may understand a situation when individuals who are alike in *every relevant respect* (not in absolutely every respect) are treated differently, or when individuals who are different in *some relevant respect* are treated alike.[7] Direct discrimination takes place when discrimination is based on unjustified criteria of different treatment. Indirect discrimination takes place when although different treatment is based on neutral criteria, it brings about unjustified exclusion of particular individuals or groups of people that are unable to meet such criteria. In other words, indirect discrimination concerns all situations when a definition of an aim of distribution or a definition of a particular social institution is unjustified. Thus, discussing discrimination, one has always to consider whether there is justification of a difference in treatment.

By genetic discrimination one usually understands: "Actions taken against or negative attitudes toward a person based on that person's possession of variation on the genome, or variations in the genome of his or her biological relatives."[8] To put it differently, genetic discrimination means that one's own genetic characteristics are unjustified criteria of a difference in treatment or are wrongly included in an aim of a distribution or a definition of an institution. One can argue that a number of differential treatments are based on inherited genetic characteristics (e.g. rewarding individual merits and punishing individual vices – taking any decisions on our inherited characteristics such intelligence, talent, appearance, inclinations). But discrimination occurs only if differential treatment is

[6] To read more about it see: M. Soniewicka, *Granice sprawiedliwości, sprawiedliwość ponad granicami* (*Boundaries of Justice, Justice Beyond Boundaries*), Wolters Kluwer, Warszawa 2010, pp. 40–61.

[7] J. Feinberg, *Social Philosophy*, *Foundations of Philosophy Series*, E. and M. Beardsley (eds.), Prentice-Hall, Englewood Cliffs, NJ 1973, p. 99.

[8] P.G. Epps, *Genetic Discrimination* [in:] *Encyclopedia of Bioethics*, vol. 2, p. 956.

unjustified, i.e. criteria are irrelevant with regard to the aim of distribution of rewards and punishments or an aim of distribution or a definition of an institution are wrong.

How may genetic discrimination manifest itself?

The consequences of the use of genetic information for health and other purposes may bring about both indirect and direct discrimination that manifests itself in several ways. First of all, one should consider indirect discrimination of the genetically least advantaged that can result from unequal access to health resources. New advanced technologies applied to medicine give people greater opportunities of enhancement than were ever known before but these new genetic technologies are not available to a broad segment of the population. Quite the contrary, access to genetic technology and genetic information is expensive and restricted to some of the most advantaged individuals in highly developed nations. Thus, exclusive genomic medicine gives rise to new challenges in the fair distribution of health care resources within and among nations. Of course, we do not have to draw any futuristic vision to understand the problem. We are all facing the problem right now in our current world. Over 50% of the causes of mortality in developing countries are completely curable in high-income countries.[9] Sometimes it is only a matter of vaccines that cost 20 cents each or even just a matter of anti-mosquito nets (one of the treatments against malaria). One cannot expect neither a similar quantity nor quality of life among all the inhabitants of our world. Today someone living in Zambia has less of a chance of reaching the age of 30 than someone born in England in 1840; somebody born in Burkina Faso can expect to live 35 years fewer than somebody born in Japan, and somebody born in India can expect to live 14 years fewer than somebody born in the USA. The unequal distribution of health resources results in indirect discrimination since people who are deprived of basic health care have no access to all other basic goods in a society. Genomic medicine is another step in medical advances that can either broaden the gap between the least advantaged and the most advantaged inhabitants of the world or narrow the gap and, since genomic medicine is based on the newest and most expansive technology, it is more probable that it will broaden the gap.[10] This is the problem of national and global distributive justice that occurs in a new challenging perspective and cannot be solved by itself. It requires global and national initiatives in public health policy

[9] Human Development Report 2005, pp. 3–25, http://hdr.undp.org/reports/global/2005/.

