Genetic Databases and Protection of Genetic Data

Abstract

This thesis deals with the processing of genetic data obtained by DNA sequencing.

The data obtained from the human genome represents a revolutionary basis for scientific

research and open the way for the treatment of some so far incurable diseases such as cancer,

AIDS, and Alzheimer's disease.

The thesis primarily focuses on the legal regulation of the protection of genetic data.

The thesis describes the processing of genetic data, including its use and dissemination, mainly

through providers of genetic databases and genome browsers for scientific research purposes.

From the perspective of the current legal framework in the Czech Republic and the European

Union, the thesis analyzes the existing level of protection of genetic data and points out evident

shortcomings. However, the thesis is not limited to a description of legal regulations

but thoroughly evaluates the issue de lege ferenda.

The aim of this thesis is to evaluate the current practice of processing genetic data,

particularly its accessibility, storage, the possibility of its anonymization, and ways of its

misuse. The thesis focuses on the issue of the implementation and consequences of the current

legal regulation mainly established by the Regulation (EU) 2016/679 of the European

Parliament and of the Council on the protection of natural persons regarding the processing of

personal data (GDPR), but also assesses the possible impacts of the proposed future legal

regulation. Special attention is given to the risks associated with the misuse of genetic data,

especially in the context of the protection of personality and possible re-identification of the

data subjects.

The last part of the thesis is devoted to the processing of healthcare data in connection

with the Proposal of the European Parliament and Council Regulation (EU) on the European

Health Data Space and the secondary use of the data for research purposes.

Key words: genetic database, genetic data, personal data protection