



Human Genetics and Genomics Law in China

Summary and Recommendations

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Highlights

- In China, literature on the ethical and legal issues of genetics and genomics is very rich.
- Discussion on genetics and genomics legislation should not be limited to the gene editing technology itself, but should incorporate the long-term impact of gene editing technology on human population reproduction and social stability.
- We must always consider whether genetic technology has truly improved human life and ensures the harmonious development of human society.

Who is this for?

The National People's Congress in China, The State Council in China, National Health Commission in China, Ministry of Science and Technology in China, Other policy makers in China

Introduction

In China, the literature on the ethical and legal issues of genetics and genomics is very rich, scattered in different literature databases and government agencies' websites, and requires careful screening and selection. Based on the existing literature, China's responses to genetic and genomic technologies are effective. The Chinese government, research institutions and relevant research groups have a comprehensive set of administrative and legal measures to manage them, and regulate their adverse consequences.

The Chinese government and academic circles attach great importance to the impact of the rapid development and wide application of genetic and genomic technologies on ethics and law, organize and carry out relevant research, and formulate relevant ethical principles, codes of moral conduct and legal provisions: on the issues related to the ethics, administrative regulations are the main ones; on the legal issues, the functions of laws and regulations are emphasized.



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On the whole, China has built on the general genetic ethics principles, ethics and legislative experience in the world, combined with the current national conditions. After more than 20 years of development and improvement, a series of ethical and legal regulatory systems suitable for the sound development of genetic technology have been formed. This system is relatively stable and dynamically adjusted.

Recommendations

- For the future, no matter how science and technology develop, ensuring people's survival, health, and overall development rights should be the basic premise of research.
- The discussion on genetics and genomics legislation should not be limited to the gene editing technology itself, but should incorporate the long-term impact of gene editing technology on human population reproduction and social stability.

It is also important to:

- Accelerate the pace of legislative research and reform, upgrade the operating mechanism of the ethics review committee to the level of laws and regulations, and strengthen the protection of human subjects through legislation.
- Learn continuously from the relevant laws and regulations and successful experiences of countries around the world, including the results of the SIENNA project, strengthen international exchanges, and establish a legal system suitable for the healthy and orderly development of genetic technology.

Final thoughts & take-aways

We must always consider whether genetic technology has truly improved human life and ensure the harmonious development of human society. The basic position of human genetics and genomics research should be to maximize its positive effects and limit its negative effects. This is a historical mission that China and other countries should jointly accomplish.

Medical clinical application is one of the most focused applications of gene editing technology, involving a complex set of stakeholders, intellectual property rights of gene editing technology and products, and the relationship between medical institutions, patients, suppliers and consumers of gene products. Gene editing technology is applied to a variety of interests, needs and involves complex legal relationships. How should we balance the interests of different stakeholders? How do we control the balance between technological development and intellectual property protection? These are the challenges faced in ethical and legal research in human genetics and genomics.

Based on the existing literature, the governance of genetics and genomics in China is effective. The ethics related to medical research and clinical practice of gene technology has been gradually established, and a series of laws and regulations have been formulated to solve the legal problems brought by gene technology. With the ongoing development of the technology, corresponding adjustments and improvements have been made to ensure the technology research and application practice cannot breach morality and law.





The Chinese government and relevant departments attach great importance to learning from international legislative experience, and gradually improve the legislative model, legal system and supervision methods, adhere to a scientific and prudent attitude, and achieve steady progress in practice to further ensure the effectiveness of government decision-making and related legislation and fairness.

Further reading

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About the SIENNA Project

In the SIENNA project, we examined China's regulatory responses, current academic literature and legal developments related to human genetics and genomics, and designed proposals to ensure that human rights and other important societal values are respected.

The EU-funded Horizon 2020 SIENNA project (Stakeholder-Informed Ethics for New technologies with high socio-economic and human rights impact) is of great significance to the research and establishment of China's genetic technology ethical framework and legal system. In the context of the integration of different cultures and economic globalization in the world today, China needs to learn from the relevant experiences and research results of other countries. Through the exchanges and cooperation of scholars and research institutions from various countries, consensus is gradually reached, and certain general ethical principles and legislative models are established on this basis, which is of great significance for human society to effectively respond to the ethical and legal issues brought about by genome technology. The SIENNA project undoubtedly played an exemplary role.

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