[10] See current data on the problem of equity in medical services based on genetics: D.C. Wertz, J.C. Fletcher, *Genetics and Ethics in Global Perspective*, Kluwer Academic Publishers, 2004, pp. 14–18; A. Krajewska, *op.cit*., pp. 206–212. About the problem of justice in the age of genetics see: A. Buchanan, D.W. Brock, N. Daniels, D. Wikler, *From Chance to Choice: Genetics and Justice*, Cambridge University Press, 2007, *passim*. See also the first article of this volume – G.J. Annas, *The Genomics Revolution in the Shadow of Auschwitz: Eugenics, Genism, and Genetic Genocide.*

that will combat new social divisions based on health status and health care opportunities.

Secondly, one should consider the direct discrimination of the genetically least advantaged that can be manifested in eugenic decisions and that can bring about changes for human species that could undermine the whole concept of justice. Eugenics is the term invented by Francis Galton, the cousin of Charles Darwin. The term comes from Greeks, where *eugenés* means "well-born," which is meant as hereditary endowed with good genetic qualities. The main aim of eugenics consists of the improvement of the human race or simply producing the best possible children. Eugenics may manifest itself in birth control aimed at "encouraging" the procreation of "fitter people" and "discouraging unfit people" from procreatrion. It may also manifest itself in the improvement of human nature by the manipulation of a genotype, where human abilities are quite restricted so far. Eugenic state policies that were rooted in social Darwinism of the late 19th century were largely discredited in the 20th century. However, the idea of eugenics itself has not been discredited yet. Quite the contrary, it is deeply rooted in people's minds and still present in social practices. Now, in the beginning of the 21st century, state eugenics is being replaced by private eugenics. It means that procreative decisions based on genetic information can be taken but only by individuals, not by the state or doctors who can neither force nor suggest them. By contrast to former authoritarian eugenics, we are now faced with liberal eugenics as Jürgen Habermas points out.[11] This liberal eugenics seems justified since it is natural for people to crave the best possible for their children or at least for having healthy children. Nevertheless, there is much concern about the whole idea of producing "better babies" that may bring about stigmatization and direct discrimination of "defected" human beings.[12] What is more, "improving humans" may create in the future a division between super-humans (improved ones) and sub-humans (not improved) that would be two separate species, called by Lee Silver the "GenRich" and the naturals.[13] If such a division appeared, the notion "justice" would be useless since one of the necessary conditions of justice is approximate equality in natural powers between and among human beings. If there would be a human race biologically endowed with such power that would

[11] J. Habermas, *Przyszłość natury ludzkiej. Czy zmierzamy do eugeniki liberalnej?* (*Die Zukunft der menschlichen Natur. Auf dem Weg zu einer liberalen Eugenik?*), M. Łukasiewicz (trans.), Warszawa 2003, *passim*, especially pp. 26 ff. About the idea of eugenics, positive and negative genetic interventions see: A. Buchanan, D.W. Brock, N. Daniels, D. Wikler, *op.cit*., *passim*. See also the first article of this volume – G. Annas, *The Genomics Revolution in the Shadow of Auschwitz: Eugenics, Genism, and Genetic Genocide.*

[12] About the problem of genetic discrimination resulted from the use of prenatal and preimplantation genetic diagnosis see A. Krajewska, *op.cit*., pp. 241 ff.

[13] L. Silver, *Remaking Eden: Cloning and Beyond in a Brave New World*, Free Press, New York 1985, pp. 110–111. I quote after G.J. Annas, *American Bioethics. Crossing Human Rights and Health Law Boundaries*, Oxford University Press, 2004, p. 50. Such a situation was vividly illustrated by the famous science-fiction movie *Gattaca* (1997) directed by Andrew Niccol with Uma Thurman and Ethan Hawke.

enable them to dominate permanently other races, justice would be impossible as David Hume writes.[14]

The whole idea of taking control over human evolution poses significant questions concerned with such notions as "better" or "improvement" with regard to a human being.[15] Such normative notions can be understood in different ways and we could never be sure if we are right about what would be better for our descendants or what kind of improvement future generations would require. As I mentioned before, it is very difficult to specify such notions as health, illness or even dysfunction of an organism since all of them require a concept of a norm which is defined in a context of a society. For instance, homosexuality was listed as a mental illness by the WHO's International Classification of Diseases (ICD) until 1990. Being different than most people does not have to be treated as having disorder. Even though most people agree that dwarfism or being deaf and dumb are dysfunctional abnormalities of the human organism, some people who are born with such features use pre-implantation genetic diagnosis (PGD) to guarantee that their children will be the same as they are. Of course, this is an exception which stays at odds with the general eugenic idea, but it shows us that there can be no consensus about justified reproductive decisions based on genetic information.

