Chapter XXX

Which Rights for Which Subjects?

Genetic Confidentiality and Privacy in the Post-Genomic Era

Antoinette Rouvroy
European University Institute, Italy

ABSTRACT

The aim of the present chapter is to elucidate the paradoxical position of the individual legal subject in the context of human genetics. It first discusses the assumed individual "right to know" and "right not to know" about genetic susceptibilities, predispositions and risks when genetic tests exist, and assess the usual assumption according to which more information necessarily increases liberty and enhances autonomy. A second section is dedicated to the issues of confidentiality, intra-familial disclosure and familial management of genetic information. The idea is suggested that those issues challenge the fundamental liberal unit of the individual traditionally understood as a stable, unitary, embodied entity.

INTRODUCTION

Notwithstanding the fears and expectations unleashed by the hype surrounding the "genetic revolution" initiated in the early nineties with the Human Genome Project, the so-called "new human genetics" has not transformed nor provided definitive elucidation of what it is to be human but has undoubtedly shifted the locus of inquiry for characterising commonalities and variations among the human species. Focusing on "genes", the scrutiny has shifted from 'visible' superficial physiognomy and anatomy, from the layer of physical appearance and expressed behaviours, and from 'incalculable' social, economical and environmental contexts, to the 'invisible' but locatable and 'calculable' internal, molecular milieu.

What may the rights and duties of the individual subject be with regard to "his" newly accessible genetic information? Does the individual have a "right to know", a "right not to know", a "duty to know" or "liberty to know" about medically or otherwise meaningful features of his own genome? Given the shared nature of genetic information, how are those rights or liberties of the subject to be weighed against competing claims by blood relatives interested in the same genetic information? Genetic information is the "locus" of intersection of a network of concurring and conflicting interests, and obfuscates the lawyers' predispositions to think in terms of dual relations of individual rights and correlative individual or collective duties.

A second section will be dedicated to the intra-familial conflicts of interests in genetic information, and to the ensuing challenges this imposes to medico-legal norms such as the health provider's duty of confidentiality. What are the possibilities and implications of acknowledging the existence of a collective 'genetic subject' transcending individual embodiment? The *subject* of genetic information and of genetic privacy (the *patient* entitled to care and confidentiality in the patient-doctor relationship) is not even easily identifiable in the genetic context. Enabling the prediction of disease or the assessment of disease-risk with varying degrees of certainty, genetic information is of course important to the tested person,[1] but may also be crucial to persons who share the same genetic inheritance and are virtually exposed to the same genetic risks. Those persons (blood relatives) may sometimes be recognized a legitimate and legally protected interest, however not usually raised up to the status of a right to force intra-familial disclosure, but requiring some procedural measures enhancing the patient's aptitudes to reflect upon the interests of those third parties and to act "morally" towards them. The moral or legal character of the obligations owned by the individual directly concerned regarding disclosure of genetic information to family members is a controversial issue. Indeed, isn't the subject of genetic information the whole 'genetic group' or genetically-related family? The dual doctor-patient relationship seems prone to explode into a complexified network of relationships extending to the whole "genetic family". The duties owed by one person *vis a vis* his relatives when aware of the presence of specific familial genetic ailments (Rhodes, 1998), or when asked to cooperate in a familial inquiry in order to establish the results of a genetic test required by one of the members of his family are to be assessed as well as the consequences of this potential collectivization of genetic rights for our representation of the liberal individual. Indeed, the extension of the medical doctor's duties towards members of the genetic group and the related issue of intra-familial disclosure of genetic information further challenge the exclusive control traditionally granted to the liberal individual over "his" personal information and biological material, and contradicts current discourses about individual self-ownership and empowerment.

THE "RIGHT TO KNOW" AND THE "RIGHT NOT TO KNOW"

A usual argument favouring the "duty to know" over the "right not to know" is that genetic risk information positively reinforce the 'genetically informed' and 'genetically empowered' individual's autonomy. The argument appears particularly compelling as a major ethical and legal imperative of neoliberal societies is the respect and, where necessary, enhancement of individual autonomy. Being aware of one's genetic risks, it is assumed, allows individuals to better adapt their lifestyle and diet, adopting a preventative attitude in order to keep healthy.[2] Yet, the relationship between genetic information and individual autonomy is much more complex than usually assumed.

What predictive genetic testing allows is the designation of patients in an anticipatory sense. Although in classical medical practice, the quasi contractual patient-doctor relationship arose because of observable symptoms, a genetic test may be offered to currently asymptomatic, healthy individuals. In the legal sphere, that shift is also resented as a disruption: what rights and obligations should the 'asymptomatic ills' be allocated by virtue of their status' as 'genetically at risk'?

18 more pages are available in the full version of this document, which may be purchased using the "Add to Cart" button on the publisher's webpage: www.igi-global.com/chapter/rights-subjects-genetic-confidentiality-privacy/21597

Related Content

Ghosts in the Machine?: On the Limits of Narrative Identity in Cyberspace
Robert Paul Churchill (2019). *International Journal of Technoethics (pp. 10-23).*
www.irma-international.org/article/ghosts-in-the-machine/216990

An Exploratory Study of the Cyberbullying and Cyberstalking Experiences and Factors Related to Victimization of Students at a Public Liberal Arts College
Ellen Kraftand Jinchang Wang (2010). *International Journal of Technoethics (pp. 74-91).*
www.irma-international.org/article/exploratory-study-cyberbullying-cyberstalking-experiences/48525

NBIC-Convergence and Technoethics: Common Ethical Perspective
Elena Grebenshchikova (2016). *International Journal of Technoethics (pp. 77-84).*
www.irma-international.org/article/nbic-convergence-and-technoethics/144828

Research on Open Innovation in China: Focus on Intellectual Property Rights and their Operation in Chinese Enterprises
Zhu Naixiaoand Huang Chunhua (2013). *Digital Rights Management: Concepts, Methodologies, Tools, and Applications (pp. 714-720).*
www.irma-international.org/chapter/research-open-innovation-china/70998

Deliberative Democracy and Nanotechnologies in Health
Aikaterini A. Aspradaki (2013). *International Journal of Technoethics (pp. 1-14).*
www.irma-international.org/article/deliberative-democracy-and-nanotechnologies-in-health/90485