

The bioethical problem of genetic information and discrimination:

The doctrine of genetic exceptionalism in policy debates

Kakuk Péter

Témavezető: Prof. Dr. Molnár Péter



UNIVERSITY OF DEBRECEN

Health Sciences Doctoral School

Debrecen

2009.

## 1. INTRODUCTION

---

The developments and progress that occurred in the past few decades in modern genetics and biotechnology are very likely to have in the long run a profound and comprehensive effect on the future of human life and society. The future of molecular genetics and its impact on society is frequently described in revolutionary terms. In many instances even the contemporary achievements are superior and applications are already available in various fields: medicine, research, agriculture. A growing number of industrial sectors are applying the new results of molecular biology that once used to be a minor subfield of biology.

The upward trend in human genetic research that started in the 1960's and the launching of the Human Genome Project (HGP) in the beginning of the 1990's brought about radical changes in the various fields of the life sciences, and also had a significant impact on research topics of the human and social sciences, and provoked intensive social debates as well. At the official launch of the HGP the decision was already made that certain percentage of the project funding should be spent on supporting specific research concerning the ethical, legal, and social issues (ELSI). As an effect of this funding, as well as the emerging strong media representation of the project, the project accompanied by an increasing interest in the various ethical, legal and social issues. The project had several aspects that made public debates, precautionary approaches, and ethical deliberations necessary and justifiable. These ethical investigations were attempting to anticipate from an ethical perspective the possible uses and future consequences of the HGP results. The historical precedents of the socio-political uses of genetics in the first half of the 20<sup>th</sup> century, the possible abuses of personal genetic data in contemporary societies, the relatively easy accessibility of a person's genetic information, the wealth and detailed nature of such information, as well as the large number of possible affected people were all aspects that borrowed a high social significance to the emerging ELSI research and bioethical reflections.

Our increasing capacity to build someone's personal genetic profile raises important questions regarding privacy, confidentiality, property, and personal autonomy. How could we provide adequate protection to genetic information? Who can have access to, and on what conditions to someone's genetic information? What kind of rights do third parties have, if any, to access individual genetic information, like employers, insurance companies, schools, or family members? A large number of diseases will be diagnosable with these emerging technologies,

before the appearance of symptoms, and even before the availability of treatments to the diagnosed condition. How will we deal with such situations embedding complex ethical dilemmas? Moreover, what kind of social changes might be generated by the project? If the social trends of describing and understanding human features and diseases will have an increasing influence, what kind of shifts could we anticipate in our conception of human nature, in our conception of the human species, in our conception of ourselves as individuals, or in our fundamental views and beliefs? Will this lead to representing ourselves as the product of genetic interactions? How will we define normality, abnormality, or various deficiencies? With recognizing the significance of these questions, and the growing intensity of public discussions established commitment and interest on an international level for fostering a diversity of approaches that were focusing on the elaboration of the ethical, legal and social issues of the HGP and biotechnology more generally.

There were 75 documents created between 2000-2005 that deal with genetic research and its applicative possibilities. These policy documents approached to regulate the usage of biotechnology and provide guidance about issues of gene therapy, genetic engineering, gene-patenting, genetic testing and screening, pharmacogenomics, cloning, stem-cell and genetic research, and genetic services. The issue of genetic information is prominent within this topical division for two reasons. Firstly, genetic information as an underlying theme is closely related to other bioethical topics in genetics, as far as reproductive decisions, genetic testing and screening, and medical diagnosis and treatments are all somehow subject to the concept of genetic information. Secondly, genetic information, unlike issues of gene therapy and human cloning, has fallen within the scope of practical feasibility of applications since the completed project of mapping, and also because of the accessibility of the practical applications that are based on our knowledge of genetic information, that might be illustrated by the rapid growth in the number of genetic tests already available in the global market.