Last but not least, one should consider all situations in which the genetically least advantaged can be discriminated against (directly or indirectly) as far as their social status and private relations, insurance, employment, education etc. are concerned. Especially worthy of attention are situations in which individuals are treated differently with regard to the information about symptoms of a disease that they may develop in the future. Let me present some examples of such situations that pose many ethical and legal questions.[16]

It may happen that people who are apparently healthy, asymptomatic individuals undergo genetic testing that detects their future illness risk. Some insurers deny coverage or raise the premiums of those asymptomatic individuals who are at risk of an illness. It means that people with a gene for a condition are treated on a par with people who have the condition. It may also happen that people who were diagnosed as having the condition undertake special treatment and prevent the onset of disease. Nevertheless, some companies deny them insurance, treating them on a par with people who develop the symptoms of a disease. It may also happen that the genetic testing or screening diagnose an illness which can be healed or reveal a predisposition or susceptibility for a disease that can be prevented by special treatment but the insurer denies the coverage and one cannot afford the special treatment or cures that are available. Thus, if one

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[14] D. Hume, *Badania dotyczące zasad moralności* (*An Enquiry Concerning the Principles of Morals*), Kraków 2005, p. 21.

[15] G.J. Annas presents deep skepticism about genetic engineering and "enhancement" of human race that can bring about genetic genocide (G.J. Annas, *American Bioethics...*, pp. 35 ff.). See also the first chapter of this volume – G.J. Annas, *The Genomics Revolution in the Shadow of Auschwitz: Eugenics, Genism, and Genetic Genocide.*

[16] All examples are created by an analogy to real situations described in an article by P.R. Billings et al., *Discrimination as a Consequence of Genetic Testing*, "The American Journal for Human Genetics" 1992, vol. 50, pp. 476–482.

does not perform the genetic test, one will not know about the disease and one will not heal or prevent it. If one does perform the test, one has no insurance to cover the treatment or cure. The first situation is better than the latter, but both are worse than the possible promise of treatment or cure based on genetic test results. Of course, analyzing the problem of the use of genetic information in the insurance system, we have to take into account all the differences between countries and, since the health insurance system in Europe and Canada, in contrast to the U.S., provides universal access to health resources, the problem of genetic discrimination may manifest itself only as far as life insurance is concerned. Thus, if we discuss the problem within European context, the possible scope of discrimination would be limited.

It may also happen that employers use the genetic tests results included in an employee's medical record in group health plans as a basis for refusing to offer health coverage as part of their benefits. Employers may also use the results of genetic tests to take such decisions as: promotion, hiring or firing etc. An employer may want to avoid additional costs that individuals at risk of a disease may produce (health insurance costs, absence in work, lower flexibility, danger – for instance when it is a job of a driver or of a pilot etc.) and to guarantee the highest possible efficiency by giving the job for the most prospective efficient workers.

What is more, an adoption agency may seek to find the best possible parents for children and to reject adoption by people who are at risk of future illnesses. For instance, a couple who is at risk of developing Huntington disease do not want to have their own children since they do not want to pass the Huntington genes to the children. They decide to adopt a child but are rejected by an adoption agency although the first symptoms of the disease usually occur when people are around 50.

Other controversies may arise, when a person who has a driving license for twenty years and has never had any accidents or traffic violations is denied by the automobile insurance company of having car insurance on the basis of genetic test results that detect a genetic disorder in the driver.

