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## SPECIAL ISSUE

Proceedings of International Conference:  
Justice in the Genomic and Digital Era

Sep. 6, 2019  
Tomsk, Russia

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*Executive Publisher*

Privacy of genetic data: issues with legislation and law enforcement in the Russian Federation  
*Anna Semiakina*

'Race' and other group discrimination in the genomic era  
*Fatos Selita, Marc Willers, Yulia Kovas*

Public Danger of Unauthorized Use of Human Genetic Data  
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*Stephen Aremu and Anna Kniazeva*

Combatting the discriminatory use of genetic data  
*Marc Willers*

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# Special Issue

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# Genomic era and new challenges for justice & regulation

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**Summary.** We are now faced with unprecedented progress in genomic research. Findings can be used for family planning, prediction, prevention and treatment of diseases, understand disabilities and behaviour disorders and to investigate crimes. DNA can be used to identify victims of disasters, locate missing persons, and even monitor trafficking of goods such as ivory or wood. They can also be used to the harm of individuals and society, including through discrimination (e.g. access to health, education) and unreasonable and unjusti-

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fied state interference in the private life of individuals (e.g. through surveillance)<sup>2</sup>.

**Keywords:** DNA profile, genome editing, genome register regulation, human rights, private and public balancing of interests.

Genomic data banks are growing rapidly. The first DNA database was created in Great Britain in 1995 and in 2017 there were DNA profiles of 4 million people, which is nearly 6% of the whole UK population<sup>3</sup>. But some countries have genetic data of almost the entire population, for example Iceland. Its database contains genotypes of the entire population (about 300,000 people)<sup>4</sup>. (*\*Population for 01.01.2019 consists 357 050*).

Created in 2002, INTERPOL's DNA database currently contains more than 180,000 profiles contributed by 84 member countries. According to Interpol's Global DNA survey results of 2008, 120 countries use DNA profiling to investigate criminal cases, 54 of which currently had national DNA databases and 26 planned to introduce them<sup>5</sup>.

This year in Russia, the decree "On RF national policy in chemical and biological security till 2025 and further perspective" was

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<sup>2</sup> Selita F. Genetic Data Misuse: Risk to Fundamental Human Rights in Developed Economies. // Legal Issues Journal, 7(1), 2019.

<sup>3</sup> About UK Biobank // <http://www.ukbiobank.ac.uk/about-biobank-uk/> (Date of access 21.11.2019).

<sup>4</sup> Генетический паспорт: что это такое, и зачем он нужен россиянам // <https://med.vesti.ru/articles/polezno-znat/geneticheskij-pasport-cto-eto-takoe-i-zachem-on-nuzhen-rossiyanam/> (Date of access 15.10.2019).

<sup>5</sup> DNA can play a crucial role in convicting – or clearing – suspects of a crime, and can also be used to identify missing persons // <https://www.interpol.int/How-we-work/Forensics/DNA> (Date of access 13.12.2019).

signed, introducing a system of genetic passports or DNA-profiles. Such passports will consist of two parts. The first part will be presented as a raw data in digital format which can be duly explained only by qualified specialist. And the second one is interpretation of this data. The last part will be updated if and when new genetic markers are discovered.

Genetic implications create new challenges for justice, particularly for criminal justice, demanding serious thought, scientific basis and public discussions. Challenges for criminal justice, related to development of genomic research, include:

1. Using of DNA and biological material for the identification of a criminal—raising issues of getting, storing and transferring biological materials and DNA-profiles and regulation of biobanks activities.

An example illustrating this point is the case of *S. and Marper v. United Kingdom* 2008<sup>6</sup> decided by the European Court of Human Rights (Strasbourg). The case concerned the retention by the authorities of the applicants' fingerprints, cellular samples and DNA profiles after criminal proceedings against them were terminated by an acquittal in the case of *S.* and discontinued in the case of *Marper*<sup>7</sup>.

The Court held that indiscriminate “blanket” retention of fingerprints, cellular samples and DNA profiles following acquittal is in violation of article 8 (right to respect for private and family life) of the European Convention on Human Rights<sup>8</sup>.

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<sup>6</sup> Case of *S. and Marper v. the United Kingdom* (No.30562/04&30566/04) <http://hudoc.echr.coe.int/eng?i=001-90051> (Date of access 15.12.2019).

<sup>7</sup> Grand Chamber judgment. *S. and Marper v. United Kingdom* 04.12.08. Press Release - Grand Chamber Judgments Published on 04/12/2008 <http://hudoc.echr.coe.int/eng-press?i=003-2571936-2784147> (Date of access 15.12.2019).

<sup>8</sup> European Convention on Human Rights [https://www.echr.coe.int/Documents/Convention\\_ENG.pdf](https://www.echr.coe.int/Documents/Convention_ENG.pdf)(Date of access 15.12.2019).



2. Origins of violence have multifactorial structure.
3. The recent international studies identify about 40 genes related to aggressive behavior.<sup>9</sup> This means that violent behavior is determined by complex and variative?? interactions between both environmental (social, cultural and etc.) and biological factors. This fact should be taken into consideration in legal regulation, prevention of crime and punishment/sentencing. Also, it poses the fundamental question of equality before the law.
4. Development of genetics is hastening the emergence of new types of socially dangerous behaviour which partly should be subjected to a criminal law. This is especially related to potential misuses of combined genomic data and other big data.

It is hard to find out exact statistics on misuse and harm in medical genetics. However, there is no universal international mechanism to regulate use of data for all stakeholders and so we faced with numerous issues.

There are international efforts and instruments in place attempting to regulate use of genetic data – the turning point made in 1997 when the Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine (ETS No. 164, 1997)<sup>10</sup> was opened for signature in Oviedo (Spain) and also known as ‘Oviedo Convention’. This was the first multilateral binding instrument entirely devoted to biolaw and into force on 1 December 1999. It has accumulated the effort on the part of the Council of Europe to keep pace with developments in the field of biomedicine and introduce principles applicable to any medical act and «new» biomedical technologies (trans-

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<sup>9</sup> Zhang-James, Y., Fernández-Castillo, N., Hess, J.L. et al. An integrated analysis of genes and functional pathways for aggression in human and rodent models. *Mol Psychiatry* 24, 1655–1667 (2019).

<sup>10</sup> Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine <https://rm.coe.int/168007cf98> (Date of access 15.10.2019).

plantation, biomedical research and genetics)<sup>11</sup>. The international treaty based on the fundamental connection between human rights and biomedicine was signed by 35 countries and ratified by 29 as some nations like UK considered it too strict. Provisions related to human genome were also incorporated to the Convention (see Chapter IV). Finally, Additional Protocol concerning Genetic Testing for Health and Statement on Genome Editing Technologies was implemented by the Council of Europe.

**Conclusion.** All benefits brought by genetics research to various fields, such as medicine, social life and law, have very complex nature. Implementation of the results of genomic research must be based on adequate balanced model of legal regulation and self-regulation as well as high ethical standards both on national and international levels. It requires efforts of interdisciplinary research teams and wide public discussions in order to protect individual, public and state interests.

**Acknowledgement:** *This work was supported by the Russian Ministry for Education and Science project No.25.8663.2017/9.10.*

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<sup>11</sup> Andorno R., *The Oviedo Convention: A European Legal Framework at the Intersection of Human Rights and Health Law*, JIBL Vol 02, 2005.