

## GENETICS AND ITS ETHICAL ISSUES

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### Annotation:

The review article examines the main ethical and legal aspects of biomedical research. It covers historical background and international regulations, principles of research ethics involving humans and animals, requirements for informed consent, protection of vulnerable groups, regulation of clinical trials and biobanking, as well as issues of confidentiality, conflict of interest, and researchers' responsibility. The article provides recommendations for compliance with ethical standards and legal regulation.

### Keywords:

genetics, ethics, genetic testing, confidentiality, discrimination, genome editing, reproductive genetics, biobanks, informed consent, DTC tests

### Introduction:

Rapid progress in genetics and genomics has expanded the possibilities of medicine: precise diagnostics, targeted therapy, prevention of hereditary diseases, and improved research. However, there are growing ethical, legal, and social challenges related to the handling of genetic data, risks to individual autonomy, potential discrimination, and unequal access to scientific outcomes. This review article aims to summarize the key issues, evaluate existing approaches to their regulation, and provide practical recommendations.

### Historical background and regulatory framework:

- Key documents and examples of abuse: eugenic practices, experiments without consent.
- International recommendations: Declaration of the World Medical Association, UNESCO recommendations on genetics, national laws on the protection of personal data and the regulation of gene therapy.

### Informed consent and sample donation:

- Consent must be informed, voluntary and documented.
- Problems of secondary use of samples and data, consent models: specific, broad, dynamic.
- Rights to withdraw consent and consequences for data that has already been used/analyzed.

### Privacy and data protection:

- Genetic data is sensitive information: risk of re-identification even with anonymization.
- Data protection legislation (e.g., GDPR) requires minimization, pseudonymization, and the rights of data subjects.
- Data access policies, cybersecurity, and institutional responsibility.

### Discrimination and stigmatization:

- Risks of discrimination based on genetic characteristics in insurance, employment, and social status.
- Legal prohibitions on genetic discrimination and mechanisms for protecting victims are necessary.

### **Reproductive genetics and preimplantation diagnostics:**

- Ethical dilemmas in preimplantation genetic diagnosis (PGD), prenatal screening, and embryo selection.
- Questions about the limits of permissible choices, eugenics, human dignity, and the rights of the unborn child.

### **Gene therapy and genome editing:**

- Separation of somatic and germline interventions: germline interventions govern inherited changes and have higher ethical and legal requirements.
- Safety issues, long-term consequences, fairness of access, and regulatory control.
- Precedents and international discussions following cases of unethical embryo editing.

### **Direct-to-consumer tests (DTC) and commercialization:**

- DTC tests expand access but raise questions about quality, interpretation, psychological consequences, and privacy.
- Commercial use of customer data and ownership of genetic data.

### **Biobanks, access, and distribution of benefits:**

- Management of sample collections and data: issues of consent, researcher access, and sharing benefits with donor communities.
- Inequality of representation in genetic databases and implications for research accuracy and fairness.

### **Ethical aspects of research and clinical practice:**

- Requirements for ethical committees, transparency, reporting, and reproducibility.
- Management of conflicts of interest between researchers, commercial partners, and patients.

### **Social and cultural factors:**

- Differences in the perception of genetics across cultures, issues of trust in science, and historical traumas (e.g., research that violates the rights of communities).
- The importance of public engagement and dialogue in policy development.

### **Regulation and international cooperation**

The need for agreed international standards in cross-border research and data sharing.

- The role of professional organizations, regulators and legal mechanisms in controlling innovation.

### **Recommendations:**

- Strengthen legal protection against genetic discrimination.
- Implement transparent consent mechanisms, including dynamic consent for long-term research projects.
- Ensure high standards of safety and quality for DTC tests and genetic services.
- Develop educational programs for specialists and the public on genetics and ethics.
- Promote equitable access to genomic medicine and inclusivity in biobanks.
- Restrict and strictly regulate germline editing until there is broad public consensus and proven safety.

### **Conclusion:**

Genetics offers immense opportunities for medicine and science, but requires a balanced ethical and legal approach. Balancing innovation with the protection of individual and societal rights is a key principle in shaping policies and practices.

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