All these hypothetical situations have already happened at least once in the USA and have brought about a fear of genetic discrimination which is manifested in a rejection of performing genetic testing and screening by many individuals. One can go one step further and imagine situations in other spheres of human life when similar discrimination may occur. For instance, the use of genetic information in relation to education may occur when people with inherited genetic predispositions or susceptibility for a disease are refused access to a particular school because of the information about their future illness risk or are treated differently in school on the basis of their genetic inheritance.[17] However, statistic research show that people generally distrust insurance companies or employers but trust the education system. Most of the people who took part in a global survey on genetic discrimination would not want to disclose their genetic test results to insurers or employers (if their health insurance depends

[17] See L.F. Rothstein, *Genetic Information in Schools* [in:] M.A. Rothstein, *Genetic Secrets: Protecting Privacy and Confidentiality in the Genetic Era*, Yale University Press, New Haven and London 1997, pp. 317–331.

on their employment), but they would want to disclose the genetic test results of their children to a school system to guarantee them the most appropriate education and treatment.[18]

Therefore, it is quite obvious that so far only discrimination in the dimension of insurance system has gained special attention, reflected in numerous legal acts that responded to the problem or the fear of the problem. The use of genetic information in relation to employment or education is very rare but the situation can be changed. In my further considerations I shall analyze the main controversies concerned with the prohibition of genetic discrimination in the example of laws prohibiting genetic discrimination in insurance which is the deepest concern of legislators around the world.

Laws prohibiting genetic discrimination

Genetic discrimination is forbidden in general by many international declarations and conventions. According to the Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine (otherwise known as the Convention on Human Rights and Biomedicine, or the Oviedo Convention),[19] all should have equitable access to health care resources (Art. 3) and any form of discrimination against a person on grounds of his or her genetic heritage is prohibited (Art. 11). What is more, any predictive genetic tests may be performed for health purposes only (Art. 12). According to the Universal Declaration on the Human Genome and Human Rights:[20] everyone's dignity and rights should be respected regardless of their genetic characteristics (Art. 2, sect. 2) and no one shall be a subject of discrimination on the basis of his or her genetic characteristics (Art. 6). Also the Charter of Fundamental Rights of the European Union proclaims that any discrimination based on genetic features shall be prohibited (Art. 21).[21]

What is more, the European Parliament stated that insurers neither have the right to require genetic testing as a condition for insurance nor to be informed about the results of genetic testing performed by the applicants. Some European countries followed the declaration of the European Parliament and prohibited the use of genetic information by insurers. In several countries insurance companies agreed upon a voluntary moratoria on the use of genetic information.

Countries that decided to regulate the use of genetic information in the field of insurance adopted either special non-discrimination and privacy acts or special rules within their existing regulations. The former model of regulation can

[18] See D.C. Wertz, J.C. Fletcher, *op.cit*., pp. 63–74.

[19] Drafted by the Council of Europe and entered into force on December, 1 1999.

[20] Drafted by the General Conference of UNESCO in 1997 and endorsed by the General Assembly of the United Nations in 1998.

[21] Drafted by the European Parliament, the Council of the European Union and the European Commission on December 7, 2000, adopted into the Treaty of Lisbon and entered into force on December 1, 2009.

be illustrated by the Genetic Information Nondiscrimination Act (GINA) passed by the House of Representatives and signed by President George Bush on May 21, 2008. According to the act, group health plans and health insurers are prohibited from denying coverage to a healthy individual or charging that person higher premiums based solely on a genetic predisposition to developing a disease in the future. The legislation also bars employers from using individuals' genetic information when making hiring, firing, job placement, or promotion decisions. The latter model of adopting special rules within other regulations can be illustrated by the Polish insurance law (Insurance Activity Act of May 22, 2003. However, the Polish law is not very restrictive in this matter and Polish labour law does not include explicitly any prohibitions of discrimination based on genetic characteristics. According to the Article 21 and 22 of the Insurance Activity Act, insurance company can *require* from an individual medical examination or diagnostic examination, *with the exception of genetic testing*, in order to estimate the insurance risk and specify rights to service and the level of premium. While GINA puts main stress on the fact of the use of genetic information in insurance, Polish law pays attention to the requirement of genetic testing, while omits the problem of taking decisions based on genetic information. Thus, GINA offers much broader protection of patient's rights since it forbids the use of genetic information (about a genetic predisposition to developing a disease) irrespective of how and from who the insurer obtained them. For instance, an insurance company could conduct tests themselves, could gain access to the medical records of an applicant that include genetic test results or could require from an applicant some specific genetic testing.