The potential abuses, specially the re-emerging possibility of genetic discrimination, and the eventual return of 20th century eugenics produced widespread fears in western societies. Within the bioethical discourse concerning genetics the problem of discriminative treatment of individuals and groups based on genetic information is deeply intertwined with the potential applications of the new technology. Public opinion polls and sociological investigations capturing the social perception of potential abuses showed that a great majority

of people relation to the widespread usage of genetic information is characterized by mistrust and suspicion. These fears arose as far as third parties - such as employers, police, insurance companies and others - could claim access to someone's personal genetic information. Thus, beside the potential beneficial applications of these new technologies, especially in medical treatment of individuals and in public health, a whole set of potential abuses and social harms might realize that certainly justifies the need of critical reflection and careful deliberation.

The general bioethical question raised by the emergence of genetic information could be summed up in the following way: How can we assure that the applications of genetic information could accomplish its potential social and individual benefits (in public health, in pharmacogenomics, in medical diagnosis, etc.), without hampering our commitment in giving due protection to individuals, and without the realization of the anticipated social harms? The need to provide appropriate protection to personal genetic information is surrounded by a consensus on an international level. Moreover, there is a relatively common agreement regarding the reasons provided for protecting genetic information. However, the way and extent of providing protection to genetic information is characterized by a diversity of approaches both in the dimension of ethical debates and regulatory efforts.

In their report, published in 2004, the independent expert group of the European Commission suggested that the regulatory and policy tendency of treating genetic information as something special emerged as a reaction to the public fears regarding the potential harmful usage and abuses of genetic information. The process of providing genetic information with an exceptional status could be illustrated by the newly appeared initiatives and efforts that were launched by influential international organizations of medical ethics, bioethics and human rights. As an example, the UNESCO's Declaration of Human Genetic Data that was published in 2003, might be cited: *"human genetic data have a special status because: they can be predictive of genetic predispositions concerning individuals; they may have a significant impact on the family, including offspring, extending over generations, and in some instances on the whole group to which the person concerned belongs; they may contain information the significance of which is not necessarily known at the time of the collection of the biological samples; they may have cultural significance for persons or groups."* The special status given to genetic information, the dominant view that genetic data is exceptional compared to other health care data, and as such requires exceptional treatment is called the

doctrine of genetic exceptionalism. The overall aim of this dissertation can be described as an approach mapping the emergence and development of the doctrine of genetic exceptionalism. How this particular representation of genetic information came into existence and became institutionalized in bioethical discourse? What kind of historical, epistemological and social conditions were necessary for the development of intensive public debates about genetic information, for the emergence of the exceptionalist policy trend, and for the emergence of representing genetic information as a serious threat to our individual and social life?

The arguments supporting the doctrine of genetic exceptionalism might be divided into two groups. In the first group are those reasons that make reference to the social representation of genetic information, which is particularly influenced by the past of genetic science, nazi racial hygiene, and the dark shadow of the eugenics movement. In a similar vein, some arguments find their support in the social representation of genetic information that is often accused of being genetic essentialists and expressions of genetic determinist views that might be illustrated by contemporary media representations of genetics. The other group of arguments find support and related to the scientific “nature” of genetic information, and refer to the representations of genes and genetic information that have their origin in the scientific discourse.

The aim of the dissertation is to analyse the bioethical discourse that developed in the last two decades on genetic information from a philosophical perspective with an emphasis on genetic discrimination. In the focus of analyses are those presumptions, concepts, beliefs and arguments that could have played a definitive role in the process, in which genetic information became a significant bioethical problem.

The social representation of genetics, and lay notions about genes and DNA have been investigated by numerous scholars and also appeared as the subject of some highly cited books in recent years. These investigations support the premise that genetics, genes, and genetic information is particularly subject to serious misunderstandings, unsupportable beliefs, and myths. The dissertation’s relevance could be supported by the feeling of uncertainty one might face when meeting the main issues and questions in the bioethical discourse on genetics. Are those frequently used conceptualizations of genetic information adequately formulated in order to reach a conception that is supportable by facts and evidences and remain free from the standard misunderstandings and myths of genetics?

