



Krzysztof Kaźmierczak

Right to genetic information relating to a person in international law

(Prawo do informacji genetycznej dotyczącej osoby w prawie międzynarodowym)

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SUMMARY

Presented dissertation is focused on the problematics of genetic information relating to a person in international law.

Last decades have seen an extremely rapid development of technology and knowledge related to human genetic information. This has led to widespread usage of such information for a great multitude of purposes, from medical to scientific research to prediction of future risks for health or personal development, creating related risks for rights and freedoms. Predictive nature of such information leads to risk of reducing a person to their genetic heritage. At the same time, shared nature of genetic information means that it may relate not only to the person from whom it was taken, but also to genetic relatives or to a broader group who shares genetic similarities. These threats lead towards the development of the concept of genetic exceptionalism, according to which particular risks associated with genetic information differentiate it from other types of information relating to a person and thus require a dedicated protection.

The purpose of research was to find answers to three questions. The first one concerns the status of personal genetic information in international law, in the light of proposals concerning the status of human genome as a common heritage of mankind. The second question concerns the existence and form of a uniform standard of protecting persons genetic information in international law. The third question concerns the role of personal data protection law in safeguarding rights and freedoms related to persons genetic information. Notion of genetic information has been used, as explained in the dissertation, to refer to all data associated with human genome – as the law has not adopted a uniform vocabulary in this area.

Dissertation consists of four chapters, preceded by an introduction, and followed by a conclusion.

Chapter I introduces main subject of analysis and presents the notion of genetic information as a subject of legislation, to explain the subject of analysis. First part provides a basic overview of most important notions. Throughout the development of genetic sciences, the notion of gene itself has undergone a significant evolution, from an abstract entity associated with inheritance, to a specific chemical substance, to a more broad and general “postgenomic meaning” which encompasses a broad subset of factors. At the same time however, all those

meanings can and are being used in discourse, to describe different elements. Analysis of possible different meanings behind the notion of genetic information is necessary to provide an answer to the scope of regulation. Evolving understanding of the gene had also a direct impact on the evolution of law in this field. The latter parts of Chapter I describe potential usage of genetic information and its specific characteristics, in order to establish the concerns it raises, regarding individuals privacy and expectations, regarding the regulation.

Chapter II describes the international framework dedicated to protection of genetic information. Last three decades have witnessed adoption of multiple documents related to this field. Most far reaching was the concept of establishing human genome as common heritage of mankind in symbolic sense, contained in The Universal Declaration on the Human Genome and Human Right from 1997. As described in the text, the meaning of this proposal was however uncertain and ultimately it has not been translated into specific legal norms.

The latter part of Chapter II describes existing framework of international law, concerning the topic of dissertation. In the last several decades a multitude of international documents of various types have been adopted, referring to this field. Analyzing the material there exists a certain level of consensus between various documents, concerning what rights an individual should have and the limitation of the usage of individual genetic information and rights such a person shall possess. Those documents lack however binding character – with the sole exception of The Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine. Therefore, as the chapter concludes, no specific framework of regulating genetic information has been adopted in international law, but a set of proposals regarding persons rights does however exist and there is an agreement as to what laws should be protected. Ultimately the concept of dedicated law concerning genetic information seems to have been rejected on the international level.

Chapter III describes the legislation on personal data protection as an alternative mean of regulating genetic information. European Union General Data Protection Regulation (GDPR) has been chosen as the subject of analysis. Reasons for such choice is its role as instrument for all EEA countries as well as the impact of European Union legislation in the area of data protection on legal systems of other countries. Furthermore, the GDPR attempts to regulate the problem through incorporation of the notion of genetic data into the document and creation of a set of dedicated provisions, and therefore is a document of particular importance in this field.

As described in the chapter, rules contained in GDPR do provide a set of safeguards and limitations, concerning the usage of persons genetic information. In particular the role of the concept of risk to rights and freedoms of a person allows the act to better adjust its requirements to a specific situation. However the personal data protection framework contained within GDPR does not answer all the interest of a person and seems not to be fully suited to the particularities of genetic information. Those issues are primarily associated with the fact that some of the unspoken assumptions of the legislator, regarding personal data, are not fully applicable to genetic information. Furthermore, inherent to the data protection system is the dualistic character of its provisions. Information either is personal data – and is protected, or is not considered as such – and then is outside of scope of regulation. In case of genetic information this does not take into consideration its potential to provide additional information on the person, of the potential for re-identification of a person once the data is anonymized. Development of appropriate standards seems possible on the basis of existing institutions of GDPR, but so far none have been adopted.

Chapter IV describes the rights of actors other than the ones whom data directly describes. Genetic information is by its very nature, shared between related persons. As such, both the relatives and entire group to whom a person belongs may possess interests related to genetic information, both in learning of what it reveals about them, as well as in preventing the dissemination of such information.

As is noticed in the text, analysis of existing jurisprudence indicates a level of recognition of the need to safeguard such rights. However, so far, the existing legislation abstains from such formal recognition. An attempt to use the framework of personal data protection in GDPR to guarantee the rights of relatives or entire groups does lead to conflicts between various interested parties. Such rights seem to not be suited to managing data belonging to multiple persons. In case of ethnic groups a number of solutions have been proposed, concerning their participation in research, and the relevant examples are analyzed. Particularly the concept of Indigenous Data Sovereignty is an international attempt to create a framework recognizing the role of groups and populations in governance and their right to data, however at the time of this dissertation being written, was not recognized in existing law and remaining only proposition.

While significant gaps in protecting persons rights can be found, as noted in the conclusion, there seems to be no specific need to adopt dedicated legislation. As was indicated in the text, there exist solutions and institutions in adopted legislation, which could be used to

adjust the existing scope of protection to the specific requirements of genetic information. What is needed is the willingness to adopt such measures. So far in many cases regulatory and advisory bodies, as well as courts, seem to be unwilling to engage the subject.

Of the four possible models of protecting persons genetic information as proposed by scholars - those being sui – generis model, privacy model, quasi-ownership model and anti-discriminatory model, dissertation analyzes the first two. The quasi ownership model has not been reflected in international framework, though it had impact on legislation on some states. Anti-discriminatory model has significant impact on the rights of a person, but involves a different scope of rights and requires a separate, dedicated analysis.

The topic of the dissertation has not been a subject to analysis in polish language. Two works on similar subject exist, but they touch the issues of informational privacy in a limited manner. Moreover, both works due to their age cannot take into consideration recent developments in legislation - mainly the General Data Protection Regulation – as well as some of relevant scientific progress in the field of epigenetics.