Actually, we can distinguish three main models of legal restrictions on the use of genetic information by insurers. The first one is aimed at the restriction of genetic information, whereas the second is aimed at restricting the management of information and the third at avoiding harm as far as the use of genetic information is concerned. The third model seems to be the most adequate when we consider the question of challenging genetic discrimination. However, it is not obvious how such aim could be efficiently guaranteed by legal regulations, especially if there is no consensus about genetic discrimination itself.

Some arguments against the prohibition of genetic discrimination

Taking under consideration the problem of discrimination in the dimension of insurance, we have to analyze whether genetic information is irrelevant or not as regards the criteria of different treatment of applicants. Insurers object to the prohibition of the use of genetic information in their procedures for many reasons. They argue that genetic information cannot be distinguished from other medical information about health status or condition of an individual that are the core basis of insurance system. What is more, the prohibition of the use of genetic information by insurers would privilege some applicants and bring about the so called adverse selection making the distribution of insurance deeply unfair, so the argument goes. Let me present the main arguments briefly.

1. Genetic information as a part of medical data

One can argue that genetic test results are a part of personal health records that cannot be isolated or distinguished. If the insurers may obtain and use other personal medical data, including family health care history, it remains quite unclear why they are prohibited from using genetic test results, so the argument goes. The insurance system was always based on personal health information that helped to estimate the future risk of a individual to an onset of disease. Such information was always the basis for specifying the premium of an individual as well as deciding about the coverage. Companies gather personal health information, including age, health care history, and family health care history, in underwriting individual insurance policies. They use statistical correlation of this data with future ill health to predict whether they result in claims for payment under an insurance policy. Furthermore, the insurance companies establish their policy terms, as well as premium amounts, on the basis of such predictions. If the estimated risk is too great or unpredictable, which means that it can bring more costs than benefits, the companies used to refuse coverage.

2. Adverse selection

What is more, insurers usually invoke the so called "adverse selection" as the crucial argument that prohibition of the use of genetic information by insurers would be unfair. If applicants for individual insurance coverage have undergone genetic testing and had no obligation to disclose the results to the insurance companies, they would be the privileged side. People with positive test results would buy the coverage and those with negative would not. Taking into account that all individuals were to be charged the same premium and offered the same coverage irrespective of their personal information, those applicants who were at the lowest risk would desert the insurance companies and there would remain only those at the highest risk who would generate inadequately high costs for the companies.[22] That would result in increasing premiums or the collapse of the system of insurance. Therefore, insurers argue that they should have the right to either require or at least to obtain and use the genetic test results of their applicants.

Some arguments for the prohibition of genetic discrimination

New regulatory regimes that meet the problems of the use of genetic information by insurance companies demonstrate quite the opposite view. The non-discrimination or privacy laws that provide double standard of protection with

[22] R.M. Berry, *Health Care and the Human Genome. Regulatory Challenge and Response* [in:] A.S. Iltis, S.H. Johnson and B.A. Hinze (eds.), *Legal Perspectives in Bioethics*, Routledge, New York, London 2008, p. 98.

regard to genetic information distinguish them from other medical or personal information. The distinction and the special protection are grounded on the argument of genetic exeptionalism.

1. Genetic exceptionalism

Sensitive data is that which requires special protection because of their nature. According to The Convention for the Protection of Individuals with regard to Automatic Processing of Personal Data of the Council of Europe of 1981, sensitive data includes information about race and ethnical origins, political opinions, religious beliefs or sexual life and orientation. There are some who argue that genetic information should be included in the list of sensitive data. As George Annas, Leonard Glantz and Patricia Roche write: "Genetic information is uniquely powerful and uniquely personal, and thus merits unique privacy protection."[23] Statements such as genetic information is unique, exceptionally sensitive and therefore requires wider and separate protection from other health related medical records is called genetic exceptionalism.[24] Genetic exceptionalism consists of both a descriptive and a normative assumption. The descriptive one is that genetic information are distinctive and can be distinguished from other medical information while the normative is that they ought to be specially protected.