During the research that resulted in this dissertation, the following questions were investigated:

1. How the concept of genes and genetic information appears in bioethical discourse?
2. What is the role of eugenics in the development of the contemporary bioethical problems of genetics?
3. How genetic determinist's views influence bioethical discourse?
4. What were the potential factors that hamper or even paralyse a more evidence oriented conceptualization in bioethical discourse, regulatory efforts and decision-making processes?

## 2. MATERIALS AND METHODS

---

The primary material of research was the bioethical discourse on genetics. The method of research was philosophical discourse analyses that approached to situate bioethical texts into their social and historical contexts. Although the notion of bioethics as a well defined discipline has received some criticism, around the 1990's a dominant approach appeared that represents bioethics as a new field of study, as a specific discipline. Historical works focusing on the emergence and development of bioethics trace the beginning institutionalization and establishment of the field around the 1960's, when representatives of diverse scientific fields started to engage themselves in discussions regarding the potential risks and threats raised by the immense progress in the biomedical sciences. Bioethics as a term was coined in 1971 by Van Rensselaer Potter in a paper that urged the global integration of biology and values. However, Potter's early conception was not as viable as the term itself that had a significant career in the academic world. According to the vision of Calahan, - the first director of *the Institute for Society, Ethics, and the Life Sciences* established in 1970 – this new type of institute would offer a place that could gather researchers with various disciplinary backgrounds to discuss the ethical, legal and social issues raised by medicine and the new biology. Since this initial step four decades have passed that clearly manifest great progress in the formation of bioethics as an academic field of study. University courses have been established worldwide, new research institutes, journals, encyclopaedias, handbooks, and scientific societies are dedicated to the field. According to the dominant view – especially in the Anglo-Saxon countries – bioethics is already a unified discipline, namely a subfield of applied moral philosophy that deals with the ethical questions of the life sciences and medicine and follows the norms and style of analytic philosophy. Numerous authors working in the field would certainly question the primacy of philosophy within bioethics. Instead, they would emphasize the interdisciplinary nature of bioethics. For example, in the *Encyclopaedia of Bioethics*, bioethics defined as the “systematic study of the moral dimensions – including moral vision, decisions, conduct, and policies – of the life sciences and health care, employing a variety of ethical methodologies, in an interdisciplinary setting”.

This dissertation has a primary focus on bioethical discourse, which is close to the conception of Onora O’Neil who avoided defining bioethics as a discipline, rather viewing the field as “a

meeting ground for a number of disciplines, discourses and organisations concerned with ethical, legal and social questions raised by advances in medicine, science and biotechnology”. The dissertation follows this wider concept of bioethical discourse that includes a much more extensive group of texts, documents and written papers. Following this broader view of bioethics, discourse analyses included papers focused on moral philosophical analyses, papers focusing on genetics from a distinct disciplinary perspective, be it legal, sociological, or psychological, and also policy documents, guidelines, recommendations, or laws.

Bioethical discourse is dominated by English language texts, though beside analysing this literature, I included also Hungarian papers of the topic. As an initial step in collecting the relevant literature, I attempted to map those works that seemed to have a strong influence and have been heavily cited by the basic works. Standard approaches and methods of reviewing the literature were less appropriate, because of the general focus of the dissertation and the extreme number of publications within the topic. Thus, my basic strategy were to collect these heavily cited papers, and books that have a focus on the ELSI aspects of genetic information, than analysing them from a philosophical point of view with the intent of mapping the basic assumptions, concepts, and models dominating this specific discourse. Following this procedure, I relied on the following books, volumes and collections: „The Oxford Handbook of Bioethics”, „Companion to Bioethics”, „Source Book of Bioethics”, „Companion to Genethics”, „Code of Codes”, „Genetic Information, Acquisition, Access, and Control”, „Genetic Secrets”, and the „Codes and Laws in the Genetic Era”. Beside the traditional online literature databases, I have used two specific databases for bioethical research, one is in the USA at Georgetown University, and the other is a government run online literature database in Germany, called the Deutsches Referenzzentrum für Ethik in den Biowissenschaften.



