

# Pro-Active Users?

The illusion of privacy and autonomous data subjects regarding their genetic information

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## Abstract

The paper compares the regulation of one of individuals' most sensitive information – genetic information in two spheres: the health care system and the commercial. The paper aims to learn what the framework of health law and bioethics could teach us about data protection in the commercial sphere. Being a leading concept in both contexts, the paper sheds a light on individuals' autonomy under each regulatory framework. In particular, the autonomy to decide how exposed their genetic information is, and what is the limit of use done with it. Looking at the way sensitive genetic information is handled in two different contexts, highlights the differences between a legally regulated field in comparison to a field regulated through the market. The paper shows that both regulatory regimes leave individuals with limited scope of plausible pro-active decisions they can actually make about their genetic information without exposing it to unsolicited privacy risks. Based on bioethical principles, the paper suggests a justification to such a limited scope of plausible actions in the context of health and genetics. However, it argues that the commercial sphere cannot justify the same rationale. Unlike patients in the context of health care providing system, who are inherently positioned in a vulnerable position, the rationale that underlies the free market requires power balance between participants and should grant consumers in the market a more pro-active role. The paper highlights blind spots in the structure that call for additional regulation to balance the power between consumers and corporates.

The paper aims to learn from the case study of genetic data collection in the context of health-care system could teach us about genetic data protection and consumers' control over their information in the commercial sphere. The second part reviews protective strategies used in the regulation of genetic information in each sphere. First it explores five regulatory strategies to protect genetic information in the context of a health care treatment: security, restricted access and acquisition, prohibition of misuse, individual rights, and individual authorization to use the information. Second, it addresses regulatory strategies to protect genetic information in the commercial context. The third part analyses the shortcoming and limitation of the regulatory strategies in each sphere, and explains different rationales to the difference in protection. The fifth part reviews potential models to address the challenges.