First of all, genetic information can be seen as highly sensitive and unique because of its special *predictive character*. It not only describes people's health in the past and present, but they may predict people's future health, detecting a predisposition or susceptibility for illness in healthy asymptomatic individuals. Thus, George Annas calls individuals' genotype profiles their "future diaries."[25] Secondly, genetic information provides much more personal information than medical data, not only information about individual's health status, but also about many other significant personal characteristics. It enables the identification of an individual. This is why genetic information can be protected in two legal regimes – of personal data and of medical data. Thirdly, genetic information is unique and highly sensitive since it reveals information not only about an individual but also about an individual's family (ancestors, siblings as well as current or future offspring). It poses questions about the limits of individual autonomy and the need for the special protection of people's privacy. Fourthly, genetic information exists beyond our control and cannot be changed by our actions or decisions. Thus, it seems that our genes reflect our fate that we do not chose and cannot change. Finally, genetic information is very easy to obtain without consent or even the knowledge of an individual. For instance, one

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[23] G. Annas, L. Glantz, P. Roche, *Drafting the Genetic Privacy Act: Science, Policy and Practical Considerations*, "Journal of Law, Medicine and Ethics" 1995, vol. 23, p. 360.

[24] See J.G. Hodge, Jr., *op.cit*., pp. 1019–1020; T.H. Murray, *Genetic Exceptionalism and "Future Diaries": Is Genetic Information Different from Other Medical Information?* [in:] M.A. Rothstein, *op.cit*., pp. 60–73; A. Krajewska, *op.cit*., pp. 59–66.

[25] G.J. Annas, *Privacy Rules for DNA Databanks: Protecting Coded 'Future Diaries'*, "Journal of the American Association" 1993, vol. 270, pp. 2346–2350.

can perform genetic testing on a tiny genetic material included in somebody's saliva left on a cup of coffee or on a licked envelope.

Although all these arguments seem very persuasive, they have been frequently questioned. Firstly, most illnesses can be seen as genetically-based so all such medical information about illnesses can be treated as genetic, irrespective of its source. Secondly, there are many sorts of information that have a predictive ability, not only genetic information. For instance, health care history or the level of cholesterol provide some kind of prediction of a future health condition. Thirdly, health records can provide many personal details as well as some information about individual's relatives. What is more, information about certain diseases based on non-genetic (e.g. environmental) conditions can be as important for the family members (a spouse, offspring or siblings) as any genetic information. It depends on a disease, not on a source of disease. Fourthly, there are many non-genetic factors relevant to an onset of a disease that are absolutely beyond our control – such as pollution, smoking parents or co-workers etc. In sum, we have to admit that it is extremely difficult to treat genetic information as something separate from medical data, even though it does not mean that genetic information does not require special protection. When we challenge the descriptive assumption of genetic exceptionalism it does not undermine the normative assumption. We can still argue that genetic information ought to be specially protected *as if they were* distinctive. However, any regulation based on these assumptions may be inefficient in practice because of all the difficulties concerned with distinguishing genetic information and the ambiguity of its definition. Therefore, I would like to consider another approach to the problem of genetic discrimination which turns back to the initially invoked problem of the justified and unjustified criteria of different treatment.

When genetic features are unjustified criteria of different treatment – challenging genetic determinism

The debate over genetic non-discrimination acts goes into blind alley when it is focused on the question of whether information is genetic or non-genetic. Instead it should be focused on its character and on the use of information, especially on its context.

It is worth mentioning that both sides of the debate – those who argue against and those who argue for genetic non-discrimination acts – usually share the faith in genes and the ability of genetic information to reveal our fate. The former argue that individuals who are different in their genetic predispositions and heredity cannot be treated alike with respect to their insurance system since such features are relevant to the aims of the distribution of health or life insurance. The latter, on the other hand, argue that since genetic features are not a matter of people's choice they cannot be the justified criteria of the distribution of health or life insurance. The problem of both lines of argumentation lies in that they

ignore the fact that genetic information cannot solely determine people's life and health condition, however its predictive value can be very strong.