### 3. RESULTS, DISCUSSION

---

3.1. The history of eugenics plays a crucial role in the bioethical discourse on genetics. The simple historical narrative built on the political applications of early genetics both increases the stakes involved in the ethical debates and regulatory efforts, and also increases the intelligibility and acceptability of the exceptional status of genetics. The main problem of this over-simplified, conventional understanding of eugenics is based on its sole focus on the history of American and German eugenics, emphasizing the most radical and outrageous consequences of the merging of genetics and politics. However, this approach fails to consider the diverse realization of eugenics programs of different countries in the early twentieth century, which did not necessarily implied everywhere the materialization of gross human rights infringements. The recent proliferation of research into the history of eugenics provides a multiplicity and a much more complicated picture regarding this earlier representation of eugenics as a more or less unified ideology. However, some elements of thought could be exposed within these historical multiplicities that are present in the various national ideologies of eugenics. One of the seemingly universal characteristics of the international eugenics movement is overall attitude that sacrifice is required by the individual in order to achieve a more important social good, and also the consequent policy initiatives that decisions regarding reproduction must be placed under social/state control. However, beyond this unity, there were considerable divergences regarding the concrete extent of the needed sacrifice and the realized social control of reproductive practices. Eugenics ideology was more or less homogenous in the fear of degeneration. Beside some differences in eugenics thinking on an international level, a remarkable diversity existed in the different countries regarding the social consequences of the movement. The results of eugenic efforts in the social arena, various interventions into individual lives, abuses and corrupt practices, and generally those practices, which are deservedly unacceptable from our contemporary human rights perspective showed a great divergence in their gravity depending on the concrete social, cultural, and political contexts eugenics efforts were embedded and developed in different countries.

3.2 The danger of creating a genetic underclass and the problem of public mistrust in new genetic testing services gained a strong emphasis among the alleged social risks of genetic information. Social research into the contemporary experience of genetic discrimination claimed to show the actual practices of genetic discrimination in various contexts: in health care insurance, life insurance, and disability insurance, in the context of employment, in clinical and health care services, and also in schools, and in the military. These earlier investigations usually based on anecdotal evidences, or minor case-studies. Thus, we lack a more robust empirical data that might be regarded as definitive in verifying the contemporary prevalence of genetic discrimination based on the new genetic testing technologies. These earlier investigation might be informative regarding the question, whether people felt in certain situations that they were victims of discrimination. However the results of these studies have a rather limited value in supporting an unbiased judgement regarding the cases, the prevalence, the nature and the extent of genetic discrimination. The long term anticipations about the potential social consequences of genetic testing and discrimination easily and quite frequently gain an apocalyptic tone, but the more closely and concretely we attempt to investigate the question of genetic discrimination, the more difficulties we meet in upholding the vision of a genetic underclass as victims of the new technology. Certainly, these observations cannot support the reassuring conclusion that genetic discrimination does not exist at all, or it could not emerge in the future even as a social trend within contemporary societies. On the other hand, based on the available studies on the contemporary experience of genetic discrimination, we cannot give support to the often asserted claim or belief that discriminatory practices based on the new genetic technologies are on the rise.

3.3 Giving a clear definition of “genetic information” became unavoidable in the regulatory context, and proved to be a rather difficult task. At least more difficult than those expected who were convinced of the exceptionality and unique nature of genetic information. Actually attempts to define it were unsuccessful in one or another aspect, while these had to choose between the two problematic alternatives of under-inclusiveness and over-inclusiveness. Under-inclusive definitions are better in defining genetic information with differentiating it from other medical information, but fail to provide the desired safeguards in some cases. Over-inclusive definitions are more proper in providing safeguards to the imagined scenarios of abuses, but fail in their definition to clearly differentiate genetic information from other health information. Thus, regulatory efforts followed two basic

approaches in providing a definition. Some of them made reference to the source of genetic information, like “the results of genetic tests”, or “DNA analyses”, that are called source based approaches. Others, following the content based approach, attempted to base their definition on the content of information, like “investigations, diagnoses and predictions that contain information about an individual genetic characteristics, or heritable attributes”. In order to avoid over-inclusiveness, at least for a certain extent, these content based definitions had further specifications. The problem of defining genetic information clearly in the regulatory context highlighted the implicit scientific uncertainty that were definitive in the emergence of the ethical, legal, and social debates on genetics. These kind of uncertainties led policymakers and legislators in some countries to postpone their regulatory response, for example in the form of establishing moratoriums.

