

## Doctoral (PhD) dissertation

Title: “The bioethical problem of genetic information and discrimination: The doctrine of genetic exceptionalism in policy debates”

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### Summary:

The emergence of the Human Genome Project and the rapid developments in molecular genetics gave rise to extensive ethical, legal and social debates regarding the potential future applications of genetic information, especially the possibility of discriminatory usages. As a result, in the course of the development of these debates, appeared the dominant policy tendency that urged the establishment of special regulations concerning genetics. The special status given to genetic information, the notion that personal genetic information should be treated as exceptional compared to personal health care data is called the doctrine of genetic exceptionalism. The dissertation attempted to map how the doctrine of genetic exceptionalism was established, what were the specific historical, epistemological and social factors that influenced its career to become the dominant policy approach within the regulatory efforts of genetic information.

The arguments supporting genetic exceptionalism might be grouped into two. One is supported by the social representation of genetic information, which is heavily influenced by the early uses of genetics, racial hygiene, and the dark shadow of the eugenics movement, and also affected by contemporary genetic determinist views. The other group of arguments make reference to the “scientific” or factual nature of genetic information, the representation of genes and genetic information within scientific discourses. The dissertation discussed: 1.) the historiography of eugenics; 2.) the contemporary experience of genetic discrimination; 3.) the various conceptions and definitions of genetic information and genes; 4.) the predictive value of genetic information; 4.) the reasons provided for genetic exceptionalist policies, their critiques and the potential pitfalls of these policies; 5.) the role eugenics plays in contemporary bioethical discourse on genetics.

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