Genetic determinism (essentialism or reductionism) is a belief that genes determine human beings and their life.[26] It is a position that neglects all other relevant and important information about human beings such as environmental and social conditions, as well as individual free will and the ability to make reflective judgments, and reduces a human being to her genes only. To challenge this statement, "we should give genes their due, but no more than that" as Thomas Murray puts it.[27] Genetic determinism is not only a cause of misunderstandings in the debate over genetic non-discrimination acts. It is also the main source of public fear of genetic discrimination and stigmatization. Therefore, I claim that the fundamental argument in favour of genetic non-discrimination acts is that they are (or ought to be) aimed at challenging genetic determinism. Since nobody should be reduced to her genetic features, differentiation in treatment based solely on genetic information about genes for the condition of disease is unjustified. Laws protecting genetic privacy and prohibiting genetic discrimination should be based on the fundamental assumption that having a gene for a condition is something different from having the condition. Thus, a healthy individual who has a predisposition or susceptibility for a disease cannot be treated on a par with an already ill individual who has developed the symptoms of a disease. It would be discriminatory since individuals who are different in some relevant respects ought to be treated differently.

Nevertheless, it does not exclude the use of genetic information as the criteria of distribution of goods (including insurance or employment) when they are relevant to the aim of distribution. If we accept that the insurance system is based on probability measures and the estimation of future risks, we should admit that actuarial methods can provide justified criteria of different treatment of applicants. Therefore, the increased likelihood of using health care services among individuals who are in a group at higher risk of the development of a disease could justify their different treatment by insurers and it should not matter if the estimation of risk is based on genetic test results or family health care history. Yet if there are no such actuarial justifications, people with a predisposition or susceptibility for a disease cannot be treated different from other asymptomatic healthy individuals. In other words, the analyses of justified and unjustified criteria of distribution of insurance should take into account distinction of information with regard to their predictive value and their statistic correlation to risk and laws prohibiting genetic discrimination should be focused on challenging the idea of genetic determinism and on highlighting the significance in the distinction between asymptomatic and symptomatic individuals as well as between the diagnosis and prognosis of a disease.

Last but not least, considering the problem of discrimination in the insurance system we have to take into account the aim of the distribution. The main aim of insurance companies is to maximize their profits. The main aim of applicants, on the other hand, is to enable their access to health services or to guarantee their

[26] P.G. Epps, *op.cit.*, p. 956.
[27] T.H. Murray, *op.cit.*, p. 70.

family members financial support when the main wage earner in the household dies. Legislators and state policies have to weigh the interests of all parties and to pursue the main aim of the health care which is promotion of public health and guaranteeing of appropriate treatment or prediction of diseases among people. To realize this aim, legislators should adopt laws that would encourage people to perform genetic testing and screening and ensure the use of genetic information for the improvement of public health condition. This is one of the greatest challenges to health care policies in the age of genomic medicine.

Concluding remarks

Genomic medicine places us in a position of significant moral choices and poses many legal challenges. It is difficult to distinguish between information derived from genetic tests and information obtained from other medical data. Thus, it is difficult to maintain the exceptional protection of genetic information. Nevertheless, the special and wide ranging protection of patient's rights and privacy is highly required. In my opinion, such protection should be understood as part of a broader project of human and patient's rights protection and interpreted in their perspective. The main goal of any legislations with respect to the subject of genetic discrimination is to find the balance between individual rights (that address such crucial ethical notions as individual autonomy, integrity, privacy, confidentiality, human identity and dignity, moral equality), insurance companies' interests and the community's interests in promoting public health. Taking it into account, one should always remember that new advances in medicine are supposed to bring us new hopes for better treatment and open new perspectives for future health care. For people who undergo genetic testing and discover the fact that they are at risk of a disease it seems to be a cruel paradox when such information is used not in order to prevent the onset of disease but in order to refuse them the possibility to undergo special treatment. They suffer firstly from having a predisposition or susceptibility to disease and secondly from being excluded from or limited in their treatment. This is exactly the situation which brings about the public fear of genetic testing or screening that is an obstacle for further genetic research and further progress in genomic medicine. Law is an instrument by which we can challenge the problem and promote sensitivity to individual rights in public health care polices.