The concept of the gene and genetic information were subject of intensive discussion within representatives from the history and philosophy of science in recent years. The results of these studies provide a useful source in mapping some of the epistemological origins of the social ambivalence and uncertainties of genetics. Moreover, the question of concept formation in bioethics might be described. Is there a simple concept of the gene that can give support to bioethical deliberations? How the concept of the gene and genetic information represented in bioethical discourse? And also, how this concept is related to the scientific conceptualization of genes and genetic information? The classical molecular concept of the gene originates to Watson and Crick work in the 1950's had a definitive role in the ethical problematization of genetics. This early molecular concept has been challenged by advances and progress in molecular genetic research from the 1970's on. As a result of these molecular advances, the gene lost its once available material identity that could unify function and structure as well. However, this early conceptualization of gene function and structure still lives as a dominant stereotype in the vocabulary of biologists. This concept with its inherent reductionist stance had a definitive role both in the public representation of genetics and in the bioethical discourse. As a consequence of the overall career of this conceptualization of genes and genetics, genetic determinist views had gained a continuous scientific support that fundamentally affected the genetic exceptionalist trend in the policy efforts. Thus, its not just the often accused media representation of genetics that is responsible for the exaggerated views on genetics, but scientific language and its reductionist conceptualization as well. Moreover, the metaphor of information has its origins in the classical molecular gene concept

that generates some misleading assumptions resulting in some policy efforts misguided attempts. In bioethical discourse DNA had been described as containing all the necessary information to build an organism. This deterministic assumption could be challenged by showing the other environmental and epigenetic factors necessary for development of an organism, but the pre-eminent role given to DNA could be hardly challenged given this metaphoric context, where DNA is logos, inscribed into the materiality of the cell. All the other factors that have an important role in development could be represented as being merely material conditions.

5.4 One of the main pillars of genetic exceptionalism is the misconceived predictive value of genetic information: one could read out the future health status of an individual from her DNA. This representation of genetic information gave a strong support for treating genetic information and the new testing technologies as something special, while its potential misuses in the insurance and employment setting could be realistically anticipated. Although, our knowledge regarding the future trajectory of the new genetic testing technologies is uncertain, we still have some knowledge about the inherent limits of DNA based genetic prediction that will be hardly overcome by technological advances alone. These inherent limits were often neglected in the bioethical discourse on genetic information and testing. Moreover, the frequent usage of Huntington disease and its newly developed genetic test as a paradigm case for understanding the upcoming problems of the new genetic tests is also supportive in representing genetic test as a strong and reliable predictor and representing genetic information as fundamentally tragic, family related and morally overcomplicated.

3.5 The doctrine of genetic exceptionalism supports the public belief that genetic information is something special and powerful. Thus, as a policy trend it continuously revitalizes misleading assumptions about our genetic knowledge. In a similar fashion, exceptionalism indirectly gives support to geneticization tendencies in our societies that might strengthen the stigmatizing value of genetic characteristics. This doctrine is highly problematic regarding its presumptions about genetic information, and as a regulatory strategy it will face further difficulties in the near future. The requirements of exceptional treatment will be hardly fulfilled, as long as we can not clearly differentiate genetic from non-genetic information. In light of the ongoing advances in genetic epidemiological research and in the development of genetic tests, almost every “non-genetic” disease could be described as

genetically determined for a certain extent. In the era of Mendelian genetics we could quite reasonably categorize a group of diseases and characteristics as having a genetic origin. Along the ongoing molecularization of genetics, these borders between nature and nurture, between environmental and genetics causation became blurred.

3.6 Eugenics plays a definitive role in contemporary debates around genetics. Even some regulations and national laws explicitly made reference to eugenic practices of the past. However, the usage of eugenics within contemporary discussions is far from being homogenous, if not incoherent. Thus the word eugenics has an underdetermined meaning that makes its very popular in both side of the debate, while it can be used in a variety of ways. Nearly “anything” might be labelled eugenic: a scientific discourse, beliefs, practices, regulation, policy initiatives. According to some participants, eugenics could be used legitimately just to intentions, others claim that it could be used just to consequences and effects. The usage of eugenics in policy debates rather gave rise to confusion than helps to create a framework where useful public dialogue might take place. Knowledge about the history of eugenics is really important in understanding bioethical discourse and social debates on genetics, but this semantically overcharged word could hardly be used in analysing and interpreting concrete policy alternatives that we are facing.

3.7 Genetics underwent huge developments since the 1950’s and since 1990’s as well. Building reliable models about the future progress of the field, and anticipating the upcoming ethical problems are both hampered by epistemological uncertainties. Beyond these initial uncertainties, a further complexity aroused as the “new” norm of participatory decision-making enforce the dialogue between experts of various disciplines and between experts and lay persons. This situation is typical in the bioethical discourse on genetics, posing a significant challenge on the integrity of crucial concepts that would be necessary for a dialogue, a debate, and decisions based on reasoned argument to appear. Moreover this situation also hampers attempts of eliminating misapprehensions and unfounded myths having its roots in concepts. Genetic determinist views and various reductionist models have been deeply embedded in bioethical discourse that can be explained by epistemological factors related to the usage of scientific and lay concepts on genes and genetic information in a diversity of context. In the context of molecular biology genetic information is primarily used to refer to the sequence of base-pairs on DNA, but remained mostly metaphorical. In the

context of public debates genetic information primarily used to refer to the meaning and knowledge that is brought to the surface with the usage of new technologies and contains information regarding a persons genetic, heritable characteristics. Without a strict technical term of information in biology, the various usages and lay understandings of genetic information can not be replaced by a science based version that might impose justifiable epistemological restrictions on the ethical deliberations regarding genes and genetic information.

#### 4. 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.

---

## 5. LIST OF PUBLICATIONS

### 5.1 *In extenso* publications in the dissertation's topic

1. **Kakuk, P.** (2006). Genetic Information in the Age of Genohype. *Medicine Health Care and Philosophy*, 9:325–337. (ESPMH Young Scholar Award 2005) <<http://www.springerlink.com/content/a137j7880512k65v/fulltext.pdf>>
2. **Kakuk, P.** (2008). Gene Concepts and Genethics: Beyond exceptionalism. *Science and Engineering Ethics*, 14: 357-375. (if: 0.4) <<http://www.springerlink.com/content/u062557805355784/fulltext.pdf>>
3. **Kakuk, P.** (2009). The Legacy of the Hwang Case – Research Misconduct in Biosciences. *Science and Engineering Ethics*, (elfogadva). (if: 0.4)
4. **Kakuk, P.** (2006). A génfogalom problémája és a génetika. *Fundamentum, Emberi Jogok Folyóirata*, 1: 23-31. <<http://157.181.181.13/dokuk/06-01-02.pdf>>
5. **Kakuk, P.** (2003). A Gén a Szent Grál és az Energiáiital. *Lege Artis Medicinae*, 13(2): 168-169. <<http://www.lam.hu/folyoiratok/lam/0302/20.htm>>
6. **Kakuk, P.** (2004). A Tájékozott Beleegyezésről Gyakorlati Szempontból. *Orvosi Hetilap*, 145(29): 1517-1522.

### 5.2 Other *in extenso* publications

1. **Kakuk, P.** (2007). The Slippery Slope of the Middle Ground: Reconsidering Euthanasia in Britain. *Health Care Ethics Committee Forum*, 19 (2): 140-154. <<http://www.springerlink.com/content/g221267684k71451/fulltext.pdf>>
2. Varga, O., **Kakuk, P.** (2006). European Union and Alternative Medicine: Some institutional and legal impacts on a developing field. *Integrative Medicine Insights*, (1): 27-33 <<http://www.la-press.com/european-union-and-alternative-medicine-some-institutional-and-legal-i-a164>>
3. **Kakuk, P.** (2006). *Bűnözők, Betegek, és Ínyencek: A moralitás problematikus helye a drogpolitikai diskurzusban.* In. Rácz, J., Takács, Á. eds. *Drogpolitika, hatalomgyakorlás, társadalmi közeg. Elemzések foucault-i perspektívából*. L'Harmattan, Budapest, 49-66.
4. **Kakuk, P.** (2001). Kritika, fikció és terápia: Foucault és a pszichoanalízis kritikája. *Thalassa*, (12) 2-3: 121-135.



### 5.3 Other publications

1. **Kakuk, P.** (2007). A paternalizmustól a közös döntéshozatalig – A veseelégtelenség indokolta terhességmegszakítás esete. *Lege Artis Medicinae*, 17(12): 926-928. <<http://www.lam.hu/index.cgi?c=http://www.lam.hu/folyoiratok/lam/0712/tart.htm&k=alap000&v=4245853660&r=377036938>>
2. **Kakuk, P.** (2005). A genetikai információ és a diszkrimináció problémája. *Beszélő*, 10; 12: 78-91.< <http://beszelo.c3.hu/cikkek/forradalmi-rendkivuli>>
3. Nemes, L., Molnár, P., **Kakuk, P.** (2004). Több dolgok vannak földön és egen. *Magyar Tudomány*, (9): 1033-1039. <<http://epa.oszk.hu/00600/00691/00009/12.html>>

### 5.4 Conference talks in the dissertation's topic

1. **Kakuk, P.** (2008). *Genetics and the Concept of the Common Heritage of Humanity – An instrument under construction*. CELAB-UNESCO Joint Workshop: “Local, Regional or International? Laws, Standards and Codes for Biotechnology” Central European University, 7-8 November, Budapest, Hungary.
2. **Kakuk, P.** (2008). *A genetikai diszkrimináció megakadályozásának közpolitikai megközelítései - Géntesztek és a Biztosítók: Tiltás vagy átláthatóság?* Magatartástudományi Napok Szegedi Akadémiai Bizottság székháza, Június, Szeged.
3. **Kakuk, P.** (2008). *Is there a crisis in the ethics of scientific research?* International Association of Bioethics: „The 9<sup>th</sup> World Congress of Bioethics” Rijeka, Croatia, 3-8 Szeptember.
4. **Kakuk, P.** (2008). *Az Eugenika Visszatérése: Etikai határmunkálatok az új genetikát övező társadalmi vitákban*. A BME Filozófia és Tudománytörténet Tanszéke, az ELTE Tudománytörténet és Tudományfilozófia Tanszéke és az ELTE Társadalomtudományi Szakkollégiumának Műhelykonferenciája: “Határmunkálatok a tudományban és a publikus tudományfelfogás”, Budapest, Május 2008.
5. **Kakuk, P.** (2007). *The governance implications of the concept of genetic information – The case of genetic testing*. International Conference, organized by ASO Brno: „Testing Genes, Profiling DNA – The Global Governance of Genomics. Hopes, Duties and Security”. Mendel Museum, Brno, Czech Republic, 1-3. November.
6. **Kakuk, P.** (2007). *Cloning, stem cell research and the Hwang Woo-Suk case*. Workshop organized by Center for Ethics and Law in Biomedicine: „Perfect Copy? - Comparative and

interdisciplinary approaches to reproductive cloning and to stem cell research” CEU, Budapest, Hungary, 2-3 March.

7. **Kakuk, P.** (2007). *A helytelen kutatási gyakorlatról: Kortárs krízis a tudományetikában?* Pécsi Tudományegyetem BTK: “II. Szaketikák konferencia”, Május 11., Pécs.
8. **Kakuk, P.** (2006). *Critiques of Genethics: The role of epistemology in bioethical reflection.* Annual Conference of EACME: „New Pathways for European Bioethics” Leuven, Belgium, 30 September.
9. **Kakuk, P.** (2005). *The Doctrine of Genetic Exceptionalism.* International Conference: „Science, Law and Ethics”, Israel, University of Haifa May.
10. **Kakuk, P.** (2005). *Genetikai Információ a Betegtájékoztatóban.* DE OEC: “II. Belgyógyászati Napok”, Április, Debrecen.
11. **Kakuk, P.** (2005). *Genetic Information in the Age of Genohype.* EACME & ESPMH International Conference on „Philosophy and Ethics of Emerging Medical Technologies”, Spain, Barcelona: August.
12. **Kakuk, P.** (2004). *Eugenika. Az Emberi Faj Nemesítése – Viták Tükrében.* Debreceni Tudományos Napok. Magatartástudományi problémák és paradigmák – történeti reflexiók. DAB székház, 22 November, Debrecen.
13. **Kakuk, P.** (2004). *A betegtájékoztató etikája.* DE OEC: “I. Debreceni Belgyógyászati Napok” Április 24., Debrecen.
14. **Kakuk, P.** (2002). *A gén problémája a bioetikai diskurzusban.* „III. Magatartástudományi Napok” Május 9-11 Debrecen.
15. **Kakuk, P.** (2004). *A betegtájékoztató etikája.* DE OEC: „I. Debreceni Belgyógyászati Napok” 19-24.. Április, Debrecen.

## **5.5 Other conference talks**

1. Demény, E. & **Kakuk, P.** (2008). *Részvételi technikák alkalmazása a nanotechnológia kockázatainak mérlegelésében: A NanoPlat project magyarországi aspektusai.* SZTE BTK Filozófia Tanszék: "Fejlődés és környezeti felelősség" környezetetikai konferencia, SZAB, Szeptember, Szeged.
2. **Kakuk, P.** & Demény, E. (2008). *A nanotechnológia etikai, társadalmi és jogi aspektusai.* Országos Nanotechnológia Konferencia: „Nanotechnológia 2008. - Magyar Helyzetkép, Feladatok az Oktatásban” November, Veszprém.

3. **Kakuk, P.** (2008). *A Genetika mint Társadalmi, Etikai és Jogi Probléma : Reflexiók az Új Genetikai Törvényről.* DE OEC, Biokémiai és Molekuláris Biológiai Intézet: "Kutatók Éjszakája programsorozat", Szeptember 26. Debrecen.
4. **Kakuk, P.** (2006). *Ethics, law and the social construction of risk: emerging ethical guidelines for an avian flu pandemic.* Workshop organized by CELAB and by the Department of Economics of the Central European University: „Avian Flu: Ethical, Social and Economic Implications”. Budapest, 7 April.
5. **Kakuk, P.** (2006). *Conflict of Interests: Nothing to Declare?* European Union, Research Training Network, DE OEC, Debrecen.
6. **Kakuk, P.** (2006). *Genetic Information, Biobanking and the Problem of Discrimination.* European Union, Research Training Network, DE OEC, Debrecen.
7. **Kakuk, P.** (2006). *The Ethics of Research and Publication: What can we learn from the Hwang Woo-Suk story?* European Union, Research Training Network, DE OEC, Debrecen.
8. **Kakuk, P.** (2004). *A tájékozott beleegyezés elve a modern orvosi etikában.* Magatartástudományi Intézet Bemutató Előadások, DAB Székház, December 9., Debrecen.
9. **Kakuk, P.** (2005). *A betegtájékoztatás laikus megértése a kockázatkommunikáció tükrében.* Országos Konferencia: „Az egészségügyi felelősségbiztosításról - felelősen" Hotel Platánus, Március 23, Budapest.
10. **Kakuk, P.** (2000). *Foucault és a pszichoanalízis.* Országos Freud Konferencia: „Temetni vagy Dicsérni Freudot” MTI, DE OEC, Április Debrecen.